

Public Guardianship: Policy and Practice

Pamela B. Teaster, PhD

Director, Center for Gerontology, Virginia Tech
pteaster@vt.edu

Stephanie Chamberlain, PhD

Department of Family Medicine, University of Alberta
Alzheimer Society of Canada Postdoctoral Fellow
sachambe@ualberta.ca

ABSTRACT

Guardianship is a process by which a court delegates to a person or entity the duty and power to make personal, property, or both person and property decisions for another individual based upon a determination that he or she is unable able to make decisions for him- or herself. Guardianship has at its foundation the protection and care of individuals unable to make decisions about their person, their property, or both; however, far too little is known about this creature of the court system. Public guardianship, or guardianship of last resort, refers to the appointment and responsibility of a public official or publicly funded entity who serves as a legal guardian in the absence of willing, able, and responsible family members or friends to serve as, or without resources to employ, a private guardian. Problems with the guardianship system include prolonged delays for an appointment, a far-too-close relationship between judges and guardians, guardians' lack of familiarity with the individuals they serve, their limited expertise in medical decision-making, and their unconscionably large caseloads. The purpose of this article is to provide a description of the guardianship system, explain what is known in the available research, and identify recommendations for policy and practice.

Keywords: public guardianship, protection, responsibility, policy, surrogate decision-maker

Tutela pública: política y práctica

RESUMEN

La tutela es un proceso mediante el cual un tribunal delega en una persona o entidad el deber y el poder de tomar decisiones perso-

nales, de propiedad o de persona y propiedad para otra persona en función de la determinación de que él o ella no puede tomar decisiones por él. o ella misma. La tutela tiene como fundamento la protección y el cuidado de las personas que no pueden tomar decisiones sobre su persona, su propiedad o ambos; sin embargo, se sabe muy poco sobre esta criatura del sistema judicial. La tutela pública, o la tutela de último recurso, se refiere al nombramiento y la responsabilidad de un funcionario público o entidad financiada con fondos públicos que sirve como tutor legal en ausencia de familiares o amigos dispuestos, capaces y responsables para servir como, o sin recursos emplear, un tutor privado. Los problemas con el sistema de tutela incluyen demoras prolongadas para una cita, una relación demasiado estrecha entre jueces y tutores, la falta de familiaridad de los tutores con las personas a las que sirven, su experiencia limitada en la toma de decisiones médicas y su gran cantidad de casos. El propósito de este artículo es proporcionar una descripción del sistema de tutela, explicar lo que se conoce en la investigación disponible e identificar recomendaciones para políticas y prácticas.

Palabras clave: tutela pública, protección, responsabilidad, política, tomador de decisiones sustituto

公共监护：政策与实践

摘要

监护是一个过程，法院通过该过程赋予个人或实体职责与权力，替另一个无法为自身做决定的个体做有关个人、财产、或二者兼有的决定。监护最根本的是为那些无法就自身、财产或二者兼有做决定的个人提供保护和关爱；然而，关于这种法律体系者的了解知之甚少。公共监护，或被称为最后手段的监护，指的是对一名公共官员或公立实体赋予责任，在缺少有意愿、有实力、有责任的家庭成员或朋友作为私人监护人，或后者没有资源雇佣一名私人监护人的情况下充当法定监护人。监护体系的问题包括预约延期的时间更长，法官与监护人之间的关系过于密切，监护人对其监护对象的不熟悉，监护人在医疗决策方面的经验有限，以及监护人过多的工作量。本文目的是对监护体系提供一个描述，解释现有研究中的已知部分，并为政策与实践提供相关建议。

关键词：公共监护，保护，责任，政策，代理决策者

The single greatest category of problems we encounter are those that address the care of decisionally incapable patients ... who have no living relative or friend who can be involved in the decision-making process. These are the most vulnerable patients because no one cares deeply if they live or die, no one's life will be fundamentally changed by the death of the resident. We owe these patients the highest level of ethical and medical scrutiny; we owe it to them to protect them from over-treatment and from under-treatment; we owe it to them to help them to live better or to die in comfort and not alone.

—Nancy Dubler, LLB, Professor Emerita, The Albert Einstein College of Medicine/Montefiore Medical Center; Consultant for Ethics, New York City Health and Hospitals, Letter 2001

Introduction

Many of the patients Dubler describes above are people with public guardians. Budget constraints, the increasingly complex health needs of younger and older individuals, and a rising number of persons needing services generally reduce the ability of public programs to adequately serve persons under guardianship needing their help. Persons under guardianship are frequently older people with dementia; adults of any age with intellectual or developmental disabilities; and individuals with mental illness, brain injuries, or substance abuse. In many cases, the people whose civil rights are transferred to a guardian have a combination of these conditions. Too often, people under guardianship, who have usually lost all their decisional rights, are ensnared in a backwater of under-resourced governmental social service and welfare machinery.

People needing public guardians as surrogate decision-makers are especially vulnerable because they rely on others for care and/or are unable to advocate for themselves. Also, the issue of abuse, neglect, and exploitation (ANE) by guardians has been highly visible nationally, with reports of systemic problems documented by the Government Accountability Office (2010; 2016), testimony before the US Senate Committee on Aging and Social Security Administration (Teaster, 2018), and a flurry of media attention in *Forbes*, *The Huffington Post*, *NPR On Point*, and *Senior Living*. Aviv (2019) describes egregious treatment by paid professional guardian April Parks. Ms. Parks warehoused people under her care in unacceptable facilities, charged unreasonably high fees, and made it impossible for concerned family members or friends to have contact with loved ones. Parks was indicted on over 250 felony counts (one for each person she served)

and sentenced to up to forty years in prison (Ferrara, 2019). Rebecca Fierle, a former guardian from Orlando, Florida, is under criminal investigation for excessive, unnecessary, and inappropriate billing for her vulnerable clients living in assisted living facilities and giving each a Do-Not-Resuscitate order (Cordeiro, 2019).

Guardianship has at its foundation the protection and care of individuals unable to make decisions about their person, their property, or both; however, far too little is known about this creature of states and the court system that was regarded by John Regan (1980) as “part Santa Claus and part ogre.” The purpose of this article is to provide a description of the guardianship system, discuss the available research, and identify recommendations for policy and practice in the public guardianship system.

Private and Public Guardianship

Guardianship is a legal process by which a court delegates to a person or entity the duty and power to make personal, property, or both person and property (plenary) decisions for another individual based upon a determination that he or she is unable to make decisions for him- or herself. A judge’s decision is predicated on a finding of “incapacity,” a judgment that may be founded on medical, cognitive, and functional components, as specified in state law. Judges hear clinical and lay evidence and have the authority to exercise broad discretion in

determining a person’s capacity, choice of the guardian(s), and the extent of the court order that conveys decision-making authority to the guardian. People subject to guardianship are any individuals deemed decisionally incapacitated.

A guardian might have complete or limited authority over a person’s health and personal affairs, financial and property affairs, or both. Guardians are fiduciaries with a high duty of care and degree of accountability. Following the appointment of a guardian, in theory, and under state law, the court maintains vigilant oversight and receives regular reports and accountings concerning the person under guardianship. In practice, courts’ monitoring varies widely; in too many jurisdictions across the country, guardians have little to no supervision at all (Karp & Wood, 2007).

Guardianship information is sparse to non-existent at state and local court levels. A national estimate put the number of adults under guardianship (both private and public) at 1.5 million, but cautioned that the number could be as low as one million or as high as three million (Uekert & Van Duizend, 2011). Although legal experts have tracked guardianship law for the past three decades, little data and empirical research exist concerning actual practices by judges, attorneys, guardians, and people under guardianship. Wood, Teaster, and Cassidy (2017) reviewed press articles, internet discussion forums, and anecdotal reports and found that “practice varies on a continuum from the heroic to the satisfactory to the deficient to the abusive, but the proportions in each category are unknown” (p. 19).

Guardianship has its genesis in the medieval English concept of *parens patriae*, which declares that the sovereign has a duty to care for people (subjects) who cannot care for themselves (Wood, 2005). In order to protect subjects from harming themselves or being harmed by others, a court appoints a guardian to make decisions safeguarding them from risk or harm. The appointment of a guardian removes a person's fundamental rights, conveying an individual's voice and decision-making authority to a legally designated, appropriate, and beneficent surrogate, radically reducing the person's legal status. In most instances, guardianship curtails a person's right to make decisions about income or assets, healthcare and treatment, marriage, voting, sexual choices, participation in social networks, and routine lifestyle choices—and can “un-person” an individual (Bayles & McCartney, 1987).

Since the 1980s, and despite reform efforts stressing the duty of the guardian to consider a person's values and preferences in making decisions, state protection nearly always eclipses individual autonomy (Center for Elders and the Courts, 2019). Guardianship's inherent tensions between autonomy and beneficence, between rights and needs, and between protection and self-determination manifest themselves in ethical conundrums, in both theory and practice.

Most guardians are private guardians and are typically family members or friends, but sometimes attorneys, corporate trustees, agencies, or even volunteers serve in this role

(Bandy et al., 2014; Bayles & McCartney, 1987; Lisi & Barinaga-Burch, 1995; Teaster et al., 2005). Unlike persons with family and friend connections, at-risk and/or low-income people usually have no one to help them and frequently fall through societal cracks. Many fail to receive needed services; fall prey to third party interests; become victims of ANE; receive inappropriate or insufficient healthcare, and have an inappropriate placement in facilities that are too restrictive for their needs (Bandy et al., 2014; Chamberlain, et al., 2019). For such individuals, who may be incapacitated and alone, the courts assign a public guardian.

Public Guardianship

Public guardianship, or guardianship of last resort, refers to the appointment and responsibility of a public official or publicly funded entity who serves as a legal guardian in the absence of willing, able, and responsible family members or friends to serve, or without resources to employ, a private guardian (Teaster, et al., 2010). Public guardian programs are funded through state appropriations, Medicaid funds, county monies, and legislated fees from the person under guardianship or some combination of these. Public guardian programs usually serve three distinct populations: (1) persons under guardianship who have lost decisional capacity, sometimes due to age-related dementia; (2) individuals age eighteen years of age and older with intellectual disabilities who may or may not ever have had decisional capacity; and (3) adults of all ages with mental illness or brain injury.

Research on Public Guardianship

Public guardianship emerged in the peer-reviewed research in the 1980s following a series of press reports detailing allegations of ANE and ageism in the public guardianship system (Bayles & McCartney, 1987). Winsor Schmidt, a pioneer in guardianship research, detailed concerns over the non-existent national reporting of guardianship, limiting the ability to identify and assess the quality of care and quality of life of those under public care (Bell, Schmidt, & Miller, 1981; Schmidt, 1984; 1990; Schmidt, et al., 1988). In the nearly forty years since his initial research, guardianship research in the United States has increased; however, critical gaps remain in knowledge with respect to prevalence, demographic characteristics, decision-making, and quality of care (Chamberlain, Baik, & Estabrooks, 2018; Kim & Song, 2018; Montayre, Montayre, & Thaggard, 2018).

As alluded to above, the number of individuals under public guardianship in the United States is unknown, due to non-existent federal surveillance and variable monitoring of state guardianship programs (Chamberlain et al., 2018; Teaster et al., 2010). However, the number of individuals requiring public guardianship is increasing, due to increasing numbers of older adults generally, coupled with the rising prevalence of age-related dementia and geographically dispersed family and friends (Carney, Fujiwara, Emmert, Liberman, & Paris, 2016). Studies in intensive care units revealed that 16 percent of patients admitted have no family or friend

guardian (White, Curtis, Lo, & Luce, 2006), and these patients account for 5.5 percent of deaths annually (White et al., 2007). For those assessed in acute care settings, a large proportion of individuals without a family or friend guardian are admitted from nursing homes (Cohen, Benjamin, & Fried, 2019; Courtwright, Abrams, & Robinson, 2017; Griggins, Blackstone, McAliley, & Daly, 2019). Research estimates that older adults under public guardianship comprise 3 to 4 percent of the nursing home population, an estimate based on anecdotal information from focus groups of healthcare leaders (Karp & Wood, 2003). Similarly, a Canadian study found a provincial (equivalent to state) prevalence of just over 4 percent of all nursing home residents under the care of a public guardian (Chamberlain, Duggleby, Fast, Teaster, & Estabrooks, 2019). Prevalence of public guardianship varied: a higher proportion of residents under public guardianship lived in larger (>135 beds) public not-for-profit urban-located nursing homes (Chamberlain, Duggleby, Fast, et al., 2019).

Only a small number of studies have conducted interviews with persons who are under public guardianship (Teaster, 2002; Teaster et al., 2010). These studies indicate that people under public guardianship experience loneliness and unmet psychosocial needs (Teaster, 2002). Persistent issues revealed in these studies show that guardians spend limited time with persons under guardianship. Guardians are surrogate decision-makers, making

personal decisions for individuals that they have little connection to and limited personal knowledge of their values or wishes (Teaster, 2002). Work to date suggests a critical need to discern more explicit pathways for discussing ethical priorities and challenges in caring for this highly vulnerable population (Moye, 2017; Verma, et al., 2019).

Recent studies of persons under public guardianship have found that they are typically older (older than sixty-five years of age) and male (Chamberlain, Duggleby, Fast, et al., 2019; Cohen et al., 2019; Courtwright et al., 2017; Griggins et al., 2019; White et al., 2006). These more recent studies examined individuals living in nursing homes or who were admitted to acute care (hospital) settings. These findings differ from earlier studies, which focused on community-dwelling populations and found that most persons under public guardianship were older women (Reynolds, 2002; Reynolds & Wilber, 1997). Public guardians who were interviewed described their perception that there had been a shift in the demographic profile of those under public guardianship, previously composed of older women who had outlived family and now reflect an increasingly complex population with mental illness and histories of marginalization (Chamberlain, Duggleby, Teaster, et al., 2019). Multiple chronic conditions, dementia, and depression are common in persons under public guardianship (Chamberlain et al., 2018; Kim & Song, 2018). Chamberlain et al. (2019) examined the characteristics and unmet needs of nursing home residents under

public guardianship and found that these residents are frequently marginalized, often having been previously homeless, and many have histories of drug and/or substance abuse and complex psychiatric conditions. They have limited or nonexistent financial resources and struggle to access even basic items (e.g., clothing, toiletries) and services outside the home.

Individuals under public guardianship are at risk of poor quality of care. Risks include overtreatment, under-treatment, or delayed treatment (Chamberlain, Duggleby, Teaster, et al., 2019; Cohen, Wright, Cooney, & Fried, 2015). Cohen et al. (2019) conducted a retrospective chart review to examine end-of-life decision-making by professional, court-appointed guardians. They found delays in decision-making for patients under guardianship (compared to those not under guardianship). Delays in care resulted in prolonged hospital stays and potentially negative consequences of hospitalization (e.g., hospital-related infection, pressure ulcers) (Cohen et al., 2019; Moye, 2017). A one-year matched retrospective cohort study in one hospital compared the length of stay for patients for whom the hospital had initiated guardianship procedures because the patient had impaired decision-making and no designated surrogate decision-maker. This study compared patients for whom the hospital had initiated a petition to the court to appoint a guardian as surrogate decision-maker (e.g., volunteer, public, family member) compared to patients that did not have a guardian appointment (Ricotta, Parris, Parris, Sontag,

& Mukamal, 2018). The guardianship process resulted in prolonged hospital stays (twenty-nine days compared to eighteen days for controls) and one in six had a hospital-associated complication upon discharge.

A qualitative study of nursing home staff found the quality of care issues for residents under public guardianship, particularly at end-of-life. Care problems included excessive medical testing, multiple trips to the hospital, and more (sometimes unwarranted) aggressive interventionist approaches (e.g., full resuscitation) (Chamberlain, Duggleby, Teaster, et al., 2019). These studies suggest that the quality of care is of critical concern for such individuals; however, studies often rely on small samples at single sites. There are currently no state or federal level data on the quality of care or health service use of individuals under public guardianship. Policies that require reporting in routinely collected administrative data are essential to identifying and mitigating the risk of care issues for these vulnerable individuals. Monitoring the use of health services and quality of care seems problematic given the recent news reports (e.g., April Parks and Rebecca Fierle, mentioned above) that describe potentially unethical care practices overseen by guardians for individuals living in care facilities.

Medical and End-of-life Decision Making

Kim and Song (2018) reviewed the literature on individuals without available or willing surrogate decision-makers

and found a variety of approaches to decision-making, including the interdisciplinary care team, physicians, judicial review, guardianship, ethics committees, or an external multidisciplinary team. They note that while there are various decision-making mechanisms, there is little understanding of the implications of these different approaches on patient/client health outcomes. Professional societies, state legislation, and hospital policies all vary on how to care for patients whose wishes and preferences might be unknown (Blackstone, Daly, & Griggins, 2019; Pope, 2017).

Associations such as the American Geriatrics Society recommend that the patient's care team make care decisions rather than a public guardian (Farrell et al., 2017). The American Medical Association (AMA) advocates that clinicians consult an institutional ethics committee for medical decisions for persons without a family or friend surrogate (American Medical Association, 2017). Institutional ethics committees are often called upon to oversee decision-making for unrepresented individuals. Some states mandate an ethics committee, and some only recommend that the care team consult with a committee. Griggins et al. (2019) described one urban hospital's development and implementation of a subcommittee within the larger institutional ethics committee that was composed of community members. Community members make recommendations to the attending physician, and disagreements or discrepancies are reviewed by the hospital ethics committee. While the use of ethics committees is relatively

widespread, they are not without their detractors (Courtwright et al., 2017).

Research on decision-making for persons without a family or friend guardian in intensive care units found that most end-of-life decisions were made by the attending physician and not an ethics committee, external judicial review, or public guardian (White et al., 2007). This is consistent with other studies of incapacitated, hospitalized patients that found that decisions to withdraw or limit treatment to patients were most often made by physicians and without external consultation (Bandy, Helft, Bandy, & Torke, 2010; White et al., 2006). There remains a prevailing concern over clinicians as sole decision-makers due to the complex social and legal considerations required to make decisions, potential conflicts of interest, and procedural fairness and equity across patients (White, Jonsen, & Lo, 2012). Critics of physicians as sole decision-makers indicate that decisions that can influence an individual's life and death should involve a diversity of expertise and points of view afforded by multidisciplinary teams and perhaps external committees (Pope, 2013).

Cohen et al. (2015) analyzed state guardianship legislation specific to guardian decision-making authority for treatment at the end-of-life. They found that there is little guidance specific to end-of-life and guardian authority over decision-making. Most states (thirty-seven) had no language related to a guardian's authority. Some states allow guardians to make decisions independently, albeit with contingencies.

The variation and complexity across the state legislation poses significant concerns about how different decision-making policies may influence the care provided to people under public guardianship.

Variation in legislation and no comparative research on the implications of decision-making mechanisms pose a substantial risk to vulnerable individuals and their care providers. Verma et al. (2019) interviewed stakeholders from healthcare, social services, and legal sectors involved in the decision-making processes for unrepresented adults. Ethical challenges include respecting autonomy when an individual's decision-making rights have been revoked, balancing safety and autonomy. Safety concerns may be associated with prolonged hospitalization and risk of moral distress among those tasked with caring for them. Caring for unrepresented individuals places an ethical and moral toll on care teams as they try to navigate making care decisions for vulnerable individuals (Chamberlain, Duggleby, Teaster, et al., 2019; Verma et al., 2019).

Disparagers and Reformers

Disparagers of guardianship regard it as an extreme form of surrogate decision-making that unnecessarily removes an individual's most basic civil rights and one that should be completely terminated. These individuals stress that the disadvantages of guardianship outweigh the potential benefits (Pope, 2017). They point out problems with the guardianship system: prolonged de-

lays in appointing a guardian, a far-too-close relationship between judges and guardians, guardians' lack of familiarity with the individuals for whom they are the decision-maker, their limited expertise in medical decision-making, and unconscionably large caseloads limiting guardians' availability to properly direct the care of individuals for whom they are responsible (Chamberlain, Dugleby, Teaster, et al., 2019; Cohen et al., 2019; Moye, 2017; Teaster, 2002). These relationships can result in unfair decisions and priorities, suspect practices, and unnecessary delays or far too hasty decisions, which affect a host of actors in the guardianship process (e.g., social work, law, medicine, finance), and most importantly, the person under guardianship.

The reformers represent a more moderate response to the many problems of public guardianship (Chamberlain et al., 2018; Karp & Wood, 2007; Moye, 2017; Teaster, 2016). Rather than dismantle and eradicate the system, the reformers sympathize with the disparagers but suggest that guardianship serves an important protective function for those who are unable to advocate and make decisions for themselves. They recommend that the processes of guardianship should be improved and stress the importance of scrutinizing who really needs guardians. Also, they call for person-centered guardianship and improvements in guardianship monitoring, including an accurate and computerized accounting of each person under guardianship in each state. The Working Interdisciplinary Network of Guardianship Stakeholders

(WINGS), discussed later in this article, is an example of a reform effort whereby people representing the multiple, converging systems that deal with guardianship attempt to make changes to the system.

Standards for Public Guardians and Decision-Making

According to the National Guardianship Association (NGA) Standards of Practice (2013), "the guardian shall protect the rights of the person with regard to sexual expression and preference. A review of ethnic, religious, and cultural values may be necessary to uphold the person's values and customs." Public guardians may serve as guardian of the property, guardian of the person, and sometimes, and in addition to guardian, as a representative payee or another surrogate decision-maker. Public guardians can also provide case management, financial planning, public education, social services, adult protective services, or serve as guardian *ad litem* or court investigator and as advisors to private guardians. The primary task of public guardianship is to serve as surrogate decision-maker (Schmidt et al., 1988; Teaster et al., 2010). In addition to the standard mentioned above, the following NGA (2013) standards provide a strong basis from which guardians should make decisions.

- Std 6(V)(F) – "Determine whether the person has previously stated preferences in regard to a decision of this nature."
- Std 7(II) – "The guardian shall

identify and advocate for the person's goals, needs and preferences.”

- Std 8(IV)(B) – “The guardian shall strive to know the person's goals and preferences.”
- Std 9 (III) – “The guardian shall encourage the person to participate, to the maximum extent of the person's abilities, in all decisions that affect him or her ... ”
- Std 9(IV) – “The guardian shall make and implement a plan that seeks to fulfill the person's goals, needs, and preferences.”¹

Advance Directives and Advance Care Planning

An approach frequently highlighted to mitigate the risk of inappropriate or inconsistent decision-making for unrepresented older adults is to emphasize pro-active advance care planning (Carney et al., 2016; Montayre et al., 2018; Thaggard & Montayre, 2019). Documenting values and goals of care prior to being incapacitated is a critical step to reducing the uncertainty that arises when individuals become incapacitated and a surrogate is unavailable. When information is known about the person's preferences, there is a lower likelihood that there will be an external judicial review and less high-intensity treatment will be initiated (Cohen et al., 2019).

Supported Decision-Making

One important way to reduce vulnerability is to restore a person's voice and,

concomitantly, respect their remaining rights. A mechanism to respect the rights of persons under guardianship is through supported decision-making. Supported decision-making is a process to assist persons in providing their wishes and preferences concerning decisions about themselves (Gooding, 2013). This process is meant to engage people in as many ways as possible to ensure that their voice and values are at the core of the decision-making process. This may include various accommodations, such as communication supports and engaging with individuals (family and friends) known to the person who may be able to assist in interpretation and the ultimate decision-making process. In instances where supported decision-making is used, the legal right to make decisions remains with the person; accommodations are provided to ensure that the person has enough supports to make his or her decision an authentic one that *he* or *she* makes (American Bar Association, 2019).

A mechanism with commonalities with supported decision-making and legislated in the Commonwealth of Virginia is the completion of a values history for all people under public guardianship (Teaster, 2016). Completion of and reference to a values history can serve as an important mechanism to ensure that, as much as possible, decisions that public guardians make are informed by client preferences and adhere to a substituted judgment standard rather than defaulting to a best interests standard because client preferences are

¹ Note that the NGA regards the guardianship plan different from a care plan.

unknown because of a lack of investigation and documentation.

Current Policy Efforts on Public Guardianship

Two major policy efforts related to public guardianship at the federal level are underway. The first is an effort to hold public hearings on issues that guardianship presents and solutions to its problems. In April 2018, the Senate Special Committee on Aging convened a hearing entitled *Abuse of Power: Exploitation of Older Americans by Guardians and Others They Trust*. In the 116th Congress in 2019, Senator Susan Collins (R-ME) introduced S.581, the Guardianship Accountability Act of 2019, which proposed designating a national online resource center on guardianship, authorized grants to develop state databases, and established procedures for sharing background information related to appointed guardians with other jurisdictions. The bill was read twice and referred to the Committee on the Judiciary (**US Senate 2019**).

A second national effort is to establish WINGS. The development of WINGS programs was conducted by the ABA Commission on Law and Aging and was supported by a grant from the Administration for Community Living. Over fifteen states received a combination of ACL-sponsored WINGS funding and state justice-initiated projects. Over ten states created a WINGS program on their own. The purpose of WINGS is to “bring stakeholders to the table for joint problem-solving and action—and to open doors to commu-

nication” (ABA 2019). WINGS efforts include statements to the national news media, restoration of rights wherever possible, collection of reliable and uniform data, enhanced oversight and record-keeping, establishment of statutorily mandated guardian-to-protected person ratios, use of supported decision-making whenever appropriate, and reference to and recognition of the values and wishes of the people under guardianship when making decisions (ABA 2019).

Recommendations and Conclusion

Both authors of this article have studied the issue of guardianship deeply. Because of their disciplinary grounding (public administration, nursing, ethics, and gerontology), they are able to stand outside the court system and make observations concerning the system as a whole. One of the authors has even served as a court-appointed private guardian, and more than once. Bearing our scholarship and experience in mind, we make the following recommendations for the system of public guardianship.

First, better data systems for guardianship programs need to be built. In this age of bigger, better, and faster technology, it is astounding that, as of this writing, no one state knows how many of its people are under guardianship. Without a reliable data collection system, it is impossible to properly monitor the system. Senator Collins’ approach to system building should be supported, adequately funded, and im-

plemented. A similar approach to data collection was developed by the Administration for Community Living for Adult Protective Services (the National Adult Maltreatment Reporting System or NAMRS) and could be implemented with state public guardianship systems. Furthermore, moving beyond basic monitoring, we recommend concerted efforts to track the service use and quality of care provided to individuals in guardianship programs.

Second, more states should adopt workable guardian to person under guardianship ratios. Currently, only seven states even reference staffing ratios in their legislation or administrative regulations contracts, ranging from 1:40 (Florida) to 1:20 (Virginia) (Teaster 2008). Without a ceiling, the ratio of guardians to person under guardianship can balloon (examples in 2010 were in Kentucky and Illinois, where at one time, the ratio was as high as 1:100). Occasion for mistreatment and misuse of the system can easily follow when numbers are far too high and monitoring is far too infrequent.

Third, states should explore increased use of mechanisms that support and restore rights completely. As discussed above, these include crafting limited orders, i.e., the creative use of least restrictive options, meaning that all rights given to the guardian do not have to be exercised solely by the guardian and that greater use of supported decision-making processes should be employed wherever possible, whether doing so eliminates the need for public guardians or enhances the ability of the

individual under guardianship to direct decisions made on his or her behalf. Better communication with the person under guardianship is also critical; one vehicle for doing so is the use of the values history form, which, in Virginia, is created, referenced, updated, and maintained in the files of each person with a guardian (Teaster 2016). Better communication with public guardians across states is another important mechanism for making practice change, and WINGS states or the NGA should commence this long-overdue initiative with dispatch.

Fourth, in many situations, guardians are called upon to make end-of-life decisions. We believe that **well-informed, well-educated, and trained guardians who know the people they serve** are in an excellent position to make medical decisions for people under guardianship. When the system works as it should, guardians are in an outstanding position to know best the values and preferences of the person(s) they serve. They are, after all, the legally designated surrogate decision-maker, a point we made above. However, to our knowledge, no evidence-based answer is available concerning the best approach. We believe that the best standards from which guardians can draw are those of the NGA (2013). The authors are not ignorant of the current realities of some public guardian programs (e.g., underfunded, a lack of training, high case-loads), which preclude public guardians from having the appropriate context for making such important decisions. For now, we believe that public guardians should make decisions in concert with

patient care teams, rather than solely making such important decisions. We do not agree that they should be excluded from the patient care team.

Finally, and not surprisingly, it is critical that more funding is provided to state guardianship programs. On the federal level, funding should be allocated to investigate the outcomes of public guardianship. Guardianship has the power to return entirely or bolster the remaining rights that an individual might have rather than eradicating all of them. To this end, it is important to both investigate the outcomes of guardianship and to establish benchmarks for acceptable public guardianship practices. Nowhere does this need arise more than in the arena of healthcare, an example of which is the COVID-19 pandemic with which we are now grappling.

To conclude, we find public guardianship only slightly changed from research conducted over ten years ago (Teaster et al., 2010). From that study, here are our slightly edited concluding paragraphs (143), entitled *The Postlude*:

... like scholars before us, guardianship continues to be instituted for third party interests rather than the best interests of the person under guardianship and who are still living in environments too restrictive due to funding inadequacies and residual ageism and other societal biases. We urge that the banner of least restriction be held high and that limited guardianships be sought, guardianships overturned when-

ever possible, and that individuals under guardianship be consulted and their wishes considered when at all possible.

Public guardianship is not social work, although it involves important elements of it. Conversely, guardianship, a creature of the courts, is not completely law. Guardianship is an amalgam of many disciplines—law, medicine, social work, psychology—most importantly, those aspects of being a human being, those under the care of the state, are still not afforded considerations as such. Living the decisional life for people under guardianship is perhaps the most important and complex state function performed. It remains shrouded in mystery for most of the public, yet, the public guardian performs a highly important state function for the most vulnerable, who deserve no less than excellence from public servants. We believe that, to live the decisional life of another person, as public guardians do, they must have the tools to perform this essential function. If not, then public guardianship does greater harm in its presence executed poorly than in its absence.

Let us not be writing these same lines ten years hence.

References

- American Bar Association. (2019). Working Interdisciplinary Networks of Guardianship Stakeholders (WINGS). Retrieved from https://www.americanbar.org/groups/law_aging/resources/wings-court-stakeholder-partnerships0/
- American Medical Association. (2017). Code of medical ethics opinion 2.1.2 Decisions for adult patients who lack capacity. Retrieved from <https://www.ama-assn.org/system/files/2019-06/code-of-medical-ethics-chapter-2.pdf>
- Aviv, R. (2019). How the Elderly Lose Their Rights. *The New Yorker*. Retrieved from <https://www.newyorker.com/magazine/2017/10/09/how-the-elderly-lose-their-rights>
- Bandy, R., Helft, P., Bandy, R., & Torke, A. (2010). Medical decision-making during the guardianship process for incapacitated, hospitalized adults: A descriptive cohort study. *Journal of General Internal Medicine*, 25(10), 1003-1009.
- Bandy, R., Sachs, G., Montz, K., Inger, L., Bandy, R., & Torke, A. (2014). Wishard volunteer advocates program: An intervention for at-risk, incapacitated, unbefriended adults. *Journal of the American Geriatrics Society*, 62(11), 2171-2179. doi:10.1111/jgs.13096
- Bayles, F., & McCartney, S. (1987). *Guardianship of the elderly: an ailing system*. New York: Associated Press.
- Bell, W., Schmidt, W. C., & Miller, K. (1981). Public guardianship and the elderly: Findings from a national study. *The Gerontologist*, 21(2), 194-202. Retrieved from <http://login.ezproxy.library.ualberta.ca/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=edb&AN=80107398&site=eds-live&scope=site>
- Blackstone, E., Daly, B. J., & Griggins, C. (2019). Making Medical Decisions for Incapacitated Patients without Proxies: Part II. *HEC Forum*. doi:10.1007/s10730-019-09388-2
- Carney, M. T., Fujiwara, J., Emmert, B. E., Liberman, T. A., & Paris, B. (2016). Elder orphans hiding in plain sight: A growing vulnerable population. *Current Gerontology & Geriatrics Research*, 1-11. doi:10.1155/2016/4723250
- Center for Elders and the Courts. (2019). Guardianship monitoring. Retrieved from <http://www.eldersandcourts.org/Guardianship/Guardianship-Monitoring.aspx>

- Chamberlain, S. A., Baik, S., & Estabrooks, C. A. (2018). Going it Alone: A Scoping Review of Unbefriended Older Adults. *Canadian Journal on Aging, 37*, 11. doi:10.1017/S0714980817000563
- Chamberlain, S. A., Duggleby, W., Fast, J., Teaster, P. B., & Estabrooks, C. A. (2019). Incapacitated and alone: Prevalence of unbefriended residents in Alberta long term care facilities. *SageOpen, 1-7*. doi:https://doi.org/10.1177/2158244019885127
- Chamberlain, S. A., Duggleby, W., Teaster, P. B., & Estabrooks, C. A. (2019). Characteristics and unmet care needs of unbefriended residents in long term care. *Aging & Mental Health, 24*(4), 659-667. doi:https://doi.org/10.1080/13607863.2019.1566812
- Cohen, A. B., Benjamin, A. Z., & Fried, T. R. (2019). End-of-life decision making and treatment for patients with professional guardians. *Journal of the American Geriatrics Society, 67*(10), 2161-2166. doi:10.1111/jgs.16072
- Cohen, A. B., Wright, M. S., Cooney, L., Jr., & Fried, T. R. (2015). Guardianship and end-of-life decision making. *JAMA Internal Medicine, 175*(10), 1687-1691. doi:10.1001/jamainternmed.2015.3956
- Cordeiro, M. (2019). Investigations of embattled guardian Rebecca Fierle include Medicaid fraud allegations. *Orlando Sentinel*. Retrieved from <https://www.orlandosentinel.com/news/florida/guardians/os-ne-rebecca-fierle-investigated-for-medicaid-fraud-20190815-yxdzazinvra65gwqolynf2vj4i-story.html>
- Courtwright, A. M., Abrams, J., & Robinson, E. M. (2017). The Role of a Hospital Ethics Consultation Service in Decision-Making for Unrepresented Patients. *The Journal of Bioethical Inquiry, 14*(2), 241-250. doi:10.1007/s11673-017-9773-1
- Farrell, T. W., Widera, E., Rosenberg, L., Rubin, C. D., Naik, A. D., Braun, U., . . . the Ethics, C. P. M. o., Care Public Policy Committees of the American Geriatrics, Society. (2017). AGS position statement: Making medical treatment decisions for unbefriended older adults. *Journal of the American Geriatrics Society, 65*(1), 14-15. doi:10.1111/jgs.14586
- Gooding, P. (2013). Supported Decision-Making: A Rights-Based Disability Concept and its Implications for Mental Health Law. *Psychiatry, Psychology and Law, 20*(3), 431-451. doi:10.1080/13218719.2012.711683
- Griggins, C., Blackstone, E., McAliley, L., & Daly, B. (2019). Making medical decisions for incapacitated patients without proxies: Part I. *HEC Forum*.

doi:10.1007/s10730-019-09387-3

- Karp, N., & Wood, E. (2003). *Incapacitated and alone: Health care decision-making for the unbefriended elderly* (Report: 1-59031-272-4). Retrieved from http://www.americanbar.org/content/dam/aba/administrative/law_aging/2003_Unbefriended_Elderly_Health_Care_Descision-Making7-11-03.authcheckdam.pdf
- Karp, N., & Wood, E. (2007). *Guarding the guardians: promising practices for court monitoring* (2017-21). Retrieved from https://assets.aarp.org/rgcenter/il/2007_21_guardians.pdf
- Kim, H., & Song, M. K. (2018). Medical decision-making for adults who lack decision-making capacity and a surrogate: state of the science. *American Journal of Hospice and Palliative Care*, 35(9), 1227-1234. doi:10.1177/1049909118755647
- Lisi, L. B., & Barinaga-Burch, S. (1995). National study of guardianship systems: Summary of findings and recommendations. *Clearinghouse Review*, 29(6), 643-653. Retrieved from http://login.ezproxy.library.ualberta.ca/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=eds_gao&AN=edsgcl.17625106&site=eds-live&scope=site
- Montayre, J., Montayre, J., & Thaggard, S. (2018). The elder orphan in healthcare settings: An integrative review. *Journal of Population Ageing*, 12, 515-532. doi:10.1007/s12062-018-9222-x
- Moye, J. (2017). Ethical concerns and procedural pathways for patients who are incapacitated and alone: Implications from a qualitative study for advancing ethical practice. *HEC Forum*, 29(2), 171-189. doi:10.1007/s10730-016-9317-9
- National Guardianship Association. (2013). *Standards of Practice*. Retrieved from <https://www.guardianship.org/wp-content/uploads/2017/07/NGA-Standards-with-Summit-Revisions-2017.pdf>
- Pope, T. M. (2013). Making medical decisions for patients without surrogates. *New England Journal of Medicine*, 369(21), 1976-1978. doi:10.1056/NEJMp1308197
- Pope, T. M. (2017). Unbefriended and unrepresented: Better medical decision making for incapacitated patients without healthcare surrogates.

- Georgia State University Law Review*, 33(4), 923-1019. Retrieved from <http://login.ezproxy.library.ualberta.ca/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=lgs&AN=125956630&site=eds-live&scope=site>
- Regan, J. J. (1980). Protecting the elderly: The new paternalism. *Law Journal Library*, 32, 1111-1132.
- Reynolds, S. L. (2002). Guardianship primavera: A first look at factors associated with having a legal guardian using a nationally representative sample of community-dwelling adults. *Aging & Mental Health*, 6(2), 109-120. doi:10.1080/13607860220126718
- Reynolds, S. L., & Wilber, K. H. (1997). Protecting persons with severe cognitive and mental disorders: an analysis of public conservatorship in Los Angeles County, California. *Aging & Mental Health*, 1(1), 87-98. doi:10.1080/13607869757425
- Ricotta, D. N., Parris, J. J., Parris, R. S., Sontag, D. N., & Mukamal, K. J. (2018). The Burden of Guardianship: A Matched Cohort Study. *Journal of Hospital Medicine*, 13(9), 595-601. doi:10.12788/jhm.2946
- Schmidt, W. C. (1984). The evolution of a public guardianship program. *Journal of Psychiatry & Law*, 12(3), 349-372. Retrieved from <http://login.ezproxy.library.ualberta.ca/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=edsgao&AN=edsgcl.3441498&site=eds-live&scope=site>
- Schmidt, W. C. (1990). Quantitative information about the quality of the guardianship system: toward the next generation of guardianship research. *Probate Law Journal*, 10, 61-80. Retrieved from <http://login.ezproxy.library.ualberta.ca/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=lgs&AN=502217021&site=eds-live&scope=site>
- Schmidt, W. C., Miller, K., Peters, R., & Loewenstein, D. (1988). A descriptive analysis of professional and volunteer programs for the delivery of public guardianship services. *Probate Law Journal*, (2), 125-156. Retrieved from <http://login.ezproxy.library.ualberta.ca/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=edsgao&AN=edsgcl.7421162&site=eds-live&scope=site>
- Senate. (2019). *Guardianship Accountability Act*. Retrieved from <https://www.congress.gov/bill/116th-congress/senate-bill/591>.
- Teaster, P. B. (2002). The wards of public guardians: Voices of the unbefriended. *Family Relations*, 51(4), 344-350. doi:10.1111/j.1741-3729.2002.00344.x

- Teaster, P. B. (2016). *The importance of the values history for public guardianship*.
- Teaster, P. B., Wood, E., Karp, N., Lawrence, S., Schmidt, W. C., & Mendiondo, M. (2005). *Wards of the state: A national study of public guardianship*.
- Teaster, P. B., Wood, E., Schmidt, W. C., & Mendiondo, M. (2010). *Public guardianship: In the best interest of incapacitated people?* Santa Barbara, CA: Praeger Publishing Company.
- Teaster, P. B., Wood, E. F., Schmidt, W. C., & Lawrence, S. A. (2008). Public Guardianship After 25 Years: In the Best Interest of Incapacitated People?, p. 41. Retrieved from <http://login.ezproxy.library.ualberta.ca/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=edsgao&AN=edsgcl.176980569&site=eds-live&scope=site>
- Thaggard, S., & Montayre, J. (2019). Elder orphans' experiences of advance planning and informal support network. *SAGE Open*, 9(3), 2158244019865371. doi:10.1177/2158244019865371
- Uekert, B., & Van Duizend, R. (2011). *Adult guardianship: a 'best guess' national estimate and the momentum for reform*. Retrieved from <https://ncsc.contentdm.oclc.org/digital/collection/ctadmin/id/1846>
- Verma, A., Smith, A. K., Harrison, K. L., & Chodos, A. H. (2019). Ethical challenges in caring for unrepresented adults: A qualitative study of key stakeholders. *Journal of the American Geriatrics Society*, 67(8), 1724-1729. doi:10.1111/jgs.15957
- White, D. B., Curtis, J. R., Lo, B., & Luce, J. M. (2006). Decisions to limit life-sustaining treatment for critically ill patients who lack both decision-making capacity and surrogate decision-makers. *Critical Care Medicine*, 34(8), 2053-2059. doi:10.1097/01.Ccm.0000227654.38708
- White, D. B., Curtis, J. R., Wolf, L. E., Prendergast, T. J., Taichman, D. B., Kuniyoshi, G., . . . Luce, J. M. (2007). Life support for patients without a surrogate decision maker: who decides? *Ann Intern Med*, 147(1), 34-40. doi:10.7326/0003-4819-147-1-200707030-00006
- White, D. B., Jonsen, A., & Lo, B. (2012). Ethical challenge: When clinicians act as surrogates for unrepresented patients. *American Journal of Critical Care*, 21(3), 202-207. doi:10.4037/ajcc2012514
- Wood, E. (2005). *History of Guardianship*. New York, NY: Springer.

Wood, E., Teaster, P. B., & Cassidy, J. (2017). *Restoration of rights in adult guardianship: research and recommendations*. Retrieved from Virginia Tech Center for Gerontology https://www.americanbar.org/content/dam/aba/administrative/law_aging/restoration%20report.authcheckdam.pdf