



Fourth Colloquium: Public Guardianship in an Age of Self-Advocacy

SUMMARY REPORT

From: Peter M. Macy, Guardian Community Trust, Inc.
To: Registrants and Subscribers to the Colloquium Series
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The Institute’s Fourth Colloquium, “Public Guardianship in an Age of Self-Advocacy,” held in Boston on June 23, 2017, lived up to its purpose: it was a lively exchange of ideas from a wide range of stakeholders about how guardianship policy affects individuals – with particular concern for the ID/DD community – and how we can work together to improve policies. Participants were affiliated with many organizations that support persons with disabilities, included the Massachusetts Developmental Disability Council, Mass Advocates Standing Strong (MASS), Mass ARC, the Committee for Public Counsel Services, the Center for Public Representation, the Disability Law Center (DLC), the Department of Mental Health, the Department of Developmental Services and the Boston Center for Independent Living.

The introductory topic for the day was public guardianship legislation,¹ which is endorsed by the Institute. Most of the discussion, however, centered on the early efforts to come up with a Supported Decision Making bill that would attract the support of all stakeholders. At the heart of the discussion was the tension between decisional support and decisional control, along with the question of who should decide how that tension should be handled.

I. Opening Remarks

Former Attorney General Scott Harshbarger welcomed those attending and briefly described the three year history of the Institute, including its efforts to reach out to all stakeholders to seek agreement on many levels, including —

- what the problems are;
- how we perceive the needs of incapacitated persons;
- the extent of unmet needs;
- how we should respond proactively.

Scott emphasized that the system needs reform. Resources are inadequate, traditional solutions aren’t working, and new approaches are required. He also reminded us that the call for a Public Guardian has been sounded for decades in Massachusetts, and that the hope for a legislative response needs the support of all who may be affected. Scott pointed out that having a public office dedicated to decisional needs would produce not just better guardians, but also better alternatives to

¹ A bill entitled, “An Act to establish the office of adult guardianship and decisional support services,” was filed in January of this year, sponsored in the House (H3027) by Rep. Paul Brodeur, and in the Senate (S1177) by Sen. Cynthia Creem.

guardianship. Over the long term, the office would help to sustain and focus debate about when and how to offer decisional support in any form.

II. Keynote Address

Our keynote speaker, Family & Probate Court Justice Megan Christopher, echoed the sense of urgency that Scott delivered, speaking from a judge's perspective. Her first comment, however, was to challenge the word "disabled" as a description of a population. Nobody can do everything; we are all, in some respects, disabled. In the context of guardianship, this means that judges must evaluate the respondent in terms of capacities as well as incapacities. The judge should give authority to a guardian only in areas where the respondent needs decisional support – and not where the respondent can function adequately on his or her own.

As a judge, Justice Christopher continues to search for the right balance between protecting the safety of individuals while preserving their autonomy. She recalled two cases that show where the system can fail. On the one hand, it fails to provide guardians for isolated and indigent persons who need a guardian without delay. She recalled the case of a homeless man that she represented as a legal aid attorney, who was severely mentally ill, for whom the court agreed that a guardian was essential. No one was available at the hearing, however, to serve, so the hearing was continued. The man disappeared before the next hearing, and so far as she knew, was never seen in the area again.

On the other hand, guardianship petitioners sometimes are filed by well-meaning relatives, where the person does not in fact need guardianship. Justice Christopher referred to such a case that recently came before her, where she spoke with the respondent and found her to have sufficient acuity and sufficient supports that a guardianship would not be appropriate. Family members sometimes don't understand why this happens. But judges must view these case solely from the standpoint of the respondent, whose right to make decisions – even bad ones – must be protected, as long as they can appreciate the consequences.

III. The Dignity of Risk

The comments of former Atty. General Harshbarger and Justice Christopher both centered on the tension that lies at the heart of guardianship policy: on the one hand we value self-determination, while on the other we strive to protect those with vulnerabilities, sometimes against their own wishes. Caroline vanBruinswaardt, Executive Director of MASS, reminded us of the "dignity of risk." Whether our laws preserve the right to make risky choices is an essential test of whether they adequately preserve the autonomy of the persons affected.

The discussion of these issues was lively and far ranging. Bob Fleischner, of the Center for Public Representation in Northampton, described the Center's pilot project in Western Massachusetts that is testing the use of Supported Decision-Making (SDM), a new approach to decisional support in which the participants have set up agreements designating their own group of supporters, with the goal of avoiding guardianship altogether. The project already has resulted in judicial approval to terminate guardianship for one of the participants.

Carrying the discussion were the panel of self-advocates affiliated with MASS, including Ms. vanBruinswaardt, Board Chairperson Anne Fracht, and Boardmember Kim Plaut, along with Christine Griffin, Esq., Executive Director of the DLC. The term, "self-advocate," means "learning how to speak up for yourself, making your own decisions about your own life, learning how to get information so that

you can understand things that are of interest to you, finding out who will support you in your journey, knowing your rights and responsibilities, problem solving, listening and learning, reaching out to others when you need help and friendship, and learning about self-determination.”²

The self-advocates were very vocal about the need for a change in policy-makers’ approach to them and their constituents. Their indictment of the system included (1) the fact that many of them have had a guardian forced upon them at age eighteen; (2) caseworkers from some State agencies are systematically disrespectful of them and their families or supports, and (3) the reality that “limited” guardianship just is not happening. They stressed their call to action, “Nothing about us without us.”

The discussion that followed was pointed. It asked not just who should be included in creating any SDM statute in Massachusetts -- noting examples in Texas and Delaware – but whether any statute should be proposed at all. The main advantage of a statute was described as creating a platform to persuade third parties, like a potential landlord, a merchant, a doctor, a school, or even a local or State agency, to recognize the self-determination of an individual with disabilities. A disadvantage of a statute is that the lawmaking process itself historically has excluded persons with DD/ID.

The Institute members are exploring whether SDM should be a key part of the work of the proposed Office of Public Guardian, consistent with title of the proposed agency, “Office of Public Guardianship *and Decisional Support Services*.” The self-advocates opposed this idea, but they remain focused on the process rather than the result. They said that they would contact their counterparts in Texas and Delaware to get a sense of how the statutes in those states impact the lives of their counterparts there. Meanwhile, the immediate issue is whether those most affected by decisional support laws can participate in the process of creating them.

The most challenging question that came out of the discussion was whether the self-advocates felt that *only* persons with DD/ID can participate in creating policies for decisional support, as opposed to that community being *part of* the policy-making process. While the question was not fully answered, there was agreement that the conversation had been constructive, and that further meetings of MASS members and the Institute would be arranged.

IV. Current Status of Public Guardianship Advocacy

Since its founding in 2014, the Institute has sought to advance the debate over public guardianship toward a better policy generally for all who are affected by it, and in particular for the “unbefriended.” We have connected with individuals and stakeholders representing more than 30 agencies in the public and private non-profit sectors. A Steering Committee for the public guardianship mission, and three other groups focused on court process, family and community guardianship issues, and legislative drafting, have formed over the same period.

Proposed legislation to establish an Office of Adult Guardianship and Decisional Support Services was filed in January, 2017, sponsored in the House by Representative Paul Brodeur, and sponsored in the Senate by Senator Cynthia Creem. This legislation is being well-received by legislators, and a large number of stakeholders now are supporting it. We don’t know, of course, whether the proposal will become law. The 4th Colloquium reminded us that many concerns remain as to how guardianship laws

² Definition provided by Wrightslaw, found at www.wrightslaw.com/info/self.advocacy.htm.

are used and enforced. The Institute remains committed, nevertheless, to providing, at minimum, a qualified public fiduciary in Massachusetts for those who truly require this kind of help.

A. Volunteer Component

An important topic that was *not* discussed at the 4th Colloquium is the use of volunteers to help carry out the tasks of the proposed public guardian. Professional case managers will be supported by trained and committed volunteers who agree to meet regularly with the individual to whom they are matched. The goal is a relationship-based program, where the agency will know enough about each person that decisions to intervene, or to not intervene, can be informed by real-time experience with the individual's strengths and weaknesses.

Volunteers will be supported, both logistically and clinically, by paid staff of the guardianship agency. Importantly, the statute provides that responsibility for outcomes remains with the agency. The agency, and not the volunteer, will be the named guardian. There will be certain decisions that may be made only by case managers. And it will be the ultimate responsibility of the Public Guardian to ensure that all reports, paperwork and communications are completed appropriately.

B. Research Agenda. A quiet but vital part of the Institute's advocacy for the unbefriended is the research that we sponsor into guardianship-related topics. Our projects to date include —

- *Completed* —

1. Title: *Examining the Need for a Public Guardian in Massachusetts – Phase 1*
PI:³ Jennifer Moye, Ph.D., Director of Geriatric Psychiatry for the Boston VA Health Care System, and Associate Professor of Psychology at Harvard Medical School.⁴
Result: Between 2,800 and 3,800 persons in Massachusetts need a guardian or conservator, but are unable to have one appointed due to a lack of private resources and the absence of any state agency charged specifically with providing guardians for the indigent.

- *Current* —

1. Title: *Examining the Need for a Public Guardian in Massachusetts – Phase 2*
PI: Jennifer Moye, Ph.D. (see bio information, *supra*)
Subject: Report on how guardianship is handled for a person who lacks suitable family or friends if he/she lacks resources to pay privately for it.

³ Principle Investigator.

⁴ Dr. Moye's study was published in HealthCare Ethics Committee Forum in 2017. See Moye, J., et al., *Ethical Concerns and Procedural Pathways for Patients Who are Incapacitated and Alone: Implications from a Qualitative Study for Advancing Ethical Practice*, HEC Forum, 2017 Jun;29(2):171-189.

(Research Agenda, continued)

2. Title: *How Guardians Make Decisions*
PI: Heather L. Connors, Ph.D. & Traci Cucinotta, LICSW, MBE
Subject: Report experience of guardians and voluntary agents as decision-makers for adults with diminished capacity, with the objective of developing a decision-making training protocol for new guardians and improving professional guidelines.
3. Title: *Costs of Failing to Provide a Public Guardian*
PI: Eliot Levine, Ph.D., Donahue Institute, University of Massachusetts Amherst.
Subject: Quantify the medical, public safety, housing and other costs that end up being paid from public revenues when decisional help is not available to those in need.

V. Summary

The Colloquium Series continues to be an important venue for the Institute to interact with the widening circle of friends and colleagues with whom we are pursuing better public policy for guardianship the Commonwealth. The task is daunting. State government does not change easily, and no one advocate can bring about adequate reform in an area as old and complicated as guardianship law.

Change, however, does happen. A local version of the Uniform Probate Code (UPC) was enacted in 2008 because enough advocates cared enough to make it so. The call for a public guardian today is, in one sense, a mission to complete the reforms that were started in 2008. The UPC strengthened procedures that protect individuals during guardianship proceedings. The task for the “unbefriended” is to protect them *after* the process is complete, by ensuring that those who truly need a guardian, but don’t have the means privately to retain someone, are not left to fend for themselves.