

Adult Children with Developmental Disabilities – Emerging Issues

By Joanne L. Erickson, Esq.

While the laws governing guardianships are now “uniform” thanks to the Massachusetts Uniform Probate Code, I find that the stories behind guardianships are anything but uniform. The forms streamline the facts and fit the cases into the new model. However, the personal stories and family histories continue to make the cases unique and challenging, as ever, especially when told by people who are living these stories every day. The dedication of families who care for their adult disabled children and siblings is a humbling experience for anyone fortunate enough to observe their efforts.

This article looks at two important developments that impact these remarkable families. The first development is that there are a growing number of adult disabled children who are now outliving their parents. Families are driven to find a plan that ensures that their loved ones will be safe and well cared for when they are no longer able to care for them. The second development is that the adult disabled population, in addition to living longer, is now experiencing age-related impairments at a much earlier age than compared with the general population. As a result, families are needing to address medical issues that compound existing impairments that their loved ones have lived with during their lives.

Case Study

It may be helpful to show how these developments can weave their way into a person’s life by looking at Brian’s story. Brian is a delightful 48 year old male with Down syndrome. He has lived with his parents his entire life – it is the only home that he has ever known. He has two older siblings who try to help their parents with Brian but they have their own family responsibilities; the family dynamic is very good. Brian interacts well with others, although sometimes he is shy, but overall, he is very trusting of people. His impairment has been diagnosed as within the moderate range, but he is able to take care of most of his daily needs with supervision. He is always in a supervised setting – either with his parents, his siblings, or program workers.

His health is generally good but when he has an issue, he is not always able to communicate his needs. He takes medication for hypothyroidism which is monitored regularly. His eating habits have always been an issue as he prefers foods that exacerbate his weight which his parents try to watch. They understand that obesity can quickly occur and that it can bring with it diabetes and other related issues. His parents always work to keep Brian physically active and bring him with them on most occasions. He has lost many of his teeth due to grinding and his parents are looking into possible transplants as he is having increased difficulty chewing food.

His parents have worked with the local agency for many years. Both Brian and his parents enjoy activities where families, such as theirs, can interact and enjoy themselves. Brian is enrolled in a work program a few days per week. However, lately there have been days when he has been less interested in going. Also, recently Brian has forgotten some regular routines that are an important part of his day such as walking the dog, taking out the trash, and getting the mail. He does not complain about things but has often appeared quieter than in the past.

Brian parents are in their late 70’s. Unfortunately, his father was recently diagnosed with cancer and his mother, who is helping with his treatments, is having some issues. Brian’s mother has been experiencing difficulty sleeping, anxiety attacks and appears to be showing signs of care-



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taker burnout as she is now care-taking for two. Over the years, state case workers mentioned to Brian's parents that they should look into being appointed as Brian's guardians. However, as they have been handling Brian's medical care for many years without incident, they did not think it was necessary. Recently, however, as they have been having their own health issues, they are now thinking that it might be a good idea to contact an attorney for assistance. They want an attorney who will understand their worries and help them get things in place should they not be able to care for Brian. They also heard of a situation through one of the families they know through the agency, where one of the parents died unexpectedly and the family had to go to court on an emergency basis. Brian's parents do not want that to happen to them.

The aging developmentally disabled population

Generally, life expectancy of adults with mild to moderate range developmental disabilities is similar to that of the general population. However, this has not always been the case. In the 1930's, a developmentally disabled person's life expectancy was 19 years whereas today it is 70 years – an increase of 250%. The disabled population's increased life expectation, like that of the general population, is due in large part to advances in medicine. Further, there has been an increase in availability of programs, services and supports for disabled individuals and their families. These quality of life improvements produce benefits that may never appear as a line item on the state budgets but are truly invaluable assets to those who participate in and benefit from these programs.

Care-taking for this population continues to primarily be done in the private family setting with an estimated 76% of persons with developmental disabilities live at home. In 25% of these households, the family caregiver was age 60 or older, and the average age of the disabled person was 38. Extended life expectancy is translating into extended caregiving periods for individuals and their families.

As seen in Brian's story, he will always need some form of supervision. The most important relationship in his life has been with his parents. As a result of their efforts, Brian can do many things for himself. He also is able to participate in activities outside the home which allows him to interact with his peers – an important part of his life. With these supports and activities, brings with it a sense of purpose, independence and accomplishment that are key elements of Brian's continued well-being. However, as we have seen, Brian's parents are aging and beginning to have their own health issues. If his quality of life is to continue after his parents are not able to care for him, a permanent legal representative (a guardian) will be needed to step in to help with his daily activities, medical decisions as well as other matters.

As Brian's parents have been in control of things throughout his life, it would seem logical for them to be his guardians. However, given their age and current situation, it would be best to appoint a guardian who will fit into the

long-term plan for Brian's care. A possible option would be to have one parent serve as Brian's co-guardian along with another individual who could serve in the event that Brian's parent is no longer able to do so. His siblings have their own families and responsibilities. Whether Brian's siblings are willing and able to take on these additional responsibilities would need to be determined. It is best if these decisions can be made in a non-crisis mode, and not on an emergency basis which can be expensive and burdensome at a difficult time. Brian's family is aware of the impact that the loss of a parent will have on Brian and they all want to mitigate that impact. A compassionate guardian/advocate for Brian can make these difficult times much smoother for him.

Age related medical issues within the adult developmentally disabled population

There are an estimated 641,000 adults with developmental disabilities. It is expected that this figure will double by 2030 to more than 1,200,000 when the baby boomers are in their sixties. Age-related medical issues are increasing in this population and are appearing earlier in individuals with disabilities.

Disabled individuals are now experiencing major changes in their health, functional abilities, and psychosocial status at a much earlier age. Cognitive and physical impairments of a disabled person's life have always impacted their health. Chronic health conditions (including diabetes, cardiovascular disease, respiratory disease and infection), pain, loss of energy and endurance are impacting disabled individuals and their families at a much younger age. Timely and appropriate diagnosis and treatment of these conditions is needed so that individuals can remain active and independent for as long as possible. In the Down syndrome population, there is a growing issue with the increase of early-onset Alzheimer's disease. The occurrence of dementia, of the Alzheimer's type, is much higher in this group (15%-40%), and it may occur as much as 15 to 20 years earlier than compared with the general population.

The subtle changes in Brian's activities and interests could be a sign that he may be experiencing cognitive changes. Reaching out to his primary care physician for assistance is the first step, which will hopefully lead to additional testing. As Brian is not a good reporter of his health, one of the most effective steps would be to arrange for an early baseline test by a neuropsychologist who is familiar with this population. This is done to determine if Brian is experiencing dementia-related symptoms. Early diagnosis and treatment will help his parents, as well as any future caretakers, to understand better what he is experiencing cognitively and physically as he ages.

Conclusion

The role of a guardian is critical. This person has authority to speak on Brian's behalf, has access to his records and has the ability to advocate for testing now and

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Stepping in When Help is Needed



When: December 6, 2011, 5:00 pm

Where: Newbridge on the Charles, Dedham, MA

Massachusetts Guardianship Association (MGA) Annual Dinner Meeting
and **RED CARPET PREMIERE** of the new training video
for family guardians and conservators

Produced by Northnode, Inc.
in collaboration with the MGA
and the Office of the Chief Justice of the Probate Court, Paula M. Carey

The video was made possible through funds provided by the MGA
and a generous grant from the Office of the Attorney General, Martha Coakley

Pre-registration is required by **November 30th** by contacting Judy Flynn
617-350-6500 or jflynn@thelegalcheckup.com

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in the future, if needed. A guardian can also arrange for suitable housing for Brian. The goal is to keep Brian in a family setting, but his parents understand that things can change as they have recently experienced. Having someone with legal authority to make decisions for Brian that are in his best when his parents are gone seems to be more and more important to them. Although a difficult decision, they have decided that they will book an appointment with an attorney who does this type of work so they can get some piece of mind about their Brian.

About the Author: Joanne J. Erickson, Esq. is an elder and disability attorney with offices in Abington, Quincy and Hingham. She assists families, disabled individuals (privately and court appointed) and is a member of the MGA Board of Directors and ARC of the South Shore.

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Estate Planning for Persons With a Disability

By E. Alexandra Golden, Esq.

Introduction

For many, “estate planning” simply means having a will. However, the scope of estate planning is much broader. Estate planning covers matters such as:

- Creating and funding trusts;
- Beneficiary designations on retirement plans, insurance policies and annuities;
- Strategic gifts and transfers of property; and planning to reduce tax liabilities; and
- Assuring eligibility for public benefits.

Most individuals under guardianship or conservatorship have never previously created a durable power of attorney (DPOA). A DPOA would designate an “attorney-in-fact” to handle certain affairs on their behalf. If these individuals had created a DPOA,, their attorney-in-fact to would have been able to engage in many estate planning tasks to the extent allowed by the terms of the document, such as make gifts, set up and funds trusts, and transfer assets to spouses.

There are a variety of reasons an individual may make substantial gifts during his lifetime. Attorneys commonly advise clients with enough wealth to make charitable donations, make gifts to family members or to set up trusts to minimize estate taxation. In particular, if a spouse is admitted into a nursing home, it may be necessary to transfer assets to the spouse who will be staying at home to help the nursing home spouse qualify for MassHealth coverage and to help the community spouse avoid impoverishment. A person with a disabled child may want to set up and fund a special needs trust, both for the child’s benefit and/or to help the person qualify for MassHealth. However, many DPOAs lack these types of provisions, or do not authorize the attorney-in-fact to take other actions which may be necessary to protect the disabled person’s interests (for example, obtaining a reverse mortgage).

Similarly, many individuals under guardianship or conservatorship never have executed a will or a trust while they still had the ability (capacity) to do so. If the incapacitated or protected person dies without such a document, assets will pass, according to the law of intestacy, to the next-of-kin. While this disposition might reflect what the incapacitated person or protected person would have wanted, there can also be disastrous results. An inappropriate person could be put in charge of the estate. Relatives whom the incapacitated person barely knew – or perhaps intensely disliked – may inherit assets. Disabled surviving spouses and children who inherit directly funds might lose public benefits. Thus, it is important for individuals to create an estate plan while they still have the capacity to do so.

Powers of Conservator and Guardians to Manage Assets Without Court Authorization Under the Massachusetts Uniform Probate Code

For those individuals who do not have a DPOA prior to losing their ability to make informed decisions, a conservator may be appointed by the court to handle certain financial affairs. The conservator has responsibilities and duties as set forth by the Massachusetts Uniform Probate Code (MUPC). A conservator is required to consider the impact of his decisions in the management of the protected person’s finances on whatever estate plan the protected person might have. G.L. c. 190B, § 5-416(d). The law allows the conservator to continue the support obligations of a protected person, such as paying for child support or tuition or the mortgage on the family home, without seeking permission of the court. G.L. c. 190B, § 5-423(c)(24). The conservator may make gifts to “charity and persons which

the protected person has expressed an intent to benefit,” as long as the total amount these gifts do not exceed 10% of the protected person’s annual income. G.L. c. 190B, § 5-424(b).

The appointment of a conservator may not be necessary for those individuals with smaller estates. Guardians may manage a small bank account for an incapacitated person without needing to be appointed as conservator or filing the required annual account. G.L. c. 190B, §§ 5-309(a), 5-209(b). There are times when persons who are appointed as guardian and/or conservator handle their own filings with the court. However, it is advisable that an experienced estate planning/elder law attorney is consulted particularly when there are more complex financial arrangements or when it is necessary to appear in court.

Protective Arrangements and Petitions for Additional Powers

Where there is an inadequate DPOA, the Massachusetts Uniform Probate Code (MUPC) has several provisions which allow any interested person, a guardian or an attorney-in-fact to seek the Court’s assistance in managing or disposing of assets without asking to be appointed as conservator. A person may petition the Court on behalf of another for a protective arrangement without seeking appointment as a permanent conservator or asking for a formal determination of incapacity. This is officially referred to as a single-transaction conservatorship. The protective arrangement may “authorize, direct or ratify any transaction necessary or desirable to achieve any arrangement for security, service, or care meeting the foreseeable needs of the protected person.” G.L. c. 190B § 5-408. These protective arrangements can include:

- Selling or mortgaging property;
- Creating and funding trusts;
- Making transfers of assets to loved ones;
- Entering into contracts to purchase annuities or life care; and
- Other matters.

Existing Conservatorships and Expanded Powers of Conservators

If a person requires a conservator or already has had a conservator appointed to act on his behalf, the process for creating or changing the estate plan is similar, but is termed: “**Conservatorship with Expanded Powers.**” The conservator must seek special permission to do such things as: make gifts in excess of 10% of the protected person’s annual income; release or disclaim property rights; create or fund a trust; change beneficiaries on life insurance policies, annuities and retirement plans; disclaim an inheritance; or

make, amend or revoke a will. G.L. c. 190B, § 5-407(d).

Process by Which the Court Gives Me Power to Make a Transfer

Unless the disabled person is already under conservatorship, you will need a medical certificate from a treating physician (or nurse practitioner/psychiatric clinical nurse specialist). The clinician must identify the diagnosis and describe how and to what extent the illness leaves the disabled person unable to make an informed decision about his financial issues. This certificate is filed along with a “**Petition for Conservatorship.**” The **Petition** form is used even if the petitioner is only seeking a protective arrangement and it is not permanent appointment as conservator. The Petition must describe the disabled person’s legal issue, identify the proposed solution and state what the harm would be to the disabled person if the Petition is not allowed. It is common to include with the Petition a detailed “**Memorandum of Facts and Law**” which provides additional description of the history, the underlying legal issues, and other information which can help a judge make his ruling. Documents such as an inadequate DPOA or a proposed trust may also be filed and can assist the court with assessing the situation.

Once the paperwork is filed, the Court will issue a **Citation** (legal notice). The Citation will set forth a deadline to file any objections. Along with the Petition and Memorandum of Facts and Law, the Citation must be served on the disabled person and sent to his next-of-kin and any interested persons. The Court will also order that the Citation be published in a specific newspaper(s), typically depending on the protected person’s location.

If no objections are filed by the deadline, the Court may proceed to appoint a Guardian *Ad Litem* (GAL). The GAL’s job is to represent the best interests of the disabled person, review the proposed estate plan and investigate the facts, and make a written report to the Court regarding her findings. Once the GAL’s report has been filed, the Court will hold a hearing and will issue a ruling. In doing so, the judge must make a written determination of what the protected person would want if not disabled and if able to assess the facts and the options, taking into consideration various factors, including:

- The financial needs of the protected person, his dependents, and the interests of the protected person’s creditors
- Reduction of tax liabilities;
- Eligibility for governmental assistance;
- The protected person’s history of giving or supporting dependents;
- The terms of any existing estate plan;
- Who the protected person might wish to benefit in making an estate plan;
- The protected person’s life expectancy and whether the protected person may be able to recover from his

illness so that the conservatorship will terminate before the protected person's death; and

- Anything other factors the court might think relevant. G.L. c. 190B, § 5-407(e).

The process for having an estate plan for a disabled person allowed by the Probate Court can be quite time-consuming, and its success depends on careful preparation of the Petition and the estate plan itself. An attorney who has experience in guardianship and elder law or estate planning will assist in making sure that the proposed estate plan is thoughtfully prepared and the necessary procedures are correctly followed.



About the Author:
E. Alexandra Golden, Esq. is the principal of Golden Law Center in Needham. The Golden Law Center provides services in the fields of guardianship, elder law, probate, estate planning and special needs planning. She serves as guardian, conservator and trustee for persons with special needs and is appointed by the Probate and

Family Court as a Guardian Ad Litem to represent the best interests of individuals with disabilities. She holds undergraduate and law degrees from Boston College. Attorney Golden is a member of the MGA Board of Directors and serves as Chair of the Education Committee. She is also a member of the Massachusetts chapter of the National Academy of Elder Law Attorneys.



Legislative Update

By John J. Ford, Esq.

Technical Corrections to the Mass. Uniform Probate Code (MUPC) (Senate 704), and The Uniform Adult Guardianship and Protective Proceedings Jurisdiction Act (H 2181)

I had an opportunity to meet with one of Senator Cynthia Creem's staff members to discuss the status of two bills of interest to the MGA, **Senate 704 and H 2181**. The staff member indicated that there was a great deal of interest in the bills and in the *proposed* Uniform Trust Act from many different quarters, urging passage by January 1, 2012.

Both S 704 and H 2181 can be downloaded from the Massachusetts Legislature website, and were on the very long list of bills at the Judiciary Committee hearing in May, 2011. Eileen Sullivan-Boss attended. However, her testimony was largely centered on the Public Guardianship Commission bill. The MGA and BBA are actively lobbying

for S 704 and H 2181 and their representatives have recently met with members of the Judiciary and the Ways and Means Committees.

I presented the staff member with a detailed explanation of the technical corrections bill, developed by Mark Leahy, Esq. and a copy of the inaugural issue of "**The Guardian**" to provide him with a clear statement of the substance and benefits of the Uniform Guardianship Jurisdiction Act and the compelling reasons for its enactment.

Both bills are lodged in the Judiciary Committee, and MGA members are encouraged to contact members of that committee and their own individual legislators to urge passage of these important bills.



About the Contributor:
John Ford, Esq. is the Director of the Elder Law Project, Neighborhood Legal Services, Inc., is a member of the MGA Board of Directors, is Chair of the Legislative Committee, and is one of the MGA founders.



Guardianship Summit 2011

By Barbara M. Ellis, RN, BSN, BSHRM, CCM, NCG
Family Guardian

The National Guardianship Network (NGN) recently convened the Third National Guardianship Summit: Standards of Excellence at the University of Utah S.J. Quinney College of Law in Salt Lake City on October 12-15th, 2011.

The Summit was a multi-disciplinary consensus conference of the NGN and co-sponsoring organization delegates that focused on post-appointment guardian performance and decision-making. Recommendations from the Summit will provide the groundwork for nationally recognized standards for guardians of adults.

The NGN is a group of national organizations dedicated to effective adult guardianship law and practice. First convened in 2002, NGN is a collaborative group of leadership organizations. NGN includes the following organizations: AARP, Public Policy Institute, American Bar Association Commission on Law and Aging, American Bar Association Section of Real Property, Trust and Estate Law, Alzheimer's Association, American College of Trust and Estate Counsel, Center for Guardianship Certification, National Academy of Elder Law Attorneys, National Center for State Courts, The National College of Probate Judges, and National Guardianship Association.

The NGN has included several additional national organizations as co-sponsors of the Summit. These included: American Bar Association Commission on

Mental and Physical Disability Law, ARC, Center for Social Gerontology, National Adult Protective Services Association, National Association of State Long-Term Care Ombudsman Programs, National Association of State Mental Health Program Directors, Older Persons Division, National Committee for the Prevention of Elder Abuse, National Disability Rights Network, and Bazelon Center for Mental Health Law.

Articles and topics presented included the following issues: Guardianship Standards and Ethics, Standards for Making Financial Decisions, Standards for Making Medical Decisions, Standards for Making Residential Decisions, Substituted judgment vs. Best Interest-The Theory and Reality Behind Surrogate Decision-Making Standards, Person-Centered Supported Decision-Making Standards, Standards for Guardianship Fees, Standards for a Guardian's Relation to the Court, and Creating and Sustaining Interdisciplinary Guardianship Committees. Three additional perspectives included: Practitioner Viewpoints to comment on the law review articles as they are developed, a Family Guardian Focus Group to articulate and advance the family guardian perspective, and Summit Outreach Events to maximize input from the broad-based members of NGN organizations. **Barbara Ellis**, MGA Board Member, and **Jane Gildersleeve**, NGA and MGA Board Member were among five family guardians selected to develop the recommendations with assistance

of three attorneys from NGA. Final recommendations were submitted to the Summit and presented to the entire Summit delegates by Melinda Coulter, a family guardian from Florida.

Final recommendations from the Guardianship Summit will be presented at NGA's Colloquium on Guardianship in Albuquerque, New Mexico on May 18, 2012. The decisions will also be published in the Spring 2012 Utah Law Review. The Uniform Adult Guardianship Protective Proceeding Jurisdiction Act (UAGPPJA) was one of the recommendations from the previous Summit known as Wingspan which has been adopted by at least 30 states to date. The website for the Summit is: www.guardianshipsummit.org.



About the Author:

Barbara Ellis earned a bachelors degree in nursing and management. Ms. Ellis is a certified case manager, a national certified guardian, and a family guardian. She is a member of both NGA and MGA, has been involved

with MGA since its inception and is a member of the MGA Board of Directors.



MGA NEW DEVELOPMENTS

7th Annual Guardianship Law Seminar: Co-Sponsored with the MGA and Suffolk University Law School: Successful Strategies for Avoiding and Litigating Guardianship Issues

The seminar will be held on **Friday, November 4, 2011, 9:00 a.m. - 4:30 p.m. at Suffolk University Law School**. A panel of judicial, medical and legal experts will be presenting on a variety of topics including: How the MUPC Impacts Litigation, Addressing Reasons for Avoiding Litigation: Costs, Financial, Emotional, Distraction from Respondent's Needs, MUPC Provides Opportunities for Negotiation & Mediation, and How to Prepare for and Succeed in Litigation.

For more information on how to register, please contact the Advanced Legal Studies at Suffolk University Law School: (617) 573-8000.

INFORMATION AND RESOURCES

I recently launched a **Question and Answer** series on the Guardianship Information page of the MGA website. There has been an enthusiastic response from family guardians, professionals, and website visitors inquiring about guardianship information and helpful resources. I will be posting a new Question and Answer topic each month. Be sure to check back often and to share the link with your clients and colleagues. Please send your topic ideas and comments to edipaola@comcast.net. Thank you! Ellen M. DiPaola, Information and Resources Chairperson

Question and Answer topics coming soon...

“When Might Someone Need a Guardianship?” by Rebecca Weintraub Brendel MD, JD, Assistant Professor of Psychiatry Harvard Medical School and Clinical Director of the Veterans Program Red Sox Foundation and Massachusetts General Hospital Home Base Program. Dr. Brendel will answer commonly asked questions on whether an adult might need a guardianship when diagnosed with a medical condition that results in decision making and daily functioning issues.

“What’s A Roger’s Guardianship?” by Joanne Moses, Esq., former Assistant General Counsel for the Department of Mental Health. Attorney Moses will answer questions that help clarify when a Roger’s Guardianship may be needed and the process for asking the court for Roger’s Orders.

Also ... *“Mediation: An Alternative to Litigation”* and *“How to File a Guardianship Petition.”* These are basic guides for the self-represented litigant.

NEW AND NOTEWORTHY

Coming soon...

Public Policy Information on Guardianship and Conservatorship

John Ford will post a **Public Policy** page on the MGA website. This page will offer information on proposed and pending legislative bills, public policy initiatives and will include links to related articles/sources for additional information.



FROM THE EDITOR

Kristen Lambert, Esq., MSW, LICSW

We welcome your feedback and input. Additionally, we are seeking contributions to future newsletters and developments of educational resources. Please contact editor, Kristen Lambert at kristen.lambert@awacservices.com.

The Guardian is an educational newsletter provided to the public by the Massachusetts Guardianship Association. The Massachusetts Guardianship Association is a non-profit organization which 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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