

A newsletter designed to provide information and resources on guardianship and conservatorship in Massachusetts

A Message from MGA President Joanne Erickson, Esq.



As I sit down to review my notes from our successful events and endeavors since this past fall, and look forward to our upcoming plans for the remainder of 2013, I am both impressed and inspired with all the MGA has done and continues to do for its constituents. For an all-volunteer nonprofit

organization, we continue to produce quality seminars, events and resources for our members and guests, including our ever-evolving online presence (www.massguardianshipassociation.org).

Looking back at this past fall and winter, I want to extend our sincere thanks to Whitney Place Assisted Living Residences in Natick for sponsoring our **Substituted Judgment panel in October**. The staff, facility and food were excellent, and the event was packed with new and seasoned MGA members. The audience enjoyed a high-level discussion regarding the nuances and challenges of substituted judgment practice from varying perspectives. Special thanks go to Dr. Bill Land for sharing his professional medical insights and practical perspectives on the topic. Additional thanks also go to MGA Board member Gary Zalkin for his perspectives as a practicing psychologist and attorney, and to Board member Sarah Boonin for moderating the panel.

We wrapped up our 2012 events with another excellent **Annual Dinner Meeting in December** at NewBridge on the Charles. Hebrew Senior Life was again a most generous and gracious host and provided all the amenities, including a beautiful space, a delicious dinner, and an impressive tour for interested guests. Our guest speaker was Attorney Deborah Thomson of The PASS Group. Deb is a long time advocate for the elderly and disabled and a well respected lobbyist. She provided a legislative update and forecast. Please read below about our Annual Dinner Meeting and enjoy the "Legislative Update" article authored by Attorney Thomson and Nomita Ganguly of The Pass Group.

The **2013 MGA Board of Directors** has expanded to 15 active members. You can read more about our new Directors below. Our Directors worked diligently in the first half of the year to reorganize and strengthen the MGA to be more responsive to its members and assist a wider, more diverse group of adults and families touched by guardianship and conservatorship. To that end, we renewed our focus on family guardians of developmentally and intellectually impaired young adults and participated in **Quincy High School's Parent Night**, offering families guardianship information. Special thanks to Kathleen Ryan and Charlie Lynch. Kathleen is a long-time advocate for children with developmental disabilities and a family guardian herself, and you can read the first of her two-part "Family Guardian's Perspective" series addressing some questions that arise for family guardians.



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As we circulate this newsletter, MGA just held a successful **Members' Roundtable**, entitled "**Special Needs Trusts – A Tool for Maximizing Financial Resources for People with Disabilities**," on June 26th at Suffolk Law School. Attorney Elise Kopley of Fletcher Tilton, PC, and Attorney Pat Freedman, Executive Director of PLAN of Massachusetts and Rhode Island, moderated the discussion. MGA members and guests enjoyed a lively and informative discussion.

I am thrilled to report even more items on the calendar for the remainder of 2013. In November, the MGA will be teaming up with the New England Chapter of Geriatric Care Managers for a panel entitled "**GCM's and Guardians: Who's on First? Protecting our Clients, Protecting Ourselves.**" The seminar is scheduled for November 20, 2013 (please see the Save-the-Date below). Of course, beaming from the success our last Annual Dinner Meeting, we are already planning for this year's **2013 Annual Dinner Meeting**, which is scheduled for December 10th. We are pleased to announce that Leo Sarkissian, Executive Director of The ARC of Massachusetts, will be our guest speaker. Save-the-Date now and look for further details in the fall.

As we did last year, we have devoted significant time and resources to continually improving our website - www.massguardianshipassociation.org. We are pleased to announce that our **Members Directory** is now up on the website and accessible by members and the public. As with all things digital, there was more to this endeavor than meets the eye! Special thanks go to Ellen DiPaola, Tracy Yanni, and Cynthia McCausland for their work on this important member benefit. Plans are now underway to launch a membership outreach campaign.

And last but certainly not least, we look forward to launching our brand new **web video entitled "Guardian of a Minor."** This will be available on our website and promises to be an invaluable resource to MGA members and others seeking information about options for minors, the guardianship of minor process, and other related information. Thanks to Eden Prendergast, Veronica Serrato, and Ellen DiPaola for their tireless efforts on this venture.

I greatly appreciate your continued support as we grow our membership and strive towards excellence in the world of guardianships and conservatorships. I look forward to seeing you at our upcoming events!



Planning a Future Home for an Adult Child with Disabilities

by **Frederick M. Misilo, Jr.***

I work with many individuals with developmental disabilities and their families as they transition from accessing child services to securing adult services. In my practice, I have seen a growing number of parents develop residences for their sons or daughters, ranging from simple one bedroom condominium settings, to apartments with roommates, to homes with paid care providers. In working with these individuals and their parents, I have compiled the following observations regarding these experiences. Additional resources can be found in my publication, "Coming of Age in Massachusetts: A legal guide for individuals with developmental disabilities and their families on transitioning to adult service," which is available online at: <http://www.fletchertilton.com/pdf/special-needs-articles/Fred%20Misilo%20-%20CoA-lo%20res%20copy.pdf>.

1. FUTURE OF GOVERNMENT RESOURCES

The future of domestic spending on programs that provide support to individuals with disabilities is uncertain. On the federal level, there will be continuing efforts to reduce the federal deficit. Individuals with disabilities, recipients of Medicaid benefits and others who rely on government assistance for health care will face the threat of reductions in appropriations, elimination of some benefits and a conversion to Medicaid block grants. These threats are real. So in planning a residential future, significant reliance must be made on private funds. While we must continue to advocate to maintain and increase federal and state appropriations as well as work toward creating more cost-effective models to use government appropriations, families must not overly rely on the hope that government resources will be the sole supports of their son or daughter in the future.

2. IMPORTANCE OF STARTING EARLY WITH A PLAN

The parents who have successfully arranged an appropriate home for their son or daughter started planning one to three years before their son or daughter moved in. The reasons for planning early are self-evident. First, you need to develop consensus within the family about whether your plans make sense and to build an internally driven commitment within the family to keep moving forward. One very obvious trap is the Get-To-It trap. These are the ideas, plans and things that need to be investigated, performed and vetted in order to move forward, but you put them on your To-Do list. The problem is that many people never Get-To-It. These are the things that you'll get to ... someday. But the list grows and grows while life just happens. Covey has written about the critical importance of prioritizing those things in our

lives that at the moment are not urgent but that are very important. The key is to differentiate those things that are truly urgent and important, from the crisis of the day or week that seems urgent but is not, in reality, all that important. My advice is to schedule some quiet time on a regular basis to write out your thoughts, talk about your plans with your spouse and other important people, and to conduct your due diligence. This can be an ongoing planning meeting for you and your family members with invitations going out to others on an as-needed basis.

3. THE USE OF LEVERAGE

Broadly speaking, leverage is creating more power through the creative use of resources.

For instance, leverage can be three or four families coming together to pool their money to create more buying power so they can purchase a home more easily together than they could on their own. Some families may have more financial resources than others, while some others may have more time to contribute. Don't minimize the value of time that can be contributed. In one successful model, two families planned an arrangement in which one family purchased a house next to the other family, who did not have the financial capital to contribute toward the purchase of the house. But the family without the available capital had something as valuable as money; they had human capital. They lived next door and provided support to the two young adults living there. It worked. Also, many retirement plans can be leveraged through a loan. Repayments must be made at a marketable interest rate, but remember, you're replenishing your own retirement account by paying down the loan. You will need to check with your retirement plan administrator to see if this is possible with your particular plan. Finally, you should evaluate the advisability of refinancing your principal residence or taking out a home equity loan.

4. THINGS CHANGE—BE FLEXIBLE

Where we live depends on many factors including the location of family and friends, our work, the type of environment we choose to live in, and a host of other considerations. Things change. We downsize, we retire, we get divorced, etc. And major life events are often accompanied by a change in living environment. In most circumstances, real property in a trust or in a corporate real estate holding entity can be exchanged with very little difficulty to accommodate changes in the location of property.

5. IDENTIFY HOUSING DOLLARS SEPARATE FROM SUPPORT AND SERVICE DOLLARS

The acquisition and regular maintenance of real estate can be budgeted and planned for in a fairly easy fashion. The source of funds to purchase may come from savings, a loan from a retirement account, a gift from family members, proceeds from a home equity loan, etc. The regular carrying cost of the home can be paid from anticipated rental income, a planned escrow account or

other anticipated revenue. Consider creating an annual budget for estimated housing costs as a planning tool. Two important sources of government funding for residential support for individuals with disabilities are the Section 8 voucher program and, in Massachusetts, the Alternate Housing Voucher Program (AHVP). Both programs are administered through housing assistance agencies and local housing authorities. Applications for rental vouchers can be obtained and filed at local housing authorities. Anticipating long waiting lists, applications should be filed if there is a tangible possibility that your son or daughter will move out of your home. Under federal regulations governing the use and administration of Section 8 housing vouchers, a person with a disability who has been granted a voucher is entitled to a reasonable accommodation in how the voucher is used. This means that the customary "arms-length" requirements between landlord and tenant can be modified. So, a family owned or controlled rental unit can be leased to a family member with a disability who has a voucher. In some circumstances, a special needs trust can be the landlord and the beneficiary of the trust can be the tenant.

6. KNOW THE SUPPORT AND SERVICE NEEDS OF INDIVIDUALS

A complete understanding of the service and support needs of each individual must be arrived at as part of the planning process. While this may seem obvious, there is one general tendency I've noticed over the years. Parents often overestimate their son's or daughter's daily living skills. Often, parents discount the value of a regular routine, the presence of familiar family members, and the often overlooked presence of verbal and non-verbal cueing that is natural in a home environment. It may be a worthwhile expense to retain the services of a qualified professional to assist you in accurately evaluating services and supports your son or daughter, as well as other prospective residents, will need when they move in to their new home. Accurately assessing the service and support needs of each individual is essential in estimating the anticipated costs of meeting those needs through appropriate staffing.

7. IDENTIFY SUPPORT AND SERVICE DOLLARS

Obviously, if your son or daughter and other prospective residents are eligible for adult services from a state agency, you should speak with the appropriate case worker assigned to their cases about your intentions. These people can be helpful in providing realistic expectations about prioritization and allocation of resources. Also, personal care assistance ("PCA") funded through the Division of Medical Assistance can be a source of support dollars. A determination of whether PCA is appropriate and the extent of the PCA support should be made as soon as possible. Finally, each resident's SSI, Disabled Adult Child (DAC) benefits and other recurrent monthly income will be available to fund a portion of the supports to be provided. It is customary that 75% of the recurrent monthly income of each resident be paid in the form of a service fee.

Also, for many families, privately paying for services and supports has become a daunting but necessary reality.

8. IMPORTANCE OF GOOD ADVISORS

Maintaining a home for a son or daughter with a disability can involve, for instance, the purchase of real estate, creating a landlord/tenant relationship, having service and supports provided on a regular basis by paid staff, maintenance and upkeep, etc. An attorney should be involved in many of these areas, including selecting the appropriate legal entity to own the real estate, creating a sensible service agreement for settings that are non-DDS or non-DMH regulated, understanding and complying with applicable labor/employment practices, and identifying potential sources of liability and taking steps to minimize and/or avoid such liability. The skills and talents of experienced staff who can manage a residential setting can be very valuable. There are a number of highly skilled administrators with years of experience in managing residential services and supports for individuals with disabilities who are available to serve on either a short-term consulting or long-term management fee basis. You don't have to reinvent the wheel! Of course, having a reliable handyman, plumber and electrician on speed-dial can save time and lower your blood pressure when the inevitable—yet unexpected—housekeeping crisis hits.

9. INTEGRATION OF THE HOUSING MODEL INTO YOUR ESTATE PLAN

You must plan for how the home will be managed when you are unable to be involved due to death or disability. A comprehensive special needs plan is an essential part of developing a home for your son or daughter with a disability. The fundamental documents must provide for the distribution of assets to the appropriate persons and trusts in the proportions desired. Durable powers of attorney with critical Medicaid planning language and health care proxies are essential. The use of a special needs trust to hold assets for the benefit of a son or daughter with a disability to pay for future services and supports is the centerpiece of this plan. These essential documents must be coupled with a realistic financial plan adequate to provide for supplemental services and supports throughout the lifetime of a son or daughter with a disability.

10. IMPORTANT PERSONAL QUALITIES: PATIENCE AND PERSISTENCE

There is no cookie-cutter approach to developing an effective and successful home for your son or daughter with a disability. It is easy to get disillusioned because solutions are slow to develop. There are many moving parts and some dead ends. The parents I've had the privilege to work with in these types of situations have demonstrated an enormous amount of patience and persistence. They share a common characteristic of expecting more from themselves than from anyone else, including the government. There is also a sense of "I know best" and "I'm going to keep trying." These personal characteristics of patience and persistence imbued with a

sense of optimism are important to move from the vision of a home to a real home.

***About the Author: Frederick M. Misilo, Jr.** is an attorney at Fletcher Tilton, PC, who concentrates



his practice in special needs planning, elder law, trust and estate administration, and service advocacy. Attorney Misilo has been deeply involved in disability issues throughout his career, including serving as Executive Director of Harbor Area Community Services, Inc., and as the Deputy Commissioner of the Massachusetts Department of Developmental Services (1991-

1994). Attorney Misilo currently serves on the Boards of the Arc of the United States, Inc., the Arc of Cape Cod, and Fallon Community Health Plan, Inc.



Things to Know: Massachusetts Guardianship Association Supports the Uniform Adult Guardianship and Protective Proceedings Jurisdiction Act

by **Eden Prendergast***

The Uniform Adult Guardianship and Protective Proceedings Jurisdiction Act ("UAGPPJ") is currently being considered by the Massachusetts Legislature as House Bill 1366. The MGA supports the passage of the UAGPPJ because it would resolve numerous multi-state jurisdictional disputes arising in adult guardianship, conservatorship, and other protective proceedings involving more than one state. Presently, the Massachusetts Uniform Probate Code does not address the issue of when Massachusetts should exercise jurisdiction in multi-state cases, nor does it address the recognition, transfer, or modification of foreign (out-of-state) guardianship and conservatorship proceedings or orders.

In an increasingly geographically mobile society in which petitioners and respondents move in and out of Massachusetts, the lack of uniform law governing the jurisdiction of guardianships and conservatorships has caused serious confusion and uncertainty, duplicative and conflicting proceedings, needless legal expenses, undue hassle for parties, and even gaps and conflicts in decision-making authority. The UAGPPJ addresses these jurisdictional problems by: clarifying when Massachusetts would have jurisdiction in proceedings involving more than one state; by fostering communication and coordination among the state courts involved; and by providing for the recognition, enforcement, transfer

and modification of foreign protective orders. These key provisions of the UAGPPJ are summarized below. The complete text of the bill can be found on the website of the Massachusetts State Legislature at <https://malegislature.gov/Bills/188/House/H1366>.

FIRST, the UAGPPJ clarifies when Massachusetts Courts have jurisdiction over guardianship and conservatorship proceedings and creates a process and hierarchy for determining which state gets jurisdiction when inter-state conflicts arise. Presently, jurisdictional problems arise when an individual in need of protection resides in one state but has assets in another, when the person seeking to be appointed as guardian or conservator resides in a different state than the person in need of protection, or when the incapacitated or protected person moves between states. Problems also arise in so-called “granny-snatching” cases when elderly individuals under guardianship or protective orders are removed by family members from the states that issued the original orders and brought to other states for the purpose of obtaining new and conflicting guardianship or conservatorship orders from the new states’ courts. Often this happens when elderly family members have substantial assets that are the source of dispute among relatives. Under the UAGPPJ, Massachusetts Courts have jurisdiction in one of four situations, discussed below. See Section 8.

Home State Jurisdiction

Under the new law, Massachusetts Courts would have jurisdiction over guardianships and conservatorships if Massachusetts were the respondent’s “home state.” See Section 8(1). Under the legislation, “home state” means “the state in which the respondent was physically present, including any period of temporary absence, for at least six consecutive months immediately before the filing . . . or, if none, the state in which the respondent was physically present, including any period of temporary absence, for at least six consecutive months ending within the six months prior to the filing.” Section 6(a)(2).

Significant Connections Jurisdiction

Even if Massachusetts were not the “home state,” Massachusetts would have jurisdiction if Massachusetts had “significant connection” to the matter on the date the petition was filed and either there was no “home state” or the respondent’s home state had declined to exercise jurisdiction. See Section 8(2)(A). Massachusetts also would have “significant connection” jurisdiction if there were no pending proceedings in another “home state” or “significant connection” state and additional conditions were met. See Section 8(2)(B). A “significant-connection state” is defined as “a state, other than the home state, with which a respondent has a significant connection other than mere physical presence and in which substantial evidence concerning the respondent is available.” Section 6(a)(3). The statute enumerates multiple factors courts should consider when determining whether a state is a “significant-connection state.” See Section 6(a)(3)(b).

Appropriate Forum Jurisdiction

Massachusetts would next have jurisdiction if the respondent’s home state and all significant-connection states had declined to exercise jurisdiction because Massachusetts was the more appropriate forum. Jurisdiction must be consistent with the Massachusetts and United States constitutions. See Section 8(3).

Special Jurisdiction

Finally, Massachusetts would have jurisdiction if the requirements for “special jurisdiction” were met. See Section 8(4). This provision of the UAGPPJ addresses emergency situations and other special cases. A court in the state where the individual were physically present could appoint a temporary guardian in the case of an emergency for up to 90 days. Also, if the individual had real or tangible property located in a certain state, the court in that jurisdiction could appoint a conservator for the property located there. See Section 9(a).

Exclusive and Continuing Jurisdiction, Declining Jurisdiction

In addition to setting forth four basic types of jurisdiction (above), the UAGPPJ clarifies that, except in certain emergency cases, the court that has appointed a guardian or issued a protective order in a case has exclusive and continuing jurisdiction over the proceeding until it is terminated by the court or the appointment or order expires by its own terms. See Section 10. This would prevent subsequent and conflicting proceedings in foreign courts. The UAGPPJ also provides authority for Massachusetts Courts to decline to exercise jurisdiction in cases in which a court of another state is the more appropriate forum. See Section 11. Next, Massachusetts Courts can decline to exercise jurisdiction or exercise only limited jurisdiction in cases, like the “granny-snatching” cases discussed above, in which jurisdiction was acquired due to “unjustified conduct.” See Section 12. The UAGPPJ also creates protocols for cases with proceedings pending in more than one state. See Section 14.

SECOND, in cases involving more than one state, the UAGPPJ would also allow a Massachusetts Court to communicate directly with a court in another state, and may include the parties in the communication. See Section 3. Also, Massachusetts Courts could request foreign courts to assist with the proceedings, including holding evidentiary hearings, ordering the production of evidence or testimony, ordering evaluations or assessments of respondents, initiating investigations, issuing orders to assure a party’s appearance, and issuing orders requiring the release of medical and other information. See Section 4. There are also procedures for taking testimony in another state. See Section 5.

THIRD, the UAGPPJ addresses the current lack of recognition and enforcement of foreign guardianships and conservatorships. Currently, a guardian or conservator who moves with the incapacitated or protected

person out of the state that issued the order may have difficulty fulfilling his or her fiduciary duties in the new state. Similarly, under current Massachusetts law, if a guardianship or conservatorship has been ordered in a foreign state, that order cannot be transferred to Massachusetts or modified by Massachusetts Courts. Instead, an individual seeking to transfer or modify a foreign order must file a new petition in Massachusetts, explain to the Court why he or she is seeking to obtain a new order despite the existence of the prior order, and hope that he or she is appointed. If he or she is appointed, it can then be challenging to terminate the preexisting guardianship order in the foreign state.

The UAGPPJ would resolve many problems flowing from this lack of recognition and enforcement by allowing for the transfer of guardianship or conservatorship cases from Massachusetts to foreign states if certain conditions were met. See Section 15. Conversely, it would allow Massachusetts to recognize guardianships or conservatorships issued in foreign states, provided notice and other requirements were met. See Section 16. Relatedly, the bill would allow guardians and conservators to register out-of-state orders with the appropriate Massachusetts Courts. See Sections 17 and 18. Once these orders are registered in Massachusetts, the guardians and conservators would be able to exercise in Massachusetts all the powers authorized in the original orders, provided they do not conflict with Massachusetts Law. See Section 19.

Status of the UAGPPJ

The UAGPPJ has been adopted in 36 states, the District of Columbia, and Puerto Rico. Currently, Massachusetts is one of only 14 U.S. states without the uniform legislation. In 2013, the legislation was introduced in Massachusetts, New York, and Mississippi. The official title of the UAGPPJ legislation in Massachusetts, House Bill 1366, is “*An act relative to uniform adult guardianship and protective proceedings jurisdiction.*” It was introduced by Democratic Representative Anne Gobi of Spencer. It was referred to the Joint Committee on the Judiciary in January 2013. Up to date information regarding the status of the bill can be found at: <https://malegislature.gov/Bills/188/House/H1366>.

A number of organizations support the UAGPPJ, including the Massachusetts Guardianship Association, National Guardianship Association, American Bar Association Commission on Law and the Elderly, American Association of Retired Persons, National Academy of Elder Law Attorneys, Alzheimer’s Association, Massachusetts Bar Association, and the Boston Bar Association.

Massachusetts should adopt the UAGPPJ. The enactment of this uniform piece of legislation will encourage efficient communication between courts of different states, and decrease confusion and unpredictability when two or more states are involved in guardianship or conservatorship proceedings. Similarly, the UAGPPJ will resolve inter-state jurisdictional conflicts and save parties time and legal fees. Most importantly, it will ensure the safety and

well-being of the individuals for whom guardianships and conservatorships are sought.



***About the Author: Edén Prendergast** graduated in 2013 from Suffolk Law School with a concentration in Health and Biomedical Law. As a third year law student, Edén served as the student Board Member to the MGA and worked as a student attorney in Suffolk’s Health Law Clinic representing low-income clients in adult guardianship proceedings and Social Security disability appeals. She is also a certified

home health aide with experience caring for both the elderly and disabled. She received her Bachelor’s Degree from Boston College in 2009.



Legislative Update: What’s New with Alzheimer’s-Related Legislation?

by Deborah Thomson and Nomita Ganguly**

This article follows-up on a piece in the last issue of *The Guardian* entitled, “Things to Know: Dementia, Alzheimer’s and Guardianship,” by Jennifer Carter of the Alzheimer’s Association of MA. You can access the prior article at: <http://www.massguardianshipassociation.org/wp-content/uploads/2012/09/MGA-Fall-2012-final-9-26-12.pdf>.

Any attorney who practices elder law is familiar with Alzheimer’s Disease and the heartbreak it causes for patients and their families. Once a little known condition often misunderstood and misdiagnosed, Alzheimer’s is a fatal, degenerative brain disease that robs individuals of their memories, their intelligence and eventually their lives. As the population of Americans age 65+ increases, so does the incidence of Alzheimer’s disease. An estimated 5.4 million Americans suffer from this illness.

The need for better treatment of Alzheimer’s disease has motivated legislators across the country to advocate for measures that will improve the lives of patients and educate policy makers about the disease. This effort has been led by the national Alzheimer’s Association and its affiliated state chapters. The Alzheimer’s Association of Massachusetts and New Hampshire has championed a number of policy and legislative initiatives. In 2012, it joined with the Executive Office of Elder Affairs and

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Report on MGA's December 2012 Annual Networking and Dinner Meeting

The MGA's Annual Networking and Dinner meeting was held last December and proved a terrific opportunity for our diverse membership to come together and exchange ideas about how we can better serve individuals in need of guardianship. Roughly 80 MGA members, new and old, along with their guests, attended our largest and most successful Annual Dinner Meeting to date. Our gracious host for the second year was Hebrew Senior Life, which provides comprehensive elder care throughout Greater Boston. Hebrew Senior Life donated its beautiful facility, Newbridge on the Charles in Dedham. Roughly 80 MGA members and guests enjoyed vibrant networking, a delicious dinner, a tour of the facility, and a thoughtful presentation by our guest speaker, Deborah Thomson.

Deborah Thomson, JD, is a principal of The PASS Group, which provides legislative and administrative advocacy services to human services agencies and advocacy organizations in Massachusetts. Attorney Thomson provided an informative update on recent legislative developments pertaining to seniors and guardianship, and provided an insightful preview of the 2013 legislative agenda on Beacon Hill.

Attorney Thomson addressed the Adult Jurisdictional Bill, which is actively supported by the Massachusetts Guardianship Association and numerous others and is detailed on pages 4 to 6 in this newsletter. She urged guests to inform colleagues and friends about the merits of the Bill and to reach out to their representatives to urge its passage in 2013.

We were pleased with the positive feedback we received from those in attendance, many of whom found the evening to be inspiring and extremely educational. Members reported leaving with a sense of collective purpose and renewed enthusiasm about the importance of our work. Overall, the event was a wonderful way to cap off a busy and productive year for the MGA and its membership.



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other stakeholders to produce an Alzheimer's State Plan. The State Plan's goal is to provide "a road map to help Massachusetts improve the quality of life for the thousands of families affected by Alzheimer's, and to minimize the public and private costs of this devastating disease."

The Alzheimer's State Plan has generated a number of bills and other vehicles to carry out its mission. In addition to

the Uniform Guardianship Jurisdiction Act legislation, which is addressed on pages 4-6 in this newsletter, the Alzheimer's Association of Massachusetts is advocating for two bills in this legislative session. The first bill, S.295/H.539, "An Act Relative to the Massachusetts Alzheimer's and Related Dementias Acute Care Advisory Committee," was filed by Senator Jehlen and Representative Canavan. The bill was drafted in response to August 2012 Town Hall meetings and focus groups of

families and professionals who identified hospital care as a problem for patients with dementia. It would create the Alzheimer's and Related Dementias Acute Care Advisory Committee to be convened by the Department of Public Health. The Committee would be composed of various stakeholders and would be tasked with creating a strategy for addressing dementia-capable care in all acute care settings and presenting this strategy to the Legislature. The Committee would also help to make certain that acute care settings are dementia capable, would coordinate with Federal agencies to provide support across the agencies that serve individuals with Alzheimer's and dementia. This is the first bill of its kind filed in the United States and, if passed, would make Massachusetts the first state to ensure dementia capable care in all acute care settings.

The second bill that the Alzheimer's Association is focused on this legislative session is S1057, "An Act relative to the Massachusetts Alzheimer's Project" (MAPA) filed by Senator Michael Moore. MAPA would create the Massachusetts Alzheimer's Project within the Executive Office of Health and Human Services (EOHHS). The mission of the project would be to accelerate the creation of treatments for Alzheimer's, to help coordinate the health care and treatment of individuals living with Alzheimer's, to include racial and ethnic minorities in the project in order to decrease health disparities, to coordinate with federal government agencies, and to share research among state agencies involved in Alzheimer's treatment. MAPA would also be critical in ensuring that the Alzheimer's State Plan implemented by Governor Patrick continues to exist through future administrations. MAPA would have EOHHS permanently assume the role of state partner in continuing to implement the State Plan. In addition, MAPA calls for a voluntary advisory committee to review the State Plan quarterly and report to the state legislators to ensure the State Plan fits the needs of constituents.

These two bills are now proceeding through the legislative process. Specifically, S.295 was given a public hearing at the Elder Affairs Committee on May 6th, and S.1057 was heard at a public hearing on April 9th by the Committee on Public Health. Advocates hope that the bills will be favorably reported by the Committees and move forward in the legislative process as quickly as possible. Advocates for Alzheimer's patients who wish to support this legislation can contact the Committee on Public Health and the Committee on Elder Affairs and urge them to give the bills favorable reports. The Alzheimer's Association will be coordinating the advocacy strategy for passage of this legislation and would welcome the support of elder law attorneys.*

Bill Summaries:

S.295/H.539 – An Act Relative to the Massachusetts Alzheimer's and Related Dementias Acute Care Advisory Committee

Lead Sponsors: Senator Patricia Jehlen, Representative Christine Canavan

Current Status: Assigned to Elder Affairs Committee (Chairs Jehlen and O'Day)

Public Hearing: May 6, 2013

Next step: Awaiting Report by Elder Affairs Committee

S.1057 – An Act Relative to the Massachusetts Alzheimer's Project

Lead Sponsor: Senator Michael Moore

Current Status: Assigned to Public Health Committee (Chairs Rodriques and Sanchez)

Public Hearing: April 9, 2013

Next step: Awaiting report by Public Health Committee

**Editor's Note: The MGA is not formally supporting legislation other than the UAGPPJ.*



**About the Authors:

Deborah Thomson is the principal of The Pass Group, which specializes in providing legislative and administrative advocacy services to non-profit organizations in Massachusetts. Ms. Thomson is an attorney with a long history of involvement in elder

and health policy issues, including legislative advocacy on Beacon Hill. She practiced as an elder law attorney in legal services for many years, served as the Director of Public Policy at the Alzheimer's Association in Massachusetts, and has been a member of numerous task forces and committees dealing with health and elder policy issues.

Nomita Ganguly, associate at The Pass Group, is an attorney with over ten years of experience in health care and human services legislative matters. Before joining The PASS Group, she worked on Beacon Hill as a researcher for the Human Services Committee, as Legislative Director for Senator Mark Montigny, and as Associate Counsel for the Senate Ways & Means Committee. She also has experience working in a non-profit setting as a staff attorney for a health advocacy organization.



A Family Guardian's Perspective on Adult Guardianship of a Developmentally Disabled Child (Part I of a II-part series)

by Kathy Ryan*

I am both the parent of an adult child with significant developmental disabilities and also an educator who works with this population of students and their families. It frequently comes as a surprise to the families with whom I work that their children will need legal guardians when they turn 18 years old. I recall when my son turned 18, I felt very strange asking a Court for legal authority to make decisions on behalf of the child I had cared for since birth. To learn, after years of caring for my son, that I was no longer legally responsible for him once he turned age 18, was just plain hard to hear. Over the years, I have had many questions about guardianship, and I have spoken with many families who share my questions. Below is part one of a two part series I will be writing to help answer some of the common questions that arise when families consider whether to seek guardianship of an adult child. Obviously, every situation is unique, and you should always seek legal advice about your particular case.

1) ***Why do I need to have a guardian appointed for my child when I have been caring for him/her since birth?***

At age 18, your child is considered to be an adult in the eyes of the law and is presumed to have all of the rights and responsibilities of an adult. That is the case regardless of any disability. If your child is unable to receive and evaluate information or to make or communicate decisions (even with assistive devices), then he or she will likely require a Court-appointed guardian who can make decisions on his or her behalf. These decisions may include medical, educational, and financial decisions, as well as decisions relating to the general support, care and well-being of your child.

2) ***My child is able to participate in decision-making, my family agrees about my child's care, and my child doesn't need any extraordinary treatment. Do I still need to seek guardianship?***

The need for a guardianship depends on the needs of your child, your child's ability to participate in decision-making, and your family situation. It is not always necessary to have a guardian appointed for a child with developmental disabilities. This may be the case when your child can participate in decision-making with some help, when he has the capacity to choose a surrogate

decision-maker of his own (like a health care proxy and/or power of attorney), when she does not require a residential placement or so-called "extraordinary" medical treatment (anti-psychotic medications, for example), when none of his providers have questioned his or your decisions, and when your family is on the same page with respect to your child's care.

Even in these situations, however, it might be worth considering a very limited guardianship that delegates only certain decision-making authority to the guardian. You can request that the Court require any guardian to involve your child in decision-making. You can seek to limit which decisions a guardian can make and which are reserved to your child. Of course, once the petition for guardianship is filed with the Court, the judge will have the final say and you cannot control the outcome, so be certain to consult with an attorney about the various possibilities before filing.

3) ***What if my family chooses not to seek the appointment of a guardian? What control, if any, are we giving up?***

First, as a parent of an adult child with disabilities, unless you have been appointed guardian, you do not have legal authority with respect to matters affecting your child. Your child might make decisions with which you disagree. Unless the Court says otherwise, he or she has the right to make decisions, even those you view as harmful. Similarly, without legal authority, you may be precluded from speaking with certain entities on behalf of your child, such as insurers like MassHealth.

If no legal guardian is appointed after your child's 18th birthday, and he or she is viewed by providers or others as unable to make decisions, it is possible a state agency could intervene and seek the appointment of a guardian. In that situation, you would be notified of the proceedings and could object or ask to intervene. Again, the judge would have the final say.

Also, in an emergency situation, in the absence of a legal decision-maker, medical providers may not look to you for help making decisions. It is possible you might disagree with the decisions being made, and in that case you might have to resort to the Courts under stressful emergency circumstances.

Finally, without a guardian, it might not be possible to access certain types of care for your child (residential placement, certain medications).

4) ***How do you decide who should be guardian? One parent? Both parents? One parent and a sibling?***

You should give very careful consideration to exactly whom you seek to have appointed as guardian(s). As each family

situation is unique, you should give thought to: the health and age of each proposed decision-maker (how long will he or she be able to exercise the authority), the amount of time each person has to devote, the proximity of each person to your child and his/her providers, the knowledge he or she possesses about your child's needs and care, and the relationship he or she has with your child. You should consider what would work best in the long-term as you and your child age. Ideally, you want to choose a guardian or guardians who can fulfill his/her responsibilities for many years to come. Ultimately, while you can request any individual(s) be appointed as guardian(s), the Court gets to decide who the guardian or guardians will be.

Another important point to understand is that the legal guardian cannot be paid for any care they may provide to your child. In some families, a parent or sibling is paid as a personal care attendant. That person cannot be the legal guardian and still receive payment. Be sure you understand any restrictions placed on legal guardianships by any program in which you or your child are participating.

Finally, co-guardianship may be a good way to ensure long-term continuity of authority. However, if you consider seeking the appointment of co-guardians, remember that those parties must work well together. The guardians must either agree on all decisions or their disagreements will need to be resolved in Court.

- 5) ***I have heard this process is relatively easy. Where can I find a little bit of legal help if I want to do some of this myself but need some advice or assistance?***

You aren't required to have a lawyer to file a petition for guardianship. However, like any legal process, guardianship proceedings can get complicated. This might be the case when extraordinary medical treatment is involved, when family-members disagree, when there are language barriers, or when you don't feel comfortable going to Court on your own.

There are several options for people seeking legal help, from paid full-representation (an attorney who you can pay to handle your case from start to finish), to "pro bono" (or free) representation, to limited assistance help (attorneys who will help with select portions of your case). You can go to the MGA website and review our membership directory, which contains the contact information of numerous attorneys who specialize in guardianships. Our membership directory can be found at: <http://www.massguardianshipassociation.org/membership/members-directory/>.

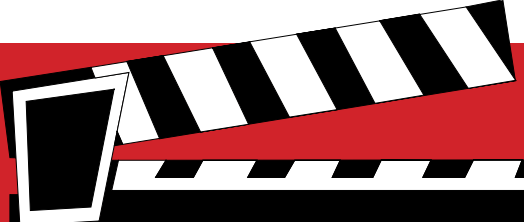
Also, our resources page (<http://www.massguardianshipassociation.org/resources/legal-help/>) contains links to legal services organizations, organizations that advocate for incapacitated persons, as well as resources on Limited Assistance Representation (LAR) and mediation.

Finally, the Volunteer Lawyers Project (VLP) runs an Attorney for the Day program at Middlesex Courthouse on Thursday mornings, one at Suffolk Courthouse on Tuesday mornings, and one at Norfolk Courthouse on Wednesday mornings. You can go to a VLP table and ask to speak to a volunteer attorney who might be able to provide additional information or assistance.



***About the Author:**
Kathleen Ryan is the Family Liaison at the Carter School in Boston. She is also the parent and legal guardian of her son Owen Schneider who is 30 years old. Kathleen has been working with families of children with developmental disabilities for more than 20 years. She is a new member of the Board of the MGA.





Coming Soon Guardian of minor web video!

We are putting the finishing touches on "Guardian of a Minor," an informational web video which will be widely accessible via the MGA website and YouTube. "Guardian of a Minor" is a narrated slide video for adults, families and professionals that can be viewed in three parts. Part 1 offers information on the different ways to care for a minor child in Massachusetts that include guardianship, caregivers affidavit authorization, and temporary agent authorization. Part 2 provides essential information and a step by step outline of the process for becoming a guardian of a minor. Part 3 discusses what happens after a guardian is appointed, including an overview of a guardian's responsibilities to the child and to the Court. A help page will accompany the web video and provide links to other helpful documents and resources.

UPCOMING MGA EVENTS

SAVE THE DATE!

GCM's and Guardians: Who's on First? Protecting our Clients, Protecting Ourselves

What? Please save the date and join us for our first GCM-NE/MGA half day conference including a panel discussion, vendors, networking, CEU's and more!

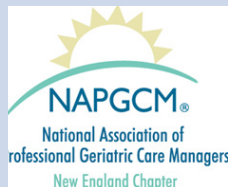
When? Wednesday, November 20, 2013
8:00am- 12:00pm

Where? Cornerstone at Milford
6 Birch Street, Milford, MA 01757

Who? All MGA Members, Friends and Guests are encouraged to Attend

How Much? \$25.00 GCM-NE/MGA members, \$35.00 non-members

Thank you to our generous host
Cornerstone at Milford



SAVE THE DATE!

The MGA's Annual Networking and Dinner Meeting

What? Enjoy an insightful presentation by Leo Sarkissian, Executive Director of the ARC of MA, Waltham. Network with a diverse group of professionals and caretakers.

When? December 10, 2013

Where? TBD

Who? All MGA members and friends are welcome!

ANNOUNCEMENTS

Volunteer Opportunities!

*Are you an attorney willing to volunteer your time to help a client with a guardianship petition?
Do you know someone who needs help filing a guardianship petition?*

4 days per week volunteers from **Volunteer Lawyers Project** assist litigants filing guardianship petitions in the Suffolk, Middlesex and Norfolk Probate Courts. VLP provides free legal assistance to low income clients living in the greater Boston area. Litigants bring their completed Clinical Team Reports (in cases involving intellectually disabled adults) or Medical Certificates to Court and get help completing their petitions. Guardians of Minors are assisted with their petitions and given information about how to obtain parental consents. Volunteers can draft petitions or provide representation for any hearing. More experienced volunteers are able to assist with Rogers cases. The guardianship clinics are a great service to clients seeking guardianships and a wonderful opportunity for attorneys to provide pro bono assistance. VLP provides training, mentoring, roundtables, Grand Rounds and primary malpractice insurance for its volunteers. Call 617-423-0648 for the schedule or information, or visit our website at: <http://www.vlpnet.org/volunteer/>.

Announcing MGA's New 2013 Board Members!

Jessica D. Baker, Esq. is a solo practitioner with a private practice in Foxboro, MA. Her practice focuses primarily on family law and guardianship issues, although she handles consumer bankruptcy matters as well. She is trained as a family law mediator. She is a 2009 graduate of Suffolk University Law School. In the summer of 2010, she began staffing the guardianship clinic at the Norfolk Probate and Family Court, and has been staffing it almost weekly since.

Patricia Freedman, Esq. is the Executive Director of Planned Lifetime Assistance Network ("PLAN") of Massachusetts and Rhode Island, Inc., the Trustee of two Pooled Special Needs Trusts for over 400 people with disabilities throughout Massachusetts and Rhode Island. She has been a legal advocate for people with disabilities for more than 30 years. She was the Director of the Pike Institute on Law and Disability at BU School of Law and the Deputy Director of the Disability Law Center in Boston. She has been a guardian and conservator for people with developmental disabilities and chaired the State Human Rights Committee at the Department of Disability Services (formerly DMR). She is currently the Board President of the National PLAN Alliance.

Cynthia E. MacCausland, Esq. provides high quality legal services in the areas of Family Law, Child Welfare, Criminal, Bankruptcy and Consumer Law. She is active in the Women's Bar Association, the Boston Bar Association and the Massachusetts Bar Association, as well as a frequent volunteer with the Volunteer Lawyers Project and Senior Partners For Justice. She has a long history of community service, including contributions to Canadian Lawyers for International Human Rights, Lawyers Feed The Hungry, and the Domestic Violence Institute at Northeastern University.

Eden D. Prendergast, JD is a 2013 graduate of Suffolk University School of Law with a concentration in Health and Biomedical Law. Eden served as student Board Member during the 2012-13 academic year. While a third-year law student, Eden served as a student attorney in the Health Law Clinic, representing clients in both guardianship and Social Security matters. She is also a certified home health aide with experience caring for both the elderly and disabled. She received her Bachelor's Degree from Boston College in 2009. She is presently studying for the Bar Exam and interested in pursuing a career in the health law field, particularly in the areas of elder law and disability rights.

Kathleen Ryan has worked for the past six years as a Family Liaison for Boston public schools at the Carter School. The Carter School serves 25 of the Boston school system's most disabled students, all of whom need a guardian when they reach age 18. Her role at the Carter School is to help families navigate the many complicated systems that provide assistance to their children. Prior to her work at the Carter, she ran a Department of Developmental Services funded family support program for children considered medically fragile and/or medically complex. Ms. Ryan is also a guardian of her 30 year old son.



FROM THE EDITOR Sarah R. Boonin, Esq.

Sarah R. Boonin, Esq. is an Assistant Clinical Professor at Suffolk University Law School, where she teaches the Health Law Clinic. She is also a member of the Board of Directors of the Massachusetts Guardianship Association.

We at MGA welcome your feedback and input on this and future newsletters. Additionally, we are seeking contributions to the next newsletter. If you would like to read or write about a particular topic in a future newsletter, please contact Sarah Boonin at sboonin@suffolk.edu

The Guardian is an educational newsletter provided to the public by the Massachusetts Guardianship Association. The Massachusetts Guardianship Association is a non-profit organization that promotes education, training, and information on guardianship and conservatorship issues within Massachusetts. Each author is solely responsible for the statements of fact and opinions expressed in their respective articles. Information contained in the articles should not be construed as legal advice. The newsletter and articles contained therein may not be reproduced either in whole or in part without express, written permission from the Massachusetts Guardianship Association.

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