# CHOOSING HOME FOR SOMEONE ELSE: GUARDIAN RESIDENTIAL DECISION-MAKING

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## I. INTRODUCTION

> Sue had lived in her own home for fifty years but recently lost it due to financial exploitation by her daughter. She wanted to live as independently as possible and to avoid living in a nursing home. The public guardianship program found her an affordable apartment in a senior residence, and arranged for in-home care, transportation, and visiting nurses when needed. Several elderly tenants in the same building used the same in-home care staff, so the hours were easier to work out. The guardianship program also sought restitution from the daughter.
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> A fifty-three-year-old man with an intellectual disability was injured on September 11, 2001. His guardian helped to negotiate a settlement, but then his family began spending the money on their own needs, and he was left to sleep on the sofa of a family friend, without services. The guardian, who was a local attorney, arranged for him to share an apartment with his sister in exchange for room and board; and applied for various public supportive services.[1]

Few things are as important as where you live, where you call home. "Home is where the heart is." "There is no place like home."[2] Home can be place where one has "deep-seated ties with family members and close friends" and "a harbor of family traditions."[3] For a frail, older person or an individual with disabilities, "home" can be a long-standing family residence, but might also be a room in assisted living, a nursing home, group home, or other option where support and services can be provided. Where you live conjures up fundamental values of independence, safety, comfort, and community engagement. A guardian with responsibility for determining where a person with diminished capacity will live takes on a charge that goes to the core of quality of life.

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[1] These profiles are based on actual cases described in the authors' interviews with guardians. *See infra* Part IV.

[2] THE WIZARD OF OZ (Metro-Goldwyn-Mayer 1939).

[3] Jon Pynoos et al., *Aging in Place, Housing, and the Law*, 16 ELDER L.J. 77, 79 (2008) (discussing the importance of the home).

Of course, a guardian's "choice" of where a person will live is set in a constellation of factors that bear on or even dictate the outcome—the person's expressed preferences, the availability of optimal settings, the financial resources available, the risk involved, the kinds of care and supervision needed, the applicable law and court order, the process of hospital discharge planning, and more.

The guardian's residential decision is set against a backdrop of federal and state long-term care policy. Without available and affordable options, a guardian will be in a bind. The extent to which these settings are readily available is influenced by federal and state priorities and budgets for institutional versus community-based care. The recent recession has put a crimp in available options, especially for low- and moderate-income individuals—which squeezes guardians into making that daunting determination of where "home" will be. By making surrogate residential decisions and providing consent for transitions from one setting to another, guardians are a key piece in the puzzle for policy-makers in designing a workable system for long-term supports and services, and in facilitating the drive toward community-based options.

Part II of this Article briefly profiles the residential options for individuals with diminished capacity. Part III reviews federal and state long-term care policy, with an emphasis on home- and community-based settings, and shows the key connection between such policy and the decisions that guardians make. Part IV describes the results of an in-depth study by the authors on guardian residential decisions, including a nationwide survey and selected guardian interviews. Part V identifies additional research on where people under guardianship live. Part VI offers a statutory analysis of guardian residential decision-making authority. Part VII sets out provisions from existing relevant guardian practice standards. Part VIII concludes with themes from our study's roundtable discussion as well as key questions bearing on guardian standards for residential decision-making. Since this Article is prepared for the Third National Guardianship Summit on standards of practice, the focus throughout is on clarifying and implementing such standards.

## II. RESIDENTIAL OPTIONS FOR INCAPACITATED INDIVIDUALS

Incapacitated adults live in a broad spectrum of settings that fall into two general categories—home- and community-based settings, and institutional settings. While there is no bright line clearly distinguishing the two, those settings grouped under "institutional" tend to be more medically based and regulated at the federal and state level, generally by health care agencies.[4] In home- and community-based settings, with some exceptions, residents usually pay privately for ownership or rental of their units and any regulation is generally on the state or local level.[5]

[4] *See infra* Part II.B.
[5] *See infra* Part II.A.

### *A. Home- and Community-Based Settings*

People with disabilities may live in private homes or apartments with informal or paid support. Other community-based options can be grouped under the term "supportive housing," which refers to residential settings offering "services such as group meals, transportation, and help with housekeeping and personal care."[6] Definitions of types of "supportive housing" are not standardized, in part because these residences are regulated by states, which use a wide range of terms. In addition, definitions change with rapid shifts in the industry.[7] Thus, the terminology in the discussion below will not always track with labels used in various jurisdictions.[8]

#### *1. Supported Living at Home*

Some incapacitated people live alone or with others in a home they rent or own, which includes no supportive services in the rental or ownership arrangement. People under guardianship likely require some assistance with activities of daily living[9] or instrumental activities of daily living,[10] either through informal family caregivers or formal home care professionals or aides. As of 2010, "at least 90% of older people receiving care in the community received family care, either alone or in combination with formal care."[11] A 2009 survey of unpaid

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[6] AARP, THE POLICY BOOK: AARP PUBLIC POLICIES 2011–2012, at 9-34 (2011) [hereinafter AARP POLICY BOOK], *available at* http://www.aarp.org/about-aarp/policies/; *see also* Rebecca Cohen, *Fact Sheet 173: Supportive Housing*, AARP PUB. POL'Y INST. (Mar. 2010), http://assets.aarp.org/rgcenter/ppi/liv-com/fs173-supportive-housing.pdf.

[7] Cohen, *supra* note 6.

[8] Some of the literature on community-based living arrangements for people who need long-term services and support recognizes the labeling problem and avoids labels that may be confusing. For example, the National Consumer Voice for Quality Long-Term Care describes the most common forms of group living options as Option #1 through Option #4 with narratives on the key hallmarks of each living arrangement. THE NAT'L CONSUMER VOICE FOR QUALITY LONG-TERM CARE, PIECING TOGETHER QUALITY LONG-TERM CARE: A CONSUMER'S GUIDE TO CHOICES AND ADVOCACY 11 (2011) [hereinafter NAT'L CONSUMER VOICE], *available at* http://theconsumervoice.org/piecing-together-quality-long-term-care/pdf.

[9] These self-care activities include bathing, dressing and using the toilet. Enid Kassner, *Fact Sheet 222: Home and Community-Based Long-Term Services and Supports for Older People*, AARP PUB. POL'Y INST., at 1 (May 2011), http://assets.aarp.org/rgcenter/il/fs90r_hcbltc.pdf.

[10] These activities allow an individual to live independently in a community and include "shopping, managing money or medications, and doing laundry." *Id.*

[11] ARI HOUSER ET AL., AARP PUBLIC POLICY INSTITUTE, TRENDS IN FAMILY CAREGIVING AND PAID HOME CARE FOR OLDER PEOPLE WITH DISABILITIES IN THE COMMUNITY: DATA FROM THE NATIONAL LONG-TERM CARE SURVEY 2 (2010).

family caregivers revealed that 29 percent of care recipients lived with their caregiver.[12]

"Living at home" may include "congregate housing," "typically an apartment building for people who live independently and want common services such as one meal a day or light housekeeping."[13] "Congregate housing does not generally provide personal care or oversight."[14] "Home" could also be an apartment in a "continuing care retirement community" (CCRC) that "provides shelter, social activities, health care, and supportive services" under a contractual arrangement with "guarantees of increasing levels of services."[15]

Low-income individuals may live in subsidized housing. Federal subsidized housing, provided through the Department of Housing and Urban Development, includes public housing, housing choice vouchers (Section 8) and privately owned subsidized housing.[16] Older people may also live in "senior housing" which is designated for people over a certain age, but typically does not provide services onsite.[17] "The most common forms of [federal] supportive housing are HUD Section 202 Supportive Housing for the Elderly and Section 811 Supportive Housing for Persons with Disabilities."[18]

*2. Group Homes*

"Group homes are small residential facilities located within a community and designed to serve children or adults with chronic disabilities. These homes usually have six or fewer occupants and are staffed twenty-four hours a day by trained caregivers."[19] Developed in response to the deinstitutionalization movement of the 1960s and 1970s, group homes aim to integrate individuals with disabilities into the community and simulate typical family life.[20] Group homes generally serve people with intellectual disabilities, brain injury, or mental illness, with services targeted to the type of disability.[21]

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[12] NAT'L ALLIANCE FOR CAREGIVING & AARP, CAREGIVING IN THE U.S. 2009, at 35 (2009), *available at* http://caregiving.org/data/Caregiving_in_the_US_2009_full_report.pdf. Care recipients in this survey included adults and children.

[13] AARP POLICY BOOK, *supra* note 6, at 9-35.

[14] *Id.*

[15] *Id.*

[16] NAT'L CONSUMER VOICE, *supra* note 8, at 7–8.

[17] *Id.* at 8.

[18] *Id.*

[19] Sandra L. Friedrich, *Group Homes*, GALE ENCYCLOPEDIA OF MENTAL DISORDERS (2003), http://www.healthline.com/galecontent/group-homes#ixzz1RdtiqXUE.

[20] *Id.*

[21] NAT'L CONSUMER VOICE, *supra* note 8, at 12.

*3. Small Residential Assisted Living*

Assisted living residences provide "personal care to [people] who need assistance with daily activities such as bathing, dressing, taking medication, and preparing meals."[22] Typically, fewer than 100 residents live in apartment-like rooms, and the facility also has dining facilities and activity rooms. Facilities offer personal and health-related services in a home-like environment, and the assisted living philosophy aims to maximize residents' privacy, independence, and autonomy.[23]

Assisted living has no federal definition, and state terms differ. As of 2007, forty-three states and the District of Columbia used the term "assisted living" in a licensing statute or regulation, but the services offered vary widely. The term may encompass "board and care homes"[24] that provide room and board as well as "limited supportive services and protective oversight"[25]—and which are less expensive than larger and more comprehensive assisted living facilities. Although the majority of assisted living residents pay privately, in some states Medicaid funds pay for the personal care services in an assisted living facility.[26]

*4. Adult Foster Care*

An adult foster care home "is one in which several older adults who can no longer live independently reside with a homeowner who provides the services they need."[27] Services commonly include assistance with activities of daily living, household chores, and meal preparation.[28] Adult foster care homes are typically regulated by states or counties, which often limit the number of residents, frequently up to six,[29] and may use different terminology (for example, "adult family care, adult family care home, and domiciliary care").[30]

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[22] AARP POLICY BOOK, *supra* note 6, at 9-35.

[23] *Id.*

[24] However, board and care homes are sometimes included under the term "adult foster care" as described at Section 4. States also may have various terms with various licensure requirements for similar settings of small size, such as domiciliary care homes, residential care facilities, or homes for adults.

[25] AARP POLICY BOOK, *supra* note 6, at 8-33.

[26] *See* NanOak, *California Assisted Living Facilities Cannot Evict for Resident's Transition to SSI Benefits*, NAT'L SENIOR CITIZENS L. CENTER, http://nsclc.org/consumer/paying-for-assisted-living (last visited Feb. 27, 2012).

[27] Keith Wardrip, *Fact Sheet 174: Adult Foster Care*, AARP PUB. POL'Y INST., 1 (2010), http://assets.aarp.org/rgcenter/ppi/liv-com/fs174-afc.pdf.

[28] *Id.*

[29] *Id.*

[30] Robert Mollica et al., *Building Adult Foster Care: What States Can Do*, AARP PUB. POL'Y INST., 1 (2009), http://assets.aarp.org/rgcenter/ppi/ltc/2009_13_building_adult_foster_care.pdf.

### *B. Institutional Settings*

While policy-makers, the aging network, and care providers are moving toward increased use of community living arrangements, institutional residential settings are still part of the array of options for incapacitated people.

#### *1. Larger, More Medically Based Assisted Living*

Assisted living residences offer a level of care that can range from light "hospitality" services to care approaching that provided by nursing facilities.[31] For residents with more intensive needs, assistance is often available twenty-four hours a day.[32]

#### *2. Nursing Homes*

Nursing homes are heavily regulated by state and federal law and "provide services and support[] to people who need round-the-clock nursing care or supervision."[33] They provide a standard set of core services that include room and board, personal care, nursing, dietary services, social services, and activities. They also must provide or arrange for an array of other therapies and treatments, such as physical, occupational, and speech/language therapy; dental care; and transportation to medical appointments.[34]

Some nursing homes have special units for residents with dementia.[35] In 2010, approximately "47% of all nursing home residents had a diagnosis of Alzheimer's or other dementia."[36] Although there were over 80,000 beds in special dementia units in nursing homes in 2010, the great majority of nursing home residents with dementia do not live in special units.[37]

Pursuant to federal Medicare and Medicaid regulation, individuals with mental illness and intellectual disabilities are not eligible for nursing home care solely based on their mental health condition.[38] They must also need the type of

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[31] Robyn I. Stone & Susan C. Reinhard, *The Place of Assisted Living in Long-Term Care and Related Service Systems*, 47 THE GERONTOLOGIST no. 3, 2007, at 23, 23–32.

[32] Jon Pynoos et al., *Homes of Choice: Towards More Effective Linkages Between Housing and Services*, 18 J. HOUSING FOR ELDERLY no. 3, 2004, at 5, 5–18.

[33] NAT'L CONSUMER VOICE, *supra* note 8, at 13.

[34] *Id.*

[35] *Id.*

[36] Alzheimer's Ass'n, *2011 Alzheimer's Disease Facts and Figures*, 7 ALZHEIMER'S & DEMENTIA no. 2, 2011, at 40. "In 2008, 68[%] of all nursing home residents had some degree of cognitive impairment, including 27[%] who had mild cognitive impairment and 41[%] with moderate to severe cognitive impairment." *Id.*

[37] *Id.*

[38] Preadmission screening and annual resident review (PASARR) is a federal requirement to determine whether a person with mental illness needs nursing home care, or can be served in the community. *See* 42 C.F.R. § 483.100 (2012).

care provided by a nursing home.[39] There is wide variation between states in the numbers of people with mental illness admitted to nursing homes.[40]

*3. Intermediate Care Facility*

An ICF-MR[41] is a federally regulated facility in which more than four people with intellectual disabilities live and receive twenty-four-hour care. Residents require a level of medical care, support, and supervision above that available in group homes.[42]

*4. Mental Health Institution*

Several types of residential facilities come under the umbrella of institutional mental health facilities:

- Psychiatric hospitals, certified under Medicaid and Medicare, primarily provide psychiatric services for the diagnosis and treatment of mentally ill persons.[43]
- State-funded mental health institutions generally are large facilities providing twenty-four-hour care and supervision for individuals with intellectual disabilities or mental illness. In response to the deinstitutionalization movement, some states have eliminated these institutions.[44] Currently, there are approximately 220 state psychiatric hospitals throughout the United States, including hospitals for children, adults, older persons, and people who have entered the mental health system via the court system.[45]
- Therapeutic communities and long-term recovery residences are programs providing structure, support, and services, with the goal of

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[39] KAREN LINKINS ET AL., U.S. DEP'T OF HEALTH & HUMAN SERVS., SCREENING FOR MENTAL ILLNESS IN NURSING FACILITY APPLICANTS: UNDERSTANDING FEDERAL REQUIREMENTS 2 (2001), *available at* http://store.samhsa.gov/shin/content//SMA01-3543/SMA01-3543.pdf.

[40] David C. Grabowski et al., *Mental Illness In Nursing Homes: Variations Across States*, 28 HEALTH AFFAIRS no. 3, 2009, at 689, 690.

[41] The term "ICF-MR" refers to Intermediate Care Facility for the Mentally Retarded. Since terminology has changed, these facilities are sometimes called ICF-DD for people with developmental disabilities or ICF-ID for people with intellectual disabilities.

[42] Center for Medicare and Medicaid Services, *Intermediate Care Facilities for the Mentally Retarded*, CMS.GOV, http://www.cms.gov/CertificationandComplianc/09_ICFMRs.asp (last visited Feb. 28, 2012); NAT'L CONSUMER VOICE, *supra* note 8, at 14.

[43] Center for Medicare & Medicaid Services, *Psychiatric Hospitals*, CMS.GOV, http://cms.gov/CertificationandComplianc/14_PsychHospitals.asp#TopOfPage (last visited Feb. 27, 2012).

[44] NAT'L CONSUMER VOICE, *supra* note 8, at 12–13.

[45] Nat'l Ass'n of State Mental Health Program Dirs., *State Psychiatric Hospitals*, NASMHPD.ORG, http://nasmhpd.org/state_hospitals.cfm (last visited Feb. 28, 2012).

returning an individual to community living. These programs often are geared toward recovery from alcohol and other substance abuse, but such addictions may be paired with mental health issues.[46]

*5. Hospitals*

Hospital stays for incapacitated people are temporary but can be lengthy. Guardians may need to decide whether to hospitalize an incapacitated person or seek treatment in the community. For people with advanced illness or frailty, this issue becomes particularly salient, as many people would prefer to die at home,[47] and hospital stays may create new health issues (such as hospital-acquired infections or disorientation).[48]

*6. Hospice*

Hospice uses a team approach to focus on "caring, not curing" and, in many cases, care is provided in the patient's home. Hospice care may also be in freestanding hospice centers, hospitals, nursing homes and other long-term care facilities.[49] The Medicare hospice benefit is designed for people near the end of life. To qualify for the benefit, two physicians (one of whom is the hospice medical director) must certify that the beneficiary has a life expectancy of six months or less. The beneficiary must agree to forgo Medicare coverage for curative treatment for the terminal condition.[50]

## III. FEDERAL AND STATE POLICIES ON LONG-TERM SUPPORT AND SERVICES

### *A. Overview of Policies and Payments*

All of the residential options and services described above form the nation's system of long-term care or "long-term support and services"[51] for older people and adults with disabilities who need assistance with activities of daily living—and

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[46] TREATMENT COMMUNITIES OF AMERICA, http://therapeuticcommunities ofamerica.org/main/ (last visited Feb. 28, 2012); *Therapeutic Community*, NAT'L INSTS. ON DRUG ABUSE, http://drugabuse.gov/sites/default/files/rrtherapeutic.pdf (last visited Feb. 28, 2012).

[47] LAST ACTS, MEANS TO A BETTER END: A REPORT ON DYING IN AMERICA TODAY 1 (2002), *available at* http://www.rwjf.org/files/publications/other/meansbetterend.pdf.

[48] Richard P. Wenzel & Michael B. Edmond, *The Impact of Hospital-Acquired Bloodstream Infections*, 7 EMERGING INFECTIOUS DISEASES no. 2, 2001, at 174, 174.

[49] *What is Hospice and Palliative Care?*, NAT'L HOSPICE & PALLIATIVE CARE ORG., http://nhpco.org/i4a/pages/index.cfm?pageid=4648 (last visited Feb. 28, 2012).

[50] CENTER FOR MEDICARE & MEDICAID SERVS., CMS PUBLICATION NO. 11361, MEDICARE AND HOSPICE BENEFITS: GETTING STARTED 1 (2011), *available at* http://medicare.gov/Publications/Pubs/pdf/11361.pdf.

[51] These two terms will be used interchangeably in this Article.

frequently who have chronic medical needs as well. Guardian decisions and advocacy on where an incapacitated person lives are framed by the system's complex array of federal and state regulatory and payment programs.

Over ten million Americans require such long-term support.[52] Informal help by family members represents the vast majority of home- and community-based services in the United States, with the economic value of such support estimated in 2009 at about $450 billion per year.[53] Often, family members turn to public programs only after resources have been expended, or the disability increases and more assistance is required.

The nation's public-private "long-term care system" is a piecemeal approach historically tipping far more toward institutional than community-based living. The primary payer for long-term services and support is the federal-state Medicaid program.[54] The Medicaid program pays for 49 percent of the long-term care costs across the country.[55] "Nursing home care averages $72,000 per year, assisted living facilities $38,000 per year, and home health services average $21 per hour."[56] Medicare and private insurance cover only a small portion these costs.

Within broad federal guidelines, states have tremendous variation in Medicaid eligibility, coverage, and procedures. Each state's Medicaid program must pay for nursing home care for eligible adults, and for home health services for people who would qualify for nursing home coverage.[57] States have the option of covering additional services including assisted living and a range of community-based options.

To qualify for Medicaid long-term care coverage, individuals must meet strict income and asset rules, as well as level of care eligibility requirements, which differ by state. Because Medicaid was designed as a program for low-income people, its financial criteria are restrictive, and many must exhaust their life savings to qualify. Thirty-four states allow higher-income people who are

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[52] KAISER COMM'N ON MEDICAID & THE UNINSURED, THE HENRY J. KAISER FAMILY FOUNDATION, MEDICAID FACTS: MEDICAID AND LONG-TERM CARE SERVICES AND SUPPORTS 1 (2011), *available at* http://www.kff.org/medicaid/upload/2186-08.pdf.

[53] LYNN FEINBERG ET AL., AARP PUB. POL'Y INST., VALUING THE INVALUABLE: 2011 UPDATE, THE GROWING CONTRIBUTIONS AND COSTS OF FAMILY CAREGIVING 1–2 (2011), *available at* http://assets.aarp.org/rgcenter/ppi/ltc/i51-caregiving.pdf.

[54] ENID KASSNER ET AL., AARP PUB. POL'Y INST., A BALANCING ACT: STATE LONG-TERM CARE REFORM 1–2 (2008), *available at* http://assets.aarp.org/rgcenter/il/2008_10_ltc.pdf.

[55] *Id.* at 1.

[56] KAISER COMM'N, *supra* note 52, at 1. For additional figures on the costs of long-term care, see METLIFE MATURE MARKET INST., MARKET SURVEY OF LONG-TERM CARE COSTS 4 (2010), *available at* http://metlife.com/assets/cao/mmi/publications/studies/2010/mmi-2010-market-survey-long-term-care-costs.pdf.

[57] JANET O'KEEFE ET AL., U.S. DEP'T OF HEALTH & HUMAN SERVS., UNDERSTANDING MEDICAID HOME AND COMMUNITY SERVICES: A PRIMER 23 (2010), *available at* http://aspe.hhs.gov/daltcp/reports/2010/primer10.pdf.

"medically needy" with high medical bills to spend down to a state eligibility level to qualify for nursing home care.[58]

In recent years, Medicaid coverage of home- and community-based long-term services and supports has been growing, allowing many older people and those with disabilities to remain in their homes and receive the help they need. Professionals provide home health care, which can include nursing, physical therapy, and other clinical services. Medicaid benefits are mandatory for eligible persons.[59] States have the option of offering personal care services under the state plan. These services may be "furnished in a home or other location" that is not a hospital, nursing home, or ICF-MR. [60] Medicaid personal care services are offered under the state plan in thirty-four states and the District of Columbia.[61]

In addition to Medicaid, the Older Americans Act[62] covers a range of community-based services through state and area agencies on aging, including home-delivered and congregate meals, transportation, in-home personal care, senior centers, legal assistance, health promotion, and adult day programs. The Department of Veterans Affairs increasingly provides community-based services for veterans and their dependents.[63] Finally, many states and localities have programs to help fill gaps in long-term services and supports.

All of these long-term services and supports are up against challenging fiscal constraints, exacerbated by the recent deep recession. A 2011 study by AARP found that thirty-one states cut non-Medicaid aging and disability long-term services and supports in fiscal year 2010, twenty-eight were expecting to cut such programs in fiscal year 2011, and some states imposed cuts to Medicaid services, "most notably personal care services."[64] At the same time, requests for long-term services and supports grew.[65] Guardians frequently face diminishing options, waiting lists, closed doors, and the need for vigorous advocacy.

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[58] For a list of states and income and asset requirements, see The Henry J. Kaiser Family Found., *Income Eligibility Requirements Including Income Limits and Asset Limits for the Medically Needy in Medicaid, 2009*, STATEHEALTHFACTS.ORG (last visited Feb. 29, 2012), http://statehealthfacts.org/comparereport.jsp?rep=60&cat=4.

[59] O'KEEFE ET AL., *supra* note 57, at 23.

[60] 42 U.S.C. § 1396d(a)(24)(C) (2006).

[61] KASSNER ET AL., *supra* note 54, at 3.

[62] 42 U.S.C. §§ 3001–3058ff.

[63] *See Geriatrics and Extended Care: Veteran-Directed Home and Community Based Services Program*, U.S. DEP'T VETERANS AFFAIRS, http://www.va.gov/GERIATRICS/Veteran_Directed_Home_and_Community_Based_Services_Program.asp (last updated Aug. 19, 2011).

[64] WENDY FOX-GRAGE ET AL., AARP PUB. POL'Y INST., WEATHERING THE STORM: THE IMPACT OF THE GREAT RECESSION ON LONG-TERM CARE SERVICES AND SUPPORTS 3 (2011), *available at* http://assets.aarp.org/rgcenter/ppi/ltc/CURRENT__Budget_Paper_v9Jan6.pdf.

[65] *Id.*

### *B. Olmstead and Its Programmatic Progeny*

The 1990 Americans with Disabilities Act[66] (ADA) requires that public agencies provide services "in the most integrated setting appropriate to the needs of qualified individuals with disabilities."[67] Historically, people with mental disabilities frequently have been segregated in isolated institutions rather than living in community settings. In *Olmstead v. L.C. ex rel. Zimring*,[68] two women who were diagnosed with mental retardation and mental illness and confined to a Georgia state psychiatric institution brought a lawsuit to enforce the ADA integration mandate.[69] The United States Supreme Court determined that

> [s]tates are required to provide community-based treatment for persons with mental disabilities when the State's treatment professionals determine that such placement is appropriate, the affected persons do not oppose such treatment, and the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities.[70]

The *Olmstead* case has gained high visibility, standing for the concept that institutionalization should be a last resort—and that states must strive to increase availability of community services and supports. Since the *Olmstead* ruling, the federal government has initiated or strengthened a number of important programs[71] to bolster home- and community-based alternatives:

- Medicaid includes a "home and community-based services waiver" option under Section 1915(c) that allows states to use Medicaid funds for community services for individuals who qualify for nursing home care. Under these "waivers"—which are outside the package of services each state sets out in its Medicaid "state plan"—states can waive the federal Medicaid rules requiring that services must be available equally to all qualified persons. Under Medicaid waivers, services may be limited by number of persons, by diagnosis or condition, or by geography. The use of waivers has grown markedly over the past two decades. Every state offers at least one waiver, and most operate several, for a total of approximately 300 waiver programs nationally.[72]

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[66] 42 U.S.C. §§ 12101–12213 (2006).

[67] 28 C.F.R. § 35.130(d) (2011).

[68] Olmstead v. L.C. *ex rel.* Zimring, 527 U.S. 581 (1999).

[69] *Id.* at 593–94.

[70] *Id.* at 607.

[71] For an informative summary of these programs, see ERIC CARLSON & GENE COFFEY, NAT'L SENIOR CITIZENS LAW CENTER, 10-PLUS YEARS AFTER THE *OLMSTEAD* RULING: PROGRESS, PROBLEMS, AND OPPORTUNITIES (2010), *available at* http://nsclc.org/wp-content/uploads/2011/07/NSCLC-Olmstead-Report.pdf.

[72] *See* 42 U.S.C. § 1396n (2006); Eric M. Carlson, *Trends and Tips in Long-Term Care: Who Benefits— or Loses— from Expanded Choices?*, 18 ELDER L.J. 191, 193–94

- Between 2001 and 2010, Congress appropriated funds for "Real Choice Systems Change Grants" for states to develop community-based alternatives to institutional care.[73]
- Since 2003, the U.S. Administration on Aging and the Centers for Medicare and Medicaid Services have collaborated to fund a program of state "Aging and Disability Resource Centers" (ADRC). ADRC programs provide ready access to consumer information on long-term supports and services. ADRC programs aim to "serve as the entry point to publicly administered long-term supports including those funded under Medicaid, the Older Americans Act and state revenue programs."[74]
- In the Deficit Reduction Act of 2005 (DRA), Congress created the "Money Follows the Person" program, providing funding for states to transition Medicaid enrollees in nursing homes to community placements.[75]
- Also in the DRA, Congress authorized a Medicaid home- and community-based "State plan amendment."[76] This program allows states to cover community-based services for individuals who do not qualify for nursing home care. Additionally, the DRA gave states the option of providing for the "cost of self-directed personal assistance services," allowing consumers to choose and manage their service providers.[77]
- The 2006 reauthorization of the Older Americans Act of 1965[78] included a Community Living Program of state grants for alternatives to nursing home placement.
- As part of the newest version of the "Minimum Data Set" (MDS), which is the nursing facility resident assessment instrument required for use with residents in federally certified nursing homes, under "Section Q," residents are asked, "[d]o you want to talk to someone about the possibility of returning to the community?" If the response is yes, "the

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(2010). Additionally, some states use broader Section 1115 demonstration waivers in enhancing community-based care. *Id.* at 199.

[73] *Real Choice Systems Change Grant Program (RCSC)*, MEDICAID.GOV, http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Support/Balancing/Real-Choice-Systems-Change-Grant-Program-RCSC/Real-Choice-Systems-Change-Grant-Program-RCSC.html (last visited Feb. 28, 2012).

[74] *Aging and Disability Resource Centers: A Joint Program of the Administration on Aging & Centers for Medicare & Medicaid Services*, ADMIN. ON AGING, http://aoa.gov/AoAroot/AoA_Programs/HCLTC/ADRC/indix.aspx, (last accessed Feb. 29, 2012).

[75] Deficit Reduction Act of 2005, Pub. L. No. 109-171, § 6071, 120 Stat. 4, 102–110 (2006) (codified as 42 U.S.C. § 1396a (2006)).

[76] 42 U.S.C. § 1396n(i).

[77] *Id.* § 1396n(j)(1).

[78] Older Americans Act Amendments of 2006, Pub. L. No. 109-365, § 409, 120 Stat. 2522, 2559–62 (codified as 42 U.S.C. § 3032k).

facility must activate a care planning process" and may make a referral to a designated local agency to explore options.[79]

- The Patient Protection and Affordable Care Act of 2010[80] included a number of key initiatives to enhance Medicaid home- and community-based services.[81]
  - The "State Balancing Incentive Payments Program" allows states that are spending less than 50 percent of their Medicaid long-term care dollars on home- and community-based services to apply for an enhanced federal reimbursement rate for all such community-based services covered under their Medicaid program.[82]
  - The "Community First Choice Option" provides coverage for attendant services to help with activities of daily living, for individuals who are eligible for nursing home services, and offers states a financial incentive for adopting the option.[83]
  - The act expands services for individuals under the Home and Community-Based State Plan Benefit, removing state authority for limitations on coverage.[84]
  - The act extended and broadened the Money Follows the Person program.[85]

In all of these ways, the federal government is seeking to achieve a better "balance" of community-based and institutional services. These "balancing" policies and programs seek to tip the scales away from the historical predominance of institutional care and resources. A 2008 AARP report on the status of such state long-term care reform efforts found:

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[79] DANN MILNE, HEALTH POLICY CONSULTING FOR CMS, MDS 3.0 SECTION Q PILOT TEST: INTERIM REPORT 6 (2010), *available at* http://www.nasuad.org/documentation/aca/Reference%20Manual/5-SectionQ%20Pilot%20Test%20Result/1-SectionQPilotTestPaper.pdf ; *see also* CTRS. FOR MEDICARE & MEDICAID SERVICES, YOUR RIGHT TO GET INFORMATION ABOUT RETURNING TO THE COMMUNITY (2010), *available at* http://www.medicare.gov/publications/pubs/pdf/11477.pdf.

[80] The Patient Protection and Affordable Care Act, Pub. L. No. 111-148, 124 Stat. 119 (2010).

[81] NAT'L SENIOR CITIZENS LAW CENTER, THE MEDICAID LONG-TERM SERVICES AND SUPPORTS PROVISIONS IN THE HEALTH CARE REFORM LAW (2010), *available at* http://naela.org/App_Themes/Public/PDF/Advocacy%20Tab/Health%20Care%20Reform/NSCLC.pdf; *see also* Gene Coffey, *The Affordable Care Act's Changes to Medicaid's Coverage for Long-Term Services and Supports*, 7 NAELA J. 93, 99–103 (2011); LINA WALKER, AARP PUB. POL'Y INST., HEALTH CARE REFORM IMPROVES ACCESS TO MEDICAID HOME AND COMMUNITY- BASED SERVICES (2010), *available at* http://assets.aarp.org/rgcenter/ppi/ltc/fs192-hcbs.pdf.

[82] NAT'L SENIOR CITIZENS LAW CENTER, *supra* note 81, at 2.

[83] *Id.* at 3–4.

[84] *Id.* at 1.

[85] *Id.* at 8.

- "There is great variation among states, ranging from 5 percent or less to more than 50 percent of Medicaid [long-term services and support] funds going toward [home- and community-based services] for older people and adults with physical disabilities."[86]
- From 1999 to 2004, "[t]he number of [home- and community-based services] participants increased . . . in 43 states and declined in seven. In 27 states, the number of nursing home participants increased over the same period, while the number declined in 24 states."[87]

### *C. Where Do Guardians Stand?*

Guardians often struggle to navigate the federal-state long-term services and supports maze. They may benefit from the array of options and find one that works. They may also run up against program deficits, waiting lists, or the sheer complexity of navigating such a labyrinth of services and eligibility requirements—so might any person or family needing long-term care. However, guardians stand in a unique position because:

*Guardians are surrogates.* Guardians make decisions on behalf of someone else. In the case of guardianship agencies, the guardian is a "stranger" to the person and may have little or no information about the values that would bear on a residential decision—but may be more familiar with the social service system than a family guardian. Family guardians may know more about what the person wants or would have wanted, but may be unfamiliar with, and intimidated by, the complex set of programs and funding sources. Moreover, family guardians may experience guilt at nursing home placement, or may be involved in conflicts with other family members about what to do. In either case, the road for a surrogate is difficult.

*Guardians are court-appointed fiduciaries*. A guardian is an agent of the court, must report to the court, and must meet judicial requirements and expectations.[88] A fiduciary duty is a very high duty of care and accountability. In making a residential decision, the guardian is acting generally under the aegis of the court.

*Guardians are responsible for society's most vulnerable, at-risk members.* Incapacitated individuals are unable to make decisions about their care, living arrangements, or finances, and a judge has determined they need a guardian to step in. Often, the guardian is the sole line of defense against abuse, neglect, and exploitation. Thus, residential decisions for these persons, who often have multiple chronic conditions and dual diagnoses such as mental illness and dementia, are especially challenging.

*Consent by guardians may be necessary to make the governmental programs work as they should*. Government efforts to "balance" the long-term services and

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[86] KASSNER ET AL., *supra* note 54, at 7.

[87] *Id.* at 9.

[88] *See, e.g.*, ARIZ. CODE OF JUD. ADMIN. § 7-202(J)(3) (2012).

supports system and to effect smooth care transitions need guardians and other authorized representatives to give timely, informed consent for a hospital discharge, and a placement in a nursing home, assisted living, group home, or other community setting for individuals unable to consent for themselves. Guardians can be the linchpin that makes the system work.

## IV. AARP/ABA SURVEY AND INTERVIEW FINDINGS

### *A. Methodology*

#### *1. Survey*

To better understand how guardians make decisions about where incapacitated people live, the AARP Public Policy Institute (AARP) and the ABA Commission on Law and Aging (ABA Commission) conducted a survey of professional guardians in August 2010. The web-based survey included twenty-five questions, most of which were multiple choice or "check all that apply." Seeking responses from a spectrum of professional guardians, the authors posted a link to the survey on five relevant, largely professional, national electronic mailing lists.[89]

After the web-based responses were screened, the survey resulted in 531 valid returns, although not all respondents answered all questions.[90] The survey is not nationally representative as respondents were self-selecting. In addition, respondents did not include family or other lay guardians as—while their responses would be quite valuable—it would have been difficult to identify these individuals.

Survey respondents fell into the following categories: individual professional guardians (41 percent); staff of non-profit guardianship agencies (15 percent); staff of for-profit agencies (5 percent); staff of public guardianship agencies (15 percent); attorneys serving as guardians (12 percent); and "other" (13 percent).[91] The size of the guardianship agencies varied: for example, 64 percent of

[89] Two of the electronic mailing lists are sponsored by professional membership organizations, the National Guardianship Association and the National Academy of Elder Law Attorneys. Two electronic mailing lists are utilized by individuals with an interest in or professional connection to the list topic—Elderbar, hosted by the ABA Commission; and Elderabuse, hosted by the National Center on Elder Abuse. The fifth electronic mailing list is comprised of public guardianship programs' staff members. Participants with interest elected to log in to the survey website and complete the survey.

[90] AARP considered a response valid if the respondent answered at least the first two questions on the survey instrument.

[91] Some of the respondents in the "other" category actually would fit into the specified categories, e.g., "for-profit care management company that acts as guardian," and some had a role in the guardianship process, but it is unclear whether they actually serve as guardian, e.g., "attorney petitioning on behalf of nursing homes/hospitals," "board member of non-profit guardianship agency."

respondents were in an agency with one to ten staff members, while 6 percent reported that their agency had twenty-one or more staff members. There was also a range of professional-staff-to-client ratios: 48 percent had a ratio of 1:19 or less, while 9 percent had a much lower ratio of one staff member for every 50 or more clients.

*2. In-depth Guardian Interviews*

To get more detailed knowledge and case examples of how guardians "choose home" for incapacitated people, the authors conducted ten in-depth telephone interviews with guardians who had responded to the survey and who had indicated their willingness to be interviewed. Survey respondents were selected with a diversity of professional roles and geographic locations. The ten interviewees included two private attorneys who serve as guardians, two guardians in private for-profit agencies, one guardian in a non-profit social service agency, and four public guardianship program directors or staff members (two were directors of the same agency at different times). These guardians practice in five Eastern states: New Hampshire, Massachusetts, New York, New Jersey, and Virginia; and three Western states: Colorado, Arizona, and Washington. They work in a mix of urban, suburban, and rural settings.

### *B. Findings from Survey and Interviews*

*1. Where Do Incapacitated Guardianship Clients Live?*

Over two-thirds of the clients of survey respondents were age sixty and older,[92] and less than one-third were age eighteen to fifty-nine.[93] Among clients age sixty and older, respondents reported that roughly half live in institutions[94] and half in community settings.[95] For eighteen- to fifty-nine-year-old adults, only about a quarter of the clients live in institutions[96] and about 70 percent live in the

[92] Respondents were asked the percentage of adult clients who were age sixty and older. The mean value of responses was 72 percent.

[93] When asked the percentage of clients age eighteen to fifty-nine, the mean value of responses was 28 percent.

[94] Mean value of 49 percent.

[95] Mean value of 48 percent. The survey defined "institution" as nursing home, ICF-MR or mental health facility. It defined "community based care" as placement in any setting outside of institutional settings, such as assisted living, independent senior residence, group homes, adult foster homes, and client's own home and family member's home. Despite these definitions, based on remarks made during the in-depth interviews, investigators conjecture that some respondents considered assisted living settings to be "institutional" rather than "community based."

[96] Mean value of 27 percent.

community.[97] This difference in the residential setting of the two age groups is striking.

*(a) Specific Residential Settings*

For clients of all ages, guardians reported in the survey that about 31 percent live in nursing homes, and about 5 percent live in ICF-MR facilities. For community-based settings, the mean values were: 23 percent in assisted living facilities, 17 percent in client's own home, 6 percent in the home of a family member, 15 percent in group homes, and 4 percent in independent senior residences. The array of settings reported appears inconsistent with the charge sometimes made that there is a link between guardianship and institutionalization.[98]

*(b) Role of Supportive Services*

Most survey respondents said their community-dwelling clients use supportive community services. The most commonly used services reported were medication management (57 percent), in-home personal care (56 percent), and transportation (54 percent). Other services used by clients of at least 30 percent of respondents were housekeeping, chore services, skilled nursing, and congregate or home-delivered meals.

Participants in the in-depth interviews elaborated on all of the supportive services needed to maintain clients in the community—and the challenges in obtaining them. They stressed four key needs that form the basis for community living: housing, home care, health care, and mental health care. They stressed four key community services that can make or break a community living arrangement: in-home care, transportation, medication management, and day programs.

- For example, a man in Massachusetts had severe dementia but was physically stable. Income through pensions and veteran affairs disability allowed him to remain in senior housing. He was in a day program for six days a week, and on the seventh day his niece cared for him. She also called him every morning to remind him to get ready for the day. He loved the day program. He was not a wanderer, was all right at night, and his stove was disconnected. He had no unsafe behaviors.
- An eighty-seven-year-old woman in New York with dementia was hospitalized after a heart attack. She was discharged to a rehabilitation facility, but owned a cooperative apartment and wanted to return there. However, she was a wanderer and could not be left alone. The guardian had the apartment evaluated for safety, arranged for home care, and got her into a day program for socialization and activities.

[97] Mean value of 69 percent.
[98] *See infra* Part V.

Without appropriate housing, guardians cannot avoid institutional placement. Interviewees emphasized that finding affordable apartments is a major challenge in a place like New York City, but less of a problem in suburban Colorado or rural Arizona. Supportive housing with on-site services is not affordable for many guardianship clients. The "success stories" recounted by interviewees reaffirm the central importance of housing:

- A woman in Brooklyn, New York could not have moved home from a period of rehabilitation therapy in a nursing home had she not retained a rent-stabilized apartment.
- A man in Colorado with mental illness and dementia was able to stay in the community because he had an apartment across the street from his guardian's office.
- A woman in New Jersey owned the building in which she lived, and the guardian arranged for renovations to accommodate her needs until her deteriorating condition necessitated a move to a nursing home.
- A younger Virginia woman with an intellectual disability was able to live in a new adult foster care home, where she got the attention and freedom she needed.

The interviewees' detailed accounts of needs and services make the challenges real. In-home care, for example, involves help with activities of daily living as well as general supervision for safety. Some clients may get by with a few hours per day, but some need care twenty-four hours a day. This round-the-clock care may actually be cost-efficient, but housing must be able to accommodate the needs of the caregiver (such as a second bedroom or appropriate sleeping space).

Medication management and monitoring of blood sugar for diabetics seem straightforward and are not time-consuming tasks, yet they are challenging to arrange because of licensing requirements and availability of services. For instance, according to interviewees, visiting nurse services may not provide blood sugar monitoring on an ongoing basis—their approach is to train a caregiver to do the monitoring. But, the guardianship client may not have the caregiver available to meet this need with the required time schedule or frequency.

Sometimes the stumbling block to community placement is a very specific need. For example, a public guardianship client in one state needed adult disposable briefs, but Medicaid would not cover the cost outside of an institution, and thus he remained in a nursing home.

Some services in the community are basic and do not require a high level of skill or professional credentials, yet are indispensable and can be in short supply or expensive. Guardians must arrange for house cleaning, transportation, home maintenance such as plumbing, home repair, snow shoveling, and trash removal, and visitation by family and friends.

*2. Factors in Making Residential Decisions*

A broad array of factors could influence guardians' decisions about residential placement. These elements include

- *financial considerations* (such as resources in the incapacitated person's estate, cost of community-based settings and supportive services, relative costs of community-based versus institutional setting, availability of Medicaid and other public resources);
- *deference to preferences* of the individual and his or her family members;
- *client needs* (such as risk to client safety or health, functional needs, extent and kinds of supervisions and services required, physical accessibility of home);
- *guardianship agency considerations* (such as the mission and priorities of agency, staffing capacity of agency); and
- *other practical considerations* (such as availability and quality of community-based settings, requirement for specific court authorization, and pressure from hospital discharge).

The factors most frequently listed as "very important" by survey respondents in making individual case decisions were: functional needs of individual, risks to safety and health, and extent and kinds of supervision required.[99] These three factors can be characterized as focusing primarily on client needs (although risk to safety and health may be directly linked to guardians' concerns about their own liability).

The next most frequent responses for "very important" factors were: resources in estate, preferences of individual, availability of public payments, and availability of community-based options. This second grouping focuses more on the practical realities of making the placement work, along with a recognition that the individual's preferences, if known, are very important to consider. About three quarters of respondents said they know the placement preferences of their clients in most or some cases. The broad spectrum of factors considered important demonstrates the tough balancing act in which guardians routinely must engage.

*(a) Agency Policies vs. Individual Case Decisions*

While "mission and priorities of your agency" did not rate highly as a factor in making individual placement decisions, 38 percent of survey respondents stated that home- and community-based placement is a high priority for their agency or practice as stated in written policy, and another 26 percent called it a high priority in practice.

[99] These three factors also headed the list if responses for "very important" and "somewhat important" were grouped together.

*(b) Factors in Choosing a Long-Term Care Facility*

In choosing a facility for a client needing institutional care, the factors most often rated "very important" or "somewhat important" were "confidence in staff" and "quality of care, including CMS ratings."[100] Factors almost as frequently rated highly include "prior knowledge of facility," "available bed" and "acceptance of new residents on Medicaid." Interestingly, guardians did not rate highly such convenience factors as proximity to office and having other clients currently residing in the facility. Only 15 percent of respondents rated the quality of institutional care received by their clients as "very good" and 38 percent rated it as "good"—leaving nearly half of respondents with clients in facilities they rated as only fair or poor, often a devil's choice for caring guardians.

*(c) Role of Court*

The survey sought information on whether and when court authorization is required for residential placement in the guardian's jurisdiction. Some 35 percent of respondents reported that they are not required to get specific court authorization before a client is institutionalized or moves. Twenty-three percent of respondents said that pursuant to state law they must obtain specific authorization to place a client in an institution and 18 percent must do so for any move by a client. These same requirements are imposed by court rule or practice for institutionalization (17 percent) and for any move (18 percent). In the in-depth interviews, guardians noted that it is expensive and time-consuming to return to court for approval of residential choices. In addition, judges often lack guidance to make these determinations.[101]

*(d) How Much Choice Do Guardians Really Have?*

Narrative comments on the survey and detailed discussion with interviewees reveal that options are a mirage and decision trees only have one branch. Guardians are limited by the realities of individual assets, perceptions of liability, and limited public resources. Survey respondent and interviewee comments illustrate the limitations:

- "Funding is the major factor for placement. If funding is available, then the options are many. If there is no funding there are few options."
- "There are the 'haves' and the 'have nots.' Community options for the 'haves' aren't difficult for the guardian to arrange, but may be next to impossible for the 'have nots.'"

[100] *See Nursing Home Compare*, MEDICARE.GOV, http://medicare.gov/NHCompare/ (last visited Feb. 24, 2012).

[101] *See infra* Part VI on statutory provisions concerning guardian residential decisions.

- "Guardians' choices of suitable residential placements are severely limited. In reality, usually there is no choice; it's just advocate for what you can get."
- "You put them where you can find someone willing to take them. So it's less a decision than the only course available. I love cases where there is a real decision."
- "By the time a case gets to court, it's often too late for community-based care, at least for older people with dementia and other chronic conditions."

*3. Guardian's Role*

Survey questions about the guardian's role provided a window on both the power of guardians to enable community living and the constraints on guardians.

*(a) Guardian's Role in Delaying or Preventing Institutionalization*

Over half of the survey respondents said that "guardianship services" delay or prevent the need for institutional care: 3 percent said this always happens; 20 percent said it occurs frequently; and 29 percent said it sometimes happens. Only 23 percent said guardianship services rarely or never delay or prevent institutionalization.

Interviewees agreed that guardianship services can delay institutionalization but generally said they cannot ultimately prevent it. One guardian stated that she had been appointed to numerous cases in which the person was still living in the community but was floundering. She was able to provide support and organize services to keep them in the community—and observed that it's easier "if they have money."

*(b) Barriers to Community Placement*

Thirty-four percent of survey respondents said lack of guardian agency staff time and/or agency funding was a barrier to maintaining clients in community settings at least some of the time. However, 40 percent of respondents stated that these factors were rarely or never a barrier.

In contrast, guardians perceived a lack of supportive in-home and social services as a barrier to community placement. If additional supportive services were available, 45 percent of respondents said that most, some, or a few clients could move from institutions to community-based settings. However, 34 percent said that they currently had no adult clients in institutions that could move to the community even if additional services were available.

One attorney-guardian interviewed observed the seeming irrationality of community-based services. "Services are uneven. Some clients are getting tons of services; others can't seem to get any. It's difficult to figure out the differences." She also observed that services may be fragmented due to the nature of the client's

disabilities and whether the client enters the social services system from the mental health, developmental disabilities, or aging side. "There's very little information that different parts of the social service system have about what other agencies can do."

*(c) Demands on Guardian Time and Resources*

According to 22 percent of survey respondents, it takes more guardian time and resources to place and maintain clients in community settings than institutional settings. But 45 percent reported that the time and resources for placing and maintaining clients in residential settings varies widely by client condition and circumstances. In the in-depth interviews, all participants said the guardian time and resources required are significantly greater for community placement.

Indeed, all guardians participating in the in-depth interviews stated that community cases are more labor-intensive. One said, "yes, it's more responsibility and liability. If someone is with them 24/7, it's not a problem. But if home care is limited, what if something happens, for example, a fire, a fall? Even with a 24/7 caregiver, since we are responsible, we must make sure the care provider is doing their job. What about medical appointments? What about administering medications? All of this takes observations, calls, etc."

Another guardian observed that organizing the caregiving and making sure it is happening takes time—and that there are always decisions that no one but the guardian can make. If there are no funds to hire a care manager, the guardian may end up doing things like "taking in the dry cleaning, replacing the smoke detector battery, or unstopping the toilet."

One public guardian stated that community-based clients definitely require more of the guardian's resources, but it varies among clients. She said community-based clients with mental illness take "at least 10 times the work" and that much of this is advocacy—to keep them in the community, to get the services they need, to do things because no one else is available. Moreover, the risks to clients with mental illness can be greater, particularly in the post-Olmstead era. One guardian said, "[f]olks in a nursing home are not going hungry, homeless, or arrested." For example, a man in Virginia lived in HUD-subsidized housing, but had both dementia and mental health problems. He wandered and police had to rescue him from busy highways. The guardian had first moved him to assisted living, but as he became more combative and his dementia increased, he went to a nursing home and now the guardian is looking for a locked unit.

A survey respondent echoes concerns about risk and liability: "Nobody will be focused on Mrs. Doe's desire to live at home when she dies in a fire trying to boil water at 2 a.m. They will want to know why I did not provide for her safety."

*(d) Resources and Relationships*

Over half of respondents (53 percent) said they conduct or contract for formal capacity assessments concerning ability to live independently when placement is in

question or when the condition of an institutionalized resident changes. Eighteen percent do not perform or secure such assessments. Almost half (46 percent) of respondents said they have an ongoing relationship with an Area Agency on Aging.[102]

*(e) Effect of Guardian Fee Structures*

Interviewees pointed out effects of guardian fee structures on placement. Public guardianship programs lack sufficient funding and staffing.[103] These deficits can impact the likelihood of community placements that are seen as resource-intensive. At the same time, employees of public guardianship and nonprofit guardianship programs work on a salaried basis and may feel less pressure to limit their time on any one case. Private guardians bill by the hour and generally have their fees approved by the court. Limited funds in the estate to pay fees and court scrutiny of fee submissions can have the effect of minimizing the time the guardian spends to advocate for, secure and maintain community placements.

*4. Structure and Availability of Long-Term Supports and Services*

The in-depth interviews revealed the complexity of deciding between home care and institutional care within the realities of today's array of long-term services and supports. Weighing the options can be confounding. Home care generally costs *less* than institutional care, but it can cost *more*. This variation can depend on the intensity and nature of the client's needs, the supply of nursing home beds, the availability of home care workers and other factors that vary by client and by marketplace. Home care could be *safer*, or *less safe*, than institutional care, depending on the care resources and staffing available for the particular client. Home care can enable the client to be *engaged* in the community, but sometimes can be *more isolating* than a group home, assisted living, or nursing home. One guardian explained that her bed-bound client became extremely isolated in her apartment, and the guardian moved her to a nursing home to increase her social contacts while also increasing the ease of providing nursing care. But moving the incapacitated person may cause transfer trauma that can mitigate the benefits provided by a different setting.

*(a) Role of Assessment and Technology*

Interviewees stressed that up-front assessments of the client are critical, including assessment for risks of falling. The client's home can also be assessed

[102] Some survey respondents had interacted with an Area Agency on Aging over time, learning about the community services available, but had less current need for such contacts, and thus the amount of interaction is likely higher than the survey indicated.

[103] PAMELA B. TEASTER ET AL., PUBLIC GUARDIANSHIP: IN THE BEST INTERESTS OF INCAPACITATED PEOPLE? 143 (2010).

for accessibility and the need for accommodations. New in-home technologies may increase the safety of community settings. These include accommodations such as chair lifts on stairs, call buttons in case of falls, cameras for remote monitoring, and medical monitoring systems. Such technology may help to tip the balance for guardians toward home-based care in the near future.

*(b) Medicaid Waivers and Federal/State Reintegration Programs*

Medicaid waivers play a role in enabling adults with disabilities to get long-term services and supports while remaining in a community living arrangement. About half the survey respondents stated that they had clients covered under Medicaid home- and community-based waivers.

In the in-depth interviews, guardians stated that Medicaid waivers can be a key asset but are often insufficient. Obtaining waiver eligibility and services is challenging: The application process can be burdensome, waiting lists are long and waiver appeals take too long. Even when the client receives waiver services, they may be inflexible in meeting particular needs, the coverage period may be too short, and many incapacitated people outgrow the waiver model as their needs intensify. Finally, they are premised upon having affordable housing, which is in short supply in many locales.

In the experience of survey respondents, federal and state programs to reintegrate individuals into the community play less of a role. Only 24 percent of survey respondents said their clients moved from institutional to community-based settings under state Olmstead plans, Money Follows the Person programs, or similar state or federal programs.[104]

*(c) Other Impacts of Public Programs*

Guardians noted in interviews that it can be extremely time-consuming to qualify a person for Medicaid. They cited a need for additional Medicaid coverage of assisted living. Assisted living can meet the needs of many clients in a more community-based setting, yet often is not covered by Medicaid, whereas nursing home placement is covered, making it an inevitable choice in making cases when personal funds run out. The constraints on public funding for home- and community-based long-term services and supports have worsened during the recent economic downturn, intensifying the scarcity of resources and creating greater challenges for guardians.[105]

[104] Almost half (46 percent) said they had no clients who moved back to the community with the help of such programs, and 30 percent either did not know or did not answer the question.

[105] *See* FOX-GRAGE, *see supra* note 64, at 3–5.

*5. Savings in State Medicaid Dollars*

Community-based long-term services and supports can be substantially less expensive than institutional care. If a guardianship program aims to maximize the number of appropriate community-based placements, it may be able to show savings to state Medicaid programs. The National Public Guardianship Study recommended that guardianship programs track cost savings to Medicaid.[106]

Only 2 percent of survey respondents said they track Medicaid savings to the state due to maintaining clients in community settings. The range in money saved—for five clients reporting—was from $20,000 to $850,000 in the previous year.

The in-depth interview with the director and staff of the Guardianship Project of the Vera Institute of Justice in New York City provided a detailed look at this program's methodology for calculating Medicaid savings attributable to their program.[107] In 2010, this public guardianship program served 111 clients and succeeded in maintaining thirty-eight (approximately one-third) in deinstitutionalized settings such as homes in the community and assisted living facilities. The total net savings to Medicaid during that year was approximately $2.5 million.[108] The overall methodology determines gross savings by subtracting the actual community-based costs per client from the amount Medicaid would have paid had the client been in an institutional setting; then the program subtracts its per capita operating costs to determine net savings. For example, for nursing home avoidance, the average Medicaid nursing home rate in New York City is about $112,000. The cost of twenty-four-hour Medicaid home care is about $81,500. The per capita operating cost of the Vera Project is $8,648.60. The net savings for a client on twenty-four-hour Medicaid home care is just under $22,000 for 2010.

There were five types of savings included in the total. The largest, *mental health facility cost avoidance* among Medicaid clients, saved approximately $1.4 million. The net savings for *nursing home avoidance* among Medicaid clients was almost $131,000. *Hospital avoidance* among Medicaid clients saved nearly $113,000 in Medicaid costs. In some cases, the project delayed the spend-down of assets and thus *delayed Medicaid eligibility* by keeping the clients in the community where care is less expensive, thus stretching their private resources. The net savings for delayed Medicaid eligibility was almost $619,000. Finally, the program paid over $203,000 in *Medicaid liens* out of their clients' assets.

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[106] *See* PAMELA B. TEASTER ET AL., WARDS OF THE STATE: A NATIONAL STUDY OF PUBLIC GUARDIANSHIP 1643 (2005), *available at* http://apps.americanbar.org/aging/publications/docs/wardsofstateexecsum.pdf.

[107] *The Guardianship Project*, VERA INST. JUSTICE, http://www.vera.org/project/guardianship (last visited Feb. 25, 2012).

[108] The Guardianship Project, Vera Inst. of Justice, Inc., Summary of Medicaid Cost-Savings in 2010 (unpublished paper) (on file with author). The paper notes that some calculations are based on cost estimates due to the inability to exact Medicaid rates or average rates for some categories of care, despite diligent efforts.

## V. ADDITIONAL RESEARCH ON RESIDENTIAL SETTINGS FOR PEOPLE WITH DIMINISHED CAPACITY

AARP has found that "the overwhelming majority of people age [fifty] and older (84%) want to 'age in place,' and that those with disabilities (87%) prefer to live in their own homes."[109] These survey results reflect anecdotal statements of general sentiment: "Ask people where they want to receive care and services and they will almost unanimously say 'in my own home!'"[110] There is little or no data to indicate whether this preference changes when someone experiences diminished capacity.

This empirical evidence reveals where older people, looking toward their future, say they want to live as they age and as they may experience a decline in mental function. However, beyond the authors' study described above, we have very little information on where incapacitated people under guardianship actually do live.

Sometimes courts and guardians face the charge that guardianship "warehouses" people; routinely placing them in a nursing home and that there is a direct link between guardianship and institutionalization. In 1987, the Associated Press (AP) study of 2,200 probate court files found that in 35 percent of files, individuals lived at home before the guardianship.[111] In 33 percent of the cases, individuals were moved during the guardianship.[112] In 64 percent of cases, individuals were in a nursing home at some point during the guardianship.[113] These findings are inconclusive as to a guardianship and institutionalization link. The AP study, predating the Americans with Disabilities Act and the *Olmstead* decision, is nearly twenty-five years old, and more recent file studies are almost nonexistent. Thus, while anecdotes and press stories may highlight the alleged link between guardianship and institutionalization, this charge cannot be substantiated or denied.[114]

Statistics on the residential settings for people under guardianship are sparse. This is a subset of the sad lack of data on adult guardianship generally. Indeed, a 2006 American Bar Association study found that "there is no state-level

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[109] KASSNER ET AL., *supra* note 54, at 1; *see also* AARP BEYOND 50.05 SURVEY 9 (2005), *available at* http://assets.aarp.org/rgcenter/il/beyond_50_05_survey.pdf (noting that most Americans over fifty want to age in place); MARY JO GIBSON ET AL., BEYOND 50.03: A REPORT TO THE NATION ON INDEPENDENT LIVING AND DISABILITY, AARP (2003), *available at* assets.aarp.org/rgcenter/il/beyond_50_il.pdf (discussing the independent living movement).

[110] NAT'L CONSUMER VOICE, *supra* note 8, at 7.

[111] Fred Bayles & Scott McCartney, Special Report, *Guardians of the Elderly: An Ailing System,* ASSOCIATED PRESS, Sept. 1987, at 4.

[112] *Id.*

[113] *Id.*

[114] *See supra* Part IV.B.1. The data from the authors' limited survey did not support such a link.

guardianship data for the majority of the reporting states,"[115] and a National Center for State Courts inquiry in 2010 concluded that "the absence of accurate caseload measures is widespread."[116] Many, if not most, courts are not readily able to determine the number or percent of incapacitated people who live in nursing homes, assisted living or in community settings. The authors' search of existing information on residential settings revealed scant information.

### *A. Public Guardianship Data*

Public guardianship programs[117] use public funds to provide guardianship services as a last resort, when there is no one else willing or appropriate to help—usually for at-risk, low-income adults unable to care for themselves, with no other recourse than to become "wards of the state."[118] The National Public Guardianship Study was a two-phased examination of state public guardianship programs conducted from 2005 through 2007, including a written survey of state programs, as well as broad-based interviews with a range of stakeholders in selected jurisdictions.[119]

The national study was able to identify very little data on where clients live. Fifteen state programs reported that their proportion of institutionalized clients ranged from 37 percent to 97 percent.[120] Eleven of these narrowed the range of institutionalized clients to between 60 percent and 97 percent.

Interviewees in some states noted that very few wards are in the community by the time they are referred to the public guardianship office, that nursing home placement often is automatic after appointment, and that wards generally have little

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[115] ERICA F. WOOD, AM. BAR ASS'N COMM'N ON LAW & AGING, STATE-LEVEL ADULT GUARDIANSHIP DATA: AN EXPLORATORY SURVEY 7 (2006), *available at* http://ncea.aoa.gov/ncearoot/main_site/pdf/publication/GuardianshipData.pdf.

[116] BRENDA K. UEKERT, NAT'L CTR. FOR STATE COURTS, ADULT GUARDIANSHIP COURT DATA AND ISSUES: RESULTS FROM AN ONLINE SURVEY 4 (2010), *available at* aja.ncsc.dni.us/pdfs/GuardianshipSurveyReport_FINAL.pdf; *see also* Brenda K. Uekert & Richard Schauffler, *The Need for Improved Adult Guardianship Data*, 93 JUDICATURE 201, 201–03 (2010) (stating that current caseload data on incoming and adult guardianship is "woefully deficient"); GORDON SMITH & HERB KOHL, UNITED STATES SENATE SPECIAL COMMITTEE ON AGING, GUARDIANSHIP FOR THE ELDERLY: PROTECTING THE RIGHTS AND WELFARE OF SENIORS WITH REDUCED CAPACITY 15 (2007) (noting that reports show "a grave lack of hard data on guardianships"), *available at* http://www.guardianship.org/reports/Guardianship_Report.pdf.

[117] "A public guardian is an entity that receives most, if not all, of its funding from a governmental entity." TEASTER ET AL., *supra* note 103, at 5. Public guardianship systems may be either "implicit," in which a state statute merely names a state agency or employee as a last resort guardian, or "explicit," in which state provisions establish an office with the sole mandate of serving as public guardian. *Id.* at 23.

[118] TEASTER ET AL., supra note 103 at 2.

[119] *Id.* at 1.

[120] *Id.* at 154.

say in placement. Others described greater efforts to locate appropriate community placements.[121]

To supplement this incomplete picture, the authors sought updated information in 2011 through national electronic mailing lists,[122] and received the following information, showing the percent of adult public guardianship clients in the community ranging from 36 percent to 65 percent:

- The Kansas Guardianship Program, serving 1,500 adults throughout the state in 2010, reported that 65 percent of its adult clients were in their own home, a home they shared, a group home or other community residential setting, while the remainder lived in nursing homes, intermediate care facilities, nursing facilities for persons with mental health problems or state psychiatric hospitals.[123]
- The Illinois Office of State Guardian, serving over 4,800 clients in 2010, stated that 36 percent of its adult clients lived in supportive housing or a similar setting, or a group home under a Medicaid waiver, while 64 percent resided in intermediate care facilities, state operated mental health centers, nursing homes, or hospitals.[124]
- The New Mexico Office of Guardianship supplied data from 2009. Of a total of approximately 800 clients, 58 percent were in their own or a family member's home, independent senior housing, or group homes; 10 percent lived in assisted living; and 32 percent were in intermediate care facilities, nursing homes, or mental health institutions.[125]

### *B. Court File Studies*

Identifying residential data from court files is more difficult than from public guardianship office files. Many courts do not separate guardianship data on adults from minors; and many track only annual filings and dispositions, but not the number of individuals currently under guardianship, let alone where they live.[126] Generally, finding such information requires examination of individual case files—which in an increasing number of courts are now electronic, but in others may be at least partially hard copy.

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[121] *Id.*

[122] The electronic mailing lists included the National Guardianship Association electronic mailing list; Elderbar, operated by the ABA Commission on Law and Aging; and Elderabuse, through the National Center on Elder Abuse.

[123] *See* E-mail from Jean Krahn, Dir., Kansas Guardianship Program, to Erica Wood, Assoc. Dir., ABA Comm'n on Law and Aging (Jan. 24, 2011, 1:38) (on file with author).

[124] *See* E-mail from Helen Godlewski, Program Dir., Office of State Guardian, Illinois Guardianship and Advocacy Commission, to Erica Wood, Assoc. Dir., ABA Comm'n on Law and Aging (Jan. 25, 2011, 7:06) (on file with author).

[125] *See* E-mail from Frank Fajardo, Manager, DDPC Office of Guardianship, N.M., to NGA listserv (Feb. 15, 2011, 5:10) (on file with author).

[126] *See supra* notes 115, 116.

A literature search identified one very small file study of only twenty cases involving older adults in New York City from 2003–2006. This study found an 86 percent rate of placement from hospital to nursing home after appointment of a guardian.[127] This finding "may merely reflect the need for skilled care among this group, or it may suggest a link between guardianship and institutionalization."[128]

- In response to the authors' electronic mailing list query asking for data on residences of incapacitated persons, the Dallas County Probate Court in Texas reported on an examination of over 2,300 adult cases. Of these cases, 53 percent of individuals lived in the home of the family member who was serving as guardian, 20 percent were in a group home, 6 percent were in their own home or a relative's home, and the remainder in assisted living, a state supported living center, or nursing home.[129]

The limited data available makes it difficult to draw conclusions about where people under guardianship live, and to what extent they live in the community as opposed to an institutional setting. Moreover, even having the raw data on "where incapacitated people live" would not give the full picture as to whether they are necessarily in the least restrictive setting. For example, some individuals might find more social interaction in assisted living or even a nursing home than living by themselves with supportive services.

## VI. STATE STATUTORY PROVISIONS ON GUARDIAN RESIDENTIAL DECISIONS[130]

Guardian decisions on where an incapacitated person will live are framed, not only by the myriad of options and real-world constraints in the system on long-term care services and supports, but also, of course, by state statutory provisions. State adult guardianship laws grant guardians varying degrees of decision-making authority over the residence of the individual through seven categories of provisions. In most of these categories, only a minority of states statutorily require court approval, leaving the guardian wide latitude.[131] However, as noted previously, of the guardians surveyed, half reported needing court approval for institutionalization and 36 percent for any change in residence, pursuant to state

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[127] Joseph A. Rosenberg, *Poverty, Guardianship, and the Vulnerable Elderly: Human Narrative and Statistical Patterns in a Snapshot of Adult Guardianship Cases in New York City*, 16 GEO. J. ON POVERTY L. & POL'Y 315, 342 (2009).

[128] *Id.*

[129] *See* E-mail from Elizabeth Hart, Dall. Cnty. Probate Court Investigator, to Naomi Karp, AARP Pub. Pol'y Inst. (Feb. 28, 2011, 3:58) (on file with author).

[130] This section is based on an unpublished paper by Amy Gioletti, 2010 Borchard Law Intern with ABA Commission on Law and Aging, Choosing Home: State Statutory Authority for Guardian Residential Decisions (Aug. 2010) (on file with author). The authors wish to thank Ms. Gioletti for her research.

[131] *See infra* Part VI.B.

law, court rule, or practice—indicating that some courts go beyond the statute to ensure oversight of living arrangements.

### *A. General Statutory Authority for Custody*

"Custody" refers to "[t]he care and control of a thing or person for inspection, preservation, or security," and can also mean "confinement of a person for that person's own security or well-being."[132] The Uniform Guardianship and Protective Proceedings Act ("UGPPA")[133] states that a guardian may "take custody of the ward and establish the ward's place of custodial dwelling, but may only establish or move the ward's custodial dwelling outside the State upon express authorization of the court."[134] Seven states have adopted this or very similar language.[135]

Twenty-one states have granted guardians additional statutory authority for custody, with provisions going beyond the UGPPA to allow a move anywhere within or outside the state without further court approval.[136] Another twelve states[137] have general wording on custody, specifying, for example, that the guardian "is entitled to custody" or to "take charge of the ward." Three of these states include a limitation—a preference for keeping the individual in his or her home rather than moving to an institution or to a different state (Illinois and New

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[132] BLACK'S LAW DICTIONARY 441 (9th ed. 2009).

[133] UNIF. GUARDIANSHIP & PROTECTIVE PROCEEDINGS ACT (1997).

[134] UNIF. GUARDIANSHIP & PROTECTIVE PROCEEDINGS ACT § 315 (1997).

[135] California, Connecticut, Georgia, Hawaii, Kentucky, Nevada, and West Virginia.

[136] These twenty-one states are: Alabama, Arizona, Delaware, District of Columbia, Idaho, Indiana, Maine, Maryland, Massachusetts, Michigan, Minnesota, Montana, Nebraska, New Hampshire, New Jersey, New Mexico, North Carolina, North Dakota, Oregon, South Carolina, and Utah. *See* ALA. CODE § 26-2A-78(c)(2) (2009); ARIZ. REV. STAT. ANN. § 14-5312(a)(1) (2005); DEL. CODE ANN. tit. 12, § 3922(b)(1) (2006); D.C. CODE § 21-2047(b)(2) (2001); IDAHO CODE ANN. § 15-5-312(a) (2009); IND. CODE § 29-3-8-2 (a)(2) (2004); ME. REV. STAT. tit.18A, § 5-312(a)(1) (2011); MD. CODE. ANN. § 13-708(b)(2) (2011); MASS. GEN. LAWS ch. 190B § 5-209(b)(1) (2010); MICH. COMP. LAWS § 700.5314(a) (2011); MINN. STAT. § 524.5-313(c)(1) (2010); MONT. CODE ANN. § 72-5-321(2)(a) (2009); NEB. REV. STAT. § 30-2628(a)(1) (2009); N.H. REV. STAT. ANN. § 464-A:25(I)(a) (2004); N.J. STAT. ANN. § 3B:12-57(f)(1) (2007); N.M. STAT. ANN. § 45-5-312(B)(1) (2011); N.C. GEN. STAT. § 35A-1241(a)(2) (2011); N.D. CENT. CODE § 30.1-28-12(2) (2010); OR. REV. STAT. § 125.315(1)(a) (2011); S.C. CODE ANN. § 62-5-312(a)(1) (2009); UTAH CODE ANN. § 75-5-312 (2)(a) (2004).

[137] These twelve states are: Alaska, Arkansas, Illinois, Kansas, Missouri, New York, Ohio, Pennsylvania, South Dakota, Texas, Vermont, and Wisconsin. ALASKA STAT. § 13.26.150(c)(1) (2010); ARK. CODE. ANN. § 28-65-301(a)(3) (2004); 755 ILL. COMP. STAT. ANN. 5/11a-17(a), 5/11a-14.1 (2011); KAN. STAT. ANN. § 59-3075(b)(2) (2008); MO. REV. STAT. § 475.120(3) (2000); N.Y. MENT. HYG. LAW § 81.22(a)(9) (2006); OHIO REV. CODE ANN. § 2111.13(A)(1) (2005); 20 PA. CONS. STAT. tit. 20, § 5512.1(b) (2005); S.D. CODIFIED LAWS §29A-5-402 (2004); TEX. PROB. CODE ANN. § 767(a)(1), § 770(a) (West 2003); VT. STAT. ANN. tit. 14, § 3069(c)(1) (2010); WIS. STAT. § 54.25(2)(d)(o) (2008).

York);[138] or requiring the guardian to give notice to anyone the court specifies before changing the person's residence (Vermont).[139] Finally, eight states do not have statutory language granting the guardian general custody of the person.[140]

### *B. Court Approval for Change of Residence*

While most states provide guardians with general authority for custody of the individual, some states require guardians to seek a court order before changing the person's residence. This includes the states noted above that have adopted the UGPPA language requiring court authorization to move the place of dwelling outside the state. In addition, three states require court authorization to move the individual to a different county within the same state.[141] Two states—Connecticut and Vermont—require court authorization for any proposed change in residence.[142] While these statutes address a change in the jurisdiction of residence, they do not focus on the kind of long-term care setting in which an individual under guardianship will live, and whether it is a move to a more or less restrictive environment.

### *C. Court Approval for Institutionalization*

Because under the *Olmstead* decision institutionalization should be a last resort, and because it can be more isolating than living in a community setting, eleven states require court approval for such a move.[143] New Hampshire and Massachusetts specify that the court must find institutionalization in the person's best interests, with New Hampshire requiring this finding "beyond a reasonable doubt."[144]

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[138] 755 ILL. COMP. STAT. 5/11a-14.1 (2011); N.Y. MENTAL HYG. LAW § 81.22(a)(9) (McKinney 2006).

[139] VT. STAT. ANN. tit. 14, §§ 3069(c)(1), 3073(a)(2) (2010).

[140] These eight states are: Iowa, Louisiana, Mississippi, Rhode Island, Tennessee, Virginia, Washington, and Wyoming.

[141] *See* FLA. STAT. §§ 744.2025(1)–(2) (2011); OKLA. STAT. tit. 30, § 1-120(A) (2011); MISS. CODE ANN. §§ 93-13-61, 93-13-63 (2007).

[142] *See* CONN. GEN. STAT. § 45a-656b(a) (2011); VT. STAT. ANN. tit. 14, §§ 3073(a)(1)–(2) (2010).

[143] These eleven states are: California, Connecticut, Illinois, Kansas, Louisiana, Maine, Massachusetts, Nevada, New Hampshire, Vermont, and Wisconsin. CAL. PROB. CODE § 2356.5(b) (West 2002); CONN. GEN. STAT. § 45a-656(b) (2011); 755 ILL. COMP. STAT. ANN. 5/11a-14.1 (2011); KAN. STAT. ANN. § 59-3076(a) (West 2008); LA. CODE CIV. PROC. ANN. art. 4566(I) (2008); ME. REV. STAT. tit. 18-A, § 5-312(1) (2011); MASS. GEN. LAWS ch. 190B, § 5-309(g) (2010); NEV. REV. STAT. § 159.113(1)(o) (2008); N.H. REV. STAT. ANN. § 464-A:25(1) (2004); VT. STAT. ANN. tit. 14, § 3073(a)(1) (2010); WIS. STAT. §§ 55.055(1)(a)–(b) (2008) (allowing temporary institutionalization without court approval).

[144] N.H. REV. STAT. ANN. § 464-A:25(I)(a)(1) (2004); MASS. GEN. LAWS ch. 190B, §5-309(g) (2010).

California has provisions that focus solely on individuals with dementia. The statute requires the court to find by clear and convincing evidence that the person has been diagnosed with dementia, is incapacitated, that placement in a nursing home would benefit the person, and that a locked facility is the least restrictive setting.[145] In Kansas, the statutory scheme encourages guardians to develop and file with the court a guardianship plan, and to state in the plan "any proposal to admit the ward to any nursing facility."[146] In New York and Texas, court approval for institutionalization is required only if the individual does not agree,[147] with Texas specifically providing that "an incapacitated person who has decision-making ability" for such a decision may be placed in an institution if he or she agrees.

In addition to the eleven states specifically requiring court approval for institutionalization, Iowa requires court approval before a guardian may place an individual in any more restrictive setting,[148] and Maryland requires approval for a change in *any* classification in abode—whether more or less restrictive.[149] However, in the vast majority of the states, courts need not be notified beforehand, nor approve a move to a nursing home, other institution, or more restrictive setting.

### *D. Consideration of Least Restrictive Setting*

In addition to court approval for institutionalization, another approach to *Olmstead* implementation is to ensure guardian consideration of the least restrictive setting. Currently, fifteen states have statutory provisions referencing the least restrictive option.[150] For example, in Alaska, a guardian must "assure that the ward has a place of abode in the least restrictive setting consistent with the

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[145] CAL. PROB. CODE § 2356.5(b) (West 2002).

[146] KAN. STAT. ANN. § 59-3076(a)(1) (West 2008).

[147] N.Y. MENTAL HYG. LAW § 81.22(a)(9) (McKinney 2006) (providing that the incapacitated person shall not be placed in a nursing home or residential care facility without the consent of the incapacitated person, so long as it is reasonable under the circumstances to maintain the person in the community); TEX. PROB. CODE ANN. § 770(a) (West 2003) (stating that the guardian may apply for residential care and services provided by a public or private facility if the person agrees to such placement).

[148] *See* IOWA CODE § 633.635(2)(a) (2011).

[149] *See* MD. CODE. ANN., Est. & Trusts § 13-708(b)(2) (West 2002).

[150] These 15 states are: Alaska, Arizona, California, Illinois, Kansas, Kentucky, Missouri, Nebraska, Nevada, New Hampshire, New York, Oklahoma, Washington, Wisconsin, and Wyoming. ALASKA STAT. §§ 13.26.150(c)(1), 116(b)(3) (2010); ARIZ. REV. STAT. ANN. § 14-5312(A)(8) (2003); CAL. PROB. CODE §§ 2352(a)–(b), 2352.5(b)(4) (West 2002); 755 ILL. COMP. STAT. 5/11a-14.1 (2011); KAN. STAT. ANN. § 59-3075(b)(4) (West 2008); KY. REV. STAT. ANN. § 387.660 (West 2006); MO. ANN. STAT. § 475.120(3)(1) (2000); NEB. REV. STAT. § 30-2628(a)(1) (2009); NEV. REV. STAT. § 159.079(4) (2000); N.H. REV. STAT. ANN. § 464-A:25(1) (2004); N.Y. MENTAL HYG. Law § 81.22(a)(9) (McKinney 2006); OKLA. STAT. tit. 30, § 3-118(B)(1)(b) (2011); WASH. REV. CODE § 11.92.043(4) (2006); WIS. STAT. § 55.055(b) (2008); WYO. STAT. ANN. § 3-2-201(a)(i) (2011).

essential requirements for the ward's physical health and safety."[151] Moreover, the guardianship plan must consider "the preferability of allowing the ward to retain local community ties" and that "services [be] provided in the least restrictive setting."[152] In Kansas, a guardian must ensure that "the ward resides in the least restrictive setting appropriate to the needs of the ward and which is reasonably available."[153] In two of the states—Arizona and Nevada—the consideration explicitly includes "financial ability.[154] Only three states—California, Illinois, and New York—presume the person's home to be the least restrictive setting, [155] but in California the presumption may be overcome by a preponderance of the evidence:

> It shall be presumed that the personal residence of the conservatee at the time of commencement of the proceeding is the least restrictive appropriate residence for the conservatee. In any hearing to determine if removal of the conservatee from his or her personal residence is appropriate, that presumption may be overcome by a preponderance of the evidence.[156]

In Nebraska, a guardian must "make every reasonable effort" to ensure the least restrictive alternative, and may authorize a more restrictive setting "only after careful evaluation"—for which the guardian may "obtain a professional evaluation or assessment that such placement is in the best interest of the ward."[157]

### *E. Consideration of Individual's Preferences*

The Uniform Guardianship and Protective Proceedings Act states that "a guardian, in making decisions, shall consider the expressed desires and personal values of the ward to the extent known to the guardian."[158] Fifteen state guardianship statutes address the need for guardians to consider the preferences of individuals in guardianship.[159] Of these fifteen states, eleven[160] have substantially

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[151] ALASKA STAT. § 13.26.150(c)(1) (2010).

[152] *Id.* § 13.26.116(b)(3).

[153] KAN. STAT. ANN. §59-3075(b)(4) (West 2008).

[154] *See* ARIZ. REV. STAT. ANN. § 14-5312(A)(8) (2003); NEV. REV. STAT. § 159.079(4) (2000).

[155] *See* CAL. PROB. CODE § 2352.5(a) (West 2002); 755 ILL. COMP. STAT. 5/11a-14.1 (2011); N.Y. MENTAL HYG. LAW § 81.22(a)(9) (McKinney 2006).

[156] CAL. PROB. CODE § 2352.5(a).

[157] NEB. REV. STAT. § 30-2628(a)(1) (2009).

[158] UNIF. GUARDIANSHIP & PROTECTIVE PROCEEDINGS ACT § 314(a) (1997).

[159] These fifteen states are: Colorado, Connecticut, Florida, Georgia, Hawaii, Illinois, Kansas, Massachusetts, New Jersey, New York, Pennsylvania, South Dakota, Virginia, West Virginia, and Wisconsin. COLO. REV. STAT. § 15-14-314(1) (2011); CONN. GEN. STAT. §§ 45a-656(b)(3)–(6) (2011); FLA. STAT. § 744.3215(1)(f) (2011); GA. CODE ANN. § 29-4-22(a) (2007); HAW. REV. STAT. § 560:5-314(a) (West 2008); 755 ILL. COMP. STAT. 5/11a-14.1 (2011); KAN. STAT. ANN. § 59-3075(a)(2) (West 2008); MASS. GEN. LAWS ch.

adopted UGPPA language concerning the preferences of individuals. New Jersey explicitly mandates that if the preferences are not known, the guardian should make an effort to find out—should "ascertain" information about preferences "upon reasonable inquiry."[161] Such language does not explicitly reference residential preferences, although where to live would commonly be among a person's high priority choices.

Four states specifically require guardians to consider an individual's housing preferences.[162] In particular, Wisconsin goes further, requiring that if the housing preferences are unknown, the guardian must "[m]ake diligent efforts to identify and honor the individual's preferences with respect to choice of place of living."[163] The Florida statute maintains the most sensitivity toward the living preferences of the individual, stating, "[a] person who has been determined to be incapacitated retains the right . . . [t]o remain as independent as possible, including having his or her preference as to place and standard of living honored."[164] Furthermore, Florida has the only statute that requires the guardian to consider the *current* living preferences of the individual.[165]

### *F. Authority to Sell Real Estate*

One aspect of the guardian's authority to make residential decisions is the authority to sell real estate—which could include the person's home, and which could force a move to another and possibly more restrictive setting.

The UGPPA allows a conservator—the guardian of the property—to "acquire or dispose of an asset of the estate" without court approval if the conservator is "acting reasonably and in an effort to accomplish the purpose of the appointment."[166] A total of twenty state statutes allow guardians or conservators to sell the individual's real estate without prior court approval.[167] Of these twenty

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190B, § 5-309(a) (2010); N.J. STAT. ANN. § 3B:12-57(f) (West 2007); N.Y. MENTAL HYG. LAW § 81.20(6) (McKinney 2006); 20 PA. CONS. STAT. ANN. § 5521(a) (West 2005); S.D. CODIFIED LAWS § 29A-5-402 (2004); VA. CODE ANN. § 37.2-1020(E) (2011); W.VA. CODE § 44A-3-1 (2002); WIS. STAT. § 54.25(2)(d)(3)(b) (2008). In addition, many states have language that urges the guardian to encourage maximum self-reliance and independence. *See, e.g.*, TEX. PROB. CODE ANN. § 602 (West 2003).

[160] These eleven states are: Colorado, Connecticut, Georgia, Hawaii, Kansas, Massachusetts, New Jersey, Pennsylvania, South Dakota, Virginia, and West Virginia.

[161] *See* N.J. STAT. ANN. § 3B:12-57(f).

[162] These four states are: Florida, Illinois, New York, and Wisconsin.

[163] WIS. STAT. § 54.25(2)(d)(3)(b).

[164] FLA. STAT. § 744.3215(1)(f).

[165] *Id.*

[166] UNIF. GUARDIANSHIP & PROTECTIVE PROCEEDINGS ACT § 425(b)(7) (1997).

[167] These twenty states are: Alaska, Arizona, Colorado, District of Columbia, Hawaii, Idaho, Indiana, Maine, Montana, Nebraska, New Jersey, New Mexico, New York, North Dakota, Ohio, Oregon, South Dakota, Utah, Vermont, and Wisconsin. ALASKA STAT. § 13.26.150(d) (2010); ARIZ. REV. STAT. ANN. § 14-5424(c)(7) (2005); COLO. REV. STAT. § 15-14-425(2)(g) (2011); D.C. CODE ANN. § 21-2070(c)(7) (2001); HAW. REV. STAT.

states, fifteen either adopted or slightly modified the language of the UGPPA.[168] None of these statutes specifically address sale of the home.

A total of thirty-two states require the guardian or conservator to get court approval before selling real estate.[169] Some nine states explicitly require a court order before a guardian or conservator may sell the person's personal residence.[170] It is notable that in Oregon, a conservator may sell real estate without a court order, but approval is required to sell the home, and is counted in both lists.[171]

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§ 560:5-425(b)(7) (West 2008); IDAHO CODE ANN. § 15-5-424(3)(g) (2009); IND. CODE § 29-3-8-4(9) (2004); ME. REV. STAT. tit. 18-A, § 5-424(c)(7) (2011); MASS. GEN. LAWS ANN. ch. 190B, § 5-423(c), 202 § 5 (2010); MONT. CODE ANN. § 72-5-427(3)(g) (2009); NEB. REV. STAT. § 30-2653(c)(7) (2009); N.J. STAT. ANN. 3B:14-23(u) (West 1983); N.M. STAT. ANN. § 45-5-424(C)(7) (2011); N.Y. EST. POWERS & TRUSTS § 11-1.1(b)(5)(B) (McKinney 2008); N.D. CENT. CODE § 30.1-29-24(3)(g) (2010); OHIO REV. CODE ANN. § 2111.20 (West 2005); OR. REV. STAT. § 125.445(7) (2011) (allowing sale of all things except the protected person's personal residence); S.D. CODIFIED LAWS § 29A-5-411(5) (2004); UTAH CODE ANN. § 75-5-424(3)(g) (West 2004); VT. STAT. ANN. tit. 14, § 2798 (2010); WIS. STAT. § 54.19(2) (2008).

[168] The states that have adopted the UGPPA language are: Alaska, Arizona, Colorado, District of Columbia, Hawaii, Idaho, Indiana, Maine, Montana, Nebraska, New Mexico, North Dakota, Ohio, South Dakota, Utah, Vermont, and Wisconsin. Oregon has substantially adopted the language of the UGPPA regarding guardian authority to sell real estate, differing only in the way the statute is written.

[169] The thirty-two states that require a court order before guardians may sell real estate are: Alabama, Arkansas, California, Connecticut, Delaware, Florida, Georgia, Illinois, Iowa, Kansas, Kentucky, Louisiana, Maryland, Massachusetts, Michigan, Minnesota, Mississippi, Missouri, Nevada, New Hampshire, North Carolina, Oklahoma, Oregon, Pennsylvania, Rhode Island, South Carolina, Tennessee, Texas, Virginia, Washington, West Virginia, and Wyoming. ALA. CODE § 26-2A-152(d)(3) (2009); ARK. CODE. ANN. § 28-65-314(a)(1) (2004); CAL. PROB. CODE § 2540(b) (West 2002); CONN. GEN. STAT. § 45a-656(a), (b) (2011); DEL. CODE ANN. tit. 12, § 3951(a) (West 2006); FLA. STAT. § 744.441(12) (2011); GA. CODE ANN. § 29-5-35(a) (2007); 755 ILL. COMP. STAT. § 5/13-5(f) (2011); IOWA CODE § 633.652 (2011); KAN. STAT. ANN. § 59-3078(f)(2) (West 2008); KY. REV. STAT. § 389A.010(1) (West 2006); LA. CIV. PROC. ANN. art. 4301 (2009); MD. CODE. ANN., EST. & TRUSTS §§ 15-102(b)(3)(c), 15-102(a)(3)(i) (West 2002); MASS. GEN. LAWS ANN. ch. 190B, §5-423(c)(8) (2010); MICH. COMP. LAWS § 700.5423(3) (2011); MINN. STAT. § 524.5-418(a) (2010); MISS. CODE ANN. § 93-13-51(1) (2007); MO. ANN. STAT. § 475.200(1) (2000); NEV. REV. STAT §§ 159.113(1)(f), 159.127 (2000); N.H. REV. STAT. ANN. § 464-A:27(I) (2004); N.C. GEN. STAT. § 35A-1301(b) (2011); OKL. STAT. tit. 30, § 4-705 (2011); OR. REV. STAT. § 125.430(1); 20 PA. CONS. STAT. ANN. §§ 5155(1), 5521(b) (West 2005); R.I. GEN. LAWS § 33-15-32 (2011); S.C. CODE ANN. § 62-5-424(C)(3) (2009); TENN. CODE ANN. § 34-1-116(a) (2001); TEX. PROB. CODE § 820 (West 2003); VA. CODE ANN. § 37.2-1023(B) (2011); WASH. REV. CODE § 11.92.090 (2006); W.VA. CODE § 44A-3-5(a) (2002); WYO. STAT. § 3-3-607(a)(v) (2011).

[170] These nine states are: Arkansas, California, Florida, Illinois, Louisiana, Kansas, Minnesota, Oregon, and Wyoming.

[171] *See* OR. REV. STAT. § 125.430(1).

These states afford direct judicial scrutiny on the question of what happens to the person's home—and thus generally whether the person can continue to live there.

### *G. Authority for Commitment to Mental Institution*

The most restrictive residential option of all is a mental health facility. While a comprehensive study on guardian mental health treatment and placement authority is beyond the scope of this Article, consideration of the guardian's authority in residential decisions is incomplete without referencing placement of individuals in mental health facilities. Although states universally provide that a civil commitment is required for any involuntary placement, the question often arises whether guardians can "*voluntarily*" admit a nonprotesting incapacitated individual to a mental health facility without going through the commitment process.

The UGPPA provides that "a guardian may not initiate the commitment of a ward to a [mental health care] institution except in accordance with the State's procedure for involuntary civil commitment." [172] Guardianship statutes in thirty-one states prohibit guardians from placing an individual into a mental health treatment facility without a civil commitment procedure, tracking the UGPPA. Some states recently have allowed guardians to make at least temporary placements if the person can benefit from such treatment and does not object. For example, 2009 legislation in Virginia allowed a guardian to consent to admission of an incapacitated person to a mental health facility for no more than ten days if (1) a facility physician states that the person has a mental illness and needs treatment; (2) the facility is willing to accept the person, and the person is screened by a local mental health agency; and (3) the guardianship order specifically authorizes the guardian to consent to such admission.[173] This applies to individuals who are declining and require treatment, and are not protesting, but may not meet the standards for involuntary commitment.[174]

## VII. GUARDIAN PRACTICE STANDARDS AND CODES OF ETHICS

In addition to statutory provisions, guardians are guided by standards of practice and codes of ethics. The National Guardianship Association (NGA) has developed both—and each has a section applicable to residential decisions.

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[172] UNIF. GUARDIANSHIP & PROTECTIVE PROCEEDINGS ACT § 316(d) (1997).
[173] *See* VA. CODE § 37.2-805.1(B).
[174] *See id.*

### *A. NGA Standards of Practice*

The National Guardianship Association *Standards of Practice*[175] include under "Duties of the Guardian of the Person" that the guardian must "see that the ward is living in the most appropriate environment that addresses the ward's wishes and needs."[176] But what does "appropriate environment" mean and how should the guardian weigh "wishes" against any counterbalancing "needs," such as the need for safety and care?

Two subpoints elucidate the mandate. First, the guardian may authorize a move to a more restrictive environment only after evaluating other options and determining that the move is "the least restrictive alternative at the time," and that it fulfills the current needs and "serves the overall best interest" of the person.[177] Second, if the guardian is considering "involuntary or long-term placement" in an institutional setting, the decision must be based on minimizing the risk of substantial harm, as well as securing the "most appropriate placement" and the "best treatment."[178] These can be slippery words that are hard to translate into practice. The *Code of Ethics* helps to flesh out a guardian's duty as to living arrangements.

### *B. State Standards of Practice*

A few states have developed standards of practice for guardians,[179] and such standards sometimes address residential decisions. Relevant standards from Arizona and Minnesota are profiled below.

1. Arizona. Arizona has a comprehensive licensing program for all fiduciaries. Under this regulatory scheme, standards of conduct for guardians are specified in the *Arizona Code of Judicial Administration*.[180] These standards are remarkably thorough as to residential decisions,[181] requiring that:

- the guardian must ensure the person resides in the least restrictive environment available;
- the guardian must make decisions in conformity with the preferences of the individual in establishing residence, unless this will result in

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[175] STANDARDS OF PRACTICE (Nat'l Guardianship Ass'n 2007), *available at* http://guardianship.org/documents/Standards_of_Practice.pdf. (The NGA Standards are currently under revision.)

[176] *Id.* at 8.

[177] *Id.*

[178] *Id.*

[179] *See* Karen E. Boxx & Terry W. Hammond, *A Call for Standards: An Overview of the Current Status and Need for Guardian Standards of Conduct and Codes of Ethics*, 2012 UTAH L. REV. 1207.

[180] *See, e.g.*, ARIZ. REV. STAT. ANN. § 7-202(J)(3) (2007).

[181] *Id.*

substantial harm, and otherwise make decisions in the person's best interests;

- the guardian may not remove the person from his/her home or separate the person from family and friends unless this removal is necessary to prevent substantial harm. The guardian must "make every reasonable effort to ensure the ward resides at home or in a community setting";
- the guardian must seek professional evaluations to determine if the current or proposed placement is the least restrictive environment for the individual. The guardian is to "work cooperatively with available community based organizations to assist in ensuring the ward resides in a non-institutional environment"[182]; and
- the guardian must monitor the placement on an ongoing basis to ensure it is appropriate and consent to changes as necessary. If the only available placement is not the most appropriate and least restrictive, the guardian must "advocate for the rights of the ward, negotiate a more desirable placement with a minimum of delay and retain legal counsel for assistance if necessary."[183]

2. Minnesota. In Minnesota, there has been no governmental action concerning standards, but the Minnesota Association for Guardianship and Conservatorship (MAGiC) has a comprehensive set of standards that include the following provisions on residential decisions:[184]

- The guardian must monitor the living situation of the individual as to: whether it is the most appropriate and least restrictive available, the person's prior lifestyle and present satisfaction, and whether the arrangement meets the needs with minimal intrusion on privacy and autonomy.
- In making this assessment, the guardian is to consider the state of repair, cleanliness, and safety of the setting; the availability of needed support systems; and the planning process for identifying the best living arrangement, in collaboration with community health care resources. The guardian must also consider the quality of the living environment including activities, atmosphere and physical condition, the quality of personal and medical care, and the presence of personal items.

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[182] *Id.* § 7-202(J)(3)(f).

[183] *Id.* § 7-202(J)(3)(b).

[184] MINN. ASS'N FOR GUARDIANSHIP & CONSERVATORSHIP, STANDARDS OF PRACTICE § III(A) (revised ed. 2009), *available at* http://minnesotaguardianship.org/index.php?option=com_content&view=category&layout=blog&id=7&Itemid=1.

### *C. NGA Code of Ethics*

The National Guardianship Association *Code of Ethics*[185] states in Rule 3 that "the guardian shall assume legal custody of the ward and shall ensure the ward resides in the least restrictive environment available." Rule 3 has eight subparts, with commentary. Together, these ethical statements send a strong message to guardians of the full extent of due diligence and extreme degree of care expected in making residential choices.

> Rule 3.1: "The guardian shall be informed and aware of the options and alternatives available for establishing the ward's place of abode."
>
> > *Code* Commentary: The guardian "has an obligation to become as familiar as possible with the available options and alternatives" for placement, and should have "a thorough knowledge of community services in order to ensure that the ward's right to live in the least restrictive environment available is upheld." The commentary defines least restrictive environment as follows:
> >
> > > For purposes of this code, the least restrictive environment is considered to be the placement that least inhibits the ward's freedom of movement, informed decision making and participation in the community, while achieving the purposes of habilitation and normalization. The guardian, in establishing the place of abode for the ward, undertakes the difficult task of ensuring the protection of the ward while at the same time maximizing the ward's freedom and independence.[186]
>
> Rule 3.2. "The guardian shall make decisions in conformity with the preferences of the ward in establishing the ward's place of abode unless the guardian is reasonably certain that such a decision will result in substantial harm."
>
> Rule 3.3. "When the preferences of the ward cannot be ascertained or where they will result in substantial harm, the guardian shall make decisions with respect to the ward's place of abode which are in conformity with the best interests of the ward."
>
> > *Code* Commentary: The comment explores what it means to ascertain the person's "preferences." It cautions the guardian that it may be necessary to look behind a statement, and make further inquiry rather than simply taking it at face value – to "use care and circumspection in attempting to ascertain the preferences." It points out that a move may be especially difficult for a person with disabilities, and that he or she might be "anxious and upset about a

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[185] NAT'L GUARDIANSHIP ASS'N, A MODEL CODE OF ETHICS FOR GUARDIANS (1988), *available at* http://ilga.gov/legislation/ilcs/ilcs4.asp?DocName=075500050HArt%2E+XIII&ActID=2104&ChapterID=60&SeqStart=19200000&SeqEnd=20000000&Print=True.

[186] *Id.* at 14.

potential change." The person "may be used to the dependency fostered in an institutional setting and react negatively to even the thought of moving." On the other hand, the person "may be so unhappy in his or her current environment as to be unrealistic about what the move portends."

For all of these reasons, the guardian is advised to seek help from treatment staff, family, friends, and others familiar with the person in giving the person "a sense of the conditions surrounding the placement in terms he or she will understand." They may be able to "arrange for the ward to visit the proposed placement location" to get a better sense of the person's reaction and to help in transitioning. Indeed, "preferences," it seems, is not such a simple thing.

Rule 3.4. "The guardian shall not remove the ward from his or her home or separate the ward from family and friends unless such removal is necessary to prevent substantial harm. The guardian shall make every reasonable effort to ensure the ward resides at home or in a community setting."

*Code* Commentary: The comment advises that if the drastic measure of removing the person from home or separating the person from family is required, the guardian should seek review by a third party (such as the court, the person's attorney, or other representative), even though this may not be required by law—or if such formal review is not available or appropriate, an informal review through "in-depth discussion with an individual knowledgeable about the ward's condition and desires."

Rule 3.5. "The guardian shall seek professional evaluations and assessments wherever necessary to determine whether the current or proposed placement of the ward represents the least restrictive environment available to the ward. The guardian shall work cooperatively with community based organizations which may be available to assist in ensuring that the ward resides in a non-institutional environment."

*Code* Commentary: The evaluations may include "assessment of the ward's functional ability, his or her health status, and treatment and habilitation needs." The guardian is advised not to hesitate about requesting clarification of the evaluation and to seek additional assessment if necessary.

Rule 3.6. "The guardian shall have a strong preference against placement of the ward in an institution or other setting which provides only custodial care."

*Code* Commentary: For placement in a custodial care institution, the guardian should seek third party review as described above, even if not required by law or court rule; and such third party review is necessary "even if the ward consents."

> Rule 3.7. "The guardian shall monitor the placement of the ward on an on-going basis to ensure its continued appropriateness, and shall consent to changes as they become necessary or advantageous for the ward."
> Rule 3.8. "In the event that the only available placement is not the most appropriate and least restrictive, the guardian shall advocate for the ward's rights and negotiate a more desirable placement with a minimum of delay, retaining legal counsel to assist if necessary."

## VIII. DISCUSSION OF FINDINGS

### *A. Themes from Roundtable*

To further explore the implications of the survey and interview findings, and to move toward policy and practice recommendations, the authors convened an interdisciplinary invitational roundtable of experts on guardianship, long-term services and supports, disabilities, legal practice, and government programs. Participants included public, private, and lay guardians, elder law attorneys, a judge, federal agency officials, aging advocates, researchers, and aging and disability organization representatives. They met for a structured day-long discussion on May 9, 2011. Participants delved into the following key themes:

1. Liability is a major concern for professional guardians, and may influence decisions about where incapacitated people live. Guardians believe their exposure may be greater if an adverse event occurs in a community setting. As referenced earlier, guardians worried that "if home care services are limited, what if something happens, for example a fire or a fall?" and noted pointedly that if such a fire occurs, scrutiny will be focused on "why I did not provide for [my client's] safety," not whether she wished to live at home. Even if the lawsuit is ultimately dismissed, the experience can be financially draining and extremely time-consuming. Some participants suggested that states should provide limited immunity for good faith performance of duties by guardians, and suggested that the adoption of state standards might pave the way for limited immunity.[187]

2. Navigating the fragmented long-term services and supports system is a struggle for guardians, as it is for most of the public. Roundtable participants agreed with study interviewees that maintaining placement in the community requires considerably more guardian time and effort than choosing an institutional setting. Area Agencies on Aging (AAAs), Aging and Disability Resource Centers (ADRCs) and other resources can help caregivers understand and access long-term services and supports. Yet the majority of guardians may not be aware of these

[187] The question of guardian immunity was addressed by the Connecticut Supreme Court in *Gross v. Rell*, No. 18548 (Conn. Apr. 3, 2012). The Court found that quasi-judicial immunity extends to guardians only when the court has expressly authorized or approved specific guardian conduct and thus the guardian is acting as an agent of the court, but not when guardian acts are not specifically authorized by the court and the guardian is acting as a fiduciary.

resources. Guardians at the roundtable indicated that a "one-stop shop" for this type of information would streamline their work. Interestingly, the roundtable participants by way of shorthand dubbed community resources for information, navigation, referral, and coordination as "Bob"—and the question then became, "should the guardian have to reach out to Bob or should Bob come to the guardian?" For example, ADRCs could develop an informational packet specifically geared toward and distributed to guardians.

3. The scope of a guardian's responsibility may need greater definition in light of the complexity of today's system of long-term services and supports. Some roundtable participants viewed guardians simply as surrogate decision-makers, while others saw an expanded obligation to research all options very thoroughly. They said the latter view might have the unintended consequence of limiting the pool of guardians willing to take on this expanded role. Rather than mandating a broader role, some participants suggested an elucidation of "best practices." Others suggested that distinct standards concerning the duty to research and identify residential and support options might apply to public guardians, private professionals, and family guardians.

It is notable that the NGA Code of Ethics states that guardians should be "informed and aware of the options and alternatives available for establishing the ward's place of abode" and commentary further suggests that a guardian "has an obligation to become as familiar as possible with the available options and alternatives." Exactly how guardians should seek out, find, and familiarize themselves with this admittedly complex and changing set of information, and link to relevant resources—and how deep to dig—requires attention.

4. What is the least restrictive environment? Many assume that the "least restrictive environment" criterion tilts toward community-based placement or "staying at home." Roundtable participants discussed what may be a false dichotomy. Assisted living or even nursing home placement may be less isolating and provide more social supports for some incapacitated people—and research suggests that some may prefer assisted living over more independent settings. The concept of "least restrictive *for the specific person*" may be more appropriate.

5. The challenges of discharge planning. Relationships between guardianship agencies—particularly public guardianship programs—and hospital discharge planners can be strained. Roundtable participants discussed the "Friday afternoon at 4:30 p.m." syndrome. Guardianship agencies receive calls that the court has made a temporary or emergency appointment in response to a hospital's petition. Pressure for hospital discharge forces them to make decisions with little information about—or time to investigate—the individual's condition, family situation, needs, or assets. Nursing home placement often becomes the default—and nursing home choice may be restricted to available beds at the moment.

Some guardianship agencies work proactively to prevent these situations through outreach to hospital discharge planners and nursing home administrators. Others push back by filing appeals and objecting to unsuitable placements. Improving the hospital-guardian relationship will require education of discharge planners and other health professionals, and participants pondered more sweeping

policy changes, such as mandates, to begin transition planning earlier in the insurance cycle.

Participants also alluded to situations in which a patient is discharged from the hospital and then readmitted within a specified time period with the same condition— most likely a preventable readmission. For example, a patient might be admitted to the hospital from a nursing home because of pressure ulcers, treated, discharged back to the nursing home, and again sent back to the hospital with pressure ulcers a brief time later. The Patient Protection and Affordable Care Act[188] seeks to reduce such instances. It provides that inpatient prospective payments to a hospital will be reduced based on the dollar value of the hospital's percentage of preventable Medicare readmissions for certain specified procedures set out in regulations.[189] Roundtable discussion highlighted the critical role of guardians in helping to ensure quality care and prevent needless readmissions.

6. Discussion about Section Q of the current version of MDS.[190] Section Q, a nursing home resident assessment tool, triggered debate over the guardian's role. Section Q is designed to explore meaningful opportunities for nursing facility residents to return to community settings, and requires facility personnel to ask residents whether they want information about community-based care. Some roundtable participants contended that these questions should not be posed to residents with guardians—and that the questions should be posed to the guardian instead or in addition. Others countered that incapacitated individuals have the right to participate in care planning. All agreed that guardians should be aware of Section Q and resulting pressures concerning nursing home placement.

### *B. Guardian Standards: Key Questions*

Reviewing the findings from the authors' background research, survey, interviews, statutory analysis, and roundtable discussion, what can be said about guardian residential decisions—clearly a key determinant of quality of life for vulnerable, incapacitated individuals? While the authors' survey has limitations—it was not nationally representative and did not include "lay" guardians—the study as a whole begins to draw a picture of guardian residential decisions today. The findings broadly appear to indicate the following:

- Younger adults with guardians seem more likely to live in community-based settings than older adults who have guardians, most likely due to dementia. Whether this is because of additional supports and case management in the disability network, a stronger tradition of disability advocacy, a greater array of options available, characteristics of their needs and risks, age bias and lack of knowledge on coping with age-related problems, or some combination thereof is uncertain.

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[188] Pub. L. No. 111-148, 124 Stat. 119 (2010).
[189] *Id.* § 3025.
[190] *See supra* Part III.B.

- A guardian's "choice" of residence frequently is not a choice, especially if there is little or no estate, but simply the best of the limited options available.
- Community-based settings are often but not always preferred, often but not always the least restrictive, and often but not always less costly. They are generally harder and more time-consuming for guardians to arrange and maintain, and carry a greater burden of risk and liability.
- There may be opportunities for states to save Medicaid resources by supporting guardianship programs that target the least restrictive setting appropriate.
- Many individuals with guardians could remain in or move to the community if more services and supports were available, but frequently by the time of the guardianship, it is too late for such options.
- Guardian evaluation of residential settings requires readily accessible information about, and understanding of, a complex set of federal, state, and local long-term supports and services on an ongoing basis.
- While court approval is required for residential decisions in some states in certain instances, a substantial proportion of guardians determines where an individual will live with little court oversight or intervention.
- The National Guardianship Association has developed a thoughtful set of practice standards and ethical guidelines on residential decisions—but these may not be known or understood by the bulk of guardians, and their implementation may be thwarted in the reality of the piecemeal, variably regulated, disparate and financially constrained long-term care environment.

While the authors' study may help to crystallize such general and impressionistic findings, a host of knotty questions bears further examination in fashioning standards for guardians:

*Guardian Balancing Act*

- How does recognition of individual preferences and values play out against mandates for the least restrictive placement?
- How can or should a guardian best balance risks to an individual's health and safety with mandates or preferences for community-based settings? How should the guardian factor in the additional risk that supportive resources available through public programs may be reduced?
- How do or should guardian fee structures and funding for guardianship services affect residential decisions?
- How should guardians best approach family conflict and risks of financial exploitation of the incapacitated person when making residential decisions?

- How far should a guardian go in expenditure of time and resources in seeking to make community placement work in tough situations? To what extent and under what circumstances is delaying institutionalization worth pursuing, given the cost to the estate or the guardian and risk to the individual?
- How are guardian residential decisions different for various populations—for example, individuals with dementia, intellectual disabilities, mental illness, or a brain injury? Should standards reflect these differences?
- What changes in guardian assessments (including capacity assessment and risk assessment) and care plans might bear on residential placement of people under guardianship?

*Guardians and Community Resources*

- How and to what extent should guardians familiarize themselves with the array of residential options in their community? What is the role of guardians versus the role of public "customer service" programs charged with helping consumers navigate the system of long-term services and supports (such as Medicaid, Older Americans Act services, and Aging and Disability Resource Centers)?
- What should be the relationship or protocol between guardians, hospitals, and long-term care discharge planners?
- What is or should be the role of guardians in a state's system of long-term supports and services? How should public policy factor in Medicaid savings to the state that result from guardian efforts to make community-based care work?

*Guardians and Court*

- What should be the role of the court in providing guardians with information and training on residential decision-making?
- Do requirements for court approval of residential decisions enhance optimal decision-making and if so, which ones and in what manner? Should guardians seek court approval or other review of residential decisions regardless of statutory or court rule requirements? Under what circumstances?
- What changes in periodic reporting and court oversight might enhance guardian residential decisions?

"Choosing home" for someone else is a highly personal, highly charged decision that guardians frequently must make, often in a crisis scenario in which there is there is no ideal option and trade-offs are tough. The challenge, then, is

finding a sound conceptual framework to guide guardians in making this life-changing determination.