

Elder and Special Needs Law Journal

A publication of the Elder Law Section
of the New York State Bar Association

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Message from the Section Chair

"People who share a common direction and sense of community can get where they are going quicker and easier because they are traveling on the thrust of one another."



This is one of the many lessons humans can learn from the instincts of the animal kingdom, particularly the flight of geese. By flying in their "V" formation, they greatly increase their range over what each goose could cover alone. This is accomplished by the fact that, as each bird flaps its wings, it creates uplift or thrust for the others following in formation.

So too it is for our Elder Law Section. This section is successful by virtue of so many members making their contribution and creating the "thrust" that allows us to accomplish great things. In all my interactions with section members over the years, and requests I have made for assistance in our programs, I cannot recall ever having received a refusal to serve. The members of this section are extremely generous with their talent and time. It makes leadership positions in the section a truly gratifying experience.

Let me begin this Message by reflecting on our Summer Meeting, which was a great success on all counts: venue, program, events and attendance. The meeting chairs, **Judith Grimaldi and Martin Finn**, did a marvelous job organizing and orchestrating the programs and events. The dancing following dinner was enjoyed by all, and allowed some to relive the music of their youth, as they cavorted across the dance floor. Our evening at Hildene House was a memorable journey back to the life of Robert Lincoln.

The substantive aspects of the program provided very timely guidance in dealing with the new federal and state legislation and regulations. The interactive panels with the audience were especially helpful in answering "What do we do now?"

As staged in "42nd Street," we now "shuffle off to Buffalo" for the Fall Meeting. This will be a first for our section in holding a joint meeting with our colleagues in the Trust and Estates Law Section. **Laurie Menzies** will be Co-Chairing with **Victoria D'Angelo**. We will start with round table discussions covering all the hot topics of the day and then move on to formal presentations examining current issues in greater detail. Many of the topics at the meeting will address Elder Law is-

ssues as they intersect with estate planning and the use of trusts. It is assured to be relevant to your practice and to the issues of mutual concern to both sections. You will also be showered with the beauty and hospitality of upstate New York, but, hopefully, not its precipitation.

Getting back to the topic of membership contribution to the section, let me provide a brief summary of the current activities of some of our committees which create the "thrust" mentioned above:

- **Estate Recovery Litigation Task Force:** Upon reviewing the Department of Health request to CMS for approval to amend the State Medicaid Plan, I appointed this task force chaired by **Rene Reixach and David Goldfarb**, and consisting of **Lou Pierro, Ira Salzman, and Aytan Bellin**, to prepare for the anticipated release of the department's emergency regulations. We needed to be ready to act quickly to challenge the regulations within the time requirements of any operative statute of limitations. This committee is also ready to assist any section member whose client is adversely impacted by the recovery regulations, and is willing to be a case of first impression.
- **The Legislation Committee (Co-Chairs: Amy O'Connor and David Goldfarb)** has had a very active 2011, as it was the core of the Budget Task Force providing white papers and comments, which became the basis for the section's negotiations with the Department of Health. More recently the committee has been working to advance its proposed legislation to address issues arising out of the decision in the Klein case, restricting the use of a health care proxy at home. The bill has sponsors in both houses, but did not get reported out of the Assembly Health Committee. The Legislation Committee is also continuing to advance its proposal to allow Q-TIP trusts with Medicaid protective language to satisfy the Right of Election. All this has been in addition to its monitoring of numerous other pieces of legislation.
- **The Mentoring Committee (Co-Chairs: Joan Roberts and Tim Casserly)** has developed a program with three components. The first is to assist newly admitted attorneys by making available one-on-one guidance with an

experienced attorney. The second is to provide as-needed access to expertise in certain areas of an Elder Law practice. And the third is focused specifically on providing mentoring to those involved in Guardianship matters. The committee is seeking members willing to serve in these capacities.

- **The Medicaid Litigation and Fair Hearings Committee (Co-Chairs: Beth Polner Abrahams and Melinda Bellus)** is pursuing an active agenda on several fronts. Of great significance to the section will be the development of a database of forms which can be accessed to bring actions against financial institutions which arbitrarily reject a legitimate power of attorney form. I have been very disheartened by the cavalier attitude of these institutions in rejecting bona fide POAs. This committee has enthusiastically agreed to develop forms and instructions to assist members in bringing these actions with a minimum of cost to our clients. A quick download of such a form and the transmittal of the same to the legal department should avert institutional obstinacy. This will have a cumulative effect as these institutions realize that Elder Law practitioners are willing to put their pleadings where their mouths are. This committee is also developing a database of information to be posted on the NYSBA website, containing a guide to preparing for and conducting a fair hearing, and the contact information regarding important offices within the state relating to fair hearings.
- **The Special Needs Planning Committee (Co-Chairs: Bob Mascali and Adrienne Arkontaky)** is continuing its role of sponsoring special needs pro bono clinics across the state, in addition to monitoring and advising the membership of changes in Medicaid affecting this area of our practice. Of particular attention will be the issue of managed care and its effect on programs within the Office for People with Developmental Disabilities, and the progress of NYS in extending the Social Security Act section 1115 waiver to individuals with developmental disabilities.
- **The Mediation Committee (Co-Chairs: Judith Grimaldi and Laurie Menzies)** will focus on raising the awareness of the benefits to be gained by resolving family conflicts within a non-litigation, and hopefully, less adversarial forum. This is one of my initiatives and I believe it holds great promise for the future. I am also pleased to report that the committee will be partnering with NY NAELA to provide training programs, so

that section members can conveniently become approved mediators as the concept of mediation gains traction.

- **The Practice Management and Technology Committee (Co-Chairs: Bob Kurre and Ron Fatoullah)** will be continuing its periodic telephone conferences with committee members to share thoughts about improving the way we practice. At my request, they are also conducting a survey of the membership to assist in understanding how other members organize and budget expenses within their offices. It will be valuable for each of us to have a better idea of priorities others might be giving to staffing, marketing, and the implementation of technology. It is also important to note that this information will be collected on a completely anonymous basis.
- **The Diversity Committee (Co-Chairs: Kerry Archer, Liz Valentin and Tanya Hobson-Williams)** will maintain a very high profile for the coming year, as the increasing of diversity within our section was an initiative created by Sharon Kovacs Gruer and will be continued this term as well. However, it is now also an initiative of Vince Doyle, NYSBA president. He has challenged Bar sections to a competition to attain certain goals, and to do so over fixed timelines. To fund this effort, our section has allocated a line item of our budget for the purpose of providing assistance to the committee in establishing outreach activities and events for this worthy goal.

These committees and those appearing on the last few pages of this publication are all in need of assistance. Your participation will be good for the committee, good for the section, and good for you. So please contact one of the listed representatives of a committee and join the flock in formation. We could use the additional "thrust" that your involvement will produce.

One more thought based on this metaphor. It is said that the geese honk from behind to encourage those up front to keep going, and when the lead goose gets tired, he/she rotates back in the wing and another goose flies point. I have been part of this formation for many years, benefiting from the leadership of others. It is now my privilege to take a turn as lead goose. To all of you who having been "honking" encouragement from behind, you have my sincerest appreciation. You have been, and are, a great source of motivation and inspiration on this journey we are undertaking together.

T. David Stapleton

Message from the Co-Editors in Chief

We hope you enjoyed the previous issue, which was the first of our newly designed and titled, *Elder and Special Needs Law Journal*, formerly known as the *Elder Law Attorney*. Our quest is to provide you with a publication that reflects the diversity of issues, challenges and changes that comprise the practice of Elder Law. In addition, we have challenged ourselves to continue to improve the quality of and respect for the publication in the community. We are continuing to develop this publication so as to attract contributions from alternative sources, such as educators looking to publish in a professional forum, to increase its exposure, and to support our already outstanding myriad contributors. As stated previously, while this is first and foremost a law journal, we will continue to invite contributions from our professional counterparts in finance, medicine, social work, law enforcement, and government, because their work so directly impacts ours.



As we continuously state, this Section, and the *Elder and Special Needs Law Journal*, address critical issues affecting the complicated planning and drafting decisions we must make as attorneys, our advocacy of elder law and special needs rights, and the community and care issues pertinent to the problems our clients and their families face. *We always welcome new ideas, new authors and your contribution to this publication.* We ask that you, our readers, keep this law journal in mind in your day-to-day interaction with other attorneys, social workers, physicians, public health professionals and others whose contributions to the community of the elderly can be reflected in these pages for the benefit of our Section.

As this issue goes to press, the Section faces numerous challenges, among them: dealing with New York State's newly enacted measures intending to reduce the State's Medicaid burden (reported in the prior issue); steeling for the anticipated New York State Department of Health regulations and guidance as to same; and bracing ourselves for the federal debt limit/deficit reductions, certain to affect our clients. As usual, this Section and this publication will pull together and report any information to support our continued effort to help you who help those who are the most fragile of our society, the elderly and the disabled. As we wait for the government to resolve these items, very little can be offered to you in this issue that has not been previously

reported. We look forward to being able to provide you with more information and guidance in the upcoming issues.

We begin in this issue with an elder abuse article from a plaintiff's attorney, Michael G. Glass, Esq. entitled, *Nursing Home Neglect—Evaluating the Pressure Sore Case*. From there we move to an article entitled, *Moral Fatigue: Ethical Reflections on the FHCDCA*, by Andrea Escobar-Plagman where she discusses how the complexity of the laws may now lead some surrogates to a state of moral fatigue that often results either in decision paralysis or in less-than-clear judgment. Continuing with this theme the next article by Lisa Furst, LMSW, and Jacquelin Berman, PhD is on *Understanding Depression among Older Adults* and then culminating in a final article of this vein on a perspective on end of life conversations, in an article entitled the *Palliative Care Information Act: A Social Perspective—What Candid Conversations Will Mean For You* by Amy Levine, who is the Director of the Doula to Accompany and Comfort program of the JBFCS in New York City. In her article Amy reviews the Palliative Care Information Act, enacted into Law February 9, 2011, and discusses how it and other issues revolving around death, and about end of life, with our clients.



We address special needs issues with an article by Craig Marcott, entitled *Funding a Special Needs Trust: How Much Is Enough?* This article is very timely. Craig Marcott has been a Certified Financial Planning Professional for 19 years and acts as Special Needs Consultant. With the government continuing to cut expenses the uncertainty of what it will continue to provide is in question. Our focus must change from a strict preservation of government benefits through use of a special needs trust to making sure that the special needs trust also has been properly funded to balance the beneficiaries' ultimate needs. For further insight, we have an article by Susan Platkin, M.D., entitled *Choice Brings Enhanced Lives for People with Developmental Disabilities*, where she describes her experience with a particular waiver program through the Office of People with Developmental Disabilities' self-determination program, Consolidated Supports and Services. This article is particularly special since Susan is not only an M.D. but also a parent of a disabled child and a founding member of the New York Self-Determination Coalition.

We have an article that addresses a very controversial tax topic these days, titled and focused on *U.S. Holders of, and Signers on, Foreign Accounts Beware: FBAR Filing Obligations Clarified and Expanded in 2011 Final Regulations*, by Elizabeth A. Whalen, Esq. Ms. Whalen highlights a very important issue particularly close to our practice: an agent under a power of attorney, although having no reason to file in his or her own behalf, may have to if the principal has the obligation to file. This is an article all should read!

In addition to these articles, we continue to report our very informative regular columns, including: Recent New York Cases, by Judith B. Raskin; Advance Directive News: Topsy Turvy Health Care Decision-Making, by Ellen G. Makofsky; Guardianship News, by Robert Kruger; Supplemental Needs Trusts: Pooled Trusts Remainder Funds—Where Does the Money Go?, by Robert P. Mascali; and What Families Should Do When a Loved One With Disabilities Is Denied the Home and Community-Based Waiver, by Adrienne J. Arkontaky, Esq.

Finally, we think you will find the Amicus Curiae Memorandum of Law in *U.S. v. Feldman/U.S. v. City of New York* (SDNY) to be an excellent and persuasive discussion about the critical need for personal care at

home and the foundation for it in the Americans with Disabilities Act.

We hope you find the *Elder and Special Needs Law Journal* valuable in your practice, and we thank you for your continuing support. If there is a topic you feel needs to be addressed please feel free to contact us.

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The Editors would like to thank the following student editors for their time and diligence in the editing of the Fall 2011 issue: David Durso (3L, St. John's University); Sarah Duval (3L, University at Buffalo); Joseph Hasenkopf (3L, Albany Law School); Sofiya Nozhnik (3L, New York Law School); Jonathan Placito (3L, University at Buffalo); and Benjamin Pomerance (2L, Albany Law School). Finally, we're pleased to welcome Marrisa Trachtenberg (J.D. 2011 University at Buffalo), previously a student editor, as our Assistant Production Editor.

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Nursing Home Neglect— Evaluating the Pressure Sore Case

By Michael G. Glass

Pressure ulcers are among the most common injuries suffered by nursing home residents.¹ They can be painful and debilitating, and are horrifying to the resident's family and to jurors alike. Practitioners should have a basic understanding of the law protecting nursing home residents who develop bed sores and be able to make a preliminary determination as to whether a bed sore case should be investigated further.



"[Bed sores] can be painful and debilitating, and are horrifying to the resident's family and to jurors alike. Practitioners should have a basic understanding of the law protecting nursing home residents who develop bed sores..."

Nursing home residents are protected by a complex web of federal and state regulations which govern almost every aspect of nursing home care.² On the federal level, in 1987, the U.S. Congress enacted a far-reaching set of reforms of nursing home regulations to improve nursing home quality.³ The legislation expanded state and federal responsibilities for nursing home supervision and increased sanctions for non-compliance. The stated purpose of the reforms was to ensure that each nursing home resident receives care which enables the resident to "attain the highest practical physical, mental and psychosocial well-being."⁴ The regulations, collected at 42 C.F.R. Part 483, set forth detailed standards for resident's rights, the quality of resident's care, proper maintenance of the facility and other facility practices.⁵

States license nursing homes and also have the authority to enact their own set of nursing home regulations to complement federal oversight.⁶ The statutory authority of the New York State Commissioner of Health to regulate nursing homes is set forth in Public Health Law Section 2803. Public Health Law Section

2803-C(3)(e) expressly states that each nursing home patient has the right to adequate and appropriate medical care. Detailed New York State regulations governing the quality of care in nursing homes are set forth in 10 N.Y.C.R.R. Part 415. The New York regulations largely track their federal counterpart, although they are not identical. Both sets of regulations must be referenced in any nursing home neglect case.

New York also protects nursing home residents with a private statutory right of action under Public Health Law Section 2801-d.⁷ PHL 2801-d is perhaps the single most powerful tool in the practitioner's arsenal. PHL 2801-d creates a private right of action for the nursing home resident who suffers any deprivation of a right or benefit conferred by statute, regulation or the nursing home contract.⁸ A prima facie PHL 2801-d case is made out when the resident proves the nursing home violated any one of the myriad state or federal regulations protecting residents and demonstrates that the violation caused the resident's injury. Under the statute, the burden then shifts to the nursing home to prove that "the facility exercised all care reasonably necessary to prevent and limit the deprivation and injury...to the patient."⁹ A prima facie case for the resident under PHL 2801-d can be easier to prove than a traditional negligence claim (in which the plaintiff must establish the facility acted unreasonably), or a medical malpractice claim (in which the plaintiff must establish departures from accepted standards of care). Significantly, PHL 2801-d also provides for minimum statutory damages, punitive damages when willful or reckless disregard of the resident's rights can be proved and, in the discretion of the court, attorney fees to the prevailing resident's attorney.¹⁰

It is against this backdrop that the pressure sore case must be evaluated. Pressure sores are prevalent in nursing homes because elderly and infirmed residents are often immobile, bed bound or chair bound. A pressure sore develops because of pressure and/or friction over an area of skin, resulting in decreased blood flow to that area.¹¹ Affected areas are typically the sacrum, coccyx, feet and heels. If the pressure is not relieved, the area develops into an open sore and death of tissue ensues. As the sore widens and deepens, layers of the skin can be eviscerated, exposing the bone below. Seventy percent of pressure sores occur in patients over the age of 70 and ninety-five percent of pressure sores develop on the lower body.¹²

Pressure sores are graded or staged according to their severity. Stage I is intact skin with a nonblanchable redness in a localized area, usually over a bony prominence. Stage II is a shallow open sore where the skin has been broken. Stage III is when the pressure sore has advanced to the point that there is full thickness tissue loss so that the fat underlying the skin is exposed. Stage IV is when the sore is so deep that underlying bone, tendon or muscle is exposed. A pressure sore may also be “unstageable,” because the base of the ulcer is covered by slough or eschar making accurate staging of the depth difficult.¹³ Most pressure sore lawsuits involve Stage III or IV pressure sores. Pressure sores in the lower extremities can cause gangrene resulting in amputation. Open bed sores anywhere on the body can become the site of an infection and progress to sepsis, and ultimately cause the death of the patient.

Both federal and state regulations speak to the issue of pressure ulcers.¹⁴ Both provide that the resident has the right to be free of pressure sores which are medically preventable. Specifically, the regulations provide that the nursing home must ensure that the resident does not develop pressure sores unless they are “clinically unavoidable.”¹⁵ If the resident comes into the nursing home with an existing pressure sore, the facility is charged with the responsibility of providing the necessary services and treatments to promote healing, prevent infection and prevent new sores from developing.¹⁶

The issue of “clinical unavoidability” is central to the prosecution and defense of the pressure sore claim. The focus is on whether the facility appropriately assessed the resident’s risk of developing a pressure sore and created a plan of care to address that risk. Often the nursing home chart demonstrates the risk was identified and a plan of care was developed. Then, the battleground shifts to the issue of whether the interventions and precautions ordered were actually implemented by the facility staff. The answers to these questions are revealed by a detailed analysis of the nursing home chart.

In addition to immobility, certain medical conditions can enhance the resident’s risk of developing pressure sores, and when they develop, make them more challenging to heal. Those conditions include urinary and fecal incontinence, peripheral vascular disease, malnutrition, diabetes, end stage renal disease, gastrointestinal disorders and malabsorption disorders, among others.¹⁷ Some medical conditions are believed to impede or prevent healing of pressure ulcers: metastatic cancer, cachexia, multiple organ failure, sarcopenia, severe vascular compromise and terminal illness.¹⁸ Resident’s rights advocates argue that the presence of risk factors put the facility on notice of the need for aggressive preventative measures. Nursing home defense

counsel, on the other hand, argue that the presence of multiple risk factors make the development of the pressure sore clinically unavoidable.

Typical interventions to prevent the development of a pressure sore for an at risk resident include routine turning and positioning to off-load pressure points, maintaining adequate nutrition and hydration, employing pressure relief devices such as a pressure relief mattress or pads or heel protectors, and providing appropriate skin cleaning and skin care.¹⁹ Many of these interventions are provided by the certified nurse assistants, who work under the supervision of the facility nurses. The facility should maintain some form of a CNA accountability record which documents on each shift whether the interventions required by the plan of care are actually being performed. Pressure sore litigation is often waged in and around the CNA accountability record. Large gaps in documenting daily care, such as the turning and positioning of the immobile resident, provide plaintiffs’ experts with a ready explanation as to why the pressure sore developed or failed to heal. Conversely, a well-documented chart of daily interventions supports the facility’s argument of “clinical unavoidability.”

Sometimes the nursing home chart has missing parts, or worse, material alterations between the chart obtained before the litigation and the chart produced during the litigation.²⁰ On an alarming number of occasions we have discovered fabrications in the notes, including the addition of turning and positioning entries which were not recorded in the earlier version of the chart, and even the administration of medications to a resident a day after his death.

The most damning pieces of evidence in the pressure ulcer case are the photographs of the ulcers themselves. Graphic photographs of the deep sores exposing, for example, the vertebrae in the sacrum are a compelling adjunct to the resident’s family’s testimony concerning pain and suffering. In every pressure sore case the family should be instructed to take multiple photographs of the ulcer, or a professional photographer should be dispatched to the hospital or facility for that purpose. If the resident has died, funeral directors will often permit a photographer to document the sores while the body is being prepared. Unfortunately, autopsies are rarely performed on elderly residents who expire in the hospital or nursing home from presumed natural causes. The nursing home and hospital charts should be scoured for any evidence that the facility took photographs to document wound care progression, and careful note should be made of any differences in the description of the pressure sore between the nursing home and the subsequent treating hospital. Once a pressure ulcer is identified, it should be measured by location, size and depth.²¹ It is not unusual to

discover that a pressure sore is described by the nursing home staff as a Stage III on the day the resident is transferred to the hospital for definitive care, and a few hours later described as a Stage IV by the hospital emergency room personnel.

As the preamble to the New York regulations reminds us, the infirm elderly are among the most vulnerable in the population.²² A large percentage of that population is at risk for developing pressure sores. Unless clinically unavoidable, pressure sores should not occur in a skilled nursing facility. Litigation of bed sore cases is one method of promoting enforcement of existing standards of care and improving quality of care throughout the industry. The practitioner would be well advised to seriously consider obtaining the nursing home chart when the family complains that a loved one has developed serious bed sores in the nursing home.

Endnotes

1. Depending on the study consulted, the incidence of pressure ulcers in the long-term care setting range from a low of 2.2% to a high of 23.9%. Janet Cuddigan et al., *Pressure Ulcers in America, Prevalence, Incidence and Implications for the Future*, 14 J. FOR PREVENTION & HEALING 208 (2001) (an executive Summary of the National Pressure Ulcer Advisory Panel).
2. See Belinda Dodds-Marshall, et al., *The Ever Expanding Claim: Causes of Action Against Nursing Homes Amendments to New York Public Health Law 2801-d*, THE RISK MGMT. Q., 13, 15 (Summer 2010) available at http://www.ahrmny.com/downloads/RMQ-Summer_2010.pdf ("it is now recognized that skilled nursing facilities and the nuclear power industry are the most heavily regulated in the Country").
3. See 42 U.S.C. §1396r (2011); see also 42 C.F.R. §§483.1- 483.480 (implementing 42 U.S.C. §1396r).
4. 42 U.S.C. §1395i-3(b)(2) (2011); 42 U.S.C. §1396r(b)(2) (2011); 42 C.F.R. §483.25 (2005) .
5. See, e.g., 42 C.F.R. §§483.10, 483.13, 483.15, 483.25, 483.30, 483.750, among other sections.
6. *Federal Regulations and Nursing Homes*, TEXAS NURSING HOME LIBRARY, <http://txnursinghomes.boomja.com/index.php?ITEM=94824> (last visited June 8, 2011).
7. N.Y. PUB. HEALTH LAW §2801-d (McKinney 2009). One of the legislative motivations for enacting PHL §2801-d was to provide "a supplemental mechanism for the enforcement of existing standards of care." See New York State Moreland Act Commission on Nursing Homes and Residential Facilities, *Assessment and Placement: Anything Goes*, pp. 4-5 (Mar. 1976). The Moreland Commission was created by Governor Carey to investigate nursing home abuse and recommend regulatory reforms. See 1975 N.Y. Sess. Laws 1764 (McKinney).
8. Applicable statutes include 42 U.S.C. 1396r and New York PHL 2803-c. Relevant regulations are found in 42 C.F.R. Part 483 and 10 N.Y.C.R.R. Part 415. In addition, the contract between the nursing home and the resident may detail resident rights. See *Morisette v. Terrence Cardinal Cooke Health Care Center*, 797 N.Y.S.2d. 856, 859 (N.Y. Sup. Ct. 2005) (referencing a nursing home patient's right to appropriate medical and nursing care pursuant to her contract).
9. N.Y. PUB. HEALTH LAW §2801-d(1) (McKinney2009).
10. *Id.* §2801-d(1), (6).
11. AMERICAN MEDICAL DIRECTORS ASSOCIATION, *PRESSURE ULCERS IN THE LONG-TERM CARE SETTING, CLINICAL PRACTICE GUIDELINE 1* (2008).
12. *Id.* at 2.
13. *Id.* at 8.
14. 42 C.F.R. §483.25(c) (2005); 10 N.Y.C.R.R. §415.12 (1991).
15. *Id.* According to the interpretive guidelines issued by CMS to nursing home surveyors, a pressure ulcer is avoidable when a pressure ulcer develops and the facility did not do one or more of the following: evaluate the resident and the resident's risk factors, define and implement interventions, monitor and evaluate the impact of interventions, or revise the interventions as appropriate. CMS, *Guidance to Surveyors*, 42 C.F.R. 483.25(c) at F Tag 314.
16. 42 C.F.R. §483.25(c)(2) (2005); 10 N.Y.C.R.R. §415.12(c) (1991).
17. See, e.g., AMERICAN MEDICAL DIRECTORS ASSOCIATION, *supra* note 11, at 4; CMS, *Guidance to Surveyors*, 42 C.F.R. 483.25 at F Tag 314.
18. AMERICAN MEDICAL DIRECTORS ASSOCIATION, *supra* note 11, at 10.
19. *Id.*
20. Pursuant to 42 C.F.R. 483.10(b)(2), the resident or his legal representative has the right to access all records pertaining to the resident. See also 10 N.Y.C.R.R. §§415.22(e), 415.3(c)(1)(iv) (1991).
21. AMERICAN MEDICAL DIRECTORS ASSOCIATION, *supra* note 11, at 10-11.
22. 10 N.Y.C.R.R. §415.1(a)(1) (1991) ("For the vast majority of residents, the residential health care facility is their last home. A license to operate a nursing home carries with it a special obligation to the residents who depend on the facility to meet every basic human need.").

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Moral Fatigue: Ethical Reflections on the FHCDA

By Andrea Escobar-Plagman

As New York State health care providers are slowly adjusting to the tri-fecta of advance care planning—the Family Health Care Decisions Act (FHCDA),¹ Medical Orders for Life Sustaining Treatment (MOLST),² and the New York Palliative Information Care Act (PCIA)³—another bill is coming before the New York State Assembly. It is called the Surrogate Decision-Making Improvement Act (SDMIA).⁴ The bill would extend the FHCDA to hospice programs,⁵ make the process for determining incapacity uniform for FHCDA surrogates as well as health care proxies,⁶ allow proxies to make decisions about artificial hydration and nutrition based on the best interest standard laid out in the FHCDA,⁷ and clarify that the patient's prior wishes, if known, cannot be overridden by a surrogate.⁸



While these provisions are ostensibly deemed necessary for individuals and families to navigate the health care system, few, if any, relate to the surrogate as a caregiver. In this role, the surrogate can often feel pressured by the matrix of laws, providers, and institutions that surrounds the patient. The provision of long-term care to patients leads surrogate caregivers to a state of moral fatigue that often results either in decision paralysis or in less-than-clear judgment. When the urgency required in some decisions is added to the clinical picture, this fatigue can be exacerbated and its effects multiplied.

There is little question that the individual's growing autonomy since *Schloendorff v. Soc'y of New York Hospital*⁹ has had a beneficial effect on patients. Autonomous decision-making in the area of medicine is, as argued by many, an extension of the right against unwanted touching. The FHCDA, as an extension of *family* autonomy, is a step in empowering families who in the past might have had to stand idly at the bedside while others made the life and death decisions concerning their loved ones. Now, those decisions have become firmly ensconced in the hands of the surrogate who, often with significant input from other family members and close friends, is in a position of making the difficult call. While it would go too far to say that this is a new historical development—families and friends have always participated in such decisions and have often

been the final decision-makers—it is the case that the FHCDA's extension of power to families and friends increases the burden on surrogates and other involved decision-makers. These developments, coupled with the realization (again, not a new insight) that decisions about life-sustaining treatments can be quite taxing on the decision-maker, should lead practitioners, providers, patients, families, and policy-makers to wonder whether family members can become so overwhelmed by *choice* that they become impotent or inefficient decision-makers.¹⁰

The FHCDA and the other laws mentioned above have been a step forward, but policy has not always focused on the surrogate decision-maker as a caregiver. Because of this, many of the gains that have been made in the legal arena can be washed away by the psychological stresses that threaten to make these new rights and powers moot. Perhaps the time has come to shift the policy-making focus to the moral fatigue of caregivers.

I define moral fatigue in the present context as a process that a family with a desperately sick person often endures. It is no surprise to those who have lived through such an illness that the task of taking care of an infirm family member can be taxing and tiring.¹¹ It stands to reason, furthermore, that the longer the demands on the caregiver's time and energy last, the more significant the impact becomes. When this long-term obligation overtakes the caregiver's ability to judiciously consider a situation in order to make an informed and considered ethical decision, we have entered into the realm of moral fatigue. This is often the result of having had to make several ethical decisions in short order. In short, we often find that caregiver surrogates and proxies who are in the position of having to make end-of-life decisions for their loved ones are susceptible to decision paralysis. Their capacity to consider relevant evidence in making these decisions can also be limited.¹² Moral fatigue thus frustrates the very objective of the recent spate of laws, as well as the autonomy and family involvement movements.

This, of course, is not an intended result, but it is a consequence that is partially due to the laws themselves. In an attempt to encourage surrogates to make the "morally and legally correct" decision on behalf of the patient, the law inadvertently places undue moral stress on the family, sometimes thwarting its very intent. In order to avoid this while preserving the previous *autonomous wishes* of the patient, caretakers must be given reasonable time and support to act in accor-

dance with the best wishes of the patient or their own well-considered substituted judgment. I argue that the sheer onus of the law may, in fact, lead family members to abandon their responsibility, thus threatening the patient's autonomy and prior wishes. In other words, moral fatigue can lead to the "let's get it over with" syndrome where surrogates pressured to make a decision in accordance with the myriad of laws may make a rushed decision which may not be the most ethical option. I will discuss some of these ethical landmines and argue that the "clear and convincing" evidentiary burden somewhat better protected the patient's interests based on my internal-versus-external decision-making model. This is not, however, a suggestion or recommendation that New York State return to pre-FHCDA law. Rather, the author's hope is that identification of the effects of a turn to family empowerment might lead to innovative policy that will address these effects.

A. Previous Law in New York State

Decision-making for individuals without a health care proxy in New York State was straightforward and strict until last year. The legal precedent arose from a series of cases beginning with the Court of Appeals case *In re Storar*.¹³ There the court held that "clear and convincing" evidence of a patient's wishes was needed in order for a decision-maker to act. That holding was re-affirmed in the 1988 case *In re Westchester Cnty. Med. Center*.¹⁴ In that case the court re-established the need for "clear and convincing" evidence of a patient's wishes and stated that the "ideal situation is one in which the patient's wishes were expressed in some form of writing, perhaps a 'living will,' while he or she was still competent."¹⁵

This meant that prior autonomous wishes are to be protected at all costs. This is one of the objectives of the new bill—the SDMIA¹⁶—which will clarify the importance and primacy of the patient's prior statements.

B. External and Internal Decision-Making Models

I have developed a *sui generis* model of decision-making which becomes noticeable where one compares the previous versus current law in New York State. I argue that patients' previous statements of their autonomous wishes may have been better protected by the "clear and convincing" standard which I label as an external decision-making method. Why external? Very often a court would be involved and the burden was on the family to produce the requisite proof of their loved one's wishes. This was a safeguard. Families worked hard to ascertain the wishes of the now-unavailable family member (and not perjure themselves in the meantime), as anyone who has read the case of *Cruzan v. Dir., Missouri Dep't of Health*¹⁷ can attest. The court would ultimately make the hard decision for the fam-

ily; either one met the evidentiary burden or not.¹⁸ Surely, one can imagine that there is some relief on the part of the harried family because the decision was **external** to them, e.g., the court made the final decision. Indeed, as the Court noted in deciding *Cruzan* in favor of the State of Missouri, the standard of proof reflects "a societal judgment about how the risk of error should be distributed between the litigants."¹⁹ I am not alone in noticing the safeguard of a high burden of proof. Robert N. Swidler in his article "New York's Family Health Care Decisions Act: The Legal and Political Background, Key Provisions and Emerging Issues" states:

In lieu of the unrealistic and harsh clear and convincing evidence standard, the state institutes safeguards, including these: it requires the attending physician and another physician to make specific clinical findings; it requires the surrogate to make certain non-clinical findings about the burdens of the treatment; it obligates the surrogate to base his or her decision on the patient's wishes if known, or else the patient's best interests; it allows persons connected with the case to challenge a decision.²⁰

Swidler goes on to express confidence in the adequacy of these safeguards while also calling for "empirical confirmation" that these safeguards are in fact protecting patient rights and helping to improve end-of-life decision-making. It is in that spirit that sensitivity to the burdens of caregiver-surrogates can help advance the policy objectives of the FHCDA.

Under the FHCDA the family is now empowered to make the decision on behalf of the patient. The decision thus remains **internal** to the family unit. However, there are rules and obligations that wear down the family. Rifts and factions can form²¹ and the family can eventually find their case in front of an ethics review committee.²²

This "new autonomy" provides for a variety of menu options in end-of-life care. It empowers patients as well as their families. Paradoxically, however, it allows for so many options that it generates the need to make many more decisions than would have been the case prior to the explosion of autonomy.²³ The family or surrogate(s) could be paralyzed by it unless effective educational programs are dedicated to explanation of the menu options. Previously, there appeared to be little moral fatigue because the ultimate decision was made by someone else.²⁴

Other relevant considerations exist. The increasing complexity of medicine threatens at times to drown

decision-makers—whether patients or surrogates—in a sea of information that blinds them to the essential choice that must be made. When physician-patient communication is not optimal, this effect can be exacerbated. The easy availability of information vis-a-vis the Internet and other media can easily generate information overload that diminishes rather than enhances decision-making capacity. The presence of these relevant and important factors, however, need not minimize the importance of moral fatigue as an element in the end-of-life decision-making process. Attention must still be paid to this internalization of the ethical burden. It is certainly true that the cat is out of the bag: families are empowered and thus often have to shoulder this ethical burden by themselves. The question now is how to respond in a way that preserves this newfound power and addresses the potential for counterproductive moral fatigue exacerbated by the internalization of the ethical burden.

C. Case Scenario

Consider a typical patient case. The conditions and illnesses are interchangeable with so many others, but in this instance will paint a practical and fairly common picture of moral fatigue and its vicissitudes: a patient without a proxy and with no history of statements concerning his end-of-life care presents with general weakness and difficulties with getting around on his own. He cannot speak and is not responsive to verbal commands. He is receiving respiratory support through a ventilator as well as nutrition from a PEG tube.

Multiple co-morbid conditions have led to his current state of affairs, and he has been under home care by his wife and other immediate family members for the past four years. He has suffered multiple brain tumors treated by surgical resections as well as radiation treatments along with at least one instance of hemorrhaging due to a subarachnoid injury. The immediate caregivers in the family have some grasp of the medical details concerning his current conditions. None have medical training, however, and the learning curve is relatively steep. The patient has no written advance directives, no proxy, and has not made verbal statements to clarify how he would want the situation handled. His wife is thus to serve as surrogate in keeping with the FHCDA.²⁵ She has been made aware of his poor prognosis and that decisions will have to be made about the PEG tube and the ventilator. She will also need to make decisions about whether to attempt to enroll her husband in a nursing home or to take him home with or without hospice support.

Given her physical and mental exhaustion, however, she wants no further interaction with the medical

providers on the case. She holds no animus toward them, but simply lacks the energy to engage in further communications. She has not given up her surrogate role, but she has asked her brother-in-law (the patient's brother) to take over all direct communications with the medical staff. She has given up hope that her husband will recover, and at this point wants her brother-in-law to manage the situation in a manner consonant with her husband's wishes (or at least what she believes to be those wishes). The brother-in-law is therefore doing all of the communicating with providers, but he relays decisions to his sister-in-law in order to come up with final decisions. It is evident to most case participants that the decision-making process is less than efficient.²⁶

The case illustrates not just these inefficiencies in communications—which in themselves run counter to the aim of policy-makers—but that the inefficiencies are often exacerbated by the menu of options. The combination of choice overload along with moral fatigue threatens therefore to seriously undermine the gains that have been made through legal and policy avenues in the last several years.

These gains—the FHCDA foremost among them—have undoubtedly made it easier for family members to gain control over the medical management of their loved ones and promote the modern goal of shared decision-making. What this has done, however, to families such as the one described above is put a greater moral burden on them to make decisions. The decision to forgo or withdraw treatment is now an *internal* one, located wholly within the family or the lone surrogate. Whereas before responsibility for forgoing or withdrawing treatment might lie in a court of law under a tough evidentiary burden, there is no longer such an external decision-maker to take the ethical onus off the family's shoulders.

It is undeniable that it is an exciting time for those interested in serving the elder population (although younger adults will also benefit from the new legislation). Nonetheless, for the average family faced with a loved one with a chronic, long, and debilitating condition, there remains a possibility of "law overload" and "moral fatigue." As professionals in this field, there is no time to waste in promoting education and community outreach programs such that patient and family outcomes mesh with policy guidelines. My goal here is rather modest; I simply desire to show that beyond the need for important technical amendments there are deep ethical, educational, and emotional concerns which still remain to be addressed by relevant stakeholders.

Endnotes

1. Chapter 8, Laws of 2010, adding N.Y. Public Health Law Article 29-CC ("The Family Health Care Decisions Act").
2. N.Y. PUB HEALTH LAW, ART. 29-CCC.
3. N.Y. PUB HEALTH LAW, ART. 29-D § 2997-c.
4. A. 7343, 234th Sess. (N.Y. 2011).
5. *Id.* § 11.
6. *Id.* § 31.
7. *Id.* § 31.
8. *Id.* § 7.
9. 211 N.Y. 125 (1914).
10. See Matthew Wynia & Kyle Dunn, *The Effects of Health Information Technology on the Physician-Patient Relationship: Dreams and Nightmares: Practical and Ethical issues for Patients and Physicians Using Personal Health Records*, 38 J.L. MED. & ETHICS 64 (2010). Wynia and Dunn consider the impact of information overload on patient decision-making, in the process discussing "mental fatigue" and "decision fatigue" as relevant factors.
11. The burden can be significant enough for it to not only increase psychological stress but negatively impact physical health as well. See also K.L. Saban, P.R. Sherwood, H.A. DeVon, D.M. Hynes, *Measures of psychological stress and physical health in family caregivers of stroke survivors: A literature review*, 42. J. NEUROSCIENCE NURSING 128 (2010), E. Grasel, *When home care ends—changes in the physical health of informal caregivers caring for dementia patients: A longitudinal study*, 50 J. AMERICAN GERIATRICS SOCIETY 843 (2002), E.T. Van den Heuvel, L.P. de Witte, L.M. Schure, R. Sanderman, & J.B. Meyboom-de, *Risk factors for burn-out in caregivers of stroke patients, and possibilities for intervention*, 15 CLINICAL REHABILITATION 669 (2001), Sevinc Tastan, Gulsah Kose, Emine Iyigun, Hatice Ayhan, Halise Coskun, & Sevgi Hatipoglu, *Experiences of the relatives of patients undergoing cranial surgery for a brain tumor: A descriptive qualitative study*, 43 (2) J. NEUROSCIENCE NURSING 77 (2011), and C. Schmer, P.W. Smith, S. Latham, & M. Salacz, *When a family member has a malignant brain tumor: The caregiver perspective*, 40 J. NEUROSCIENCE NURSING 78 (2008).
12. Decision paralysis is a researched phenomenon. It does not merely extend to patients and non-professional decision-makers in the area of medicine, but to doctors and other medical professionals as well. See Donald L. Redelmeier & Eldar Shafir, *Medical decision making in situations that offer multiple alternatives*, 273 (4) J. AMER. MED. ASSOC. 302 (1995) on the impact on physicians.
13. 420 N.E.2d 64 (1981).
14. 534 N.Y.S.2d 886 (1988).
15. *Id.* at 892.
16. A. 7343, 234th Sess. (N.Y. 2011).
17. 497 U.S. 261 (1990).
18. A family could appeal the decision, but only a few cases will make it to the Court of Appeals, much less the United States Supreme Court as *Cruzan* did.
19. *Cruzan* at 283 [citing *Santosky v. Kramer*, 455 U.S. 745, 755 (1982)].
20. Robert N. Swidler, *New York's Family Health Care Decisions Act: The legal and political background, key provisions and emerging issues*, 16 (JUNE) N. Y. ST. B. A. J. 18 (2010).
21. See Tia Powell, *Extubating Mrs. K: Psychological aspects of surrogate decision making*, 27 J.L. MED. & ETHICS 81 (1999). Powell describes a fairly typical and perhaps common case involving such a family rift.
22. N.Y. PUB HEALTH LAW, ART 29-CC § 2994-m.
23. I am not mounting a criticism of the patient autonomy movement *per se*. For a critique rooted in the view that the FHCDA represents a desirable step away from individualistic autonomy and "toward a more relational framework of decision making..." see Mary Beth Morrissey, *Educating Ethics Review Committees in a More Humanistic Approach to Relational Decision Making*, 16 (1) N. Y. ST. B. A. HEALTH L. J. SPEC. ED.: IMPLEMENTING THE FAMILY HEALTH CARE DECISIONS ACT 65, 67 (2011).
24. I do not intend to imply that before the FHCDA, decision-making was not heart wrenching or difficult. It certainly was, but the burden has shifted to the family solely now and that can be quite intimidating. As a member of various ethics committees, I see first-hand the strain put on families to navigate the law in a **very short** amount of time. That is certainly a topic for another article.
25. N.Y. PUB HEALTH LAW, ART 29-cc §2994-d.1.
26. This should be no surprise. The effects of stress on decision-making are well-studied. For a recent literature review of the impact on stress on traumatic decision-making, see, e.g., Kathleen M. Kowalski-Trakofler, Charles Vraught, & Ted Scharf, *Judgment and decision making under stress: An overview for emergency managers*, 1 (3) J. EMERG. MANAG 278 (2003). See also J.D. Bremner, *Traumatic stress: Effects on the brain*, 8 DIALOGUES IN CLINICAL NEUROSCIENCE 445 (2006).

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Understanding Depression Among Older Adults

By Lisa Furst and Jacquelin Berman

Mr. R. has missed his meeting with you again, for the second time in the last two weeks. Over the past several months you have recognized changes in Mr. R., as his once vibrant personality has become lackluster. He has lost weight, seems overly emotional and is unable to focus on what you are saying to him. You wonder if he could be having problems with his memory, but it seems to you as if there is something else going on. Perhaps Mr. R. is suffering from depression.

A. What Is Clinical Depression?

Aging well is possible, but not without sound mental health. The majority of older adults are, and will continue to be, major contributors to our society as they live longer and healthier lives. Mental disorders, such as clinical depression, can rob older adults of their capacity to age successfully. Many of us use the word “depression” in ordinary language to refer to feelings of sadness or disappointment arising in response to difficult situations or life experiences. Everyone feels sadness from time to time—this is a normal and common human emotional experience. Clinical depression, however, is not the same thing as ordinary sadness. Rather, it is a treatable mood disorder that causes a disturbance in one’s emotional state and is accompanied by a range of symptoms, including emotional, physical, cognitive and behavioral signs or symptoms.

There are several types of clinical depression, the most common of which are *major depression*, *dysthymia* and *minor*, or *subsyndromal depression*. While these conditions are related, they differ in their exact presentations and vary in terms of the severity and duration of symptoms.

1. Major Depression

Major depression can be experienced as a one-time episode, a series of episodes or a chronic, recurrent problem that continues for months or years. Major depression is characterized by having at least 5 out of a total of 9 symptoms for at least two weeks, nearly every day. These symptoms must also cause significant distress and/or impairment in day-to-day functioning. In order to be diagnosed with depression, someone must experience one or both of the “cardinal” symptoms listed below:

- Depressed mood most of the day, nearly every day
- Loss of interest or pleasure in activities one usually enjoys¹

Many of us most commonly associate major depression with having a persistently down, depressed or hopeless mood most of the time. However, it is possible to be diagnosed with clinical depression even when a persistently depressed mood is not present. Long-lasting lack of interest or pleasure in activities that one normally enjoys, plus at least four other symptoms, is also considered major depression. In the research literature, this kind of depression has been termed “depression without sadness” and many consider this presentation to be more typical of older adults than younger individuals.²

“Mental disorders, such as clinical depression, can rob older adults of their capacity to age successfully.”

In addition to having at least one of the two cardinal symptoms above, someone must also experience at least four of the symptoms listed below to be diagnosed with major depression:

- Diminished or increased appetite, often leading to weight loss or gain;
- Sleeping difficulties, such as insomnia or sleeping too much;
- Fatigue and/or loss of energy;
- Feelings of worthlessness or excessive or inappropriate guilt;
- Difficulty thinking, concentrating or focusing;
- Noticeable restlessness or slowness of movement arising from mental tension or mood;
- Recurrent thoughts of death or of suicide (not including fear of dying or thinking about mortality as a result of growing older).³

2. Dysthymia

Dysthymia is a type of clinical depression in which someone experiences fewer depression symptoms than in major depression, but over a relatively long period of time. Unlike major depression, in which someone might experience “depression without sadness,” a diagnosis of dysthymia always includes having a persistently depressed mood, most of the day, nearly every day, for at least two years. In addition to depressed mood, a person with a diagnosis of dysthymia must

also experience at least two, but no more than four, of the symptoms below:

- Diminished appetite or overeating
- Difficulty sleeping or oversleeping
- Fatigue and/or low energy
- Poor self-esteem
- Difficulty concentrating or making decisions
- Hopelessness⁴

3. Minor or Subsyndromal Depression

Minor depression, also known as *subsyndromal* or *subclinical depression*, is not yet a type of depression that can be formally diagnosed using the current edition of the *Diagnostic and Statistical Manual of Mental Disorders (DSM)*, the diagnostic guide used by medical and mental health professionals. However, the research literature on depression increasingly has identified this disorder as a subtype of depression, and it may warrant diagnosis in future editions of the *DSM*.

In research, minor depression occurs as at least two, but fewer than five, symptoms of depression for at least two weeks. Like major depression and dysthymia, minor depression usually includes having a depressed mood or a loss of interest or pleasure in activities normally enjoyed. The major difference between minor depression and major depression is that minor depression has fewer symptoms; the major difference between minor depression and dysthymia is that minor depression often occurs episodically, rather than as a chronic problem lasting at least two years, as dysthymia does. Despite the lower number or duration of symptoms, minor depression can cause significant distress and some researchers believe that it may be a precursor to more severe forms of depression.⁵

B. The Epidemiology of Clinical Depression

In our work with older adults and their providers, we often hear people ask questions such as, “Isn’t it normal for people to be depressed when they get old?” or “I’m eighty years old, and I have health problems and I can’t do what I used to be able to do—doesn’t it make sense that I’m depressed?” All too often, older adults and the people who work with them are quick to assume that depression is a normal function of the aging process; unfortunately, this assumption may delay or prevent timely diagnosis and treatment of depression.

Clinical depression is a mood disorder that affects approximately 16.5% of the adult population in their lifetimes,⁶ with approximately 6.7% of adults affected in any 12-month time span.⁷ Unfortunately,

many people in our society equate aging with depression, and assume that older adults are, by virtue of their age, psychologically frail. Older adults and their practitioners often assume that the prevalence of clinical depression increases with age, but epidemiological research finds that this is not the case. In fact, the prevalence of depression seems to decrease with age. For example, recent data from the Substance Abuse and Mental Health Services Administration’s National Survey on Drug Use and Health indicates that in 2008, the 12-month prevalence for adults 50 years and older was 4.5%, compared to 8.7% for adults aged 18-25 and 7.4% for adults aged 26-49.⁸ Additionally, a number of studies document that among community-dwelling older adults, the prevalence of depression ranges from 1%-4%.⁹

1. Risk Factors for Depression

While older adults, by and large, do not experience clinical depression more frequently than younger individuals, the development of depression among older adults may be influenced by a variety of risk factors that are particularly germane to this group. It is likely that depression arises within a complex array of biological, psychosocial, and socioeconomic risk factors. These include:

- Chronic physical illness (such as cardiovascular disease, diabetes, arthritis)
- Sensory impairment (vision or hearing loss)
- Mobility impairment
- Functional disability (decreased ability to perform tasks of daily living)
- Relationship loss
- Loss of social status (particularly important in our culture, which does not esteem older adults)
- Past or recent traumatic experiences
- Lack of social and/or emotional support
- Lower income status
- Lower educational attainment

2. Depression and Suicide

If clinical depression occurs less often among older adults, why should we be so concerned about it? The short answer is that in addition to worsening medical outcomes and decreasing quality of life, clinical depression kills. Older adults have the highest risk of suicide of any age group. Older adults who have depression are more at risk of death by suicide than either their peers who do not have depression or the general population.¹⁰ Older adults, though they comprise less than

13% of the population, complete 16% of all suicides.¹¹ It is estimated that thoughts about suicide are estimated to occur among 5-10% of the general population of older adults.¹²

The risk factors that are associated with suicide include, but are not limited to:

- Older age (suicide risk goes up with age)
- Ethnicity (Caucasian older adults complete suicide at a higher rate than other ethnicities)
- Gender (older men complete suicide at a much higher rate than older women)
- Death of a spouse or partner
- Living alone and/or social isolation
- Chronic medical co-morbidities

In addition to suicide, depression can also increase an older adult's risk for financial exploitation and fraud.

C. Treatment Options for Older Adults

The good news about depression is that effective treatments are available and can benefit older adults significantly. The two major types of treatment for depression include various types of psychotherapy and antidepressant medications. Though both types of treatment may be used alone, the optimal treatment for clinical depression is a combination of psychotherapy and medications. A study of older adults with major depression found that up to 90% of those who did not receive treatment experienced subsequent depressive episodes; a relapse rate of 43% was observed in older adults who received antidepressants alone and the lowest relapse rate of 20% was found in older adults who were treated with both psychotherapy and medications.¹³

The most effective forms of psychotherapy for older adults with depression include cognitive-behavioral therapy (CBT), problem solving therapy (PST) and interpersonal psychotherapy (IPT). CBT and PST help older adults with depression to identify the negative and/or distorted ways of thinking that contribute to depressed mood as well as to focus on solving concrete life difficulties that may be contributing to or exacerbating depression. IPT focuses on relationship difficulties that may be underlying depressive symptoms. In general, older adults achieve the same symptom-reduction benefits from antidepressant medications as the general population. Older adults may benefit from a variety of classes of antidepressant medications, but the exact medication best suited to a particular older adult needs to be determined by a number of factors, including current health status, other medications currently being used and other clinical considerations.

D. Where to Go for Help

Older adults seeking an evaluation for and treatment of depression have several options. One is to visit a primary care physician, who can identify any medical conditions that may be contributing to or causing depression symptoms, and who may be able to screen for and provide a diagnosis of clinical depression. Whenever possible, however, it is generally best to refer older adults to geriatric mental health specialists, as many primary care doctors lack the time and training to adequately address the needs of older adults with clinical depression.

"[W]ith treatment and support, recovery from depression, and healthy aging, are possible!"

To find a geriatric psychiatrist who is a member of the American Association for Geriatric Psychiatry, you can use the search engine found on the Geriatric Mental Health Foundation's website at <http://www.gmh-fonline.org/gmhf/find.asp>. Additionally, older adults and their families can find psychiatrists and other mental health providers who accept Medicare at www.medicare.gov. Another source of information about providers is the National Suicide Prevention Lifeline (1-800-273-TALK), a national network of crisis intervention centers who can link callers to local practitioners in their community.

Depression is a serious illness, and can drastically decrease an older adult's ability to age successfully. But with treatment and support, recovery from depression, and healthy aging, are possible!

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Jacquelin Berman received her MSW and PhD in Social Work from Columbia University. As Director of Research at the New York City Department for the Aging (DFTA), she has overseen a range of research and demonstration projects. She is the co-author, with Lisa Furst, of *Depressed Older Adults: Education and Screening*. Dr. Berman is currently the Principal Investigator for a federally funded grant through the Administration on Aging infusing mental health programming in an evidence-based chronic disease program (CDSMP). Dr. Berman recently completed the Elder Abuse Prevalence Study in New York State (the first of its kind in the United States), where she was co-Principal Investigator.

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Funding a Special Needs Trust: How Much Is Enough?

By Craig Marcott

Your client is trying to plan for the future of their special needs child and wants to make certain that he or she will be financially secure after the parent(s) is gone. You are in the process of creating the necessary legal documents including a special needs trust. The client then asks you how much should the trust be funded with? How much is enough?



Many parents have already addressed this question without considering the impact of their decision. They may have defaulted to an equal division of their estate among their children, without considering whether an equal division is, in fact, equitable. This approach often occurs as a result of wanting to be “fair” to all of their children in combination, with a lack of understanding of the potential future costs of providing their special needs child with the opportunity to live the fullest life possible. In other words, the parents may be inadvertently denying their special needs child the same opportunity that they wish for their other children.

A. Preliminary Considerations

The decision-making process should begin by determining how much is actually required to properly fund the trust. For purposes of our discussion, let’s assume that the parents are planning to fund a third-party special needs trust. In order to begin to determine how much should be placed into the trust, they need to:

1. Identify the Short-Term, Intermediate, and Long-Term Costs of Services for Their Special Needs Child

What are the additional support costs that are incurred on an annual basis? What supplemental expenses can be foreseen—both in the near future and down the road as their child matures? Medical and dental expenses? Vacations? Will their child be traveling to visit siblings or other family members? Will they need a traveling companion? What about computers, college, hobbies, etc.?

2. Consider Their Child’s Future Living Arrangements

Do they anticipate some type of independent living, or perhaps a group home? Will they need to purchase or rent residential property? Parents who expect their

child to live in a group home arrangement often underestimate the costs of providing for the “extras” that contribute to a full life. They believe that the government will provide for all, or nearly all, of the child’s needs. Parents often fail to take into account such things as significant events (e.g. 40th and 50th birthday parties), travel (and travel companions), family traditions, and future medical needs.

3. Determine Whether the Special Needs Trust Will Need to Pay a Trustee to Manage Trust Assets

Will an advocate be required? If so, how much will that cost?

4. Perform a Capital Needs Analysis

A dollar will be worth only a fraction of its current value 30 or 40 years from now. Parents—or a professional advisor—will need to do a capital needs analysis to determine the present value of money required for the short-term, intermediate and long-term goals they have identified.

5. Plan for a Longer Life Span

Longevity is increasing at a phenomenal rate, both for the disabled and non-disabled populations. We now plan for people to live into their nineties. Fifty years ago, people with Down Syndrome had a life expectancy of less than 40 years. Now the average life expectancy is 57. With technological and medical advances on a nearly vertical slope, we can expect this trend to continue, which means that parents have to plan for providing for their special needs child for a longer time period.

6. Consider How Life Will Change for Their Disabled Child and His Siblings After the Parents Are Gone

Families are living farther apart geographically, even globally. If parents want their disabled child to visit his or her siblings, they may need to provide for that in their trust. Many changes occur as we get older, and particularly after the death of the last parent.

7. Identify and Maximize Government Benefits Such as Supplemental Security Income (SSI) and Social Security Disability Income (SSDI)

These benefits can help offset some of the costs and expenses outlined above.

Looking ahead, there will be more people competing for fewer resources. The disabled population in general has greater health care needs. If parents want their

special needs child to continue to have access to choice in health care, they need to plan to finance access to that care; otherwise choice is going to be restricted.

B. Funding Strategies

It quickly becomes apparent that there is no simple formula for calculating the amount needed to fund a special needs trust. To do so requires a comprehensive approach that incorporates both legal and financial factors, as well as government benefits. Anything less is a piecemeal solution to a complex problem.

There are certain strategies for funding a special needs trust. Numerous articles have been written about the tax consequences of using qualified (tax-deferred) assets such as 401(k)s, 403(b)s, and traditional IRAs to fund the special needs trust. While these usually represent one of the two largest components of a person's estate—the other being their home—they are not the most desirable assets to use to fund the trust.

The home also has its disadvantages, one of them being its lack of liquidity. A poor market climate at the time of death of the last remaining parent could result in a trust funded with a lesser amount than was anticipated. A mortgage on the home may result in other issues that would need to be addressed.

C. Life Insurance Considerations

Cash equivalents such as savings and checking accounts and CDs are reasonable investments, but they usually comprise a relatively small portion of the estate. This leaves us with life insurance, which, not being subject to ordinary income tax, often makes it the preferable method for funding a special needs trust.

Most attorneys are aware that a second-to-die insurance policy is usually the least expensive way to fund a special needs trust. This type of policy also has several additional advantages. First, it is available to divorced parents and parents who have never married. Second, if one of the parents has medical issues, the policy may still be underwritten since the policy only pays out upon the death of the second spouse. The disadvantage of this type of policy is that there is no payment of death benefit upon the death of the first spouse, so the family's situation needs to be evaluated so as to best determine how their needs can be met. It should be noted that a new life insurance policy that addresses this issue has recently been approved in New York.

More confusion seems to arise regarding the use of whole life vs. guaranteed Universal Life (UL) insurance. Each type of insurance has its proponents. Those in favor of whole life will often point out that it builds up a

cash value which can be used to eventually pay the premiums, therefore reducing the chance of a lapsed policy.

Let's take a closer look at this argument. Assume that a 40-year-old male is trying to decide between purchasing a whole life policy and a guaranteed UL to fund his child's special needs trust. Let's assume he will receive a preferred rating. Using one of the major insurance carriers, a \$1 million death benefit (DB) will require an annual premium of approximately \$13,500. It will be 15 years before there is enough cash value in the policy to pay the annual premium under the "current assumptions." These assumptions are not guaranteed.

A UL policy providing the same DB can be purchased for approximately \$5,500 per year. Of course, that must be paid over the individual's entire lifetime. However, he can, if he wishes, arrange to pay the entire policy cost over 15 years with an annual premium of slightly less than \$10,000. The advantage is that this DB and associated premiums are not based on assumptions, but instead are guaranteed.

Proponents of whole life insurance will point out, and rightly so, that there is no cash value build-up in the guaranteed UL. But what happens if and when the policy owner seeks to access the cash value in the whole life policy? A withdrawal of cash value is a loan, and therefore reduces the DB. This may have advantages for certain individuals with wealth. But if our primary objective is to fund the special needs trust, this defeats our purpose, which is to adequately fund the trust and provide financial security for the future of a child with special needs. In addition, many families with special needs children have less income, more medical expenses, and a greater need for permanent insurance. The additional cost of whole life insurance often translates into a reduced DB to fund the special needs trust.

Developing a cash flow projection which reflects income and expenses over a couple's lifetime is extremely helpful when attempting to determine what is affordable. It also allows a planner to see how different sources of income such as SSI or SSDI, as well as major events such as retirement, will affect future projections.

On a final note, parents should always plan conservatively. In order to provide their child with the opportunity to achieve his or her greatest potential, they must first establish a safety net. This means planning for the worst. They must provide the financial security necessary to allow their child to fail, if he or she is to ultimately succeed. Using a comprehensive approach will help them avoid gaps in their planning and give them a better chance of properly funding the special needs trust for their special needs child.

Craig Marcott has been a Certified Financial Planner™ Professional for 20 years. He is also a Special Needs Consultant and helps parents make certain that their special needs child has the opportunity to achieve his greatest potential. He is guardian of his brother Scott, who has Down syndrome. Mr. Marcott currently serves on the Board of Directors of the Financial Planning Association and is associated with numerous other agencies such as the Suffolk and Nassau chapters of the Association for the Help of Retarded Children, the Long Island

Family Support Services Advisory Council, the National Down Syndrome Congress and Gerontology Professionals of Long Island. Mr. Marcott is also a professional speaker and has appeared before groups such as the New York State Office For People With Developmental Disabilities (OPWDD), Parent To Parent of New York State, The Annual Awareness Conference, BOCES (Eastern and Western Suffolk), Family Residences & Essential Enterprises, and numerous other agencies and school districts.

NYSBA Guidelines for Obtaining MCLE Credit for Writing

Under New York's Mandatory CLE Rule, MCLE credits may be earned for legal research-based writing, directed to an attorney audience. This might take the form of an article for a periodical, or work on a book. The applicable portion of the MCLE Rule, at Part 1500.22(h), states:

Credit may be earned for legal research-based writing upon application to the CLE Board, provided the activity (i) produced material published or to be published in the form of an article, chapter or book written, in whole or in substantial part, by the applicant, and (ii) contributed substantially to the continuing legal education of the applicant and other attorneys. Authorship of articles for general circulation, newspapers or magazines directed to a non-lawyer audience does not qualify for CLE credit. Allocation of credit of jointly authored publications should be divided between or among the joint authors to reflect the proportional effort devoted to the research and writing of the publication.

Further explanation of this portion of the rule is provided in the regulations and guidelines that pertain to the rule. At section 3.c.9 of those regulations and guidelines, one finds the specific criteria and procedure for earning credits for writing. In brief, they are as follows:

- The writing must be such that it contributes substantially to the continuing legal education of the author and other attorneys;
- it must be published or accepted for publication;
- it must have been written in whole or in substantial part by the applicant;

- one credit is given for each hour of research or writing, up to a maximum of 12 credits;
- a maximum of 12 credit hours may be earned for writing in any one reporting cycle;
- articles written for general circulation, newspapers and magazines directed at nonlawyer audiences do not qualify for credit;
- only writings published or accepted for publication after January 1, 1998 can be used to earn credits;
- credit (a maximum of 12) can be earned for updates and revisions of materials previously granted credit within any one reporting cycle;
- no credit can be earned for editing such writings;
- allocation of credit for jointly authored publications shall be divided between or among the joint authors to reflect the proportional effort devoted to the research or writing of the publication;
- only attorneys admitted more than 24 months may earn credits for writing.

In order to receive credit, the applicant must send a copy of the writing to the New York State Continuing Legal Education Board, 25 Beaver Street, 8th Floor, New York, NY 10004. A completed application should be sent with the materials (the application form can be downloaded from the Unified Court System's Web site, at this address: www.courts.state.ny.us/mcle.htm (click on "Publication Credit Application" near the bottom of the page)). After review of the application and materials, the Board will notify the applicant by first-class mail of its decision and the number of credits earned.

Choice Brings Enhanced Lives for People with Developmental Disabilities

By Susan Platkin

I have two daughters. My 24-year-old daughter Ruth loves sports, playing monopoly, and parties. She works at Walgreens; when her supervisor transferred to another store she requested that Ruth come with her. Ruth has volunteered over 1,000 hours at a nursing home, where she wheels patients to their therapies, and has helped out at a pre-school, where she tutored a 4-year-old who was having difficulty learning his letters.



She grocery shops, (carefully checking ads for coupons and sales), and prepares meals. Some days she goes to the library, buys stamps at the post office, or picks up food for the cats. Sports are her passion; she plays basketball and soccer, runs 5k races, and swims.

My other 24-year-old daughter has diagnoses of intellectual disability and bipolar disorder. In high school, she frequently had to be removed from her classroom because of screaming, cursing, or other disruptive behaviors. Out of school now, she needs to have someone with her constantly, as her understanding of the world is limited, and her judgment is poor.

Although these sound like 2 different individuals, I have but one 24-year-old daughter, Ruth. The rich life Ruth has now as an employee, friend, and contributing member of her community can be largely attributed to the Office of People with Developmental Disabilities' (OPWDD) self-determination program, Consolidated Supports and Services (CSS).

CSS is funded through the Medicaid Home and Community Based Waiver (HCBS) 1915(c) waiver. Implemented in New York in 1991, the program "waives" usual Medicaid requirements and gives states the ability to use Medicaid funding to support people in communities instead of institutions.

Eligibility for HCBS 1915(c) waiver services in New York State requires:

- Developmental disability (see below)
- Eligibility for intermediate care facilities for people with mental retardation (ICF/MR) level of care

- Medicaid enrollment
- Individual living in their own or family's home, Family Care Home, Individual Residential Alternative, or a Community Residence
- Availability of services (not an entitlement)

The definition of "developmental disability" in New York State is found in subdivision 22 of section 1.03 of the Mental Hygiene Law, as amended by Chapter 269 of the Laws of 1990. The most recent amendment of this law was enacted on July 31, 2002.

"The rich life Ruth has now as an employee, friend, and contributing member of her community can be largely attributed to the Office of People with Developmental Disabilities' self-determination program, Consolidated Supports and Services."

Developmental disability means a disability of a person which:

- (1) is attributable to mental retardation, cerebral palsy, epilepsy, neurological impairment, familial dysautonomia or autism;
 - (2) is attributable to any other condition of a person found to be closely related to mental retardation because such condition results in similar impairment of general intellectual functioning or adaptive behavior to that of mentally retarded persons or requires treatment and services similar to those required for such person; or
 - (3) is attributable to dyslexia resulting from a disability described in subparagraph (1) or (2) of this paragraph;
- (b) originates before such person attains age twenty-two;
 - (c) has continued or can be expected to continue indefinitely; and

- (d) constitutes a substantial handicap to such person's ability to function normally in society.

Therefore, CSS is funded similarly to traditional day and residential services. However, because CSS participants are given both employer and budget authority over their funds, they are able, with the help of family, friends, and chosen professionals, to control choices as large as where and with whom to live, work, and play, and as small as what to make for dinner and when to get up on Sunday morning. Unfortunately, these choices that we take for granted have been, and often continue to be, denied to people with developmental disabilities.

Self-determination for people with developmental disabilities was first piloted on a large scale in 1996 through a grant by the Robert Wood Johnson Foundation to 18 states. A study of the project results by the Center for Outcome Analysis showed not only increased participant satisfaction, but also lower costs, important in these tough economic times.¹

What are the benefits of self-determination? People's everyday lives reflect who they are as individuals. David (the names are changed), who is a night owl and loves airplanes, works the midnight to eight AM shift at an airport, with the one-to-one support he needs. Jane, who loves to sing, hires a graduate voice student for support, and gets voice coaching thrown in. Mark's dream was to be a deejay, but is thrilled to have a paid job at a local rock station. Three young women live together in an apartment, each with their own day support, sharing evening and night staff. None of these outcomes would be possible without the flexibility and control that self-directed services provide.

More advantages? When my daughter has a difficult day, we can adapt her schedule, without losing necessary staff support. If she loses a job, instead of sitting at home, as would happen with traditional supported employment, her staff will work with her to find a new one. If someone working with her is not a good fit, we can hire someone who is better suited to her. This level of flexibility is helpful for anyone, but critical for people with complex needs.

Last week I was in a store with Ruth when an elderly man came up to us and greeted her by name; he looked at me a bit suspiciously. It turned out he was the owner of a local restaurant where my daughter had

frequently eaten with one of her support staff. I have no doubt that if he saw my daughter being yelled at, or led out of the store unwillingly, he would have checked to see what was going on. As a parent, this meeting reassured me that others are looking out for my child.

How do people access self-determination in New York State? Currently, "the waiver is designed to afford every participant (or the participant's representative) the opportunity to elect to direct waiver services...."² Each Developmental Disabilities Service Office has a liaison for CSS; just call your local office. Of note, OP-WDD is beginning a five year plan to subsume 1915(c) Waiver services under an 1115 Research and Demonstration Waiver. However, indications are that self-directed services will still be an option.

In reality I have two daughters. Both have jobs they love, passionate interests, and friends, and both give back to their communities. One has achieved her successes the conventional way, while the other has achieved hers through self-determination, funded through the Medicaid Waiver.

For further information on self-determination, see the NY Self-Determination Coalition website at www.nyseldf.org.

Endnotes

1. James W. Conroy et al, *Outcomes of the Robert Wood Johnson Foundation's National Initiative on Self-Determination for Persons with Developmental Disabilities*, Center for Outcome Analysis (2002), available at <http://www.outcomeanalysis.com/DL/pubs/RWJ-SD-Final-Report.PDF>.
2. Application for 1915(c) HCBS Waiver: NY.0238.R04.00 - Oct 01, 2009. Appendix E: Participant Direction of Services, E-1: Overview (3 of 13), available at <https://www.cms.gov/MedicaidStWaivProgDemoPGI/MWDL/itemdetail.asp?filterType=none&filterByDID=-99&sortByDID=2&sortOrder=ascending&itemID=CMS1229194&intNumPerPage=10>.

Susan Platkin, M.D., is a founding member of the New York Self-Determination Coalition, an ad hoc group of parents and professionals dedicated to promoting self-determination for persons with developmental disabilities. She also serves on the Board of Directors of New York State Parent to Parent. Over the past 20 years she has advocated on both state and local levels for the inclusion of children and adults with disabilities in their schools and communities.

U.S. Holders of, and Signers on, Foreign Accounts Beware: FBAR Filing Obligations Clarified and Expanded in 2011 Final Regulations

By Elizabeth A. Whalen

Any U.S. person who has a financial interest in, or signatory or other authority over, one or more “financial accounts” maintained with a financial institution in a foreign country is required to file Form TD F 90.22-1, “Report of Foreign Bank and Financial Accounts” (by June 30th of the following year) if the aggregate amount in all such accounts exceeds U.S. \$10,000 at any time during the year.¹ Commonly known as the “FBAR” form, this filing obligation first came to the attention of the U.S. public in 2008 in connection with the widespread publicity received by the U.S. Department of Justice’s prosecution of UBS AG for conspiring to defraud the United States by impeding the Internal Revenue Service (IRS). The IRS’s subsequent release of the October 2008 revised Form TD F 90.22-1 with instructions greatly expanding the filing requirements caused an uproar among tax professionals, as the revisions imposed filing obligations in many instances where practitioners generally had not considered the FBAR obligation to apply.² The IRS’s subsequent issuance of informal (and often conflicting) advice “clarifying” the October 2008 form instructions created even further confusion.³



Clarity is much needed in this area since the potential penalties for failing to file a required FBAR, or for omitting a properly reportable account from a filed FBAR, can be quite severe. Willful violations may result in criminal penalties that include both monetary fines and prison terms.⁴ Civil penalties for failure to file (or omission) also are severe: a willful failure may result in a penalty measured as the greater of \$100,000 or 50% of each unreported account balance at the time of the violation, for each year the failure continues; and, starting with the 2004 FBAR, even a nonwillful failure may result in penalties of up to \$10,000 for each unreported account.⁵

On February 23, 2011, Treasury’s Financial Crimes Enforcement Network (FinCEN) released final regulations amending certain FBAR reporting requirements (Final Regulations).⁶ The Final Regulations became effective March 28, 2011 for FBAR forms that are required to be filed on June 30th, 2011 and all subsequent

calendar years. Although they fail to incorporate many of the comments submitted in response to the issuance of the proposed regulations, the Final Regulations do clarify a number of previously unresolved issues and provide some relief from a few overly burdensome requirements. In addition, a number of recent IRS pronouncements have further clarified the filing requirements. This article describes these clarifications within the broader context of explaining the FBAR filing obligations commonly seen in an elder care practice.⁷

A. “U.S. Person”

Only “U.S. persons” must file FBARs. A U.S. person is defined as a U.S. citizen or resident, or an entity (even if disregarded for tax purposes) created, organized or formed under the laws of the United States, any state thereof, the District of Columbia, U.S. Territories and Insular Possessions (Guam, Puerto Rico, the Virgin Islands) or the Indian Tribes.⁸ Residency is determined under Code Section 7701(b)⁹ but requires using the definition of U.S. described in the previous sentence, and is defined without regard to elections under treaties or paragraphs (g) or (h) of Code Section 6013. A person may establish non-residency only by proving that he neither holds a green card nor meets the Code Section 7701(b)(3) substantial presence test, and has not made an election to file jointly with a U.S. spouse under Code Section 7701(b)(4).

B “Financial Interest in, or Signatory or Other Authority Over”

A U.S. person has a financial interest in any account as to which he is the owner of record or holds legal title (whether or not the account is maintained in whole or part for his benefit, or solely for the benefit of others); and any account maintained for his benefit as which the owner of record or holder of legal title is a person acting as an agent, nominee, attorney or in some other representative capacity with respect to the U.S. person.¹⁰ If an account is maintained in the name of more than one person, each U.S. person in whose name the account is maintained has a financial interest in that account. A U.S. person also has a financial interest in accounts outside of the U.S. owned (or where legal title is held) by certain entities if he owns (directly or indirectly) more than 50 percent of the following entities owning or holding legal title to such account: 1) the voting power or total value of shares of a corporation; 2) the interest in profits or capital of a partnership;

and 3) the voting power, total value of equity or assets, or interest in profits of any other such entity.¹¹

Where a trust (or an entity owned by a trust) is the owner of record or holds legal title to a foreign account, up to four different classes of trust parties potentially have a reportable financial interest in such account requiring an FBAR filing each year: 1) U.S. trustees; 2) the trust (if created under “U.S.” law); 3) a U.S. person who is the grantor and has an ownership interest in the trust during the year (as determined under Code Sections 671–679); and 4) any U.S. person who has a present beneficial interest in more than 50 percent of the assets or from which such person receives more than 50 percent of the income.¹² (The measure used to determine “income” is not defined: trust accounting income? DNI?). Discretionary beneficiaries are not required to file based solely on their discretionary status, and remainder interests do not meet the “present beneficial interest” standard. If the trust itself or the trustee or other fiduciary is a U.S. person and files an FBAR disclosing the trust’s foreign financial accounts, the trust beneficiaries are not required to file for that year.¹³ The rule requiring any trust with a U.S. protector to file first introduced in the 2008 amended FBAR instructions, was not included in the Final Regulations in response to public comments. Finally, an anti-avoidance rule applies to entities created to evade the FBAR filing requirements, unless a good faith effort is made to comply with the FBAR rules.¹⁴

“Signature or other authority” is defined as “the authority of an individual (alone or in conjunction with another) to control the disposition of money, funds or other assets held in a financial account by direct communication (whether in writing or otherwise) to the person with whom the financial account is maintained.”¹⁵ Authority to trade the assets in the account does not, without more, give rise to a filing obligation.¹⁶ Officers and employees of publicly traded entities, their subsidiaries, or whose securities (or ADRs) are registered under section 12(g) of the Securities Exchange Act (applicable to companies having more than \$10 million in assets and 500 or more shareholders), and of banks and other financial institutions that are registered with and/or audited by certain U.S. government agencies are expressly exempt from filing provided they have no financial interest in the accounts they have signatory authority over.¹⁷

Perhaps the most commonly overlooked document in the estate planner’s arsenal precipitating FBAR filing obligations is the power of attorney, as these customarily are prepared as part of the standard estate planning package. This practice predates the time that the legal community received notice that they may have FBAR consequences. As further discussed below, granting another access to a foreign safety deposit box causes that box to become a reportable financial account for FBAR

purposes, even if such power has never been utilized. Holding a power of attorney over foreign accounts constitutes signatory authority and triggers a filing obligation, even though the agent has no financial interest in the account at the time the power is granted, may never have such an interest and may never actually exercise his rights under the power.¹⁸

The Final Regulations’ addition of the “present beneficial interest” language required to trigger a trust beneficiary filing is very welcome since it eliminates the burden for beneficiaries with conditional future rights that may never mature. Unfortunately, however, a similar carve out was not added to the signatory authority provisions of the Final Regulations. Thus, although the holder of a power of attorney may not consider his rights under the instrument “currently exercisable” while the grantor is still vital and in charge of his own affairs, the standard form of power is in fact “currently exercisable” at the time it is executed unless the power expressly provides for a condition to action by the holder.

C. “Financial Account”

To rise to the level of an “account,” a formal relationship to provide “regular services, dealings and other financial transactions” must be established; merely “conducting transactions such as wiring money or purchasing a money order” does not rise to the level of an account where no relationship is otherwise in place.¹⁹ The term applies to accounts that are obviously financial accounts (i.e., all accounts maintained with foreign financial institutions outside of the U.S.) as well as some assets not generally thought of in that manner (such as a safety deposit box, regardless of the contents, if any person other than the owner has the power to access it, whether or not previously utilized).

Thus, accounts such as savings, checking, demand or time deposits (CDs) and any other account maintained with a person engaged in the banking business are reportable accounts, as are all “securities accounts” (accounts with any person engaged in the business of buying, selling, holding or trading stock and other securities). The term also includes any account that is an insurance or annuity policy with a cash value, even if no distributions are made;²⁰ any account with a person that acts as a broker or dealer for futures or options transactions in any commodity on or subject to the rules of a commodity association or exchange; any account with a person engaged in the business of accepting deposits as a financial agency; any mutual fund or similar pooled fund which issues shares available to the general public that are subject to regular determination of net asset value and redemption; and “other investment funds” (undefined, but hedge funds, venture capital funds and private equity funds specifically are exempted).²¹

Whether or not an account is subject to income tax has no relevance in determining whether it is reportable for FBAR purposes. Accordingly, interests in foreign pension funds and other foreign tax exempt defined benefit and contribution retirement funds must be reported, despite their similarity to IRAs and Roth IRAs.²² Conversely, interests in U.S. pension funds and retirement plans are not reportable by the participant/beneficiary even if they hold primarily foreign assets.²³ These plans themselves are required to file FBARs on their own behalf to report the foreign accounts held.

D. "Financial Institution in a Foreign Country"

A foreign country is any country other than those included in the definition of United States described above for purposes of determining who is a U.S. person.²⁴ Both the account and the financial institution itself must be outside of the U.S. An account held in the U.S. branch of a foreign bank or securities firm is not a reportable account; nor is an account maintained with a U.S. bank acting as custodian for assets outside of the U.S., provided that the custodial arrangement does not permit the U.S. person to directly access foreign assets in foreign financial institutions (i.e., an omnibus account).²⁵

E. Other Matters for Fiduciaries

The Final Regulations also clarify a number of technical matters in connection with FBAR reporting and required recordkeeping. Practitioners acting as or advising trustees of trusts holding foreign accounts (and other signatories) should take note that the Final Regulations did not eliminate the requirement that U.S. persons with signature authority over more than 25 accounts include the identity of all U.S. persons with a financial interest in the accounts. Public comments that such requirement imposed a greater recordkeeping burden on parties with no financial interest in such accounts than it did on the account beneficial owners apparently did not persuade FinCEN.

Another recent development affecting the FBAR obligations of trustees and other "signatory authority only" filers (who have no financial interest in the foreign accounts required to be reported) was the June 16, 2011 issuance of Notice 2011-54.²⁶ The Notice extends by another four months (until November 1, 2011) the deadline for filing 2009 and earlier FBARs required solely by virtue of such signatory authority, which were previously deferred under Notice 2009-62²⁷ and/or Notice 2010-23.²⁸ Notice 2011-54 does not alter the June 30, 2011 deadline for 2010 FBAR filings by such persons, nor does it change the one-year extension (until June 30, 2012) to file FBARs granted in FinCEN Notice 2011-1 (May 31, 2011)²⁹ to certain individuals with signature authority over the accounts of their employer and/or affiliates, provided the employer or another member of its controlled group meets certain requirements.

Conclusion

Although the Final Regulations alleviate a few of the more onerous filing requirements circulated since 2008, they also expand the reach of the FBAR to assets not commonly thought of as "financial accounts." Practitioners will have to modify their general counsel to clients to encompass advice concerning the continuing nature of the FBAR obligation and the ongoing due diligence required on the part of trustees, holders of powers of attorney and other "signatory authority only" parties such as agents. Practitioners should also keep in mind that while IRS administers the FBAR review and penalty process, the FBAR form itself is not protected by Code-based confidentiality restrictions afforded to taxpayer data.³⁰

Advice concerning the FBAR form should be "When in doubt, file!" as the penalties for even mere oversight can be severe. There is very little guidance available to protect the nonfiler or those who file an FBAR but inadvertently fail to report accounts. The IRS's recent administration of the FBAR penalty process has been heavy-handed and not applauded for its reasonableness, as many practitioners learned to their chagrin during the 2009 Offshore Voluntary Disclosure Initiative.

Endnotes

1. 31 C.F.R. § 1010.306(c) (2011); 31 C.F.R. § 1010.350(a) (2011). The authority for the FBAR filing obligation is derived from 12 U.S.C. § 1829(b), §§ 1951–1959 and 31 U.S.C. §§ 5311–5314 and 5316–5332, otherwise known as the "Bank Secrecy Act" (BSA). The BSA authorized the Department of the Treasury to promulgate regulations and to establish recordkeeping and filing requirements. See 31 C.F.R. § 1010.100 (2011) et seq. Authority to administer the Final Regulations described in this article is found at 31 C.F.R. § 1010.810(g) (2011). References herein to the BSA are cited as "U.S.C.," and references to the relevant regulations thereunder as "31 C.F.R." to distinguish them from references to the Internal Revenue Code and regulations (see *infra* note 9).
2. For example, to single-member U.S. limited liability companies and other U.S. entities that are disregarded for tax purposes.
3. This informal advice was given during IRS telecasts with practitioners, on its website and dedicated phone line for FBAR guidance, and in statements made by IRS personnel published in newspaper and tax articles.
4. See 31 C.F.R. § 103.59 (2011).
5. See 31 C.F.R. § 5321(a)(5) and Internal Revenue Manual (IRM) 4.26.16.4.
6. Amendment to the Bank Secrecy Act Regulations – Reports of Foreign Financial Accounts, 76 Fed. Reg. 10,234, 10,235 (February 24, 2011).
7. As opposed to, e.g., a corporate business context.
8. 31 C.F.R. § 1010.350(b) (2011).
9. All "Section" references herein are to the Internal Revenue Code of 1986, as amended (the Code).
10. 31 C.F.R. § 1010.350(e) (2011).
11. *Id.*

12. 31 C.F.R. 1010.350(e)(2)(iv) (2011). The instructions accompanying the 2011 revised FBAR form paraphrase this requirement: “[a] greater than 50 percent present beneficial interest in the assets or income of the trust for the calendar year.” Perhaps the IRS, who administers for the FBAR form and instructions, concluded this wording was clearer than FinCEN’s Final Regulations language. The likely result of creating such a discrepancy is missed required FBAR filings notwithstanding the exercise of due diligence.
13. 31 C.F.R. § 1010.350(g) (2011).
14. 31 C.F.R. § 1010.350(e) (2011).
15. 31 C.F.R. § 1010.350(f) (2011).
16. Amendment to the Bank Secrecy Act Regulations– Reports of Foreign Financial Accounts, 76 Fed. Reg. 10,234, 10,235 (February 24, 2011).
17. Exemptions for certain persons having signature authority are set forth in 31 C.F.R. § 1010.350(f)(2) (2011).
18. FAQ 7, FAQs Regarding Report of Foreign Bank and Financial Accounts (FBAR) - Filing Requirements, <http://www.irs.gov/businesses/small/article/0,,id=210244,00.html> (last visited July 1, 2011).
19. 31 C.F.R. § 1010.350(c) (2011).
20. *Id.* The FBAR obligation is imposed on the policy owner, not the beneficiary (compare to rules for U.S. trusts).
21. 31 C.F.R. § 1010.350(g) (2011).
22. Q. 37 of IRS June 1, 2011 FBAR Webinar presentation.
23. 31 C.F.R. § 1010.350(g) (2011).
24. 31 C.F.R. § 1010.100(hhh) (2011).
25. *Cf. supra* note 18.
26. 2011FED ¶46396 (June 16, 2011).
27. 2009-35 I.R.B. 260 (August 31, 2009).
28. 2010-11 I.R.B. 441 (February 26, 2010).
29. As revised by FinCEN Notice 2011-2 (June 17, 2011).
30. *See* Code Section 6103.

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Palliative Care Information Act: A Social Perspective—What Candid Conversations Will Mean for You

By Amy Levine

On February 9, 2011, Albany enacted a law requiring physicians and nurse practitioners to offer terminally ill patients¹ information and counseling concerning palliative care and end-of-life options. An excerpt from the NY State Department of Health website reads:



Chapter 331 of the Laws of 2010 (commonly known as the Palliative Care Information Act) amends the Public Health Law by adding section 2997-c, which requires physicians and nurse practitioners to offer terminally-ill patients information and counseling concerning palliative care and end-of-life options. Under the law, information and counseling concerning palliative care and end-of-life options must be offered only to patients with an illness or condition that is reasonably expected to cause death within six months. Palliative care, as defined by the law, is “health care treatment, including interdisciplinary end-of-life care, and consultation with patients and family members, to prevent or relieve pain and suffering and to enhance the patient’s quality of life, including hospice care.”²

The law is intended to ensure that patients are fully informed of the options available to them when they are faced with a terminal illness or condition, so that they are empowered to make choices consistent with their goals for care, and wishes and beliefs, and to optimize their quality of life. The law is not intended to limit the options available to terminally ill patients. Nor is it intended to discourage conversations about palliative care with patients whose life expectancy exceeds six months. As discussed below, it is often appropriate to discuss palliative care with patients earlier in the disease progression.³

Tasks of Dying: Where Do You Fit In?

I will not be discussing the impact of this law in legal terms or your formal responsibility as a practitioner. I will, however, discuss the impact of this law in light of your contributions in assisting your aging clients with one of the end-of-life tasks—“wrapping up worldly affairs.” Dr. Ira Byock, a palliative care physician and others have identified tasks associated with this stage of life.⁴ The population that you may serve will, at some time or another, be facing a life-limiting illness and, in facing that realization that their lives are coming to an end, they will be seeking your expertise.

“You may be practiced in discussing the law, but perhaps not be as equally comfortable with conversations about dying.”

Ultimately, you may be viewed by your clients and their families as part of the continuum of end-of-life care. As clients and their families are engaged in candid conversations with their health care provider regarding their prognosis and treatment and service options, your client may be also engaged in conversations with you. The end-of-life conversations that begin in your client’s physician’s office may be continued in your office. You may be practiced in discussing the law, but perhaps not be as equally comfortable with conversations about dying.

Death-Defying Society

In my own observation with the current culture in the United States, as baby boomers inch their way to older age, our energy is primarily focused on what we can fix, such as looking younger. Although much is written about death and dying and the need for openness about death, much is also written on our denial of death and dying. A recent blog by a physician on usage of the word “expired” when a patient died rather than using the word “death” identified the physician’s levels of denial.⁵ We are often most comfortable focusing on what we can fix, and dying, ultimately, is not one of them. As a society, we have a low tolerance for feeling inadequate.

My own experience has taught me that candid conversations about life-limiting illness, dying, and death, are taboo subjects.⁶ In health care settings these candid conversations often happen after a physician “breaks the news,” but then it is the social worker, nurse or chaplain who is there to have the candid conversations with the patient. Often I have been called by a physician to “come now!” when a patient “wants to talk.” “Wants to talk” generally has meant expressing emotions around life-limiting illness and death, which many, but by no means all, physicians will avoid. Even patients are concerned about how their family and friends will respond. In my experience with patients that I have seen in hospice settings, I have met many who feel hesitant to share their diagnosis and prognosis with family and friends, stating, “I don’t want them to feel uncomfortable.”

As someone who works in end-of-life care, I experience the resistance to discussing these subjects in the reactions of my friends and family, and in social situations. The word “hospice” is a conversation stopper. In essence, the message is “Don’t talk about it!” At home, around the dinner table, in response to the perfunctory “How was your day?” I have been met with moans from the family asking “Do you really have to bring that up now!” In social situations, in response to “What do you do?” my straightforward response “I work in hospice” is most often met with “How nice!” and then the listener is off to get a drink, never to return.

Practice Overcoming Avoidance of this Taboo Subject

The less often we engage in conversations on the subject of dying, the more inadequate we feel about our ability to have these conversations. We want to say something that will fix it, and change the reality, and when that cannot be achieved we might stay silent because we do not want to cause harm. We have been practicing avoidance.

As a result of living in a society that denies death, we simply do not get practice in what to say. We do not share our experiences around serious illness and dying. We do not get the chance to develop language as we have for nearly all other life experiences. We have conversations about birth, adolescence, first dates, marriages, and the list goes on. Similarly, we need to practice talking about the unavoidable process of dying.

The Palliative Care Information Act marks a shift in our society’s discourse on the subject of life-limiting illness. In mandating medical personnel to have these conversations, the new law challenges all of us to ac-

knowledge the final stage of life. You may experience a rise in conversations around end-of life-issues that find their way into your daily life. The prevalence of these conversations may ultimately lead you to develop the ability to find the words.

Dying is a painful subject for most and that will not change. The challenge will be everyone’s challenge as this discourse shift occurs. Key to achieving a level of comfort with these discussions is the understanding of your own level of discomfort around the subject.⁷ This awareness will prepare you in responding to a client who may be grappling with a terminal illness. Your awareness of the law may provide you with an opportunity to encourage your clients to pursue their questions and concerns with their physician, a social worker, a nurse or another member of their health care team. Ultimately, this new law will force us all to face our unavoidable vulnerability and feelings of inadequacy in the face of death.

Endnotes

1. Palliative Care Information Act, NY CLS Pub Health § 2997-c (2011).
2. *Id.*
3. *Id.*
4. Ira Byock, M.D., *Working Set of Landmarks and Developmental Taskwork*, DyingWell.org, <http://www.dyingwell.org/landmarks.htm> (last visited July 7, 2011).
5. Danielle Ofri, M.D., *Doctors and the ‘D’ Word*, The New York Times Well Blog (May 26, 2011, 1:02PM), <http://well.blogs.nytimes.com/2011/05/26/doctors-and-the-d-word>.
6. Michael Kearl, *Typologizing Cultural Orientations to Death*, Guide to the Sociology of Death: Death Across Space and Time, <http://www.trinity.edu/MKEARL/death-1.html> (last visited July 7, 2011).
7. Amy Levine Consulting, <http://amylevineconsulting.com> (last visited July 7, 2011).

Amy Levine is the Director of the Doula to Accompany and Comfort program of the JBFCS in New York City. The Doula to Accompany and Comfort program trains, supervises and places volunteers who visit people with a life expectancy of 18 months or less. Amy Levine is also a consultant providing professional training and consultation for health care providers on end of life conversations, and develops end of life programming. Ms. Levine has extensive experience in hospice and served as the Clinical Supervisor of a Princeton, New Jersey psychiatric counseling program for older adults. She received her Master’s degree in Social Work from New York University.

Personal Care at Home and the Americans with Disabilities Act: How Much Care Is Enough, and Who Decides?

On January 11, 2011, the U.S. Attorney for the Southern District of New York filed a complaint against The City of New York alleging that the City committed fraud on Medicaid by improperly authorizing 24-hour, community-based personal care services, and that it disregarded the rules requiring that doctors, nurses, and social workers make recommendations regarding enrolling consumers in home care.

On August 12, 2011, New York Lawyers for the Public Interest, Legal Services New York City, Self-Help Community Services, Inc. and Cardozo Bet Tzedek Legal Services joined numerous other national, state, and local advocacy organizations, and organizations that work in New York State and elsewhere to ensure that public benefits programs are designed and operated in

a manner that complies with the Americans with Disabilities Act, filed an *Amicus Curiae* Memorandum of Law in Support of the City’s pending Motion for Summary Judgment. This Memorandum is included in this issue because it provides a very comprehensive review of the laws, rules, regulations, cases and fair hearings that concern compliance with Title II of the Americans with Disabilities Act of 1990, which requires the City to provide services to Medicaid-eligible individuals with disabilities in the most integrated setting as required by *Olmstead v. LC ex rel. Zimring*, 527 U.S. 581, 600-602 (1999).

The City’s Motion for Summary Judgment and the list of signatories to the *Amicus* brief are available at <http://wnylc.com/health/news>.

UNITED STATES DISTRICT COURT SOUTHERN DISTRICT OF NEW YORK

-----X
UNITED STATES OF AMERICA ex rel., :
DR. GABRIEL FELDMAN, :
 :
Plaintiff, :
v. :
 :
THE CITY OF NEW YORK, :
 :
Defendant. :
-----X

Civil No. 09 Civ. 8381 (JSR)
ECF Case

-----X
UNITED STATES OF AMERICA, :
 :
Plaintiff, :
v. :
 :
THE CITY OF NEW YORK, :
 :
Defendant. :
-----X

MEMORANDUM OF LAW OF *AMICUS CURIAE* IN SUPPORT OF THE CITY OF NEW YORK'S MOTION FOR SUMMARY JUDGMENT

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INTRODUCTION AND SUMMARY OF ARGUMENT

Amici are national, state, and local advocacy organizations representing people with disabilities who need Medicaid long-term care services, and organizations that work in New York State and elsewhere to ensure that public benefits programs are designed and operated in a manner that complies with the Americans with Disabilities Act ["ADA"]. *See*, *Interests of Amici*, annexed as Appendix. We urge this Court to consider the interests and rights of those Medicaid recipients who, though not before this Court as parties, will be the most impacted by the resolution of this litigation. This population is comprised largely of elderly persons and people with disabilities for whom access to 24-hour Medicaid personal care services ["PCS"] is vital to enable them to avoid institutionalization and remain in their homes.

The plaintiff United States ["the Government"] claims that New York City ["the City"] has unlawfully authorized PCS. The Government does not allege that the City filed false claims by granting personal care to people who were not poor enough to qualify for Medicaid, or who did not need Medicaid services. Instead, the Government claims that, for the small number of PCS recipients whose mental and physical disabilities are so severe that they undisputedly need

extensive personal assistance,¹ the City has unlawfully provided that assistance, even though the alternative to doing so would have been to provide those same services in a nursing home, rather than in the recipient's own home in the community. The Government also claims that in a small number of cases the City authorized too much care for some people with undisputedly severe disabilities. *Amici* write to demonstrate to the Court that the City's granting of these benefits was not a "false claim," because they were required by the ADA, the Rehabilitation Act of 1973, and state-level administrative and judicial determinations regarding the administration of the PCS program. And finally, *amici* write to correct the Government's suggestion that nursing homes provide individuals such as those profiled in the Complaint with a "higher level of care" than is provided by PCS in the home setting.

In making determinations regarding the authorization of PCS, the City must comply with state and federal Medicaid law and regulations, including technical recordkeeping and procedural requirements. *See* 18 NYCRR 505.14. The City must also comply with Title II of the Americans with Disabilities Act of 1990² ["ADA"], which requires the City to provide services to Medicaid-eligible individuals with disabilities in the most integrated setting. *Olmstead v. LC ex rel. Zimring*, 527 U.S. 581, 600-602 (1999); *D.A.I. v. Paterson*, 653 F.

Supp. 2d 184, 187 (E.D.N.Y. 2009). Finally, the City must comply with a large body of judicial and administrative precedent governing the administration of the PCS program developed over decades of litigation and administrative review. To impose financial sanctions on the City for the small number of cases in which decision makers erred, if at all, on the side of maintaining vulnerable people in the community rather than sending them to nursing homes, sends a destructive message to state Medicaid programs nationwide and threatens to undermine clear national policy favoring integration.

Since the *Olmstead* decision, federal policy has increasingly encouraged states to “rebalance” their Medicaid long-term care services toward community-based services, reduce reliance on institutional settings, and to administer all their Medicaid programs in light of *Olmstead*’s mandate to provide services in the most integrated setting possible. A decision that subjects the City to sanctions unless it blindly defers to the Local Medical Director would lead to illegal reductions and denials of personal care services. The inevitable result would be increased institutionalization, a result diametrically opposed to the ADA’s integration mandate and clear national policy.

I. The Americans with Disabilities Act Mandates the Authorization of Personal Care Services that Prevent Institutionalization of Eligible Medicaid Beneficiaries

A. Olmstead Requires New York City to Provide Services in the “Most Integrated Setting”

The Government never acknowledges that the inevitable result of denying 24-hour care to individuals with extensive needs is increased institutionalization, which implicates the ADA. In the landmark decision of *Olmstead v. L.C.*, 527 U.S. 581, 600-02 (1999), the United States Supreme Court held that Title II of the ADA prohibits a government entity from causing the “unnecessary segregation” of people with disabilities by providing services in institutions when those individuals can receive services in a community-based setting. This obligation may be excused only where the public entity demonstrates that the requested modifications would “fundamentally alter” its service system or result in an undue financial or administrative burden. The Supreme Court’s opinion was based in part upon a regulation implementing the ADA that requires states and other government entities to administer services in the “most integrated setting appropriate to the needs of the qualified individuals with disabilities.” 28 C.F.R. § 35.130(d). The preamble to the ADA states, “Historically, society has tended to isolate and segregate individuals with disabilities, and, despite some improvements, such forms of discrimination against in-

dividuals with disabilities continue to be a serious and pervasive social problem;” 42 U.S.C. § 12101(2). Courts interpreting the ADA in the years since *Olmstead* have repeatedly recognized that a governmental entity’s failure to provide services to a qualified person in a community-based setting violates the ADA. *See, e.g., Fisher v. Oklahoma Health Care Auth.*, 335 F.3d 1175, 1181-82 (10th Cir. 2003); *D.A.I. v. Paterson*, 653 F. Supp. 2d 184, 187 (E.D.N.Y. 2009); *Brantley v. Maxwell-Jolley*, 656 F. Supp. 2d 1161 (N.D. Cal. 2009); *Peter B. v. Sanford*, C.A. No. 6:10-cv-00767-JMC, 2011 WL 824584 (D.S.C. Mar. 7, 2011) (adopting report and recommendation of Magistrate Judge reported at 2010 WL 5912259 (D.S.C.); *Pitts v. Greenstein*, Civil Action No. 10-635-JJB-SR, 2011 WL 2193398 (M.D. La. June 6, 2011).

The provision of Medicaid PCS enables individuals to receive their Medicaid services in the most integrated setting.³ For this reason, courts have enjoined cuts to existing Medicaid programs that provide services to allow individuals to remain in community-based settings. *See, e.g., Fisher*, 335 F.3d at 1175; *Brantley*, 656 F. Supp. 2d at 1161; *Cota v. Maxwell-Jolly*, 688 F. Supp. 2d 980, 994 (N.D. Cal. 2010) (granting injunction against law that would heighten requirements for in-home care, in part on theory that it would lead to unnecessary institutionalization in violation of *Olmstead*); *Peter B.*, 2011 WL at 824584; *Marlo M. ex rel. Parris v. Cansler*, 679 F.Supp.2d 635(E.D.N.C. 2010); *Pitts*, 2011 WL at 2193398; *Crabtree v. Goetz*, No. Civ. A. 3:08-0939, 2008 WL 5330506 (M.D. Tenn. Dec. 19, 2008).

Even the threat of institutionalization may constitute a harm serious enough to warrant granting preliminary injunctive relief against proposed cuts to home care and personal care programs. *See Pitts*, 2011 WL at 2193398. In recent policy guidance about enforcement of *Olmstead*, the United States Department of Justice Civil Rights Division opined,

...[T]he ADA and the *Olmstead* decision extend to persons at serious risk of institutionalization or segregation and are not limited to individuals currently in institutional or other segregated settings. Individuals need not wait until the harm of institutionalization or segregation occurs or is imminent. For example, a plaintiff could show sufficient risk of institutionalization to make out an *Olmstead* violation if a public entity’s failure to provide community services or its cut to such services will likely cause a decline in health, safety, or welfare that would lead to the individual’s eventual placement in an institution.⁴

In New York State, *Olmstead* was applied to enjoin the state “fiscal assessment law,”⁵ which generally barred authorization of 24-hour “split-shift” Medicaid PCS, based on their cost exceeding a limit set by the same statute. The Court held that application of the law would have resulted in unnecessary nursing home placements and therefore enjoined the law’s enforcement, pending a remand to the State to establish the “fundamental alteration” defense to the ADA claim. *Sanon v. Wing*, No. 403296/98, 2000 N.Y. Misc. LEXIS 139, at *5 (Supreme Court, N.Y. Co. Feb. 25, 2000).⁶ The *Sanon* court ruled that:

...[New York City and State R]espondents must address the requirements of the ADA in considering the provision of services. Unless respondents can demonstrate that accommodating Medicaid recipients who otherwise qualify for 24-hour home care would result in a fundamental alteration in the Medicaid program, respondents must provide services in “the most integrated setting appropriate to the needs of” petitioners. 28 CFR 35.130(d)....

Id. The state “fiscal assessment” statute expired under a sunset clause before the government respondents conducted the ADA fundamental-alteration analysis. See *supra* n. 5. In other cases, courts have ruled that costs to the public entity are not the only factor in evaluating a fundamental alteration defense, and that a “a state defendant cannot rely on budgetary constraints alone as the basis for a fundamental alteration defense.” *V.L. v. Wagner*, 669 F.Supp.2d 1106, 1122 (N.D. Cal. 2009) (enjoining California from implementing cuts to In-Home Supportive Services program); see also *Pa. Protection & Advocacy, Inc. v. Pennsylvania Dep’t of Pub. Welfare*, 402 F.3d 374, 380 (3rd Cir. 2005); *Townsend v. Quasim*, 328 F.3d 511, 520 (9th Cir. 2003).

B. New York’s City’s Personal Care Services Program Furthers Federal Policy by Reducing the Institutional Bias in Medicaid Spending

The *Olmstead* decision has brought about a sweeping change in national long-term care policy. Motivated in part by *Olmstead*, and by the *Olmstead*-consistent philosophy of maximizing independence, both Congress and federal agencies have acted to increase access to Medicaid home- and community-based services [“HCBS”]⁷ for persons in need of long-term care.⁸ Most recently, the Patient Protection and Affordable Care Act of 2010⁹ [“PPACA”] further expanded state opportunities to provide services in the community to Medicaid beneficiaries needing long term care.¹⁰

Despite this progress, nationally and in New York State, however, the provision of long-term care services remains slanted unduly toward institutionalization.¹¹ In 2009, the Medicaid expenditures for nursing home care in New York State amounted to \$6.8 billion, serving an average 90,701 Medicaid recipients per month, compared to \$2.5 billion spent on PCS, serving an average of 71,199 recipients per month.¹² With nearly three times as many Medicaid dollars spent on institutional care for only 27 percent more people than received PCS, New York reflects the national bias toward institutionalization. New York City, however, where reliance on nursing home care is significantly less than it is in the rest of the state, deviates from the institutional bias in Medicaid spending. In its recent report on Medicaid PCS usage in New York City, the United Hospital Fund stated, “Personal care is a particularly substantial and important component of Medicaid long-term care service delivery and spending; 84 percent of Medicaid personal care spending statewide takes place in the city.”¹³ In comparison, only 53 percent of all nursing home spending statewide takes place in New York City, even though twice as many Medicaid recipients live in the City as the rest of the state.¹⁴ There is no doubt that the more robust PCS program in New York City, which includes 24-hour PCS availability, accounts for a higher ratio of community-based care in New York City.¹⁵

C. Medicaid Costs Would be the Same or Higher if Personal Care Services Were Denied or Terminated, Undermining the Assertion of “False Claims”

This is not a case where the Medicaid program has suffered a financial loss by virtue of services being provided to individuals who did not need them and qualify for them. The Government does not allege that patients A through G in the Amended Complaint did not need long-term care services. Rather, the complaint in essence asserts that the services should have been provided in a “higher level of care” setting, which, for persons with undisputedly extensive needs, amounts to nursing home care. Similarly, those patients who the Government claims should have received less than 24-hour daily care might well have required nursing home placement absent the provision of PCS because the inadequate hours would render it unsafe to remain home. Since the average monthly Medicaid payment for nursing home care in New York City is approximately \$7,500 per month,¹⁶ it is clear that, had funds not been expended on PCS, an equal or higher amount would have been expended on nursing home services for which the patients were undeniably eligible.

When weighing the cost to Medicaid of PCS versus nursing home care, one must include more than just the *per diem*, *per capita* cost. In considering whether the

ADA permitted the state to limit PCS services on the basis of cost, the *Sanon* court directed that the ADA analysis must include whether "... there are increased hospitalization costs incurred when people are placed in [nursing homes] compared to hospitalization for those receiving home care." *Sanon v. Wing, supra*. On that issue, a recent study found that average annual Medicaid spending *increased* after New York City Medicaid recipients stopped receiving Medicaid PCS.¹⁷ Annual inpatient hospital costs that averaged \$1,628 for individuals receiving PCS skyrocketed to \$5,568 after they stopped receiving personal care.¹⁸ As expected, skilled nursing facility (nursing home) costs also skyrocketed from an annual average of \$260 for the study cohort while they were receiving personal care to \$23,248 after PCS stopped. These high Medicaid costs following the cessation of Medicaid PCS refutes the Government's implicit assumption that the Government and taxpayers spent Medicaid dollars that would not otherwise have been spent in the absence of the City's authorization of PCS.

II. Nursing Homes Do Not Provide a "Higher Level of Care" Than Personal Care Services in the Individual's Home

The opinion of a Local Medical Director ("LMD"), such as Relator, that some PCS recipients are ineligible for PCS services and need to be placed in a nursing home (which the Government euphemistically refers to as a "higher level of care")¹⁹ is often reversed by the State after a fair hearing (see Point III, *infra*), and, if sustained, would likely violate the ADA. In fact, nursing homes do not generally provide a "higher level of care." In a nursing home, the individuals profiled in the Amended Complaint and thousands of other PCS recipients like them would receive the same unskilled "level" of services as the PCS they receive in their homes. However, because of limited staffing, nursing homes are less able to attend to each resident, and thus maintain his or her health and safety, than is the PCS attendant who assists only a single individual in the home.

While it is true that nursing homes *can* provide skilled nursing services, most nursing home residents neither need nor receive *skilled* services.²⁰ Rather, most residents need and receive only *unskilled* assistance with activities of daily living from nurse aides and feeding assistants, the same level of care that PCS aides provide in the homes of PCS recipients.²¹ The individuals profiled in the Amended Complaint and others like them may need a higher *amount* or number of PCS hours, but not a higher *level of care*.²²

Furthermore, with no meaningful minimum staffing requirements enacted on a state or federal level,²³ most nursing homes do not have sufficient staff to pro-

vide long-term custodial care and services of reasonable quality, and as such do not provide a "higher level of care." A 2010 study by the Kaiser Family Foundation found that limited on-site staffing contributed to a measurable increase in avoidable hospitalizations for long-term Medicaid nursing home residents.²⁴ In interviews, nursing home staff attested to their inability to provide adequate assistance to all the residents for whom they were responsible—sometimes 60 at a time—with resulting injuries to some residents. *Id.* In light of this testimony, it seems ironic that for "Patient C" profiled in the Amended Complaint, the LMD denied personal care services because of concern that the patient would be at risk "during the home attendant's bathroom breaks when she would be unsupervised." See First Amended Complaint ¶ 45. A number of reports show that, not only do nursing homes not provide a higher level of care, they also do not provide a higher quality of care or better health outcomes. A 2001 study conducted for CMS concluded that minimum staffing levels of 4.1 hours of direct nursing care (including professional nurses and nurse aides) per resident per day are needed to avoid "critical quality of care problems."²⁵ Studies indicate that between 92 and 97 percent of the nation's nursing homes reported staffing levels that did not meet these recommended staffing levels.²⁶ In addition, a 2000 government study concluded that over 50 percent of U.S. nursing homes would have to double current staffing levels to meet these minimally adequate staffing ratios.²⁷ With the correlation between the sufficiency of nursing home staff and the quality of nursing home care well established,²⁸ the enhanced quality of care available through the one-on-one care of a PCS aide is a logical corollary.

Oversight surveys also reveal significant deficiencies in nursing home care nationally and in New York.²⁹ The U.S. Government Accountability Office found that in 2007, nursing homes nationwide were cited for an average of 7.0 deficiencies per home, and almost 74 percent of nursing homes surveyed were cited for quality-of-care deficiencies, including improper care relating to "nutrition, hydration, pressure sores, activities of daily living, infection control practices, range of motion, vision, hearing, urinary incontinence, medications, psychosocial functioning, and ability to care for residents with specialized conditions...."³⁰ State Survey reports have indicated that 113 of New York's 657 nursing homes were cited for deficiencies that resulted in "actual harm or immediate jeopardy" to residents.³¹ At least part of these deficiencies likely stem from insufficient staffing.

The evidence indicates that nursing homes would provide neither a "higher level" of care nor care of a higher quality for the vast number of elderly and disabled Medicaid beneficiaries, including those identified

in the Amended Complaint. These individuals, who need frequent and regular unskilled assistance with the wide range of activities of daily living, can be safely maintained in their homes with adequate amounts of home care services. They are more likely to receive the assistance they need at the time that they need it—and in the setting they and their families prefer—if they receive care in their homes rather than in nursing homes.

III. The City Must Comply with a Body of Judicial and Administrative Precedent and Regulation in Authorizing Personal Care Services

The Government portrays the assessment of PCS as one in which the Relator, as the LMD, makes a final determination based solely on his or her medical opinion regarding an individual's functional needs and the hours of PCS needed. The reality is much more complex. A plethora of court decisions and settlements, as well as state and federal administrative precedent and guidance, provide additional layers of requirements to the assessment and authorization regulations. The Government absurdly suggests that the City must refuse to comply with administrative hearing decisions or policy directives issued by the State Department of Health, or even with federal court decisions, if they conflict with the LMD opinion. This is obviously not the case.

A. Due Process Rights, Codified in State Regulation, Prohibit the City from Terminating or Reducing Services on a "Re-authorization" Absent a Showing of Medical Improvement or Other Change in Circumstances

Much of the Government's claim alleges that the City unlawfully re-authorized ongoing services without conducting the series of assessments required under 18 NYCRR § 505.14(b). The mere fact that a particular nursing or other assessment was not completed, or cannot be located, is hardly proof that an individual was not eligible for continuing PCS services and that the City was engaged in fraud. On the contrary, in *Mayer v. Wing*, 922 F. Supp. 902 (S.D.N.Y. 1996), the federal district court granted a preliminary injunction and class certification finding that the City had engaged in a pattern of illegally reducing PCS during the periodic re-authorizations. The Court found that these reductions were arbitrary and capricious and violated due process, and enjoined the City from reducing hours on reauthorizations unless there was evidence of medical improvement or a change in circumstances. The *Mayer* provisions were subsequently promulgated as a regulation at 18 NYCRR 505.14(b)(5)(v).³²

The types of chronic medical conditions that afflict PCS recipients generally do not improve; rather, they

steadily worsen over time. See *UHF Report - 2010*, *supra* n. 13. Their functional need for assistance becomes greater as they age and develop other conditions. With medical conditions that are degenerative but medically stable, more than 40 percent of elderly "dual eligible" PCS recipients had been receiving PCS for at least seven years, and another 21 percent for between four and seven years. *Id.* at 3. Absent a major new medical event, the onset of a new diagnosis that in some way disqualifies the individual from eligibility, or a change in social circumstances that reduces the need for Medicaid-funded services (such as the new availability of a son or daughter to provide informal care), there are simply no grounds to reduce or discontinue services at a routine re-authorization. The fact that a particular LMD might believe that an individual previously authorized for a certain amount of services could do with less care—or now needs a "higher level of care"—would not alone justify a reduction or discontinuance under *Mayer*. The Complaint cites the absence of certain assessments in the City's files for Patients E and F as *per se* evidence that the City illegally re-authorized services. However, absent an adequate showing that the medical conditions or other circumstances of these individuals changed substantially, rendering them ineligible for services, there is simply no merit to the Government's allegation.

B. Eligibility Criteria for PCS Must be Applied According to State Guidance, Administrative Precedent, and the ADA

The City's assessment of whether an individual is eligible for PCS, or instead needs a so-called "higher level of care," most commonly referring to nursing home care, must comply with state guidance, administrative precedent, and ADA regulations. The state PCS regulations include essentially two eligibility criteria: first, that the medical condition be stable and not require the skilled care of a nurse or other professional,³³ and second, that the individual be "self-directing," or, if not mentally able to direct her own care, have someone else to direct the personal care aide and make decisions about daily activities.

On the second criterion, whether an individual is "self-directing," state guidance expressly lists behaviors of individuals who, though not self-directing, are nonetheless eligible for PCS as long as they have someone to direct their care:

...a. the recipient may be delusional, disoriented at times, have periods of agitation, or demonstrate other behavior which is inconsistent and unpredictable;

b. the recipient may have the tendency to wander during the day or night and

to endanger his or her physical safety through exposure to hot water, extreme cold, or misuse of equipment or appliances in the home; or

c. the recipient may exhibit other behaviors that are harmful to himself or to herself or to others such as hiding medications, taking medications without his or her physician's knowledge, refusing to seek assistance in a medical emergency, or leaving lit cigarettes unattended. The recipient may not understand what to do in a medical emergency or know how to summon assistance....

New York State Dep't. of Social Services, *Fiscal Assessment and Management of Personal Care Services*, Administrative Directive No. 92-ADM-49, p 5, available at http://onlineresources.wnyc.net/pb/docs/92_adm-49.pdf. The fact that this directive lists these behaviors as typical of people who are eligible for PCS if they have someone to direct their care, shows that the Relator and other LMDs err by citing these symptoms as reasons to infer the individual needs a "higher level of care" than PCS.³⁴

Far from approving PCS for people who are not eligible, the City frequently errs by denying eligibility for PCS based on finding that individuals do not meet PCS eligibility criteria. These determinations are frequently found to be erroneous by the New York State Department of Health ["SDOH"] in decisions after administrative hearings. As the final decision of the State agency, these decisions are binding under *stare decisis* principles. *Charles A. Field Delivery Service v. Roberts*, 66 N.Y.2d 516, 495 N.Y.S.2d 111 (1985); *Long v. Perales*, 568 N.Y.S.2d 657 (2d Dept. 1991). *Amici* have successfully represented hundreds of individuals in these "fair hearings," in which SDOH has specifically reversed LMD findings that the medical condition is not "stable," that the individual needs a higher level of care, or that PCS is "not appropriate."³⁵

The City's application of eligibility criteria for PCS must also comply with the ADA and its regulations, which provide, in part:

A public entity shall not impose or apply eligibility criteria that screen out or tend to screen out an individual with a disability or any class of individuals with disabilities from fully and equally enjoying any service, program, or activity, unless such criteria can be shown to be necessary for the provision of the service, program, or activity being offered.

28 C.F.R § 35.130(b)(8). Consistent with this non-discrimination requirement, the State has reversed City determinations denying care to individuals needing PCS due to mental, rather than physical impairments.³⁶ One-quarter of all PCS recipients—and 31 percent of "high intensity" recipients—have a mental health diagnosis; 22% of "high-intensity" PCS recipients have either dementia or Alzheimer's disease. *UHF Report - 2010*, supra n 13 at 8.

When the City determines whether health and safety can be reasonably maintained by PCS, it:

...must ensure that its safety requirements are based on actual risks, not on mere speculation, stereotypes, or generalizations about individuals with disabilities.

28 C.F.R § 35.130(h), published September 15, 2010. The LMDs' opinions finding PCS inappropriate must be rejected when based on such speculative generalizations. The City's denial of PCS based on the Relator's opinion that Patient C in the Government's complaint was ineligible based on her psychiatric condition, for example, would violate the ADA.³⁷

C. The City's Determinations Regarding the Number of Hours of PCS to Authorize are Governed by a Multitude of Court Decisions and Administrative Precedent and Guidance

The Government claims that the City unlawfully authorized 24-hour PCS when it ignored the LMD's findings that Patients A, B and D had no "excessive" or "compelling" night-time needs. The City's determinations, however, must accord with a complex web of court decisions, settlements, and administrative hearing precedent and guidance. If an LMD's determination to deny or reduce services conflicts with these authorities, and under these other authorities an individual is entitled to PCS services, the City is correct in authorizing or maintaining PCS. Moreover, given the requirements under *Olmstead* described above, the City's authorization of PCS services in difficult "borderline" cases which prevent unnecessary institutionalization cannot be illegal or "false claims."

City PCS authorizations must comply with a State Medicaid directive that requires the provision of PCS to ensure "...the appropriate monitoring of the patient while [the PCS aide is] providing assistance with the performance of a Level II personal care services task, such as transferring, toileting, or walking, to assure the task is being safely completed."³⁸ This directive was issued to address a pattern in which the City and other local districts were wrongfully denying PCS based on their conclusion that the individual needed only

“safety monitoring,” and not other PCS tasks. The State directive clarifies that PCS includes:

...the appropriate monitoring of the patient while providing assistance with the performance of a Level II personal care services task, such as transferring, toileting, or walking, to assure the task is being safely completed.

Id.

Numerous fair hearing decisions cite this directive as authority for reversing the City’s denials of PCS, and affirm that PCS is appropriate and necessary in the very instances in which the Relator would find the applicant needs a “higher level of care.”³⁹ For example, in Hearing No. 5304352Q, dated October 22, 2009, the State reversed the City’s decision relying on the Relator’s recommendation to deny services because the applicant needed “constant safety supervision to prevent further falls.” See, Declaration in Support of City’s Motion to Dismiss Complaint, Exhibit C, Document 26-3, Decision pp. 2, 8 (7 & 13 of 15). Citing GIS 03 MA/03, the decision concludes that “any safety supervision Appellant may require is ancillary to assistance with indoor ambulation.” See, *Id.* at 9 (14 of 15).⁴⁰

CONCLUSION

For the foregoing reasons, the reasons stated in the brief of the City, and any other reasons that may appear to this Court, the Government’s motion for summary judgment should be denied and the City’s motion for summary judgment should be granted.

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Respectfully submitted,
s/ David Silva

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Endnotes

1. Under state regulations, PCS may be authorized for an amount of time ranging from several hours per week to 24 hours of continuous care—known as “split shift”—seven days per week. See N. Y. COMP. CODES R. & REGS. tit 18, §§ 505.14 (a)(6)(i)(b) and (a)(3). Only 1,200—or three percent—of the 42,800 people receiving PCS in December 2007 received 24-hour “split-shift” Medicaid personal care in New York City, the highest amount of services available, while 49% of PCS recipients received fewer than 7 hours/day (49 hours/week). Alene Hokenstad, United Hospital Fund, *An Overview of Medicaid Long-Term Care Programs in New York* (2009) (Table 3.1 p. 9), available at <http://www.uhfnyc.org/publications/880507>. This proportion has reportedly not significantly changed. The small number signifies two things—that those needing split shift care are a small outlier group, and that the City rarely approves split-shift care. In fact, in the experience of *amici*, few people obtain it without going to a fair hearing held by the New York State Department of Health.
2. 42 U.S.C. § 12132.
3. The Center for Medicare & Medicaid Services (“CMS”), the federal agency administering the Medicaid program, has long recognized that PCS and other home care services are a critically important tool available to states to allow them to maintain individuals in the community and thus meet their obligation to provide services in the most integrated setting. See CMS, *Olmstead Update No. #3* (July 25, 2000), available at <http://www.cms.gov/smdl/downloads/smdl072500b.pdf> with other State Medicaid Director letters at <http://www.cms.gov/SMDL/SMD/list.asp>. In this letter, CMS (then HCFA), in clarifying for states that eligibility for home health services could not be limited to individuals who are homebound, stated that:

The restriction of home health services to persons who are homebound to the exclusion of other persons in need of these services ignores the consensus among health care professionals that community access is not only possible but desirable for individuals with disabilities. New developments in technology and service delivery have now made it possible for individuals with even the most severe disabilities to participate in a wide variety of activities in the community with appropriate supports. Further, ensuring that Medicaid is available to provide medically necessary home health services to persons in need of those services who are not homebound is an important part of our efforts to offer persons with disabilities services in the most integrated setting appropriate to their needs, in accordance with the Americans with Disabilities Act.
4. United States Department of Justice, *Statement of the U.S. Department of Justice on Enforcement of the Integration Mandate of Title II of the Americans with Disabilities Act and Olmstead v. L.C.* (June 22, 2010), available at http://www.ada.gov/olmstead/q&a_olmstead.htm.
5. N.Y. Soc. Serv. L. § 367-k, added L 1991, Ch. 165, § 23, eff. July 1, 1991, expired by a sunset clause July 1, 1999.
6. The statutory cost limit essentially prohibited 24-hour “split-shift” care, the same amount of service the Government challenges as excessive in the instant case.
7. The term “HCBS” is used in two ways—as the title for a specific group of Medicaid “waiver” services that provide community-based alternatives to institutional care, and more generically to describe a wide variety of community-based services funded by Medicaid as well as other payors. Medicaid PCS services are not “waiver” services but are one of many HCBS services in the generic sense. See U.S. Dept. of Health & Human Services, *Understanding Medicaid Home and Community Services: A Primer* (Oct. 2000) available at <http://aspe.hhs.gov/daltcp/reports/primer.htm>.
8. Beginning in 2000, Congress appropriated money for states to apply for Real Choice Systems Change Grants for Community Living. In the Deficit Reduction Act of 2005, Congress added the Money Follows the Person program to fund transitions out of nursing facilities, and the HCBS State Plan Benefit program to allow state Medicaid programs to more easily offer packages of HCBS. In the 2006 reauthorization of the Older Americans Act, Congress directed the Administration on Aging (AoA) and state aging agencies to reshape the long-term care delivery system to provide more HCBS. See Eric Carlson and Gene Coffey, National Senior Citizens Law Center, *10-Plus Years After the Olmstead Ruling – Progress, Problems and Opportunities* (2010) available at <http://tinyurl.com/olmstead-nsclc-report>. See also CMS *Olmstead Update No. #3*, *supra* n 3, as an example of federal guidance implementing *Olmstead*.
9. PPACA, Pub. L. No. 111-148.
10. The PPACA expanded the Money Follows the Person and the HCBS State Plan Benefit programs. It also initiated a Medicaid State Balancing Incentive Payments Program that will give states financial incentives to increase the percentage of persons who receive long term care services through HCBS rather than in nursing homes. The law also added a new service—the “Community First Choice Option”—to Medicaid’s menu of benefits. PPACA, Pub. L. No. 111-148.
11. In describing the *status quo* in 2010, Congress stated in enacting the PPACA, “Despite the...*Olmstead* decision, the long-term care provided to our Nation’s elderly and disabled has not improved. In fact, for many, it has gotten far worse.... Although every State has chosen to provide certain...[Medicaid] home and community-based [services]...these services are unevenly available within and across States, and reach a small percentage of eligible individuals.” Pub. L. No. 111-148, § 2406.
12. New York State Dep’t of Health, *Medicaid Expenditures for Selected Categories of Service by Category of Eligibility – 2009*, posted at http://www.health.state.ny.us/nysdoh/medstat/quarterly/aid/2009/cy/docs/2009_cy_aid.xls.
13. Sarah Samis, Michael Birnbaum, United Hospital Fund, *Medicaid Personal Care in New York City: Service Use and Spending Patterns* (2010), p. 1, available at <http://www.uhfnyc.org/publications/880720> [hereinafter “UHF Report—2010”].
14. 1.389 million Medicaid recipients live outside of NYC compared to 2.717 million in NYC. NYS Dep’t of Health, *Medicaid Eligibles & Expenditures*, available at http://www.health.state.ny.us/nysdoh/medstat/el2007/2007-cy_eligibles.xls (based on 2007, last complete year posted at <http://www.health.state.ny.us/nysdoh/medstat/medicaid.htm#table2>) (accessed August 5, 2011). \$3.59 billion was spent by Medicaid for nursing home care in NYC compared to \$3.16 billion elsewhere in New York State; *Id.* at http://www.health.state.ny.us/nysdoh/medstat/ex2007/cy_07_ex.xls (based on 2007 data).
15. The higher ratio of community-based care in New York City is further enhanced by the lower reliance in New York State on HCBS waiver services compared to other states, where there are significant waiting lists for these services. In 2009, 340,000 adults were on waiting lists for waiver services nationally, not one of whom was in New York State. Unlike PCS, which, as a service under the state Medicaid plan must be available to those determined eligible with no waiting list, states may have a waiting list for waiver services. Kaiser Family Foundation, *New York: Waiting Lists for Medicaid 1915(c) Home and Community-Based (HCBS) Waivers* (2009) posted at <http://www.statehealthfacts.org/profileind.jsp?rgn=34&cat=4&ind=247>.
16. Based on NYS Dep’t of Health, *New York State 2009 Nursing Home Rates*, posted at http://www.nyhealth.gov/facilities/long_term_care/reimbursement/docs/nursing_home_rates_2009.xls (calculated by taking average daily rate for

- all nursing homes in the five boroughs of New York City, excluding pediatric and AIDS/HIV rates, multiplying by 365, and dividing by 12).
17. See *UHF Report – 2010*, *supra* n. 13, p. 14, Table 13.
 18. This is all the more notable since this study solely concerned “dual eligibles,” those receiving both Medicaid and Medicare. *UHF Report – 2010*, *supra* n. 13, p. 2. For this population, Medicare is the primary payor of hospital costs. For those personal care recipients not included in this study, whose sole insurance is Medicaid—approximately 30 percent of this service population—these hospital costs would be significantly higher. *Id.*
 19. Nursing home care is the only alternative for most PCS recipients who have 24-hour per day needs. The “Lombardi” long-term home health care waiver program has a monthly cost cap with aide service limited to roughly 36 hours a week in New York City. N.Y. Soc. Serv. L. § 367-c; Hokenstad, United Hospital Fund *supra* at n 1. p. 9. “Beneficiaries may have to disenroll and seek services elsewhere if their needs increase above the threshold.” *Id.* Services by certified home health agencies, 18 N.Y.C.R.R. § 505.23, are primarily short-term visiting nurse and home health aide services following a hospital or rehabilitation stay. Long-term patients must be transferred to the PCS program within four weeks. N.Y. Soc. Serv. L. § 367-p. Managed long term care plans may authorize 24-hour care but average hours per week ranged from 32 to 50 in 2009 cost reports. N.Y. Pub. Health L. § 4403-f, amended L. 2011 Chapter 59, § 41; See *Personal Care Aide Utilization Comparison in Managed Long Term Care Plans in NYC* (4Q 2009), posted at <http://wnylc.com/health/download/258/>.
 20. Under the Medicaid program, a “nursing facility” provides nursing services and/or room and board and “physical care.” See 42 U.S.C. § 1396r; 42 C.F.R. § 483.10(c)(8)(i); N.Y. Pub. Health L. §§ 2801(2) and (4)(b); 10 N.Y.C.R.R. § 415.2(k). Medicaid services in a nursing facility may be provided by either registered or licensed nurses or certified nurse aides. See 42 C.F.R. § 483.30; 18 N.Y.C.R.R. § 505.9(e); 10 N.Y.C.R.R. § 505.9(e); 42 C.F.R. §§ 440.40, 409.31-409.33 with 42 C.F.R. § 440.167.
 21. Medicaid PCS are provided by a trained personal care aide acting under nursing supervision. See N.Y. Soc. Serv. L. § 356-a (2)(e); 18 N.Y.C.R.R. § 505.14 (d)(e) and (f).
 22. As in most cases involving individuals who have no skilled needs, but only require intensive assistance with activities of daily living, it appears that Patients D and E were safely maintained in their homes with 24-hour home care services for several years until the natural ends of their lives. See First Amended Complaint ¶¶ 49 and 50.
 23. See 42 CFR § 483.30(a) and (b); 10 N.Y.C.R.R. § 415.13(a) (2) and (b)(3)(generally requiring “sufficient” nursing staff and requiring [unless waived] that an RN be employed for a consecutive eight-hour shift, seven days a week, with one RN or LPN to serve as a charge nurse and requiring that facilities with an average occupancy of 61 or more residents also employ an RN as a full-time director of nursing).
 24. Michael Perry et al., The Henry J. Kaiser Family Foundation, *To Hospitalize or Not to Hospitalize? Medical Care for Long-Term Care Facility Residents* 3, 4 (2010) posted at <http://www.kff.org/medicare/8110.cfm>.
 25. U.S. Dep’t of Health and Human Services, Health Care Financing Administration, *Appropriateness of Minimum Nurse Staffing Ratios in Nursing Homes. Phase II Final Report to Congress* (December 2001) 3-30 - 3-31 [hereinafter “2001 Report to Congress”] (citing 4.1 - 4.65 mean total of nursing aides or 2.4-2.8 hours per resident per day). See also John F. Schnelle, et al., *Relationship of Nursing Home Staff to Quality of Care*, Health Services Research 39:2, 225-250, 248 (April 2004) (confirming correlation between nursing home staffing and quality of care, particularly for nurse aide staffing above 2.8 hours per resident per day).
 26. 2001 Report to Congress *supra* n 24, 3-30, 3-31 (stating that “... it would be predicted that homes that report 2.8 to 3.2 [nurse aide hours per resident per day]... would perform significantly better than all other homes in...[labor-intensive daily care activities, such as feeding assistance, toileting assistance, repositioning, and exercise care]); see also Schnelle et al., *supra* note 24, at 227.
 27. *Id.* at 227, citing U.S. Department of Health and Human Services, Health Care Financing Administration, Executive Summary, *Report to Congress: Appropriateness of Minimum Nurse Staffing Ratios in Nursing Homes* (2000).
 28. Inadequate staffing is associated with limited feeding assistance, poor skin care resulting in decubitus ulcers or bed sores, lower activity participation, and less toileting assistance, while increased staffing is positively associated with fewer decubitus ulcers, fewer catheterized residents, and fewer urinary tract infections. See W.D. Spector & H. A. Takada, *Characteristics of Nursing Facilities That Affect Resident Outcomes*, 3 Journal of Aging and Health 427-54 (1991). Insufficient staffing also contributes to low morale and frustration among employees, which further decreases their ability to effectively and respectfully address resident needs. U.S. Dep’t Health and Human Services Office of Inspector General, *Psychosocial Services in Skilled Nursing Facilities* OEI-02-01-00610 at i-ii (2003). Inadequate staffing also places residents of nursing homes at greater risk of falling compared with those in the community, increasing their risk for injury, loss of physical functioning, and loss of social interaction. Clemens Becker & Killian Rapp, *Fall Prevention in Nursing Homes*, 26 Clin. Geriatr. Med. 693, 693 (2010); Meg Butler et al., *The Risk of Hip Fracture in Older People from Private Homes and Institutions*, 25 Age and Ageing 381, 384 (1996). In addition, nursing home residents are also more vulnerable to depression. Namkee G. Choi et al., *Depression in Older Nursing Home Residents: The Influence of Nursing Home Environmental Stressors, Coping, and Acceptance of Group and Individual Therapy*, 12 Aging & Mental Health 536, 544 (2008); see also Namkee G. Choi et al., *Risk Factors and Intervention Programs for Depression in Nursing Home Residents: Nursing Home Staff Interview Findings*, 52 J. Gerontological Soc. Work 668, 682 (2009) (finding that nursing home staff attribute patients’ depressive symptoms to loss of autonomy and independence, social isolation, and loneliness).
 29. States monitor their own nursing homes by performing routine on-site “certification surveys” and on-site “complaint surveys” after complaints. The deficiencies found are categorized by both severity and by the perceived scope of the problem. NYS Dep’t of Health, *Detail of Certification and Complaint Survey in About Nursing Home Reports* (Oct. 2009) posted at http://www.health.state.ny.us/facilities/nursing/about_nursing_home_reports.htm#inspection. See, e.g., State Dep’t of Health, *Deficiency Details, Certification Survey, August 2009*, posted at http://nursinghomes.nyhealth.gov/nursing_homes/deficiency/629/RXCW (suggesting nursing home’s inability to assist individuals with severe dementia and/or aggressive behaviors); State Dept. of Health, *Deficiency Details, Complaint Survey, October 2010*, posted at http://nursinghomes.nyhealth.gov/nursing_homes/deficiency/629/7N2V/printable (issuing deficiency citation for failing to supervise resident with dementia and risk of falls who eloped from nursing home).
 30. CMS, *Trends in Nursing Home Deficiencies and Complaints*, Publication No. OEI-02-08-00140 at 6 (September 2008); See also NYS Dep’t of Health, *Deficiency Categories: Quality of Care in About Nursing Home Reports* (October 2009), available at http://www.health.state.ny.us/facilities/nursing/about_nursing_home_reports.htm#comdefqoc (Accessed May 2011).
 31. U.S. Government Accountability Office, *Nursing Homes: Federal Monitoring Surveys Demonstrate Continued Understatement of Serious Care Problems and CMS Oversight Weaknesses*, Publication No. GAO-08-517 at 32 (May 2008).

32. Similarly, in *Granato v. Bane*, 74 F.3d 406 (2d Cir. 1996), the district court held that PCS services could not be terminated without a pre-termination hearing after a temporary hospital stay, and required that an individual's PCS services must be reinstated upon discharge from the hospital, pending a hearing. The State DOH codified this holding in guidance issued as NYS Dept. of Health Local Comm'r. Mem. 99-OCC-LCM-2 (April 22, 1999) posted at <http://www.wnyc.com/pb/docs/99OCCLCM2.pdf>.
33. 18 N.Y.C.R.R. § 505.14(a)(4)(i)(c)(defining "stable" as "...not expected to exhibit sudden deterioration...and...does not require frequent medical or nursing judgment to determine changes in the...plan of care..." and not in need of "skilled professional care").
34. See, e.g., First Amended Complaint, ¶¶ 49-50 (referring to LMD's conclusion that patient D, who appears to have a daughter who directs her care, should receive a "higher level of care" and should no longer receive split shift PCS because she "is unable to direct care, has inappropriate judgment, wanders, is up all night, and has shown oven/stove misuse;" referring to LMD's determination that Patient E's split-shift PCS should be discontinued because her condition was "unstable," as she "threatened to jump from the window, and will turn the stove on").
35. *Amici* have compiled summaries of over 150 hearing decisions in which the State ordered the City to provide 24-hour split-shift care, or reversed determinations that individuals need a "higher level of care." See Selfhelp Community Services, Inc., *Medicaid Home Care Hearing Digest*, posted at <http://wnyc.com/health/file/106/> (see decisions coded as "SS" for split-shift and "HL" for "higher level of care"). Copies of any decisions cited in this memorandum of law are compiled and posted at <http://wnyc.com/health/download/259/>. In Hearing No. 5314839J (Sept. 18, 2009) (attached to Declaration in Support of City's Motion to Dismiss Complaint, Exhibit D, Docket entry 26-4 pp. 7-8 (11-12 of 13); also available at <http://wnyc.com/health/download/259/>), SDOH rejected the opinion of the LMD—known to be the Relator—that the medical condition of advanced cancer was "unstable" merely because it was terminal, since it was not expected to exhibit sudden deterioration or require frequent nursing judgment. In Hearing No. 5585727L (Nov. 1, 2010), available at http://www.otda.ny.gov/fair%20hearing%20images/2010-11/Redacted_5585727L.pdf and <http://wnyc.com/health/download/259/>, SDOH rejected the City's determination that the individual was not able to self-administer medication and wandered, so was ineligible for PCS).
36. In Hearing No. 5209193H (July 6, 2009), available at <http://wnyc.com/health/download/259/>, the State's reversal of the City's determination corrected a blatantly discriminatory denial of services based on the LMD's opinion that the applicant had no physical impairment. "The LMD incorrectly concluded that because the Appellant's medical condition (Alzheimer's) does not physically preclude the appellant from completing various personal care and chore tasks, the Appellant does not need assistance with and is independent for such tasks. On the contrary, as contended in...the medical request and the Agency's affiliation report, the Appellant, because of her neurological condition, is unable to perform or complete such tasks by herself."
37. The LMD determined that Patient C was "no longer appropriate" for PCS services because she "engages in self-endangering behavior" such as "getting out of bed without assistance" which had resulted in falls." First Amended Complaint ¶ 45.
38. NYS Dep't of Health, General Information System GIS 03 MA/003, *Rodriguez v. Novello*, Jan. 24, 2003 ["GIS 03 MA/003"], posted at http://www.health.state.ny.us/health_care/medicaid/publications/docs/gis/03ma003.pdf.
39. See, e.g., Hearing No. 5596164J (Jan. 10, 2011), available at http://www.otda.ny.gov/fair%20hearing%20images/2011-1/Redacted_5596164J.pdf and <http://wnyc.com/health/download/259/> (reversing denial of PCS based on an alleged need for a "higher level of care," citing GIS 03 MA/003, and ordering 8 hours/day, stating, "[t]he premise upon which the LMD and the nurse's assessment concluded that Appellant needs safety monitoring as a stand-alone function is puzzling, considering the totality of evidence presented at the hearing"; See also Hearing No. 5029256Z (August 5, 2008), available at <http://wnyc.com/health/download/259/>).
40. Another standard that would supersede a conflicting LMD opinion is the so-called "Mayer-3" rule prohibiting the use of "task-based assessment" for individuals who need 24-hour care, even if some of that care is provided by informal caregivers. The State agreed to codify this prohibition at 18 NYCRR 505.14(b)(5)(v)(d), in partial settlement of *Mayer v. Wing*, 922 F. Supp. 902 (S.D.N.Y. 1996), modified in part, unpublished Orders (May 20 and 21, 1996). Examples of fair hearing decisions reversing the City based on this standard include No. 5458362P (June 24, 2010)(ordering split-shift based on Mayer-3 and expressly rejecting the conclusion of the LMD—known by *amici* to be the Relator); and Hearing No. 4691096K (Feb. 6, 2007)(remanding to the City to assess whether appellant, who lives with daughter, is a Mayer-3 case); both available at <http://wnyc.com/health/download/259/>.

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Recent New York Cases

By Judith B. Raskin

Article 81: Penalty Period

Article 81 guardian argued that a three year look back should be applied to property transferred in 2005. Denied. No gift was made.¹

Mrs. Abrams deeded her house to a daughter, Marcia Abrams, in October, 2005 for no consideration, apparently for the purpose of protecting the property from Mrs. Abrams' son. In a subsequent proceeding to appoint an Article 81 guardian, Marcia Abrams was appointed personal needs guardian and another daughter, Dianne Roberts, was appointed property guardian. The parties entered into a stipulation to sell the house, pay off a reverse mortgage and put the net proceeds into a trust account for the benefit of Mrs. Abrams. When the uncertainty of ownership caused a problem with a potential sale, the court issued an order declaring Marcia Abrams the owner but additionally ordered that the net proceeds be held in trust for the benefit of Mrs. Abrams.

Subsequently, Mrs. Abrams moved to New Jersey to be with her daughters. They hired an attorney to transfer the guardianship to New Jersey and to prepare a Medicaid application for Mrs. Abrams who was then a nursing home resident. When filing her final account in New York, Marcia Abrams sought the court's confirmation that the proceeds from the property were not part of the final account as the property was owned by Marcia Abrams since 2005.

The Court held that the proceeds must be part of the accounting. The look-back period, three years in 2005, never commenced because a gift was never made. The Court had previously ordered that the transfer to Marcia Abrams was to protect the asset from mismanagement and waste and that the proceeds were to be held for Mrs. Abrams' benefit.

Probate: Undue Influence v. Duress

Named executor and sole beneficiary moved for summary judgment in action to set aside will. Denied on claim of duress. Granted for all other claims including undue influence.²

Decedent left a \$2.8M estate. The surviving co-executor grandnephew, who was also the sole beneficiary, submitted the will for probate. The will named him as contingent beneficiary but he became the sole beneficiary due to the prior deaths of the decedent's sisters. Four nieces and nephews contested the probate on several grounds including undue influence and duress. The proponent moved for summary judgment. His sis-



ter testified to the decedent's fear and distrust of the proponent. In considering the motion, the court extensively reviewed the evolving legal issues of undue influence and duress.

The court denied summary judgment on the claim of duress but granted it for all other claims including undue influence. It held that there was insufficient evi-

dence to support undue influence but it remained an issue of fact as to whether the decedent felt threatened by the proponent to the extent that she was afraid to make changes to her will.

Article 81: Attorney Fees

Attorney guardian sought legal fees for preparation of annual accounts. Denied.³

The court directed an attorney and Article 81 Guardian of the Property for Soledad P. to stop taking attorney fees for her preparation of the annual accounts without court approval. In response the attorney/guardian sought approval of her fees already taken and approval of an ongoing yearly fee to be taken without court approval.

The court denied the application, finding that the services for which the attorney sought fees were routine duties of a property guardian.

Article 81: Appointment

Brother petitioned for appointment as personal needs guardian where his children were remainder beneficiaries of the AIP's significant trust. Independent guardian appointed.⁴

Until the summer of 2010, the AIP's mother was her caregiver. Shortly after her mother's death, the AIP's brother left his Florida residence to stay temporarily in the AIP's basement apartment and oversee her care needs. The AIP had significant assets in a trust with her brother as trustee and his children as remainder beneficiaries. Brother petitioned for appointment as Article 81 personal needs guardian. His plan was to place his sister in a nursing home and sell her house.

The evidence and court evaluator's report detailed the AIP's need for assistance and supported keeping

her at home. A neighbor testified that brother was not fully addressing the AIP's needs and that he was protecting the trust assets for his children.

The court appointed an independent personal needs guardian. The AIP's brother had an interest adverse to that of his sister and if appointed could gain financially to his sister's detriment. The fact that his children were remaindermen did not in itself preclude his appointment but the court saw an actual conflict in this case.

Endnotes

1. *Matter of Abrams*, 921 N.Y.S.2d 485 (N.Y. Sup. Ct. 2011).
2. *Matter of Rasasco*, 31 Misc. 3d 1214(A) (N.Y. Sur. 2011).
3. *Matter of Soledad P.*, 90281-1994, NYLJ 1202493066135, at 1 (N.Y. Sup. Ct., Bronx, decided April 28, 2011).

4. *Application of A.M.*, 917XX10, NYLJ 1202493613803 (N.Y. Sup. Ct., Bronx, decided April 25, 2011).

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Advance Directive News: Topsy-Turvy Health Care Decision-Making

By Ellen G. Makofsky

Surrogate health care decision-making recently became a topsy-turvy event in *Matter of Zornow*, a Monroe County case.¹ Joan Zornow was a 93-year-old nursing home resident who suffered from advanced Alzheimer's disease. Mrs. Zornow never executed a health care proxy and a dispute arose among her seven children concerning a directive to withhold food and water. A son, Douglas Zornow, contended that his mother had verbally instructed him and other siblings that she did not want artificial nutrition and hydration if she were unable to orally ingest food and water.² Two successive Medical Orders for Life Sustaining Treatment ("MOLST") existed for Mrs. Zornow and indicated that artificial nutrition and hydration were not to be initiated and that Mrs. Zornow was not to be hospitalized unless she suffered from pain or severe symptoms which could not otherwise be controlled.³ Carole Zornow, a daughter, stated that her mother indicated a contrary wish by affirmatively requesting artificial feeding and that her mother repeated the direction to her nurse who then recorded the direction in the nursing facility's health care records.⁴ The dispute precipitated a guardianship proceeding whereby Carole Zornow sought the power to make end-of-life health care decisions for her mother.



The Court held that the statements made by Douglas Zornow and his siblings about Joan Zornow's wishes were "too vague, too general, not related to, and [were made] prior to any specific condition and, therefore, did not comply with the clear and convincing standards required by the Court of Appeals...."⁵ On the other hand, the Court found that the statement of Carole Zornow and the nursing home record which included the notation that her mother wanted to receive artificial nutrition and hydration met the clear and convincing standard. With this finding, Judge William P. Polito permanently revoked prior health care directives and the MOLSTs. Carole Zornow and Catholic Family Services were appointed as co-guardians.⁶

Mrs. Zornow lacked capacity, lacked a health care proxy and was a resident of a nursing home, so the

Court turned to the Family Health Care Decisions Act ("FHCDA") as the controlling statute in regard to surrogate health care decision-making. Pursuant to the FHCDA, a guardian is the prioritized person with the power to make medical decisions and the decisions must be made in accordance with the patient's wishes, which include the patient's religious and moral beliefs.⁷ The Court put great emphasis on the fact that Mrs. Zornow was a Catholic and determined that "the applicable principles to be applied to Mrs. Zornow's end-of-life decision [making] were those of her Roman Catholic religious belief."⁸ The Court stated that, "Mrs. Joan Zornow, a Roman Catholic, is obligated by her religious beliefs to continue to receive artificially administered food and water..."⁹ and directed the appointed co-guardians to consult with someone well trained in Catholic moral theology to make decisions on artificially administering food and water.¹⁰ The decision does not discuss or attempt to evaluate what Mrs. Zornow's personal wishes were in regard to artificial nutrition and hydration.

"In [the] topsy-turvy [Zornow] decision, individual wishes in regard to health care are dismissed and a straight and narrow Catholic position is the only acceptable path for a Catholic in need of surrogate medical decision-making. No meandering along the path of faith is permitted."

What the decision does do, in detailed page after detailed page, is to present the Catholic position on forgoing food and water. The Court rejects the idea that a Catholic may select "cafeteria Catholicism" and pick and choose which part of the faith to follow.¹¹ In this topsy-turvy decision, individual wishes in regard to health care are dismissed and a straight and narrow Catholic position is the only acceptable path for a Catholic in need of surrogate medical decision-making. No meandering along the path of faith is permitted.

So what does this mean? Are all health care wishes of practicing Catholics to be ignored by surrogate decision-makers where the incapacitated person's wishes do not comport with Catholic doctrine? Let's hope not.

Endnotes

1. *Matter of Zornow*, 31 Misc. 3d 450, 919 N.Y.S.273 (N.Y. Sup.Ct. Monroe Co., 2010).
2. *Id.* at 275.
3. *Id.* at 275. (The MOLSTs were executed on September 15, 2009 and September 18, 2009).
4. *Id.* at 275.
5. *Id.* at 275, citing *Matter of Westchester County Med Ctr*, 72 NY2d 517, 531 N.E.2d 607 (1988).
6. *Id.* at 275. The DNR was the only accepted health care directive which was not revoked by the Court.
7. N.Y. Pub. Health Law § 2994-d(4)(A)(i) (Consol. 2010).
8. *Id.* at 276.
9. *Id.*
10. *Id.*
11. *Id.* at 284.

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The NYSBA Family Health Care Decisions Act Information Center

The NYSBA Health Law Section has a web-based resource center designed to help New Yorkers understand and implement the Family Health Care Decisions Act—the law that allows family members to make critical health care and end-of-life decisions for patients who are unable to make their wishes known.

The screenshot shows the homepage of the NYSBA Family Health Care Decisions Act Information Center. At the top, there is a navigation bar with links: My NYSBA | Login | Join | Renew | Web Survey | FAQ | Online Store | About NYSBA | Contact | Site Map. Below this is the NYSBA logo and the text "NEW YORK STATE BAR ASSOCIATION Serving the legal profession and the community since 1876". A search bar is located on the right. On the left, there is a "MEMBER LOGIN" section with fields for "username" and "password", and a "Login" button. Below the login section is a "JOIN / RENEW" button. A sidebar on the left lists various resources: Home, My NYSBA, Blogs, CLE, Committees, Events, For Attorneys, and For the Community. The "For the Community" section is expanded, showing links to Client Rights and Responsibilities, Court Interpreters, Family Health Care Decisions Act Resource Center, Find Information About NY Attorneys, Free Legal Assistance, Servicios Legales Disponibles en su Comunidad, and Law, Youth & Citizenship Program. The main content area is titled "Family Health Care Decisions Act Information Center" and contains text explaining the FHCDA, its purpose, and a list of available resources including summaries, FAQs, and related laws.

www.nysba.org/fhcda

Guardianship News

By Robert Kruger

When writing about property management guardianship issues, I find that subjects are often recycled. For example, I have argued that the Part 36 income cap rules are driving the experienced practitioners out of the system, while fewer and fewer younger and less experienced practitioners appear to take their place.



I have noted how, once upon a time, guardians could be compensated for preparing annual accountings but now they are not. A recent opinion by Judge Howard Sherman of the Bronx County Supreme Court entitled *Matter of Soledad P.*, decided April 28, 2011, confirms this observation. *Soledad P.* involved a fiduciary who, without judicial approval, over many years, paid herself modest commissions and fees. The result was a sizeable surcharge. I have noted, as private practitioners are marginalized by the income cap rules and the caution of guardianship judges when they award fees, that there will likely be some effort made to create a public guardianship program or, at the very least, appoint not-for-profit agencies as Property Management Guardians. I suspect that it will then be discovered that the not-for-profit/public guardianship model is flawed, but for different reasons. There will be fewer scandals, although executives for not-for-profit corporations are not immune from the sin of avarice. The real problem will occur when the poorly paid and poorly trained social workers employed by these not-for-profit/public guardianship agencies screw up, as they inevitably will. This will happen because of the lack of knowledge, and unwillingness to acknowledge that experienced attorneys who are professional guardians actually know something of use to their wards and the families of the wards. The stories hitting the newspapers then will involve neglect and abuse, rather than financial mismanagement and self-dealing.

But that is for another day. Instead of focusing on property management issues, because of the repetitiveness with which those issues surface, I find myself drawn to the personal needs side of guardianship and the incredible difficulties that some wards and some families present. I have mentioned in prior discussions a ward named Teresa, for example. In particular, I have discussed that her father is a petty chiseler who attempts to appropriate, actually steal, small portions of

her estate. I have not discussed, however, the incredible range of personal needs problems that Teresa represents and what a management problem it is to simply keep her alive.

I was appointed her Property Management Guardian in 2003. At that time, Teresa presented as a 12-year-old developmentally delayed Special Education student who was legally blind and suffering from kidney failure (she already had a new kidney by the time I was appointed guardian). She had stunted growth and, though she was 12, she appeared to be 7. She had other medical issues as well, but the big ones were kidney failure, diabetes and blindness. She had (and has) a very effective social demeanor, and she appeared to function at a low-normal IQ range. Actually, she is far more impaired than that.

"Teresa['s]...father is a petty chiseler who attempts to appropriate, actually steal, small portions of her estate."

As time passed, I purchased a house for the guardianship and the family, consisting of her father, her sister (one year older than Teresa), her brother (one year younger than Teresa), and the father's significant others, reside there. At the outset, my most pressing challenge was to make certain that the father did not find a way to scheme his way into her funds. Initially, the guardianship was to last seven years, to be reviewed at that time because, as aforesaid, Teresa "presented" well. I was one of those who thought that the guardianship might indeed be terminated when she reached the age of 18 or 19. When the matter was reviewed by the court in mid-2009, to my surprise, Teresa agreed with me that her money should neither be returned to her nor be managed by her father. Had Teresa opposed the extension, all of us, the court included, would have genuflected and terminated the guardianship. Therefore, I continued as Property Management Guardian.

A sea change occurred in early 2010 when I received a phone call from a social worker at New York Presbyterian Hospital advising me that Teresa had been admitted and that she was threatening to commit suicide. I had never lost a ward in that manner and I had no intention of losing a ward now. As a family nominee, I did not need permission to hire other professionals. Therefore, I hired an excellent care manager to help determine what brought Teresa to threaten suicide.

I learned that Teresa had been going to the emergency room with increasing frequency and that her replacement kidney was failing. Within weeks, she restarted dialysis. On top of this, behaviorally, she was prone to violent tantrums and had, in a way, intimidated her family. Therefore, initially, we hoped the dialysis would result in fewer medical emergencies. But what did the threat of suicide mean? And the behavior? We had a learning curve of our own.

As her kidneys were failing, and as she started dialysis, adherence to an appropriate diet was essential. Foods with excessive sodium or sugar, or too much liquid intake, are deeply problematic for Teresa, as they are for other kidney failure patients. When Teresa was pitching a fit, she was demanding that her father buy her double cheeseburgers. Her stepmother was giving her orange juice. The family had no clue about dietary discipline and, because Teresa's tantrums often occurred in the midnight hours, the family was short of sleep and desperate to go back to bed and, quite simply, to shut Teresa up. Hence, she often got what she wanted rather than what she needed. To change this dynamic, I hired a companion recommended by the care manager. The companion would buy food that was appropriate for Teresa, but Teresa's younger brother would throw it out. We tried putting a lock on the refrigerator because Teresa's fluid intake was grossly excessive. The lock was broken. The family resented having a companion for Teresa, viewing her as a spy on the family, rather than as life support for Teresa. The dietary dysfunction was so pronounced that the number of times that Teresa was dialyzed increased from three times a week to six times a week. I am advised that a continuation of that regime could cause Teresa's premature death. It could absolutely cause repeat hospitalizations. Her health is so compromised that her life expectancy is not good (perhaps another four or five years), but the frequency of dialysis will shorten that already truncated life expectancy much sooner.

In a decision that was wholeheartedly supported by the care manager, I had determined that Teresa, if possible, should be removed from the house and placed in an environment where we could protect her. Note, as stated previously, Teresa owns a home. I was proposing to take Teresa (and not the family) out of the home that Teresa owned and find another place for her. Perhaps a group home, perhaps an apartment, but not her own home. My reasons for leaving the family in the home were practical ones. Evicting the family could take an unconscionable period of time, given that there were by now two small babies in the family along with the brother, sister, stepmother, and father.

I also obtained permission from the court to hire a colleague of mine, Lisa Friedman, because Lisa knows a tremendous amount about resources for the devel-

opmentally disabled population...certainly more than I do. I had hoped that we could find a group home for Teresa, but that was not going to happen quickly, and probably not at all. Teresa is medically unstable (the kidneys and the dialysis), she is blind, she is much more developmentally disabled than we initially thought...her IQ is probably between 50-60, rather than the 75 figure I had initially assumed. In addition to the complex medical issues she presents, she was throwing tantrums on a regular basis. She was going to be a behavioral handful and it was going to be difficult to find a residence that could accommodate her dialysis, her blindness, her intellectual limitations and her temper tantrums. We did not have any volunteers queuing up to accept her in a group home.

Consequently, I asked the court's permission to rent an apartment for Teresa. Teresa would live in this apartment with 24-hour care. The visits from the family were going to be carefully rationed and orchestrated so that Teresa was not manipulated nor overly stressed by the visits. Teresa accepted this arrangement without resistance. We think that some part of her knew that staying in the house was potentially lethal for her. The family did not fight it either, probably because they realized that with Teresa in an apartment, they could get a good night's sleep.

The court did not rubber stamp this arrangement. There was deep uneasiness about the house... why should we allow the family to continue to live in the house when Teresa doesn't? Why should we rent an apartment when she has a house? The money is supposed to be there for Teresa and we are using it to continue to maintain the expenses of the house such as real estate taxes, fuel, insurance, etc. What is the benefit to Teresa to keep the house? The answer is reasonably clear. We feel strongly that if the family were hurt by Teresa's moving, she would refuse to move. The family's acquiescence might be said to be purchased by keeping them in the house and not disrupting the family or, for that matter, pauperizing the family because the father is not a high earner. Far from it.

Today, Teresa is down to three dialysis sessions a week rather than six. Her behavior in her new apartment, which is not that far from where her family lives, has improved but is far from perfect. She still pitches a fit occasionally and when she does she can be violent. She came after our primary companion with a knife. We are not optimistic about finding a group home for her, but we are optimistic that we can keep her in this apartment safely and allow her to socialize either with friends or with a sheltered workshop as she stabilizes.

We have also attempted to get Teresa accepted by Medicare. I am advised that people undergoing dialysis are Medicare-eligible. I just received a rejection letter

from the Social Security Administration because Teresa did not have the requisite number of earning credits. I am appealing that decision because I believe that working the requisite number of quarters is not relevant. What I hope is that Teresa is categorically eligible for Medicare because of the dialysis.

We are terminating her medical insurance, and we have now obtained a Supplemental Needs Trust and Medicaid. As the events described in this article evolved, it became clear that, if we're going to get Teresa into a day program, she needed to become a client of Office of Mental Retardation and Developmental Disabilities, on Medicaid, and with a Supplemental Needs Trust.

What is of continuing amazement to me is the number of professionals who are focused on Teresa's well-being: the care manager, the court-appointed counsel, the primary companion, and Lisa Friedman, plus the weekend substitutes, myself, the court and the court examiner, and even her family, despite their dysfunction. It is astonishing how much time and ef-

fort has been put into saving Teresa's already truncated existence. Obviously, this story does not have an end. Instead, it will be continued as things evolve.

Robert Kruger is an author of the chapter on guardianship judgments in *Guardianship Practice in New York State* (NYSBA 1997, Supp. 2004) and Vice President (four years) and a member of the Board of Directors (ten years) for the New York City Alzheimer's Association. He was the Coordinator of the Article 81 (Guardianship) training course from 1993 through 1997 at the Kings County Bar Association and has experience as a guardian, court evaluator and court-appointed attorney in guardianship proceedings. Mr. Kruger is a member of the New York State Bar (1964) and the New Jersey Bar (1966). He graduated from the University of Pennsylvania Law School (1963) and the University of Pennsylvania (Wharton School of Finance (B.S. 1960)).

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Supplemental Needs Trusts: Pooled Trusts Remainder Funds—Where Does the Money Go?

By Robert P. Mascali

Some time ago an elder law practitioner who had a client in a pooled trust account mentioned to me that his client had recently passed away with a sizeable balance in his account, and while he realized that the funds would remain with the non-profit trust, his question was: what would happen to those funds?



One of the unique characteristics of a pooled first party supplemental needs trust is the way in which funds remaining upon the death of the participant are handled.¹ In order for a standard, self-settled first party supplemental needs trust to be an exempt transfer, it is required to provide by its terms that any remaining funds must first be utilized to reimburse the state for medical assistance provided during the lifetime of the beneficiary pursuant to the State Medicaid Plan² with the balance, if any, distributed according to the settlor's wishes. However, a pooled trust may direct that these funds, or a portion of them, remain with the charitable organization that manages the pooled trust without the necessity for a "Medicaid payback."³ Many elder law practitioners and other professionals in the field are unfamiliar with what actually happens to the remainder funds upon the death of the beneficiary, and many also question how these funds are handled by the non-profit administrator.

In an often cited 2001 NAELA article entitled "The Dark Side of Pooled Trusts," Renee Lovelace, a well-respected elder law practitioner, raised the issue of potential conflict of interest in the administration of a pooled trust and listed certain suggestions for the management of these remainder funds, some of which have been incorporated into the policies of various pooled trusts during the past decade.⁴ A recent case in New York found in favor of the pooled trust on the conflict of interest issue where the non-profit operated a pooled trust and also provided services to the beneficiary.⁵

It is important to bring this issue in from the dark and shed some light on how charitable organizations are managing and administering these remainder funds. First, it is important to note that OBRA 93, the federal law that exempts transfers to a pooled trust, does not require that the pooled trust have any par-

ticular direction as to the disposition of the funds remaining in the account upon the beneficiary's death. Instead, the statute initially permits the managing non-profit agency to retain all of the funds but further provides:

[t]o the extent any amounts remaining in the beneficiary's account upon the death of the beneficiary are not retained by the trust, the trust [will] pay to the State[s] from such remaining amounts in the account an amount equal to the total amount of medical assistance paid on behalf of the beneficiary under the State [Medicaid] plan[s].⁶

It remains an open question as to what requirements a particular state may or may not impose in connection with the distribution of remainder funds in a pooled trust upon the death of the beneficiary. The underlying issue is the applicability of the preemption doctrine, which may be a subject for a future article in this series. Suffice it to say, some states will only approve a pooled trust to operate within the state provided the trust directs that all or a specified portion of the remainder funds are used to reimburse that state for Medicaid paid on behalf of the deceased beneficiary.

In New York State, Social Services Law Section 366(2)(b)(2)(iii) is consistent with the federal pooled trust statute and consequently there is no specific requirement as to the disposition of the remainder funds. However, as recently as two years ago, then Governor Paterson's Executive Budget Proposal, contained in the Health Article VII Bill for the fiscal year 2009-2010, sought to include a proposal that would "cap" the amount that a non-profit organization operating a pooled trust may retain at ten percent of the funds remaining in the account upon the death of the beneficiary, with the balance going to the state as a Medicaid payback.⁷ Advocates for non-profit organizations and for individuals with disabilities and other interested parties were able to defeat this proposal and no similar proposal has been introduced since then.

While it seems certain that, for the time being at least, pooled trusts in New York State are not required to "pay back" remainder funds to Medicaid to the extent the funds are retained by the trust, a question still remains as to what is meant by "retained by the trust." Certainly, the remainder funds must be retained by the

non-profit trust for the furtherance of its charitable mission and cannot be used to support the administration or overhead of the non-profit organization. But other questions persist:

- 1) Must the funds be used for the benefit only of the then-current members of the pooled trust or may the funds be used to benefit disabled individuals who are not pooled trust participants?
- 2) May the funds be used to offset the general administrative costs and expenses of the non-profit organization?

Last year, around the same time as it promulgated the changes to the POMS regarding early termination,⁸ the Social Security Administration (SSA) also indicated in letters sent to some pooled trust administrators that it was considering the issuance of a directive that the SSA considered the term “retained by the trust” to mean that these remainder funds could only be used for the benefit of the then-current pooled trust beneficiaries or used to cover the administrative costs of the pooled trust and not the non-profit organization. At the invitation of the Social Security Administration, a group of pooled trusts submitted a letter to two senior officials of the SSA listing examples of the different types of items that were paid for, or supported by, the remainder funds, among them:

- 1) Grants for the benefit of disabled individuals who were not then participants in the pooled trust but who had specific needs that were not being met (e.g. clothing, minor home renovations);
- 2) Support for agency services in areas such as guardianship, home visiting and case management for the benefit of disabled individuals that are not funded, or are underfunded, at the agency level;
- 3) Payments for disabled individuals to attend summer camps, sporting, concert and cultural events;
- 4) Payments for medical related items for disabled individuals that are not covered by public benefits; and
- 5) Support for the administrative costs of the pooled trust such as by the reduction of fees for participants.

As a result of this effort, the Social Security Administration deferred any further action on what it considered to be meant by “retained by the trust” but it more than likely will continue to be an issue for pooled trust administrators.

In New York State there are at least nineteen non-profit organizations operating pooled trusts and each one has its own distinct policy as to disposition of funds remaining in an account upon the death of a participant.⁹ Any person considering the establishment of a pooled trust account should contact the non-profit organization directly to ascertain its policy on the use of funds remaining in an account upon the death of a beneficiary.

Endnotes

1. This article concerns with those pooled trusts that are “first party.” Some charitable organizations also administer “third party” pooled trusts but since those trusts do not require a payback for Medicaid, the use of remainder funds is less restricted.
2. 42 U.S.C. §1396p (d)(4)(A) (2011).
3. 42 U.S.C. §1396p (d)(4)(C) (2011).
4. Renee Lovelace, *The Dark Side of Pooled Trusts*, NAELA QUARTERLY, 6–9 (Sum. 2001).
5. *Matter of Smergut*, 2011 NY Slip Op 21068 (N.Y. Sup. Ct. 2011).
6. 42 U.S.C. §1396p (d)(4)(C)(iv) (2011).
7. S. Assem. B. S58/A158, Part C, Section 74 (N.Y. 2009).
8. See Amy O’Connor & Robert P. Mascali, 20 N.Y. St. B.A. ELDER L. ATT’Y, No. 4, at 14–16 (Fall 2010); see also POMS SI 01120.199.
9. See N.Y. HEALTH ACCESS, LIST OF POOLED SNTs IN NEW YORK STATE (2011), <http://wnylc.com/health/entry/4/>.

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What Families Should Do When a Loved One with Disabilities Is Denied the Home and Community-Based Waiver

By Adrienne J. Arkontaky

The New York State Office of People with Developmental Disabilities (OPWDD) administers many programs that benefit individuals with disabilities. One important program operated by OPWDD is the Home and Community-Based Services Waiver (HCBS Waiver). This waiver is a program of supports and services that enable children and adults with developmental disabilities to live in the community as an alternative to living in an institutionalized setting.¹ The program requires an applicant to have a diagnosis of a developmental disability.²



The services available through this program include habilitation services, respite care, adaptive technology and probably most important for many individuals, access to Medicaid and Medicaid service coordination.

There are very strict eligibility criteria. An individual must have a diagnosis of a developmental disability, and be eligible for an Intermediate Care Facility for persons with Mental Retardation and Developmental Disabilities (ICF/MR) level of care. The person must also be Medicaid eligible and have a desire to live in the community as opposed to an institutionalized setting and be able to do so with appropriate supports. Typically an individual will apply to the local Developmental Disabilities Service Organization (DDSO) or the Department of Community Mental Health in the county where the individual resides.

Once the individual completes the application for the Home and Community Based Waiver, the application is submitted to the DDSO for review and an initial determination is rendered. The applicant, parent or advocate is notified of the decision. If a determination is favorable, further assessment of what services are appropriate for the individual is done. The HCBS Waiver is a program that seeks to tailor services for the unique needs of the individual with developmental disabilities.

However, this article addresses the situation where the decision is not favorable. In the last few weeks, we

have seen several clients who for different reasons were not found eligible for the HCBS Waiver and the families decided to invoke the appeals process.

Typically OPWDD reviews the application and all related documents (assessments, evaluations and reports) and issues a letter of determination addressing the reason for the denial. The letter sent to the applicant/parent and/or advocate should provide an explanation for the determination. Typically, the notice will specifically state the services that the applicant cannot access through the program. For example, the applicant may not be able to access residential habilitation, Individualized Residential Alternative (IRA) and/or Medicaid service coordination through OPWDD. It is important to note that eligibility for other services provided by New York State Medicaid may not be affected by the adverse determination.

Once the applicant receives the notice of denial, the applicant has a right to appeal the decision. The applicant (and/or parent or advocate) can request a meeting with the DDSO office and/or ask for a state fair hearing.

The notice of denial will provide the applicant with specific information regarding how to appeal the decision including the correct person to call to request a conference with the DDSO. In addition, we advise clients to immediately request a fair hearing to protect the applicant's rights. At the time of this article, the parent and/or advocate may call 1-800-342-3334 or fax a copy of the notice to 518-473-6735 or complete and send the online request form at <http://www.otda.state.ny.us/oah/forms.asp>; or send a copy of all pages of the completed notice to the Fair Hearing Section, New York State Office of Temporary and Disability Assistance, PO Box 1930, Albany, NY 12201-1930.

It is important for the applicant and parent and/or advocate to maintain copies of all documentation that was submitted to OPWDD. The determination notice and request for fair hearing requests that the person completing the form provide a reason why the determination was incorrect. It is important for families to review the eligibility criteria for the HCBS Waiver before completing this portion. The person completing the notice should provide as much information as possible as to why the applicant's developmental disabilities fit the eligibility criteria.

It is also important to request a fair hearing within sixty (60) days of the date of the notice received by the applicant. Once the request for a fair hearing is submitted, the New York State Office of Temporary and Disability Assistance will assign an Administrative Law Judge to decide whether the determination was correct. As with any other fair hearing, the applicant can be accompanied by an attorney, relative, friend or someone to the hearing. The applicant can present evidence and/or testimony to support the fact that the denial was improper. The applicant can and should request copies of the documents on which the determination was made and an entire copy of the file from the DDSO. It is important that the file be obtained as soon as possible so that the attorney representing the applicant can prepare the case. In many cases regarding a denial of the HCBS Waiver, it is important for the attorney to provide additional documentation that the applicant does in fact have a developmental disability.

At the same time a fair hearing is requested, the applicant may request a "second step review." Typically the review and conference includes a face-to-face interview at the DDSO office. A committee meets and reviews all documentation provided to OPWDD. The committee often interviews the applicant. It is very important that families once again seek to provide documentation that the applicant fits the eligibility criteria.

If OPWDD still believes that the applicant is not eligible for the HCBS Waiver services, it will issue another determination that must provide the reasons why the applicant was denied eligibility. Once the applicant receives the determination letter, the applicant has the right to a third step review of the decision. All the documentation will be sent to a 3rd Step Eligibility Review Committee at the OPWDD Central Office in Albany, New York. If the 3rd Step Committee deems the individual ineligible, there is still a right to a fair hearing to challenge the determination.

Once again, it is important for families to remember that many denials occur because the reviewing committee does not have access to correct documenta-

tion. In many cases, families can produce additional testing and/or evaluations to support the case. Neuro-physiologists, physicians, geneticists and other professionals knowledgeable in the area of developmental disabilities are great resources.

It is also important that if a family is initiating a fair hearing, an evidence packet should be requested from OPWDD. In addition, families should recognize that after they exhaust their administrative remedies, they may pursue an Article 78 hearing.

In the end, if the person with disabilities is found ineligible for the HCBS Waiver the family may also explore other waivers and/or programs that might be available to the person with disabilities. Many times, persons are eligible for Medicaid or a Waiver administered through the Office of Mental Health.

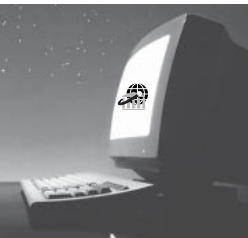
Endnotes

1. http://www.health.state.ny.us/health_care/medicaid/program/longterm/omrdd.htm.
2. HCBS: 14 NYCRR 625-10.3.

Adrienne Arkontaky is a Partner with Littman Krooks LLP with offices in New York City, Westchester and Dutchess counties. Adrienne's areas of practice include Special Needs Planning, Special Education Law and Guardianship. She represents parents of children with special needs throughout New York State in Special Education advocacy matters. She is a member of the New York State Bar Association, Westchester Bar Association and Westchester Women's Bar Association. She is also a member of the Council of Parent, Advocates and Attorneys (COPAA). She serves as acting president of Family Ties of Westchester and is a member of the board of the John A. Coleman School with campuses in New York City and White Plains. Adrienne lectures to parents and organizations throughout New York State on issues affecting families of loved ones with special needs. She is the parent of a child with special needs.

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Excerpts from the Elder Law Section's Summer 2011 E-News

The E-News was submitted by Deepankar Mukerji, Chair of the Communications Committee, and Howard S. Krooks, Antonia Martinez, Co-Chairs

Estate Recovery Regulations Imminent

As reported by the new Section Chair, T. David Stapleton, regulations regarding the expanded estate recovery rules are expected soon. A draft of the regulations, which are appended to a NYSDOH request to amend the State Medicaid Plan, but not the official release, is available on the NYSDOH website at the following link: http://www.health.ny.gov/regulations/state_plans/status/coverage/original/docs/os_2011-06-21_spa_11-42.pdf.

Provided that HHS does not object to the amendment, we would expect that regulations will be issued soon; however, there may be substantive changes to the draft, so practitioners are warned not to rely on this version.

New Committee

A new Elder Law Mediation Committee has been formed by the Section. Anyone interested in joining should contact Co-Chairs Judy Grimaldi and Laurie Menzies.

Second Circuit Rules on Health Care Proxies Outside of a Hospital Setting

This case has been the subject of much discussion at Section meetings. Rita Stein, on behalf of herself and as executrix of the estate of her deceased husband Milton Stein, brought an action against the County of Nassau, the Nassau County Police Department, and four emergency responders. Rita claimed that the emergency responders violated her and her husband's Fourth, Fifth, and Fourteenth Amendment rights and committed the state-law torts of assault and negligence when they refused to transport Milton—who was unresponsive at the time—to the hospital of Rita's choosing and then physically prevented Rita from interfering with their provision of emergency medical care to Milton.

Milton had appointed Rita as his health care agent in 1990, pursuant to a statutory Health Care Proxy; however, the District Court found that the applicability of health care proxies to non-hospital settings had not been "clearly established" at the time of the incident, and therefore qualified immunity barred Rita's suit against the emergency responders.

The Second Circuit found that under New York law, the creation of a health care proxy did not trigger an agent's authority to make health care decisions on behalf of her principal. Instead, that authority "commence[s] upon a determination, made pursuant to [New York Public Health Law § 2983(1)], that the principal lacks capacity to make health care decisions." N.Y. Pub. Health Law § 2981(4). That determination must be made by an attending physician in writing. Since there was no indication that such a determination had been made in this case, the emergency responders had no reason to believe that Rita had authority to act on Milton's behalf and were entitled to qualified immunity. The Second Circuit granted summary judgment for the emergency responders on the constitutional claims; however, it remanded the case to the District Court to examine the tort claims, since these claims did not necessarily involve the Health Care Proxy.

Stein v. Barthelson, decided April 8, 2011. 09-3682-cv (2nd Cir.).

Legislative News from the Health Care Issues Committee

NYS Assembly Member Richard Gottfried recently addressed the amendments to the Health Care Proxy laws and the Family Health Care Decisions Act which were considered in the recent legislative session.

He reported as follows: The "clean up" bill which proposed several technical amendments to the Family Health Care Decisions Act (FHCDA) did not pass as originally proposed; however, a pared-down version of the bill was passed expanding the application of surrogate decision-making beyond hospital settings, as allowed under the current law, to also include hospice settings as well. It did not expand further to include home health care services as proposed, which could be addressed in future legislative sessions.

The important issue of "medical futility"—allowing doctors to determine that continued treatment may be discontinued if such treatment is determined to be medically futile—was inadvertently dropped from the FHCDA when the DNR option was absorbed into the law and was addressed in this revision. This was an issue which drew a great deal of attention from both sides and brought support for the bill as it gave the pa-

tient or agent the right to make choices even if contrary to the doctor's orders.

In addition, legislation was proposed, as a result of the outcome of the *Stein* case, which would allow a health care agent to make a determination of which hospital the principal should be transported to by EMS or ambulance when the principal is unresponsive without a prior determination of incapacity by a medical professional. This exception to the prior capacity determination was limited to transportation and selection of medical facility. This amendment to the health care proxy law was proposed in a separate bill by Senator DeFrancisco. Said legislation did not pass this session and will need to be re-introduced at the next legislative session

Assembly Member Gottfried also addressed the efforts to curb the NYS budget deficits through changes to the delivery of Medicaid home care services. The budget process focused on the extraordinary growth in home care expenditures which occurred in NYC with certain agencies while other agencies' billing remained level. In order to address this rise in costs, specifically in the home care industry, reimbursement methods have been restructured. As a result, beginning April 2012, all home care cases expected to continue for more than 120 days must be converted to managed long-term case service or long-term home health care programs (known as the Lombardi program or LTHHCP) or other case management programs. This change is subject to receiving a federal waiver. In anticipation of this deadline, many certified home health agencies (CHHA's) are transitioning cases to managed long-term care agencies, causing an upheaval in client care. Fair hearings and advocacy to insure safe and appropriate care plans for the home care patient during these conversions to managed care will be the newest challenge to elder law practitioners. Most managed care agencies, due to their fiscal constraints, will be unable to provide the high-hour coverage to Medicaid recipients receiving sleep-in or split-shift work to the degree being provided now. The projected reduction in services, as seen in the preliminary transition cases, is causing families to either provide supplemental care at a greater sacrifice or to accept nursing home care for the Medicaid recipient.

Attorney-in-Fact Lacks Authority to Amend Irrevocable Trust

Petitioner, Linda LiGreci, Settlor's daughter, brought an action seeking the removal of the Trustee, Settlor's brother, pursuant to a Trust Amendment she signed as Agent under a validly executed Power of Attorney.

Settlor, Nicholas LiGreci, created the LiGreci Irrevocable Trust on November 5, 1991 and appointed his brother, John T. LiGreci, as Trustee. On April 20, 2010, Settlor signed a Power of Attorney granting full authority as agent to his daughter, the Petitioner, who the following month executed an "Amendment to the LiGreci Irrevocable Trust," seeking to remove her uncle as Trustee and appoint her son in his place. Each of the three beneficiaries named in the trust executed a proper consent to said amendment and on June 3, 2010, Nicholas LiGreci expired.

The creator of a trust has a statutory right under EPTL Section 7-1.9 to amend an otherwise irrevocable trust during his lifetime by obtaining the "written consent acknowledged or proved in the manner required by the laws of this state for the recording of a conveyance of real property, of all the persons beneficially interested in a trust property." This is, however, a personal right that terminates at death.

A similar fact pattern arose in *In re Goetz*, 8 Misc. 3d 200, 793 N.Y.S. 2d 318 (2005), where the Settlor had reserved to himself the right to amend the trust terms during his lifetime and executed a Power of Attorney appointing his wife as agent. The Settlor later sought to amend the trust and signed the necessary paperwork, however, not in the presence of a notary, rendering it a nullity. Settlor's wife signed the amendment in her capacity as Settlor's agent and this too was held to be ineffective as this was a personal right of the Settlor.

In this case, the Trust stated in clear terms that it was irrevocable and "shall not be subject to any alteration or amendment." The Court held that the right to revoke an irrevocable trust is personal to the Settlor, absent specific language in the instrument stating otherwise. Here, Settlor did not have such language and personally never exercised his statutory right to do so. Although the Power of Attorney in existence specifically granted the agent the authority to create trusts and appoint trustees, it made no mention about restructuring a prior estate plan. For nineteen years Settlor's brother acted as Trustee and managed the Trust. There was no credible evidence in the court record that Settlor sought his removal. The Power of Attorney did not authorize agent to reform Settlor's prior estate planning and the Court, therefore, set aside the amendment dated May 19, 2010.

Perosi v. LiGreci, decided 2/14/11 (Supreme Court, Richmond County) 2011 NY Slip Op. 21048.

In Burial Dispute Among Family Members, Decedent's Intentions Control

In this case, a dispute arose over the disposition of the remains of a decedent between his niece, Grace D., who had been appointed his personal needs guardian, and the decedent's sister, Vita P., who had been his property management co-guardian. Decedent's sister sought cremation of her brother's remains and subsequent transport to her residence in Vermont. Decedent's niece sought a Catholic funeral and burial customary of a Knight of the Order of the Holy Sepulchre. The funeral home in possession of his remains sought clarification by court order to determine which family member is to be given priority in decision making. The Court found that, although the law favors a surviving spouse and next of kin, the testamentary wishes of a decedent are paramount. It is only in the absence of decedent's express wishes that a relative's desire should be considered.

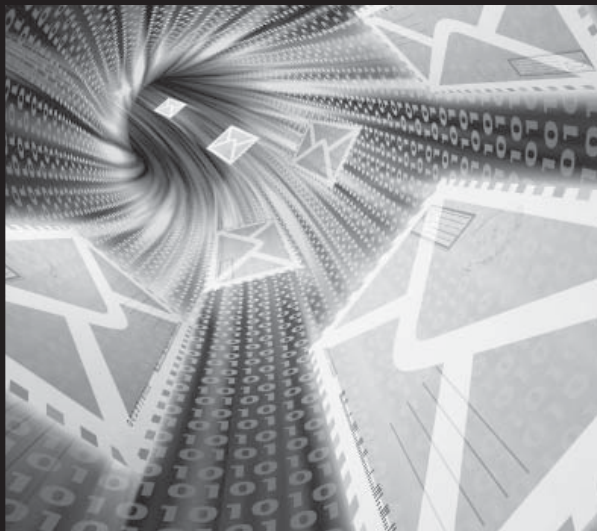
In this case, decedent had no surviving spouse or children; his two sisters and his niece constituted his next of kin in the second and third degree respectively. At the hearing, decedent's sister, Vita P., testified both she and her sister wished to be cremated and both

wanted their brother's remains treated similarly but admitted decedent had never expressed such a desire. Grace D., decedent's niece, testified she wanted her uncle buried in the Catholic cemetery plot purchased by decedent thirty-five years ago. Grace D. stated her uncle was a religious man, actively involved in the church choir as its director of several decades and a member of the Knight of the Order of the Holy Sepulchre.

The Court noted that each of decedent's parents as well as a predeceased sibling were buried, not cremated, and concluded that decedent's purchase of the cemetery plot in 1975, which included a fee for permanent care, indicated his wishes that the plot be used and perpetually tended. The Court also noted that Vita P.'s concerns had more to do with expense than decedent's personal wishes and ordered decedent's remains to be buried at the cemetery plot owned and purchased by him in the religious burial garb normally used for the interment of a Knight of the Order of the Holy Sepulchre.

In the Matter of the Appointment of Grace D., decided 2/22/11 (Supreme Court, Nassau County, No. 29490) 2011 NY Slip Op. 21069.

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If you have written an article you would like considered for publication, or have an idea for one, please contact *Elder and Special Needs Law Journal* Co-Editors:

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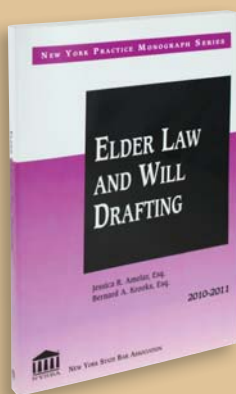
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