

# **EXAMINING THE NEED FOR A PUBLIC GUARDIAN IN MASSACHUSETTS: Phase 1**

**3/11/2016**

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## ACKNOWLEDGEMENTS

This project was funded by the Guardianship Community Trust, Inc., a non-profit organization located in Andover, Massachusetts, that is working to advance scholarship and social policy to address unmet decisional needs of the indigent in Massachusetts. In addition, this material is the result of work supported with resources and the use of facilities at the Boston Veterans Administration Healthcare System.

We thank the individuals who participated in our research interviews and who each gave generously of their time to speak with us about this important issue. Their commitment to the clients they serve was palpable and sincere.

In addition to the information cited throughout the report, we acknowledge four key source documents that have informed the design and interpretation of results.

1. Harshbarger, S. Public Guardianship in Massachusetts: Where we are and where we should be headed; 1996.
2. Northeastern University School of Law Legal Skills in Social Context Social Justice Program in conjunction with Greater Boston Legal Services Elder Unit, Law Office 1 (James Carregal, Shantanu Chatterjee, Ethan Dively, Tara Dunn, Alexis Erkert, Eileen Henderson, Alexandra Mahabir, Heather Manly, Gabriella Roselli, Karim Sabbidine, Paige Zacharakis and Peter Enrich, Adam Nussenbaum, Mado Glass, Rachel Green, Catherine Biondo). Public Guardianship: Best Practices Analysis for Massachusetts; 2015.
3. Teaster PB, Wood E, Schmidt WC, Lawrence SA, Mendiondo, M. Public Guardianship: In the Best Interest of Incapacitated People? Praeger Publishing Company; 2010.
4. Teaster PB, Wood E, Karp N, Lawrence S, Schmidt WC, Mendiondo M. Wards of the State: A National Study of Public Guardianship; 2005.

## EXECUTIVE SUMMARY

**Background:** A public guardianship system is essential to providing surrogate decision-makers for our most vulnerable adults – those who (a) lack capacity, (b) do not have a family or friend who can serve as a surrogate and advocate, and (c) do not have means to pay a private guardian. Massachusetts does not have a comprehensive public guardianship system. This project aims to describe what happens in Massachusetts to adults in these situations. Our hope is that an understanding of the current approach and its consequences will provide evidence to support future solutions.

**Challenges in Research:** We faced a challenge in documenting this problem given that Massachusetts, like most states, does not have a systematic data base for guardianship. Recently, the state has instituted a “Mass Courts” data base. This data base is an important step in quantifying those placed under guardianship in any given year and in providing a system for monitoring annual reports. However, this data base cannot answer specific questions about types of guardianship appointments (e.g., whether a person is a family member or independent guardian) and the experiences of those under guardianship.

**Goals of this Research:** We aim to describe what happens when individuals need a guardian, do not have family or friends to serve, and do not have means to pay. Because of the challenges in documenting this issue, we approached our research in multiple phases. In “Phase One” of the project we gathered quantitative and qualitative data. Our quantitative analysis considered existing numerical data regarding the scope of public guardianship in other states to estimate the need within the Commonwealth. Our qualitative analysis used data we gathered by interviewing a sample of agency, court, and clinical stakeholders. We used these data to describe the current approach to public guardianship and problems therein, but also to inform future research. In “Phase Two” we plan to complete larger and more representative surveys and/or set up tracking systems within agencies to more systematically document the issue.

**Limitations of this Research:** This report does not aim to provide the entire story of guardianship in Massachusetts, but instead, one chapter in an ongoing story. Guardianship reform advocates will find that many important issues in guardianship are not addressed in this report. For example, this report only looks at the issue of appointments, not outcomes or monitoring. We do not examine cost savings that might come from various public guardianship systems – as we do not have a system in Massachusetts to study. We recognize that many different types of clients may need guardianship, but we do not focus on issues confronting a single sub-population.

We do enter the report with some assumptions, namely, we strenuously believe in the importance of exhausting all less restrictive options and other interventions prior to the use of guardianship. Therefore this report does not advocate for the blanket use of guardianship or try to define what “good guardianship” is, but investigates what happens in Massachusetts to adults who have been determined to need a guardian but do not have family or friends to serve or means to pay. Although Massachusetts often turns to attorneys to serve as guardians, we do not advocate for or against the use of attorneys in this report – we merely report the current situation in these cases, which appears to most often rely on attorneys as guardians.

The research team investigated whether those interviewed believed that a Public Guardianship system is needed within Massachusetts. We understand our data may be used to support this effort but in gathering these data we endeavored to stay neutral on policy solutions.

## Key Findings:

**Estimated Scope of Need:** Based on information from other states, we estimate that approximately 4,100-4,700 adults in Massachusetts may lack decisional capacity and need a surrogate but do not have one. Massachusetts provides state-funded guardianship to approximately 900 adults through Executive Office of Elder Affairs, Department of Mental Health, or Department of Disability Services funds, meaning 3,200-3,800 adults have a surrogate need that is not addressed through a state funded program. It is not clear how many of these adults receive some form of guardianship through the *pro bono* approach described below and how many go without appropriate surrogates.

**Likely Over-Use of Guardianship in MA:** It may be that Massachusetts over-uses guardianship to resolve surrogate issues in the absence of a default surrogate consent statute. In addition, more systematic efforts to identify family and use less restrictive alternatives, as described by some of those we interviewed, should be employed.

**Current Approach:** Currently, the primary approach to providing guardians is a “soft” *pro bono* tradition wherein attorneys are asked to provide these services without compensation. This *pro bono* method is not intentional, planned, nor managed but rather has become the default custom in Massachusetts.

**Problems with Current Approach:** This soft *pro bono* approach is riddled with problems including:

1. Identifying guardians to serve
2. Engaging guardians once appointed and sustaining their involvement
3. Finding guardians to meet the needs of special and most challenging populations
4. Losing sight of the needs of the incapacitated individual

**Conclusion:** Within Massachusetts many vulnerable adults who lack capacity and do not have family or friends to serve as surrogates lack appropriate surrogates and advocates. The current system produces negative consequences for many individuals needing or currently under guardianship.

**Next Steps:** Although imperfect, we find the information presented herein to provide compelling evidence that the current system needs to be fixed – such as through programmatic and legislative solutions. Based on our data it appears these solutions should include increased efforts to avoid guardianship (e.g., better use of screening for less restrictive alternatives; consideration of default surrogate consent mechanisms) and the development of a public guardianship system.

The data presented here can be strengthened by future studies of four types:

1. Data tracking. As a first step we need to quantify who is currently receiving soft *pro bono* guardianship. This could be done prospectively by asking the courts to add field(s) to the Mass Courts data tracking system, and retrospectively by examining guardianship filings to determine who was appointed to serve as guardian. This would not reflect the numbers of individuals who might need a public guardian but for whom that was not pursued. To determine this number would require a coordinated data collection effort by major public agencies and hospitals.
2. Surveys of clinicians. The qualitative data collected here could be used to inform a survey study of clinicians which would validate the findings herein.

3. Surveys of professional guardians. Similarly, a survey study of professional guardians (perhaps identified using retrospective court filing review as noted in #1) could further substantiate the findings herein and gain the perspective of guardians themselves.
4. Interviews with those under or formerly under guardianship.

## Examining the Need for a Public Guardian in Massachusetts, Phase I

### BACKGROUND

Adult 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 an individual determined by the court to be incapacitated (ABA-APA, 2006). Historically, the concept of guardianship derives from ancient Rome, and then English law based on the doctrine of “*parens patriae*” – the responsibility and power of the state to act as parent in protecting the individual, and also the assets of an individual (Sabatino & Basinger, 2000). Adult guardianship models recognize that some individuals require protection and care, and in the end, it is the responsibility of the state to provide such protection.

However, as guardianship has evolved, some commentators have criticized contemporary guardianship as being overly paternalistic and unaccountable. Further, guardianship in the United States has drawn criticism since at least the 1970s for insufficient protections for the person under guardianship; specifically, there have been concerns regarding limited due process, lack of protection of rights, poor interface between medical providers and the court, overly intrusive interventions leading to the loss of all decision-making rights, and the potential for guardianship to hasten institutionalization (Horstman, 1975; Mitchell, 1978; Moye et al., 2007a, 2007b; Zimney & Grossberg, 1998).

The past 20 years have witnessed an explosion of statutory reform in adult guardianship within the United States (Moye & Naik, 2011; Wingspan Conferees, 2001; Wood, 1988-2015). These reforms have addressed various key components of guardianship processes: appointment of the guardian, monitoring of the guardian, inter-jurisdictional matters, and refining public guardianship practices.

Various model laws, termed “uniform laws” have been drafted to guide states in reforming guardianship, primarily the Uniform Guardianship and Protective Proceedings Act, adopted in whole or in part by a number of states. Internationally, similar reforms are also occurring. These shifting perceptions of guardianship are also evident in the United Nations Convention on the Rights of Persons with Disabilities (CRPD, 2008). The CRPD “marks an important step towards equality, dignity and access to society for elderly people, with and without disabilities” pp. 527-28). As of January 2016, it has 160 signatories including states and the European Union. It has not been ratified in the United States for reasons not concerning Article 12 discussed below.

Article 12, entitled “Equal recognition before the law,” emphasizes the necessity of a “supported decision-making” model as an alternative to imposed guardianship (or substitute decision-making). Essentially, instead of enacting laws that substitute a guardian’s decision for the decision of the individual, the CRPD’s proposed model states that (1) all people have the right to make decisions and choices about their own lives, and that (2) everyone at times may seek and need help from family and friends, and so those lacking capacity should be entitled to that same right. The document recognizes that some persons do indeed need assistance to exercise their legal capacity, and the onus of responsibility for providing support and safeguards is placed on the state (CRPD, 2008).

## KEY TERMS

**Guardian.** We will use the term “guardian” to refer to an agent appointed by a court to make personal and/or financial decisions for another, unless we are making a specific distinction. In some states, those who make personal decisions are called guardians, and those who make financial decisions are called conservators. For expedience, we will use the single term guardian. The need for adult guardianship is determined by functional need, not diagnosis or age, and is typically used for individuals with diminished capacity associated with dementia or other neurocognitive illnesses more common in older adults; serious mental illness; and in some cases, significant and pervasive developmental disability. This list is not comprehensive – other conditions may also lead to incapacity, such as traumatic brain injury and persistent vegetative state.

**Public Guardian.** We will use the term “public guardianship” to mean a state-funded system, typically enacted through legislation, for both healthcare and financial decision-making for the “unbefriended” (Teaster et al., 2007). However, this report does not recommend the best legislative and structural mechanism for public guardianship.

**Capacity.** We do not address the specific methods for determining decision-making capacity in this report. We do stress that determination of capacity requires extreme care. We also acknowledge that there are differing opinions concerning the need for a surrogate decision maker versus the need for collaborative and supportive decision-making. For example, most clinicians agree that a person with end-stage dementia who is mute would not be able to (currently) express a choice in his or her care needs a surrogate decision maker. However, a person with a severe and persistent mental health disorder, such as schizophrenia, may have periods of decisional capacity or incapacity depending on the severity and state of the illness. Alternatively, a person with a stable but significant intellectual disability may present a different clinical picture and surrogate need. Other populations, such as those with traumatic brain injury, may also have different needs. Legal scholars, clinicians, ethicists, and advocates continue to debate these complex issues related to capacity and decision-making. The target of this research is “adults with significantly diminished decisional capacity,” such as found in advanced dementia and for which most third parties agree evidences decisional incapacity.

In 2008, the Commonwealth of Massachusetts re-enacted its guardianship statute, closely following the model law, the Uniform Guardianship and Protective Proceedings Act (NCCUSL, 1997). Subsequently, Massachusetts courts have worked to address other aspects of guardianship, such as guardianship monitoring. However, an area that Massachusetts has yet to address is the issue of public guardianship or guardianship of last resort. In addition, Massachusetts is one of a handful of states that does not have a default surrogate consent law setting out a hierarchy composed mostly of family members who are authorized to make selected health care decisions if there is no advance directive and no guardian<sup>1</sup>.

As such, technically, if an individual has not executed a health care advance directive or power of attorney appointing a healthcare agent, and is not able to make health care decisions, a guardianship must be sought. However, in practice, there is likely some degree of judgment applied (i.e., not following the law to the letter), such that physicians may look to family members when all are in agreement. Of note, the Veterans Health Administration (“VA”) follows federal policy and not state law in this matter, using default surrogate consent for veterans within their hospitals. In addition, Massachusetts is unique in having a special provision

<sup>1</sup> Up to date information about states with default surrogate consent laws can be found at the American Bar Association Commission on Law and Aging website.

requiring guardianship of an incapacitated person when antipsychotic medication is prescribed, a so-called “Rogers” guardianship or “Rogers” monitor, named after the case law leading to the practice.

While data are scant it is believed that most guardians are family members or friends (Quinn, 2005). However, some individuals do not have a family member or friend to serve in the role of guardian, or their family member or friend is unwilling, unsuitable, or abusive. As such, these individuals, often indigent, need some other individual or entity to serve. The majority of states address this issue via a statutorily created office of the public guardian, while others specify an agency to act as a last resort when there is no one willing and able to serve. Such offices provide guardians for individuals who lack family members or friends to serve in this role and provide other crucial oversight of this vulnerable population (Teaster et al., 2010).

## GOALS OF THIS PROJECT

This project is referred to as “Phase One” with the hope of identifying areas for future “Phase Two” research. We set forth two aims and related hypotheses below.

**Aim 1. Obtain information about public guardianship processes from state agencies, courts, and institutions, focusing on perceived needs for public guardianship.**

**Hypothesis 1.1: There is an unmet need.** In the Commonwealth of Massachusetts, there are some number of adult individuals with (a) significantly diminished decisional capacity (e.g., advanced dementia), (b) who need a surrogate decision maker, but (c) have no legally authorized surrogates or no appropriate legally authorized surrogate, and (d) have no family or friends to assist in decision-making, and are without the financial resources to obtain a guardian through a guardianship agency. In the literature, such individuals may be referred to as “unbefriended” (Karp & Wood, 2003), although we will avoid that term.

**Hypothesis 1.2: There are complex pathways for resolving surrogate issues.** In the absence of a public guardianship system in the state, there are various surrogate outcomes for these individuals. These outcome categories are relevant to acknowledge in that individuals in any of these categories may be appropriate for public guardianship if such a system existed but may not be now identified as such.

**Aim 2. Explore avenues for documenting the extent of unmet need within the agency.**

**Hypothesis 2.1: There is incomplete information.** Scant, incomplete documentation of the scope of this problem exists. Departments, courts, and institutions may have some data on “unbefriended” individuals, but there will be gaps in documentation.

**Hypothesis 2.2: Interviewees can generate ideas for improving documentation.** Senior staff in state departments, courts, and healthcare institutions will have ideas for how to document the scope of the need based on the knowledge of their systems and processes that may be used in “Phase 2” of this project.

As our interviews unfolded we found participants not able to provide strong data on the scope of unmet need. Therefore we added a quantitative analysis of public records to our project to estimate the unmet need extrapolating from other states. Therefore, our final report presents both quantitative and qualitative data.

### 1. Quantitative.

We asked three Massachusetts agencies to estimate the number of individuals provided guardianship through their agency via Commonwealth funds. Further we added an examination of public guardianship systems in other states to extrapolate an estimation of the unmet need for public guardians in Massachusetts.

### 2. Qualitative.

We conducted interviews with key agencies, courts, and healthcare institutions to learn more about how the current processes are working to identify problems and best practices.

## QUANTITATIVE ANALYSIS

### MASSACHUSETTS

#### METHOD

Agencies provided estimates of individuals served through guardianship services each year (Table 1).

#### RESULTS

The Executive Office of Elder Affairs (EOEA) has a budget to support guardianship services. The office contracts with local guardianship agencies to provide guardianship services for older adults. These older adults enter the program via a protective report made through the local elder service agency. Although there is no fixed fee per guardianship, the total budget is able to provide guardianships for 170 individuals each year. When those “slots” are filled, EOEA cannot provide additional services. When a “slot” is open and the EOEA regional manager determines that guardianship is an appropriate remedy for the protective issue, the older adult is referred to the program. When a client’s condition improves, it is sometimes possible and appropriate to terminate the guardianship, thereby creating more open “slots” for guardianship. Others exit the program when they die.

The Department of Mental Health (DMH) files a large number of guardianship petitions each year (approximately 2,400), but these are for “Rogers” monitors only and are not to provide general medical and financial decision-making (although, as will be described later, some Rogers monitors are pressed into such service). The DMH budget is used to support guardianship services for a small number of high need clients.

The Department of Disability Services (DDS) petitions for the appointment of guardians for individuals and for Rogers guardians, as needed. DDS supports over 12,000 individuals under guardianship and with Rogers monitors. The majority of guardians are unpaid family members. Of this total, DDS funds 726 paid guardians each year.

Together, these three agencies support guardianship services for approximately 916 individuals annually (Table 1).

TABLE 1. INDIVIDUALS UNDER PROFESSIONAL GUARDIANSHIP IN MASSACHUSETTS (ANNUALLY)

PROVIDED THROUGH STATE FUNDING VIA AGENCIES		
Agency	Number	Notes
EOWA	170	25,000 elder abuse reports each year
DMH	<20?	2,400 guardianships (mostly Rogers Monitors)
DDS	726	DDS supports > 12,000 individuals under guardianship and with Rogers Monitors, mostly unpaid family members.
Total	916	
PROVIDED THROUGH OTHER FUNDING		
Grant or donation funded		Unknown
Independent professional paid through estate		Unknown
Other		Unknown
NOT FUNDED		
Independent professional unpaid		Unknown
Other		Unknown

The Commonwealth has only recently begun

SNAPSHOT: PUBLIC GUARDIANSHIP IN MA

**916 adults are provided guardianship through state funding annually. We have no data on those provided professional guardianship through other mechanisms.**

tracking the number of individuals *placed* under guardianship each year but does not have data for the total number of individuals *currently* under guardianship (i.e., this year and previous years). In addition, it does not track whether the guardian is family, friend, professional paid through the estate, professional paid through an agency, or other mechanism. There are private professionals for-profit or non-profit agencies that might serve as guardian, but these agencies were not mentioned by those we interviewed. Importantly, the number of adults served under the current system outside of these agencies is unknown.

NATIONAL COMPARISON

METHOD

Descriptions of state guardianship sources were found through online searches of state government offices. These sources were reviewed to find descriptions of the size and budget of the guardianship services provided by each state. States were categorized by guardianship model used (Teaster et al., 2005; Teaster et al., 2010) (Table 2).

**Important! These data should be interpreted with caution.** There is no national data base of adults under guardianship. States varied in the availability, timeliness, and clarity of their data. We attempted to record data relevant to adults only (excluding children). We used online sources only and did not attempt to verify numbers with state governments. These numbers are accurate to the best of our ability – but record keeping regarding guardianship is notoriously poor. Also, it is likely that states have unmet needs, and so the reported number may not be the same as the number of persons needing guardianship services. Further, states will vary in their subgroup population – for example, a substantial number of adults under guardianship are older (Quinn, 2005); states vary in the percentage of population who are older.

TABLE 2. STATES UNDER FOUR GUARDIANSHIP MODELS WITHIN THE UNITED STATES

Independent State Office	Within Social Service Agency Model			County Model	Court Model
5 States	32 States			10 States	6 States
AK	AR	MA	RI	AL	DE
IL	CO	MI	SC	AZ	HI
KS	CT	MN	SD	CA	MS
NM	FL	MT	TN	DE	WA
OR <sup>a</sup>	GA	NH	TX	IL	DC
	IN	NJ	UT	NV	NE <sup>a</sup>
	IA	NY	VT	NC	
	KY	OH	VA	ND	
	LA	OK	WV	WI	
	ME	PA	WI	MO	
	MD		WY		

<sup>a</sup>Recently established

CLIENT ESTIMATE

RESULTS

Five states provide public guardianship through an independent state office of the public guardian. As Oregon’s program was only recently established, we currently focus on four states that have had independent state office programs for a longer period (Table 3). The per capita rate of public guardianship ranges from 1 per 921 to 1 per 2,393 persons. The average per capita rate of guardianship ranges from .0004769 to .0006475 (depending on calculation method). If Massachusetts were to have a similar rate of public guardianship considering our state population (6,745,408; 2010 U.S. Census), there would be 3,217 to 4,368 (depending on calculation method) persons provided state funded guardianship.

TABLE 3. INDEPENDENT STATE OFFICE MODEL: ESTIMATED PER CAPITA GUARDIANSHIP

State	# Clients <sup>a</sup>	State Pop	Ratio	1 per
AK	800	736,732	0.0010859	921
IL	5383	12,880,580	0.0004179	2,393
KS	1507	2,904,021	0.0005189	1,927
NM	1183	2,085,572	0.0005672	1,763
Average			0.0004769 <sup>b</sup>	1,544 - 2,097 <sup>d</sup>
			0.0006475 <sup>c</sup>	

<sup>a</sup> Refers to those under guardianship through state funding only

<sup>b</sup> Weighted average dividing sum of all clients (8,873) by sum of state population (18,696,905).

<sup>c</sup> Unweighted average of all 5 states, treating each state equally despite different population size.

<sup>d</sup> Per capita range using weighted and unweighted averages.

The per capita rate of guardianship for states using the “social service” model, meaning that one or more social service agencies provide guardianship services using state funds, varies more substantially (Table 4), ranging from 1 per 645 to 1 per 26,076 persons. This is due in part to some states having guardianship through an agency serving only one client sub-population. Extrapolating from the five states with the most robust programs (KY, MN, NH, ME, VT<sup>1</sup>), the average per capita rate of guardianship is .00092 or approximately 1 funded guardianship per 1,087 residents. If Massachusetts were to have a similar rate of public guardianship given the state population (2010 U.S. Census), there would be 6,206 persons provided state funded guardianships.

We did not determine estimates using the county model, as these programs do not necessarily apply to all counties within a state, thus making comparisons more difficult.

TABLE 4. SOCIAL SERVICE AGENCY MODEL: ESTIMATED PER CAPITA GUARDIANSHIP <sup>a</sup>

State	# Clients	State Pop	Ratio	1 per
AR	180	2,966,369	0.0000607	16,480
CO	530	5,355,866	0.0000990	10,105
FL	2,671	19,893,297	0.0001343	7,448
GA	853	10,097,343	0.0000845	11,837
IN	253	6,596,855	0.0000384	26,075
KY	2,652	4,413,457	0.0006009	1,664
ME	1,500	1,330,089	0.0011277	887

<sup>1</sup> Results are based on adult guardianship programs in MN, NH, ME, and VT. The guardianship program in KY does not clearly differentiate the sub-populations they serve (adults, children, and individuals with developmental disabilities), but noted that the majority of their cases are from Adult Protective Services.

MD	772	5,976,407	0.0001292	7,741
MN	3,400	5,457,173	0.0006230	1,605
MT	360	1,023,579	0.0003517	2,843
NH	950	1,326,813	0.0007160	1,397
NJ	700	8,938,175	0.0000783	12,769
NY	9,573	19,746,227	0.0004848	2,063
PA	4,752	12,787,209	0.0003716	2,691
RI	90	1,055,173	0.0000853	11,725
TN	400	6,549,352	0.0000611	16,375
TX	1,349	26,956,958	0.0000500	19,984
UT	200	2,942,902	0.0000680	14,715
VT	971	626,562	0.0015497	645
VA	601	8,326,289	0.0000722	13,854
WV	700	1,850,326	0.0003783	2,643
Average			0.0002169 <sup>b</sup>	2,931 - 4,609 <sup>d</sup>
			0.0003412 <sup>c</sup>	

<sup>a</sup> Only able to determine program size for 21 states.

<sup>b</sup> Weighted average dividing sum of all clients by sum of state population.

<sup>c</sup> Unweighted average of all 21 states, treating each state equally despite different population size.

<sup>d</sup> Per capita range using weighted and unweighted averages.

TABLE 5. TOP 5 SOCIAL SERVICE AGENCY MODEL: ESTIMATED PER CAPITA GUARDIANSHIP

State	# Clients	State Population	Ratio	1 per
KY	2,652	4,413,457	0.0006009	1,664
ME	1,500	1,330,089	0.0011277	887
MN	3,400	5,457,173	0.0006230	1,605
NH	950	1,326,813	0.0007160	1,397
VT	971	626,562	0.0015497	645
Average			0.0007202 <sup>a</sup>	1,083- 1,389 <sup>c</sup>
			0.0009235 <sup>b</sup>	

<sup>a</sup> Weighted average dividing sum of all clients by sum of state population.

<sup>b</sup> Unweighted average of all 5 states, treating each state equally despite different population size.

<sup>c</sup> Per capita range using weighted and unweighted averages.

The summary of estimates provided using the independent state office and top 5 social service model comparisons range from 3,217 to 6,229; the average across the four estimates is 4,668, and across the weighted estimates only is 4,038. Given that Massachusetts currently provides state funding for guardianship for 916 persons, this suggests that approximately 3,200-3,800 adults may require but are not provided state-funded guardianship.

**SNAPSHOT: UNMET  
NEED**

**Based on these  
estimates:  
approximately 3,200-  
3,800 persons without  
family or friends may  
need guardianship  
services but are not  
provided state-funded  
guardianship in the  
Commonwealth.**

## BUDGET ESTIMATE

As further background to the above calculations and to facilitate budgetary forecasting, we examined the budgets of nine state programs (four independent state programs and the five largest social service programs (KY, MN, NH, ME, VT). We examined online descriptions and state budgets for the most recent year for which data were published (most often 2013). All nine of the programs appear to combine guardianship services for adults with developmental disabilities with those for adults with other conditions that may impair capacity. As before, these numbers should be interpreted with caution.

## STATE INDEPENDENT OFFICE MODEL PROGRAMS

**Alaska**

The Public Guardian Section is located within the Office of Public Advocacy and provides guardianship and conservatorship services for individuals who are found by the court to be in need of a protective order. The Office of Public Advocacy budget of \$24,907,000 includes guardianship and conservatorship services to vulnerable Alaskans, legal advocacy services to children, and elder fraud services<sup>1</sup>.

**Illinois**

Within Illinois, the Guardianship & Advocacy Commission has three components: (1) Office of State Guardian (OSG; guardianship services for incapacitated adults), (2) Legal Advocacy Service (LAS; legal advice and representation for disabled children and adults, including assistance with treatment and placement issues), and (3) Human Rights Authority (HRA; conducts investigations of complaints of rights violations for persons with disabilities; mainly volunteer effort). The Commission's total budget is \$9,442,256<sup>2</sup>.

**Kansas**

The Kansas Guardianship Program uses volunteers who are trained and supervised. The program works with the Kansas Department of Social and Rehabilitative Services, who identifies those in need (usually via Adult Protective Services and state hospital referrals) and then matches volunteer guardians to the ward in need. Then, the Department petitions the court for appointment of the volunteer (note, the Guardianship Program does not petition). After appointment, the program contracts with volunteer services and provides any necessary funding and training. The program budget appears as \$1,158,250<sup>3</sup> for an estimated average cost per protected person of \$769 (budget divided by client *N* from Table 3).

**New Mexico**

<sup>1</sup>[https://www.omb.alaska.gov/ombfiles/14\\_budget/Admin/Proposed/comp43.pdf](https://www.omb.alaska.gov/ombfiles/14_budget/Admin/Proposed/comp43.pdf)

<sup>2</sup><http://www.illinois.gov/gov/budget/Documents/Budget%20Book/FY%202015%20Budget%20Book/FY2015BudgetByLineItemData.xls>

<sup>2</sup><http://www.illinois.gov/gov/budget/Documents/Budget%20Book/FY%202015%20Budget%20Book/FY2015BudgetByLineItemData.xls><sup>3</sup> [http://budget.ks.gov/publications/FY2014/FY2014\\_GBR\\_Vol1--Corrected\\_1-28-2013.pdf](http://budget.ks.gov/publications/FY2014/FY2014_GBR_Vol1--Corrected_1-28-2013.pdf)

<sup>3</sup>[http://budget.ks.gov/publications/FY2014/FY2014\\_GBR\\_Vol1--Corrected\\_1-28-2013.pdf](http://budget.ks.gov/publications/FY2014/FY2014_GBR_Vol1--Corrected_1-28-2013.pdf)

In New Mexico, the Office of Guardianship is in the Developmental Disabilities Planning Council, which contracts with providers of guardianship services. The budget appears as \$2,954,759 (76% of “total funds” of \$3,887,841<sup>1</sup>) for an estimated average cost per protected person of \$2,498 (budget divided by client *N* from Table 3).

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## SOCIAL SERVICE MODEL PROGRAMS (5 LARGEST)

### Kentucky

Kentucky’s public guardianship program appears to accept cases from the court and implement public guardianship through field offices. They collect fees from those who can pay, which are circulated back into the state public guardianship fund. The annual budget appears to be \$6,236,407<sup>2</sup>, averaging \$2,342 for each incapacitated adult served (budget divided by client *N* from Table 4).

### Minnesota

In Minnesota, the Department of Human Services (DHS) is named the public guardian. Services are carried out by the DHS Public Guardianship Office and lead agencies in the home county of the adult under guardianship. Agencies in the home county establish contracts for guardianship to avoid conflict between being a service provider and a guardian as stipulated in state law. If indigent, cost of guardianship services (including court costs, attorneys’ fees for both the petitioner and the protected adult, and any ongoing guardian fees) are covered by the county or social services department. If able, guardianship services are paid for by the protected adult’s estate according to a fee schedule. Guardianship services appear to be funded from the DHS Continuing Care Administration annual budget of \$25,900,000<sup>3</sup>.

### New Hampshire

In New Hampshire, the Department of Health and Human Services (DHHS) establishes contracts with two nonprofit agencies, one of which is the “Office of the Public Guardian.” These agencies provide the state with fixed costs for services. If indigent, the state covers court fees. For nursing home residents, the fixed cost is \$260 per month (\$3,120 per year) and for community based residents the cost is \$265 per month (\$3,180 per year)<sup>4</sup>.

### Maine

In Maine, the Department of Health & Human Services (DHHS) acts as public guardian or conservator with 2 offices: (1) DHHS Office of Elder Services serving incapacitated adults except those with developmental disabilities or autism, and (2) DHHS Office of Cognitive & Physical Disability Services serving incapacitated adults with developmental disabilities or autism. A budget of \$6,288,044<sup>5</sup> appears to be established for protective services and guardianships.

<sup>1</sup><http://www.nmddpc.com/media/files/NMDDPC-2012AnnualReport.pdf>

<sup>2</sup><http://osbd.ky.gov/Publications/Documents/Budget%20Documents/2014-2016%20Budget%20of%20the%20Commonwealth/Operating%20Budget%20-%20Volume%20I%20%28%20Part%20B%29.pdf>

<sup>3</sup> <http://www.mn.gov/mmb-stat/documents/budget/gov-budget-archives/gov-2015/background/h55.pdf>

<sup>4</sup> <http://www.courts.state.nh.us/probate/guardianshipfaq.pdf>

<sup>5</sup> <http://www.maine.gov/budget/documents/2016-2017GFBienPartA.pdf>

**Vermont**

Vermont has two programs for public guardianship administered through the Commissioner of Department of Disabilities, Aging, and Independent Living that are divided into (1) Adults 60 years and older, and (2) Adults with Developmental Disabilities. The public guardianship programs appear to be funded through the department’s annual budget of \$180,931,930 for developmental services<sup>1</sup>.

**Summary of State Budget Allocations**

In sum, the average annual estimated cost per protected person was similar in three states (NM=\$2,498, KY=\$2,342, NH=\$3120-\$3180, average \$2,663). If Massachusetts had a similar per person rate and provided for 3,200 persons, the Commonwealth would need to allocate \$8,521,600 to fully meet the need. However, this figure needs additional study and adjustment. It does not include the potential for increasing family surrogates without guardianship programs and the use of explicit and well-managed volunteer guardianship programs that may supplement independent state offices. Kansas, which has an explicit, programmed, and managed volunteer guardianship program, has an average cost of \$769.

Further, not reflected in the above estimates is the complicated issue of potential cost offset. There have been studies of potential savings that may be accrued via the provision of guardianship services for the states of Virginia<sup>2</sup>, New York<sup>3</sup>, Florida<sup>4</sup>, and Washington<sup>5</sup>. Suffice to say that the above estimates represent cost investments and do not reflect potential cost savings or offsets.

SNAPSHOT: BUDGET FORECAST

**Based on these estimates: approximately \$8,521,600 is needed to fund Public Guardianship but this estimate does not include potential cost offsets.**

**QUALITATIVE ANALYSIS**

**METHOD**

**1. Sample Size and Composition**

We invited senior leaders and clinicians within departments, courts, and institutions relevant to guardianship processes to participate in structured phone interviews (Table 6). We interviewed

<sup>1</sup><http://finance.vermont.gov/sites/finance/files/pdf/state%20budget/FY15/FY%202015%20Big%20Bill%20GovRec.pdf>

<sup>2</sup> Schmidt, W., Teaster, P., Abramson, H., & Almeida, R. (1997). Second year evaluation of the Virginia guardian of last resort and guardianship alternatives demonstration project.

<sup>3</sup> <http://www.vera.org/sites/default/files/resources/downloads/Guardianship-Practice-a-Six-Year-Perspective.pdf>

<sup>4</sup><http://elderaffairs.state.fl.us/doea/Evaluation/Statewide%20Public%20Guardianship%20Annual%20Report,%202009.pdf>

<sup>5</sup> [http://www.wsipp.wa.gov/ReportFile/1097/Wsipp\\_Public-Guardianship-in-Washington-State-Costs-and-Benefits\\_Full-Report.pdf](http://www.wsipp.wa.gov/ReportFile/1097/Wsipp_Public-Guardianship-in-Washington-State-Costs-and-Benefits_Full-Report.pdf)

leaders in agencies who are typically involved in providing services to the target populations (e.g., older adults with dementia/other neurocognitive disorder, serious mental illness, developmental disability) and those involved in guardianship proceedings.

TABLE 6. PARTICIPANTS IN INTERVIEWS

Category	Targets	Completed	Response Rate
Clinical	Hospitals Long term care	Clinical & Legal Staff	12 85%
Agencies / Entities	Executive Office of Elder Affairs Department of Mental Health Department of Disability Services Disabled Persons Protection Commission MA DD Council	4	80%
Courts	Judges Judicial Case Managers Mental Health Legal Advisors Commission	4	27%
<b>Total</b>		<b>20</b>	

## 2. Human Subjects

The planned research was reviewed by VA Boston Healthcare System Institutional Review Board and determined to be human subjects exempt under CR 46.101(b). The project was reviewed and approved by the VA Boston Healthcare System Research Committee for scientific merit.

## 3. Recruitment

Relevant individuals were contacted by the PI or research assistant via letter (email or paper) and then via telephone to explain the project and request permission to interview.

## 4. Interviews

Participants completed a structured telephone interview with at least two individuals, a lead interviewer and a note taker. Interview questions are taken from those used in studies of public guardianship in other states, namely *Public guardianship and the elderly* (Schmidt et al., 1981) and *Wards of the state: A national study of public guardianship* (Teaster et al., 2010), which were adapted and refined by the research team for this project (Appendix A). Minor modifications for flow and typographic errors were made after the initial interview. Interviewers had the flexibility to follow-up on responses with additional questions for further clarification.

## RESULTS

## 1. PREVALENCE

All interviewees (100%) stated that they “encounter adults who need a guardian (for healthcare or financial decisions) who have no family/friend, nor the financial means to pay a professional to serve in that role, so-called ‘unbefriended’ adults.” Similarly, all interviewees (100%) stated that they would support a **Public Guardianship System**. Some qualified their support to assert that such a system would need an appropriate caseload of guardian-to-person under guardianship to function.

Most (95%) support a **Default Surrogate Consent Statute**. Most interviewees believe that a Default Consent provision would decrease the number of guardianships overall, allowing appropriate family members to serve as surrogates for health care decisions with fewer obstacles and thereby reserving public guardianship as truly a last resort function.

## 2. PATHWAYS TO SURROGATE OUTCOMES

Interviewees described a variety of outcomes for such vulnerable adults, including paths generated to avoid guardianship. It is useful to outline five common pathways as a framework for subsequent results. In each of these pathways, the triggering event is the admission or encounter with an adult who lacks decision-making capacity, has no known advance directive document executed, and is without family or friends to make decisions. We use the abbreviation PIN for “Person in Need” in the tables below.

**Pathway 1: Less restrictive alternative to guardianship is identified and used.**

Interviewees described examples of exhaustive and ultimately successful searches for family and/or friends who agreed to serve in the surrogate role, followed by engagement in that role.

SNAPSHOT: DEFAULT  
SURROGATE CONSENT

**Most interviewees believe that a Default Consent provision would decrease the number of guardianships overall, allowing appropriate families to serve as surrogates.**

Triggering Event + PIN			#1
Can Family or Friend be Discovered?	Y	Can/Will IP execute POA?*	Y
N		N	Execute (no g-ship)
Can capacity be enhanced? Can a service address the need?			Y
N		N	Enhance/Provide (no g-ship)
		Can F/F Petition if provided supports?	Y
		N	Provide
			NA
Agency/ Institution Petitions			Family petitions
Agency Funded Guardian	Independent Guardian		Family Guardian
	Paid      Unpaid		

In some cases, the individual was unable to make a healthcare decision but had the capacity to execute an advance directive and did so. This is one example of a less restrictive alternative to guardianship. The person was assessed to be able to use a less restrictive option and a family/friend was identified to permit that use. Another example could be determining that the appointment of a representative payee would resolve the surrogate need in cases in which the only issue is management of public benefits, thus obviating the need for guardianship. *These examples highlight the importance of considering less restrictive alternatives as the first course of action.* Of note, Veterans Health Administration (VA) medical centers follow the federal default surrogate consent policy for veterans being treated within VA hospitals. VA interviewees described examples where the found family/friend could make the medical decision in the absence of a previously-executed advance directive following the VA default surrogate consent policy. Interviewees described creative approaches to finding family or friends, which are outlined in Appendix B.

**Pathway 2: Individual regains capacity; no guardianship needed.** In other cases, the search for family is not productive, and guardianship proceedings are initiated by the healthcare institution. Interviewees from healthcare institutions spoke of the often protracted time required to establish guardianship. Therefore, some have established a practice of moving quickly in initiating guardianship if it appears it may be necessary. However, in some of these cases as the clinical team progresses in care, a clinical intervention improves capacity (e.g., delirium clears, or medication enhances acuity) or resolves the capacity issue (e.g., a case manager is able to provide sufficient support), and the guardianship is no longer needed. *These examples illustrate the practice of strong attention to enhancing and restoring capacity which may lead to avoiding guardianship altogether.*

Triggering Event + PIN				#2
Can Family or Friend be Discovered?	Y	Can/Will IP execute POA?*	Y	Execute (no g-ship)
	N		N	
Can capacity be enhanced? Can a service address the need?			Y	Enhance/Provide (no g-ship)
	N		N	
		Can F/ F Petition if provided supports?	Y	Provide
			N	NA
Agency/ Institution Petitions			Family petitions	
Agency Funded Guardian	Independent Guardian		Family Guardian	
	Paid	Unpaid		

**Pathway 3: Family/friend identified and serves as guardian.** In other situations, a patient may be thought to be without family or friends, but someone is identified; however, the individual cannot execute an advance directive and/or guardianship is needed to resolve the issue. Examples of this situation may be outside the VA, where default surrogate consent is not permitted by law, or situations where ongoing surrogate support in the form of guardianship is needed (e.g., perhaps both individual and financial decisions are needed in an ongoing manner). In some of these situations, the family might be persuaded to petition for guardianship, but in other situations, the family does not have the instrumental or financial resources to petition but will serve as guardian if an agency or institution initiates the petition. *These examples highlight that family and friends may be able to serve as guardians when provided appropriate support by an agency or institution for the petitioning process and ongoing support once they are appointed as guardian.*

Triggering Event + PIN				#3
Can Family or Friend be Discovered?	Y	Can/Will IP execute POA?*	Y	Execute (no g-ship)
	N		N	
Can capacity be enhanced? Can a service address the need?			Y	Enhance/Provide (no g-ship)
	N		N	
		Can F/ F Petition if provided supports?	Y	Provide
			N	NA
Agency/ Institution Petitions				Family petitions
Agency Funded Guardian	Independent Guardian			Family Guardian
	Paid	Unpaid		

**Pathway 4: Agency serves as guardian.** Interviewees also provided examples of appropriate and successful use of “public guardianship,” or state funded guardianship established through an agency serving at-risk adults.

In one example of state funded guardianship services managed by the EOEA, an adult protective report was made for an adult found living in squalor in the family basement. The adult had lived with parents, but after the parents died, was increasingly less able to function. When the adult was placed under guardianship, the guardian was able to initiate appropriate healthcare and housing. After receiving these services, the adult’s capacity improved, guardianship was terminated, and rights were restored. The guardian continued on as the agent under power of attorney as requested by the adult. *This example illustrates the role guardians can take in arranging appropriate care, maximizing functioning, and efficiently using resources when funded to follow a person over an appropriate time period.*

Triggering Event + PIN				#4
Can Family or Friend be Discovered?	Y	Can/Will IP execute POA?*	Y	Execute (no g-ship)
	N		N	
Can capacity be enhanced? Can a service address the need?			Y	Enhance/Provide (no g-ship)
	N		N	
		Can F/ F Petition if provided supports?	Y	Provide
			N	NA
	Agency/ Institution Petitions			Family petitions
Agency Funded Guardian	Independent Guardian			Family Guardian
	Paid	Unpaid		

**Pathway 5: Attorney “Soft pro bono” or “Quid pro quo.”** All those interviewed also spoke of a common pathway in which no family or friends can be located, a guardian is needed, agency funding is not available, and thus the individual is appointed a guardian through the state’s “soft *pro bono*”<sup>1</sup> method. In this method, further described below, attorneys are “encouraged” or “cajoled” by a petitioner or judge into serving as guardian in a *pro bono* capacity using an unspoken or sometimes explicit *quid pro quo* arrangement. The term “soft *pro bono*” is used to distinguish this from explicitly designed *pro bono* programs in which *pro bono* volunteers serve in this capacity. Such programs include a number of structures and safeguards including training, monitoring, evaluation, and quality control measures. These structures and safeguards are not present in Massachusetts.

<sup>1</sup> This term is credited to Esther Lardent.

Triggering Event + PIN				
Can Family or Friend be Discovered?	Y	Can/Will IP execute POA?*	Y	#5 Execute (no g-ship)
	N		N	
Can capacity be enhanced? Can a service address the need?			Y	Enhance/Provide (no g-ship)
	N		N	
		Can F/ F Petition if provided supports?	Y	Provide
			N	NA
Agency/ Institution Petitions				Family petitions
Agency Funded Guardian		Independent Guardian		Family Guardian
		Paid	Unpaid	

In addition to the outcomes above, some interviewees noted that there are situations for which a surrogate decision maker may be beneficial but is not pursued because of the perception of a lack of options or solutions. For example, some speculated that protective service workers or other front line clinicians may not suggest guardianship because they understand the means to identify and provide guardians is so limited.

### 3. STRONG PRACTICES

Interviewees expressed concern about the current system of providing guardianship for those without family or friends but who need a surrogate. In addition, participants mentioned examples of practices that worked well, as highlighted below:

- A. Recognize good guardians.** The majority of those interviewed spoke about the selfless work by some unpaid guardians. For example:

*Blessedly, we have a couple of really solid citizens who are willing to do this – it is hard work. For example, we had a gentleman found down on the railroad tracks. He lived in woods. We got some info from the hospital he came from – there were a couple of buddies who slept outside – but no one who could step up and act. We had to get a court appointed lawyer. That is not always easy to get someone to act as a guardian for people who have no means to pay. They take on a lot of responsibility. We may also be asking them to help us do a Medicaid application – it is a lot of work – we need them to go in and find bank accounts, where is the social security check being deposited. They have to scramble around for information.*

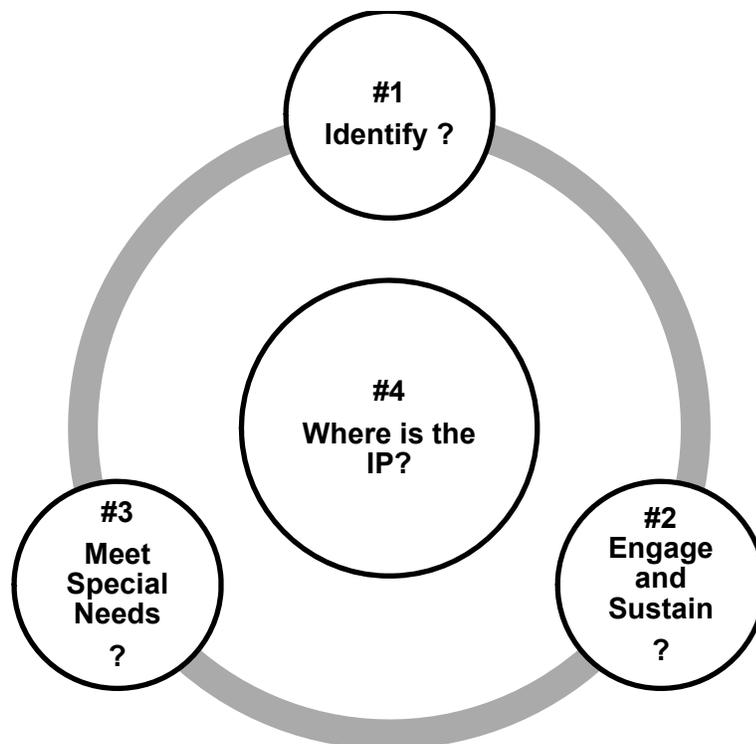
With the current system it may be that such caring and sometimes even heroic actions by guardians generally go unrecognized. Other states and programs have developed ways to recognize excellent guardians, such as state associations for guardianship.

- B. Employ a creative and exhaustive search of family or clinical history.** We were quite impressed by the creativity of those we interviewed who find family members to serve. For example, clinicians within hospitals maintain relationships with staff across programs that serve indigent adults (e.g., homelessness programs) and reach out to these staff to learn more about the person in need. A list of resources used to find family noted by interviewees appears in Appendix B. At times, these searches may not yield family but still reveal information important to inform care. For example, an interviewee at a healthcare institution described extensive efforts to learn the identity and care preferences of a person in their care. Although family could not be found, the search revealed information about the individual's previous goals of care as expressed through an Advance Directive executed within a separate healthcare institution. This information was critically important to the guardian in approaching difficult end-of-life care decisions.
- C. Support families.** We were also impressed by efforts that maximized the appropriate and constructive engagement of family members who serve as guardians. For example, the Norfolk Court has a family clinic in which professionals provide assistance to family members in completing petitions, care plans, annual accounting, and other paperwork required by the courts. The court recognizes that being a guardian is a serious and sometimes overwhelming commitment. The paperwork requirements and complexities sometimes exceed the abilities and resources of family members. Some family members may not have the educational background or skills needed. Others may find the paperwork not clear to a lay person as compared to an attorney. Some may have health concerns or diminishing abilities themselves.
- D. Avoid guardianship through less restrictive options.** We asked about processes for using less restrictive approaches to decision-making. As required by law, healthcare institutions ask individuals about their desire to execute an Advance Directive upon admission (when possible, e.g., when the person is conscious). We also learned about strong institution-wide efforts to support clinicians, patients, and families in having conversations about goals of care and in executing Advance Directives, such as the Beth Israel Deaconess' "Conversation Ready" project described in Appendix C. These screening and diversion practices were not employed in the courts.

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#### 4. DIFFICULTIES

Interviewees across agencies, courts, and healthcare institutions raised concerns about problems created by the lack of a sufficient public guardianship system. We have grouped these concerns into the four categories shown in Figure 1, which are further discussed in the paragraphs below.



#### #1 IDENTIFYING GUARDIANS TO SERVE

Petitioners and courts spoke about the difficulty of identifying guardians in the “soft” *pro bono* system. Interviewees spoke of time invested, inefficient use of funds, and the crisis created.

*Everyone will scramble. Oftentimes, it comes from a hospital – they want to transfer to rehab facility, and no one is identified who can consent. So some of the hospitals have some attorney; they have created their own list of people they would recommend. The same hospital attorneys understand we have what we call “the List<sup>1</sup>”. We no longer can print these lists out. Those on the list have to be attorneys who are willing to take guardianship for no fee to be a fiduciary. The list is pretty short. A lot of attorneys-- this is not what they are looking to do – you have to be an attorney to be on that list.*

*Counsel comes to my counter and says “we don’t have anyone” and “anyone we thought we could hasn’t returned my calls” – I want the court to appoint. We then look to that list, once the judge decides, we will do guardianship, possibly before, administrative staff will start to call attorneys on the list. What happens is the attorney isn’t answering the phone right away, has to do conflict check – there is this crisis mode. The attorneys do try to come in with the name of somebody. It may take several days, but generally the court will find someone to do it even if it has to go off the list and we say “call so and so and see if they will take the case.”*

<sup>1</sup> Details changed to protect identity of interviewee

Another interviewee noted:

*We are finding fewer people willing to be guardian, and those there aren't doing a great job. We need data on whether there's follow up, are they really doing their job? A lot of them aren't, and a lot are, because they aren't being paid.*

Many noted how this situation is not sustainable for the well intentioned:

*A problem is how few people there are who can do this. Often, the people who do it take on too many cases, and then they're not doing as good a job as we wish they would in being this person's guardian. Both locating people willing and those people may be overloaded. We can't keep going to the well.*

*"Guardian angels" have taken our hardest cases, and they get burned out.*

Others seemed uncomfortable with the "black market" approach to finding a guardian:

*It is getting harder and harder to get good people to do this.*

*To say that the current system is working is like saying our democracy is working because there's no civil war.*

Clinicians in particular noted adverse outcomes for individuals associated with the difficulty of locating appointed guardians. They expressed concern about delays in discharge leading to risks for the patient that include that the patient is not in the least restrictive environment, not getting needed care (e.g., rehabilitation), while being exposed to hospital related risks, for example:

*I've gotten on the phone and begged someone to take someone. We had a 19 year old with a head injury after a motor vehicle accident. Every day they stay here they are losing their rehab ability. And really it is because they don't have a legal guardian, not because [of] insurance. Really awful.*

*There are patients who stay longer than they need to, at higher risk of infection and fall, less autonomous, worse for family and staff members, only here because of delay in guardianship, and that is extended when you don't have an involved family member.*

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## #2 ENGAGING AND SUSTAINING GUARDIANS ONCE APPOINTED

These clinicians also noted that a guardian may be appointed but only as a temporary guardian without incentive within the system to determine whether a longer term guardian might be able to advocate for care for the individual. Both courts and clinicians discussed this concern. For example, a court staff person stated:

*It happens frequently with homeless people. We had homeless guy with no one, and they needed a guardian and couldn't find anyone, so they came to court and asked what to do. Unless there's a Rogers component, there won't be someone to take that case. We took him to our list and eventually found someone to do the case. Sometimes, the person who says they'll do the case will only do it temporarily, with temporary guardianship and get the person through what they need.*

A clinician stated:

*The person gets discharged by the rehab into the community. They say, “We can’t continue the guardianship because we don’t have someone to continue the guardianship.” They [the patient] gets lost and then show up again, and we start again.*

Further, clinicians in particular bemoaned the consequences of working with over-worked and under (not) paid guardians. While clinicians spoke of good guardians, they also described situations where they had difficulty getting a guardian to respond when needed. One respondent stated:

*Some guardians are completely invested, and they are such a pleasure to work with, they are really looking out for and trying to understand this person. With others, they are spread so thin and their time is so limited, it’s a struggle to reach out to them.*

When asked about the qualities of a “good guardian,” one respondent replied with a markedly low standard: “someone who answers the phone and visits once per quarter.” In addition to difficulties in getting calls returned, the clinicians spoke of guardians who return calls but are reluctant to expend time on the case.

Clinicians spoke of guardians not knowing a person under guardianship had died. Agencies spoke of the difficulty replacing “soft” *pro-bono* guardians who wish to retire or who die. Other respondents noted that guardians may not have training or expertise relevant to the individual’s needs. For example, the present system relies almost exclusively on attorneys. In some cases, attorneys may not be the best guardians. Attorneys have the legal and financial skills but not all attorneys have the social services, health care, gerontological, or disability background to be the most appropriate surrogate.

A clinician stated, *We don’t have the luxury of finding the perfect person for the patient.*

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### #3 MEETING NEEDS OF SPECIAL POPULATIONS

As difficult as the situation is on a day-to-day basis, interviewees also noted particular populations that were nearly impossible to serve. These populations include: adults who have multiple problems that span multiple agencies (e.g., dementia and psychosis); those who are involved with the Department of Corrections; those whose paranoid disorder causes them to be hostile to guardians; and those with specific psychiatric disorders. For example:

*The hardest to find is people who are willing to take eating disordered patients; they are hardest to deal with. Verbal, smart patient who can manipulate the system and people. They don’t have capacity or understand their disease. Need someone to make hard decisions for them. Even if they have family, we’ll get an independent guardian.*

As our population ages, we are likely to see more intersections of clinical needs, such as adults with serious mental illness or with developmental disabilities who in later life develop dementia.

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### #4 LOSING SIGHT OF THE NEEDS OF THE INDIVIDUAL

The needs of the individual can take on a role that is diminished by the challenges posed by the current system. Clinicians spoke about the real concerns of the impact of the current system on the individual. These concerns include the aforementioned delays in discharge to less

restrictive environments that are more consistent with the client's needs and preferences. But interviewees were also concerned about the inability to meet the client's needs, preferences, and values on a more basic level. For example:

*We had a challenging patient – waiting for years to get into a specialty nursing home all male unit – usually a 1-2 year wait list. We are about ready to discharge him, then I found out the guardian has gone to Florida. We've tried to contact him several times. One of the ongoing issues is the patient wants to have Cheetos, and he is at a high aspiration risk – but it is a quality of life issue. The patient himself is willing to say DNR/ DNI, but I want Cheetos. The guardian, because he is in Florida, has not made a decision. He says, I'll get back to you later, I'll address that when I get back. He is not going to get back until after Thanksgiving. For months on end the guardian has been putting us off.*

The current practice of appointing guardians working on a *pro bono* status as requested via a hospital may create a potential conflict of interest. Are the guardians – awaiting a quid pro quo pay-off – supposed to represent the individual's preferences or the hospital's preferences? Can the guardian advocate for the incapacitated adult under a substituted judgment standard while also preserving relationships with hospital counsel? One interviewee's comments seemed to indicate a focus that was more on the hospital's needs than of the incapacitated person's wishes:

*Some guardians really don't get their role. Their biggest mistake taking too much guidance from incapacitated person. That is not what you are supposed to do. A guardian may say "I have been named the guardian and the patient doesn't want to go, so I'm not going to force." This happens more often with family guardians than corporate. Family has a harder time shifting their thought process to being independent of incapacitated person.*

These issues may be magnified when guardians are not paid and therefore unable to follow the person over time, and who may not be able to advocate to achieve long term outcomes consistent with the individual's needs and preferences. In many cases, it appears that guardians may be appointed for "discharge purposes only." In addition to not supporting optimal long-term outcomes for the individual, the short-term nature of appointments significantly decreases the potential to achieve cost savings by discovering untapped assets.

In summing up the situation, an agency staff member stated:

*I don't think that individuals are well served by a system that considers the medical and other life decisions as a "freebie" for poorly paid Rogers Monitors.*

## FUTURE RESEARCH

Interviewees were asked for their perspectives on future research into this issue. In addition, 18 individuals in attendance at the November 10, 2015 Colloquium on Public Guardianship sponsored by the Massachusetts Guardianship Policy Institute provided thoughts on future research. In these interviews and colloquium feedback we identified four target populations or data bases for future research, including:

- (1) Tracking with “Mass courts” data base (44% of those at the colloquium would prioritize this area);
- (2) Surveys of guardians (78% favored);
- (3) Surveys of clinicians (44% favored);
- (4) Interviews with individuals under guardianship (or formerly under guardianship) (67% favored).

Some colloquium attendees emphasized the importance of “listening to the perspective of all these to understand how to improve the whole.” Specific suggestions for future research relative to these four targets are provided below.

### 1. IMPROVED TRACKING WITH “MASS COURTS” DATA BASE

“Mass Courts” is a relatively new data base system that for guardianship cases includes: name of person under guardianship, name of guardian, date appointed, and date annual report is due. This new system is allowing the courts to track completion of annual reports by guardians. There was interest among interviewees and Colloquium attendees to use this data base to provide a basic understanding of the scope of guardianship in the Commonwealth, including the number of individuals placed under guardianship.

There are several additional data fields not tracked in the “Mass Courts” data base but that might be gleaned through review of the guardianship paperwork that would allow a more complete accounting, such as:

- The percentage of guardians who are family, friend, agency, or independent
- The demographic characteristics of those under guardianship (i.e., age, race, income)
- The prevailing diagnoses (e.g., how many individuals have developmental disability vs. dementing illness vs. mental illness vs. head injury)
- The prevalence of guardianships for “discharge only” purposes
- Longitudinal outcomes for the individual

The ability to characterize those persons under guardianship could be informative in planning a public guardianship system that meets the demographic needs. As noted by a Colloquium attendee, “grasping the scope of the Commonwealth’s need is crucial to a realistic assessment of need [for public guardianship] and how we can address it.” In addition, such an analysis might shed a light on the need for programs that might avoid guardianship – such as more robust screening and application of less restrictive alternatives, and programs that might assist guardians – such as more support for families. Further, data on racial and economic characteristics might identify disparities in the system that are important to remedy.

### 2. SURVEY OF CLINICIANS

The clinicians we interviewed provided critical and sometimes alarming “behind the scenes” perspectives on the impact of the current guardianship system on patients. We stress that these interviews represent only a very tiny sample of the larger clinician population.

To substantiate their perspectives, we need a larger and more representative survey. Information from the current interviews could be used to generate items that could have scale response categories to quantify the qualitative comments. Items might cover areas such as:

- Experiences with guardians
- Availability of guardians
- Types and length of delays in establishing guardianships
- Consequences from delays
- Other gaps and barriers to providing care
- Times guardianship isn’t pursued because it’s considered hopeless
- Resources that might promote less restrictive alternatives to guardianship

### 3. SURVEY OF GUARDIANS

Colloquium attendees were most interested in research that would survey guardians – perhaps in part because the perspective of guardians was not obtained in “Phase 1” of the research presented at the Colloquium. Specific issues to address with guardians were identified by attendees as well as those interviewed. They include:

- Perspectives on what needs to be changed in the system
- Experience with the court process
- Experience providing guardianship services
- Most challenging types of decisions and issues
- Help needed in performing the role of guardian
- Frequency of visits with the individual served
- Time spent vs. time actually required to sufficiently serve
- Payment received and/or needed; amount of time compensated vs. uncompensated
- Differences in experiences between family and professional guardians

In addition to guardians, attendees suggested interviews or surveys with attorneys appointed to represent the individual under guardianship, also called respondents’ attorneys.

### 4. INTERVIEWS WITH THOSE UNDER GUARDIANSHIP

Individuals under guardianship are another population of interest. This population poses specific problems, including that those under guardianship would require consent from the guardian (i.e., for IRB purposes) (Teaster, 2002). Analyses would have to consider potential differences between guardians who consent versus do not consent. In addition, some individuals under guardianship could participate meaningfully (e.g., individuals with developmental disabilities) whereas some could not (e.g., individuals with advanced dementia who no longer speak or communicate). One target population could be those placed under temporary guardianship who recover capacity (Teaster, 2002) such as those with head injuries whose cognition improves over time.

Potential areas to address with persons under (or formerly under) guardianship include:

- Did you have any problems when your guardian was appointed?
- What does your guardian do for you?
- What do you wish your guardian did for you?
- Do you have any problems with your guardian?
- Where do you need the most help in making choices?
- How often do you see the guardian?
- Do you have thoughts on changes to the system?
- What areas do you feel you do/do not need decisional support in?

## CONCLUSIONS

In 2008 Massachusetts enacted a new guardianship statute, joining the rest of the United States in enhancing due process protections in the guardianship process. However, Massachusetts lags behind other states in other aspects of guardianship. In particular, it does not have an adequate public guardianship system. Furthermore, it is one of only a handful of states without a default surrogate consent law. In the absence of a default surrogate consent law, the guardianship system is likely over-used as compared to other states, resulting in further case backlog and and costing systems unnecessarily.

Interviews with a group of stakeholders with diverse perspectives on public guardianship in Massachusetts revealed a number of key conclusions:

- **When an impoverished adult lacks decisional capacity and needs a surrogate decision maker – and after all efforts to maximize capacity, apply supported decision-making, locate advance directives and powers of attorney, and find family and friends have been exhausted – a surrogate appointment by a court may be needed.**
- **There exist creative approaches to avoiding guardianship.**
  - Based on our interviews, hospitals have developed innovative programs and procedures to prevent guardianship, including facilitation of advance directives/powers of attorney and identifying family/friends.
  - The Veterans Health Administration effectively employs default surrogate consent, consistent with the majority of states who have such statutes.
  - However, some interviewed did not report systematic approaches to screen for less restrictive alternatives to guardianship, indicating these innovative practices should be widely shared and increased. Family and friends, although perhaps at times more challenging for hospitals to work with than a so-called independent guardian, are recognized as appropriate surrogates in most states for most health care surrogate issues.
- **At present, approximately 1,000 adults are provided a “public” surrogate via state funding, through EOEA, DMH, or DDS funds.**
  - These appointments may support the adult in obtaining needed healthcare and hopefully in establishing or maintaining a lifestyle consistent with his or her values and preferences in an ongoing manner.

- **Extrapolating from other states, we estimate that roughly 3,200-3,800 adults in Massachusetts lack decisional capacity and need a surrogate but do not have one.**
  - Current data systems cannot tell us how many of these adults receive guardianship under *pro-bono* or other means, or go without appropriate surrogates and advocates.
- **Massachusetts has no comprehensive system to provide court-appointed surrogate decision makers for these vulnerable adults in need. The primary method of providing court appointed surrogates is a “soft” *pro bono* tradition wherein attorneys are asked to provide these services without compensation. This *pro bono* method is not intentional, planned, nor managed but has become the default approach in Massachusetts.**

Attorneys participate in this approach

- Out of an earnest desire to provide pro bono service to those in need, or,
  - Because of perceived pressure from colleagues or the courts, or,
  - Because of an expectation of subsequent compensation on a separate matter (i.e., “quid pro quo”).
- **Our data suggest there are innumerable problems with current practices, which include difficulties in four areas outlined in this report:**
    - Identifying guardians to appoint
    - Engaging and sustaining guardians’ involvement once appointed
    - Finding guardians for the most challenging populations
    - Losing sight of the needs of the incapacitated individual
  - **These difficulties result in significant consequences to the individual including delays in discharge to less restrictive care and the absence of an appropriate advocate. Further, while not a focus of this study, we expect these guardianship practices result in unnecessary costs to the Commonwealth – for example agency and court time spent in locating guardians or court costs associated with repeated temporary guardianships.**

**In conclusion**, those who are incapacitated and alone, who lack family and friends to guide their care and who lack resources to pay others to do so – are amongst the most vulnerable in our society. As our healthcare has become more complex and expensive, and as our population has aged, Massachusetts has relied on a patchwork approach to providing public surrogates. Many good and well-intentioned individuals creatively strive to stretch this band-aid to cover the need, but it falls substantially short in appropriately meeting the need. It appears that the lack of a systemic approach is riddled with costs for both the individual and the Commonwealth. The results of the current interviews suggest that the current system is broken and needs urgent attention.

## NEXT STEPS

In addition to programmatic and legislative solutions to fixing the public guardianship problem, we recommend advocates consider ways to avoid guardianship through increased use of screening and diversion and consideration of default surrogate mechanisms.

Although imperfect, we find the information presented herein to provide compelling evidence that the current system needs to be fixed. These data can be strengthened by improved data tracking systems (starting perhaps with Mass Courts), surveys of guardians and clinicians to validate these qualitative data, and interviews with persons under or formerly under guardianship.

## REFERENCES

- American Bar Association and American Psychological Association Assessment of Capacity in Older Adults Project Working Group (ABA-APA). *Judicial determination of capacity of older adults in guardianship proceedings: A handbook for judges*. Washington DC: American Bar Association and American Psychological Association; 2006.
- Convention on the Rights of Persons with Disabilities (CRPD). *Convention on the Rights of Persons with Disabilities Vol Chapter IV (15)*. New York: United Nations; 2008
- Horstman P. Protective services for the elderly: The limits of *parens patriae*. *Missouri Law Review*. 1975;40:215-236.
- Kanter A. The United Nations Convention on the Rights of Persons with Disabilities and its implications for the rights of elderly people under international law. *Georgia State University Law Review*. 2009;25(3):526-573.
- Karp N, Wood E. *Incapacitated and Alone. Healthcare Decision-making for Unbefriended Older People*. American Bar Association Commission on Law and Aging; 2003.
- Mitchell A. Involuntary guardianship for incompetents: A strategy for legal services advocates. *Clearinghouse Review*. 1978;12:451-468.
- Moye J, Marson D, Edelstein BE. Assessment of Capacity in an Aging Society. *American Psychologist* 2013; 68(3): 158-171.
- Moye J, Naik A. Preserving Rights for Individuals Facing Guardianship. *JAMA: Journal of the American Medical Association* 2011; 305:936-937.
- Moye J, Wood E, Edelstein B, Wood S, Bower EH, Harrison JA, Armesto JC. Statutory reform is associated with improved court practice: Results of a tri-state comparison. *Behavioral Sciences and the Law* 2007a; 25:425-426.
- Moye J, Wood S, Edelstein B, Armesto JC, Bower EH, Harrison J, Wood E. Clinical evidence in guardianship of older adults is inadequate: Findings from a tri-state study. *The Gerontologist* 2007b; 47:604-612.
- National Conference of Commissioners on Uniform State Laws (NCCUSL). *Uniform Guardianship and Protective Proceedings Act*. 1997; <http://www.law.upenn.edu/bll/ulc/fnact99/1990s/ugppa97.htm>.
- Reynolds SL. 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*. 2002;6(2):109-120.
- Quinn MJ. *Guardianship of adults: Achieving justice, autonomy, and safety*. New York: Springer; 2005.
- Sabatino CP, Basinger SL. Competency: Reforming our legal fictions. *Journal of Mental Health and Aging*. 2000;6(2):119-143.
- Schmidt WC, Miller KS, Bell WG, New BE. *Public Guardianship and the Elderly*. Ballinger; 1981.

Teaster PB. (2002). The wards of public guardians: Voices of the unbefriended. *Family Relations*, 51, 344-350.

Teaster PB, Wood E, Schmidt WC, Lawrence SA, Mendiondo, M. *Public Guardianship after 25 years: In the Best Interest of Incapacitated People?* Praeger Publishing Company, 2010.

Teaster PB, Wood E, Karp N, Lawrence S, Schmidt WC, Mendiondo M. *Wards of the State: A National Study of Public Guardianship*; 2005.

Wingspan Conferees. *Wingspan: The second national guardianship conference, recommendations*. 2001; [www.naela.com](http://www.naela.com). Accessed December 29, 2006.

Wood E. *Directions of Reform. 1988-2014*;  
<http://www.abanet.org/aging/legislativeupdates/home.shtml>.

Zimny GH, Grossberg GT. *Guardianship of the Elderly*. New York: Springer; 1998.



## APPENDIX A: INTERVIEW QUESTIONS

### COURTS

1. Please briefly describe how much of the court's time is taken up by guardianship cases, including both contested and uncontested cases.
2. In estimating your court's involvement with guardianship cases it would be helpful for us to know if you have a judicial case manager who screens cases prior to hearing to divert appropriate cases to less restrictive alternatives to guardianship. Yes No  
If yes, please describe.
3. Do you encounter cases where there is a clear need for a guardian or conservator, but for whom there is no suitable person to serve? Yes No
  - 3A. Roughly what is the frequency of cases in which there is no one to serve? Do you encounter them weekly, or monthly, or just occasionally during a one year period. Can you state the frequency as a percentage of your guardianship versus conservatorship cases? Can you estimate the number during the past year?
  - 3B. What is the procedural path of these kinds of cases? May petitions be filed without a proposed fiduciary? What happens if the proposed fiduciary is not suitable?
  - 3C. What does the Court do in these kinds of cases in terms of appointing a guardian?
  - 3D. Do you have any comments about what might be done to remedy the challenge of cases having no suitable fiduciary? Would a public office to provide fiduciaries be helpful?
4. Using a scale of most challenging to least challenging, where would you place these kinds of cases (where there is no person to serve as guardian)? When no person to serve as guardian.
5. What makes these cases challenging? Can you provide an example of such a case?
6. Do you think there are cases in which an individual needs a guardian but there is no petition because no guardian has been identified? Yes No  
If Yes, Can you make an informed "guestimate" of the number of such cases? (i.e., cases you don't see).
7. Does your court have a record keeping system for tracking guardianship cases with absent or unsuitable fiduciaries? As we move forward in trying to document the need for an office of public guardian, what are your recommendations for how documentation of the need might be approached?

## AGENCIES

1. Please briefly describe the mission of your agency and who you serve.
2. Do you encounter adults who need a guardian (for healthcare or financial decisions), and they have no family/friend, nor the financial means to pay a professional, to serve in that role, so called “unbefriended” adults?  
Yes No
3. Can you describe an example of such an adult (with no specific descriptors that would possibly identify a particular individual) so that I can better understand the type of client you may serve who has this issue?
4. For such individuals, do you have mechanisms to provide a guardian? Yes No
5. Can you please describe those mechanisms to provide guardianship for persons who need a guardian but have no family or friend to serve in that role, including formal and informal processes? For example:
  - Are guardianship services provided by your agency, or contracted out?
  - Have you developed relationships with any public or private agencies or individuals to provide guardians?
6. Do you have a system of tracking the numbers of adults provided a guardian annually by these mechanisms? (If no, go to question 10) Yes No
7. How many adults are provided guardians through these mechanisms? If known, how many receive guardianship services, how many receive conservatorship services and how many receive both?
8. What is the ratio of decision-making guardianship staff to persons under guardianship? i.e., what is the average staff caseload?
9. What is the average annual expense to your agency for guardianship services and/or What is the per person cost?
10. Do you have a system of tracking the number of adults not provided a guardian – i.e., who need a guardian but are not able to be served by these mechanisms? (If no, go to question 12) Yes No
11. How many adults are there served through your agency who need guardians and cannot get one?
12. If you are not able to find a guardian for everyone who needs one, how do you prioritize?
13. Have you developed a formal procedure for screening for less restrictive options when you receive a request for guardianship/conservatorship services?
14. How might we collect more precise data on the number of adults in need of a guardian without family or friends to serve in that role and their characteristics?
15. What data do you think we should collect?
16. Do you think it would be useful or possible for us to talk to anyone else in your agency? If yes, who Yes No
17. Is there anything else you would like to share regarding this issue?

HEALTHCARE INSTITUTIONS

1. Please briefly describe the mission of your agency and who you serve.
2. Do you encounter patients [residents, for long-term care] who need a guardian (for healthcare or financial decisions), and they have no family/friend, nor the financial means to pay a professional, to serve in that role, so called “unbefriended” adults? Yes No
3. Can you describe an example of such an adult (with no specific descriptors that would possibly identify a particular individual) so that I can better understand the type of client you may serve who has this issue?
4. What sorts of problems or concerns do you have when you are faced with a person who needs a surrogate decision maker but does not have one?
5. Does your Institution ever decline admission in such cases? Yes No
6. Do you keep any records of the number of such adults you encounter as patients each year? If yes, how many? If no, can you estimate? Yes No
7. For such individuals, do you have mechanisms to provide a guardian? Yes No  
Can you please describe those mechanisms, including formal and informal processes? For example, have you developed relationships with any public or private agencies or individuals to provide guardians? Do you have other mechanisms for obtaining informed consent to care in such situations? Yes No
8. If yes, can you describe it? Can you comment on the effectiveness of these mechanisms?
9. How we might collect more precise data on the number of adults in need of a guardian (without family or friends to serve in that role), and their characteristics?
10. Do you think it would be useful or possible to set up a system for collecting data on this issue going forward, particularly if we could help you with that to minimize burden on staff? Yes No
11. If yes, what data do you think we should collect?
12. Do you think it would be useful or possible for us to talk to staff in your institution (with permission by you and consent by the individual) to better understand these issues? Yes No
13. If yes, who do you think we should talk to and why?
14. Is there anything else you would like to share regarding this issue?

## APPENDIX B: BEST PRACTICES FOR FAMILY SEARCH

As outlined in Pathway 1, interviewees recounted examples of encountering adults with no family or friends who were easily identifiable. Particularly challenging cases are those where the person is unconscious or brain injured and unable to communicate, the person is experiencing paranoia (e.g., due to schizophrenia) and is guarded around strangers, or the person has a dementing illness and is experiencing memory loss and confusion. Interviewees described cases where a patient was homeless and was not carrying any form of identification.

Interviewees described the thorough and inventive searches they undergo to find family and/or friends willing to serve as guardian. Beyond locating a suitable guardian, these searches also help clinicians better understand the individual's needs and preferences. Here are some of the strategies they utilize:

- 1) **Work with police to confirm identity.** In cases where the individual was carrying no identification and was unable to communicate, clinicians worked with police to get the IP fingerprinted and identified.
- 2) **Comb through belongings.** In cases where the individual is carrying personal belongings, interviewees reported that they “*go through anything the patient comes in with*” in order to find clues about the IP's identity, residence, history, finances, and any friends or family.
- 3) **Social media.** Clinicians reported searching for the individual on social media websites to identify family and friends. Interviewees stated that this method was often very fruitful in learning about the individual's background, interests, and social network.
- 4) **Collaborate with collateral agencies.** As one interviewee stated,

*We work with collateral agencies, if they have been involved with elder services or living in housing we talk to housing managers to get as much background as possible. MGH has a Boston homeless team and the healthcare for homeless service front line team may be familiar with them.*

Interviewees also discussed reaching out to homeless shelters where the IP may have stayed and other hospitals or nursing homes where the IP may have received care. Interviewees stated they maintain relationships with other institutions to help facilitate this process.

- 5) **Find evidence of previous healthcare decisions.** Clinicians reported communicating with other healthcare providers who had previously served the individual, which provided useful information about the individual's preferences. Because many hospitals encourage or require patients to complete healthcare proxy or Do Not Resuscitate / Do Not Intubate (DNR/DNI) paperwork, these may be on file at another institution. The individual may also have refused or accepted certain treatments, or discussed healthcare preferences more broadly with the providers. One interviewee described the following case:

*We learned he had had a hospitalization one year prior and found he had been to a nursing home for a short rehabilitation; they had addressed decisions with him when he was there. He had signed a DNR form, and the nursing home sent it over to us.*

*This was helpful because his prognosis was so poor. To know that his wish was not to be intubated and resuscitated, and at that time he was intubated, so his guardian found it helpful to know it was his wish to not have that. We were able to fulfill his wishes.*

Even after guardianship is obtained (either through the identified family/friend or through a professional guardian), these dedicated clinicians' work was not over. Interviewees stated that they made an effort to communicate what they had learned about the individual to help the guardian make decisions that would best reflect the individual's wishes. As one interviewee stated,

*An independent guardian has no prior relationship with this patient so it's a complete stranger coming in, making very challenging decisions, sometimes life or death. What we try to do is explore as much about a patient's past as possible. So that when the guardian comes in we can give history – social history beyond just medical history – so that the guardian has at least some background based on not just what the medical team is recommending but what the patient would want. Quite often we don't have that background information so the guardian works with the medical team and the patient doesn't have a voice in that.*

Another interviewee noted the challenges in balancing the individual's desire for autonomy with safety:

*[We have seen] vulnerable elders living in a train station or the airport and they're verbalizing that they're fiercely independent and want to remain so, but they've been admitted multiple times to a hospital and they're not clothed properly for the cold weather and they won't let us contact family or we can't find family and the guardian is having to help make decisions about where the patient will go after discharge – nursing home, assisted living, etc. They're able to interact with the patient but they [the IP] don't have a realistic view of what they're capable of doing.*

## APPENDIX C: PROMOTING EXECUTION OF POA AND HCP BEST PRACTICES

### **BIDMC “Conversation Project”**

Beth Israel Deaconess Medical Center in Boston is one of 10 healthcare organizations in the country participating in the pioneering “Conversation Project.” The Conversation Project is an organization dedicated to helping patients, physicians, and families have discussions about their wishes for end-of-life care. The project began in 2010 and has partnered with the nonprofit organization Institute for Healthcare Improvement to disseminate their programming to a select group of hospitals.

Becoming “Conversation Ready” has involved teaching hospital staff to initiate conversations about the patient’s wishes for care. Importantly, these conversations are recorded and entered into the patient’s medical record so that the patient’s preferences can be retrieved at a later date if needed. BIDMC has also adopted a policy of checking for a healthcare proxy (HCP) before any planned procedure and strongly encouraging patients to draft a healthcare proxy if none is in place. Once the HCP is secured, it is entered into the medical record, where there is a special tab that can easily bring up information about the HCP.

One interviewee noted that the project has a lot of buy-in and cooperation from hospital staff:

*There are a lot of efforts from physicians as well – we have a lot of good physician leadership around this. We are doing a lot of work on the Conversation Project; one of our physicians has been a real champion on being “conversation ready.” Not just appointing a proxy, but asking “what would you want?” ... There are some really fabulous champions here... Every single day there is some conversation I have when someone re-asserts the need – “Do they have a healthcare proxy, can they still do a healthcare proxy?”*

BIDMC also has been running an initiative for more than 15 years coinciding with the Friday after Thanksgiving, which the state designated as “Massachusetts’ Advance Directive Day.” BIDMC has used that day to focus on educating patients, families, and staff about the importance of filling out a health care proxy or advance directive. The initiative is titled “Let’s Talk Turkey.”

### **MGH Guardianship Team**

Massachusetts General Hospital has created a Guardianship Team to specifically focus on cases where a guardian is needed. The Team consists of a clinical social worker, a psychiatric clinical nurse specialist, two lawyers, one individual who is a psychiatrist and a lawyer, and a project specialist who tracks data. The social worker and nurse make up the “front line clinical team” and work directly with patients, families, and healthcare providers as soon as a potential guardianship case is identified. The lawyers assist in preparing legal documents and coordinate representation for the cases in court. The clinical team members also act as liaison between the patient, family, lawyers, and hospital, keeping both the patient’s family and multidisciplinary teams up to date with court proceedings.

Interviewees stated that one of the goals of the Guardianship Team was to reduce the length of stay for patients requiring guardianship. An interviewee reported that the Team has been

successful in speeding the time to secure a guardian and reducing length of stay and delays, resulting in an impressive estimated annual savings to the hospital of \$825,000.

The Guardianship Team has also educated hospital staff about the importance of seeking out existing healthcare proxies, and executing new healthcare proxies whenever possible.

### **Informal programs**

Other interviewees discussed the benefit of executing a healthcare proxy and negating the need for guardianship. They reported raising the topic with patients and staff members without formal procedures required by their healthcare institution.

**APPENDIX D: GUARDIANSHIP NEEDS ASSESSMENT TEMPLATE BEST PRACTICES**

These examples provide ideas for screening patients for the need for guardianship, including less restrictive alternatives, and demonstrate the issues that healthcare institutions consider in the guardianship process.

**VA EXAMPLE**

Patient Name:  
 Patient Address:  
 Treatment Team:

The patient was examined by on XXX,201X and has been deemed to lack capacity for decision-making related to healthcare and discharge planning.

Does the patient have a Durable Power of Attorney for Healthcare or appointed healthcare proxy? Yes or No

Are copies of documents DPOA for Healthcare or DHCP on file at the VA BHS? Yes or No

Does the patient require the appointment of a Guardian? Yes or No

Comments:

Does the patient require a Rogers decision? Yes or No

Anti-psychotic medications:

Financial situation (as assessed by social worker):  
 Social Security amount

Application for Social Security Representative Payee initiated on  
 SSA contact (name/telephone #):  
 NSC pension

Request for appointment of VA Fiduciary with VBA Field Examination office initiated on  
 VBA contact (name/telephone #)  
 SC compensation

Request for appointment of VA Fiduciary with VBA Filed Examination office initiated on .  
 VBA contact/telephone:

Other income  
 Savings

Family constellation and support systems

Comments:

Healthcare/discharge plan for patient:

This request pursuant to guardianship and all supportive documentation was forwarded on via facsimile, Legal Counsel, Regional Counsel, VISN1, who will review the request and assign it to either a VA or private attorney.



<p><b>Does the patient have a Health Care Proxy?</b></p> <p>If no completed HCP form, have you inquired with family members about the existence of a HCP? If yes, please list such family members.</p> <p>If no completed HCP form, have you inquired with prior health care providers, in particular the patient's PCP, about the existence of a HCP? If yes, please list such providers.</p> <p>If no completed HCP form, have you or the family members inquired with the patient's attorney or other estate planner about the existence of a HCP?</p>	<p>Yes: <input type="checkbox"/> Attached: <input type="checkbox"/> No: <input type="checkbox"/></p> <p>Yes: <input type="checkbox"/> No: <input type="checkbox"/></p> <p>Family Members:</p> <p>Yes: <input type="checkbox"/> No: <input type="checkbox"/></p> <p>Providers:</p> <p>Yes: <input type="checkbox"/> No: <input type="checkbox"/></p>
---	---

**All Immediate Family Members, a/k/a Heirs-at-Law (*whether involved in patient's care or not*):**  
**Please attach second sheet if more space is needed.**

Name:	Relationship:	Phone:
Address:		
Name:	Relationship:	Phone:
Address:		
Name:	Relationship:	Phone:
Address:		

**Proposed Guardian:**

Name:	Phone:
Address:	
<b>Does the patient have:</b>	
Power of Attorney?	Yes: <input type="checkbox"/> Attached: <input type="checkbox"/> No: <input type="checkbox"/>
<b>Please attach a copy of the current meds and all documentation regarding Power of Attorney/Health Care Proxy</b>	



*EXAMINING THE NEED FOR A PUBLIC GUARDIAN IN MASSACHUSETTS: Phase 1*

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