Guardianship for Adults without Surrogates in Massachusetts

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INTRODUCTION

This report provides detailed findings from three surveys conducted in the Commonwealth of Massachusetts:

- A survey of clinicians involved in discharge planning and case management
- A survey of hospital counsel who pursue guardianship for patients
- A survey of guardians

This extensive set of quantitative and qualitative findings provides the most comprehensive understanding to date of guardianship for adults without family or friends to serve as healthcare agents in the Commonwealth of Massachusetts.

Guardianship is a last resort in such situations – when all efforts to support decision-making abilities and employ less restrictive options have been exhausted. Guardianship in Massachusetts may be over-used in the absence of a default surrogate consent statute successfully employed in most states and the Department of Veterans Affairs, as well as specific Rogers Case Law.

Clinicians' responses to this survey reveal the complexity that is guardianship in the realities of healthcare today. Guardianship is seen as at times the best solution to resolving issues of surrogate decision making for adults who need but lack surrogates. Clinicians describe many examples of interventions provided by guardians that are critical to the health and well-being of clients. Yet, clinicians express frustrations with delays in appointment and the consequences for patients under their care. In addition, clinicians provide examples of less than optimal guardianship – showing that guardianship, while needed, continues to need attention, monitoring, and reform.

These responses are rounded out by those of counsel working with hospitals and by guardians who completed surveys. Based on counsel reports it takes an average of 17 days to find an individual willing to serve as guardian *pro bono* after typically 5 refusals. *Pro bono* guardians describe the rewards and challenges of their roles, and unfortunately, some note that they are seeking to limit or end future *pro bono* work.

We hope that you will read these findings in detail. We further hope they will be useful in providing a fuller portrait of the status of guardianship for individuals without surrogates in Massachusetts, recognizing and celebrating the good work of many guardians, and providing direction for ongoing reform. By joining the voices of clinicians, counsel, guardians, and those subject to guardianship, we believe we can best arrive at the most equitable and compassionate solutions.

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BACKGROUND

Most humans make important decisions in a social context, relying upon the input and support of family, friends, and professionals. In the United States there is also a tradition within healthcare ethics and law that each person has a presumption of capacity and the right to make decisions about their healthcare, housing, finances, and other domains of their life. Occasionally neurocognitive or neuropsychiatric illness affects the ability of a person to make a decision. For example, a person may fall, have a head injury, and become unconscious. In situations such as these we rely upon family, friends, or those we have delegated through advance directive and powers of attorney instruments to make decisions on our behalf that are consistent with our values. However, some adults – for a variety of reasons – may not have family or friends and may not have completed advance directives. Historically, in the literature, adults with diminished capacity and who need but lack surrogates have been called "unbefriended,"[1] and more recently "unrepresented." These adults are in a vulnerable situation – in need of support and advocacy – particularly when facing a medical crisis. Finding solutions to this issue spans healthcare, law, and ethics.

There are at least four approaches to healthcare decision making when individuals cannot make decisions themselves (Sabatino, 1991/1992). As noted above, ideally, adults direct or delegate family or friends to make health decisions for themselves, planning for a time when they may lack the capacity to do so themselves. When there is no advance planning and no designation of a power of attorney or health care agent, health decisions may devolve to a "default surrogate" as defined in state law. These laws set out a hierarchy of family and friends who are authorized to make selected health care decisions if no advance directive was executed. When these mechanisms fail – in states with no default consent law such as Massachusetts, or when patients have no family or friends to serve as surrogates, or when those family and friends are unsuitable or abusive – clinicians may displace the decision to others such as hospital ethics committees. Finally, a court may be asked to appoint a decision maker through a guardianship mechanism (Castillo et al., 2011; Connor, Elkin, Lee, Thompson, & Whelan, 2016).

DEFINITION OF 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. 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).

Public Guardian. We will use the term "public guardianship" to mean a state-funded system of last resort, typically enacted through legislation, for both healthcare and financial decision-making for the "unbefriended" (Teaster, Wood, Lawrence, & Schmidt, 2007). "Unbefriended" is a term used to describe adults who appear to have no family or friends to serve as surrogates.

Capacity. We do not address the specific methods for determining decision-making capacity in this report, however the determination of capacity requires extreme care and an emphasis should be placed on means to enhance decisional abilities. For more information see the ABA-APA handbook Assessment of Older Adults with Diminished Capacity (ABA-APA, 2008).

Benefits and Risks of Guardianship

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. Adult guardianship models recognize that some individuals at times require an officially designated surrogate or advocate, and in the end, it is the responsibility of the state to provide such a person if no other solutions are available. Individuals experience benefits of guardianship if a guardian is able to manage a task that results in a benefit to the individual's quality of life, according to the individual's values. For example, a guardian may be able to arrange home care services,

[1] Some find the term "unbefriended" to be stigmatizing or inadequately descriptive. We will refer to the term in this document because it is commonly used and no suitable, brief, commonly accepted alternative has emerged.

advocate that the individual's healthcare values are respected, and complete financial paperwork important for the receipt of healthcare.

However, as guardianship has evolved, some commentators (e.g., National Association to Stop Guardian Abuse, https://stopguardianabuse.org) have criticized contemporary guardianship as being, at times, overly paternalistic and in some instances abusive. Further, guardianship in the United States has drawn criticism since the 1970s for insufficient protections for the person subject to 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., 2007).

Guardianship in Massachusetts

In 2008, the Commonwealth of Massachusetts re-enacted its guardianship statute, closely following the model law, the Uniform Guardianship and Protective Proceedings Act (1997) with the aim of addressing some of the above-mentioned concerns. Subsequently, Massachusetts courts have worked to address other aspects of guardianship, such as guardianship monitoring.

Public Guardianship. An area that Massachusetts has yet to address is the issue of public guardianship or guardianship of last resort. While data are scant, it is believed that a majority of guardians are family members or friends (Quinn, 2004). A public guardianship system is essential to providing surrogate decision-makers for adults 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. 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 the population in need (Teaster et al., 2007).

Default Surrogates. 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[2]. The absence of a default surrogate consent statute is relevant to the issue of public guardianship – and more generally to the issue of how state resources are directed in guardianships. Technically, if an individual has not executed a health care advance directive or power of attorney appointing a health care agent, and is not able to make healthcare decisions, a guardianship must be sought. Thus although data are lacking, Massachusetts may expend more resources on guardianship than other states because of the need for families and friends to go through a guardianship process. A default surrogate consent statute would allow appropriate surrogates to act, reserving the courts for only the most necessary cases – for situations where there is no family or friend, or situations where there is conflict or problems with a family or friend in that role. As it is always a goal to reserve the court intrusion as a last resort, a default surrogate statute may support that goal. Default surrogate laws, also the policy within the Veterans Healthcare Administration, allow supportive family, who know the patient well, to be able to make healthcare decisions. On the other hand, some may argue that not all family members in the decisional hierarchy necessarily know or would abide by the individual's values and preferences or are able or willing to act in the individual's best interest.

Rogers Monitors. In addition, Massachusetts is unique in having a special provision requiring specific guardianship authority for 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. Rogers monitors are paid by the court, but only for the function of monitoring anti-psychotic medication. The Rogers guardianship mechanism has not been carefully studied but could as well lead to an over-pursuit of guardianship. In addition, once in place, providers may turn to guardians appointed only for the Rogers authority, to make other decisions in the absence of any other surrogate decision maker and thus abrogate the rights of the person subject to guardianship.

PREVIOUS GCT STUDY

[2] 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.

In 2015 we completed "Phase 1" of our guardianship research, funded by the Guardianship Community Trust (Moye, Catlin, Kwak, Wood, & Teaster, 2017; Moye, Wood, Teaster, Catlin, & Kwak, 2016). The 2015 project had two parts. First, we completed a quantitative estimation of the need for public guardianship in Massachusetts, based on per capita estimates pro-rated from comparable states. States were categorized by guardianship model used (Teaster et al., 2007). A detailed accounting of these analyses is available in the final report (Moye et al, 2016). 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 need, but are not provided, state-funded guardianship.

Second, we then completed 20 qualitative interviews with stakeholders in government agencies, the courts, and clinical settings. Qualitative interviews suggested that there are innumerable problems with current practices for guardianship for adults without surrogates including problems identifying potential guardians to appoint; engaging and sustaining guardians' involvement once appointed; finding guardians for the most challenging populations, and; losing sight of the specific needs of the 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.

On the basis of these analyses, we concluded that 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, yet it is the default approach in Massachusetts.

Attorneys participate in this approach for several reasons: out of an earnest desire to provide *pro bono* service to those in need; 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").

PRESENT STUDY

The current survey builds on the prior research. It aims to validate and expand upon the results of the qualitative interviews through a broader based sample of clinicians, counsel working with hospitals, and guardians. We will first present the results of the clinician survey. Then, we will present the results of the surveys from counsel and guardians.

CLINICIAN SURVEY

METHODS

RECRUITMENT

We aimed to recruit 100 clinicians, targeting primarily social workers involved in the discharge process within Massachusetts hospitals, long-term care facilities, and homeless shelters. We targeted the following sites, with the goal of a 15% response rate. Distributions from sites were based on the distribution of these settings in the Commonwealth.

Table 1. Setting	Proposed Sample
Skilled Nursing Facilities	65
Rest homes	11
Acute Medical hospitals	12
Psychiatric hospitals	3
Homeless shelters	9
Other	
Total	100

We targeted these settings because individuals without families or friends to serve as surrogates are most likely to be living in isolated settings (e.g., at home/apartment alone or homeless) and encounter the need for a surrogate during an acute medical or psychiatric crisis, or when moving from acute to residential settings. We did not target assisted living centers, as within Massachusetts few of these are subsidized, and admission tends to be a more exacting process by those with financial means. Thus, we did not expect the issue of public guardianship to be common in assisted living settings. We did not target clinical outpatient services and programs (e.g., service programs for developmental disability sometimes

called "ARC") because we aimed to target settings where there were likely to be decisional crises such as those occurring in hospital settings.

To recruit participants, the Project Manager (PM) contacted healthcare facilities and asked to speak to a discharge social worker. She then explained the purpose of the project and asked if the social worker was willing to receive an e-mail message. The PM made an attempt to speak to each social worker in person rather than to leave a voice mail message, although voice mail was used if a clinician was repeatedly unavailable. Some clinicians asked that the survey be sent via letter or fax rather than via e-mail.

The Project Manager made direct outreach (primarily telephone) to 791 clinicians (see Table 2). In addition, the Principal Investigator contacted colleagues by e-mail. Further, information about the survey was distributed by e-mail to the Guardian Community Trust contact list and to the Phase I participants to enlist their help in recruiting interested colleagues.

Participants for whom we could identify an e-mail address, street address, or fax number received an e-mail message, letter, or fax inviting their participation in a survey. Those who preferred completed the survey online. Alternatively, those who preferred fax or hard copy completed the survey on paper and then either faxed or conventionally mailed the completed survey to the Project Manager or Principal Investigator who entered their responses online. In lieu of direct compensation for their time, participants were offered the chance to enter a random drawing to receive one of four iPads. Participants interested in being considered for the iPad drawing entered their names into a second survey, unlinked to their main survey response, which was anonymous. iPads were distributed after recruitment was closed.

Table 2. Contacts made by Project Manager

Setting	Phone calls	E-ailmg sent	Faxes sent	Letters sent	Total
Nursing homes	400	70	8	34	512
Rest homes	72	6	13	0	91
Acute hospitals	79	15	6	0	100
Psychiatric hospitals	18	1	0	0	19
Homeless shelters	60	8	0	1	69
Total	629	100	27	35	791

SURVEY INSTRUMENT

A survey instrument was developed based on the qualitative interviews completed in Phase I. Questions were reviewed by the research team, including two expert consultants in guardianship. See Appendix A for the survey instruments.

The following definitions were provided in the survey and are used in presenting the results.

Guardian: A person appointed by a court to make personal or health decisions for another. (A person appointed by the state to make financial decisions is called a conservator. In this survey, for brevity, we will use the general term guardian to refer to both roles). In this survey, we are focusing on guardians of adults only. Guardians may be related to the person or unrelated.

Unrelated Guardian: A professional providing guardianship services as part of their business, with no prior familial or social relationship with the person. Unrelated guardians may be paid or *pro bono.*

***Pro Bono* Guardian:** A subset of Unrelated Guardians, who receive little or no compensation for their work. *Pro Bono* Guardians often are lawyers, but not always.

ANALYTIC STRATEGY

Quantitative analyses consist of descriptive data summarizing survey responses including percent endorsement for nominal and ordinal data, and mean endorsement for ordinal and interval data. Cross-tabular comparisons examined differences between sample subgroups on the basis of setting or facility bed size using contingency coefficient for nominal data and gamma coefficient for ordinal data. Where appropriate, mean scores were compared through analysis of variance.

Qualitative analyses of four open-ended guardianship questions were completed by a four-person team. Response data were transferred from the survey

response data base to an Excel data base and reviewed to inform the coding process.

Generating and Refining Codes. Three coders independently coded each response. More than one code could be assigned to a response if indicated. Coding was discussed in one-hour review sessions attended by the 3 coders and an arbiter. Coding discrepancies were resolved through team consensus, whereas the creation of new codes and definitions was achieved through team discussion. After each coding session, code names and definitions were revised and updated. We used this approach for the entire data set in an iterative fashion. After full coding, the Project Manager checked all responses for consistency with the final codebook.

Generating and Analyzing Themes. Following the generation of specific codes two members of the team grouped the coded units into themes for presentation. The Project Manager excerpted exemplar responses, which were reviewed by the project team.

ETHICAL CONSIDERATIONS

Prior to data collection, a project proposal was submitted to the VA Boston Research and Development (R&D) Committee (for scientific merit) and Institutional Review Board (IRB) (for human subjects review). The project was approved by the approved by the R&D committee and was determined to be human subjects exempt by the IRB committee as no individually identifiable information was collected.

RESULTS

PARTICIPANTS

81 clinicians from Massachusetts participated in the clinician survey, for a participation rate of 10.2%.

Discipline

Most (42%) identify their highest degree as MSW. Others identify as nurses, physicians, master level clinicians other than social work, or other.[3]

[3] We asked for the highest degree not discipline. We made assumptions about disciplines based on degree reported, specifically MSW = Social work; MS or MA = Masters degree in psychology; MSN = Masters degree in nursing.

Table 3. Discipline	n	%
Social Work (BA or MSW)	34	42.0
Psychology MA or MS	6	7.4
RN (RN or MSN)	5	6.2
MD	4	4.9
Other / Response unclear	22	27.2
Missing	10	12.3
Total	81	100.0

Setting

About half (42%) of the participants work in long-term care, 28% in medical hospitals, and the remaining in other inpatient and outpatient settings including local senior centers and aging services agencies, Adult Protective Services, and home care.

Table 4. Setting - Detail	N	%
Hospital - Medical	23	28.4
SNF/ LTC	34	42.0
Hospital - Psychiatric	4	4.9
Rest Home	4	4.9
Home Care	2	2.5
COA or ASAP	3	3.7
APS	3	3.7
Outpatient	4	4.9
Missing	4	4.9
Total	81	100.0

Subsequent analyses examined potential differences by setting; for these the setting variable is collapsed into three categories as shown in Table 5.

Table 5. Setting - Collapsed	N	%
Hospital	27	33.3
SNF and Rest Home	38	46.9
Outpatient and All Other	12	14.8
Missing	4	4.9
Total	81	100.0

Bed Size

Participants work with institutions with a range of bed-size, from 0-50 (18.1%) to more than 500 (8.3%), the largest subgroup worked in 101-200 bed facilities (36.1%). [4]

[4] For bed size we have responses for 72 participants but above only 65 report working at an institution. We hypothesize 7 reported bed size for an affiliated institution.

Table 6. Bed Size - Detail	N	%
0-50	13	16.0
51-100	15	18.5
101-200	26	32.1
201-500	12	14.8
>500	6	7.4
Missing	9	11.1
Total	81	100.0

In subsequent analyses, we examined differences by bed size as shown in Table 7.

Table 7. Bed Size - Collapsed	N	%
50-100	28	34.6
101-200	26	32.1
201+	18	22.2
Missing	9	11.1
Total	81	100.0

QUANTITATIVE ANALYSES

FREQUENCY OF INTERACTIONS WITH GUARDIANS

Knowledge of Guardian Payment Status

We aimed to gather information about clinicians' interactions with *pro bono* guardians. However, we were uncertain if clinicians were aware of whether guardians were working *pro bono* or receiving compensation. Therefore, prior to asking about their interactions with guardians, we asked about clinicians' knowledge of guardians' payment status. About two-thirds (61.7%) of the clinicians rarely or never know whether the guardian is working *pro bono*.

Table 8. When working with guardians who are not related to your client how frequently are you aware whether the guardian is working *pro bono*?	N	%
Always	7	8.6
Often	11	13.6
Sometimes	13	16.0
Rarely	26	32.1
Never	24	29.6
Total	81	100.0

We instructed clinicians that for the rest of the survey, we would be asking about their experiences with *Pro Bono* Guardians in Massachusetts, and, if they were unsure of the payment source, they should respond using their experiences with any Unrelated Guardians.

Quantity of Guardians Encountered

Most clinicians (81%) interact with a small number of guardians each year. Information about frequency of interaction sets the stage for some of the subsequent responses about experiences.

Table 9. In the past year, how many different pro bono guardians have you encountered in your work?	N	%
A few (1-5)	64	79.0
Some (6-10)	7	8.6
Many (11-20)	6	7.4
A lot (21+)	2	2.5
Missing	2	2.5
Total	81	100.0

Frequency of Interaction with Guardians

Clinicians estimate they interacted with guardians most often on a quarterly basis (46.2%) with a range of weekly to annually.

Table 10. In the last year, how frequently did you interact with *pro bono* guardians?	N	%
Weekly	4	4.9
Monthly	21	25.9
Quarterly	36	44.4
Annually	17	21.0
Missing	3	3.7
Total	81	100.0

Frequency by Setting. There were no statistically significant differences in frequency of contact by setting.

Table 11.	Weekly/ Monthly	Quarterly	Annually	Total
Hospital	16	9	2	27
	32.7%	42.9%	50.0%	36.5%
SNF / Rest Home	28	6	1	35
	57.1%	28.6%	25.0%	47.3%
Outpatient /	5	6	1	12

Other	10.2%	28.6%	25.0%	16.2%
Total	49	21	4	74
	100.0%	100.0%	100.0%	100.0%

χ^2 (4) =6.87, p=.14, N =74. C = .29, p=.14

Frequency by Bed Size. Those who work in smaller facilities see guardians more frequently than those who work in larger facilities.

Table 12.	Weekly/ Monthly	Quarterly	Annually	Total
Small (1-100)	22	5	0	27
	45.8%	26.3%	0.0%	38.6%
Medium (101-200)	18	6	1	25
	37.5%	31.6%	33.3%	35.7%
Large (200+)	8	8	2	18
	16.7%	42.1%	66.7%	25.7%
Total	48	19	3	70
	100.0%	100.0%	100.0%	100.0%

χ^2 (4) =8.16, p=.09, N =70. γ = .42, p=.008

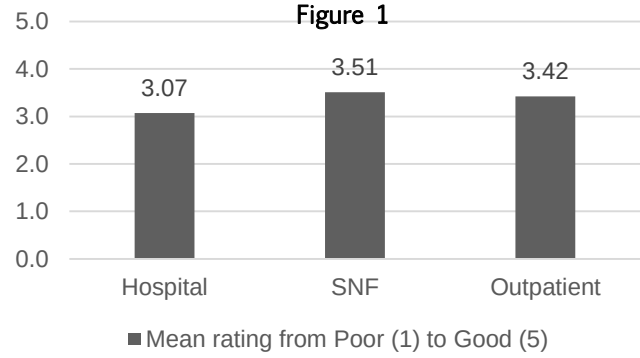
QUALITY OF EXPERIENCES WITH GUARDIANS

Most clinicians describe variable experiences or usually good experiences with guardians. Only a small percentage (6.4%) state that their experience is usually or always poor. Nearly one-third of the clinicians say their experiences with guardians is usually or always good; about half report variable experiences – some good and some bad.

Table 13. How would you describe your experiences with *pro bono* guardians?	N	%
Always Poor	1	1.2
Usually Poor	4	4.9
Varies	44	54.3
Usually Good	25	30.9
Always Good	4	4.9
Missing	3	3.7
Total	81	100.0

Experiences by Setting. Clinicians situated in hospital settings rated their experiences with guardians as worse than those in skilled nursing settings, as depicted in figure 1.

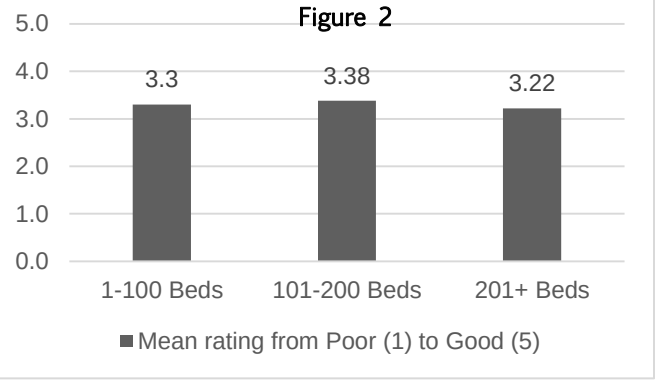
Figure 1



F(2,71)=3.04, p=.05
Post hoc with Bonferroni Correction, Hospital< SNF, p=.05

Experiences by Bed Size. There were no statistically significant differences in experiences with guardians by facility bed size. These ratings are depicted in the figure 2 below.

Figure 2



Graph depicts mean rating of quality of experience by facilities of different bed sizes on a 1-5 scale, higher numbers = more positive experience. F(2,66)=0.23, p=.79

EXPERIENCES WITH GUARDIANS VARY

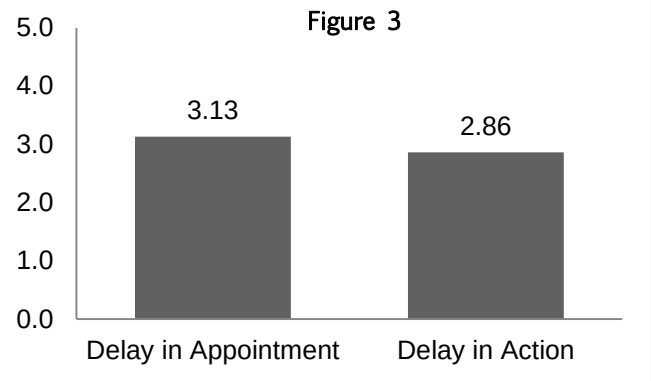
Experiences with guardians were more positive than negative, with variability. Narrative examples of experiences are found here.

DELAYS IN APPOINTMENTS AND ACTIONS BY GUARDIANS

Based on qualitative interviews, we anticipated that delays would be a concern for clinicians. Therefore, we asked about their experiences of delays with the guardianship process or with guardians themselves. Some (39.5%) report experiencing delays in appointments often or always, and about one-fifth (21.0%) report delays in getting an already appointed guardian to act often or always.

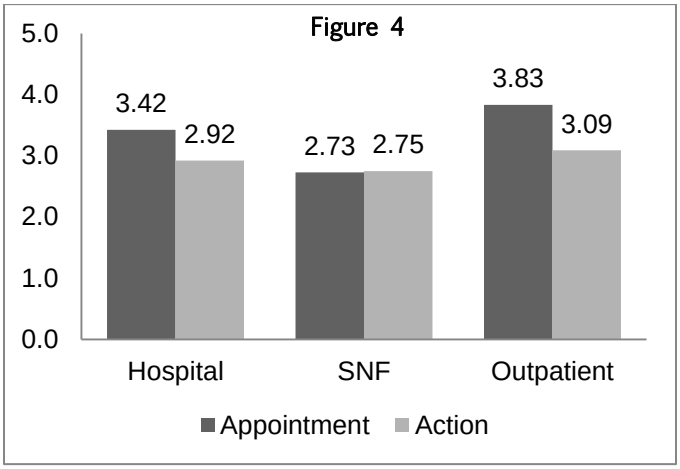
Table 14. Do you experience delays in	Appointment		Action	
	N	%	N	%
Never (0%)	9	11.1	7	8.6
Seldom (25%)	15	18.5	19	23.5
Sometimes (50%)	19	23.5	29	35.8
Often (75%)	21	25.9	11	13.6
Always (100%)	11	13.6	6	7.4
Missing	6	7.4	9	11.1
Total	81	100.0	81	100.0

Clinicians perceive court delays in appointment more common than guardian delays in action once appointed as depicted in Figure 3.



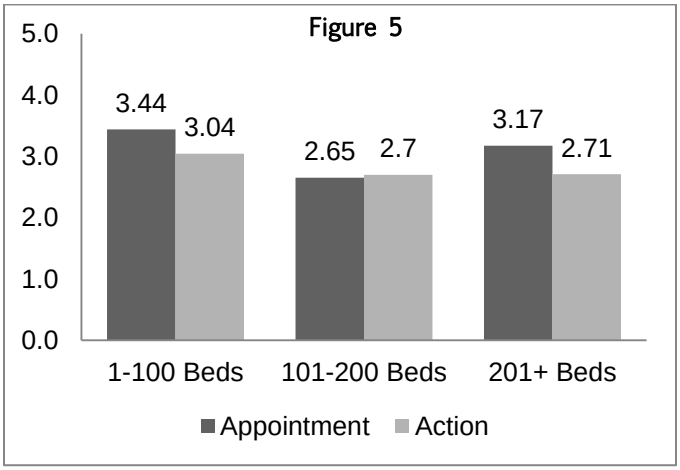
Graph depicts mean rating of the frequency of delay from 1-5 scale by type. t=2.20, p=.03

Delays by Setting. Those in outpatient settings report more frequent delays in appointments than those who work in SNF settings. Other differences were not statistically significant.



Graph depicts mean ratings of frequency of delay on 1-5 scale. For Appointment: $F(2,68)=5.04$, p=.009 [Post hoc with Bonferroni Correction, Outpatient < SNF, p=.02]. For Action: $F(2,65)=0.49$, p=.62

Delays by Bed Size. There were no differences in ratings of the frequency of delays in comparing facilities of different bed sizes.



Graph depicts mean ratings of frequency of delay on 1-5 scale. Appointment: $F(2,63)=2.60$, p=.08 Action: $F(2,61)=0.84$, p=.44

CONSEQUENCES OF DELAYS

We asked about a number of specific consequences associated with delays as suggested in responses qualitative interviews in our first study. Clinicians most often report prolonged hospital stays (65.8%) and their own personal distress (67.5%). About half of the participants also report delays in surgery, delays in transitioning to end of life care, inability to provide something to improve quality of life, going forward with a medical decision, and pain for the patient.

In comparing reasons, delays in obtaining a guardianship appointment are more often associated with prolonged hospital stays. Delays in being able to get an appointed guardian to act are most likely to be associated with transitioning to hospice or palliative care and providing the patient something to improve quality of life, and the experience of clinician distress.

Table 15. Have you ever experienced any of the following for adults who have diminished capacity and no family or friend to serve as surrogate?	Yes %[a]	Reason % (if recall)[b]	
		Appoint	Act
I experienced distress in my clinical role because of an inability to act	67.5	29.6	34.6
Prolonged hospital stay, past a medically necessary point	65.8	40.7	27.2
Unable to provide the patient something that may improve quality of life	57.0	21.0	33.3
Delay in appropriately transitioning the patient to hospice or end of life care	51.9	19.8	34.6
Delay in treatment or surgery	49.4	24.7	14.7
We just had to make a healthcare decision on behalf of the patient	48.1	13.6	17.3
The patient was in physical or psychological pain	48.1	21.2	22.2
Delay in authorizing charges/coverage for care	40.3	18.5	18.5
We had to continue with what seemed like medically non-beneficial care	39.0	18.5	18.5

[a]Items displayed in descending order of frequency.
[b]Since clinicians could not always recall these numbers should not be interpreted as absolute numbers, but instead to give an indication of relative frequency.

Consequences of Delays by Setting. Most of the consequences are more frequently reported by clinicians who work in the hospital setting. Within the hospital setting the most frequently cited issue was of prolonged hospital stay. In the long-term care setting, the most frequently cited concern for the patient was a delay in transitioning to hospice and palliative care. In the outpatient setting, the most frequently cited concern for the patient was prolonged hospital stays and delays in authorizing charges.

Table 16. Have you ever experienced any of the following for adults who have diminished capacity and no family or friend to serve as surrogate?	Setting			
	Hspl %	SNF %	Otpt %	*C*
I experienced distress in my clinical role because of an inability to act	**84.6**	50.0	75.0	.32*
Prolonged hospital stay, past a medically necessary point	**92.6**	43.2	**75.0**	.43**
Unable to provide the patient something that may improve quality of life	**74.1**	43.2	58.3	.27*
Delay in appropriately transitioning the patient to hospice or end of life care	**66.7**	47.2	33.3	.23
Delay in treatment or surgery	**74.1**	35.1	41.7	.34**
We just had to make a healthcare decision on behalf of the patient	**61.5**	36.1	50.0	.23
The patient was in physical or psychological pain	**81.5**	25.7	41.7	.45**
Delay in authorizing charges/coverage for care	33.3	37.8	**70.0**	.23
We had to continue with what seemed like medically non-beneficial care	**65.4**	22.2	33.3	.37**

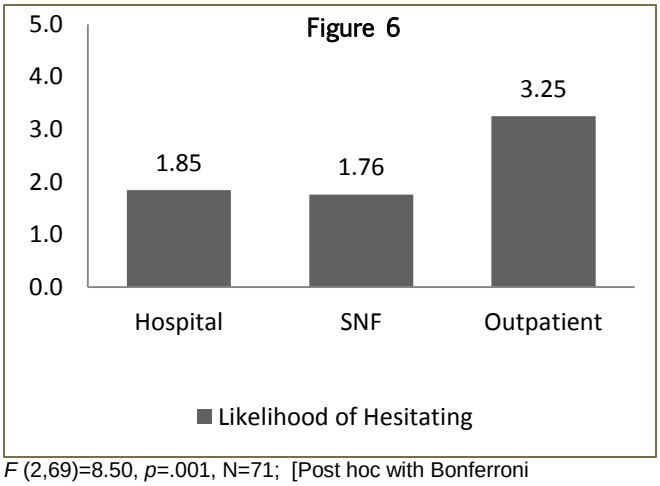
*p <.05, ** p < .001.

HESITANCY TO PURSUE GUARDIANSHIP

About half of the surveyed clinicians do not hesitate to pursue guardianship even given these experiences, whereas about half do. Only 13.6% state that they often or always hesitate to pursue guardianship.

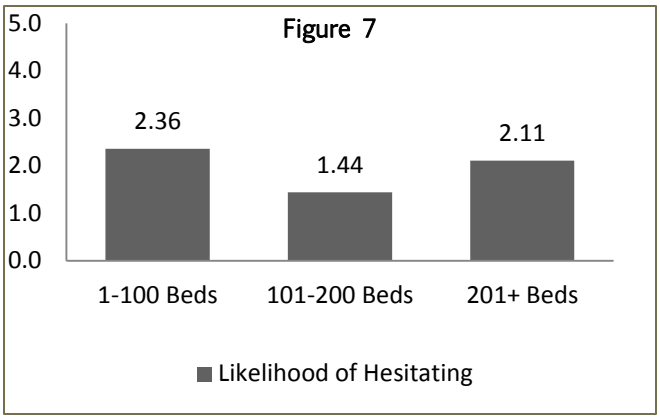
Table 17. Do you ever hesitate to pursue guardianship because you know it may be difficult to locate a suitable guardian	N	%
No never	39	48.1
Yes, rarely	10	12.3
Yes, sometimes	16	19.8
Yes, often	9	11.1
Yes, always	2	2.5
Missing	5	6.2
Total	81	100.0

Hesitancy by Setting. Those who work in outpatient settings are more likely to hesitate to pursue guardianship, as shown in Figure 6.



F (2,69)=8.50, *p*=.001, N=71; [Post hoc with Bonferroni Correction, Outpatient > Hospital, *p*=.002, Outpatient >SNF, *p*=.001]

Hesitancy by Bed Size. Those who work in smaller facilities are more likely to hesitate pursuing guardianship as shown in Figure 7.



F (2,65)=4.44, *p*=.02, N=67; [Post hoc with Bonferroni Correction, Small > Medium, *p*=.02]

MECHANISMS FOR RESOLUTION

Availability

What options can clinicians use when they find themselves in a situation where a decision is needed for a client who cannot make one him or herself, and has no appropriate or available family members or other surrogates? Clinicians working in hospitals have the most access to ethics committees and risk management officers. Most clinicians in all settings have peers with whom they can consult.

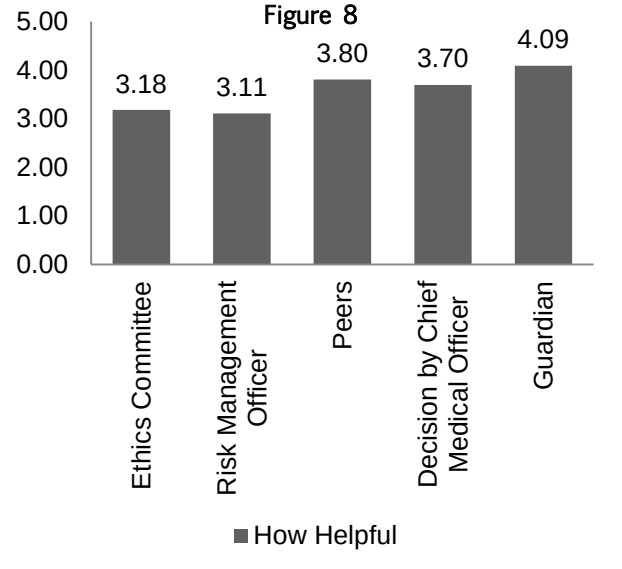
Table 18.	Availability of Mechanism (Yes/ No)				
Mechanism	Hspl %	SNF %	Outpt %	All %	*C*
Institutional Ethics Committee	96.0	60.0	50.0	70.8	.38*
Institutional Risk Mgment Officer	92.0	51.4	50.0	65.3	.38*
Consultation with peers	96.0	76.5	83.3	84.5	.24
Consultation or decision by Chief Medical Officer	72.0	84.8	75.0	78.6	.15
Obtain a guardian	100.0	94.3	83.3	94.5	.24

*p <.05, ** p < .001.

Helpfulness

Despite having variable experiences with guardianship and concerns about delays, as described in previous questions, here clinicians rate guardianship as the most helpful mechanism when they need a decision for a person in the face of a serious medical illness.

Figure 8



Clinicians' ratings of the helpfulness of each of these mechanisms did not differ by the setting in which they worked (analyses not shown here, all mean comparisons were not statistically different).

QUALITATIVE ANALYSES

QUESTION PROMPTS

Clinicians answered four open-ended questions about guardianship.

1. If willing/ able can you share an example of a best/ most helpful experience you have had with a *pro bono* guardian?

2. If willing/ able can you share an example of a worst/ most harmful experience you have had with a *pro bono* guardian?

Following forced choice questions about potential consequences of delays,

3. Have you observed other negative consequences to delays in finding a guardian or in communicating with guardians? E.g., consequences for the facility, staff, etc.?

In addition, they answered,

4. Would you like to share any other comments or concerns regarding adult guardianship?

An additional question concerning recommendations regarding advance directives was coded separately and is presented later.

CODING CATEGORIES

In coding descriptions of experiences with guardians we use three broad categories – attitudes, behaviors, and interventions. Each of these broad themes has specific positive and negative content as would be expected by the question prompts. Additional content related to the courts, law and procedure, and to end of life care.

Guardians	Policy
• Attitudes • Behaviors • Interventions	• Court • Procedure • End of Life

Specific codes are detailed in the tables that follows. Examples of responses are provided after the table. ID numbers are provided for each exemplar to identify unique participants. Minor typographical or grammatical errors in responses were corrected to enhance clarity.

Table 19. Guardians: Attitudes, Behaviors, and Interventions of Guardians		
Theme	Valence	Code Names
Attitudes and general characteristics of guardians	Positive	1. Responsive/ Responsible Guardian a. Knowledgeable b. Caring c. Volunteerism / Altruism d. Involved 2. Generally good – broad
	Negative	1. Non-Responsive/ Non- Responsible Guardian a. Is not knowledgeable b. Is not caring c. Not altruistic/ self-serving d. Is not Involved e. Does not know patient f. Resents/complains about appointment g. Not proximal 2. Generally bad – broad
Behaviors of guardians	Positive	a. Communication quick / effective b. Visits patient/ team c. Team plans/ Care plans d. Respects wishes e. Family
	Negative	a. Does not communicate quickly & Unavailable b. Does not visit ward/ team c. Does not attend team meetings/ care plans d. Does not respect patient wishes e. Would not act f. Acted without authority g. Perceived or alleged mis-use of funds h. Breach of ethics
Interventions of guardians with consequences for individual	Positive	1. Intervention/ Action/ Consequence a. Housing b. Finances c. Care transition d. Improved quality of life e. Safety f. Improved medical outcomes 2. Positive consequences for patient – broad
	Negative	1. Intervention/ Action/ Consequence a. Housing problem b. Financial problem c. Care transition problem d. Reduced quality of life e. Safety problem f. Medical problem g. Burial problem 2. Negative consequences for patient – broad

Table 20. Policy: Court, Law/Procedure, or End of Life Issues	
Court delay	a. Delay due to court staffing b. Delay due to court scheduling
Law and Procedure	a. Guardian Authority b. Guardians hard to find c. Lapse in guardianship coverage
End of life issues	a. EOL - broad b. EOL – specific to Advanced Directives
Other	a. Family Problems

GUARDIAN-FOCUSED COMMENTS

Attitudes and General Characteristics of Guardians

Caring / Not Caring. In describing examples of good and not good guardians, participants refer to their perceptions of the guardian being caring and supportive. Many specific actions could be considered caring – we noted though that some perceived a general quality of being caring.

- *"A Guardian who really cares for her clients that has advocated and visited regularly while keeping her boundaries and sense of humor."* (#6)
- *"Very supportive and immediate reaction"* (#28)

Knowledgeable/ Not Knowledgeable. Similarly, clinicians value when guardians displayed knowledge – especially in complex situations. Again, many specific actions require a body of knowledge, but some clinicians appreciate the knowledge of guardians more generally.

- *"Guardian who responded in a timely fashion, had face to face interactions and visits with both residents and their case management team. Guardians who also understood the legal system and needs for obtaining authorization to admit to a SNF or authorization for advanced directives." (#3)*
- *"Guardian attempted to obtain information about pt's identity from various sources including immigration and social security office in another state." (#79)*

In contrast, when asked to describe examples of "bad" guardians there were occasions where clinicians express frustration at the perceived lack of knowledge of a guardian.

- *"I once worked with a guardian (Attorney) who was trying to place someone in LTC and was appalled to find out how much of the persons money would need to be used to spend down to the nursing home. I thought, seriously, haven't done this before? Also, trying to get a guardian takes multiple!!!! telephone calls, I know they're busy but really, it's your ward, call me back."* (#61)
- *"Guardian had difficulty discussing their role to a Veteran w/ dementia. The guardian expressed anxiety and uncertainty during these meetings, which was transferred to the client. Despite education on how to best interact with this client, she regularly triggered him and therefore I think avoided him and interactions or decreased the length of meetings."* (#70)

Altruism / Lack of Altruism or Self Serving. Another characteristic valued by clinicians, particularly for pro-bono guardians, are perceptions that the guardian was selfless, altruistic, and appreciation that the guardian was volunteering his or her time.

- *"The pro bono guardians I have worked with are very responsive and take their responsibility seriously. One such guardian expressed the need to give back and hence the reason for volunteering."* (#15)
- *"Have worked with one pro bono guardian in particular in a high profile case who was great. Would come visit his client in the hospital often, very communicative & caring, really seemed to*

take value in this elderly patient despite not being financially compensated" (#72)

- *"This person is a guardian for several residents at my facility and even though he is pro bono for one or two residents, he does not spend less time with their cases than with those he gets paid for."* (#82)

Alternatively, clinicians express frustration when guardians serving pro bono seemed themselves frustrated by the situation or limiting their involvement because of this status.

- *"One guardian that was pro bono used to tell me all the time that he was pro bono and was not getting paid for his service He eventually stopped being a guardian by the court."* (#27)

- *"We had a guardian one time where she declined to file a petition for advance directives in court because she said she was not going to get paid for the time spent on it."* (#59)

Involved/ Not Involved. Clinicians describe guardians who are involved in their cases, taking the time and energy to do good work.

- *"Guardians that are responsive and willing to be involved in patient's care are the most helpful"* (#7)

- *"Family services in [name redacted] - do a very good job they are always attentive to their clients and visit regularly to insure their needs are met."* (#17)

Clinicians note other examples of guardians being uninvolved in the protected person's care, which causes many problems.

- *"Very few pro bono guardians are involved."* (#18)

- *"The difficult cases have more seemed like the guardian had too many clients and didn't have the time to properly address each one. We had one where the guardian was supposed to address in court his opinion on a recommended treatment -- he spent a few minutes at bedside, barely met patient, didn't speak with MD, didn't review documentation..."* (#72)

Generally Good / Generally Bad. Some comments about guardians are not specific but reflected a general sense of the guardian.

- *We have had generally good experiences"* (#43)

Behaviors of Guardians

Clinicians refer to a number of specific behaviors as being key to their perceptions of the guardian. In some cases, we found that the presence or absence of the same behavior (e.g., visiting) as key. Other examples were of specific positive or negative behaviors only.

Communicative / Not Communicative. Clinicians greatly value when guardians are communicative and responsive to calls, emails, texts, and faxes.

- *"Most helpful is when the guardian returns calls in a timely way, completes and files necessary paperwork to admit to SNF or files petition to expand guardianship powers to allow end of life decision making."* (#55)

- *"The guardian responded to calls immediately and made the decisions she was allowed to make for the pt."* (#69)

Clinicians express frustration when guardians are difficult to reach and communication was challenging.

- *"Guardians who did not return calls to clinical teams."* (#3)

- *"One of my pt has had court appointed guardian for almost one year, I've made several attempts to contact, no response. Happy to say this pt has not had any health issues but I think a guardian should at least make some contact."* (#23)

- *"We have had Guardians that do not respond to calls from the Doctors when the patient is critically ill."* (#80)

Visits Individual/ Does Not Visit Individual. Clinicians took note of whether the guardian visits the individual under guardianship – and value when that occurred.

- *"Guardian who responded in a timely fashion, had face to face interactions and visits with both residents and their case management team."* (#3)

- *"It is rare that a guardian will visit a patient at the hospital, but I recall having one guardian who visited with his patient a few times throughout his admission."* (#59)

Similarly, clinicians expressed frustration when they perceived the guardian as not or rarely visiting.

- *"Think the worst thing is when appointed guardians chose to never come into a facility to actually talk to the person they are guardian and are not knowledgeable enough to make informed decisions."* (#16)

- *"Never saw guardian unless she needed a form filled out for the court"* (#21)

Participates in Team Meetings and Care Planning. Similarly, clinicians took note of when guardians are present in meetings with professionals to discuss the plan of care.

- *"Guardian did not come to care plan meetings but called in during the meetings so she could stay updated. Very involved."* (#21)

- *"It is most helpful when a newly appointed guardian makes it a priority to meet their client/our patient and participate in a team meeting to discuss the diagnosis, prognosis and treatment options so that a plan of care can be developed. Furthermore, that the guardian provide a reliable method to contact them in a timely manner."* (#37)

Likewise, clinicians do not appreciate guardians who were not active in care planning.

- *"Guardians that are too busy to discuss their client's case for weeks after being appointed and are difficult to reach even by phone when there are pertinent clinical updates to share or a need for consent. Guardians that will not participate in obtaining the needed verifications to submit a Mass Health application on their client's behalf."* (#37)

Respects Wishes/ Does not Respect Wishes. Clinicians may have a good sense of the patient's values – particularly when the relationship is longer term. Clinicians appreciate guardians who seemed to make an effort to "respect the wishes" of the individual under guardianship.

- *"Recently, guardian participated in a conference call with family to address advanced directives, resulted in hospice services for it. Guardian was respectful of family wishes, attentive to resident's quality of life."* (#20)

Clinicians are troubled when they perceive that guardians did not respect the individual's wishes, potentially compromising end of life care.

- *"Denying a resident DNR status even though they would vocalize that they did not want this."* (#49)

Family. *Pro bono* guardians may be involved when an individual lacks family, or when an individual has family but that family is unable or unwilling to serve as guardian. In these situations, clinicians take note of when guardians made an effort to work with family members.

- *"I know one pro bono guardian who met regularly with the client, providers and family. This person really made a difference in the quality of care the person received."* (#67)

In-Action and Over-Action. In describing examples of "bad" guardians, clinicians cite two general behaviors – a failure to act, and also action without authority.

- *"Guardian was unwilling to act on behalf of the resident and make decisions regarding discharge planning."* (#3)

- *"Guardian who was acting without proper authorities for nursing home placement etc."* (#3)

- *"I had an experience with a 'professional Guardian' who identified himself wrongly as the patient's guardian and made a decision for surgery."* (#80)

Malfeasance and Breach of Ethics. While infrequent, clinicians also describe behaviors which they perceive to be unethical, such as a perceived misuse of funds or other behavior they found unethical.

- *"Pt had a personal needs account with $1,500 at time of his death. His next of kin was an elderly brother also in nursing home (Indigent). The 'pro bono' guardian billed the NH PNA account for $1,500 for her time instead of giving it to his brother."* (#17)

- *"Another employee at the organization where the guardian worked came to the Council on Aging where I work and discussed the case with the client at the lunch table in front of other lunch guests."* (#33)

- *"Not knowing patient had guardian after 19 days in hospital and learned 10 min before he is to be d/c to hospice. Guardian told me that he wanted to avoid going back to court so he advised patient's mother to have patient sign a Health Care Proxy, I told him that this was not legal, he said it was. Had to cancel hospice transfer."* (#79)

Does Not Know Individual. At times, clinicians assert that the guardians seemed not to even know the ward.

- *"Attorney who did not return calls or signs faxed paperwork as requested, didn't visit or even know resident."* (#20)

Not Proximal or Unavailable. Clinicians also express frustration with guardians who are geographically distant and not available when needed.

- *"Not always available - often they do not live in the immediate geographical area"* (#18)

- *"My experience is that Pro Bono Guardians are mostly less available and paperwork is typically out of date...which in some cases makes guardianship not applicable"* (#52)

Actions (and Inactions) with Consequences for Wards. Another way in which clinicians define "good" and "bad" guardians were the specific actions or interventions they did that created a specific benefit to the person under guardianship.

Housing. Clinicians appreciated guardians who assisted in resolving housing problems and expressed frustration with guardians whose inaction led to housing problems.

- *"Guardian very actively appealed loss of services for consumer, actively pursued alternative housing, very involved with Quality Of Life for consumer."* (#36)

- *"Guardian totally dragged feet on working during a very small window of opportunity to transition consumer to an assisted living residence."* (#36)

Financial. Clinicians applaud guardians whose actions resolved financial concern, and noted when guardians' inaction created financial concerns.

- *"The court-appointed guardian has taken control of the elder's finances to the point of distributing her check to her weekly."* (#33)

- *"A pro-bono attorney was appointed guardian when hospital filed petition for guardianship to assist with discharge back to community. This attorney did that, and then disappeared and failed to follow-up with the ward and failed to return calls, etc. made on his behalf. The ward lost his MassHealth because guardian did not file paperwork. The ward's dementia progressed significantly and he became at-risk and unsafe in his assisted living program - requiring more level of care. He faced eviction for the two previously stated reasons."* (#40)

Care Transitions. Clinicians value guardians whose involvement facilitated important care transitions and express disappointment with guardians whose inaction caused a delay or loss of an important care transition.

- *"Getting a patient reluctantly out of an unsafe home setting and into an assisted living facility which they ultimately liked very much"* (#31)

- *"Patient was discharged from hospital AMA rather than go to rehab on several occasions causing readmit to hospital. Another patient could not be admitted to long term care facility due to no guardianship in place. This patient was prone to wandering from my unlocked facility"* (#23)

- *"Guardian refused to come to the hospital to get paperwork to sign and file to admit to SNF. Told us to 'get the janitor to sign it for me.' Delayed discharge by several days."* (#55)

Quality of Life. At times, a guardian's actions are seen to have positively benefited the quality of life of the person under guardianship. Similarly, inaction is seen to negatively affect quality of life.

- *"Guardian very actively appealed loss of services for consumer, actively pursued alternative housing, very involved with Quality Of Life for consumer."* (#36)

- *"Recently, guardian participated in a conference call with family to address advanced directives, resulted in hospice services for it. Guardian was respectful of family wishes, attentive to resident's quality of life."* (#28)

- *"Guardian had difficulty discussing their role to a Veteran w/ dementia. The guardian expressed anxiety and uncertainty during these meetings which was transferred to the client. Despite education on how to best interact with this client, she regularly triggered him and therefore I think avoided him and interactions or decreased the length of meetings."* (#70)

Safety. Clinicians are appreciative when guardians' actions address an ongoing safety, abuse, or risk issue, and note when safety or risk worsened.

- *"Pro-bono attorney responded quickly to very serious case of elder neglect. Was able to get comfort measures for elderly patient quickly who was suffering and alternative living/care arrangements were made quickly while working with law enforcement against neglectful party."* (#40)

- *Just having a guardian take a case to help a vulnerable victim when they have no one, and ensuring that their basic or emergent needs are getting met, that they are safe and free from abuse."* (#34)

- *"A pro-bono attorney was appointed guardian when hospital filed petition for guardianship to assist with discharge back to community. This attorney did that, and then disappeared and failed to follow-up with the ward and failed to return calls, etc. made on his behalf. The ward lost his MassHealth because guardian did not file paperwork. The ward's dementia progressed significantly and he became at-risk and unsafe in his assisted living program - requiring more level of care. He faced eviction for the two previously stated reasons."* (#40)

Medical Problems. Not surprisingly, in these healthcare contexts, the actions of guardians, and sometimes, the more general situation of the inadequate system led to health consequences for the person under guardianship – either a problem being resolved, or a problem worsening.

- *"I know one pro bono guardian who met regularly with the client, providers and family. This person really made a difference in the quality of care the person received."* (#67)

- *"There has been only 1 who has been less-involved, and there were challenges related to medication changes and finding secure housing due to this."* (#67)

Burial. A specific negative consequence mentioned in one instance was a problem with a burial.

- *"Gave me the wrong funeral info for a resident and her burial was delayed."* (#19)

POLICY FOCUSED COMMENTS

Court Delay

Clinicians are frustrated with delays attributable to the court system. Sometimes their comments were general – and sometimes they referenced staffing or scheduling.

- *"Court staffing and scheduling delays is a big factor in this"* (#66)

- *"The court process takes a long time"* (#7)

- *"Often I have experienced the above conditions while waiting for court to hear a case to decide if guardianship is needed"* (#52)

- *"Reasons include wait time for guardianship hearings to occur, lack of court appointed counsel for patients in a timely manner, lost files by the court further delaying scheduled hearings, amount of time it takes for Mass Health applications to be*

approved so that rehab or long-term care facilities will admit patients from hospitals." (#37)

Law and Procedural Issues

Guardians are hard to find. Clinicians cite the difficulty finding individuals to serve as guardians.

- *"In addition to finding a guardian is the time it takes to get a court date."* (#78)
- *"Attorney guardian essentially just quit and left us in a lurch. We have had to find a new guardian and it is not going well, still in process."* (#2)
- *"Under Protective Services--after calling a list of 18 registered guardians/lawyers to look for a pro bono- all refused. We then had to stand in front of a judge to ask for judge to appoint- we went through at least 4 judge appointed guardians (which took months) before someone agreed to take. This put strain on rehab that was not getting paid where elder remained until guardian appointed. Pro Bono guardians are very, very rare when it comes to cases for Protective Service clients. These cases are difficult, often with difficult family members and court/legal issues tend to be lengthy making it difficult to even find a pro bono guardian"* (#35)

Lapse in Guardians. When guardians moved or died, individuals under guardianship may have experience a lapse in having a surrogate.

- *"A woman's court appointed guardian died. She had a DNR signed by the guardian (before it needed to be ordered by Court). When guardian died she became a full code. While waiting for court appointed guardian to be appointed her heart stopped, CPR was started and she was hospitalized. Guardian was appointed and order to take off machines occurred and she died at the hospital. The delay was about Court. We did not initially file an emergency guardianship and in hindsight should have. Issue was that she was not at risk so we did not file for emergency guardianship."* (#6)
- *"Attorney guardian essentially just quit and left us in a lurch. We have had to find a new guardian and it is not going well, still in process."* (#2)

Authority. Clinicians express major frustrations when guardians stated that they were unable to make certain decisions or felt unsure about the extent of their authority. At times this was specific to end of life care (further described below) and in another instance it pertained to other issues.

- *"Not always clear what the guardian can and cannot consent to - re funeral/ burial etc."* (#48)
- *"Difficulty changing people's advanced directives to CMO when they are on hospice/ end of life care"* (#7)
- *"Inability to change advance directives as needed"* (#31)
- *"Sometimes the guardian is in place, but the process to get authority to make decisions like nursing home placement or hospice care takes way too long and the patient suffers."* (#80)

End of Life

A particularly strong concern of clinicians was the experience of end of life care for individuals under guardianship. Sometimes they describe general difficulties with end of life care and care transitions, and other times they specifically referenced advance directives.

- *"Guardian stated inability to decide advance directives without a special court permission. Causes unnecessary discomfort, even harm to very ill, elderly patient."* (#13)
- *"Difficulty changing people's advanced directives to CMO when they are on hospice/ end of life care"* (#7)
- *"Guardian did not have authority to make end of life decisions and had to go back to court to get it. Pt. had to be treated on a vent until court would hear the case. Took 24 hours.* (#69)
- *"The real issue is the length of time it takes the court to address end of life care. This is very frustrating when there is a frail elderly dementia or chronically ill patient who is declining and the requirements around obtaining permission for end of life care options. Guardians don't have the authority to make the decision. I know that this is*

not in their authority to act. It is the legal system; there is no balance." (#15)

ADVANCE DIRECTIVES

Guardianship is a last resort mechanism to be exercised after all efforts to support decision making ability are put into place and after less restrictive alternatives are exhausted. In an ideal world, guardianship would seldom be used – if an individual completes an advance directive (AD) and/or power of attorney in which he or she identifies and directs a surrogate. However, guardianship is necessary, in part, because individuals find themselves in a medical crisis having not completed an advance directive and in situations and states where default surrogate consent is not available or appropriate. For this reason, we were interested to learn from clinicians in the field their ideas about how to get more patients completing advance directives, naming powers of attorney, and other less restrictive alternatives to guardianship.

Our fifth open-ended question was:

5) Do you have any thoughts about how we might increase the execution and use of Advance Directors or Powers of Attorney to avoid guardianships?

Forty-one participants responded. As this question did not pertain to guardianship, the responses did not fall into the same content as the coding book developed for the other free response questions. Responses fell into four categories as identified by the project coordinator and reviewed by the project team: education, early start, change in culture and policy. Concerns about end of life care were noted in both educational and policy categories.

Education

Clinicians note the need for general public education.

- *"Education to the public to have them in place"* (#47)
- *"Education to senior centers, LTC staff, councils on aging. Social media"* (#21)
- *"Any type of public relations campaign in local and national media, with the additional help of known personalities."* (#33)

Many clinicians describe the necessary locus of change as the Primary Care office – through education for Primary Care physicians and then passing this information on to patients at routine visits.

- *"Further education to primary care providers to have these AD discussions with ALL of their patients as part of routine care and treatment."* (#37)
- *"These discussions should be a part of routine primary care discussions, unfortunately they are left to the acute care services which is possibly the worst time for anyone to make such decisions. Change is needed in primary care."* (#76)

Clinicians also state the need for education specifically on end of life issues and what exactly treatment entails:

- *"Having clarity on end of life care."* (#15)

Early Start

Starting advance directives paperwork as early as possible is seen by clinicians as an effective strategy.

- *"Have paperwork done at an early age as soon as possible, have the conversation"* (#19)
- *"Start AD's as early as possible."* (#63)
- *"Ensure that these topics are addressed timely and before capacity is diminished when possible to ensure the person's wishes are being met."* (#9)

Culture Change

Clinicians would like to see a change in culture around how advance directives are treated and spoken about. Many referenced the advance care planning "conversations" that are challenging yet so important.

- *"Provide education and training to primary care physicians to integrate these conversations into their practice."* (#41)
- *"Encourage medical professionals and other professionals to make it part of regular conversations with people - signing and distributing directives."* (#40)

Policy Change

Clinicians called for changes to policy – at the legislative or medical center level.

- *"Decision making statute"* (#43)

- *"It would also be helpful to have an easier way to share information between hospitals and rehabs and doctors any time an advance directive is invoked. Often a hospital will invoke one and rehab facilities or Primary doctors will not know and confusion will arise over who is making decisions."* (#40)

- *"Connect having a valid written Health Care Proxies to license renewal, PCP visits, etc."* (#66)

- *"The process is too slow. I have arranged for a family member to talk with the guardian about his thoughts/wishes for his family member. This occurred 2 months ago and no action has been taken. While the client is currently medically stable he is in his 80's with dementia and a heart can stop at any time. Everyone who knows this client believes he would not want CPR. We will have to proceed with CPR + if his heart stops."* (#6)

Clinicians spoke of a desire to change the role and authorities of guardians.

- *"I feel strongly we need to change the role of the guardian to allow them to participate in advance care planning, rather than waiting until there is a crisis, and then having to go to the court to extend the privileges to make 'end-of-life decisions'"* (#74)

- *"We also need to expand the role of the guardian, to allow them to contribute to advance care planning for patients, rather than having to wait until there is a crisis, to get authority to make end-of-life decisions"* (#75)

COUNSEL SURVEY

METHODS

RECRUITMENT

We aimed to recruit 50 individuals who serve as legal counsel with hospitals in Massachusetts. The distribution of hospitals to contact mirrored those in the Commonwealth.

Table 21. Setting	N	%
	Actual	Goal
Acute hospitals	78	27
Non-Acute hospitals	46	16
Psychiatric hospitals	18	6
Total	142	50

We chose to include legal counsel because counsel employed by hospitals frequently encounter guardianship concerns when a patient without a surrogate is in need of a substitute decision-maker to approve a change in care or discharge. In Massachusetts, the hospital is obligated to begin court proceedings to appoint a guardian, and because there is no public guardianship system, must find a guardian willing to serve. We learned in Phase 1 that this process can be difficult and may lead to negative outcomes for patient and hospital.

Counsel were recruited in several ways. The Project Manager contacted healthcare facilities and asked to speak to the legal counsel. She then explained the purpose of the project and asked if counsel was willing to receive an email. An attempt was made to speak to each attorney in person rather than to leave a voice mail. Several law organizations, including the Boston Bar Association and Massachusetts Bar Association, were contacted by email and social media. Surveys were distributed at a National Academy of Elder Law Attorneys conference meeting in Boston. Additionally, 6 probate courts across the state agreed to post flyers advertising the study. Finally, the Project Manager contacted Phase I participants and Guardian Community Trust contacts to enlist their help in disseminating the survey.

The survey distribution and prize entry procedure were the same as described in the clinician section previously (see page 7).

We had a limited response rate. Some counsel that the Project Manager communicated with expressed interest in the survey but a lack of time/availability to complete it, while others expressed a reluctance to participate in research. Many counsel were not willing or able to speak over the phone and administrative staff declined to provide other contact information.

SURVEY INSTRUMENT

A survey instrument was developed based on the qualitative interviews completed in Phase I. Questions were reviewed by the research team, including two expert consultants in guardianship. Please refer to Appendix A for the survey instruments.

ANALYTIC STRATEGY

Quantitative analyses consisted of descriptive data summarizing survey responses including percent endorsement for nominal and ordinal data, and mean endorsement for ordinal and interval data.

RESULTS

PARTICIPANTS

Twelve individuals completed the survey. Two of these stated they worked as supervisors. Six were employed by hospitals / healthcare organizations; 5 for law firms serving hospitals; 1 for a state agency. Over the course of one year, the 12 participants had a wide range of frequency with which they addressed the challenge of finding guardians for adults without surrogates, averaging about 3 times per month (range 2-200; M=35.83, SD=55.59).

COUNSEL SNAPSHOT

On average

- 5 persons refuse to serve *pro bono* until someone is found
- 17 days pass before a person is located
- Meanwhile, the vulnerable adult waits.

CHALLENGES

Strategies for Finding Persons to Serve

We asked a number of questions to better document how hospital counsel finds individuals to serve as guardians for individuals without surrogates.. First, we asked <u>how</u> they locate guardians willing to serve pro-bono; the most common approach is referring to a list developed and calling friends/ associates, next is working with courts, and finally "other" approaches such as searching for family and friends.

Table 22. Strategies	N	%
I have a list of those who have been willing to serve in the past	7	58.3
I call friends or associates	7	58.3
I ask judges, judicial case managers, or other court staff for assistance	5	41.7
I work with state agencies	1	8.3
I reach out to the Massachusetts Guardianship Association	0	0
Other	4	33.3

Refusals to Serve

Not all those potential guardians who are contacted agree. Participants state that, on average, 5 individuals (SD=2.86) declined before a person was found. Common reasons for declining to serve as guardian include preference for paid work (91.7%, n=11) not enough time in schedule (75%, n=9), the difficulty or complexity of case (66.7%, n=8); won't take certain types of cases (41.7%, n=5), with lack of training or expertise rarely cited (16.7%, n=2).

Delays in Finding Persons to Serve

Next, we asked <u>how long</u> it can take to find someone willing to serve. On average, it takes 17 days (SD=16.03) to find someone to serve. Overall, the typical time from the recognition of the need for appointment to obtaining an appointment is 1-6 months, most often in the 1 week to 1 month range. The longest participants have waited ranges from 1 month to more than 12 months.

Table 23. What is the length of delay between the time you need a (non-emergency) pro bono guardian and the time one is appointed?					
	≤ 1 mo %	1-3 mos. %	3-6 mos. %	6-12 mos. %	12 + mos. %
Typical	60	10	30	0	0
Longest ever	10	50	10	10	20

Missing data, n=2.

Types of Delays

Reasons for the delay between identifying the need for a guardian and an appointment are most often due to finding someone to serve, followed by getting a court date.

Table 24. Cause for Delay	Often %	Some-times %	Never %
Finding someone to serve	73	27	0
Getting a court date	60	30	10
Getting clinician to complete a Medical Certificate or Clinical Team Report	30	40	30

Missing data, n=1-2

Hesitation to Pursue Guardianship

Most (75%, n=9) state that they have hesitated to pursue guardianship because they know it will be difficult to find someone willing to serve. Further, more than half (58%, n=7) have observed situations where a person in need was unable to obtain a guardian, ranging from one to "dozens" of times over the course of a year. Participants reported that it is sometimes difficult to get timely responses from *pro bono* guardians.

Table 25. Have you ever had difficulty getting a timely response from a Pro bono Guardian?		
	N	%
Always (100% of the time)	1	9.1
Often (75% of the time)	1	9.1
Sometimes (50% of the time)	9	81.1
Rarely (25% of the time)	0	0
Never (0% of the time)	0	0
Not answered	1	

Missing data, n=1

COUNSEL PERCEPTIONS ON PUBLIC GUARDIANSHIP

When asked whether Massachusetts would benefit from a Public Guardians Office or a formal statewide system for assigning public guardians, all (100%) of the participants said yes. Participants elaborated in comments[5]:

- *"… It is sad, but there are many instances in which people who are elderly, homeless or have mental health issues and do not have capacity to make their healthcare decisions, have no one who will make these decisions for them. … Serving as a guardian can be time-consuming and may be perceived as a burden. It would be very beneficial to Massachusetts to have a formal statewide guardianship system because it may make the flow of these cases in the Family Court system more efficient. At times I dread seeking a court-appointed guardian because I know that the burden will fall on me to try to find a guardian who is willing to serve pro-bono …"* (#3)

- *Homeless individuals (mainly from substance use disorders or chronic mental illness) and un-befriended elders typically have poor to no friend or family to approach. Pro bono lawyers will help in a crisis … but hesitate to be permanent guardians. … The fact that being in an acute hospital for prolonged period is bad per se is not a reason. Two legal factors are also bad: (1) needing to get special permission for nursing home placement and (2) the complications wrought by the 33 year-old Rogers case and its archaic concepts about antipsychotic medication. …"* (#4)

- *"It should be clear that I am responding from a state agency. We believe our system would benefit from a public guardian office that has the capacity to serve state agency clients."* (#9)

- *"There are far too many emergencies that we encounter and are unable to find a guardian. The Office of Public Guardian would hopefully resolve this problem."* (#10)

- *"A Public Guardian Office or formal statewide system would be extremely valuable. When family*

[5] Responses were edited for minor typographic errors only. Excerpts were selected to illustrate main points.

members are not available to serve, the only local candidates are attorneys and others who need to be compensated (although modestly) for their time. If there are no other sources of funding, this organization--as the petitioner--ends up agreeing to pay the guardian's costs." (#12)

GUARDIAN SURVEY

METHODS

RECRUITMENT

We aimed to recruit a sample of 50 professional guardians within Massachusetts using a "snowball sampling" method. We knew it would be challenging to recruit guardians, as there are no records of individuals who serve as guardians except those who self-identify or are known by others to serve. We know from our previous interviews that agencies and courts have developed lists of individuals willing to serve. We also learned that Rogers Monitors may be asked to exceed their designated powers to make decisions about general healthcare. We were uncertain how to estimate the sample size, but hoped to obtain a sample size of 50. However, we were only able to recruit 11 participants. As such we will present their results but treat the data more qualitatively.

Participants were recruited in several ways. The Project Manager emailed the 81 members of the Massachusetts Guardianship Association (whose contact information is publicly available on their website). The Project Manager also contacted by phone and email four agencies which have state contracts to provide guardianship services. The Guardian Community Trust email list was also contacted. Additionally, 6 probate courts across the state agreed to post flyers advertising the study. Phase I participants were contacted to enlist their help in sharing the survey. Finally, the Project Manager asked clinicians recruited for the clinician survey if they knew of any guardians to share this survey with. Many clinicians and former participants were understandably reluctant to provide the Project Manager with contact information for guardians, but some were willing to forward an email. In lieu of direct compensation for their time, participants were offered to enter a drawing to receive one of four iPads.

We had a limited response rate. One of the challenges in recruiting guardians is that names and contact information for guardians serving *pro bono* are not publicly available through the courts or any database. As our results show, *pro bono* guardians also often have large caseloads and can be difficult for even medical staff to contact.

SURVEY INSTRUMENT

A survey instrument was developed based on the qualitative interviews completed in Phase I. Questions were developed and reviewed by the research team, including two expert consultants in guardianship. Please refer to Appendix A for the survey instruments.

ANALYTIC STRATEGY

Quantitative analyses consist of descriptive data summarizing survey responses including % endorsement for nominal and ordinal data, and mean endorsement for ordinal and interval data.

RESULTS

PARTICIPANTS

Eleven individuals completed the guardian survey. Seven identified their degree as JD. The remaining four identified their degree as BS, MS, PA (Physician Assistant) certificate, and some college. Seven were solo practitioners, 1 from a law firm or group practice, 2 from a guardianship agency, and another is a retired individual who was "just someone who wanted to help."

This is an experienced group of guardians with a significant amount of their caseload focused on guardianship. They have worked from 1 to 30 years in their current setting (M=13.50, SD=10.38), with up to 38 years of total work experience (M=27.60, SD=8.93). Participants report that 5 to 100% of their caseload is devoted to guardianship (M=57.73, SD=37.51).

GUARDIANSHIP CASELOAD

For these 11 guardians, caseloads range from 1-45 individuals for guardianship (M=10.55, SD=14.21), and 1-20 individuals for conservatorship (M=7.44, SD=8.13). Of these caseloads, the percent of cases that

involve a Rogers monitor role ranged from 0-100% (*M*=31.91, *SD*=39.45). Participants estimate that on average, a guardianship case takes about 19.17 hours per year, with time fairly evenly divided between face to face visits (21% of time), discussions with clinicians (29%), documentation (31%), and court time (19%).

Extrapolating across these numbers, on average, guardians spend 4 face-to-face hours with each person under guardianship per year. 44% of those surveyed often or very often are not able to spend as much time with such clients as they would like.

PAYMENT SOURCES

In this sample, 60.45% of the guardianship work is *pro bono*, while 43.50% is paid. For individuals with no means to pay for guardianship through their estate, the following payment sources were identified.

Table 26. Payment Source Used	N	%
Receive payment from state agency such as Executive Office of Elder Affairs, Department of Mental Health, Department of Disability Services	1	11.1
Receive payment under Rudow Regulations[6], and this covers all my expenses	0	0
Receive payment under Rudow Regulations[6], but I provide other services pro bono	2	22.2
Receive payment as Rogers Monitor, and this covers all my expenses	0	0
Receive payment as Rogers Monitor, but I provide other services pro bono	3	30.0
Provide services pro bono after the person runs of out of money to pay	7	63.6

N=9, Missing data (not answered) n=2

Additional comments about payment are:

- *There is also a population that have Medicaid from another state which does not recognize Rudow [6] orders and, if they are not on antipsychotic medication, means that there is no payer source.*
- *I find the Rudow process too complex, so I simply don't charge*
- *I have not received Rudow payments or Rogers Monitor in years. Submitted documentation to the court and never received anything despite follow up in many cases. Stopped taking them and/or filing any paperwork for payment.*
- *The person for whom I currently serve as guardian/ conservator has the means to pay, but I was asked to serve pro bono and I have.*

[6] In Massachusetts, Rudow reimbursement or payment refers to the reimbursement of guardianship fees through a deduction from the individual's MassHealth payments. It is named from the case establishing this practice, Rudow v. Commissioner of the Division of Medical Assistance, 429 Mass. 218 (1999).

MOTIVATIONS FOR ACCEPTING PRO BONO CASES

Participants state a variety of reasons for accepting *pro bono* cases, most often because it is personally rewarding, and to a lesser extent, to gain experience and develop referrals. Most did not identify specific issues that would cause them to be unwilling to accept certain cases, although two guardians said they would be reluctant to accept individuals with sex offender status. History of assault, criminal conviction, and non-English speaking were not seen as concerns. However, two individuals noted that they do not plan to take any more *pro bono* guardianship cases.

Table 27. Reasons for Serving	Not at all %	Some-what %	Very much %
Personally rewarding	0	57.1	42.9
Encourages courts or colleagues to potentially refer more lucrative cases	50.0	33.3	16.7
Gain experience	42.9	57.1	0
Perceived pressure from courts or colleagues	71.4	14.3	14.3
Assists with credentialing	100	0	0
I receive payment for the Rogers monitor aspect (for appropriate cases)	71.4	14.3	14.3

N=6-7; Missing data (not answered) = 4-5

CHALLENGES

Guardians were then asked to describe what was most challenging in their work. This is valuable information and may also provide direction for future programming or education. Making decisions about living situation and end of life care is the most challenging.

Table 28.

	How Challenging		
Task	**Not at all %**	**Some-what %**	**Very %**
Completing a Medicaid application	25.0	25.0	50.0
Making decisions about supervised living placements	12.5	50.0	37.5
Understanding psychiatric medications and their implications	25.0	62.5	12.5
Working with the courts	50.0	50.0	0.0
Completing required paperwork for the courts	37.5	62.5	0.0
Making end of life care decisions	12.5	62.5	25.0
Working with adults with certain types of conditions	12.5	75.0	12.5

N=8; Missing data (not answered) = 3

Qualitative responses provide examples of challenging situations:

- *I had a man in his 60's, mildly retarded, extremely behavioral, stuck at a hospital for 13 months because no nursing home would take him, became extremely ill while at hospital (needing feeding tube and trach). I spent a ton of time dealing with medical issues that were not related to his anti-psychotic medications. I spent 150+ hours on this case over 18 months.* (#1)

- *Having to petition the courts to allow end of life directives concurrent with the elder's wishes instead of allowing the elders to go through severe medical procedures such as amputation.* (#4)

- *The day I was to move my client out of his apartment and to assisted living, the movers found bedbugs. I had to call an exterminator to fumigate the apartment and have the movers come back a different day. On the way to the assisted living facility, I took the client to Target to get all new clothes, including underwear, socks and belt (the facility wanted NOTHING from his apartment). I had him change in the dressing room at Target and threw his old clothes away in the barrel in the parking lot. While in Target we also had to get several changes of clothes, new shoes, toiletries and the like. VERY challenging day!* (#7)

- *Dealing with a woman who required constant contact and who was very unpleasant toward all...* (#8)

A GUARDIAN EXPLAINS

WHY SERVE?

By definition, these people have no one else to serve in this capacity for them. While I find it personally rewarding, what really motivates me is that I believe it is my obligation to use my law degree to help people who otherwise wouldn't be able to obtain these services.

SYSTEM LEVEL CHANGES

We asked guardians for their thoughts on "system level changes" (we did not ask clinicians or counsel this question). Although only a small number of guardians completed the survey, they provided valuable suggestions for improving the system. Participants gave suggestions for improvement in the system including payment sources, more education to families and individuals, and more cooperation within the courts and between agencies.

- *"... There needs to be a way for Guardians to get paid for an individual who, for example, is in a nursing home, not on anti-psychotic medication and only receives SSI. This is a typical client for whom there is no payer source. A Rudow order does no good when their only income is $72.80 which is what MassHealth allows them to keep each month. And, with the lack of anti-psychotic medication, you cannot be paid from the court. I have several of these kinds of cases."* (#1)

- *A fund to pay for the cost of my yearly filings and costs associated with death.* (#11)

- *I would like to see the court appointed attorneys to work cooperatively with the guardians and their attorneys instead of challenging and questioning unnecessarily and thus impeding the elderly persons care. I would like to see the courts providing some briefings and in general more info to the wards as well as their families regarding the extent of the authority and the role of the guardian.* (#4)

- *I would like to see more guardians available to serve.* (#8)

TRAINING

When asked about their interest in further training, participants identified the following topics and relevant issues:

- *I think there needs to be training within the Court as far as processing Guardians payments. I have been waiting 12 months so far for payments from Essex County!.* (#1)

- *Training regarding safety vs liberty to make own decision of elderly persons. Training regarding Rogers Authority, psychiatric medications, and its implications. Training and information about entitlements, housing (including subsidized as well as private where the elder pays mortgage or threatened by a reverse mortgage), and supervised settings such as rehab, rest homes, nursing homes, foster care etc,. Training and info about Medicare as well as Mass Health rules and regulations.* (#4)

- *Ongoing training is helpful but the reality is the forms that are involved in guardianship work these days is oftentimes duplicative and requires hours of prep time.* (#6)

- *I've been lucky enough (and have had few enough clients) to have a good relationship with the care providers. I think a good and open relationship with the care providers (including the residence staff) is key.* (#7)

- *Clarity as to what a guardian can decide re extent of care and MOLST*[7] *decisions.* (#9)

- *There should be a free course given by a professional to teach the new people what is expected. Also what is the responsibility of the Guardian? No one tells a person what it is all about.* (#10)

- *Classes on the different paperwork.* (#11)

SUGGESTIONS FROM GUARDIANS

- Expand payment sources
- Employ cooperative law models
- Educate individuals and families about guardianship
- Coordinate with elder care agencies
- Develop a uniform payment system in the courts
- Collaborate closely with healthcare providers
- Clarify MOLST and care authorities of guardians

[7] MOLST stands for Massachusetts Medical Orders for Life-Sustaining Treatments. It is a form that allows patients to make their wishes and preferences known regarding life-sustaining treatments. It is different from a health care proxy form. More information can be found here: http://www.molst-ma.org

SUMMARY

These findings are based on surveys of 81 clinicians situated in hospitals, skilled nursing facilities, and outpatient settings, about half of whom were social workers, along with 12 counsel for hospitals and 11 guardians.

- Clinicians' experiences with guardians are quite variable. Qualitative responses provide rich examples of situations in which proactive guardians intervened to end abuse, obtained needed services, and advocated for the individual's needs.

- Clinicians report pockets of problems with some guardians and concerns about delays in the system.

- Clinicians express frustration with delays, most often waiting for an appointment for an unbefriended adult, and note significant consequences for patients including:

    - prolonged hospital stays beyond medical necessity, causing them to experience distress in their clinical role
    - delays in surgery
    - delays in transitioning to end of life care
    - inability to provide resources or interventions to improve quality of life

- Hospital counsel report delays in finding a person to serve as guardian for an unbefriended adult – taking a mean of 17 days with an average of 5 refusals.

- Guardians express a desire to serve *pro bono* but note also that they have limits and that there are many challenges in being a guardian, including complex paperwork and serious decisions affecting someone else's quality of life and quality of care.

- Despite their frustrations with aspects of guardianship, clinicians nonetheless see guardianship as the most helpful mechanism for resolving the issue of surrogate consent for adults who lack the ability to make a medical decision and have nobody to support or provide decision making.

- Ethics Committees and Risk Management Officers were not available to half the clinicians in skilled nursing and outpatient settings. When these options were available, they were seen as less helpful than guardianship.

- Hospice and end of life care concerns were threaded throughout the responses of clinicians, counsel, and guardians. There is a difference in approaches by clinicians and the courts, where courts seek to limit guardians' ability to make end of life care decisions and clinicians would prefer that guardians could be more involved in end of life care decisions. Clinicians and guardians also indicate that if they weren't limited by barriers of seeking court approval, guardians could be more proactive in establishing DNR/DNI and other advance care planning that limit unnecessary aggressive medical interventions at the end of life and allow for a more comfortable end of life experience. There appears to be a lack of understanding of the realities of hospice and palliative care for older adults with serious life limiting illnesses within the courts.

RECOMMENDATIONS

1) Resolve delays in appointment of guardians by establishing a public guardianship system or other workable approach to providing a pool of available, trained guardians. A major problem with the current approach is the excessive delays to guardianship appointment generated mostly by the challenge of finding an individual willing to serve.

2) Identify and address additional reasons for court delay in appointment.

3) Promote guardian and surrogate decision-making training and resources. Variations on surrogate needs appear to include crisis decision making, ongoing case management, financial decision making, and end of life care. Various pathways and educational curricula may be important for surrogates filling these roles.

4) Increase rate of completion of advance directives through education and outreach strategies.

5) Develop approaches short of guardianship for individuals who cannot give informed consent for treatment and have no one to serve.

6) Create avenues for individuals who would like to do advance care planning – and can still plan ahead – but lack agents. Volunteer agent programs, senior services, and other agencies may fill a role. Individuals also need a mechanism to record values even if no agent can be found so that subsequent decision-makers have a record of the person's values.

7) Encourage development of additional institutional ethics committees and risk management officers to resolve some surrogate issues without guardianship.

8) Enact a surrogate default consent law to reduce instances in which a guardian is appointed only to make health care decisions and in which there is an available, appropriate, and knowledgeable family member to consent.

9) Convene an interdisciplinary working group on end of life care that includes stakeholders from relevant agencies and clinicians with expertise in hospice and palliative care to develop pathways for compassionate end of life care, based on contemporary models of palliative practice. Include necessary training on use of MOLST.

APPENDIX A: SURVEYS

GUARDIANSHIP SURVEY FOR CLINICIANS

Short name: Introduction

PURPOSE: We are surveying clinicians about your experiences with indigent adults with no family or friends to serve as surrogates, for whom the state may appoint a Pro Bono Guardian. If you do not have any such experiences, then please disregard this survey.

DEFINITIONS: We will use the following definitions in this survey.

Guardian: A person appointed by a court to make personal or health decisions for another. (A person appointed by the state to make financial decisions is called a conservator. In this survey, for brevity, we will use the general term guardian to refer to both roles). In this survey we are focusing on guardians of adults only.

Guardians may be related to the person or unrelated.

Unrelated Guardian: A professional providing guardianship services as part of their business. Unrelated guardians may be paid or pro bono.

Pro Bono Guardian: A subset of Unrelated Guardians, who receive little or no compensation for their work. Pro Bono Guardians often are lawyers, but not always.

INSTRUCTIONS:

1. Make your best guess! For some of these questions we will ask you to estimate how often you experienced something. We understand you will most likely not have specific records and will make your best guess.

2. No identifying information! In your responses please do not include any identifying information about guardians or patients.

This project has been approved by the Research and Development Committee of the VA Boston Healthcare System. This survey has been programmed so that your responses are anonymous, including not collecting your "IP Address." We thank you for your participation.

Q1 – We want to focus on your work with Pro Bono Guardians in Massachusetts.
When working with Unrelated Guardians, how frequently are you aware whether the guardian is working pro bono?

☐ Always (100% of the time) ☐ Often (75% of the time) ☐ Sometimes (50% of the time) ☐ Rarely(25% of the time) ☐ Never (0% of the time)

Q2 – For the rest of the survey, we will be asking about your experiences with Pro Bono Guardians in

Massachusetts. If you are unsure of the payment source, you may respond using your experiences with any Unrelated Guardians.
In the last year, HOW FREQUENTLY did you interact with Pro Bono Guardians?

- Weekly (>1 time/ week)
- Monthly (1-3 times per month)
- Quarterly (3-4 times per year)
- Annually (1 time per year)

Q3 – In the past year, HOW MANY DIFFERENT Pro Bono Guardians have you encountered in your work with patients or residents?

- A few: 1-5
- Some: 6-10
- Many: 11-20
- A lot: 21+

Q4 – How would you DESCRIBE YOUR EXPERIENCES with Pro Bono Guardians?

- Always good
- Usually good
- Varies - sometimes good and sometimes poor
- Usually poor
- Always poor

Q5 – Because Pro Bono Guardians are not paid, difficulties may arise.
Do you experience delays in ...

Matrix row labels are in this column	How Often do you experience delay?				
	Always (100% of the time)	Often (75% of the time)	Sometimes (50% of the time)	Seldom (25% of the time)	Never (0% of the time)
Finding someone WILLING TO BE APPOINTED as a Pro Bono Guardian.	○	○	○	○	○
Getting an already appointed guardian to ACT	○	○	○	○	○

Q6 – Do you ever hesitate to pursue guardianship because you know it may be difficult to locate a

suitable guardian?

- ○ No, never
- ○ Yes, rarely
- ○ Yes, sometimes
- ○ Yes, often
- ○ Yes, always

Q7 – Have you experienced any of the following for adults who have diminished capacity and no family/friend to serve as surrogate?

Matrix row labels are in this column	Has this happened?		If yes, do you remember the reason? (check any that apply)		
	Yes	No	Can't Recall / Other	Difficulty FINDING a guardian to serve	Difficulty GETTING a guardian to act
Prolonged hospital stay, past a medically necessary point	○	○	☐	☐	☐
Delay in treatment or surgery	○	○	☐	☐	☐
Delay in appropriately transitioning the patient to hospice or end of life care	○	○	☐	☐	☐
Unable to provide the patient something that may improve quality of life	○	○	☐	☐	☐
Delay in authorizing charges/coverage for care	○	○	☐	☐	☐
We just had to make a healthcare decision on behalf of the patient	○	○	☐	☐	☐

We had to continue with what seemed like medically non beneficial care					
I experienced distress in my clinical role because of an inability to act					
The patient was in physical or psychological pain					
Other					

If Other, describe:

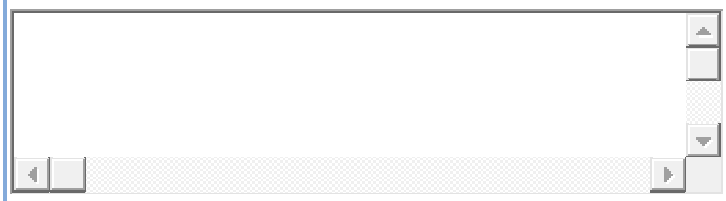
Q8 – When you need a serious medical decision made for an incapacitated adult without a surrogate, which mechanism is most helpful?

Matrix row labels are in this column	Not Helpful		Somewhat Helpful		Very Helpful	
	1	2	3	4	5	NA
Consultation with Institutional Ethics Committee						
Consultation with Institutional Risk Management Officer						
Consultation with peers						
Consultation / decision by Chief Medical Officer						
Obtain a guardian						
Other						

Q9 – If willing/ able, can you share an example of a BEST/MOST HELPFUL experience you have had

with a Pro Bono Guardian?

Q10 – If willing/ able, can you share an example of a WORST/MOST HARMFUL experience you have had with a Pro Bono Guardian?



Q11 – Do you have any thoughts about how we might increase the execution and use of Advance Directives or Powers of Attorney to avoid guardianships?

Q12 – Would you like to share any other comments or concerns regarding adult guardianship?

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Q13 – What is your primary employment setting?

- Hospital or Medical Center addressing acute needs
- Skilled Nursing Facility also called "long term care" -- may include rehabilitation and nursing home type care

- Psychiatric hospital
- Homeless shelter
- Rest home
- Other

Please specify

If Other, please describe

Q14 – How many "beds" does your facility have?

- 0-50
- 51-100
- 101-200
- 201-500
- >501

Q15 – How many years have you been employed?

In your current setting?

In total? (i.e., since your degree)

Q16 – What are your highest professional degrees?

GUARDIANSHIP SURVEY FOR COUNSEL

Short name: Introduction

PURPOSE: We are surveying hospital legal counsel in Massachusetts about your experiences with indigent adults with no family or friends to serve as surrogates, for whom the state may appoint a *Pro Bono* Guardian. If you do not have any such experiences, then please disregard this survey.

DEFINITIONS: We will use the following definitions in this survey.

Guardian: A person appointed by a court to make personal or health decisions for another. (A person appointed by the state to make financial decisions is called a conservator. In this survey, for brevity, we will use the general term guardian to refer to both roles). In this survey we are focusing on guardians of adults only.

Guardians may be related to the person or unrelated.

Unrelated Guardian: A professional providing guardianship services as part of their business. Unrelated guardians may be paid or *pro bono.*

***Pro Bono* Guardian**: A subset of Unrelated Guardians, who receive little or no compensation for their work. *Pro Bono* Guardians often are lawyers, but not always.

INSTRUCTIONS:

1. Make your best guess! For some of these questions we will ask you to estimate how often you experienced something. We understand you will most likely not have specific records and will make your best guess.

2. No identifying information! In your responses please do not include any identifying information about guardians or patients.

This project has been approved by the Research and Development Committee of the VA Boston Healthcare System. This survey has been programmed so that your responses are anonymous, including not collecting your "IP Address." We thank you for your participation.

Q1 – If you provide direct services, answer the following questions using your personal experience. If you do not provide direct services but provide formal supervision of other lawyers at your institution, check the box below and answer the questions using the experiences of those you supervise.

☐ I do not provide direct services. Responses below are based on experiences providing formal supervision.

Q2 – Approximately how many times per year do you work to find a guardian for an adult who is indigent and has no family/friends able to serve as guardian?

Frequency per year

Q3 – Please describe what percentage of the time you find guardians for indigent adults who are paid (through

an agency, through serving as a Rogers Monitor, or otherwise) vs. who serve pro bono .

The sum of the responses must be 100

% Paid

% Pro Bono

Q4 – How do you find guardians willing to serve pro bono ? Check all that apply.

- ☐ I have a list of those who have been willing to serve in the past.
- ☐ I call friends or associates.
- ☐ I ask judges, judicial case managers, or other court staff for assistance.
- ☐ I reach out to the Massachusetts Guardianship Association.
- ☐ I work with state agencies.
- ☐ Other

Q5 – How long does it take you to find someone willing to serve as a Pro bono Guardian?

Specify how many hours, days, weeks, or months

Q6 – When searching for a Pro bono Guardian, how many people generally decline before one accepts?

Q7 – What are the typical reasons you hear for why the candidate doesn't want to take on the pro bono guardianship?
Please check all that apply

- ☐ Not enough time in schedule
- ☐ Preference for paid work

- [ ] Lacking training or expertise for the case
- [ ] The difficulty or complexity of the case
- [ ] Won't take certain types of cases as a rule (e.g., sex offender, eating disordered, etc.)

Please describe any other reasons you have encountered

Q8 – What court system do you work in? Check all that apply.

- [ ] Bristol County Probate and Family Court
- [ ] Barnstable County Probate and Family Court
- [ ] Berkshire County Probate and Family Court
- [ ] Dukes County Probate and Family Court
- [ ] Essex County Probate and Family Court
- [ ] Franklin County Probate and Family Court
- [ ] Hampden County Probate and Family Court
- [ ] Hampshire County Probate and Family Court
- [ ] Middlesex County Probate and Family Court
- [ ] Nantucket County Probate and Family Court
- [ ] Norfolk County Probate and Family Court
- [ ] Plymouth County Probate and Family Court

- [ ] Suffolk County Probate and Family Court
- [ ] Worcester County Probate and Family Court
- [ ] Other

Q9 – What is the length of delay between the time you find you need a (non emergency) pro bono guardian and the time one is appointed?

	Type of Experience				
	1 week to 1 month	**1-3 months**	**3-6 months**	**6-12 months**	**12 + months**
Typical					
Longest ever					

Q10 – What is causing the delay? Check all that apply.

	Often a cause for delay	**Sometimes a cause for delay**	**Never a cause for delay**
Finding someone to serve			
Getting a court date			
Getting a clinician to complete a Medical Certificate or Clinical Team Report			
Other			

If Other, please describe

Q11 – Have you ever hesitated to pursue guardianship in situations where you need a surrogate because you know it may be difficult to locate a guardian?

Yes

No

Q12 – Have you observed cases where a person in need was unable to obtain a guardian?

Yes

No

Q13 – If yes, how many times have you observed this over the last year?

Frequency per year

Q14 – We are interested in whether Pro bono Guardians may present limitations in availability or responsiveness. Have you ever had difficulty getting a timely response from a Pro bono Guardian?

Always (100% of the time)

Often (75% of the time)

Sometimes (50% of the time)

Rarely (25% of the time)

Never (0% of the time)

Q15 – Do you think that Massachusetts would benefit from a Public Guardians Office or a formal statewide system for assigning public guardians? Feel free to leave comments about how you think the system could be improved.

Yes

No

Comments?

Q16 – What is your current workplace setting?

Hospital or medical center

- Skilled Nursing Facility also called "long term care" -- may include rehabilitation and nursing home type care
- Psychiatric hospital
- Homeless shelter
- Rest home
- Other

Q17 – How many years have you been employed

In your current setting? _____

In total (since your degree)? _____

GUARDIANSHIP SURVEY FOR GUARDIANS

PURPOSE: We are surveying guardians to gather information about your experiences serving as pro bono guardians for adults who have diminished capacity and are indigent and isolated.

FOCUS: In this survey we are only focusing on your work:

- as a guardian for adults in Massachusetts

- in the professional context (i.e., not including times where you have been appointed guardian for a family member or friend).

INSTRUCTIONS:

MAKING ESTIMATES: In the questions below we will ask you to make some estimates about client load and hours. We appreciate that this will vary widely between clients, as there is no "typical" client. However, in the interest of limiting the burden on your time, we just want you to provide your best "ballpark" estimate.

MAKING COMMENTS: Many questions have comment boxes. Please do not feel you need to provide a comment for every question. We simply want you to have the option if want to say more or explain.

PROVIDING EXAMPLES: Please do not include any identifying information about those you work with.

This project has been reviewed and approved by the VA Boston Healthcare System Research and Development Committee. This survey has been programmed so your responses are anonymous, including not collecting your "IP address." Your responses to this survey are much appreciated.

Q1 – What percentage of your overall professional workload is devoted to Guardianship or Conservatorship of adults in Massachusetts?

Q2 – What is your guardianship "caseload"? That is, approximately how many people do you typically serve as guardian for AT ONE TIME? Note: please list only the cases for whom you serve as the guardian, and not any cases for which you provide oversight or other services without being listed as the guardian.

Matrix row labels are in this column	Caseload (# of persons)
Guardian of Person	
Conservatorship	

Text box for comment if desired

Q3 – What percentage of adults for whom you serve as guardian include Rogers authority?

Q4 – Have you ever provided guardianship services for adults without a means to pay through their estate? Please check all that apply

Matrix row labels are in this column	Yes	No
Receive payment from state agency such as Executive Office of Elder Affairs, Department of Mental Health, Department of Disability Services		
Receive payment under Rudow Regulations, and this covers all my expenses		
Receive payment under Rudow Regulations, but I provide other services pro bono		
Receive payment as Rogers Monitor, and this covers all my expenses		
Receive payment as Rogers Monitor, but I provide other services pro bono		
Provide pro bono services for adults whom I know at the outset have no means to pay		
Provide services pro bono after the person runs of out of money to pay		
Other		

If other, please describe

Q5 – Approximately what percentage of your guardianship work is pro bono versus paid?

The sum of the responses must be 100

Pro bono

Paid

Q6 – QUESTIONS 9-13 refer to your work as a Pro Bono guardian for indigent adults who lack capacity and have no family or friends to serve as guardian.
If you do not provide pro bono guardianship for such clients, please skip to Q14.

What is your typical or average hours spent per such Pro Bono clients annually (consider face to face as well as documentation and court time).

Q7 – Approximately how does your time break down for such Pro Bono clients?

The sum of the responses must be 100

Face to face with client

Discussions with clinicians

Documentation

Court time

If yes, why is that?

Q9 – What motivates you to accept Pro Bono guardianship cases?

Matrix row labels are in this column	Not at all	Somewhat	Very much
Personally rewarding			
Encourages courts or colleagues to potentially refer more lucrative cases			
Gain experience			

Perceived pressure from courts or colleagues			
Assists with credentialing			
I receive payment for the Rogers monitor aspect (for appropriate cases)			
Other			

If other, what?

Q10 – Are there types of clients that you would not be willing to take on pro bono?

- No, I'm willing to take on any type of case
- Those with a history of assault
- Those with sex offender status
- Those who do not speak English
- Those with an eating disorder
- Those with criminal convictions
- Other

If other, please describe:

Q11 – Which aspects of your work as a guardian are most challenging?

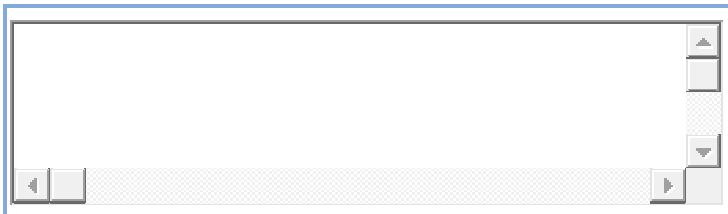
Matrix row labels are in this column	Not at all challenging	Somewhat challenging	Very challenging

Completing a Medicaid application			
Making decisions about supervised living placements			
Understanding psychiatric medications and their implications			
Working with the courts			
Completing required paperwork for the courts			
Making end of life care decisions			
Working with adults with certain types of conditions			
Other			

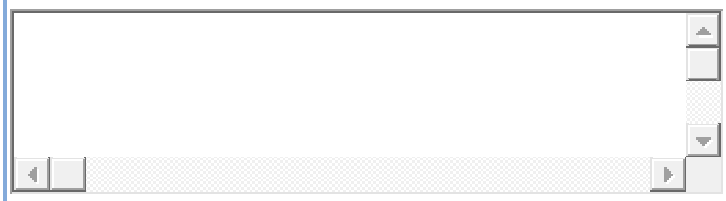
If other, please describe

Q12 – Please provide an example (identifying information removed) of a particularly challenging situation you faced as a guardian.

Q13 – SYSTEM LEVEL CHANGES: What would you like to see changed about current guardianship processes, and in particular addressing the surrogate needs of "unbefriended" clients? Consider the law, court rules and regulations, and documentation.



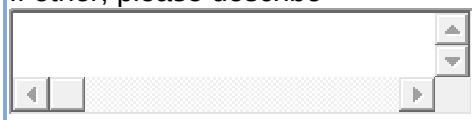
Q14 – GUARDIAN LEVEL CHANGES: Is there any specific training you wish you had in regards to your guardianship work? What would make your job easier?



Q15 – What is your primary practice setting?

- ○ Solo Practitioner
- ○ Law Firm or Group Practice
- ○ Legal Services
- ○ Guardianship Agency
- ○ Other

If other, please describe



Q16 – How many years have you been employed

In your current setting? _____

In total? (i.e., since your degree) _____

Question cannot be deleted because it is the source of a pipe. Delete all pipes using the question as a source before deleting the question.

Q17 – What are your highest professional degrees?

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