AARP Public Policy Institute

Choosing Home for Someone Else: Guardian Decisions on Long-Term Services and Supports

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Research Report

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Choosing Home for Someone Else: Guardian Decisions on Long-Term Services and Supports

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AARP's Public Policy Institute informs and stimulates public debate on the issues we face as we age. Through research, analysis and dialogue with the nation's leading experts, PPI promotes development of sound, creative policies to address our common need for economic security, health care, and quality of life.

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EXECUTIVE SUMMARY[1]

Few things are as important as where you live, where you call home. For a frail older person or individual with disabilities, "home" can be a long-standing family residence with help, but might also be a room in a nursing home, senior housing residence, assisted living facility, group home, or other supportive setting. A guardian with responsibility for determining where a person lives takes on a charge that goes to the core of quality of life.

A guardian's "choice" of where a person lives may be dictated by a constellation of factors: the person's expressed preferences, scarcity of optimal settings, financial resources, perceived risk, the kinds of care and supervision needed, applicable law and court order, process of hospital discharge, and more. State budget cutbacks have curtailed available options, especially for low- and moderate-income individuals, thus limiting a guardian's choices in making the determination of where "home" will be.

This report presents findings from an in-depth study by the authors on guardian residential decisions. The study, based on a survey of professional guardians, presents original research on where people under guardianship live, how guardians make residential decisions, and how they seek to balance independence and perceived risk, often in the face of restricted options. It suggests ways in which guardianship and Long-Term Services and Supports (LTSS) affect each other.

The Role of Guardians in Long-Term Services and Supports (LTSS)

Guardianship is a relationship created by state law in which a court gives one person or entity (the guardian) the duty and power to make personal and/or property decisions for another (the incapacitated person or ward). A judge appoints a guardian upon finding that an adult lacks capacity to make decisions for him or herself.

A current "best guess" national estimate of the number of adults under guardianship in the United States is approximately 1.5 million.[2] The need for guardianship and other surrogates will grow as the population ages, and as the prevalence of Alzheimer's disease, the number of "old old," and the number of individuals with intellectual disabilities, mental illness, and traumatic brain injury all increase.[3]

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[1] The Public Policy Institute study for this report also served as the basis for an article by the authors titled "Choosing Home for Someone Else: Guardian Residential Decision-Making," *Utah Law Review* No. 3 (2012), pp. 1445–1490.

[2] Because data are scant and vary in quality, this is an estimate only, and the number of active pending adult guardianship cases could range from fewer than 1 million to more than 3 million. See B. Uekert and R. Van Duizend, "Adult Guardianships: A 'Best Guess' National Estimate and the Momentum for Reform," *Future Trends in State Courts 2011*, pp. 107–112. (Williamsburg, VA: National Center for State Courts, 2011)

[3] See N. Karp and E. Wood, *Guarding the Guardians: Promising Practices for Court Monitoring* (Washington, DC: AARP Public Policy Institute, December 2007). Also see National Guardianship Association, http://www.guardianship.org; National Center for State Courts, Center on Elders and the Courts, http://eldersandcourts.org; and M. J. Quinn, *Guardianships of Adults: Achieving Justice, Autonomy, and Safety* (New York, NY: Springer Publishing Company, 2005).

Guardians may be family members, friends, volunteers, or professional guardians. Professional guardians may be individuals, private nonprofit or for-profit agencies, public guardianship agencies, attorneys, or financial institutions (for property decisions).

Guardians are challenged in finding LTSS for incapacitated individuals. They are responsible for society's most vulnerable, at-risk members, and their consent may be necessary to make LTSS programs function as they should. They often run up against program deficits, waiting lists, and the sheer complexity of services and eligibility requirements. But their role is unique:

- ***Guardians are surrogates***, making decisions on behalf of someone else.
- ***Guardians are court-appointed fiduciaries*** who must report to the court and meet judicial requirements.
- ***Guardians are responsible for society's most vulnerable, at-risk members***, who may have multiple chronic conditions and may be threatened by abuse, neglect, or exploitation.
- ***Consent by guardians*** may be necessary to make governmental programs function as they should. Government efforts to "balance" the LTSS system and to promote smooth care transitions need guardians to give timely, informed consent for discharge and placement.

Findings from a Study on Guardian Residential Decisions[4]

Where Do People under Guardianship Live?

- Older adults (60+) with guardians are less likely to live in community settings than younger adults with guardians. For individuals age 60+, guardians reported that roughly half live in institutions and half in community settings; but for those age 18 to 59, only about a quarter live in institutions.
- For all ages, the survey of adults with guardians shows that 30 percent live in nursing homes, 5 percent in intermediate care facilities, 23 percent in assisted living, 17 percent in the person's own home, 6 percent in the home of a family member, 15 percent in group homes, and 4 percent in independent senior residences.
- About half the survey respondents had clients who receive services under Medicaid home- and community-based waivers. The supportive services most frequently used were medication management, in-home personal care, and transportation.
- Many guardians said some, most, or at least a few of their clients could move to a community setting if additional supportive services were available.
- More than half the guardians surveyed said guardianship services including care management could sometimes or frequently delay or prevent institutional care. However, some guardians said that by the time of the guardianship, it is often too late for community-based options, as 24-hour care and medically oriented supervision may be needed.

[4] The authors' study included a web-based survey of more than 500 professional guardians, as well as in-depth guardian interviews and an interdisciplinary roundtable discussion. This study did not include family guardians, whose responses could be considerably different.

How Do Guardians Make Residential Decisions?

- Guardians rated as the "most important" factors in making residential decisions the functional needs of the individual, the perceived risks to client safety or health, and the extent and kinds of supervision required. Other important factors were the person's preferences, the estate's resources, and the availability of options.
- Guardians said community settings are often—but not always—preferred because they are less restrictive, less isolating, and less costly. However, community settings are more difficult for guardians to arrange and supervise.
- Guardians contended that their "choice" of residence is frequently not really a choice—especially if there is little or no estate, the individual lacks community supports, or affordable housing is not available—but simply the best of the limited options.
- Many believe that individuals could remain in or move to the community if more housing and supports were available.
- Sometimes pressure for hospital discharge forces guardians to make decisions on the spot with scant information. Nursing home placement often becomes the default.
- Guardians said they need more easily accessible information on the services and options available.
- Maintaining an individual in the community rather than an institution requires considerably more guardian time and effort and is perceived to carry a greater burden of risk to the person and liability for the guardian. More than a third of guardians said lack of time and funding is a barrier to keeping clients in the community.
- Because community services and supports can be less expensive than institutional care, guardianship programs that aim to maximize appropriate community placement may be able to save state and federal Medicaid funds. However, only a few programs track such savings.
- The authors' review of state statutes showed that while court approval sometimes is required for guardian residential decisions, guardians frequently determine where an individual will live, with little judicial oversight. Beyond statutory requirements, guardians may be guided by professional standards of practice.

Looking Ahead: Suggestions for Next Steps

"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 no ideal option. Some recommendations to ensure ongoing support to guide guardians in making this life-changing determination follow:

1. Standards should outline decision-making steps for guardians to make person-centered residential decisions.
2. States should seek to expand home- and community-based services, better balance services from institutional to non-institutional settings, and promote affordable, accessible housing. Guardians should be vigorous advocates for such approaches.
3. Information on available options should be easily accessible for guardians in real time.

4. Policies should encourage early guardian involvement in hospital and nursing home discharge planning. Discharge planners and nursing home administrators should engage in outreach to guardianship agencies to determine how best to address emergency situations.
5. State Medicaid agencies should recognize the role of guardians in LTSS. They should consider factoring in Medicaid savings to the state resulting from guardian efforts to identify services and make community placements work.
6. Courts should work with community partners to provide professional and family guardians with training on residential options, decision making, and person-centered planning. Judges should be educated on the array of community-based services available.
7. Guardianship statutory provisions, court rules, and practices should promote community settings when not inconsistent with the person's preferences. Appropriateness of residence should be a key part of guardianship monitoring.

INTRODUCTION[5]

Sue had lived in her own home for 50 years. She recently lost her home because her daughter misappropriated her funds. She wanted to live as independently as possible and to avoid 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.

Jack, a 53-year-old man with an intellectual disability, was injured on 9/11. 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 services.

Source: These profiles are based on actual cases described in the authors' interviews with guardians.

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."[6] Home can be the place where one has "deep seated ties with family members and close friends" and "a harbor of family traditions."[7] 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 an assisted living facility, nursing home, group home, or other setting with supports and services. Where you live involves 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.

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

Without affordable residential options, a guardian will be in a bind. The extent to which such options are readily available is influenced by federal, state, and local priorities and budget for institutional versus community care. State budget cuts have limited available options, especially for low- and moderate-income individuals. Thus, guardians may have few choices as they make the daunting determination of where

[5] The Public Policy Institute study for this report also served as the basis for an article by the authors titled "Choosing Home for Someone Else: Guardian Residential Decision-Making," *Utah Law Review* No. 3 (2012), pp. 1445–1490.

[6] *The Wizard of Oz* (Metro-Goldwyn-Mayer 1939).

[7] J. Pynoos, C. Nishita, C. Cicero, and R. Caraviello, "Aging in Place, Housing, and the Law," *Elder Law Journal*, Vol. 16, No. 1 (2008), pp. 77–105 (discussing the importance of the home).

"home" will be. At the same time, by making surrogate residential decisions and providing consent for transitions from one setting to another, guardians can help to make the LTSS system work and facilitate the drive toward community-based settings.

This report is based on a survey of professional guardians and describes the results of an in-depth study of guardian residential decisions. The study presents original research on where people under guardianship live, how guardians make decisions about living arrangements, and how they seek residential settings that are safe and enhance independence—often in the face of restricted options. It suggests ways in which guardianship and LTSS affect each other.

The report offers a basic background on adult guardianship and on federal/state LTSS policy. It describes the results of an in-depth study by the authors on guardian residential decisions, including a review of existing data, a nationwide survey, selected guardian interviews, and insights from an interdisciplinary roundtable. It also offers a statutory analysis of guardian residential decision-making authority, describes key provisions of guardian practice standards, and concludes with a discussion of the findings and additional questions.

BACKGROUND AND METHODOLOGY

Adult Guardianship

Guardianship is a relationship created by state law in which a court gives one person or entity (the guardian) the duty and power to make personal and/or property decisions for another (the incapacitated person or ward). A judge appoints a guardian upon finding that an adult lacks capacity to make decisions for him or herself.

Guardianships are established through a legal process outlined in state law. The process begins with a petition alleging incapacity, followed by a court hearing, a judicial finding on capacity, and the appointment of a guardian. The judge may appoint a guardian of the person only, a guardian of the property only (often known as a "conservator"), or guardian for both the person and the property. The appointment may be an emergency order if the person is at risk of immediate harm. The appointment also may be "limited" to specified areas of decision-making. Guardians may be family members, friends, private nonprofit agencies, private for-profit agencies, public guardianship agencies, attorneys serving as guardian, financial institutions (for property decisions), or volunteers. Upon appointment, the guardian may be required to post a bond, and must submit periodic reports and accountings to court.

A current "best guess" national estimate of the number of adults under guardianship in the United States is approximately 1.5 million.[8] The need for guardianship and other surrogates will grow as the population ages, and as there are more people with Alzheimer's disease, more "old old" people, and more individuals with intellectual disabilities, mental illness, and traumatic brain injury.[9]

Residential Options for People under Guardianship

Incapacitated adults—like other older adults and individuals with disabilities—live in a broad spectrum of community and institutional settings. While there is no bright line clearly distinguishing the two, in community settings (with some exceptions), residents usually pay privately for ownership or rental of their units, and any regulation is generally at the state or local level. Institutional settings tend to be more medically based and more highly regulated by federal and state entities.

Federal/State Long-Term Services and Supports (LTSS)

Policies and Payments

The public-private LTSS "system" that confronts guardians—as well as all others seeking long-term services—is a piecemeal approach, with public spending historically

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[8] Because data are scant and vary in quality, this is an estimate only, and the number of active pending adult guardianship cases could range from fewer than 1 million to more than 3 million. See B. Uekert et al., "Adult Guardianships: A 'Best Guess' National Estimate and the Momentum for Reform," *Future Trends in State Courts 2011*, pp. 107–112.

[9] See N. Karp et al., *Guarding the Guardians: Promising Practices for Court Monitoring*. Also see National Guardianship Association, http://www.guardianship.org; National Center for State Courts, Center on Elders and the Courts, http://eldersandcourts.org; and M. J. Quinn, *Guardianships of Adults: Achieving Justice, Autonomy, and Safety* (New York, NY: Springer Publishing Company, 2005).

Community Settings versus Institutional Settings for Persons Living Under Guardianship

Community Settings	Institutional Settings
Supported living at home	Larger and more medically based assisted living
Congregate housing	Nursing homes
Apartment in continuing care retirement community	Intermediate care facilities for individuals with intellectual disabilities
Low- or moderate-income apartment (including HUD "senior housing")	Mental health institutions
Small community group homes (serving adults with intellectual disabilities, mental illness, or brain injury)	Hospitals
Small residential assisted living	Residential hospice programs
Small adult foster care homes	

Source: Survey of Agency/Professional Guardians on Residential Decisions for Adult Clients, AARP Public Policy Institute, August 2010.

tipping far more toward institutional than community living. The primary payer for LTSS is the federal-state Medicaid program, which pays for 62 percent of the LTSS costs across the country.[10] Medicare and private insurance cover only a small portion of the costs.

Within broad federal guidelines, states have tremendous variation in Medicaid eligibility, coverage, and procedures. In recent years, Medicaid coverage of community-based LTSS has been growing, allowing many beneficiaries to remain in their homes and receive the help they need. State Medicaid programs may include personal care services "furnished in a home or other location"[11] that is not a hospital, nursing home, or intermediate care facility. Personal care services are offered under Medicaid state plans in 34 states.[12] Additionally, "home and community services waivers" allow states to use Medicaid funds for community services for individuals who qualify for nursing home care.[13] Also, the Older Americans Act[14] and the Department of Veterans Affairs (VA)[15]

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[10] C. V. O'Shaughnessy, *The Basics: National Spending for Long-Term Services and Supports (LTSS) 2011* (Washington, DC: National Health Policy Forum, February 1, 2013). Accessed on April 1, 2013, at https://www.nhpf.org/uploads/announcements/Basics_LTSS_02-01-13.pdf.

[11] 42 U.S.C. §1396d(a)(24)(C).

[12] E. Kassner, S. Reinhard, W. Fox-Grage, A. Houser, and J. Accius, *A Balancing Act: State Long-Term Care Reform*, at 3, AARP Public Policy Institute, #2008-10 (July 2008).

[13] These are known as Section 1915(c) waivers. See 42 U.S.C. §1396n(c); 42 C.F.R. §441.300 et seq. Additionally, some states use broader Section 1115 demonstration waivers in enhancing community-based care. See E. Carlson, "Trends and Tips in Long-Term Care: Who Benefits – or Loses – From Expanded Choices?" *Elder Law Journal*, Vol. 18, No. 191 (2010), pp. 191–212.

[14] 42 U.S.C. 35, §3001 et. seq.

[15] U.S. Department of Veterans Affairs, Veteran-Directed Home and Community Based Services Program. Accessed on July 28, 2011, at http://www.va.gov/GERIATRICS/Veteran_Directed_Home_and_Community_Based_Services_Program.asp.

cover a range of community-based services. Finally, many states and localities have programs to help fill service gaps.

All of these LTSS are up against challenging fiscal constraints, exacerbated by the recent Great Recession. A study by AARP found that 14 states cut non-Medicaid aging and disability LTSS in fiscal year FY 2011. In comparison, in FY 2010, 31 states indicated they would reduce funding for non-Medicaid programs. At the same time, requests for LTSS grew. Although demand has increased since the beginning of the recession, state funding for these programs has not kept pace.[16]

The *Olmstead* Decision; Promoting Community-based Programs

The 1990 Americans with Disabilities Act[17] requires that public agencies provide services "in the most integrated setting appropriate to the needs of qualified individuals with disabilities."[18] The landmark 1999 U.S. Supreme Court decision *Olmstead v. L.C.*[19] determined that

> [s]tates are required to place persons with mental disabilities in community settings rather than in institutions when the State's treatment professionals have determined that community placement is appropriate, the transfer from institutional care to a less restrictive setting is not opposed by the affected individual, and the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities.[20]

The *Olmstead* case means that institutionalization should be a last resort—and that states must strive to increase community services and supports. The federal government has initiated a number of important programs[21] to bolster community alternatives, seeking a better service "balance," and tipping the scales away from the historical predominance of institutional care. A 2011 AARP report found that the percent of Medicaid and state-funded LTSS spending going toward home- and community-based

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16 M. Cheek, M. Roherly, L. Finan, E. Cho, J. Walls, K. Gifford, W. Fox-Grage, and K. Ujvari, *On the Verge: The Transformation of Long-Term Services and Supports* (Washington, DC: AARP Public Policy Institute, February 2012).

17 42 U.S.C. §12101 et seq.

18 28 C.F.R. §35.130(d) (2011)

19 *Olmstead v. L.C.*, 527 U.S. 581 (1999).

20 *Id.* at 607.

21 For an informative summary of these programs, see E. Carlson and G. Coffey, *10-Plus Years After the Olmstead Ruling: Progress, Problems, and Opportunities* (Washington, DC: Nat'l Senior Citizens Law Center, 2010). Accessed at http://www.nsclc.org/about-us/nsclc-in-the-news/NSCLC%20Olmstead%20Report.pdf. For example, "aging and disability resource centers" 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." Also see Administration on Aging, Aging and Disability Resource Centers. Accessed on July 29, 2011, at http://acl.gov/Programs/Integrated_Programs/ADRCs/Index.aspx. Additional programs bolstering community-based settings include "Real Choice Systems Grants," "Money Follows the Person," Medicaid home- and community-based "state plan benefits," the Older Americans Act, "Community Living Program," and several key initiatives under the Patient Protection and Affordable Care Act of 2010.

services for older people and adults with physical disabilities ranged from 10.5 percent to 63.9 percent.[22]

Where Do Guardians Stand?

Guardians often struggle to navigate the federal-state LTSS maze. They may find an option that works—or they may run up against program deficits, waiting lists, closed doors, or the sheer complexity of services and eligibility requirements. Although any person, professional, or family looking for LTSS might face similar obstacles, guardians stand in a unique position:

Guardians are surrogates. Guardians are making 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. On the other hand, family members appointed as guardians, who were not surveyed for this report because they would have been difficult to identify, 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. In either case, the road for a surrogate is challenging.

Guardians are court-appointed fiduciaries. Guardians are agents of the court; they must report to the court and must meet judicial requirements and expectations. Guardians owe a fiduciary duty to incapacitated persons, which 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, and/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. Residential decisions for these persons, who often have multiple chronic conditions and dual diagnoses such as mental illness and dementia, are challenging.

Consent by guardians may be necessary to make the governmental programs function as they should. Government efforts to promote home- and community-based care and smooth care transitions of incapacitated individuals require timely, informed consent for discharge and placement by guardians and other authorized representatives. Guardians sometimes can be the linchpin that makes the system work.

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[22] S. Reinhard, E. Kassner, A. Houser, and R. Mollica, *Raising Expectations: A State Scorecard on Long-Term Services and Supports for Older Adults, People with Physical Disabilities, and Family Caregivers* (Washington, DC: AARP Public Policy Institute September, 2011).

Study Methodology

Literature Search

The authors conducted a literature search for information on where individuals under guardianship live. When this yielded little data, they sought basic statistical information through largely professional, national Listservs.

Survey

To better understand guardians' decisions about where incapacitated people live, the authors conducted a web-based survey of professional guardians in August 2010. The survey included 25 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 national Listservs.[23] Because they would have been difficult to identify, the survey did not include family and other lay guardians, whose responses could be considerably different.

After the responses were screened, the survey resulted in 531 valid returns. The survey is not nationally representative, as respondents were self-selecting and, as stated above, did not include family or other lay guardians. Survey respondents included individual professional guardians (41 percent); staff of nonprofit 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). The size of the guardianship agencies varied—for example, 64 percent of respondents were in an agency with 1 to 10 staff members, while 6 percent reported that their agency had 21 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 1:50 or more.

In-depth Guardian Interviews

For a closer look at how guardians "choose home" for incapacitated people, the authors conducted 10 in-depth telephone interviews with guardians who had responded to the survey, and who had a diversity of professional roles and geographic locations. The 10 interviewees included two private attorney guardians; two guardians in private, for-profit agencies; one guardian in a nonprofit social service agency; and four public guardianship program staff. These guardians practice in five Eastern states (New Hampshire, Massachusetts, New York, New Jersey, and Virginia) and three Western states (Colorado, Arizona, and Washington), in a mix of urban, suburban, and rural settings.

AARP Public Policy Institute Innovation Roundtable

To get an interdisciplinary viewpoint, the authors in May 2011 convened a structured invitational roundtable of experts including public, private, and lay guardians; elder law attorneys; a judge; federal agency officials; aging advocates; researchers; and aging and disability organization representatives.

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[23] Listservs included the National Guardianship Association Listserv; ELDERBAR, operated by the ABA Commission on Law and Aging; ELDERABUSE, through the National Center on Elder Abuse; National Academy of Elder Law Attorneys Listserv; and a Listserv comprised of public guardianship program staff.

FINDINGS

Existing Data on Where People under Guardianship Live

AARP has found that "the overwhelming majority of people age 50 and older (84 percent) want to 'age in place,' and that those with disabilities (87 percent) prefer to live in their own homes."[24] There are little or no data to indicate whether this preference changes when someone experiences diminished capacity or—beyond the current study—where incapacitated people under guardianship actually do live.[25]

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. However, guardianship file studies are scant, and while anecdotes and media stories[26] may highlight the alleged link between guardianship and institutionalization, this charge cannot be substantiated or denied.

The authors' search of existing information on residential settings revealed little information from public guardianship programs[27] and court files. The National Public Guardianship Study, examining state public guardianship programs from 2005 to 2007, found very little data on where clients live. Fifteen state programs reported that the proportion of institutionalized clients ranged from 37 percent to 97 percent—and 11 of these narrowed the range of institutionalized clients to between 60 percent and 97 percent.[28] According to this study,

> Interviewees in some states noted that very few individuals are in the community by the time they are referred to the public guardianship office, that nursing home

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[24] N. Farber, D. Shinkle, J. Lynott, W. Fox-Grage, and R. Harrell, *Aging in Place: A State Survey of Livability Policies and Practices* (Washington, DC: AARP Public Policy Institute and National Conference of State Legislatures 2011 at 1).

[25] Statistics on adult guardianship, let alone where incapacitated people live, are sparse. See E. Wood, *State Level Adult Guardianship Data: An Exploratory Survey* (Washington, DC: National Center on Elder Abuse, 2006), accessed at http://www.ncea.aoa.gov/Resources/Publication/docs/GuardianshipData.pdf; and Conference of State Court Administrators, *The Demographic Imperative: Guardianships and Conservatorships* (December 2010), accessed at http://cdm16501.contentdm.oclc.org/cdm/singleitem/collection/famct/id/308/rec/1. 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 facilities, or community settings.

[26] A landmark 1987 Associated Press study of 2,200 probate court files found that during the guardianship, in 33 percent of the cases, individuals were moved, and in 64 percent of cases, individuals resided in a nursing home at some point. F. Bayles and S. McCartney, *Guardians of the Elderly: An Ailing System: A Special Report* (Washington, DC: Associated Press, 1987).

[27] Public guardianship programs 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." P. Teaster, E. Wood, W. Schmidt, and S. Lawrence, *Public Guardianship After 25 Years: In the Best Interest of Incapacitated People?* University of Kentucky and ABA Commission on Law and Aging (2007). See also Phase I of the National Public Guardianship Study, P. Teaster, E. Wood, N. Karp, S. Lawrence, W. Schmidt Jr., and M. Mendiondo, *Wards of the State, A National Study of Public Guardianship 13* (2005). The two-phase study was published in P. Teaster, E. Wood, S. Lawrence, W. Schmidt Jr., and M. Mendiondo, *Public Guardianship: In the Best Interests of Incapacitated People?* (Chicago, IL: Praeger, 2010).

[28] *Ibid.*, at *Public Guardianship After 25 Years*, Conclusion #3, p. 90.

placement often is automatic after appointment, and that incapacitated persons generally have little say in this placement decision. Other states and programs described making greater efforts than in the past to locate appropriate community placements.[29]

To supplement this incomplete picture, the authors sought updated statistics in 2011, and received 2009 to 2010 information from three state professional guardianship programs (Kansas, Illinois, and New Mexico)[30] that shows a wide variation in the proportion of adult clients in community and institutional placements, with the percent of clients in the community ranging from 36 percent to 65 percent.[31]

Identifying residential data from court files is more difficult than from public guardianship office files. The literature search identified one very small file study of only 20 cases involving older adults in New York City from 2003 to 2006. This study found an 86 percent rate of placement from hospital to nursing home after appointment of a guardian. This finding "may merely reflect the need for skilled care among this group, or it may suggest a link between guardianship and institutionalization."[32]

In response to the authors' data query, the Dallas County Probate Court in Texas reported on an examination of more than 2,300 adult cases which included those with family guardians. Of these cases, 53 percent of individuals lived in the home of the family member who was serving as guardian;[33] 20 percent were in a group home; 5 percent were in their own home or a relative's home; and the remainder were in an assisted living facility, a state supported living center, or a nursing home.[34]

Survey and Interview Findings

Because existing data are so limited, it has been difficult to draw conclusions about where people under guardianship live. The authors' survey provided valuable new information—at least as to clients of professional guardians. Family guardians might show different outcomes.

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29 *Ibid*.

30 Family guardians might have shown different results.

31 Email responses on file with the ABA Commission. The Kansas Guardianship Program data showed 65 percent of clients in their own home, shared homes, group homes, or other community settings; and 35 percent in nursing homes or other institutional settings. The Illinois Office of State Guardian showed 36 percent of clients in supportive housing or similar arrangements, or group homes under a Medicaid waiver; and 64 percent in intermediate care facilities, state operated mental health centers, nursing homes, or hospitals. The New Mexico Office of Guardian reported 58 percent of clients in their own or family member's home, independent senior housing, or group homes; 10 percent in assisted living; and 32 percent in intermediate care facilities, nursing homes, or mental health institutions.

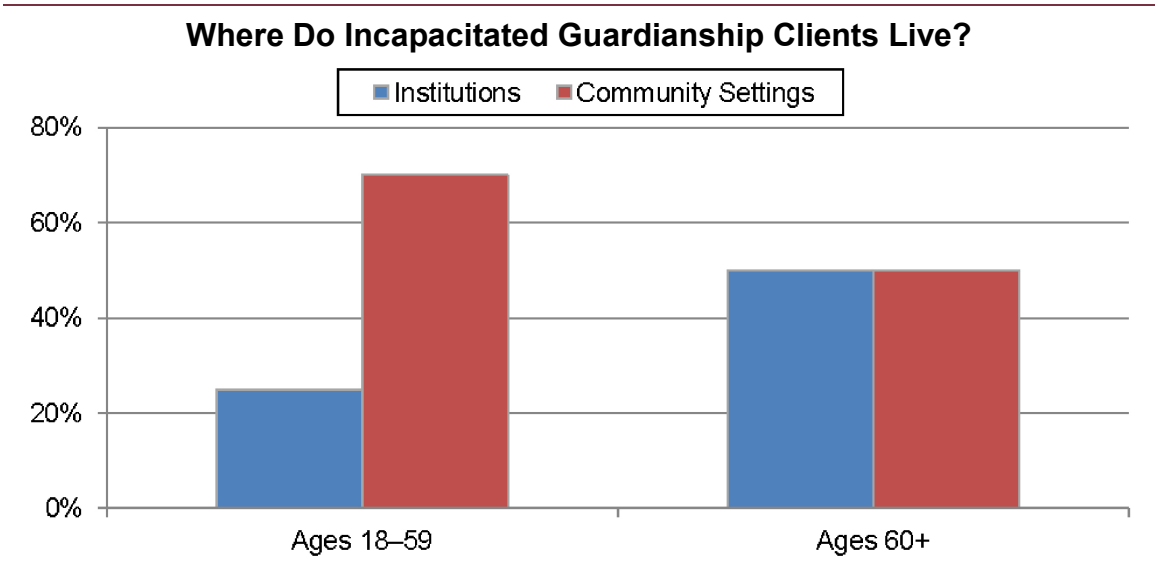
32 J. Rosenberg, "Poverty, Guardianship, and the Vulnerable Elderly: Human Narrative and Statistical Patterns in a Snapshot of Adult Guardianship Cases in New York City," *Georgetown Journal on Poverty Law Policy*, Vol. 16, No. 315, Spring 2009.

33 Because file studies include family guardians, they may show different residential patterns than the authors' survey.

34 Email on file with the ABA Commission on Law and Aging.

Where Do Incapacitated Guardianship Clients Live?

More than two-thirds of the clients of survey respondents were age 60 and older,[35] and less than one-third were age 18 to 59.[36] Among clients age 60 and older, respondents reported that roughly half live in institutions[37] and half in community settings.[38] For 18-to-59-year-old adults, only about a quarter of the clients live in institutions,[39] and about 70 percent live in the community.[40] This difference in the residential setting of the two age groups requires further research.[41]



Source: Survey of Agency/Professional Guardians on Residential Decisions for Adult Clients, AARP Public Policy Institute, August 2010.

a. Specific Residential Settings

For clients of all ages, guardians reported that about 30 percent live in nursing homes. About 5 percent live in intermediate care 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

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35 Respondents were asked the percentage of adult clients age 60 and older. The mean value of responses was 72 percent.

36 When asked the percentage of clients age 18 to 59, the mean value of responses was 28 percent.

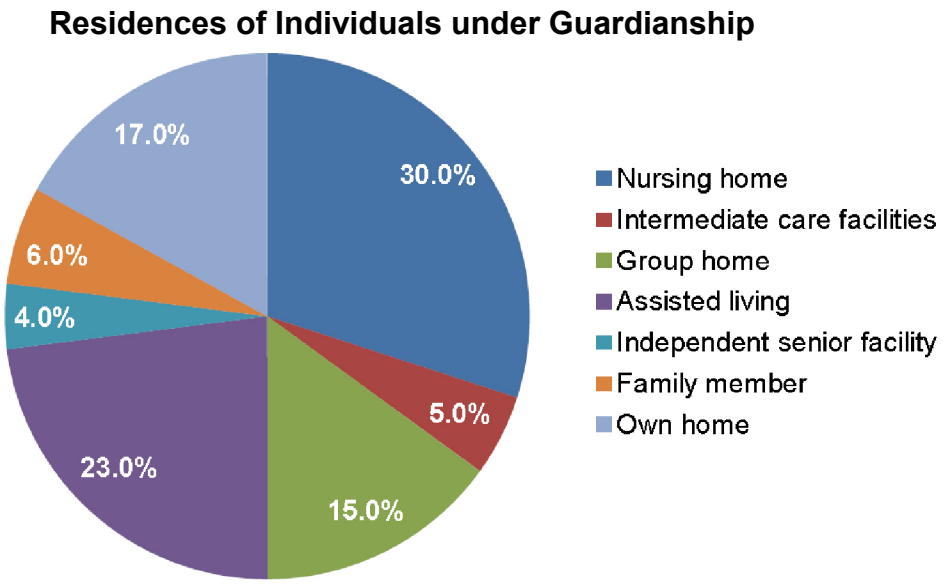
37 Mean value of 49 percent.

38 Mean value of 48 percent. The survey defined "institution" as nursing home, ICF-MR (Intermediate care facility for the mentally retarded) 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 home, adult foster home, 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."

39 Mean value of 27 percent.

40 Mean value of 69 percent.

41 See "Discussion of Findings" on p. 26 for possible interpretations.



Source: Survey of Agency/Professional Guardians on Residential Decisions for Adult Clients, AARP Public Policy Institute, August 2010.

independent senior residences. The array of settings reported appears inconsistent with the charge of a causal connection between guardianship and institutionalization.[42]

b. Role of Supportive Services

Most survey respondents said their community-dwelling clients use supportive community services, most commonly 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 are housekeeping, chore services, skilled nursing, and congregate or home-delivered meals.

Interviewees elaborated on the use of supportive services to keep clients in the community, stressing four key services that can make or break a community living arrangement: in-home care, transportation, medication management, and day programs.

Without appropriate housing, guardians cannot avoid institutional placement. Interviewees noted 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 after rehabilitation therapy in a nursing home had she not retained a rent-stabilized apartment, as she would have nowhere else to go with her limited income.
- A Colorado man with mental illness and dementia could stay in the community because he had an apartment across the street from his guardian's office.

[42] See p. 12 above.

- 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 an adult foster care home, where she got the attention and freedom she needed.
- A man in Massachusetts has severe dementia but was physically pretty stable. Income through pensions and VA 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 fine at night, and his stove was disconnected. He had no unsafe behaviors.
- An 87-year-old woman in New York with dementia was hospitalized after a heart attack. She was discharged to a rehabilitation facility, but owned a co-op 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.

Source: These profiles are based on actual cases described in the authors' interviews with guardians.

The interviewees detailed the challenges of finding supportive services. Regarding in-home care, for example, some clients may get by with a few hours per day, but others need 24-hour care. In some cases family caregivers may provide the needed services, but in others the guardian may have to find paid caregivers such as direct care workers. In addition, for around-the-clock care to work, housing must be able to accommodate the needs of a caregiver (e.g., a second bedroom or appropriate sleeping space). Medication management and monitoring of blood sugar for diabetics seem straightforward and are not time-consuming, yet may be challenging to arrange. For instance, according to those interviewed, visiting nurse services will probably not provide blood sugar monitoring on an ongoing basis, opting instead to train a caregiver. But a caregiver may not be available to meet this need with the required time schedule. Sometimes the stumbling block is very specific. For example, a public guardian in one state said that a client needed adult disposable briefs, but Medicaid would not cover the cost outside of an institution; thus, he remained in a nursing home.[43]

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 (plumbing, home repair, snow shoveling, or trash removal), and visitation by family and friends.

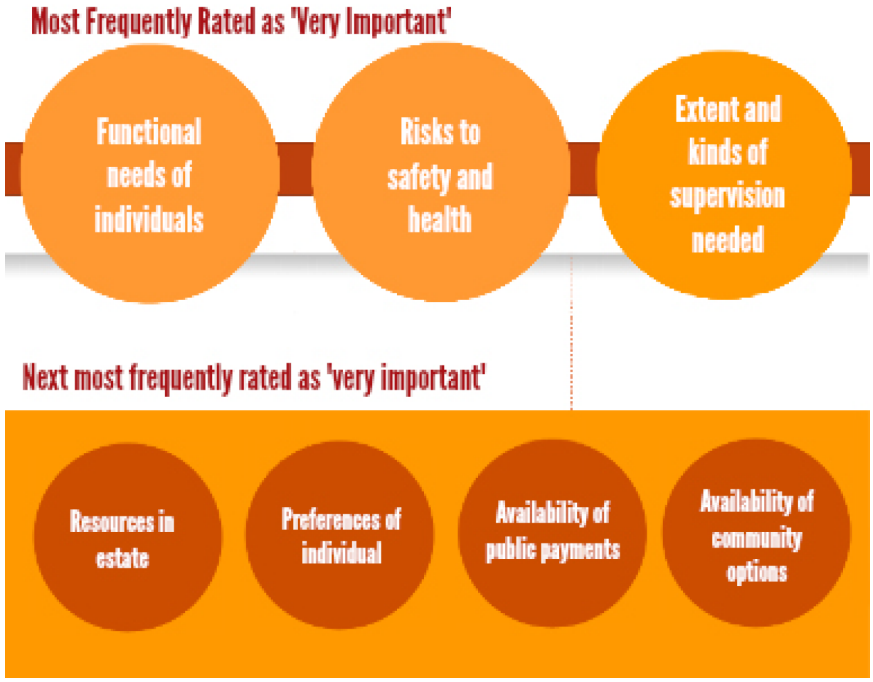
[43] Although almost all states cover adult disposable briefs outside of an institution, they set rules about the circumstances which qualify for coverage such as limiting the supply or requiring prior authorization.

Factors in Making Residential Decisions

A broad array of factors could influence guardians' decisions about residential placement. The factors most frequently listed as "very important" by respondents were functional needs of individuals, perceived risks to safety and health, and extent and kinds of supervision required.[44] These factors focus 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 the individual, availability of public payments, and availability of community options. These factors focus more on the practical realities of making the placement work, along with recognition of the individual's preferences, if known.[45] The broad spectrum of factors that guardians consider demonstrates the tough balancing act in which they routinely engage.

Factors in Making Residential Decisions



a. Agency Policies vs. Individual Case Decisions

Although "mission and priorities of your agency" did not rate highly as a factor in making placement decisions, two-thirds of the respondents viewed it as a high priority.[46]

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

[45] About three-quarters of respondents said they know the residential preferences in most or some cases.

[46] Thirty-eight percent of respondents stated that community 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.

b. Factors in Choosing an Institutional 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."[47] 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 individuals in facilities they rated as only fair or poor, often a difficult choice for caring guardians.

c. Role of Court

The survey sought information on whether court authorization is required for residential placement, by statute, court rule, or practice. Some 35 percent of respondents reported that they are not required to get specific court authorization before a client is institutionalized or moved. However, 41 percent reported a statutory requirement for court approval—23 percent specifying court approval for institutionalization and 18 percent for any client move. A total of 35 percent of respondents said court rule or practice requires approval—17 percent for institutionalization and 18 percent for any move.[48] Interviewees 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.[49]

d. How Much Choice Do Guardians Really Have?

Guardian comments revealed that options often are a mirage and decision trees have only one branch. Guardians are limited by the realities of the individual's 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.'"
- "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."

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47 See *Nursing Home Compare*, http://www.medicare.gov/NHCompare/.

48 Some respondents cited both statutory and rule/practice requirements.

49 See p. 24 below on statutory provisions concerning guardian residential decisions. Despite the large number of states with no or minimal statutory requirements for approval, a majority of the survey respondents noted such requirements.

Guardian's Role

Survey questions about the guardian's role provided a window on the power of guardians to enable community living, the constraints on guardians, and the constant struggle to balance independence and safety.

a. Guardian's Role in Delaying or Preventing Institutionalization

Over half 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 (things guardians do) can delay institutionalization but generally said they cannot ultimately prevent it. One guardian stated that she has been appointed to numerous cases in which people were still living in the community but were floundering. She was able to organize services to keep them in the community—and observed that it's easier "if they have money."

b. Barriers to Community Placement

Some 40 percent of survey respondents said lack of guardian agency staff time or agency funding was rarely or never a barrier to maintaining clients in the community, but 34 percent called these factors a barrier at least some of the time.

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

One attorney-guardian 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 45 percent of survey respondents, the time/resources for placing and keeping clients in residential settings varies widely by circumstances, but 22 percent reported that it takes more guardian time/resources to place and keep clients in community settings than institutional settings.

All guardians interviewed stated that community cases are more labor-intensive and liability-prone. One said "yes, it's more responsibility and liability. If someone is with them 24/7, it is less of a problem. But if home care is limited, what if something happens, such as a fire, a fall? Even with a full-time caregiver, the guardian is responsible for

making sure the care provider is doing the job. What about medical appointments? What about administering medications? All of this takes observations, calls, and attention."

Another guardian observed that organizing and monitoring the caregiving takes time—and that there are always decisions that no one but the guardian can make. But 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 abide by their preferences, to keep them in the community, to get the services they need, and to do things because no one else is available.

Moreover, the risks to clients with mental illness can be greater in the community: "Folks in a nursing home are not going hungry, homeless, or arrested." For example, one client lived in subsidized housing but had both dementia and mental health problems. He wandered and police had to rescue him from busy highways. The guardian first had moved him to an assisted living facility, 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.

> *"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."*
>
> —*Survey respondent*

d. Effect of Guardian Fee Structures

Interviewees pointed out effects of guardian fee structures on placement. Public guardianship programs lack sufficient funding and staffing,[50] which 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 their fees must be approved by the court. Limited funds in the estate to pay fees and court scrutiny of fee submissions can minimize the time the guardian spends to advocate for, secure, and maintain community placements.

Structure and Availability of LTSS

The guardian interviews revealed the complexity of deciding between home care and institutional care within the realities of today's array of LTSS. Home care generally costs less than institutional care, but 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

[50] P. Teaster et al.

sometimes can be more isolating than a group home, assisted living facility, or nursing home. One guardian explained that her bed-bound client became extremely isolated in her apartment, so the guardian moved her to a nursing home to increase her social contacts as well as for the ease of providing nursing care. But moving an incapacitated person may cause unsettling transfer trauma.

a. Role of Assessment and Technology

Interviewees stressed that up-front assessments of the client are critical, including assessment for risks of falls. Also, the client's home can be assessed for accessibility and the need for accommodations. New in-home technologies may increase the safety of community settings, including chair lifts on stairs, call buttons in case of falls, cameras for remote monitoring, and medical monitoring systems.

b. Medicaid Waivers and Federal/State Reintegration Programs

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

Interview participants stated that Medicaid waivers can be a key asset but are often insufficient. Getting waiver eligibility and services is challenging: the application process can be burdensome; waiting lists are lengthy; and waiver appeals take too long. Even when the client receives waiver services, the services may be inflexible in meeting particular needs, and many incapacitated people outgrow the services covered under the waiver as their needs intensify. Finally, services are premised on having affordable housing, which is in short supply in many locales.

c. Other Impacts of Public Programs

Guardians noted that it can be extremely time-consuming to qualify a person for Medicaid. They also claimed that because Medicaid covers nursing home placement but frequently not assisted living, a nursing home is all too often an inevitable choice when personal funds run out. Finally, the guardians decried the constraints on public funding for community services, which have worsened during the recent economic downturn, creating greater challenges.[51]

Savings in State Medicaid Dollars

Community-based LTSS can be (but is not always) 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 save state and federal Medicaid funds. The National Public Guardianship Study[52] recommended that guardianship programs track cost savings to Medicaid. 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 programs reporting) was $20,000 to $850,000 in the previous year.

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[51] C. V. O'Shaughnessy.

[52] P. Teaster et al.

The director of the Guardianship Project of the Vera Institute of Justice in New York City discussed the program's Medicaid savings. The average annual Medicaid cost to keep an indigent individual in a nursing home in New York City is approximately $112,000. Since its inception, the program has maintained one-third of its clients in community settings, thereby saving New York State more than $2.5 million in Medicaid dollars annually. The program serves just over 100 clients, but if additional clients were added, the program could save a substantially increased amount of state Medicaid dollars. The overall program's 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. The director noted that "effective guardianship that allows people to remain in their homes and maintain their independence is both more humane and more cost-effective. Our data, based on case-specific analysis of each client, shows that living at home can roughly double the time it takes for someone to need Medicaid."

Source: Vera Institute of Justice.[53]

Themes from the AARP Public Policy Institute Innovation Roundtable

To analyze the survey and interview findings in an interdisciplinary context, the authors convened a one-day roundtable sponsored by the AARP Public Policy Institute in May 2011. It included a cross-section of practitioners and experts in guardianship, aging/disability, and LTSS. Key themes included the following:

1. ***Navigating fragmented LTSS*** is a struggle for professional guardians, as it is for most of the public. Roundtable participants agreed with study interviewees that maintaining residence in the community requires considerably more guardian time and effort than choosing an institutional setting. Area Agencies on Aging, Aging and Disability Resource Centers, and other resources can help in identifying and accessing LTSS. Yet the majority of guardians may not be aware of these resources. Guardians at the roundtable indicated that a "one-stop shop" for this type of information would streamline their work.
2. ***The scope of a guardian's responsibility*** may need greater definition in light of LTSS complexity. Some roundtable participants viewed guardians simply as surrogate decision-makers, while others saw an expanded obligation to research the ever-changing options very thoroughly.[54] Exactly how guardians should seek out,

[53] *The Guardianship Project Issue Brief – Guardianship Practice: A Six-Year Perspective* (December 2011), accessed at http://www.vera.org/content/guardianship-practice-six-year-perspective. In the interview, the director explained that there were five types of savings—mental health facility cost avoidance, nursing home avoidance, hospital avoidance, delayed Medicaid eligibility, and payment of Medicaid liens.

[54] The National Guardianship Association *Code of Ethics* (Rule 3.1) 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." Accessed at http://www.guardianship.org.

find, and familiarize themselves with the complicated sets of information on LTSS and link to relevant resources requires attention.

3. ***What is the least restrictive environment?*** Many assume that the "least restrictive environment" criterion tilts more toward the community as opposed to institutional care. Roundtable participants said this may be a false dichotomy. Assisted living or even nursing home placement may be less isolating and provide more social support for some individuals, and some may prefer assisted living over more independent settings. The concept of "least restrictive *for the specific person*" may be more appropriate.

4. ***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. With little or no notice, guardianship agencies may receive calls indicating that the court has appointed the agency as a temporary or emergency guardian in response to a hospital's petition. Pressure for hospital discharge forces agencies to make decisions with scant 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 frequently is restricted to available beds at the moment.

   Some guardianship agencies work proactively to prevent these situations, engaging in 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. Participants also pondered more sweeping policy changes, such as mandates to begin transition planning earlier in the insurance cycle.

   Additionally, roundtable participants alluded to situations in which a patient is discharged from the hospital and then readmitted within a specified time period with the same condition—that is, 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 seeks to reduce such instances. It reduces inpatient prospective payments to a hospital based on the dollar value of the hospital's percentage of preventable Medicare readmissions for certain specified procedures.[55] Roundtable discussion highlighted the critical role guardians play in helping to ensure quality of care and prevent needless readmissions.

5. ***Liability*** is a major concern for professional guardians (including attorney guardians) and may influence decisions about where a person lives. 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, such as a fire, 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 the client wished to live at home. Even if a lawsuit is ultimately

[55] Pub. L. No. 111-148, Section 3025.

dismissed, the experience can be financially draining and extremely time-consuming.[56]

Statutory Provisions on Guardian Residential Decisions[57]

Guardian decisions regarding where an incapacitated person will live are framed not only by real-world LTSS constraints but also by state statutory provisions. State adult guardianship laws grant guardians varying degrees of authority over the residence of the individual, often leaving the guardian wide latitude. Some states require court approval for changing a person's residence, for a move outside the state, or for institutionalization, but many do not. Some states provide that the guardian must consider the least restrictive setting or the expressed desires of the individual to the extent known, but such considerations are difficult to monitor. Many states allow a guardian to sell an individual's real estate—including a personal residence—without prior court approval. Finally, a majority of states prohibit guardians from placing an individual in a mental health facility without a civil commitment procedure.

Overall, while court approval for residential decisions is required in some states in certain instances, a substantial portion of guardians determine where a person will live with little judicial oversight or intervention.[58]

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 has developed both—and each has a section applicable to residential decisions.[59]

The National Guardianship Association (NGA) *Standards of Practice*[60] require the guardian to "see that the ward is living in the most appropriate environment that addresses the ward's wishes and needs."[61] They also require that the guardian authorize a

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[56] The question of guardian immunity was addressed by the Connecticut Supreme Court in *Gross v. Rell* (SC 18548), April 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; it does not apply when guardian acts are not specifically authorized by the court, and the guardian is acting as a fiduciary.

[57] This section is based on work by Amy Gioletti, 2010 Borchard Foundation Center on Law and Aging Intern with the ABA Commission on Law and Aging. The authors wish to thank Ms. Gioletti for her research. For additional information on state statutes including specific statutory citations, see N. Karp and E. Wood, "Choosing Home for Someone Else: Guardian Residential Decision-Making," *Utah Law Review* No.3 (2012), pp. 1445–1490.

[58] N. Karp and E. Wood, *Utah Law Review* No. 3 (2012).

[59] Additionally, a few states have developed standards of practice for guardians, and such standards sometimes address residential decisions. See K. Boxx and T. Hammond, *A Call for Standards: An Overview of the Current Status and Need for Guardian Standards of Conduct and Codes of Ethics* (Utah Law Review 2012). See especially *Arizona Code of Judicial Administration*, 7-202(J)(3); and Minnesota Association for Guardianship and Conservatorship, MAGiC *Standards of Practice*, III(A).

[60] National Guardianship Association, *Standards of Practice*, adopted 2000, Third Ed. 2007. Accessed at http://www.guardianship.org/documents/Standards_of_Practice.pdf.

[61] *Ibid.*, at Standard 12(A).

move to a more restrictive setting only after evaluating other options. 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."[62]

The *Standards* language can be hard to translate into practice, and the NGA *Code of Ethics*[63] helps explain a guardian's duty. The *Code* says the guardian should "ensure the ward resides in the least restrictive environment available," and provides extensive commentary that sends a strong message to guardians of the full extent of due diligence and extreme degree of care expected in making residential choices.[64]

To strengthen guardian standards, the National Guardianship Network[65] in 2011 convened the landmark Third National Guardianship Summit, a consensus conference on post-appointment performance and decision making for adults. The Summit adopted a set of guardian standards, including specific standards on residential decision making[66] that reflect many of the themes in the authors' study,[67] including the guardian role in

- Identifying and advocating for the person's goals, needs, and preferences;
- Investigating options;
- Giving a priority to community settings when not inconsistent with the person's preferences;
- Making and implementing a person-centered plan;
- Maximizing self-reliance and independence;
- Seeking court or third-party review before a move to a more restrictive setting;
- Monitoring residential settings on an ongoing basis; and
- Promoting relationships important to the person, unless it will substantially harm the person.

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62 *Ibid.*, at Standard 12 (A)(1) & (2).

63 National Guardianship Association, *A Model Code of Ethics for Guardians* (1988). Accessed at http://www.guardianship.org/documents/Code_of_Ethics.pdf.

64 See summary of commentary on NGA *Code of Ethics* Rule 3.

65 The National Guardianship Network includes national organizations dedicated to improving adult guardianship law and practice—AARP; the ABA Commission on Law and Aging; the ABA Section of Real Property, Trust and Estate Law; the Alzheimer's Association; the American College of Trust and Estate Counsel; the Center for Guardianship Certification; the National Academy of Elder Law Attorneys; the National Center for State Courts; the National College of Probate Judges; and the National Guardianship Association.

66 For the full set of Summit Standards and Recommendations, see http://epubs.utah.edu/index.php/ulr/article/viewFile/833/642.

67 The authors' study served as one of the nine Summit background papers.

DISCUSSION OF FINDINGS

Although difficult questions remain, this study begins to draw a picture of guardian residential decisions today. The findings suggest the following:

1. ***Younger vs. Older Adults.*** Younger adults with guardians seem more likely to live in community-based settings than older adults who have guardians. It is uncertain whether this difference is due to additional supports and case management in the disability network, a stronger tradition of disability advocacy, or a greater array of options available. Other possible factors include the characteristics of each group's needs and risks, age bias, guardian lack of knowledge on coping with age-related problems, or some combination thereof.
2. ***Restricted Choice.*** 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.
3. ***Guardian Balancing Act.*** Guardians routinely walk a fine line, balancing competing tensions. In the real world of fluctuating personal conditions and LTSS resources, how can a guardian best balance perceived risks to an individual's health and safety with preferences for community settings? How far should a guardian go in the expenditure of time and resources when seeking to make community placement work in tough situations? Under what circumstances is delaying institutionalization worth pursuing, given the perceived risk to the individual as well as cost to the estate and/or the guardian? Constantly weighing these competing factors in a "person-centered" framework is at the heart of the guardian's role—making it one of society's most difficult tasks.
4. ***Perceptions of Community Placement.*** Community settings are often—but not always—preferred, least restrictive, and less costly. They are generally harder and more time-consuming for guardians to arrange and maintain, and carry a greater burden of risk to the individual's safety and liability for the guardian. There may be opportunities for states to save Medicaid resources while honoring personal preferences by supporting guardianship programs that target the least restrictive setting appropriate.
5. ***Need for Services and Supports.*** Many individuals with guardians could remain in or move to the community if more services and supports were available. However, by the time of the guardianship, it is frequently too late for such options, as the person requires full-time care and medically oriented supervision.
6. ***Information for Guardians.*** To make informed decisions about residential settings, guardians must understand the complex set of federal, state, and local LTSS and have ready access to resources on available options on an ongoing basis.
7. ***Guardian Fee Structures and Funding.*** How do or should guardian fee structures and funding affect residential decisions? Inadequate public and nonprofit guardianship agency funding may thwart community placement that is time- and staff-intensive, yet staff on salary may have the flexibility to attend to problematic cases. Private professional guardians may erode the estate with fees for time spent trying to find the optimal home.

8. ***Court Oversight.*** While court approval is required for residential decisions in some states and for some residential decisions, in certain instances, guardians frequently determine where an individual will live, with little court supervision.
9. ***Guardian Standards.*** The National Guardianship Association has developed a thoughtful set of practice standards and ethical guidelines on residential decisions, but many guardians may not be familiar with or understand them. In addition, many guardians attempting to comply with these standards and guidelines may be thwarted by the reality of the piecemeal, financially constrained long-term care environment.

LOOKING AHEAD: SUGGESTIONS FOR NEXT STEPS

"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 no ideal option and trade-offs are tough. The challenge, then, is ensuring ongoing support to guide guardians in making this life-changing determination, through steps such as the following:

1. ***Residential Decision-making Standards.*** Clear and widely known standards, such as those recommended by the Third National Guardianship Summit, should set out steps for person-centered residential decisions. Research should examine how such steps might vary for different populations; i.e., individuals with dementia, intellectual disabilities, mental illness, or brain injury.
2. ***Expansion of Community Options.*** States should seek to expand home- and community-based services, better balance services from institutional to noninstitutional settings, and promote affordable, accessible housing. Guardians and guardianship organizations should be vigorous advocates for such policies and the budgetary support needed to implement them.
3. ***Guardian Role in Discharge Planning.*** Institutional policies should encourage early guardian involvement in hospital and nursing home discharge planning. Discharge planners and nursing home administrators should engage in outreach to guardianship agencies to tackle difficult patterns and emergency situations. Research should identify best practices in how guardianship agencies can better work with discharge planners and nursing homes.
4. ***Medicaid Cost Savings.*** State Medicaid agencies should recognize the role of guardians in the array of LTSS, and consider factoring in Medicaid savings to the state resulting from guardian efforts to make community-based care and transition planning work.
5. ***Education for Guardians and Judges on Community Options.*** Courts should work with state units on aging, disability agencies, aging and disability resource centers, social services, long-term care ombudsman programs, and guardian associations to provide professional and family guardians with information and training on residential options, decision making, and person-centered planning. Judges should be educated on the array of community-based services available.
6. ***Court Oversight.*** Statutory provisions, court rules, court forms, and examination of guardian reports and care plans should promote community settings when not inconsistent with the person's preferences, and provide for a reasonable review upon a move to a more restrictive setting. Appropriateness of residence should be a key part of guardianship monitoring.

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