NYSBA

Elder and Special Needs Law Journal



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



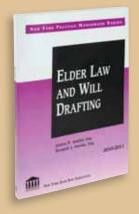
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SPECIAL SECTION: FAMILY HEALTH CARE DECISIONS ACT

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Elder law cuts across many distinct fields including (1) benefits law, (2) trusts and estates, (3) personal injury, (4) family law, (5) real estate, (6) taxation, (7) guardianship law, (8) insurance law and (9) constitutional law. The first part of Elder Law and Will Drafting provides an introduction to the scope and practice of elder law in New York State.

The second part provides an overview of the will drafter's role in achieving these goals.

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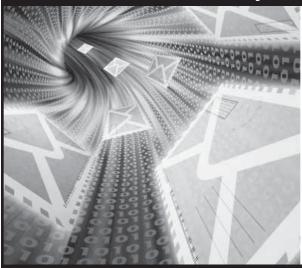


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Request for Articles



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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Articles should be submitted in electronic document format (pdfs are NOT acceptable), along with biographical information.

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Message from the Outgoing Chair

Support Our Section



I was honored to have served as Chair of the Elder Law Section during the past year. It has been an exciting, busy year for our Section.

With the hard work of the officers and executive committee members, our Section has taken a leading role in lobbying Albany and also in proposing affirmative legislation to protect the elderly and

those with disabilities in New York. We have provided many substantive programs to educate our members on cutting edge topics, furthered initiatives to improve guardianship proceedings and the administration of supplemental needs trusts, conducted pro bono clinics to assist elderly New Yorkers and those with disabilities, established an Ethics Committee and a Social Security Disability and SSI Committee to further assist our members, and also established a Diversity Committee and a foreign language database of our members who are fluent in other languages, so that our members may more easily serve those who are not fluent in English. The Elder Law Section's language database currently encompasses sixteen (16) languages, spoken by over forty-five (45) attorneys, and it continues to grow. This database is intended to assist us in better serving our culturally diverse communities.

Due to the dedication and hard work of Amy O'Connor, David Goldfarb and Val Bogart, along with our Section's Budget Task Force and our lobbyists, the proposal by the Medicaid Redesign team to impose a penalty period for uncompensated transfers with regard to community Medicaid, and the proposal to take away spousal refusal with regard to community Medicaid, were not put into the final budget bill. The expanded estate recovery legislation included in the bill was made subject to regulations, and our Section is actively working to have input with regard to those regulations, which have not yet been enacted as of the date this was written. The Section thanks the Budget Task Force members Cora Alsante, Michael Amoruso, Howard Angione, Val Bogart, JulieAnn Calareso, Ann Carrozza, Tim Casserly, Anthony Enea, David Goldfarb, Jeanette Grabie, Howard Krooks, Tammy Lawlor, Kate Madigan, Robert Mascali, Matt Nolfo, David Okrent, Fran Pantaleo, Amy O'Connor, Lou Pierro, Rene Reixach, Joan Robert, Vincent Russo, Ira Salzman, T. David Stapleton and Richard Weinblatt.

Moreover, our Section's proposal to modify the health care proxy statute in response to the *Stein* case was presented to and approved by the executive committee of the New York State Bar and is now a proposal backed by the entire New York State Bar Association. The modifications in the proposal include removing the prerequisite of having an attending physician determine the principal's decisional incapacity when the principal is out of a hospital or health care facility, and permitting the health care agent to make the decision to transport the principal to a particular hospital or other medical institution when the principal is unconscious or unresponsive.

Our recent UnProgram, chaired by Robert Kurre and Sal DiCostanzo, was an extremely successful program that received rave reviews by the attendees. Bob and Sal did a terrific job organizing the meeting, the facilitators led interesting discussions and the participants learned a lot from the program. We also recognize the contributions of Lisa Bataille and Kathy Heider, who consistently manage the Section's affairs in an efficient manner.

Your dynamic incoming Chair, T. David Stapleton, will lead this Section to new heights. He has already started a mentoring program to assist our new attorneys, and has put out a call for members to volunteer to assist new members. I am sure that under David's astute leadership, our Section will thrive as a resource for the members of NYSBA.

Thank you again for the honor of serving as your Chair.

Sharon Kovacs Gruer

Message from the Incoming Chair

"It was the best of times, it was the worst of times..."



T. David Stapleton

So opens Dickens' "A Tale of Two Cities." This seems an appropriate expression to reflect the stress endured by the Elder Law Section during the last few years, as it sought to fulfill its responsibilities as guardians of the rights of the elderly, the disabled, the infirm, and the disadvantaged. In those years, we successfully overcame serious threats

to the eligibility and funding limitations of programs relied upon by our constituencies. This year, however, as we are all acutely aware, those public benefit programs are under even greater siege at all levels of government. The good news at this time, and the reason for my optimism, is that, through the efforts of my predecessors and the talent of our Section infrastructure, we are well-organized and mobilized in the effort to limit the adverse consequences of these threats, and to continue to adapt, in order to successfully fulfill our role as guardians.

At the outset, let me express how truly honored I am by the privilege of serving as your Chair. At the same time, I am humbled and motivated by the road and challenges that lie ahead. Fortunately, this Section is blessed with a talented and dedicated group of officers to assist in this journey: **Anthony Enea**, as Chair-Elect; **Fran Pantaleo**, as Vice-Chair; **Rich Weinblatt**, as Secretary; **JulieAnn Calareso**, as Treasurer; and **Marty Finn**, as Financial Officer. This team, together with our highly capable and energized Executive Committee, provides great reassurance that our Section will continue to thrive and be effective in the face of these challenges.

As **Sharon Kovacs Gruer**, our outgoing Chair, takes her final bow and moves on to that coveted position of Immediate Past-Chair, I would like to express the gratitude of the Section, and my personal admiration, for a job well-done. As Chair-Elect over the past year, I have had a ring-side seat to appreciate Sharon's deft handling of the multitude of issues that have affected our Section, particularly our "Battle of the Budget," and the programs she has instituted: the foreign language database, the promotion of the special needs aspect of our Section, and an outreach for greater Section diversity, to name just three. The "Battle of the Budget" has been raging for 6 months and, as I write this, is still ongoing. Under her leadership, we have been able to overcome the many challenges to eligibility, but still struggle with the budget provision to expand estate recovery. Sharon has served us well, pouring her heart, soul and spirit into this effort. She has earned her place in the pantheon of dedicated and highly effective past Section Chairs. Well done, Sharon!

However, Sharon would be the first to emphasize the role played by the members of the Section's Budget Task Force and the Legislation Committees in achieving these objectives. I would like to personally express our deep appreciation to **Amy O'Connor**, **Val Bogart** and **David Goldfarb**, who did the heavy lifting in the preparation of position papers and legislative alternatives, and the others serving on those committees, all of whom dedicated so much of their time and talent to our unified effort to educate and persuade the representatives in Albany. We owe them an enormous debt of gratitude.

The great attribute of this Section is that it does such a magnificent job of representing the interests of its membership and facilitating its professional growth. That representation is at many different levels: the higher profile of the programs, Listserve, and this publication, down to the more behind the scenes role of lobbying to protect the rights of our constituencies, and the committee work in between. What makes all this so effective is the willingness of the members to become involved and contribute to the greater good of the Section and the profession. As I embark on my journey as Chair, let me put out a call to all Section Members to volunteer to become more involved. There are many opportunities to participate: working on committees (there's a list near the back of this publication), writing an article on an issue affecting our practice or the import of one of your recent cases, advising any one of the officers or members of the Executive Committee of a particular issue of concern, and, last but not least, attending our quarterly meetings.

In particular, let me encourage more of our upstate members to become involved. The experience of being involved with the Section will provide immediate benefits in all the ways set forth above, but most importantly will enhance your knowledge and confidence in this ever-changing and demanding field of practice. Furthermore, your contribution will be very important to the Section, because we need input by practitioners from all areas of the state.

Attending Section meetings is an energizing experience, both from an educational and social

perspective. The substantive programs address the concerns of the day, and keep us up-to-date on the latest issues and the best practices to respond to those issues. The networking opportunities are also important. "Networking" has an opportunistic tone to it, but, as it relates to a welcoming Section like ours, it is more the meeting of other members, sharing ideas, and bonding at a very professional level. Looking over my more than 20 years of attending these meetings, I cannot imagine practicing effectively in the field of Elder Law without the knowledge, relationships and, friendships acquired at these meetings. I genuinely look forward to every opportunity to get together with this great group of men and women whom I truly admire.

Speaking of Section meetings, we have an exceptional Summer Meeting planned for your educational and recreational enjoyment at the Equinox in Manchester, VT from August 18-20. The meeting will be Co-Chaired by Judie Grimaldi and Marty Finn, who have put together a great program. Thursday will be dedicated to our usual Elder Law Update, and then to dispersing the "legislative fog" created at both the state and federal levels. It will also include a panel discussion on "What do we do now" to adapt to this new environment. Friday will concentrate on health care and home-based service issues at both the federal and state level, and the impact on our clients. Saturday will focus on the future direction of the practice of law, and tips and concepts in office management and will include an interactive panel discussion. Thursday night, after dinner, and as the sun sets beyond the Green Mountains, we will have "Dancing with the Chairs," with a DJ playing "ELDOO-WOP" music. Friday night there will be a reception at Hildene, the home of Robert Todd Lincoln, where we will also be entertained by a hands-on demonstration of Falconry. You won't want to miss this meeting, so make your reservation early.

Then—**WELCOME TO THE REAL UPSTATE**. On October 12-14 our Fall Meeting will be a joint meeting with the Trusts and Estates Law Section in Buffalo, N.Y. This will be the first joint meeting between the two Sections and the timing couldn't be better. **Laurie Menzies** is serving as our Co-Chair, and it will be a great opportunity to share ideas and approaches to the common issues we face, most notably "enhanced estate recovery" and the new two-year estate tax rules. Laurie has promised that there will be no significant snowfall during the conference.

As for my own aspirations for the forthcoming year, I expect to be involved in promoting and advancing the work of our committees and the very active legislative agenda of our Section. That agenda will, among other issues, attempt to resolve the troublesome aspects of the *Stein* and *Deanna W*. cases, the pending revision of the Right of Election statute, and the adoption of the Uniform Adult Guardianship and Protective Proceedings Act.

From a programmatic standpoint, I look forward to initiating a mentoring program to assist the more newly enrolled members of our Section in getting up to speed in their practice. It is also a goal of mine to bring greater attention and scrutiny to the unlicensed practice of law that is creeping into the field of Elder Law.

On a final note, I would like to thank the past Chairs, current officers, members of the Executive Committee and of our Section, who have wished me well, and offered their assistance for the coming year. It is most gratifying and reassuring. With all your help, I look forward to a challenging, but productive and rewarding, year of service to the members of this Section and to our role as the guardians of our constituencies.

My Friends, let me leave you with the words of Albert Camus, French author and Nobel Prize winner:

"Don't walk behind me; I may not lead. Don't walk in front of me; I may not follow. Just walk beside me; and be my friend."

T. David Stapleton

Message from the Co-Editors in Chief

You are reading the Elder and Special Needs Law Journal, formerly known as the Elder Law Attorney. For quite some time, this journal has reflected the fact that Special Needs Law is an important part of the practice of so many Elder Law attorneys. So, when we proposed the change of name at the Executive Committee meeting in



May, it was greeted with enthusiasm and immediately approved. Furthermore, the emphasis in this journal is the law, including the myriad rules and regulations that determine how we devise solutions for our clients' problems. 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 addresses problems that our clients and their families face that cannot all be solved with a legal answer.

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-today 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.

The Elder Law Section leaders have long advocated for seniors and their families, and never more so than during this national economic recession. As this Summer 2011 issue goes to press, we are facing severe federal and state budget cuts in services and benefits. New York State is taking measures intended to reduce the State's Medicaid burden, and Valerie Bogart and David Goldfarb were among those who lobbied for this Section's Budget Task Force. They have each provided summaries of the proposed budget-driven legislation pending in New York State, which is expected to have a radical effect on provider reimbursement and the way in which services like home care will be authorized, reimbursed, and provided, as well as the potential for expanded estate recovery by Medicaid. We are all familiar with the last-minute wrangling in Congress during December 2010, which gave us the Tax Relief, Unemployment Insurance Reauthorization, and Job Creation Act of 2010 and significant changes to the federal estate tax laws. Nathaniel Corwin reviews the major features of the 2010 Tax Relief Act, the planning opportunities for



our clients, and the many questions still to be answered about how planning done during 2011-2012 may be affected by Congressional action taken for 2013 and beyond.

As we know, the attorneys in the "Elder Law" section are increasingly representing families who must deal with children and other relatives with "special needs." Adrienne Arkontaky now covers these issues for us in a regular column. Also in this issue, Andrea Blau, a clinical and legal consultant, addresses Individual Education Plans and critical knowledge that advocates should have for helping clients negotiate their way through this complex practice area to get the best results for their children. Further, we are pleased to include the first in what will be a regular column on Special Needs Trusts, which was initiated by Robert Mascali.

Nursing homes, sadly, are the final residence for many elders, and so how they care for patients and how they are paid is relevant to us. In the Fall 2010 issue, Matthew Nolfo and Vincent Mancino reviewed nursing home collection cases and explored some of the factual distinctions arising in those cases, including the potential effect of a signed Admission Agreement and/or Power of Attorney and numerous liability issues. In this issue, Nancy Levitin discusses Medicaid qualification and nursing home collections from the point of view of the facilities that are pressed to continue to provide care while families continue to pursue Medicaid qualification, and the inevitable conflict between the provider's fiscal concerns and the family's.

Theoretically, at least, the national emphasis on caring for elders is to prioritize the availability of care in the community. Families with elders at home are usually juggling a great deal. Many need the help of aides, yet are often unaware of the basic laws that govern their domestic employees, and are surprised to learn that they are "employers" and that there are penalties for non-compliance with the law. In the Winter 2011 issue, Evan Gilder covered the Domestic Worker Bill of Rights, and in this issue he discusses the New York Wage Theft Prevention Act, which became effective in April, 2011, concerning an employer's obligation to give employees notice of their pay rate and payday, wage statements, and retention of payroll records.

In this issue we also have a number of articles concerning Guardianships, in addition to the column from our regular contributor, Robert Kruger. We all know that caring for elders and others with decreased capacity is a problem increasing while the resources to address the problems are decreasing. One such article is from Laura Negron and Julia Kaminsky of The Vera Institute of Justice's Guardianship Project, which was created as a demonstration project to find innovative approaches to personal and property management, and individualized treatment plans, all for the purpose of enabling clients to be maintained in, or moved back to, deinstitutionalized settings. With ever-tightening public and private resources, this is compelling for far more than "just" the preservation of the individual's dignity and self-determination.

Guardian and surrogate decision-making in the health care context is a concern of the Family Health Care Decisions Act, adopted in 2010, which was the subject of a prior column by Ellen Makofsky, who contributes a column on Advance Directives for this publication. In this issue, we are pleased to include an article from physicians Barbara Paris and Jennifer Breznay, who explore the impact of the FHCDA on decision-makers, and the convergence of medical advancements and the law.

The politics of health care, including long-term care, continues to occupy media time like a longrunning soap opera, but with far greater consequences. Neil Rimsky gives us an overview of the impact of the Patient Protection and Affordable Care Act of 2010 on the elderly. The federal court challenges to the Act will be continuing for some time to come, and the political discourse makes it hard for all but those most inside the Beltway to follow the matter. What we do know is that there will be profound changes in the years to come in how we deliver and pay for institutional care, home care, and other community-based options, such as independent living assisted living and continuing care retirement communities.

We are also very pleased to bring you a special section on the Family Health Care Decisions Act with articles from NYSBA's Health Law Journal, which published a special issue on this subject in the Spring 2011. When we proposed this to Robert Swidler, Editor of the Health Law Journal, he was very receptive and generously facilitated our correspondence with the authors whose articles you will find here. The Health Law Journal's Spring 2011 issue includes even more articles well-worth reading, but we simply could not reprint them all. In the course of our work with the Health Law Journal, we were somewhat surprised to learn that there is only a very small overlap in Section membership yet, we know, a very large overlap in the concerns of our respective Sections. We look forward to future collaborative opportunities, with crosspublication for contributing authors to this law journal as well.

Finally, we have included from Judith Raskin and Natalie Kaplan of the Section's Ethics Committee the results of their first ethics poll; and further excerpts from the Elder Section's E-News, which we initiated in the Spring and will continue.

We hope you find *Elder and Special Needs Law Journal* valuable in your practice, and we thank you for your continuing support.

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ELDER LAW SECTION

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Sweeping Cuts in Medicaid Enacted in State Budget on April 1, 2011

By Valerie Bogart and Trilby de Jung

The New York State Health Budget (the "Budget") enacted in late March, 2011 makes fundamental and farreaching changes to New York's Medicaid program, with savings reported at \$2.8 billion. The proposals that were presented to the legislature in the Governor's 30-day amendments represented a package



Valerie Bogart

submitted by the Medicaid Redesign Team (MRT), a group of stakeholders convened by Jason Helgerson, New York's new Medicaid Director.

Three-way negotiations resulted in some adjustments to the MRT proposals, but the vast majority of what was finally adopted reflect the recommendations of the MRT. Notably, the MRT included only one consumer seat, occupied by Lara Kassel, the coordinator of Medicaid Matters New York, a coalition of over 130 consumer and provider groups that advocates for consumer access to Medicaid. Medicaid Matters abstained from voting on the MRT's final package, which was presented to the full committee with virtually no time for discussion or revision.¹

Generally elder lawyers and other consumer advocates are primarily concerned with restrictions on eligibility. While these are of concern, clients also need to be aware of reductions in provider reimbursement, and changes in the systems for approving and providing Medicaid services. Changes in payment and systemic changes like mandating enrollment in "managed care" organizations can potentially be more detrimental in terms of limiting client access to services, than restrictions on eligibility. This Budget emphasized the latter type of Medicaid reduction massive cuts in provider reimbursement and huge changes in the way in which services like home care will be authorized, reimbursed, and provided.

The sheer volume of changes proposed to the Medicaid program made lobbying efforts by consumers particularly challenging. There was simply not enough time and resources to strategize and present opposition to many of the cutbacks that were enacted. Even a week after the Budget was enacted, the harm of some of these proposals has been evident. At the end of the day, the negotiated Budget represents a few victories, but contains many changes to the Medicaid program that we fear will present significant barriers to accessing care. The changes most pertinent for elder law practice are reviewed here.²

A. Positive Items in the Budget



Trilby de Jung

1. Eligibility

The law does not enact any restrictions on eligibility. At least in part, the reason eligibility restrictions were not enacted is to comply with the "maintenance of effort requirement" in the Affordable Care Act (ACA)—the federal health reform law. The ACA requires states "to maintain Medicaid eligibility standards, methods and procedures" in effect on March 23, 2010 until Center for Medicare and Medicaid Services (CMS) finds the State's insurance exchange is fully operational, estimated to be January 1, 2014. An exception is made if the State certifies that it has a budget deficit. Even then, changes may be made only for those not eligible on the basis of disability (or pregnancy) and for those whose income is above 133% of the Federal Poverty Level.³ Because of this requirement, New York is not likely to cut back eligibility standards, methods and procedures until 2014.

Here are the victories on eligibility issues:

- a) Spousal Refusal was not eliminated, as proposed by the Governor. The NYSBA Elder Law Section legislative committee worked hard defeating this proposal.
- b) No penalties on "transfers of assets" for community-based Medicaid: The MRT had proposed extending the transfer penalty to include community Medicaid. This proposal did not make it into the Governor's Article VII bill, probably because of the maintenance of effort requirement described above.
- c) Increased income level in limited cases: The law authorizes the State to request permission from the federal government to increase the amount of the income level for community Medicaid (\$767 for one), to take into

account housing costs. However, the initial Governor's proposal was diluted in the final budget, and, if approved by CMS, will only apply to individuals discharged from nursing homes who enroll in a Managed Long Term Care plan. At least for those individuals, it will decrease the spend-down and obviate the need for enrolling in a pooled trust.⁴

d) Medicaid Buy-in Program for Working People with Disabilities⁵ (under 65, disabled and working): This program allows Medicaid eligibility up to 250% of the Federal Poverty Level for working people with disabilities who are under age 65. All retirement savings such as IRAs will now be exempt, even without being in pay-out status. Also, they will have higher asset levels (\$20,000-one, \$30,000-two). There is no minimum amount an individual must work for this program as long as it is bona fide. For more information see http://wnylc.com/health/entry/59/.

2. Service Issues

- a) No increases in co-payments for Medicaid, Family Health Plus and Child Health Plus.
- b) No elimination of the "prescriber prevails" protection in the prior authorization procedures for prescription drugs in fee-forservice Medicaid (meaning those Medicaid recipients who are not in managed care). However, the Budget does eliminate the pharmacy "carve-out" to Medicaid managed care, which means very few Medicaid enrollees will be accessing prescription drugs on a fee-for-service basis. Managed care plans will undoubtedly be applying utilization controls to prescription drugs going forward (see expansions to Medicaid managed care, below). This provision also does not apply to Medicare recipients, since they must obtain all of their prescriptions through Medicare Part D and not Medicaid.
- c) Management of behavioral health services: various advocacy organizations working with people with mental impairments supported the designation of regional entities for the management and administration of behavioral health services. The Commissioners of the Office of Mental Health, OASIS (substance abuse) and Health are authorized to enter contracts without competitive bidding, with initial plans to be designated by April 1, 2013.⁶

3. Enhanced Transparency for Medicaid Administration

> The Health Department must now post New York's Medicaid plan, along with every amendment and change, every application or draft application for a federal waiver or state plan amendment, and the status of waiver applications or proposed plan amendments.

- B. Reductions in Medicaid Benefits and Potential Barriers to Accessing Care
- 1. Limits on Services
 - a) Occupational Therapy, Physical Therapy and Speech Therapy are limited to 20 visits per year.⁷ This is a flat limit on services—the final Budget did not include the Assembly proposal to allow the physician to request an override on an individual basis, as is now possible with utilization limits on physician's, dental and mental health visits, lab tests and prescriptions. The new limits do not apply to people with developmental disabilities.

Compare with Medicare: In 2011, Medicare will cover up to \$1,870 for physical and speech therapy combined, and another \$1,870 for occupational therapy. Physician may request additional services beyond these caps.

- b) Enteral formula and nutritional supplements such as Ensure are limited to cover nasogastric, jejunostomy, or gastrostomy tube feeding—or inborn metabolic disorders, or to address metabolic or growth disorders in children—no other nutritional dietary supplements are covered.⁸
- c) Prescription footwear and inserts⁹ such as orthotics are only allowed for part of a lower limb orthotic appliance, as part of a diabetic treatment plan, or to address metabolic or growth disorders in children. Already a 62-year-old disabled woman with anterior metatarsaglia, severe arthritis and impaired toes in both feet was denied a custom-made shoe she needs to control pain and enable her to walk without risk of falling—she will likely need surgery as a result.

Compression stockings only for pregnancy or treatment of venous stasis ulcers.¹⁰

- d) Prescription drug coverage under Medicaid
 - i. **Prescription opioid analgesics** are limited to four prescriptions in a 30 day period—for which doctor must request prior approval.¹¹ (Dual eligibles should

not be impacted since Part D covers these drugs).

- Part D: Medicaid used to provide wraparound coverage for four classes of prescription drugs—it would pay for a drug if a Part D plan did not include the drug on its formulary. The four classes were anti-psychotics, anti-depressants, anti-retrovirals, and anti-rejection drugs. This wrap-around coverage is ending¹² AND for those who don't have Part D, these classes of drugs will no longer be exempt from prior authorization requirements.¹³
- iii. Before, prescription drugs were "carved out" of Medicaid managed care plans (Medicaid HMO)—meaning that Medicaid paid for drugs on a feefor-service basis. Now, the Medicaid HMO will be paying for drugs along with other medical services, likely leading the HMO to impose "utilization controls" on brand name drugs. The plans are responsible for providing most medically necessary health care services to their enrollees.¹⁴
- e) Nursing Home Bedhold—Nursing homes will no longer be paid for days that residents are temporarily hospitalized (bedhold) unless 50% of all residents who have Medicare are in a Medicare Advantage (Medicare HMO) plan.¹⁵ Before, the bedhold requirement was triggered by a low vacancy rate, for the reason that Medicaid only needs to hold a bed if the vacancy rate is very low. While the reasoning for the change was not given, one possibility is that it is believed that a Medicare HMO will strictly screen hospital admissions to ensure they are medically necessary—as reduced admissions are a goal of health reform generally.
- f) Changes to the Home Care Programs: While these changes reduce reimbursement for services, and do not directly reduce entitlement to home health services, they will inevitably reduce access by consumers because providers cannot and will not authorize home health services if the Medicaid payment is not adequate to meet their costs.

i. Certified Home Health Agency (CHHA) home health aide services:

Immediate Cuts in Reimbursement¹⁶—

(effective 4/1/11) patient specific expenditure caps set based on the provider-specific average total Medicaid claims per patient in 2009 and statewide average, with a case mix factor and regional wage index factor. Within a week after the law passed, CHHAs are refusing to authorize 24-hour care and refusing to reinstate such services after a hospital stay.

On April 8, 2011, the State Commissioner of Health issued a Dear Administrator Letter to CHHA Directors reminding them of the requirements under state law and regulation that prohibit arbitrary reductions and terminations of home health services. The letter is posted at http://wnylc.com/health/ download/238/.

Advocacy Tip: Make sure the treating physician prescribes hours client needs specifically and in writing, and provide to CHHA; also cite the *Catanzano* case to CHHA's managers and counsel—which requires that they reinstate same hours after a rehab/hospital stay that client had before as long as doctor prescribes them, subject to giving notice with hearing rights to client.¹⁷

- ii. **Elimination of Trend Factor**—CHHAs, Long Term Home Health Care Programs (LTHHCPs), AIDS home care programs, Personal Care Services programs, and Assisted Living Programs will receive no trend factor for the period April 1, 2011 through March 31, 2013.
- iii. 2% Across-the-Board Cut for the period April 1, 2011, through March 31, 2013, CHHAs and other home- and community-based service providers that receive Medicaid payments will be subject to actions to achieve savings equivalent to a 2% across-the-board rate cut, although this savings could be achieved via an alternative method, at the discretion of the commissioner of health and the director of the budget based upon consultation with the health care industry" provided such alternative achieves the requisite savings.
- iv. Episodic Payment system effective April 1, 2012¹⁸— CHHAs will receive a flat rate for 60 days of care, based on a formula based on client's acuity, diagnoses, etc.

This system will be similar to what Medicare already uses for home health services, and to "DRG's" in hospitals. Consumers predict that these changes will reduce access to home health services significantly for those outliers who need high hours of care, since the home health agency will no longer be paid fee-for-service for every hour of service they approve.¹⁹

- v. Mandate to Enroll in Managed Long Term Care—All long-term CHHA cases (need services for more than 120 days) will be transitioned to Managed Long Term Care—see more below.
- vi. Living Wage Mandate: A new "living wage" mandate for home health and personal care aides is based on a proportion of the New York City living wage law for personal care aides (currently \$10 with benefits and \$11.50 without benefits). The mandate applies only to aides who are serving cases paid for in whole or part by Medicaid, whether in personal care, certified home health agencies, or Managed Long Term Care, long term home health care programs (Lombardi), or managed care plans, or as employees of licensed home care services agencies.

The mandate will be phased in over a number of years—three years beginning March 1, 2012 for New York City and four years for Nassau, Suffolk, and Westchester counties beginning March 1, 2013. In the first year in each geographic area, aides must be paid 90% of the total compensation mandated by the living wage law of New York City, 95% in the 2nd year, 100% in the 3rd, and in the suburban counties, 115% in the fourth year. There is no wage mandate for providers outside of New York City, Nassau, Suffolk, and Westchester.

- vii. **Personal Care (Home Attendant)** including Consumer Directed Personal Assistance Program (CDPAP)²⁰
 - a. Level 1 (housekeeping) services maximum reduced from 12 to 8 hours per week.
 - b. Authorizes the Commissioner to set standards for "high-intensity" highhour personal care services users, pursuant to emergency regulation.

Will likely make standards stricter for 24-hour care.

- c. All long-term personal care cases (greater than 120 days) will be transitioned to Managed Long Term Care—see more below.
- viii. Mandates Enrollment in Managed Long Term Care (MLTC)²¹ for anyone over age 21 who needs home and community based services (as specified by the Commissioner) for more than 120 days. This is likely to be everyone receiving personal care (home attendant), CHHA services, and Consumer-Directed Personal Assistance Program services. Before it becomes mandatory, a federal waiver must be applied for and approved.

Similar to regular managed care, Managed Long Term Care pays a plan a capitated monthly payment, with which the plan must authorize and provide all long-term care services, including home care, day care, PERS, and short-term rehabilitation. A small number of fully capitated "PACE" plans also include primary and hospital care under both Medicare and Medicaid.²²

- a. Persons subject to mandatory enrollment will be assigned to a plan, if they do not select one within 30 days of the date on which they are given the choice of plans. This is a significant change from the current procedures, under which enrollment in MLTC is voluntary, and in which a MLTC consumer may disenroll at any time, effective the first of the following month.
- b. Plans are to contract directly with the State Department of Health and perform assessments for their members' care needs every six months. The role of local districts (DSS) in assessing and providing long term care is thus significantly reduced.
- c. Which programs will consumers be able to enroll in? —a certified MLTC "...or other program model that meets guidelines specified by the Commissioner that support coordination and integration of services... The guidelines must

address... [the various requirements in the MLTC law,]... and payment methods that ensure provider accountability for cost-effective quality outcomes. Such other program models may include Long Term Home Health Care Programs (Lombardi) that comply with such guidelines."

- d. MLTC plans will be required to offer CDPAP services. It remains to be seen exactly how this mandate will be carried out. At present only one MLTC plan in New York City, Independence Care Systems, provides CDPAP services through the Concepts agency. There is an inherent conflict between the idea of consumer-directed personal assistance and the outside management of one's care plan by a nurse.
- e. The law provides a few categories who are excluded from mandatory enrollment:
 - Not expected to be eligible for Medicaid for at least six months—this applies to undocumented immigrants who qualify only for emergency Medicaid and not full Medicaid. It may also exclude people who have a spend-down.
 - (2) Has Medicaid only for TB treatment, or through the Breast Cancer Treatment Program.
 - (3) In hospice.
 - (4) Has Medicaid as secondary coverage with Medicaid paying premium for primary coverage.
 - (5) Receives family planning.
 - (6) Native Americans.
 - (7) Certain categories are temporarily excluded—only until "program features and reimbursement rates" are approved by the Department of Health and Office for People with Developmental Disabilities—those who are:
 - (a) In Nursing Home Transition & Diversion Waiver,

Traumatic Brain Injury, or OPWDD waivers,

- (b) In regular Medicaid managed care (364-j),
- (c) In Assisted Living Program.
- f. Transition: all current home care recipients will be assessed by the assigned MLTC plan, which will be required to provide "transitional care" for 30 days while they do assessment.
- Public Input: The commissioner, g. shall seek input from representatives of home and community-based long term care services providers, recipients, and the Medicaid managed care advisory review panel, among others, to further evaluate and promote the transition of persons in receipt of home and community-based long term care services into managed long term care plans and other care coordination models and to develop guidelines for such care coordination models. The guidelines shall be finalized and posted on the department's website no later than November 15, 2011.
- h. Living Wage Mandate—MLTC plans must pay aides wages in accordance with living wage requirements. See *supra*.
- g) Expansion of Mandatory Managed Care.²³ The Budget also accepts the recommendations of the MRT for dramatic expansion of mandatory managed care for the Medicaid recipients not utilizing long term care services—accomplishing this expansion in two ways.
 - Expands the number of services that will be included under the capitated rate paid to managed care plans.
 Behavioral health services are to be covered by Regional Behavioral Health Organizations. Prescription drugs will be included as will additional long-term care services, including personal care and nursing home care—once federal waiver approvals are secured.
 - ii. Subjecting more populations to mandatory enrollment. Last year the State Health Department brought

virtually all of the state's SSI population, as well as New York City residents living with HIV and AIDS, into the mandatory program. The Budget continues the expansion by narrowing the remaining exemptions and exclusions from mandatory enrollment.

- The only populations that will remain exempt from mandatory enrollment after this year's budget takes effect are:
 - a. Individuals with a chronic medical condition who are being treated by a specialist physician that is not associated with a managed care provider in the individual's social services district may defer participation in the managed care program for six months or until the course of treatment is complete, whichever occurs first; and
 - b. Native Americans.
- iv. Excluded categories will be limited to:
 - Dual eligibles in "capitated demonstration for long-term care" (a/k/a Managed Long Term Care);
 - 2) Dual eligibles in "original Medicare"—meaning they are not enrolled in a Medicare Advantage plan. (Those who are in a Medicare Advantage plan may soon be required to enroll in the same plan's Medicaid Advantage plan, so that the plan controls both Medicare and Medicaid services. Federal approvals to make this enrollment mandatory have not yet been secured.);
 - Those who will receive Medicaid for less than 6 months (for example, Emergency Medicaid for undocumented immigrants or Spend Down);
 - 4) Those with Medicaid for tuberculosis (T.B.) related services;
 - 5) In hospice;
 - 6) Persons with other cost-effective third party insurance;
 - Receiving only family planning services and infants living with a mother in jail;
 - 8) Those eligible for Medicaid under

the Breast Cancer Treatment Program.

- v. New mandatory categories (when rates are approved by the Office for Mental Health, OPWDD, the Office on Alcohol and Substances Abuse Services, and the Offices on Children and Families), will include persons who are in:
 - residential alcohol or substance abuse program or facility for the mentally retarded;
 - 2) Intermediate Care Facility for the mentally retarded or who has characteristics and needs similar to such persons;
 - have a developmental or physical disability and receive home and community-based services or careat-home services through existing 1915(c) Home and Community Based Services waivers or who have characteristics and needs similar to such persons;
 - 4) Medicaid Buy-in for Working People with Disabilities;
 - 5) Lombardi program or inpatient services in a state-operated psychiatric facility or a residential treatment facility for children and youth;
 - are certified blind or disabled children living or expected to be living separate and apart from the parent > 30 days;
 - 7) nursing home residents,
 - are foster children in the placement of a voluntary agency or in the direct care of the local social services district;
 - 9) are homeless persons or family; and
 - 10) individuals for whom a managed care provider is not geographically accessible so as to reasonably provide services to the person.
- h) Global Cap on Medicaid Spending.²⁴ Budget language creates a global cap on Medicaid spending, subject to federal approval. The cap is to be based on the 10-year rolling average of increases in the Consumer Price Index. When the cap is exceeded, reductions are triggered. The Budget requires that these

reductions be uniform among categories of services and geographic regions to the extent possible, but does provide grounds for non-uniformity which include "the need to maintain safety net services in underserved communities."

Negotiations on this provision, which has greatly alarmed both providers and consumer advocates, resulted in new language that calls for the Department of Health to produce monthly reports of spending by region and health care sector during 2011-2013. The Director of Budget, in consultation with the Department of Health, is to determine the extent to which actual spending is likely to exceed the cap and then develop a Medicaid Savings Allocation Plan to close the gap. The new language requires the Budget Director and the Health Commissioner to consult with the Legislature and health care stakeholders, including consumers, to develop the plan. The plan must comply with all federal laws and regulations, and should not impose an undue administrative burden on Medicaid applicants and recipients or on health care providers. The plans are to be posted on the web and distributed to legislative committees.

For specific page references to all of the changes referenced above, as well as cross references to existing law that has been amended, consult the 2011-2012 Health Article VII Summary Chart.

For a discussion of the expansion of "Estates" Subject to Medicaid Lien after Death—see the separate article in this issue by David Goldfarb.

Endnotes

- Western New York Law Center, *Devastating Cuts to NYS* Medicaid Program Proposed, available at http://wnylc.com/ health/news/14/ (see article for additional information on the MRT proposals as submitted) (last accessed Apr. 18, 2011).
- 2. For detail on the changes made by Laws 2011, Chapter 59, including cross references to legislation and amended statutes, consult the 2011-2012 Health Article VII Summary Chart. http://wnylc.com/health/download/237/. The law can be downloaded at http://public.leginfo.state.ny.us/menuf.cgi—search for A4009-D.
- CMS Letter to State Medicaid Directors, Maintenance of Effort, 2/25/11, http://www.cms.gov/smdl/downloads/SMD11001. pdf (last accessed Apr. 25, 2011).
- 4. All references are to Laws 2011, Chapter 51 (See note 2, *supra*), Part H, sec. 74, p. 166.
- 5. Part H, sec. 54, p. 156.
- 6. Part H, sec. 42-c, 42-d.
- 7. Part H, sec. 27, p. 122.

- 8. Part H, sec. 23, p. 120.
- 9. Id.
- 10. Id.
- 11. Part H, sec. 23 p. 121.
- 12. Part H, sec. 20 p. 120.
- 13. Part H, sec. 21 p. 120.
- 14. Part H, sec. 5 p. 114.
- 15. Part H, sec. 69 p. 166.
- 16. Part H, sec. 3 p. 112.
- 17. See http://wnylc.com/health/afile/76/99/; http://wnylc. com/health/entry/76/, and http://wnylc.com/health/ news/18/ (last accessed Apr. 25, 2011).
- 18. Part H, sec. 4, p. 113.
- Valerie J. Bogart, Medicaid Certified Home Health Services— Background and Threatened Reductions, Elder Law Attorney, Vol. 20 No. 1, p. 24 (Winter 2010).
- 20. Part H, sec. 89, p. 171.
- 21. Part H, sec. 41, 41-a, 41-b, pp. 136 et seq.
- 22. David Silva and David Kronenberg, Medicaid Managed Long Term Care in New York, Parts I and II, Elder Law Attorney, Winter 2010, Vol. 20, No. 1, and Summer 2010, Vol. 20, No. 2 published by the New York State Bar Association, One Elk Street, Albany, NY 12207, available at http://wnylc.com/health/entry/114/, (including links to MLTC plan lists and other information) (last accessed Apr. 25, 2011).
- 23. Part H, sec. 77, 77-a, 79-c pp. 166-169.
- 24. Part H, sec. 90, 91 et seq., p. 171 et seq.

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New York State's 2011 Budget Bill: Expanded Estate Recovery

By David Goldfarb*

As you probably know by now, as part of this year's budget bill, Medicaid estate recovery has been expanded beyond assets passing under the terms of a valid will or by intestacy. Under the prior law, Medicaid estate recovery was limited to an individual's property included within the individual's estate passing under the terms of a valid



will or by intestacy, and would not include property passing to a beneficiary outside of estate administration such as through a beneficiary designation or by operation of law (these rules do not apply to the estate of a legally responsible relative, such as a spouse). However, a Medicaid recipient may only have assets valued at \$13,800 plus limited exempt resources. Therefore usually the only property in a recipient's estate was likely to be a personal needs account with a maximum of \$13,800, a homestead valued under \$758,000, an exempt family business, such as a farm, or a retirement plan that was in payout status. Aside from estate recovery, if the person was in a nursing home, the Medicaid agency is likely to have asserted a lien against the homestead if it was determined that the individual was permanently absent and unlikely to return to the home.

The 2011 Article VII Budget Bill¹ provides:

Subdivision 6 of section 369 of the social services law, as added by chapter 170 of the laws of 1994, is amended to read as follows:

6. For purposes of this section, [theterm] an individual's "estate [means] includes all of the individual's real and personal property and other assets [included within the individual'sestate and] passing under the terms of a valid will or by intestacy. Pursuant to regulations adopted by the commissioner, which may be promulgated on an emergency basis, an individual's estate also includes any other property in which the individual has any legal title or interest at the time of death, including jointly held property, retained life estates, and interests in trusts, to the extent of such interests; provided, however, that a claim against a recipient of such property by distribution or survival shall be limited to the value of the property received or the amount of medical assistance benefits otherwise recoverable pursuant to this section, whichever is less. Nothing in this subdivision shall be construed as authorizing the department or a social services district to impose liens or make recoveries that are prohibited by federal laws governing the medical assistance program.

At the time of this writing there are no regulations or emergency regulations implementing this law. However, the law does raise some important issues which may be resolved by the regulations. The New York State Bar Association has a Task Force that is making recommendations to the Department of Health regarding these regulations. When I refer to "we" or recommendations being made by "us," I am referring to that Task Force.

Will there be expanded estate recovery against existing life estates and trusts? The Task Force has taken the position that expanded estate recovery should only affect transfers and conveyances after the effective date of the regulations. Any other retroactive effect of the statute would be unfair and raise Constitutional questions regarding the taking of property.

The statute clearly only affects "retained life estates." We believe it is also the intent to affect only other retained interests. This would eliminate the problems caused by including lifetime interests in trusts created by third parties such as third party supplemental needs trusts, pooled third party supplemental needs trusts, QTIP trusts, credit shelter trusts and trusts created for descendants.

Third party trusts are frequently created for minor children or grandchildren pursuant to an individual's Last Will and Testament. For example, a grandparent may create a trust for the benefit of all of his grandchildren to provide for their educational expenses. If a grandchild who is the beneficiary of such a trust becomes Medicaid eligible and then dies, it would be unfair to include the grandchild's interest in the trust for estate recovery purposes. The intent of the grandparent to provide for all of his grandchildren's educational expenses would be defeated. This would cause a chilling effect on all trusts established for purposes having nothing to do with Medicaid protection.

Also, an interest in a trust at the time of death should be limited to a "beneficial" interest. Powers such as a limited power of appointment or a power to substitute property do not create any beneficial interest in the holder of the power and are often created for tax purposes. We do not believe it was the intent to include powers in a trust (such as a limited power of appointment or a power to substitute property) as an "interest at the time of death."

There is obviously a problem in valuing the individual's interest at the time of death. If there is to be any estate recovery from life estates or income only trusts, an artificial value will have to be assigned to the life estate or income interest. Will it be the value at the moment before death? Will that value be based on life expectancy tables? Life estates are considered to have a zero value for eligibility (see 96 ADM-8), since there is no market for them, so any attempt to count them as having a value for estate recovery would be inconsistent with both current policy and the economic reality it reflects.

Aside from these questions, such recoveries potentially conflict with existing New York laws. Life estates terminate upon the death of the life tenant, and upon the life tenant's death the remainder interest passes to the remainderman. If the remainder beneficiary is ascertainable at the time the life estate is created, the remainderman has a future estate that is indefeasibly vested. EPTL § 6-4.7 defines a future estate indefeasibly vested as "...an estate created in favor of one or more ascertained persons in being which is certain when created to become an estate in possession whenever and however the preceding estates end and which can in no way be defeated or abridged." This is the case with most transfers of real property with a retained life estate. The assignment of an artificial value to the life estate after the death of the life tenant for the purposes of estate recovery reduces the vested property right interest of the remainderman. The same reasoning applies to an income interest in a trust and the remainder interest. Furthermore, pursuant to EPTL § 6-5.1, the remainderman's property right interest is alienable. A remainder interest may have been sold or transferred by the remainderman prior to the life tenant's death. Estate recovery against a life estate would therefore generate a conflict between Medicaid's rights and the rights that may have been conferred by a remainderman, leading to a significant amount of litigation against third party transferees. EPTL § 6-5.1 states: "Future estates are descendible, devisable and alienable, in the same manner as estates in possession."

The preceding paragraph highlights the problems that this recovery statute will create for title to real property. Not only is there a potential conflict with the EPTL provisions, but every transfer of property where the title search reveals a transfer by survivorship of a joint tenant or vesting of a remainder interest where there was a life tenant will raise the issue of a potential recovery claim by Medicaid. However, unlike a Medicaid lien, there is no recording of the claim, and unlike an estate claim there is no set period for raising such a claim.

The state already imposes a transfer penalty for the full value of property transferred to an irrevocable trust, thus recognizing that the transfer was of the full value of the assets in the trust, regardless of a retained interest or benefit. Imposing an estate recovery would be inconsistent with the transfer penalty policy. Additionally, certain transfers are exempt from Medicaid penalties. For example, a homestead may be transferred to a spouse; a child who is blind, disabled or under age 21; a sibling who has an equity interest in the home and who resided in the home for at least one year before the person was institutionalized; or a child who resided in the home for at least two years before the person was institutionalized and provided care to maintain the person at home ("caretaker child"). It would conflict with federal and state Medicaid law to recover against these transfers of a homestead even if they were subject to a retained life estate.

Likewise certain transfers in trust other than the homestead are exempt from Medicaid transfer penalties. For example, assets other than a homestead may be transferred to a trust for the sole benefit of the spouse; to a trust established for the sole benefit of a disabled child; or to a trust established for the sole benefit of a disabled person under the age of 65. To recover against these trusts (even if there is a retained life interest) would conflict with state and federal Medicaid law.

Claims against retirement plans would conflict with Employee Retirement Income Security Act of 1974 and CPLR 5205. These accounts are traditionally protected from creditors. EPTL § 13-3.2(a) provides that the rights of beneficiaries of a pension, retirement, death benefit, stock, bonus or profit-sharing plan, system or trust or (insurance proceeds) "shall not be impaired or defeated by any statute or rule of law governing the transfer of property by will, gift or intestacy." For the protection of these accounts after the owner's death see Matter of Gallet, 196 Misc. 2d 303, 308, 765 N.Y.S.2d 157, 161 (Sur. Ct., New York Co. 2003). Estate recovery against retirement plans would therefore generate a conflict between Medicaid's rights and the rights of the beneficiaries leading to a significant amount of litigation. Likewise, life insurance should not be considered to be a recoverable asset. Life insurance is not subject to claims of creditors, and it should not be considered in Medicaid estate recovery.

In summary, the ambiguities, conflicts with other state laws, constitutional issues, and conflicts with federal and state Medicaid laws will cause challenges and litigation that will ultimately cost the state more than the potential savings from expanded estate recovery. Hopefully, the regulations will limit some of these problems.

Endnote

1. The law can be read at 2011 N.Y. Laws 59. the law can be read at http://public.leginfo.state.ny.us/menuf.cgi—click on Chapters, then 59.

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*The author would like to thank the members of the Task Force on Estate Recovery and other members of the Elder Law Section who contributed to the various memoranda submitted to the legislature and the Department of Health. This article is in part derived from the examples and ideas in those memoranda.

Editors' Notes

Deborah Sacks regrets the omission of her co-authors in an article that appeared in the *Elder Law Attorney* Spring 2011 issue. The correct citation should be: Sacks D., Das D., Romanick R., Caron M., Morano C., Fahs MC. The Value of Daily Money Management Programs for Older Adults. NYSBA *Elder Law Attorney*, Spring 2011, Vol. 21, No. 2, pp 26-32.

The full report upon which this article was based was published in June 2009. It is available at http://www.brookdale.org/pdf_docs/Value_of_DMM_Report.pdf. The authors ask that you please refer to the report for the complete study, and the acknowledgment of the generous support of several foundations and endowments, and the important contribution of expert advisors too numerous to mention here.

* *

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Advocating for "Appropriate" Special Education Services: Focusing on the IEP

By Andrea F. Blau

Increased public responsibility for the identification and education of children with special needs, virtually nonexistent 50 years ago, has become almost commonly acknowledged within the United States. While this increase in public awareness is partially due to the increased media focus (especially when



celebrities' children are involved), a more academic truth lies at the heart of the matter. Whether grappling with the impact learning challenges have on their children's ability to succeed in school, behavior, and ultimate candidacy for college and the workplace, or the intensive responsibility of preparing their children with developmental disabilities to "simply" function independently, there seems hardly a family these days that is not "faced with the unexpected" when it comes to educating their children.

Over the past three-and-a-half decades, we have seen a dramatic change in society's commitment to children with special needs.¹ Forty years ago, publicly funded residential facilities, like Willowbrook State School on Staten Island, were little more than institutions where the disabled were "warehoused" rather than educated. Public school education for intellectually or physically challenged children within one's home community was not commonplace and it was very difficult for parents with severely disabled children to raise their children at home. Society was still very frightened of people with disabilities, whom they preferred remain invisible. For many families, having a child with severe disabilities was overwhelming and advocating for their rights not even a consideration.

The complexion of things began to change in the late '60s and early '70s (the evolution of which we post-war Baby Boomers are extremely proud). Based on judicial decisions that were outgrowths of the equal rights movement,² parent advocates^{3,4} began to promote their children with disabilities as important members of society with constitutionally protected rights. Ultimately, legislators⁵ took action to safeguard those rights. And while "education" is not formally seen as a Constitutional entitlement, viewed as state rather than federal responsibility,⁶ the right to a free

and appropriate public education (FAPE) in the leastrestricted environment (LRE), similar to that provided to "typical" or "nondisabled" children and adolescents, was seen as guaranteed to disabled children by the Fourteenth and parts of the Fifth Amendments of the Constitution.⁷ Over the next several decades, the evolution of that commitment, the Education for All Handicapped Children Act of 1975, the Individual with Disabilities Education Act of 1997, and the Individuals with Disability Education Improvement Act of 2004 (IDEIA), reflects the legislative commitment to "our national policy of ensuring equality of opportunity, full participation, independent living, and economic selfsufficiency for individuals with disabilities."⁸

As very comprehensively discussed by our esteemed colleague Adrienne Akrontaky⁹ (please reread this seminal ELA article), the IDEIA in its current incarnation is perhaps the most relevant law governing special education today. Since an overview of this statute is available to our readership via Ms. Akrontaky's ELA column, I will not discuss the specific features of the statute here. However, as a clinical consultant and expert witness (as "Dr. Blau") involved in the statute's clinical implementation since its inception as P.L. 94-142 in 1975¹⁰ and as legal consultant (as "Blau Esq.") to attorneys embroiled in special education advocacy (litigation and mediation¹¹), perhaps providing a few brief guidelines regarding the complex task of securing appropriate educational services might be useful to our readership.

There are, however, three fundamental issues worthy of note as background to these guidelines.

First, the term "appropriate" has never actually been defined within the federal statute, the Department of Education (DOE) regulations promulgated to direct state implementation, or by the states themselves.^{12,13} The four basic features of a "free appropriate public education" are described virtually identically by the statute, the DOE and the state regulations as special education services that have been provided at public expense and supervision, meet the State standards, include appropriate preschool, elementary, or secondary education, and are provided in conformity with the individualized education program (IEP) as mandated.^{14,15,16} Yet what is actually educationally appropriate for any individual special needs student has been left vague.^{17,18}

Second, education has been acknowledged by the courts^{19,20} as under state rather than federal

jurisdiction. States are not required under federal mandate to comply with the IDEIA. However, if the states want to benefit from federal funding under this statute, they must comply with the statute. Virtually all 50 states (and the District of Columbia) apply for funding under this act.²¹

Third, the Supreme Court has granted certiorari for only one case that has challenged the interpretation of the "appropriateness" feature of the IDEIA. In Board of Education v. Rowley (1982),²² services of a sign language interpreter had been denied to a hearing impaired student by her local public school. Justice Rehnquist noted that the statute was grounded, in light of the legislative history, on the provision to handicapped students of a "basic floor of opportunity"²³ for free access to individualized public education in the least restrictive setting. The Rowley Court affirmed the state's right to deny the requested services by holding that the student was being educated appropriately as evidenced by the student's earning above average grades.²⁴ They further held that it was up to the states to decide on the particular methods to educate their students.²⁵ Justice Rehnquist, however, additionally cautioned against over-inclusiveness in the application of this holding, noting that:

> Because in this case we are presented with a handicapped child who is receiving substantial specialized instruction and related services and is performing above average in the regular classroom of a public school system, we confine our analysis to that situation.²⁶

While the current legislative intent, as clearly noted in the preamble cited above, and the stringent accountability measures listed within the reenacted statute, suggest a much higher level of educational outcome than basic opportunity and free access, the courts still largely rely on "The Rowley Standard" to gauge educational appropriateness in compliance with the statute.²⁷

From a pragmatic perspective, when advocating for special education services, we as attorneys need to be better versed in what constitutes an "appropriate" education for our clients' particular profiles, despite the vagaries noted above. While some of us would like nothing better than to be part of the "dream team" for whom the Supreme Court grants certiorari to take on the 30-year-old *Rowley* decision, our initial work is far more modest: identifying the specific services needed and assisting our clients in both justifying and securing those services when interacting with their schools. This is needed before deciding whether or how we go into battle. More practically speaking, we must be knowledgeable about what essential elements need to be incorporated within our client's Individual Education Progam (IEP), pinpointing the specific services and goals that will actually allow our client to be appropriately educated. If the requested services are included on the IEP but are not being provided or the student is not making the requisite documented progress in educational goals, your client has the basic elements with which to challenge the appropriateness of the education being provided and will allow you to move forward with power.

Below are a few important points for us, as attorneys, to keep in mind when advising or representing our clients, whether a parent requesting the addition, change, or removal of special education services or a school district with the same agenda but from a different vantage point!

The IEP is the legal document, the actual blueprint, describing the student's disability, educational needs, goals, and services, including school placement, to be provided at public expense. (Again, I refer our readership to Adrienne Arkontaky's ELA article.²⁸ For valuable information on the transitional planning aspects of the IEP, please read the article by Patricia Howlett, Maggie Blair, and Charles F. Howlett in the Spring 2011 ELA.²⁹) The IEP is generated by a Committee on Special Education (CSE) comprised of mandated members of the school system, the parents of the student with special needs, sometimes the student, and other professionals and advocates that the school and/or parent choose to bring.³⁰ The IEP, once generated, must be followed as written. The school is held accountable for its implementation.

While an IEP is typically reviewed yearly, IEP meetings may be requested by either the parent or school personnel at any time. If there is consensus among the CSE team, mandated services might relatively quickly be added or modified. If a related service or a specific accommodation is needed for a child to achieve an educational goal, it must appear on the face of the IEP. If not explicitly incorporated into the IEP, even if the service or accommodations are verbally agreed upon at an IEP meeting, holding a school accountable for their provision or for additional compensatory services or reimbursement for services not publicly provided will not be assured.

A collaboratively well-written IEP serves both as the best assurance of appropriate services and as the primary means of dispute prevention in special education.³¹ Everyone on the CSE team has the child's best interest in heart, at least at some level. Try to encourage that perspective and, if needed, have the child attend the meeting as his/her own advocate. It will be more difficult for the team to deny services with the student present. If the provision of services or placement decisions seem likely to be in dispute, encourage your client to bring his/her own assessments with recommendations, doctor's prescriptions, and even draft goals to the IEP meeting. Parents are entitled to have independent evaluations done if they question the assessments made by their school districts. In fact, if they request an assessment and the school does not have the personnel available to complete the assessment in a reasonable period of time, the parents may offer to provide their own assessment which may be used at the IEP meeting as the basis of the IEP or, if proper notice is given, may ask for the school district to fund their independent assessment.

If feasible, never have a client enter an IEP meeting, or a mandatory dispute resolution meeting,³² unprepared. Your presence, as an attorney, might not always be warranted or welcomed at these meetings. But your role in advising your client how to navigate through the system will provide important support even when you are not sitting by their side. The adversarial stance between parents and school systems has evolved over many years, perhaps deepening despite legislative efforts to lessen the discord.³³ You might not need to prepare your client at the same level as you would should they be providing testimony at an impartial, state or federal hearing on the issue, but they do need to be prepared and fully aware of their legal rights when attending an IEP review.

Parents are typically outflanked by the number of school personnel and professionals attending IEP or dispute resolution meetings. Assure your client that they have the right to veto any recommendation made by the CSE. While they do not hold any legal power to mandate that any of the services they are requesting be provided, their input is statutorily protected and they do have authority to veto a recommendation.³⁴

Make certain that your client does not feel "pressured" into agreeing to a service or placement about which they are uncertain. Prearrange with your client to ask for a break and have them call you if they are confused. If you are not accessible, make certain your client understands that, while perhaps inconvenient, they would do better to request an adjournment and reconvene the IEP meeting on another date than agree to services (or the nonprovision of services) under pressure.

Make certain that your clients are aware of the procedural guidelines and have exhausted all of the administrative remedies as they try to resolve their differences with their school.³⁵ Did they clearly inform their CSE or appropriate school personnel that a service or assessment was needed? Did they do so in writing? Did they get a written reply? If no reply was given did the parents make a second request? Did they send the request certified return receipt so that there is proof

of delivery? While labor intensive, the proper paper trail is extremely important in securing appropriate services.

More special education hearings are perhaps won and lost due to IEP procedural technicality violations than based on the actual merits of the case. This point is relevant to our clients from a range of perspectives. First, even if a hearing officer or judge feels that it is beyond his or her scope of power or jurisdiction to challenge the appropriateness of an IEP based on what the parent claims are substantive issues (e.g., the child not making sufficient progress, or the methodology being employed is in dispute), if a procedural violation is found (e.g., the parent was not given notice prior to a change in the student's level of services), then the IEP may be deemed null and void. This then allows the parent the opportunity to negotiate afresh, with supportive documentation, for the methodologies that he or she may feel are essential to his or her child's educational progress.

On the other hand, and this is very important to attorneys representing school districts as well as parents, the timeliness of a parent's claim, regardless of the substantive issues, may preclude any further action on the parent's part. There are very stringent statutes of limitations regarding when a claim or an appeal may be filed by either side. Parents have only two years from the time they recognize that an IEP is inadequate to file for a hearing. Parents who are new to the IEP process are typically unaware of this strict guideline, even if they are provided with the mandatory list or website by their school district with their rights and procedural safeguards.

The notion of pendency³⁶ (the Stay-put Rule) is extremely important, especially when a client is about to lose services or a preferred placement. From the time a hearing is filed throughout the appeal process, change in placement or services may not be done without parental consent. Filing for hearings, therefore, serves as a means to ensure that placement or services are maintained until the conflict is resolved or a final determination made.

One of the most important items to note is that even if the actual components of an "appropriate education" are not fully defined by statute or regulations, the terminology "appropriate education" should underlie the theory of your case as well as appear in the reports and services being advocated by your client's team of professionals. All the school is mandated to provide is an appropriate education. A student who is managing fairly well but would do better with a different methodology or additional supports may not prevail in gaining those services at the hearing level or withstand an appeal. The school is only required to provide an "appropriate," not the optimal, education. Make sure that all reports that your client provides (assessments, recommendations, etc.) state that these services, methods, or technologies are the exclusive means with which the student can be educated appropriately. Promoting the services as necessary to improve or optimize current performance levels will only serve to diminish your case.

The best way to get a specific methodology mandated and implemented is to have that methodology written on the IEP. Schools are often reluctant to make a commitment to a specific methodology, and since the schools are seen as the specialists in making these determinations, getting a particular methodology which a parent might feel is essential to the student's education written on the face of an IEP is often difficult. If the IEP team is unwilling to include the methodology and the parent is convinced that unless mandated it will not be provided, there still may be a way to insure that the methodology is employed. Write the goals in such a way that they can be successfully implemented only if the desired methodology is used. The services of an experienced professional may be needed to craft these goals, but it is well worth the investment.

While the cost of a specific school placement, service, or piece of equipment may be high, that fact alone should not preclude its provision to your client if it is the only appropriate option in meeting your client's educational needs. It is common practice for school systems to do what they may to avoid recommendations that are costly. There simply are never enough funds to meet student needs and the costs involved in special education are particularly high. Parents are often told that special education services are either not needed or not an option simply because of their cost. The IDEIA makes it very clear that in designing a student's IEP the appropriateness and necessity of the service is determinative, not cost. Clients need to be practical in what to expect in today's economic climate and sensitive to budgetary restrictions, but they should not be held hostage by it.

Make certain your client's homework is done prior to entering an IEP meeting. It is not unusual for members of the CSE to attend an IEP meeting ill prepared with one or more of the attendees (including school administrators) unfamiliar with your client's specific needs and the educational options (placement, services) that might best meet them. Often educational goals have not yet been written or large areas have been left for development at the meeting itself. Do your due diligence prior to the meeting. Make certain your client is prepared with specific placement, support services, and educational goals in mind, justifying why any alternatives would not be appropriate. Try to find out who will be attending the review ahead of time. This will often provide your client with clues as to which direction the wind is blowing; that is, if the

school is gearing up for a fight or is approaching the meeting in a more collaborative spirit.

If your client is attending an "at risk³⁷" IEP meeting, suggest that the meeting be tape-recorded. It is within your client's legal rights to tape-record the meeting, provided ample advanced written notice is given to the school. The school is then also free to record the meeting. If the school balks, suggest to your client to offer the school a copy of the recording. Having the discussion recorded will be quite valuable. It is not unheard of for agreed-upon services or accommodations to be omitted on the final IEP document. While these services may not be authorized until they actually appear on the IEP, if your client files for a hearing, providing transcripts of these discussions may be extremely revealing.

The official IEP document varies in format. New York City has recently adopted a new and rather lengthy form which includes sections devoted to the student's present levels of performance and individual needs, effects of those needs on general education, special factors, measureable annual goals, protocols for reporting to parents, recommended programs and services (including projected initiation dates), testing accommodations, coordinated transition activities, participation in state and district assessments, participation with students without disabilities, special transportation, placement recommendations, summary section with student information and recommendations, promotion criteria, other program concerns and an IEP meeting attendance page. It is essential that your client review each and every line on their child's IEP. Remember this is the document which contains all services for which the school is held accountable. A second scrutiny is in order once the finalized IEP document is sent to the parent (often a few weeks after the meeting). A lack of precision or even inadvertent omissions on the IEP will reduce its effectiveness as well as your client's rights to secure those missing elements that have gone "unnoticed."38

In conclusion, we are meeting more and more families in need of appropriate special education services. Hopefully, the above "tips" may prove useful. They are to be viewed as preliminary safeguards and are neither exhaustive nor always plausible.

Ensuring that students with special needs receive a truly appropriate education is extremely complex. The 40-year evolution in securing appropriate educational outcomes for these students, while heavily laced with discord between parents and schools, is also matched by unrivaled collaborative efforts and successes. As long as the best interest of the child remains at the heart of the effort and the legal focus remains on following the procedural protocols while substantively justifying the appropriateness of the educational programs being promoted, the power imbalances between schools and parents can be effectively neutralized, if not cured. In my own experience, as a professional in this field for 40 years, I have seen hundreds of students with special needs actually lead fuller, productive lives as the result of a truly appropriate education.

Endnotes

- 1. A.F. Blau & A.L. Allbright, *50-State Roundup: Ensuring Children* with Disabilities a Free Appropriate Public Education, 30 MENTAL & PHYSICAL DISABILITY L. REP. I, 11-19 (2006).
- 2. Brown v. Bd. Of Educ., 347 U.S. 483 (1954).
- 3. Pa. Ass'n for Retarded Children v. Commonwealth, 343 F. Supp. 279 (E.D. Pa 1972).
- 4. Mills v. Bd. Of Educ. 348 F. Supp. 866 (D.D.C. 1972).
- Education for All Handicapped Children Act of 1975, Pub. L. No. 94-142, 89 Stat. 773 (1975) (codified as 20 U.S.C. §§1400-1482).
- 6. San Antonio Indep. Sch. Dist. v. Rodriguez, 411 U.S. 1, 42-43 (1973).
- For a brief discussion of this evolution and the judicial standard, see A.F. Blau, *The IDEIA and the Right to an* "Appropriate" Education, B.Y.U. EDUC. & L.J. No.1, 1-23 (2007).
- 8. 20 U.S.C.A. § 1400(c)(1).
- 9. A. Arkontaky, Special Needs Forum, NYSBA Elder Law Attorney, Vol. 18, No. 2, 33-36 (Spring 2008).
- 10. See supra note 5.
- A.F. Blau, Available Dispute Resolution Processes Within the Reauthorized Individual with Disabilities Education Improvement Act (IDEIA) of 2004: Where Do Mediation Principles Fit In? PEPPERDINE DIS. RES. LAW JOURNAL Vol. 7, No. 1, 65-86 (2007).
- 12. See supra note 1.
- 13. See supra note 7.
- 14. 20 U.S.C. § 1401(18) (1975).
- 15. 20 U.S.C.A. § 1401(9) (2004).
- 16. 34 C.F.R. § 300.13(a)-(d) (2005).
- 17. Bd. of Educ. v. Rowley, 458 U.S. 176 at 189 (1982) ("noticeably absent from the language of the statute is any substantive standard prescribing the level of education to be accorded to handicapped children").
- 18. See supra note 7.
- 19. See supra note 6.
- 20. See supra note 17 at 208.
- 21. See supra note 11 at 65.
- 22. See supra note 17.
- 23. Id at 201.
- 24. Id at 209-210.
- 25. Id at 210.
- 26. Id at 202.
- 27. Id at 211.
- 28. See supra note 9.
- P. Howlette, M. Blair, and C. Howlett, *The Least Restrictive Environment: The Tie That Binds Guardianships and Educational Needs*, NYSBA Elder Law Attorney, Vol. 21, No. 2, 4-9 (Spring 2011).

- 30. For specific information governing the development of an IEP in New York State please refer to the Regulations of the Commissioner of Education-Part 200.
- 31. See supra note 11 at 76.
- 32. Following the filing of a due process complaint, prior to scheduling an impartial hearing, a dispute resolution session, where parents and school personnel have a final opportunity to air and resolve their disputes, is mandatory unless both parties elect mediation or wave in writing. For a listing and explanation of the various dispute resolution options afforded your clients please refer to *See supra* note 11 at 65-86 and *See supra* note 30.
- 33. See supra note 11 at 66-75.
- 34. Id. at 74.
- For a very user friendly guidebook on the reauthorized IDEIA of 2004, see R. Chapman, *The Everyday Guide to Special Education Law: A Handbook for Parents, Teachers and Other Professionals,* 2008 edition published by The Legal Center for People with Disabilities and Older People, Denver, CO. www.thelegalcenter. org.
- 36. 20 U.S.C. §1415(j) and 20 U.S.C. §1439(b).
- 37. See supra note 11 at 79.
- 38. I recently encountered a client whose daughter was severely physically impaired and could not tolerate being on the lift bus for more than an hour each way. The parent had to literally drive her daughter to school every day for a full academic term, simply because the CSE team did not list the "last on/first off" phrase under the transportation accommodations section on the IEP document when retyping it, despite the agreement, as the client had provided the requisite medical documentation, at the CSE review. The parent, in good faith, did not catch the omission when the completed IEP was mailed to her and despite assurances from her school district that this would not present a problem, the transportation vendor refused to comply without the official mandate which took over six months to secure.

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Institutional Guardianship: A Team Approach Paves the Way Home for Some

By Julia Kaminsky and Laura Negrón

The ride to Ms. B's house is a long one. Debbie, her case manager, brings treatment plans to review on the way, though even now, after two years of monthly visits to Ms. B's home, it still jars her concentration when the train she has boarded outside The Guardianship Project's downtown Brooklyn office emerges above ground, and she sees that the grandiose columns,



Julia Kaminsky

tree-lined public square and limestone statues have given way to overgrown train tracks and crookedshingled houses covered with indiscernibly scrawled graffiti.

In spite of its proximity to squalor, Ms. B's home is now a comfortable one, thanks to the array of services provided by The Guardianship Project, a demonstration project of the Vera Institute of Justice designed as an innovative model of institutional guardianship dedicated to serving elderly and disabled New Yorkers who have been adjudicated as incapacitated under Article 81 of the New York State Mental Hygiene Law. The Project's clients, located primarily in Brooklyn and Manhattan, in some of the City's most marginal neighborhoods, are largely indigent: Approximately 83% live on less than the average annual per capita income in New York City (\$30,415), and nearly 40% live below the federal poverty level (\$10,830).¹

Using a team approach, The Guardianship Project delivers intensive case and property management, and financial and legal services, regardless of clients' ability to pay, and strives to maintain clients in the least restrictive environment possible. Although staff creates an individualized treatment plan for each client, and moves clients home only when it is medically feasible and in the client's best interests to do so, the Project has succeeded in maintaining approximately onethird of its clients in deinstitutionalized settings, such as apartments in the community and assisted living facilities.

Ms. B, a 71-year-old woman with advanced dementia, is one of the roughly 100 clients currently served by the Project, which has served close to 200 clients since its inception in 2005. When the Project

was appointed as Ms. B's guardian, she, like many clients, was languishing in a nursing home, where a niece had placed her against her will. She had almost no income or assets, and although she owned a house, her niece had sold all the furniture and put the house on the market.

Despite these obstacles, it was clear that Ms. B



Laura Negrón

wanted to go home and was robust enough to do so. The Project's property manager and legal team took the house off the market, successfully litigated a non-payment proceeding against the second-floor occupants to generate much-needed rental income, arranged for a close family member to move in to help with household tasks and pay rent, and obtained a reverse mortgage that gave Ms. B the resources to live in the community. Case management staff secured furniture and home care, coordinated her discharge and move home, and enrolled her in a low-cost adult day care program, where she receives social and cognitive stimulation. Ms. B has been noticeably more responsive since moving home and beginning the day program. As with all of the Project's clients, staff continues to visit her monthly, rather than the statutory minimum of four times per year, and also supervises her home care, helps make medical decisions on her behalf, and manages her finances and property.

Caring for the elderly in their homes when appropriate is often not only more humane, but more cost-effective than institutional care. Medicaidfunded nursing home care in New York costs an annual average of nearly \$112,000 per patient,² whereas 24-hour Medicaid home care is roughly \$81,500 per year.³ By maintaining clients at home, in 2010 alone the Project's services have saved New York State approximately \$2.5 million⁴ in Medicaid expenses. Since the Project became operational, the total Medicaid savings approaches \$8 million.⁵ Moreover, the Project's services often help delay clients' Medicaid eligibility. As an example, Ms. B earned nothing more than a monthly pension of \$250 at the time of appointment. With monthly private pay nursing home rates averaging \$10,579 in New York City, she would have been quickly spent-down and

on Medicaid had she remained in a nursing home, thereby costing the State as much as \$112,000 per year. Instead, the Project's scrupulous financial and property management services have helped to maximize her limited resources, such that Ms. B continues to private pay for home care, and in fact may likely never need Medicaid.

There are many challenges inherent in delivering institutional guardianship services geared toward moving home elderly people who want and are able to do so with support services. In some instances, prior hoarding has been so severe that there is literally no walk space, and in others, haz-mat suits must be donned before entering bedbug- and rat-infested apartments. In yet other situations, the property is dangerously dilapidated or in foreclosure. For the majority of Project clients, who have little to no assets, the cost of cleaning, repairs, and medical supplies is a major impediment. Simply securing adequate home care can be a monumental feat. And in this fiscally strained climate, accepting new cases to help meet the needs of New York City's sizeable indigent elderly population remains an ongoing challenge. Despite these obstacles, however, the Project has welcomed new cases and remains open for business, celebrating each individual success story at weekly team meetings.

Inspiration derived from clients is largely what keeps Project staff going. When Debbie re-boards the train after her visit, she is pleased that Ms. B is not just stable, but thriving. With senior citizens already comprising 13% of New York City's population, and poised to increase to nearly 18% by 2030,⁶ she can't help but wonder, as the train lurches past the rows of decaying houses, how many frail and impoverished elderly people there are, just out of sight behind the crumbling walls, who had no one to visit them today.

Endnotes

- U.S. DEPT. OF HEALTH & HUMAN SERVICES 2009 HHS POVERTY GUIDELINES, http://aspe.hhs.gov/poverty/09poverty.shtml (last visited Apr. 14, 2011).
- January 1, 2009 Nursing Home Rates, available at New York State Department of Health Long Term Care Medicaid Reimbursement, http://www.nyhealth.gov/facilities/long_ term_care/reimbursement/#nhr1 (last visited Apr. 15, 2011). Using the spreadsheet entitled "January 1, 2009 Nursing Home Rates," we factored in only nursing homes based in New York City and averaged their rates to arrive at the average Medicaid nursing home rate in New York City.
- 3. Telephone interview with Annette Holm, Deputy Director for Field Operations, New York City CASA Medicaid Home Care,

in Brooklyn, NY. (Dec. 2, 2010). According to Ms. Holm, CASA Medicaid Home Care costs \$16.95 per hour, and a 24-hour aide is paid this rate for 12 hours, and then receives \$20 for the remaining 12 hours. Therefore, the daily rate for Medicaid Home Care is \$223.40, which, multiplied by 365 days in a year, is \$81,541.

- 4. Julia Kaminsky, Project Analyst, the Vera Institute of Justice, Inc. Guardianship Project, Summary of Medicaid Cost-Savings in 2010 (Mar. 17, 2011) (unpublished manuscript, on file with the Vera Institute of Justice, Inc. Guardianship Project). We conducted a cost-benefit analysis assessing the Medicaid costsavings generated by The Guardianship Project in 2010 and since the Project's inception in 2005. The analysis measured savings across the following categories: nursing home, hospital, and mental health facility avoidance among Medicaid clients; private-paying community clients who would be enrolled in Medicaid had they been institutionalized; and Medicaid liens paid by the Project on behalf of its clients.
- 5. Id.
- Cornell University Program on Applied Demographics, New York State Data Projection by County, http://pad.human. cornell.edu/counties/projections.cfm (last visited Apr. 15, 2011). According to the Cornell University data, in 2010 there were 19,617,941 New Yorkers, 2,555,434 of whom were over 65. It is projected that in 2030, there will be a total of 20,415,446 New Yorkers, and the number of people over 65 will increase to 3,646,477.

Julia Kaminsky serves as the Project Analyst for the Vera Institute of Justice Guardianship Project, where she works closely with the director on communications and development initiatives. She has blogged about guardianship and is lead writer for the Project's first newsletter. Julia earned her bachelor's degree in International Studies from Middlebury College.

Laura Negrón has more than 30 years of public interest experience in nonprofit management, fundraising, community relations, and program development across a variety of areas including elder care, youth programs, higher education, government, social services, and the law. Prior to joining Vera Institute of Justice in 2010 as director of The Guardianship Project, Ms. Negrón worked as a staff attorney with the Office of the Nassau County Attorney. She was also dean of institutional advancement for Long Island University's Brooklyn **Campus and a Charles Revson Public Interest Fellow** at Human Rights Watch. She holds both a Master's degree in social work from Hunter College and a JD from the City University of New York's School of Law, where she was managing editor of its journal, New York City Law Review. For more information about The Guardianship Project, call (347) 296-1874.

Protracted Medicaid Disputes: The Provider's Perspective

By Nancy Levitin

As a nursing home attorney who previously worked at Legal Services for the Elderly, and then as an elder law attorney, I know I may be seen as having "switched sides." I used to represent health care consumers, and now I represent health care providers; however, I try not to look at it that way. Almost always, the interests of



health care consumers and providers converge.

Skilled nursing facilities and the residents who occupy them have a shared interest in giving and receiving high quality care, and in having Medicaid pay for that care when warranted. On the issue of reimbursement, nursing homes and residents alike celebrate the arrival of a Medicaid budget in the mail.

That said, dissension is inevitable when a nursing home resident's debt to the facility continues to mount while the resident tries to establish his or her eligibility for Medicaid. As the nursing home presses for payment, the resident often insists that Medicaid should cover the charges. When the resident refuses to pay for care that he or she maintains should be covered by Medicaid, the nursing home is often unwilling to continue to provide care without getting paid for doing so.

The potential for conflict is apparent, and the time can come when the provider and consumer have to go to their respective corners. The provider asserts a right to pursue collection of an unpaid bill, and the consumer insists on the right to seek third party coverage of the debt. Despite having been told by more than one elder law attorney that nursing homes are not permitted to exercise legal measures to collect private payment on the accounts of Medicaidpending residents, I have not yet been referred to any persuasive legal authority to this effect.

A. Relevant Regulations

The regulation most often cited as authority in New York for the prohibition against suing Medicaidpending nursing home residents for collection is 10 N.Y.C.R.R. §415.3(b). Within this regulation are two subsections that elder law attorneys have argued limit a provider's right to pursue a Medicaid applicant or appellant for private payment.

1. 10 N.Y.C.R.R. § 415.3(b)(2)

This subsection of the regulations prohibits nursing homes as follows:

The nursing home ...shall not charge, solicit, accept or receive, in addition to any amount otherwise required to be paid by third-party payors, any gift, money, donation or other consideration as a precondition of admission, expedited admission or continued stay in the facility except that arrangements for prepayment for basic services not exceeding three months shall not be precluded by this paragraph.

Section 415.3(b)(2) limits the rights of nursing homes to bill existing or prospective patients *in advance* of rendering care and services to them or *in addition* to amounts payable by third party payors (e.g., like Medicare). When a nursing home resident has received care and services without paying for same, and no third party coverage is available, and a nursing home demands payment of the outstanding charges under threat of legal action, the nursing home is not seeking payment as a "precondition of admission, expedited admission or continued stay" or "in addition to any amount otherwise required to be paid by third party payors."

The resident in these cases has already been accepted for admission by the nursing home, the debt has already accrued, no other payment source is available, and the resident's continued stay in the facility is ensured unless the facility initiates a separate discharge proceeding under 10 N.Y.C.R.R. §415.3(h). Thus, nothing in §415(b)(2) prevents a nursing home, like any other provider of goods and services, from taking legal steps to secure payment of an outstanding receivable.

2. 10 N.Y.C.R.R. § 415.3(b)(3)

This subsection of the regulations imposes the following additional prohibition on nursing homes: "The nursing home...shall not require residents or potential residents to waive their rights to Medicare or Medicaid benefits."

A defendant in a collection action filed by a nursing home for payment of an outstanding debt is unrestricted in his or her right to pursue Medicaid coverage of that debt. There is nothing that occurs in the course of the litigation that impedes, impairs, or otherwise limits the right of the defendant to complete a Medicaid application or appeal a Medicaid denial. Certainly the nursing home plaintiff, who shares the defendant's interest in securing a Medicaid budget, will not require the resident to waive the right to Medicaid benefits.

Pursuing Medicaid coverage and defending a private collection action are not mutually exclusive. In fact, nursing homes usually go to great lengths to preserve Medicaid as a potential payment source for their residents, even after legal action is initiated.

3. 18 N.Y.C.R.R. §360-7.5(a)(3)

Whereas the previously referenced sections do not *prohibit* nursing homes from demanding private payment from individuals seeking to have their medical bills covered by Medicaid, this regulatory section implicitly *permits* this to occur by contemplating a situation where a Medicaid applicant or the applicant's representative is entitled to reimbursement of out-of-pocket expenses incurred paying medical bills while Medicaid coverage is being pursued.

Section 360-7.5 sets forth the method by which Medicaid pays for medical care. Paragraph 3 of the Section describes the exceptional circumstances under which payment will be made to a recipient or the recipient's representative instead of to the enrolled Medicaid provider. The exception is stated as follows:

> Payment may be made to a recipient or the recipient's representative for paid medical bills if:

> (a) an erroneous MA [Medical Assistance] eligibility determination is reversed (whether the reversal is due to the social services district discovering its own error or is the result of a fair hearing decision or court order), or the social services district fails to determine MA eligibility within the time periods set forth in section 360-2.4 of this Part; and

(b) the erroneous eligibility determination or the delay in determining eligibility caused the recipient or the recipient's representative to pay for medically necessary services which otherwise would have been paid for by the MA program.

The regulation goes on to provide that, for purposes of this section, the rate of reimbursement derives from the reasonable out-of-pocket expenditures of the recipient or the recipient's representative, and not the Medicaid reimbursement rate in effect at the time the services were rendered.

If private payment could not permissibly be demanded of a patient who was pursuing third party coverage from Medicaid, why would the Medicaid regulations provide a method for reimbursing patients and their representatives who use their personal funds to cover the cost of necessary medical care received during the pendency of a Medicaid application or appeal?

4. 42 C.F.R. § 483.12(c)(2)

This federal regulation governs the admission, transfer and discharge rights of nursing home residents. The cited subsection, which requires nursing homes to provide all residents with equal access to quality care, provides as follows:

> The facility may charge any amount for services furnished to *non-Medicaid residents* consistent with the notice requirement in §483.10(b)(5)(i) and (b) (6) describing the charge; [*emphasis added*].

Medicaid applicants and Medicaid appellants are not Medicaid residents. Whereas nursing homes must accept Medicaid reimbursement on the accounts of their Medicaid residents, this regulation makes clear that facilities are free to charge non-Medicaid residents the private pay rate at least until such time as they become Medicaid residents.

B. Relevant Statutes

Most often, elder law attorneys cite the New York Public Health Law (NY Public Health Law) as containing the purported ban against private collection actions where Medicaid is being pursued in connection with an unpaid nursing home bill. Like the abovereferenced regulatory sections, there is also no statutory authority in the NY Public Health Law or elsewhere banning private collection actions against Medicaidpending nursing home residents.

1. NY Public Health Law § 2801-d

Section 2801-d of the NY Public Health Law gives nursing home residents a private cause of action against a facility that has violated their rights, but this section is of no use to a defendant/ nursing home resident who is being sued for collection by an unpaid nursing home. The applicability of § 2801-d hinges on the potential plaintiff/nursing home resident being deprived of a "right or benefit." No viable cause of action exists under § 2801-d without the violation of a right or benefit. Subsection 1 of § 2801-d defines the "right or benefit" that entitles a nursing home resident to sue the nursing facility for damages based upon the deprivation of same as "any right or benefit created or established for the well-being of the patient by the terms of any contract, by any state statute, code, rule or regulation or by any applicable federal statute, code, rule or regulation...."

No contract, statute, code, rule or regulation gives a nursing home resident the "right" to pursue Medicaid immune from a collection action for an unpaid invoice. Similarly, no legal authority entitles a nursing home resident to any "benefit" of the Medicaid program before that resident has been found to qualify for Medicaid. In the absence of such a "right or benefit," Section 2801-d does not insulate nursing home residents against private collection actions while they pursue potential Medicaid coverage.

In addition to requiring any private cause of action under § 2801-d to redress an independently created "right or benefit," a § 2801-d plaintiff must have suffered "deprivation and injury" from the nursing home's violation of the right or benefit. As already noted, no right or benefit is implicated when a Medicaid-pending resident is sued by a nursing home to collect an accrued debt. Furthermore, there is no deprivation and injury to a nursing home resident who is named as a defendant in a collection action. The resident remains free to pursue his or her Medicaid application, and all available administrative and judicial appeals related thereto.

In the absence of any protected "right or benefit," and in the further absence of any "deprivation and injury," § 2801-d has no relevancy to private collection actions against Medicaid-pending residents. As a purely academic exercise, however, it is interesting to note that *even if* a Medicaid-pending resident had a right not to be sued for collection, and *even if* such a suit caused such resident "deprivation and injury," a defendant nursing home would *still* be free of liability under § 2801-d if it exercised "all care reasonably necessary to prevent and limit the deprivation and injury for which liability is asserted."

In most cases, as noted above, nursing homes are as eager as elder law attorneys to secure Medicaid coverage for their residents. Nursing homes therefore usually take independent steps to pursue Medicaid reimbursement for residents with unpaid accounts.

Where the nursing home has filed a Medicaid application for the resident, and requested the resident's Medicaid documentation, that nursing home has taken the reasonable measures needed to limit the injury to the resident while pursuing payment of the uncovered cost of care. For this additional reason, nursing homes that take independent measures to secure Medicaid coverage for their residents, while suing those same residents for collection, have nothing to fear from § 2801-d.

2. NY Public Health Law § 12

While it may go without saying, in the absence of any violation of the NY Public Health Law, Section 12 of that statute likewise fails to bolster any claimed prohibition against nursing homes suing Medicaidpending residents for collection.

Section 12 of the NY Public Health Law is entitled "Violations of health laws or regulations; penalties and injunctions," and it spells out the damages payable to persons harmed by health care providers who violate any provision of the Public Health Law. The Public Health Law does not prohibit medical providers from suing patients who have not paid for their medical care, Medicaid-pending or otherwise, so Section 12 has no bearing on the issue at hand.

Conclusion

Almost every nursing home would rather get paid by Medicaid than sue a resident in a private collection action. That said, nursing homes cannot afford to care for residents who have not qualified for Medicaid without either 1) having security that funds will be available to pay the bill in the event Medicaid coverage is not ultimately secured, or 2) initiating legal proceedings to protect themselves in case the resident is never approved for Medicaid.

This is where nursing home attorneys and elder law attorneys part ways. A nursing home, like any other provider of goods and services, has the right to be paid in a timely manner. When timely payment is not forthcoming, nursing homes enjoy the same rights as every other business and individual to use the legal system to get paid.

Nursing homes that file private collection actions do not interfere with the rights of their residents to pursue Medicaid; do not require private payment instead of, or in addition to, accepting Medicaid reimbursement; are not billing their residents in advance for services not yet rendered; and always remain willing to accept Medicaid (plus any Net Available Monthly Income obligation) as payment in full if and when the resident is approved for coverage.

I confess to having felt the ghost of Benedict Arnold while pursuing private payment from Medicaid-pending residents on behalf of my nursing home clients; however, unlike Benedict Arnold, who sold out the Americans after defecting to the British Army, I always root for the success of the elder law attorney behind every Medicaid application or appeal. I know that when a hard-won Medicaid budget is finally in hand, we both feel the same urge to frame it. We are united in this regard. Nancy Levitin, Esq. is a Partner with Abrams, Fensterman, Fensterman, Eisman, Greenberg & Formato, LLP where she represents health care providers on reimbursement issues.

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 researchbased 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.

The Clinical Impact of the Family Health Care Decisions Act on the Role of Guardians and Other Surrogates

By Barbara Paris and Jennifer Breznay

Technological advances in medicine allow people increasingly more opportunities to choose among a wide array of treatment options ranging from aggressive life-sustaining treatments to end of life comfort care. People are living longer with complex, chronic and acute illnesses and understanding various options is difficult



Barbara Paris

and confusing. For example, the same treatment may be life sustaining, futile, or palliative, depending on the medical circumstances. Patients' and surrogates' choices are also influenced by the physical, emotional and financial burdens for themselves and their loved ones that they envision will be incurred by these decisions.

Although adults in New York State have the right to accept or refuse all life-sustaining treatments, approximately 40% of hospitalized adults cannot make their own treatment decisions¹ and health providers, proxies, surrogates and guardians are all challenged with making these decisions based on a hierarchy of bioethical standards, patient's known wishes, substituted judgments and patient's best interests,² as well as adhering to the law. The law reflects society's values including self-determination, personal wishes, preferences and desires and strives to implement the least restrictive interventions to preserve a person's autonomy. Most recently, the Family Health Care Decisions Act (FHCDA),³ enacted in 2010, gives surrogates and guardians more flexibility in their capacity to participate in decisions about life-sustaining treatment. For example, as outlined in the health care proxy statute enacted in 1991 in New York State,⁴ a proxy can make all health care decisions except decisions about artificial nutrition and hydration unless the agent has reasonable knowledge of the patient's wishes in this regard. Under the more recent FHCDA, surrogate decision makers, including guardians, can withhold and withdraw life sustaining treatments if the surrogate determines that the treatment would pose an extraordinary burden on the patient and two attending physicians concur that the patient's life expectancy is six months or less, or the patient's illness is incurable.

Pertinent to this, The New York Times featured a guardianship case on March 4, 2011.⁵ The article

discusses an older legal immigrant, hospitalized for almost a year in a persistent vegetative state following a brain hemorrhage. Two of the patient's six children are American citizens and have been involved in their mother's care whose life has been sustained with a feeding tube. The hospital had a legal guardian appointed citing concerns as



Jennifer Breznay

whether the family members were legally appropriate decision makers. The guardian subsequently withdrew the patient's feeding tube, stating that the family could not demonstrate that their mother would have wanted to live in a persistent vegetative state sustained by a feeding tube. The guardian presumably invoked the principles of known prior wishes and best interests in deciding to withdraw the feeding tube and limit the patients care to comfort-only measures. This case begs the question as to whether guardians have the same level of compassion and "interest" in the patient as do loving family members. Although the family was described as distraught over "ending someone's life by hunger as morally wrong and unrecognized in their culture," they were ineffective in demonstrating to the guardian or to the hospital that they were representing their mother's values. From a medical standpoint, this patient is dying of her underlying medical illness that left her in a persistent vegetative state. As patients in a persistent vegetative state do not perceive hunger, the feeding tube is only serving to prolong the dying process. Many would view the palliative approach taken by the guardian as the more humane and compassionate plan in the face of family members who were unable to step away from their own grieving and allow their mother to die comfortably. Some will use this case to argue that we are moving one step closer to "death panels" with dispassionate decision makers whose only interest is saving health care dollars. On the other hand, as guardians may be remunerated for their services, they may actually have monetary incentives to prolong the patient's life.

Historically, guardians have taken a much more conservative approach to end-of-life decision-making and withholding or withdrawing of life-sustaining treatments. Indeed, prior to the implementation of the FHCDA prioritizing guardians as surrogates, a guardian was required to petition the court in order to withhold or withdraw nutrition and hydration, as well as to withdraw other life-sustaining treatments such as breathing tubes. With the implementation of the FHCDA, life-sustaining treatment decisions can be made in facilities working with hospital staff adhering to specific guidelines.

A recent systematic review of 40 studies⁶ providing data on 2,844 surrogates, over half of whom were family members, concluded that making treatment decisions has a negative emotional effect on at least one third of the surrogates which can be substantial and last for months to years. The greatest stress involved end-of-life treatments. As poignantly noted in this article, stress can undermine the surrogate's ability to make decisions that protect the patient's interests and promote the patient's preferences. Conversely, other research has shown that families may not view a surrogate's deviation from their own preferences as an affront to their autonomy, recognizing the burden of these decisions. Indeed, many surrogates rely on other factors such as their own best interests or mutual interests based on documents with which they have little familiarity.⁷

Guardians for a person are likely to increase as the proportion of older persons in the population increases. Many of these guardians will be courtappointed strangers to the patient, rather than family members. How can we be confident that when we are no longer able to advocate for ourselves, someone else will make decisions in an objective unbiased way? The Health Care Proxy Law was an attempt to achieve that goal, yet less than 20% of the population has appointed a health care proxy, and many who have did so without discussing their wishes or values with the proxy. Others, who have discussed their wishes with their proxy, either verbally or in a living will, in many instances also will not succeed in having their wishes implemented, as proxies can be uncomfortable limiting treatments. Even when the patient retains decisionmaking capacity, a proxy can be very persuasive. A recent article entitled *The Power Proxy* discusses the case of an elderly patient who chooses to be guided by his son who insists on a trial of chemotherapy for his metastatic cancer. The patient dies, inadequately palliated, because the family held out for a miraculous recovery. In the end, the son is able to assuage his own guilt by recalling that the patient himself signed the consent for chemotherapy.⁸

The FHCDA is a major step in the right direction in approaching the objectives of respecting patients' values and acting in their best interests. By broadening the powers of surrogates, and therefore guardians, facilities and health care providers, working with families and other guardians, have more opportunities to make decisions about all medical treatments without having to petition the court, yet with many safeguards in place to protect the patient. The urgency for clinicians to learn how to support patients as they make choices that are best for them is eloquently articulated in an editorial titled *What Is the Right Intensity of Care at the End of Life and How Do We Get There*?⁹

Health care providers and surrogates must all now embrace this opportunity to responsibly communicate and use this newfound power to develop medically appropriate compassionate goals of care for patients who are approaching end-of-life.

Endnotes

- Raymont V, Bingley W, Buchanan A, David AS, Hayward P, Wessely S, et al. Prevalence of Mental Incapacity in Medical Inpatients and Associated Risk Factors: Cross-Sectional Study. 364 Lancet. 1421-27 (2004). [PMID:15488217].
- Berger J, DeRenzo E, Schwartz, J. Surrogate Decision Making: *Reconciling Ethical Theory and Clinical Practice.* Ann Intern Med. 2008; 149:48-53.
- 3. McKinney's Public Health Law, Ch. 45, Art. 29-CC (2010).
- The Health Care Proxy Law. Guidebook for Health Care Professionals. The New York State Department of Health & The New York State Task Force on Life and the Law. January 14, 1991.
- 5. Sontag, Deborah. *Immigrant's Health Crisis Leaves Family on Sideline*. New York Times, March 3, 2011.
- Wendler D, Rid A., Systematic Review: The Effect on Surrogates of Making Treatment Decisions for Others, Ann Intern Med. 2011; 154:336-346.
- Vig E, Taylor J, Starks H, et al. Beyond Substituted Judgment: How Surrogates Navigate End-of-Life Decision Making. 54 J AM Geriatr Soc 1688, 1688-93 (2006).
- Srivastava, Ranjana. *The Power Proxy.* N Engl J 2010; Med 363; 19:1786-1789.
- 9. Curtis J, Engelberg R. *What Is the "Right" Intensity of Care at the End of Life and How Do We Get There?*, 154 Ann Intern Med. 183, 183-284 (2011).

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Impact of the Patient Protection and Affordable Care Act

By Neil T. Rimsky

A great deal of ink has been spilled on the impact of the Patient Protection and Affordable Care Act¹ (PPACA) on the medical profession, not to mention society as a whole, including the economy. Early on, the issue was the "public option," with one side calling it absolutely essential, and the other side



calling it the socialization of the government. After the public option was removed, the focus was on the "individual mandate," requiring the purchase of health insurance, which remained in the signed version of the bill.

Predictably, there have been challenges, both in the courts and in Congress, following the November 2010 elections.

There are powerful truths on both sides of the argument. Those in favor of the PPACA, including the individual mandate, argue that the United States is one of the few industrialized nations that does not offer universal health care. Moreover, these proponents point to the economic theory of adverse selection. If the purchase of health insurance is not mandated, then logically, healthy persons will opt not to purchase the insurance while persons who are not as healthy will purchase the insurance. Insurance companies will experience higher costs which will be reflected in higher premiums, creating a cycle of increasing, spiraling costs, with fewer people who can afford the insurance. The only solution is to level the field with mandated insurance.

If everyone purchases insurance, then premiums of the healthy, as well as the premiums of the not healthy, support the same costs. Insurance premiums would remain at an affordable level, which is the goal of PPACA.

Opponents of the individual mandate attack the legislation on several grounds. First, they consider the mandate as beyond the scope of Congressional authority, or for that matter, the authority of the federal government. The federal court cases we discuss below are focused on the Commerce Clause. Does the federal government have the authority to tell persons that they must buy insurance? If the Commerce Clause can support such an intrusion, then what are the limits of federal power over individual lives?

Another argument put forward by the opponents of PPACA is that keeping costs down will logically require rationing of finite resources. Government bureaucrats will be making choices on the allocation of limited resources, which ultimately impact the quality of life. Such decisions are not, this argument goes, the appropriate domain of the federal government.

Both sides maintain that only their approach is the way to fiscal solvency. Proponents start with the assumption that universal health care is a basic right. The current situation, with spiraling costs, results in large percentages of uninsured. The uninsured consume a large portion of Medicaid costs for basic health care services by use of emergency facilities, which can be reduced dramatically. The opponents see another government entitlement that inevitably results in huge government expenses. During a recession, when finances are strained, the last thing we need are more entitlement programs.

As of this writing, there are five federal Court opinions, which are split three to two in favor of the legislation. Three district courts have found that the individual mandate is a proper exercise of the commerce power. *Liberty University, Inc. v. Geithner;*² and *The Thomas More Law Center v. Obama;*³ and *Mead v. Holder.*⁴ Two have held that the individual mandate violates the Commerce Clause. *Virginia v. Sebelious;*⁵ and *Florida v. U. S. Dept. of Health and Human Services.*⁶

In *Mead*, the most recent decision, Judge Gladys Kessler rejected the idea that the Commerce Clause can only control physical, not mental, activity. "It is pure semantics to argue that an individual who makes a choice to forgo health insurance is not 'acting,' especially given the serious economic and healthrelated consequences to every individual of that choice. Making a choice is an affirmative action, whether one decides to do something or not to do something."

The decision in *Florida v. U.S. Department of Health and Human Services* was different. This action was brought by the Attorneys General and/or Governors of 26 states, among others. The Court, here, looked at the Commerce Clause and determined that a decision not to purchase insurance was beyond the scope of Congress to control. This decision, penned by Roger Vinson, Senior U.S. District Judge, on January 31, 2011, went the farthest, declaring that by reason of the individual mandate violating the Commerce Clause, the legislation, as a whole, was struck, as the individual mandate was deemed not severable from PPACA.

There is no question but that the matter will be appealed and likely brought to the Supreme Court, unless Congress acts first to change the legislation.

Given the uncertainly, why are we paying attention to this legislation? To that inquiry there are several responses, the first of which is that the act may stay intact when brought to the Supreme Court. Or that, despite the most recent decisions, the individual mandate will be severable from the legislation.

The primary reason to study the Act is that it offers a look into Congress's view of the issue of long term care. What this legislation was offering and what insight that gives us into the future are critical issues. Even the Vinson decision refers to the "Independence at Home" project for the chronically ill, reviewed below as the Community First Option.

The trends potentially forecast by the PPACA are important. Baby Boomers are beginning to retire. The cost of custodial care on our society has grown exponentially. We're not limiting our analysis to the actual cost of programs, although those are significant. We also include loss of opportunity, loss of efficiency in the workplace, and the emotional and financial drain on family members who serve as caregivers.

How does the PPACA impact the elderly, and particularly with respect to long term care? How do the provisions impact those programs we know? Is there any impact on institutional care, home care, and other community based options, such as independent living, assisted living and continuing care retirement communities?

What trends are evident? This review does not attempt any thorough analysis. Indeed, a thorough analysis is not possible, as so much is left to action of the Secretary of Health and Human Services.

One of the central themes of PPACA regarding custodial care is the push to keep people in the community. Government supported home based care is not available in all jurisdictions across the country. New York supports a generous home based care program. As of this writing, the New York program encourages community based care primarily providing that the look-back period is limited to three months, and, more critically, there are no periods of ineligibility for home care. In other words, persons across the State can transfer assets and apply for home care the following month. Although the uncompensated transfers will be seen, there is no period of ineligibility. New York also permits the spousal refusal in home based care. Moreover, spousal refusal remains available for home based care.

On the other hand, there are other factors that limit the availability of home care. The first that comes to mind is the lack of public transportation, which limits the ability of qualified aides to get to the client's home. Home care is therefore primarily limited to areas with adequate public transportation.

A second factor that limits the availability of home care is relative cost. There are two competing considerations. The cost of nursing homes in the New York Metropolitan regions can easily be \$13,000 to \$15,000 a month. By comparison, the cost of home care at \$220 a day for a live-in, or \$6,500 a month, is a relative bargain. But that is not how it plays out in Medicaid reimbursement, and that is the crux of the second consideration. The reimbursement rate at a *nursing home* can be 55% to 60% of the private pay rate. However, the reimbursement cost of *home care* is often equal to or in excess of similar care available privately. Therefore, we are faced with the absurd argument that persons be placed in nursing home for financial reasons.

Community First Option

Little has been done to curb the inherent prejudice against home care found in Medical Assistance programs. PPACA attempts to address this prejudice with the Community First Option, found in §2401 of the Act. Beginning October of 2010, a State may provide through a State plan the provision of medical assistance for home and community based attendant services and supports for individuals who are eligible for medical assistance, for an individual who has been determined to require institutional level of care, and as to whom there has been a determination that, absent such services, the individual would be in a facility, but only if the individual chooses to receive such homeand community-based attendant services and supports.

The legislation provides that States shall make available home- and community-based attendant services and supports to eligible individuals, to assist in accomplishing activities of daily living, or ADLs. Such services shall be under a person-centered plan, agreed to by individuals in writing as appropriate.

These services shall be in a home or community setting (not a nursing home, mental hospital or intermediate care facility for mentally retarded) and under agency provider model or other model, the furnishing of which is selected, managed and dismissed by the individual (or the individuals representative); and controlled to the maximum extent possible by the individual and provided by an individual who is qualified to provide such services including family (defined by the Secretary of Health and Human Services). Services to be provided under PPACA shall include acquisition, maintenance and enhancement of skills necessary for the individual to accomplish ADLs, as well as back up systems or mechanisms (beepers or electronic devices) to ensure continuity of services and supports, and voluntary training on how to select, manage and dismiss attendants.

Excluded from such services are room and board, assistive technologies, other than those above, medical supplies or equipment and home modification. However, permissible home and community based services and supports may include:

> expenditures for transition costs, such as rent and utility deposits, first month's rent and utilities, bedding, basic kitchen supplies and other necessities required for an individual to transition from nursing facility, and

expenditures relating to a need identified in an individual's personcentered plan of services that increase independence or substitute for human assistance, to the extent that expenditures would otherwise be made for human assistance.

Under PPACA, payments to States, under Federal Medical Assistance for home and community based attendant services and supports, are increased by 6%. For a State to qualify, the State must develop and implement its program in collaboration with a Development and Implementation Council, established by the State that includes a majority of members with disability and elderly individuals. The State must provide the consumer controlled home and community based attendant services and supports to individuals on a statewide basis and in a manner that provides such services and support in the most integrated setting, appropriate to the individual's needs, without regard to age, nature of disability, of the form of home and community based attendant services.

During the first fiscal year of implementation, the State must maintain or exceed the level of State expenditures for Medical Assistance that is provided to individuals with disabilities or the elderly. The State must establish and maintain a comprehensive quality assurance plan with respect to community based attendant services and supports that includes standards for agency based and other delivery models with respect to training and appeal rights, incorporates feedback from consumers, monitors health and well being of each individual who receives home and community based attendant services and supports, including a process for mandatory reporting of allegations of neglect, abuse or exploitation and provides information about quality assurance. Each State must collect and report information, under Federal oversight, including data on how the State provides home and community based attendant services and supports, cost of services and supports, and how state persons who qualify for institutions or under a waiver program choose to receive home and community based services in lieu of institutional care. The States must comply with Fair Labor Standards.

How the Community First Option will play out is a matter of speculation. Much of the development and success of the program will be in the regulations to be promulgated by the Secretary of Health and Human Services (HHS). The Secretary of HHS must conduct an evaluation of the provision of home and community based attendant services and supports, to determine the effectiveness of the provision of such services and supports, in allowing individuals receiving such services and supports to lead an independent life to the maximum extent possible, the impact on the physical and emotional health of individuals who receive services, and a comparative analysis of the costs of services provided under the State plan to provide nursing home or institutional services.

The following are some of the additional provisions of the PPACA.

Money Follows the Person

PPACA extends provisions of Deficit Reduction Act 2005, known as "money follows the person." This grant supports two-fold Medicaid programs, first, to transition people who have lived in nursing homes back to their homes, apartments or group home, second, to change state policies so the Medicaid funds for long term care services follow the person.

Senior Housing Facility Demonstration Project

The Medicare Advantage Senior Housing Facility Plan is defined as a Medicare Advantage Plan that restricts enrollment to individuals who reside in a Continuing Care Retirement Community (CCRC), provides primary care onsite, provides transportation to beneficiaries to specialty providers outside the facility and has participated in a demonstration project for not less than a year. Although this provision sounds encouraging, Medicare covers skilled care, while CCRCs offer multiple levels of care, including custodial care. The benefits here would apply only to skilled care.

CLASS Act

This is the Community Living Assistance Services and Supports Act, known as the CLASS Act. This appears to be a variation of the concepts that generated the partnership program. The individual pays into a program and later gets the benefits provided by the federal government. The CLASS Act establishes a national *voluntary* insurance program for the purpose of purchasing community living assistance services and supports to: 1) provide individuals who have functional limitations with tools to allow them to maintain their personal and financial independence and live in the community; 2) alleviate burdens on family caregivers; 3) address institutional bias by providing a financing mechanism that supports personal choice and independence to live in the community.

To enroll, the "Active Enrollee" must pay premiums when actively employed for at least 60 months. Premiums must be paid for at least 24 consecutive months, if there is a lapse of premiums. Benefits are triggered if the individual is determined by a licensed health care professional to either require substantial supervision or be unable to perform two or more Activities of Daily Living for at least 90 days. Benefits include a \$50/day minimum with no lifetime limits.

Medicare

Two changes to Medicare should be noted. First, the PPACA tries to correct the available information that Medicare Advantage Plans cost more per patient than ordinary Medicare. PPACA creates performance bonus payments for Medicare Advantage Plans (Medicare C) based on the Plans' level of coordination and management. The Plans must not charge more for covered services than what is charged under traditional fee for service plans.

Second, the PPACA also addresses the problems of the Donut Hole in Medicare Part D plans. Drug manufacturers must provide 50% discount for prices of drugs in the donut hole. The Secretary of Health and Human Services can mandate certain drugs be covered if the Secretary determines that the drug is essential to the health of Part D beneficiaries.

Elder Justice

There are two other provisions worthy of note. The first tries to address the rise of elder abuse with the Elder Justice Act. Elder abuse is broadly defined to include the knowing infliction of physical or psychological harm or knowing deprivation of goods or services that are necessary to meet essential needs or to avoid physical or psychological harm. Elder justice is viewed from both a societal and individual perspective. The societal perspective is to prevent, detect, and prosecute elder abuse, neglect and exploitation, while the individual has the right to be free from abuse. Regulations to be issued include the formation of the Elder Justice Coordinating Council as well as an Advisory Council on Elder Abuse, Neglect and Exploitation.

Nursing Home Transparency

Finally, the PPACA includes provisions to insure transparency of information on the administration of nursing homes. The PPACA provides for identification of the governing body, officers, partners and directors as well as accounting accountability requirements. The act envisions websites shall offer comparative evaluations of facilities.

Endnotes

- 1. 42 U.S.C. §18001 et seq.
- 2. 2010 WL 4860299 (W.D.Va. 2010).
- 3. 720 F.Supp.2d 882 (E.D. Mich. 2010).
- 4. (D.C. 1:10-CV-00950-GK).
- 5. 728 F.Supp.2d 768 (E.D. Va. 2010).
- 6. 2011 WL 285683 (N.D. Fla. 2011).

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FOREIGN LANGUAGE DATABASE

Are you fluent in another language (both reading and writing)? If so, please let us know. Your colleagues may have referrals for you. Many of our members have potential clients who speak languages other than English. These potential clients need attorneys who speak their language. If you can READ, WRITE and SPEAK another language, please let us know, so that we can include you in the database.

Please send your name, address, email, phone, and fax, as well as the languages other than English in which you are fluent, to Sharon Kovacs Gruer's assistant, Melinda, at MelindaY@SharonKovacsGruer.com.

The 2010 Tax Relief Act—An Overview of the Law and Its Impact

By Nathaniel L. Corwin

On December 17, 2010, President Obama signed into law the Tax Relief, Unemployment Insurance Reauthorization, and Job Creation Act of 2010 (2010 Tax Relief Act),¹ bringing about yet another round of significant changes to the federal estate tax laws. The law postponed for two years (until January 1, 2013) the return to the higher estate,



gift and generation-skipping transfer tax rates in effect prior to 2002. The law also retroactively reinstated the estate tax to January 1, 2010, but permits the estate of a 2010 decedent to elect out of the federal estate tax, instead having the estate subject to the modified carryover basis rules of 2010 established under the Economic Growth and Tax Relief Reconciliation Act of 2001 (EGTRRA).²

A. Summary of the 2010 Tax Relief Act

The 2010 Tax Relief Act has reestablished the basic estate, gift and generation-skipping transfer (GST) tax infrastructure that was in place prior to 2010. Within that infrastructure the changes brought about under the new law are extensive, if only temporary. Major features of the new law include the following:

- The retroactive increase in the estate tax applicable exclusion amount to \$5 million for estates of decedents dying between January 1, 2010 and December 31, 2012;
- The retroactive decrease in the estate tax rates, with the top rate set at 35%;
- The reunification of the gift tax with the estate tax commencing January 1, 2011 (increasing the gift tax exemption to \$5 million), with the top gift tax rate set at 35%;
- The indexing for inflation of the estate tax and gift tax applicable exclusion amount beginning on January 1, 2012;³
- The introduction of "portability" for married couples, allowing the executor of the estate of a spouse dying in 2011 or 2012 to elect to pass to the surviving spouse any unused portion of the deceased spouse's applicable exclusion amount;⁴
- The reinstatement of the income tax basis step-up rules retroactive to January 1, 2010; and

• The retroactive change to the GST Tax exemption to \$5 million for transfers in 2010, 2011 and 2012.

Many of the major taxpayer-friendly features of the 2010 Tax Relief Act expire on December 31, 2012. Unless a new law is passed by Congress and signed into law by the President, the federal exclusion amount for estate and gift tax purposes will drop back to only \$1 million, with a top estate tax rate of 55% and the GST exemption will fall to \$1.3 million. The portability provisions allowing spouses to pass to the surviving spouse the unused portion of the applicable exclusion amount will expire as well.

B. Planning for Portability

The portability feature introduced by the 2010 Tax Relief Act provides that a surviving spouse may use any unused portion of the deceased spouse's \$5 million applicable exclusion amount. The deceased spouse's executor must make an election on a timely filed federal estate tax return, regardless of whether a return is otherwise required. If a surviving spouse is predeceased by more than one spouse, the amount of unused exclusion that is available for use by the surviving spouse is limited to the lesser of \$5 million or the unused exclusion of the last deceased spouse. Under the 2010 Tax Relief Act, portability is available only for deaths occurring in, or gifts made, during 2011 and 2012.

Credit Shelter (By-Pass) Trust Planning has long been a cornerstone of a sound estate plan for married couples. While the new portability feature may, upon first impression, appear to have rendered Credit Shelter planning obsolete, a closer view shows otherwise. The reasons include those discussed below.

- The portability feature may not be reenacted after January 1, 2013;
- Appreciating assets in the surviving spouse's estate will not be sheltered from possible future estate taxation to the same extent as assets held in a credit shelter trust. Once funded, assets in a credit shelter trust, regardless of any appreciation in value between the time of funding at the death of the first spouse and the termination of the trust, will be sheltered from further estate taxation.⁵ In contrast, the portability provisions will be capable of sheltering at most an aggregate amount of \$10 million;⁶
- The federal law does not affect state estate tax laws, such as New York State's, which impose a separate state estate tax liability without

affording a portability provision. In such states, preservation of the state exempt amount in the first spouse's estate must be achieved by an actual disposition of assets to a credit shelter trust or other non-charitable beneficiaries other than the surviving spouse;

- Assets held in a credit shelter trust should provide superior creditor protection to assets personally held by the surviving spouse;
- Leaving all assets outright to the survivor risks the possibility of a change in the estate plan (whether intentional or unintentional) by the surviving spouse. A trust enables the first spouse to direct the disposition of the remainder of the assets in the trust; and
- The portability provisions do not apply to the GST exemption.

C. Credit Shelter Formulas

Because the federal applicable exclusion amount has been increased to \$5 million, married couples with Wills containing Credit Shelter dispositions must review the funding formula contained in the Will to examine whether the formula results in an inadvertent underfunding (or overfunding) of the amount passing to the surviving spouse. Illustratively, assume that husband, having an estate worth \$5 million, has a Will providing for creation of a trust for his wife equal to the federal applicable exclusion amount with the balance of the estate passing outright to her. His death in 2009, when the applicable exclusion amount was \$3.5 million, would have resulted in a credit shelter trust funded with \$3.5 million, with the balance of \$1.5 million passing outright to his wife. Death in 2011 would result in the entire \$5 million passing into the credit shelter trust and nothing passing to his wife. Such a result could be contrary to the original intentions of the testator. In addition, in states such as New York which have a lower estate tax threshold⁷ than the federal applicable exclusion amount, the triggering of a sizable state estate tax bill upon the death of the first spouse may prove to be an additional unwelcome surprise⁸ as many married couples wish to defer payment of any estate tax until the death of the surviving spouse.

D. Gift Planning

Under the provisions of EGTRRA, the gift tax exemption diverged from the estate tax applicable exclusion amount after 2001, remaining at \$1 million even during the 2010 period of federal estate tax repeal. Reunification of the gift tax with the estate tax under the 2010 Tax Relief Act for the two year period commencing January 1, 2011 offers tremendous wealth transmission possibilities for individuals with the net worth to afford large inter-vivos transfers. For the next two years, taxpayers may make gifts of up to \$5 million per person or up to \$10 million for a married couple, outright or in trust, without incurring federal gift taxes. Of course, when analyzing the potential tax savings associated with a gift, it is critical to take into consideration that the donee of a gift receives the donor's income tax basis in the gifted assets,⁹ rather than the stepped up basis that would apply if the property were owned by the donor at death.¹⁰ Hence the potential capital gain and income tax liabilities to the donee upon a later sale should be analyzed as compared to the estate tax consequences of retaining the assets.

Planning should also consider how a potential gift will benefit the taxpayer under the unified estate and gift tax system. While gifts remove the gifted assets from the taxpayer's gross estate, taxable gifts¹¹ must be added to the donor's taxable estate on the estate tax return for purposes of determining the estate tax due at death. Thus gifts within the gift tax applicable exclusion amount may not offer a significant computational tax rate advantage to testamentary transfers.¹²

From a transfer tax perspective, therefore, advantages to be gained by making substantial gifts should include the removal of the appreciation of the gifted assets from the donor's estate and the ability to transfer the gifted assets at less than their full value through some form of leveraged transfer, some examples of which are discussed below. Taxpayers domiciled in states that impose an estate tax but no gift tax may also consider the potential for gifts to reduce state estate taxes.

1. Removal of Appreciation of Gifted Assets from the Donor's Estate

A fundamental transfer tax benefit of gifting is the removal from the donor's estate of the potential estate tax on any appreciation in value of the gifted property taking place after the gift. For example, a gift of \$1,500,000 would remove approximately \$615,000 in additional appreciation before income taxes in the donor's estate after ten years, assuming a modest 3.5% annual rate of return.

2. Application of Valuation Discounts

Application of valuation discounts may be appropriate in a variety of gifting scenarios, and when properly planned, may reduce a taxpayer's overall transfer tax liability. The most commonly applied discounts are the discount for lack of marketability and the discount for lack of control. Depending upon the facts, when combined, discounts for lack of marketability and lack of control can decrease the fair market value of the gifted assets reportable on the gift tax return by percentages ranging from 15% to 50%. Provided the donor does not retain excessive control over the gifted asset,¹³ discounted gifts can enable a taxpayer to decrease the value of the taxable estate at a transfer tax cost far less than the actual fair market value of the gifted assets,¹⁴ while at the same time removing from the estate any subsequent appreciation on the gifted assets. Fortunately, proposed legislation which was considered by Congress that would have limited or prohibited the application of valuation discounts for lack of marketability and lack of control to non-operating family entities such as family limited partnerships and limited liability companies was not included in the 2010 Tax Relief Act.

3. Transfers in Trust with Retained Interest

The Internal Revenue Code and regulations specifically authorize certain transfers allowing the donor to make a gift in trust to his or her beneficiaries of a remainder interest in the subject property, with the remainder interest valued at less than the total value of the property at the time of the gift. Two such tools are the grantor retained annuity trust (GRAT) and the qualified personal residence trust (QPRT).

a. The GRAT¹⁵ is an irrevocable trust to which a donor transfers assets in exchange for an annuity for a fixed term of years chosen by the donor. The value of the gift equals the fair market value of the property transferred to the GRAT less the value of the annuity retained by the donor, using the interest rate determined under §7520 of the Internal Revenue Code for the month of the transfer of the property to the GRAT.¹⁶ Upon expiration of the term, if the donor is living, any remaining trust assets pass to the beneficiaries free of gift tax. The §7520 rate is known as the "hurdle rate" because the assets contributed to the GRAT must appreciate above that rate to pass wealth to the beneficiaries. Proposed legislation which would have made GRATs less likely to achieve their objectives, by requiring at least a ten-year term and requiring a remainder with some reportable value (that is, prohibiting "zeroed-out GRATs"),¹⁷ was not included in the 2010 Tax Relief Act.

b. The QPRT¹⁸ is an irrevocable trust to which a donor transfers his or her principal residence or vacation residence for a fixed term of years chosen by the donor. Upon transfer, the donor will be treated as having made a taxable gift in an amount equal only to the discounted present value of the remainder interest in the residence, determined by reference to the fair market value of the residence at the time of transfer and applicable IRS actuarial tables.¹⁹ In determining the amount of the discount, the §7520 rate is applied for the month of the transfer of the residence into the QPRT. During the fixed term, the donor retains the full right to the use and occupation of the residence and remains responsible for the payment of expenses.²⁰ Upon the expiration of the fixed term, the property is distributed to the beneficiaries.²¹ QPRTs are an attractive estate planning vehicle for those taxpayers who wish to achieve a significant gift without affecting liquidity.

As with other completed gifts, any subsequent appreciation on property gifted into a GRAT or a QPRT is also removed from the donor's estate. Application of valuation discounts to the subject property will further enhance the effectiveness of these gifting methods.²²

4. Reduction of State Transfer Taxes

In states such as New York which impose an estate tax but not a gift tax, gifts can result in considerable state estate tax savings.²³ For example, a New York State decedent with a \$5 million estate dying in 2011 would face a New York State estate tax liability of approximately \$391,600. Had that same decedent previously gifted \$1.5 million to his or her heirs, the New York State estate tax would drop to approximately \$229,200, resulting in a New York State estate tax savings of \$162,400.

E. GST Planning

The 2010 Tax Relief Act raised not only the estate and gift tax applicable exclusion amounts, but also raised the GST exemption to \$5 million per person for transfers in 2011 and 2012. One of the impediments to making large gifts, whether outright or in trust, to grandchildren and more remote descendants (skip persons) is the GST tax which may be imposed in addition to gift and estate taxes. The substantial increase in the GST exemption provides an expanded window of opportunity for taxpayers to transfer wealth to grandchildren and more remote generations at little or no transfer tax cost.

High net worth individuals should give particular consideration during the next two years to the creation of multi-generational and dynasty trusts. Such trusts may be established for the benefit of children, grandchildren and beyond (subject to the applicable state law's rule against perpetuities) by a husband and wife funded with up to \$10 million, free of gift or GST tax, assuming no prior use of those exemptions. Once funded, and assuming allocation of GST exemption to the trust, the assets, and any appreciation thereon, will be free from further gift, estate or GST taxes. The leverage which may be gained by funding with life insurance or assets having the potential for appreciation and which may be subject to valuation discounts enhances the significant intergenerational wealth transfer opportunities available during the next two years.

Caution With Opportunity

It is far from certain what Congress will do during the next two years regarding estate, gift and GST tax reform. Planners should pause to consider the possibility that come January 2013, federal transfer tax laws may indeed revert under the sunset provisions to the pre-EGTRRA levels, dropping the estate and gift tax exclusions back to \$1 million with a top rate of 55%.²⁴ Numerous other scenarios are possible including repeal or a reversion to the rules in place during 2009, reestablishing a \$3.5 million estate tax and GST exclusion, a \$1 million gift tax exclusion and top rates of 45%.²⁵ While the possibility of a return to lower exclusion amounts argues in favor of making substantial gifts during the two year window, a note of caution may be in order.

The present law does not address the treatment of taxpayers who have made the maximum of \$5 million in gifts and subsequently die at a time when the exclusion amount has reverted to a lower threshold. How would the estate of a taxpayer who has made transfers in excess of the then current applicable exclusion amount be treated? Grandfathering provisions would seem logical, but predicting what the federal government will do with respect to transfer tax planning has become virtually impossible. While planners and taxpayers can hope that the next round of legislative changes will bring a greater degree of permanence to our transfer tax laws, planning necessarily must take place within the current legal framework. The next two years will be an eventful period for the estate planning attorney, as taxpayers seek to take advantage of the historic wealth transmission opportunities presented by the 2010 Tax Relief Act.

Endnotes

- 1. Tax Relief, Unemployment Insurance Reauthorization, and Job Creation Act of 2010. Pub. L. No. 111-312, 124 Stat. 3296 (2010).
- 2. Economic Growth and Tax Relief Reconciliation Act of 2001. Pub. L. No. 107-16, 115 Stat. 38 (2001).
- 3. 26 U.S.C. § 2010(c)(3)(B) (2010).
- 4. 26 U.S.C. § 2010(c)(4) (2010).
- 5. Imposition of a GST tax may be possible depending on the terms of the trust, the identity of the beneficiaries and the extent to which GST exemption has been allocated to the trust.
- This limitation is, however, subject to the inflation adjustment commencing January 1, 2012 provided under 26 U.S.C. § 2010(c)(3)(B) (2010).
- 7. N.Y. Tax Law § 951 (McKinney's 2010).
- 8. Without consideration of deductions, the New York State estate tax on a \$3.5 million credit shelter disposition would be approximately \$229,200. The New York State estate tax on a \$5 million credit shelter bequest would be approximately \$391,600. Depending on the facts, payment of a state estate tax upon the death of the first spouse may or may not be prudent tax planning.
- 9. 26 U.S.C. § 1015 (1984).
- 10. 26 U.S.C. § 1014 (2010).
- 11. "Taxable gifts" are gifts in excess of the annual exclusion amount (presently \$13,000) which do not qualify for the marital or charitable deduction.
- 12. Gifts of a present interest do offer the advantage of enabling the donor to utilize the annual per donee gift tax exclusion, which is currently \$13,000. Additionally, taxable gifts occurring more than three years prior to death which exceed the gift tax exemption amount and result in the payment of a gift tax do have a computational advantage over estate taxable testamentary transfers. The gift tax is a tax exclusive computation (calculated on the amount received by the

beneficiaries without including the amount on which the gift tax is paid) while the estate tax is a tax inclusive calculation (calculated on the total assets owned at death, including the amount used to pay the estate tax). This computational advantage is eliminated under the "gross up" rule if a taxable gift occurs within three years of death, as the gift taxes paid on the gift must be included in the gross estate under 26 U.S.C. § 2001.

- See Estate of Strangi v. Commissioner, T.C.M. 2003-145 (2003), affirmed, 417 F.3d 468 (5th Cir. 2005); Estate of Disbrow, T.C.M. 2006-34 (2006).
- 14. Valuation discounts may also be appropriately taken on an estate tax return. However, certain discounts may be lost if the taxpayer retains ownership of one hundred percent of an asset at death.
- 15. 26 U.S.C. § 2702(b) (1996) and C.R.R. § 25.2702-3.
- 16. The § 7520 rate is published monthly by the IRS pursuant to Internal Revenue Code § 7520 and is used to calculate the present value of term interests, life interests, annuities and remainders. 26 U.S.C. § 7520 (1988).
- See Patricia Galteri, Nathaniel L. Corwin and Carmela T. Montesano, Grantor Retained Annuity Trusts: An Estate Planning Golden Opportunity, NYSBA Elder Law Attorney, Vol. 20, No. 4, at 28 (Fall 2010).
- 18. 26 U.S.C. § 2702 (1996) and C.R.R. § 25.2702-5(c).
- 19. C.R.R. § 25.2712-5; C.R.R. § 20.2031-7(d); IRS Pub. 1457 and IRS Pub. 1458.
- 20. If the residence is sold prior to the expiration of the fixed term, the trust may hold a replacement residence (provided the purchase occurs within a two-year qualifying period), or the after-tax proceeds must be held in a separate account in which case the donor's interest in the trust will be converted into a GRAT for the remainder of the fixed term.
- 21. If the taxpayer wishes to continue living in the residence after the expiration of the fixed term, he or she must rent the residence from the remainder beneficiaries (any such rental should be at fair market rental, determined by an independent appraiser).
- 22. In the QPRT context, married couples may consider each creating a separate QPRT, each a one-half tenancy in common interest in the residence to their separate QPRT. A discount may be appropriate in valuing the fractional tenancy in common interests in the property, resulting in a further reduction in the value of the gift.
- 23. New York repealed its gift tax effective January 1, 2000. Laws of 1997, ch. 389, § 219 (Part A), subsections (1) and (2). New York's estate tax exemption level is currently \$1 million. The estate tax imposed equals the lesser of (a) the federal state death tax credit which would be allowable to the estate using the federal table in effect as of July 22, 1998, or (b) the federal estate tax that would be imposed on the estate, but assuming a federal unified credit equivalent of \$1 million. The computation can lead to unexpected results. Estates of less than the New York estate tax threshold of \$1 million may nevertheless be subject to New York estate tax if prior federal taxable gifts have been made.
- 24. The GST exemption will also fall to \$1 million (with an inflation adjustment), with a top rate of 55%.
- See Department of Treasury, "General Explanations of the Administration's Fiscal Year 2012 Revenue Proposals" (Feb. 14, 2011).

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The Impact of the Wage Theft Prevention Act on Domestic Employees in New York State

By Evan M. Gilder

As a follow-up to our previous article on Domestic Employers, there is another amendment to New York's Labor Law that impacts domestic employees. This legislation relates specifically to notices employers are required to give employees with respect to wage-related matters. The new legislation, the New York Wage Theft Prevention Act (the Act),



was signed into law on December 10, 2010, and became effective April 9, 2011. The legislation deals primarily with an employer's obligation to give employees notice of their pay rate and payday, wage statements, and retention of payroll records, and sets forth penalties for noncompliance. The following is a summary of the many changes made to the Labor Law by the Act.

A. Notice of Pay Rate and Payday

Employers must provide each employee with a written notice (in English and in the language identified by the employee as his or her primary language at the time of hiring) pertaining to pay rates and paydays at the time of hiring and on or before February 1 of each subsequent year of employment. The requirement means that all existing employees must receive this notice on or before February 1, 2012. The notice, the form of which will be prepared by the New York Department of Labor (the NYDOL) and posted on the NYDOL's website, must include the following:

- The rate or rates of pay and the basis of the rate (including overtime rates if the employee is not exempt from overtime compensation), whether paid by the hour, shift, day, week, salary, piece, commission, or by another method;
- Allowances (including tip, meal, or lodging allowances), if any, claimed as part of the minimum wage;
- The regular payday designated by the employer;
- The name of the employer, and any "doing business as" names used by the employer;
- The physical address of the employer's main office or principal place of business and the mailing address, if different;

- The telephone number of the employer; and
- Such other information as the NYDOL deems material and necessary.

Whenever such notice is provided to an employee, the employer must obtain from the employee a signed and dated written acknowledgment of receipt of the notice, which acknowledgment must also include an affirmation by the employee that he or she identified his or her primary language to the employer and that he or she received a copy of the notice in such language (or, as provided below, in English). Each such notice and acknowledgment must be retained by the employer for at least six years.

The Act requires the NYDOL to prepare dual language templates that comply with the above requirements. As of the writing of this publication, the DOL template is available in four languages (English, Spanish, Chinese and Korean). The NYDOL has stated it will also supply this documentation in Creole, Polish and Russian. If the employee identifies a language for which a template is not available from the NYDOL, the employer is only required to provide an English language notice or acknowledgment. Employers are not subject to penalty for any errors or omissions in the non-English portion of any notice provided by the NYDOL.

The new notice required under the Act replaces and expands the October 2009 legislation that required only written notice of pay rates and pay days at the time of hire.

B. Notice of Information Changes

In addition to the above notices, employers are also required to notify each employee in writing of any change to the information described in the bulleted items above at least seven calendar days prior to the time of such change, unless the change is reflected on the wage statement described below.

C. Wage Statements

With every payment of wages, employers must provide each employee a statement that includes, at a minimum, the following information:

- The dates of work covered by the wage payment;
- The name of the employee;
- The name, address and phone number of the employer;

- The rate or rates of pay and basis thereof, whether paid by the hour, shift, day, week, salary, piece, commission, or by another method;
- Gross wages;
- Deductions;
- Allowances, if any, claimed as part of the minimum wage; and
- Net wages.

Domestic employees, for whom all are considered non exempt employees, the statement must include: the regular hourly rate or rates of pay; the overtime rate or rates of pay; the number of regular hours worked; and the number of overtime hours worked.

A statement must be given with each payment of wages. The wage statement may be provided electronically, but workers must be able to access their statements on a computer provided by the employer and be able to print a copy for their records.

D. Retention of Payroll Records

Employers must establish, maintain and preserve for not less than six years contemporaneous, true, and accurate payroll records showing for each week worked the hours worked as well as the other information required to be included in each employee's wage statement, as described above.

E. Posting Requirements

The Act gives the Commissioner of Labor the power to require employers found to have violated the wage payment laws to post a notice of the violation for a period not to exceed one year in an area visible to employees, summarizing the violations found and other information deemed pertinent by the Commissioner. If the violation was willful, the Commissioner can require the employer to post such a notice in an area visible to the general public for a period not to exceed 90 days.

F. Retaliation

The Act amends the provisions of the Labor Law prohibiting retaliation against an employee for action taken, or believed by the employer to have been taken, by such employee with regard to Labor Law violations. In addition to the existing right to impose a civil penalty against the employer of between \$1,000 and \$10,000, such civil penalty may be imposed against the person who retaliated, and the Commissioner may now also order injunctive relief, liquidated damages against the employer or such person of up to \$10,000, rehiring or reinstatement to a former or equivalent position and an award of lost compensation or an award of front pay in lieu of reinstatement and an award of lost compensation. Any employer or his or her agent, or the officer or agent of any corporation, partnership, or limited liability company, or any other person who violates the anti-retaliation provisions of the Law shall be guilty of a class B misdemeanor.

G. Penalties for Noncompliance

Not surprisingly, penalties for violation of the Labor Law have been increased significantly by the Act, as follows:

- An employee who is not provided the notice of pay rate and payday described above within 10 business days of his or her hire date may recover damages of \$50 per work week with a maximum amount of up to \$2,500.
- An employee who is not provided the wage statement described above may recover damages of \$100 per work week with a maximum amount of up to \$2,500.

In summary, in order to minimize risk to families, household employers need to insulate themselves with documentation that states the terms of employment and rates of pay. Household employers must think of themselves as a business and manage the underlying risk that is associated with being an employer.

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Ethics Poll Conducted by the Elder Law Section Ethics Committee

By Judith B. Raskin and Natalie J. Kaplan

The Elder Law Section Ethics Committee e-mailed a poll on February 7, 2011 to all Section members. A week later the Committee e-mailed Poll #1 Results and Commentary, set forth below.

POLL #1: RESULTS

Poll #1 asked the question:

A sole agent under a durable power of attorney comes to see you for legal advice regarding her mother, the principal. You have never met or represented her mother. Who is the client?



Judith B. Raskin

The poll offered three choices. The distribution below shows the results from 229 entries received:

Agent	52.4% (N = 120)
Principal	31.0% (N = 71)
Either agent or principal	16.6% (N = 38)

Based on the authorities consulted, we conclude that the answer is "Either agent or principal," recognizing that the protection of the principal takes priority in either case.

COMMENTARY

We encountered conflicting views on "who is the client?" The ABA Commission on Law and Aging takes the view that: "The client is the person whose interests are most at stake...."¹ Russo & Rachlin appear to concur, saying, "The elder law client is best described by the legal services relevant to the needs of the individual...."²

The Aspirational Standards of the National Academy of Elder Law Attorneys was the only source to consider the issue, specifically in the context of an agent under a Power of Attorney. Aspirational Standard B(6) says that an elder law attorney:

> [i]n representing a client who is a fiduciary under a power of attorney... ensures that the client understands that the duties of both the fiduciary and the attorney ultimately are governed by

the known wishes and best interest of the principal.^{3, 4}

The commentary to Aspirational Standard B (6) states that the person seeking legal advice, or for whom legal advice is sought, "is presumptively the client...." But it continues, saying that if the identified client is not present, "[t]he attorney may determine that a different person is the client."⁵



Natalie J. Kaplan

Proponents of the agent-as-client note that an incompetent principal could not engage in an attorneyclient relationship to communicate, give directions, or make decisions.

The current New York Rules of Professional Conduct do not address this issue.

SUMMARY

To summarize, in the Committee's view:

- 1) the client can be the agent, in a fiduciary relationship, or the principal;
- 2) the attorney makes the choice;
- 3) the attorney may presume the agent is acting in the principal's best
- 4) interest and need not consult separately with the principal;
- 5) the interests of the principal are paramount.

Endnotes

- 1. A.B.A. Commission on Law and Aging, *Understanding the Four C's of Elder Law Ethics* (Nov. 2003) 1, http://www. americanbar.org/content/dam/ aba/migrated/aging/ PublicDocuments/4cs_bro.authcheckdam.pdf.
- 2. Vincent Russo & Marvin Rachlin, *New York Elder Law and Special Needs Practice*, 2010 Ed. 4 (2010).
- 3. Nat'l Acad. of Elder Law Attorneys, Professionalism in Ethics Committee, *Aspirational Standards for the Practice of Elder*

Law with Commentaries, 2 NAELA J. 7 14 (2006) (discussing Aspirational Standard B (6)).

- 4. N.Y. Gen. Oblig. Law §5-1501(a) (2009) ("an agent acting under a power of attorney has a fiduciary relationship with the principal").
- 5. Nat'l Acad. of Elder Law Attorneys, *supra*, note 3.

Judith B. Raskin is a partner in the firm of Raskin & Makofsky located in Garden City and practices in the areas of elder law and trusts and estates. She is a Certified Elder Law Attorney (CELA) by the National Elder Law Foundation. She maintains membership in the National Academy of Elder Law Attorneys, Inc., the Estate Planning Council of Nassau County, Inc., and the New York State and Nassau County Bar Associations. Judy is a past chair and current member of the Alzheimer's Association, Long Island Chapter Legal Committee. Judy has also contributed the Recent New York Cases column since 1995.

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Recent New York Cases

By Judith B. Raskin

Medicaid Recovery

An executor appealed from an order granting the Dept. of Social Services full recovery from decedent's estate for benefits provided to his wife less benefits left to his disabled child. Recovery modified. *Matter of Schneider*, 70 A.D.3d 842, 894 N.Y.S.2d 162, (App. Div. 2nd Dep't 2010).



The Department of Social Services (DSS) filed a claim against decedent's estate of \$386,382.77, the full cost of institutional benefits provided to decedent's wife. The executor petitioned to invalidate the claim. The decedent had excess resources at the time of the Medicaid application of \$268,048 and excess monthly income of \$157.80. Surrogate's Court, Nassau County, denied the petition except for that portion going to decedent's disabled child. The executor appealed.

The Appellate Division modified the decision below to grant the petition in the amount of \$279,883 comprising the excess resources plus the excess income over the covered period less the benefit to the disabled child. DSS can only recover the excess resources at the time of application and the amount of the excess income over the benefit period.

Gifting by Article 17A Guardian

Article 17A guardians submitted an application requesting the authority to gift their ward's assets to reduce estate tax. Granted. *Matter of Joyce G.S.*, 2010 NY Slip Op. 20518; N.Y. Misc. LEXIS 6142 (Sur. Ct., Bronx County, Dec. 22, 2010).

The 17A guardians for Joyce G.S. had applied to the Surrogate's Court, New York County, to make gifts of their ward's assets to reduce estate tax. Surrogate Glen had previously denied the request, finding that Article 17A does not provide for substituted judgment. The only recourse would be for the guardians to file under Article 81.

The Bronx County Surrogate's Court reversed. The court based its reversal on: 1) prior instances where an Article 17A guardian was authorized to make gifts; 2) change in common law no longer denying substituted judgment in cases where the ward never was competent to express his wishes; and 3) the substituted judgment provisions in Article 81 codifying common law. After addressing the factors for authorizing gifts as set forth in Article 81, the court authorized gifts, finding that Joyce G.S. would continue to have sufficient funds to provide for all of her needs, that she had a close relationship with her family, the ultimate beneficiaries of the gift, and that she would want her estate taxes reduced.

Power to Amend Trusts

Petitioner sought an accounting from the trustee she removed and replaced while acting as attorney in fact. Denied. *Perosi v. Ligreci and Desantis*, 2011 NY Slip Op. 21048; 2011 N.Y. Misc. LEXIS 341 (N.Y. Sup. Ct., Richmond County, Feb. 14, 2011).

In 1991 Nicholas LiGreci created the LiGreci Irrevocable Insurance Trust naming his brother, John T. LiGreci, as trustee, his accountant as successor trustee and his three children as beneficiaries. On April 20, 2010, Mr. LiGreci executed a Power of Attorney appointing his daughter, Linda LiGreci Perosi, as agent and her son as successor agent. The document's Statutory Major Gift Rider did not include the power to amend or revoke previously executed trusts or other estate planning documents.

On May 19, 2010, Linda Perosi, as attorney in fact, executed an amendment to the trust removing the trustee and successor trustee and appointing in their place her son Nicholas Pelosi as trustee and a successor trustee. The beneficiaries all consented in writing to the amendment. Nicholas LiGregi died 15 days later without signing the amendment. Linda Perosi petitioned for an order requiring the original trustee, John T. LiGreci, to account.

The court denied the petition. Nicholas LiGreci could himself amend the trust pursuant to EPTL Sec. 7-1.9, but Linda Perosi, the attorney in fact, could not sign the amendment on his behalf. The statutory support for a creator to amend or revoke an irrevocable trust is personal. It can only be accomplished by an attorney in fact if the Power of Attorney specifically grants the power to do so. The court noted that this also applied to other estate planning instruments.

Denial of Exceptional Circumstances for Raised MMMNA

The Dept. of Social Services appealed from a decision that living expenses exceeding the MMMNA constituted exceptional circumstances resulting in significant financial distress. Reversed. *Balzarini v. Suffolk County Dept. of Social Services, et al.*, Court of Appeals, Feb. 15, 2011).

John Balzarini applied to Suffolk County Department of Social Services for institutional Medicaid benefits. His available income was \$2,414.67. His wife's income of \$2,444.77 was slightly above the Minimum Monthly Maintenance Means Allowance (MMMNA) of \$2,378 and her resources were below the Community Spouse Resource Allowance. Mr. Balzarini appealed the agency determination that he pay \$2,414.47 toward his nursing home bill. He unsuccessfully argued that his wife needed a raised MMMNA due to the cost of her living expenses which totaled considerably more than the MMMNA. He argued that these expenses rose to the level of exceptional circumstances and resulted in significant financial distress. The itemized living expenses included mortgage payments, common charges and real estate taxes on their condominium, transportation costs, food, clothing, drugs, utilities, and credit card bills predating nursing home for purchases unrelated to health care or catastrophic events. At the Fair Hearing, the Administrative Law Judge for the New York State Department of Health concluded that all of the claimed expenses were ordinary costs of living and did not rise to the level of exceptional circumstances.

On further appeal, the Appellate Division reversed, and held that with the exception of the credit card debt, the claimed expenses were necessary and constituted exceptional circumstances.

The agency appealed. The Court of Appeals reversed, denying an increased MMMNA. Ordinary living expenses are provided for in the state's calculation of the MMMNA. Mrs. Balzarini had control over her living expenses. She did not suffer financial hardship as a result of exceptional circumstances.

Residential Facility's Trust for Resident's Funds

Petitioner residential facility sought appointment of a special guardian to transfer a resident's lump sum disability payment to its community trust. Granted with appointment of guardian. *Matter of Smergut*, 2011 NY Slip Op. 21068 (N.Y. Sup. Ct., Nassau County, March 1, 2011).

The Alleged Incapacitated Person in this Article 81 proceeding, LD, lived at Life's WORC for 18 years. When she was retroactively awarded a Social Security Disability payment of \$102,000, Peter Smergut, as Executive Director of the facility, petitioned for the appointment of a special guardian to transfer the funds to the Life WORC's community trust. Several organizations, the New York State Office for People with Developmental Disabilities, the Consumer Advisory Board, and the New York Civil Liberties Union opposed the use of the facility's trust. The objections cited conflict of interest, statutory violations and certain provisions in the trust. The court rejected the arguments against placing the funds in the facility's trust. As a protection the court found LD to be an incapacitated person and appointed LD's sister as guardian of the property with the obligation to account every year.

Statute of Limitations on Medicaid Recovery Claim

The Dept. of Social Services appealed from an order denying its claim for recovery from an irrevocable trust. Appeal denied based on statute of limitations. *Christopher v. Tomeck*, 2011 NY Slip Op. 01547 (N.Y, App. Div. 3d Dep't. March 3, 2011).

Medicaid covered Edward Tomeck's nursing home costs beginning in 1997. His wife, who died in 2002, had retained excess resources and filed as a refusing spouse. In 2004, plaintiff agency sought reimbursement from Mrs. Tomeck's estate consisting of an irrevocable trust she created based on an implied contract to pay for her husband's care. The respondent trustee of the trust argued that there could be no recovery from the trust. The Surrogate's Court, Saratoga County, granted summary judgment to the estate finding no implied contract with the refusing spouse and lack of jurisdiction over the trust. The Appellate Division affirmed. The Court of Appeals held that there was an implied contract and remanded the matter to the Appellate Division for the jurisdictional question. The Appellate Division found no personal jurisdiction because the trustees were not named parties in the action.

In June, 2008, plaintiff agency brought a claim against the trustees. The Surrogate's Court awarded summary judgment to the defendant trustees on the merits and did not address their assertion that the action was barred by the statute of limitations. Plaintiff appealed.

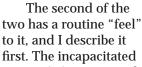
The Appellate Division affirmed for the respondent trustees based on a six-year statute of limitations. The statute started to run either when Mrs. Tomeck filed her notice of spousal refusal, her final transfer of funds to her trust, or the latest of possible dates, in February, 2002, when Mrs. Tomeck notified the agency that her funds were transferred to the trust.

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Guardianship News: Mental Illness

By Robert Kruger

I had petitioned for guardianship for a mentally ill person before. I had never petitioned for guardianship for a mentally ill person who was an inpatient in a psychiatric hospital before. Now I have...twice.





person (IP), a paranoid schizophrenic Iraqi war veteran (Desert Storm), had a psychiatric history of repeated hospitalizations. He had a history, as well, of hospital generated hearings to compel him to accept medications which, as we know all too well with the mentally ill, the patient often refuses to take. Routinely, the cause of a patient's decompensation is often traceable to his or her refusal to take prescribed medications.

The Court appointed Mental Hygiene Legal Service (MHLS) to represent the IP. I certainly anticipated the IP's opposition to the appointment of a guardian, and MHLS's embracing the role of adversary. That is one of the reasons I view the commencement of a guardianship for a mentally ill person with a certain uneasiness. What is my proof? Is there competent evidence? Or double or triple hearsay? Will the family testify? What is the quality of their evidence? I anticipate a fight from MHLS and am concerned at the very outset, when drafting the petition, with whether I can prove petitioner's allegations by competent evidence.

The alleged incapacitated person (AIP), until the day before the hearing, refused to talk to his MHLS attorney. Obviously, the attorney could not receive direction from his client. At the request of MHLS, we adjourned the initial return date of the hearing to enable MHLS to represent the client at a hearing, brought by the hospital (Creedmoor) pursuant to Kendra's law, to obtain permission to medicate the client against his will.

MHLS counsel, as a result of the client's refusal to talk to him, recognized that a guardian was needed and, one day before the hearing, when his client, at last, agreed to and did talk with him, he counseled him to accept his sister as guardian. The client did, with some reluctance, acquiesce, and the guardianship proceeding ended, for my purposes at least, satisfactorily.

I am less certain that the family feels the same way, because Creedmoor discharged him two weeks after the guardianship hearing. I thought the discharge unduly hasty because the IP is not a well man. Far from it.

With mental illness, the termination of a hearing, even if the result is a "favorable" one, does not insure a successful outcome. The patient is likely to destabilize and implode again, and again. This guardian, therefore, may have the authority to protect her brother, but will she have the power, after his release from Creedmoor, to do so?

The first guardianship, unlike the second described above, was quite far from a garden variety affair. The "patient" in this first case was a hugely successful financial services individual who suffered a traumatic brain injury in a vehicular accident: a helicopter crash. Over a period of years, he became hypomanic, traveling the globe in frenetic pursuit of his next big deal. Alcohol fueled part of his hypomania,¹ as did an aggressive pursuit of women. What is apparent from a distance (the order appointing a guardian was signed several months ago) is how grandiose he was. He really did travel the globe; he really did blow through millions of dollars. Again, his decompensation was traceable in no small part to his refusal to accept medication.

This patient also had several hospitalizations in his past. His family, several of whom were attorneys, tried to help him, but they were also afraid of him, and in awe of him. There were lethal weapons available to him, including guns and swords (yes, swords)... and that was surely reason to be fearful of him. The "awe" sprung from his financial success, which was as extreme in its way as was his behavior.

The family finally had to act last year because the trial lawyer handling the negligence case (the helicopter crash) could not obtain his client's cooperation to attend discovery. The case was at risk of dismissal for failure to respond to discovery demands. The decision to proceed occurred at the same time as the AIP decompensated in a huge way, following a ten day stay at Bellevue. For example, his generosity. He purchased a Mercedes for two women he met in a bar; he gave several people (including some men) blank checks signed by him. After our successful petition for guardianship, efforts are under way to claw back close to \$3,000,000.00, much of it from a large financial institution who ignored written demands from family and counsel to stop honoring his checks.

The incidents described above, plus a few others, resulted in the family alerting the police, who picked him up and brought him to a psychiatric hospital. While he was hospitalized, his family came in from out of state, authorized the guardianship, and we filed.

Our great concern was whether the psychiatric hospital would release him before the guardianship hearing. The Court Evaluator (who shared our concern) and I approached the guardianship judge with the notion that a Kendra's law retention hearing be held by the guardianship judge.

There appears, to me at least, to be nothing in Kendra's law that prevents a retention hearing before the guardianship court. For example, on the surface, there seemed to be no jurisdictional obstacle that would derail us if we needed a retention hearing before the guardianship judge.

In practice, there was a very big obstacle. The hospital usually acts as petitioner in a retention hearing, even though the family can petition. Having the hospital petition, if they are willing to do so, solves many problems, such as obtaining psychiatric testimony. Also, the hospital's counsel is thoroughly versed in these matters. It is a very big part of their job. When the notion of holding a retention hearing before the guardianship court was broached to the hospital, the hospital opposed this. The hospital believed, with some logic, that the hospital medical team is the best judge of the need for a retention hearing. In addition, the guardianship judge was not buying this idea either.

Then, we attempted to produce the patient for the guardianship hearing, and we served the hospital with a subpoena, which they ignored. The hospital, through counsel, expressed concern that the IP would escape.

The denouement: the hospital petitioned for a retention order and obtained it...one day after the guardianship hearing. Therefore, the IP was not able to flee before the guardianship hearing was held.

The IP, somewhat earlier in the guardianship, sought to retain his own counsel. The court authorized a retainer of \$25,000.00 for his counsel but the fee was never paid and counsel backed out. This is an overly simplified narrative of a mini-drama, with much back and forth, involving wire transfers on accounts with insufficient funds, and account numbers that may or may not have been erroneous. On the day of the hearing, the IP did not have counsel and he was not produced.

The hearing, after all of the angst about a hearing and about flight, was smooth. The trial lawyer handling the personal injury lawsuit had, a year before the guardianship was filed, retained the services of a renowned neuro-psychiatrist to evaluate (not treat) the IP. At the hearing, it was her testimony that convinced the judge that appointing a guardian was warranted. The IP's brother was appointed both personal needs and property management guardian.

At the Kendra's law retention hearing, the IP was released, subject to his accepting Authorized Outpatient Treatment ("AOT") from an ACT Team, the "T" standing for treatment. Failure to cooperate with the ACT team is serious business; failure to cooperate will land the patient back in the psych hospital summarily. Our result, the imposition of an ACT Team, is probably the best result possible. The duration of the ACT Team is six months, renewable for another six months. It is not a permanent solution, but it is the best result available.

As with the other patient, one simply does not know when the next crisis will arise. One does know, or suspect, that there will be another crisis eventually.

Endnote

1. He was originally diagnosed as bipolar.

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 in 1963 and the University of Pennsylvania (Wharton School of Finance (B.S. 1960)).



The Effect of a Special Needs Trust on Benefits Other Than Supplemental Security Income and Medicaid (Part 2)

By Adrienne J. Arkontaky

On August 10, 1993, OBRA 1993 officially authorized the transfer of assets of a person with a disability under the age of 65 to a special needs trust (42 U.S.C. § 1396p(d)(4)(a)). Under the rules set forth in OBRA 1993, when the assets of a person under the age of sixty-five are transferred to a special needs trust (SNT) set up by a parent, grandparent,



legal guardian or by court order, the transfer does not trigger a penalty for Supplemental Security or Medicaid purposes. Accordingly, there should be no period of ineligibility.

The assets in the SNT will not be counted as available resources, provided there is a "Medicaid payback" provision in the SNT. The state must be paid back for "for an amount up to the total Medicaid benefits provided to the beneficiary" (42 U.S.C. § 1396p(d)(4) (a)). New York State enacted legislation that addressed this issue also. N.Y. Soc. Serv.L. § 366(2)(b)(2)(iii)(A) was enacted in 1994. The Estates Powers and Trust Law EPTL § 7-1.12(a)(v)(5)) also discusses the rules regarding third party and first party special needs trusts.

The use of special needs trusts provides an important planning tool for those persons with disabilities who require the support of needs-based government benefits. Third party supplemental needs trusts, if drafted properly, should not affect access to government benefits in any case. For the purpose of this article, any reference to a "special needs trust or SNT" will refer to a "first party special needs trust" established with the assets belonging to an individual with disabilities.

As we discussed in the first part of this series, SSI and Medicaid are the two major needs-based government benefits that persons with disabilities utilize in New York State.

However, there are many other needs-based programs that have specific rules regarding transfers to and disbursements from special needs trusts. We will take a look at several of those programs and the various rules regarding the use of an SNT. A discussion of the various programs was provided in the first part of this two-part series available in the Winter 2011 issue of *Elder Law Attorney*. This article is also available on the New York State Bar Association website. Temporary Assistance (TA), specifically the Family Assistance and Safety Net Assistance, programs provide cash assistance to qualifying individuals and families. TA does not treat a properly drafted SNT as an available resource for the purposes of determining eligibility.

Typically, lump sum income transferred or monies spent generally trigger a period of ineligibility (18 NYCRR § 352.29(h); 2001 New York State Office of Temporary and Disability Assistance (OTDA) Letter, p. 3). However, the OTDA notes an exception when the monies are transferred directly into the SNT.

Timing of the transfer is crucial and the SNT must be created prior to or at the same time that the lump sum is received. Disbursements from an SNT are sometimes treated as income. As a general rule, education expenses, certain medical expenses not covered by Medicaid, child care costs, and other supplemental costs associated with the special needs of the individual are not counted as income. It is important to determine what expenses are exempt and what expenses are not exempt when advising clients. Information may be found in the OTDA letter referenced. In addition, income cannot be diverted into an SNT in an effort to reduce countable income for purposes of TA eligibility.

The Food Stamp Program (FS) is a benefit that helps individuals and families with limited income to purchase food. Recipients receive a monthly benefit that varies according to household size. There are restrictions associated with resources and income in this program. Information regarding eligibility requirements may be found at www.otda.ny.gov.

Generally, the assets transferred to an SNT and the income accruing from the transfer are not countable resources for the FS program (7 C.F.R. § 273.8(e)(8) (i)). Certain disbursements to the trust beneficiary are counted as income. However, disbursements to a third party will not result in countable income for the FS participant and the household. The above regulation suggests that an appointment of trustee must either be an organization or via court order. The OTDA letter, however, does not discuss the issue of trustees but practitioners should consult the OTDA Food Stamp Source Book for more information on this issue.

Under the federal regulations, the SNT is only considered inaccessible if the trustee uses the funds to make investments on behalf of the trust or to pay the educational or medical expenses of any person named by the household creating the trust. Families must be very careful when spending trust assets, as certain expenditures may disqualify their eligibility for the food stamp program (7 C.F.R § 273.8(e)(8)(iv)).

There is disqualification up to twelve months for transferring assets in the three months prior to submission of an application or after an eligibility determination. Even though an SNT is considered an exempt resource, since the look back period is only three months, it might be prudent to wait three months after a transfer to an SNT to apply (or re-apply) for the program after the transfer.

Disbursements from an SNT are counted as income. However, there are specific rules in the OTDA Food Stamp Source Book that are dedicated to disbursements from an SNT. It is important to seek guidance from the Source Book on disbursements from an SNT before advising a client. One noteworthy exception to the income rule is that an SNT disbursement that is not payable to the FS household, but is instead directed to a third party, is generally excluded. Income cannot be placed in an SNT to reduce countable income.

The Home Energy Assistance Program (HEAP) assists families to pay fuel and utilities. Since there is no asset limit for participation in the HEAP program, the existence or transfer to an SNT will not affect HEAP eligibility. There are no directives on transfer penalties associated with the HEAP program. However, clients should be careful of transferring assets after an emergency condition (the triggering factor for the program) occurs. This type of transfer might potentially render an applicant ineligible for the program. Although there is very little guidance provided regarding the HEAP program and SNT disbursements and income, it is generally understood that income placed in an SNT will not reduce countable income for eligibility purposes.

The Senior Citizen Rent Increase Exemption (SCRIE) exempts low-income senior citizens from rent increases in certain situations (9 NYCRR § 2202.20). There is no resource test for this program and therefore the existence of an SNT will not affect eligibility. Transfers to an SNT also should not affect eligibility. However, it is unclear whether disbursements from an SNT are treated as income to maintain eligibility (9 NYCRR § 2202.20(d)). Again, an SNT cannot be used to reduce countable income.

Subsidized housing programs provide assistance with securing low-cost housing to qualified individuals and families. In all the programs, the participating individual or family pays a portion of the rent. Although Section 8 Housing (one of the programs available) does not specifically discuss an asset or resource limit, a significant amount of assets will affect the amount of housing subsidy and eligibility for the program. HUD looks at income produced by the asset or "imputed" income if the asset is not actually producing income. HUD assigns a fixed interest rate to the asset. Actual or imputed income can cause the subsidy to be reduced or terminated (See 24 C.F.R. § 5.609(b)(3); 24 C.F.R. § 982.445).

Special Needs Trusts are not counted as assets as long as the household member has no control over the asset. However, there is a transfer penalty for transfer of assets including transfer into an SNT (24 C.F.R. § 5.603). There are some exceptions to the transfer penalty for certain types of transfers such as inheritances, insurance payments and retroactive social security payments (24 C.F.R. § 5.609(c)). HUD regulations discuss two types of income for purposes of eligibility for Section 8 housing. Particular types of income count for purposes of eligibility (24 C.F.R. § 5.609(b) and other types do not (24 C.F.R. § 5.609(c)). Sporadic or temporary payments generally do not count. It is important for practitioners to refer to the HUD regulations before advising a client on whether a distribution from an SNT will be counted as income for the purposes of qualifying for the program.

There is no HUD regulation guidance on whether income can be placed in an SNT for purposes of reducing countable income, as is the case with many of the other programs mentioned in this article.

As you recall, Family Health Plus (FHPlus) is a Medicaid program for uninsured adults between the ages of 19 and 64. There are no asset limits for this program but there are income limits. Generally any income or dividends produced by assets are counted towards the income limits. There are no transfer penalties and even though there is no steadfast rule or administrative directive on point, a participant probably cannot place income in an SNT to reduce countable income.

Please remember that program requirements and rules change periodically so practitioners should check the various reference sources in this article for up-todate information on the various programs.

I would like to thank Sara Myers of Enea Scanlon & Sirignano LLP for reference information provided for this series of articles.

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Supplemental Needs Trusts: News, Views, and Then Some

By Robert P. Mascali

This is the first of what is expected to be a regular column for the *Elder and Special Needs Law Journal* that will report and comment upon current cases and issues in the establishment, administration and management of supplemental needs trusts: first party, third party and pooled trusts.



As most readers of

this law journal know, a Supplemental Needs Trust (sometimes referred to as a Special Needs Trust, or commonly an SNT) is a legally recognized way for property to be set aside for the ultimate benefit of an individual with disabilities while not interfering with eligibility for various governmental benefits (usually Medicaid and/or Social Security Income (SSI)). The funds are held by a trustee and can be used for personal living expenses that are not provided by these governmental programs but which serve to enhance the life of the disabled person. There are two different types of SNTs: those set up with the funds of disabled individual (a first party SNT) and those set up with the funds of a third person, usually a family member (a third party SNT). In addition, some charitable organizations operate "pooled trusts" which are essentially a number of supplemental needs trusts that are combined together for investment and management purposes but whose funds remain separate and distinct for the benefit of the individual.¹ The rules covering each type of trust, for instance how they can be established and what happens to the money upon the death of the disabled individual, are quite complex and anyone considering establishing an SNT should always consult with an attorney who is familiar with these types of trusts.

An often cited concern for families or professionals who are considering establishing a pooled trust is the perception that a conflict of interest may exist where the non profit organization administering the pooled trust may also be a provider of services to the disabled beneficiary and/or may have an interest in the funds that remain upon the death of the beneficiary. In order to satisfy Medicaid and SSI regulations, a self settled first party trust must provide that upon the death of the beneficiary any remaining funds are to be used to "payback" for benefits provided during the beneficiary's lifetime. However, as a general rule pooled trusts are not obligated to use the remaining funds to reimburse for supplied public benefits provided these remainder funds are retained by the trust.² The many pooled trusts operating in New York have differing policies as to the disposition of the remaining funds and that is generally one of the questions that should be asked when considering establishing such an account (see note 1, *supra*). While most, if not all, non-profit pooled trusts go to considerable lengths to disclose the potential for a conflict of issue and properly deal with it, the perception often continues.

A recent case in the Supreme Court, Nassau County discussed the conflict issue and then approved the establishment of pooled trust, notwithstanding that the non-profit that was administering the pooled trust also provided services to the disabled beneficiary. In the case of *Matter of the Application of Peter Smergut*, Executive Director of Life's WORC, Inc. (LD 29901-2010), Judge Diamond rejected the pointed opposition from the State of New York through its Office for People With Developmental Disabilities, the state agency responsible for overseeing the provision of services to individuals with developmental disabilities; the Consumer Advisory Board, an independent entity that was involved because the disabled beneficiary is a class member protected by the Willowbrook Consent Decree³ and by the New York Civil Liberties Union. Each of these parties contended that while some sort of a supplemental needs trust was advisable, the funds should not be deposited with the Life's WORC pooled trust since it is the service provider and would also retain the funds remaining upon the death of the beneficiary, thereby possibly making disbursement decisions with an eye towards the impact upon the amount to be left to the non-profit upon the beneficiary's death. The NYS Attorney General's office has indicated it intends to file a Notice of Appeal.

Citing a similar case from Suffolk County (*Matter of Cannatella*, Index Number 8353/10) the court found that while in certain circumstances a showing of an improper conflict may be made, it rejected a finding that such a conflict can be automatically presumed in the absence of specific proof that the service provider has in the past acted inappropriately. Consequently, the court did appoint the guardian under Article 81 of the Mental Hygiene Law to establish the pooled trust but it also imposed reporting and other restrictions

in connection with the guardian's duties in order to minimize any potential for a future conflict of interest.

An interesting case from the state of Washington re-affirms the discretion afforded to a trustee of a supplemental needs trust. In the Matter of the Mark Anthony Fowler Special Needs Trust decided February 8, 2011, the Washington Court of Appeals reversed a lower court finding that had questioned the trustee's investment decisions that had resulted in a substantial loss in market value and held that judicial interference is not warranted in reviewing the decisions made by a trustee in a discretionary trust simply because the court would have come to a different decision.⁴ In the Fowler case the trust portfolio had dropped from a little over \$1,000,000.00 to less than \$750,000.00 as of the date of the accounting, generally reflecting the performance of the markets from October 2007 to February 2009. Implicitly faulting the trustee for these losses, the lower court wanted the trustee to develop a plan to place all of the remaining assets in FDIC-insured accounts, but the appellate court reversed and found no breach of fiduciary duty or abuse of discretion on the part of the corporate trustee, Wells Fargo, N.A.

Endnotes

- 1. http://wnylc.com/health/entry/4/.
- 2. U.S. Social Security Administration § SI 01120.203.
- 3. New York State Asso. for Retarded Children, Inc. v. Carey, 393 F. Supp. 715 (E.D.N.Y. 1975).
- 4. In re Mark Anthony Fowler Special Needs Trust, 2011 Wash. App. LEXIS 358 (Wash. Ct. App. Feb. 8, 2011).

Mr. Mascali is Associate General Counsel at NYSARC, Inc. Prior to his current position with NYSARC he was Managing Attorney for the New York State Office of Mental Retardation and Developmental Disabilities and was primarily responsible for providing legal advice on guardianship matters and supplemental needs trusts. Before his government service Mr. Mascali was engaged in private practice in the New York metropolitan area concentrating on real property and estate and trust matters. He is a member of the New York State Bar Association and the Elder Law Section, the Trusts and Estates Section and is also a member of NAELA. Mr. Mascali is a graduate of St. John's University (1973) and Law School (1976).

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

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

Medicaid Redesign Team

The Governor's Medicaid Redesign Team proposed a number of significant changes to the Medical Assistance program in New York which the Governor has adopted as part of his proposed budget. The Elder Law Section continues to monitor the legislation very closely and advocate against the changes which will affect our clients' access to care and quality of services.

A detailed summary of the proposals can be found at the following link: www.nysba.org/ ElderMedicaidChangesSummary.

Ahlborn Distinguished from an Estate Recovery Claim Thereby Allowing Medicaid to Recover All Medical Expenses Paid from the Estate of a Medicaid Recipient (Not Just the Portion of a Personal Injury Settlement Allocated to Past Medical Expenses)

In The Matter of Heard, 2010 Slip Op 08146, 911 N.Y.S.2d 534 (4th Dep't 11-12-2010).

This case involved an appeal from an order of the Surrogate's Court, Monroe County, entered on November 30, 2009, that determined that the lien of the Monroe County DSS was not limited to the portion of a tort settlement allocated to the cost of decedent's medical care. The issue is whether Monroe County DSS is entitled to recover from the estate of a decedent where the source of estate funds is a tort settlement paid for injuries sustained by the decedent when he fell in the nursing home where he resided. The Surrogate's County had allocated the entire amount of the settlement to decedent's pain and suffering. The Executor of the estate argued that under Arkansas Dep't. of Health & Human Servs. v. Ahlborn (547 U.S. 268), Monroe County DSS could recoup only that part of the settlement that was paid for medical services provided to treat decedent for the injuries related to his fall in the nursing home.

DSS argued that it was not asserting a lien akin to the one asserted in *Ahlborn*. Instead, it was basing its lien on Section 369(2)(b)(i)(B) of the Social Services Law, which allowed it to recoup costs expended for medical assistance of an individual who was at least 55 years old when he or she received such assistance. The Appellate Division, Fourth Department, concluded that the Executor's reliance on *Ahlborn* was misplaced, since in *Ahlborn* the state agency was seeking to recover a lien from a living person and thus its rights were governed by 42 USC Section 1396p(a), which is codified in the Social Services Law at Section 104-b. In this case, however, DSS is seeking to recover under Social Services Law Section 369(2)(b)(i)(B), not Section 104-b, inasmuch as it seeks to recover from decedent's estate rather than from a living person.

Court Awards Fees from SNT under SCPA 17-A

In Re Jon Z., 29 Misc. 3d 923 (2010), 2010 NY Slip Op 20385, 907 N.Y.S. 2d 595, Surrogate's Court, Broome County, decided August 17, 2010.

In a guardianship matter, the co-guardians under SCPA Article 17-A brought a petition for payment of fees and disbursements. Jon Z's mother filed a cross motion requesting that payment be made from Jon Z's SNT.

Jon Z's parents, who are divorced, were previously removed as co-guardians due to their mutual inability to work productively for the benefit of their autistic son, Jon Z, age 22. The Court determined on the cross motion that because Jon Z is now over 21, his parents are no longer obligated to pay his support and are therefore not required to pay the commissions and legal fees of the independent co-guardians.

In deciding whether payment should be made from Jon Z's SNT, funded with \$139,000, the Court considered *Matter of Arnold O.*, 279AD2d 774 (3d Dept 2001) and *Matter of Pineda*, NYLJ, May 28, 1997, at 26, col. 3 (Sup Ct, NY County). Both held that payment for legal fees and guardianship services made from an SNT for Article 81 guardianships is proper. Here, the Court found that the services of the guardians under SCPA Article 17-A are essentially the same as the services of guardians in an Article 81 guardianship and determined compensation should be at the rate of \$200 per hour for legal services, \$100 per hour for guardianship services, and \$50 per hour for paralegal services, awarding the independent co-guardians \$41,872.

The Court also discussed criteria for reasonableness of attorney's fees and the Surrogate

Court's authority, citing *Stortecky v. Mazzone*, 85 NY2d 518 (1995). The following factors are to be considered in the determination of reasonableness on a *quantum meruit* basis: the time spent in rendering legal services, the nature of the services, the difficulties of the case, the value of the estate, the results obtained, and the professional standing of counsel.

The Community Living Assistance Services Support Act—A Long Term Care Option in the Health Care Legislation

This article, contributed by Judith D. Grimaldi, continues the series on the Health Care Reform Act by the Section's Health Issues Committee.

The Community Living Assistance Services Support (CLASS) Act, which is included in the Health Care Legislation passed in March 2010, is one of the key sections of the legislation under attack and may not survive the current budgetary reviews. The program has evolved into a mix of government run benefits and long term care services available to the participant on a voluntary basis. Those who opt into this program will be required to pay a set premium expected to average \$125 per month in order to receive cash support for their long term care estimated to begin at \$50.00 per day.

The expected date of implementation was slated to be January 1, 2011; however, the requirement that the program cannot rely on taxpayer dollars and operate in the black is causing the legislation to falter. It is believed that the program is not fiscally sound as structured. Before people can begin signing up to participate, the Secretary of Health and Human Services must develop and release the details of the plan no later than October 1, 2012. There is an effort now to meet this deadline and work out the financial issues. If the Secretary is successful, individuals may be able to sign up in 2012 or 2013.

This program, as drafted, will be open to individuals 18 years of age and older who are employed as defined under the Social Security Act including self-employed, members of the military and working students, though the final plan may broaden the pool of participants. Institutionalized persons will not be eligible to enroll. People cannot be excluded from enrolling due to pre-existing health conditions such as a physical disability.

If an employer elects to participate in the CLASS Act, employee enrollment will be presumed for all of its employees. It will be up to the worker to "opt out" of the program; otherwise the premium will be automatically deducted from his or her pay. An employer may also choose to subsidize the premiums. Working individuals whose employer did not choose to participate and the self-employed must act independently to participate. In general, after signing up for the program, a participant will need to pay premiums for 60 months and be actively at work for three years before receiving benefits. So long as a person keeps paying premiums after the three year work requirement is met, a person is still considered a CLASS Act plan participant. For example, a person who retired from work completely after the three year period would be eligible for benefits, assuming he or she met the five year vesting requirement, had kept up with the premium payments, and had a qualifying level of disability. Special rules will apply for people who are enrolled for a time, drop out, but then sign up again.

Premiums must be set by the Secretary by October 1, 2012. The premium will be based on the age of the participant and once established for the individual it will not change unless the entire class of enrollees receives a premium increase. There will be caps on premiums for low income workers and students younger than 22 years of age.

The law requires the Secretary to determine the details and to choose between a loss of the ability to perform 2 activities of daily living or a more stringent point (3 activities of daily living) to serve as the minimum level of disability to qualify for benefits. In either case, the level of disability would need to be expected to continue for at least 90 days to count as a qualifying level of disability for the CLASS Act plan. The Secretary will also design the details of how the assessment process (to determine eligibility for benefits) will work.

The plan will pay a cash benefit of no less than \$50/day and increase based on the level of disability; however, the benefit amount is being reconsidered. The cash benefit could also be used to maintain the home and non medical services that support the individual's ability to remain independent at home. The benefit cash amount will be pegged to an assessment of a person's need for help due to a physical or cognitive limitation. A benefit payment scale, developed by the Secretary, will result in higher cash benefits for people with greater need for help with their basic activities of living. The cash benefit amount will increase annually to keep up with inflation. There is no lifetime limit on the benefits. When a CLASS Act plan participant has a qualifying level of disability and begins receiving cash benefits, benefits continue until the person no longer has a qualifying level of disability. Over a lifetime, a person could have several separate instances of qualifying for benefits.

The CLASS Act cash benefits will be disregarded in determining eligibility for federal programs such as

Medicaid. An institutionalized CLASS Act participant will be able to retain five percent of the benefits paid out in addition to the personal needs allowance; the remainder will be payable towards the cost of care. A participant who is in a Medicaid home and community waiver program will be able to keep 50% of the cash benefits. For those who receive benefits, one can arrange for payment through a representative payee, similar to SSI and Social Security.

Finally, how does this impact on our practice? A government-backed marketing initiative will begin to inform the public on this new long term care option. encouraging more demand for community based

services. Firms need to start asking questions on how this Act can be incorporated into the long term care planning provided to clients.

The Health Care Reform Act offers a number of community based options such as: Accountable Care Organizations, bundled payments, medical homes, and quality-based incentives paired with continued reductions to payments to home care agencies, along with the CLASS Act. Providers will need to develop strategic partnerships or alignments to coordinate these services. Our clients will want us to advise them about the options and analyze the risk factors of this program. Stay tuned and be prepared.

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Surrogate Decision Making for Incapable Adult Patients with Mental Disabilities: A Chart of Applicable Laws and Regulations¹

By Robert N. Swidler

Introduction

The Family Health Care Decisions Act governs health care decisions for patients in hospitals or nursing homes who lack capacity and who did not previously appoint a health care agent. However, a section in the FHCDA identifies circumstances where decisions for adult patients with mental disabilities are governed by laws



or regulations other than the FHCDA, specifically NY Surrogate Court Procedure Act Article 17-A (the Health Care Decisions Act for People with Developmental Disabilities), MHL Article 80 (Surrogate Decision Making Committees), or OPWDD or OMH surrogate decisionmaking regulations.²

The following two charts are intended to help hospitals and nursing homes identify the applicable decision-maker, and the applicable law or regulation, for consent to treatment, or to withdraw or withhold life-sustaining treatment, for adult hospital and nursing home patients with mental disabilities in different circumstances. There is a chart for patients with developmental disabilities, and a chart for patients with mental illness.

During Nov. 2010–Jan. 2011, Greater New York Hospital Association convened a group that reviewed and proposed corrections and improvements to an earlier version of these charts.³ Eileen Zibell, Associate Attorney for OPWDD, John Tauriello, Counsel to OMH, and John Carroll, Deputy Counsel to OMH, also participated in that review, and suggested edits to the charts. This revised version is the product of that review.

A few caveats:

- These charts reflect only the views of the author.
- These charts do not reflect the official guidance of any state agency.

- Some of these issues are not clearly resolved, or are subject to conflicting interpretations.
- These charts point to the applicable laws and regulations and the decision maker, but do not summarize other requirements or conditions relating to such decisions.
- Ultimately, users must rely upon the language of the applicable laws and regulations, and any official guidance provided by the applicable agency. These charts are not a substitute for legal advice.

Even with those caveats, these charts should be useful. Please direct any corrections, suggestions to swidlerr@nehealth.com.

The Need for Reform

The charts describe what the law is, not what it should be. But it is difficult to examine these charts without recognizing a need for reform. Indeed, the very fact that there is a need for complex charts like these to navigate among multiple laws and regulations reveals a pressing need for simplification, such as through the consolidation, elimination, or reconciliation of some of these laws and regulations. The Legislature, when it enacted the FHCDA, anticipated this need and directed the NYS Task Force on Life and Law to form a special subcommittee to consider extending the FHCDA to cover life-sustaining decisions for persons with mental disabilities, thereby replacing at least some other laws and regulations. L.2010, ch.8, § 28.1.

But the charts also reveal other specific problems and anomalies that could be addressed more promptly, without waiting for or intruding upon the Task Force's assignment. In this author's view, the following steps would help reduce confusion, and improve decision making for persons with mental disabilities:

1. Amend SCPA §1750-b to confirm that a surrogate decision is not necessary if the developmentally disabled person made a prior oral or written decision, or appointed a health care agent, and had capacity at the time. (This would confirm Chart 1 boxes 1B and 2B).

- 2. Amend 14 NYCRR §633.10(a)(7)(iv)(c) to include domestic partner or close friend on OPWDD's surrogate priority list. (This would affect Chart 1 boxes 4B and 6B).
- 3. Amend the FHCDA to make the MHL Art. 80 surrogate decision-making committee (SDMC) available as an optional alternative to securing a decision pursuant to the FHCDA, as opposed to the required decision-maker. (This would affect Chart 1 boxes 5A and 5B).
- 4. Amend SCPA §1750-b to allow a DNR order to be entered based on medical futility for a patient who does not have a family member or friend to act as surrogate, eliminating the need to SDMC approval of such cases. (This would affect Chart 1 box 5B).
- Repeal PHL Article 28-B, the DNR Law for patients of mental hygiene facilities, because there is no need for the law. For patients in OPWDD facilities, DNR orders generally are issued pursuant to SCPA §1750-b, not PHL Art. 29-B. For patients in psychiatric hospitals and general hospital psychiatric units, DNR orders should

be made subject to the FHCDA—a change that would eliminate the confusion and illogic of inconsistent DNR procedures within general hospitals that have psychiatric units. (This would confirm Chart 1 boxes 6B and 7B, and affect Chart 2 boxes 6B and 7B).

6. Amend SCPA §1750 to restore role of MHLS with respect to DNR orders to what it was under the former DNR Law: for patients who are in or transferred from a mental hygiene facility, notice of a DNR order went to the mental hygiene facility director, not to MHLS; and the order would be temporarily stayed if there was an objection by the facility director, not by MHLS. As an alternative, require notice of DNR orders to MHLS but provide that its objection will not cause a stay of the DNR order unless it sets forth a specific basis for asserting that the DNR order is improper. (This would affect the procedures within Chart 1 column B rows 3-7).

A final note: If the Legislature adopts amendments that impact these charts, revised charts will be placed on the NYSBA Family Health Care Decisions Act Information Center website, www.nysba.org/fhcda.

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Surrogate Decision Making for Incapable Adult Patients with Developmental Disabilities:

A Chart of Applicable Laws and Regulations

	Follow the rules in the first row that applies:	Decisions in Hospitals and Nursing Homes		
		A Consent to treatment	B Decision to withdraw or withhold life-sustaining treatment (including entering a DNR Order)	
1	Patient, previously when capable, left prior written or oral directions	Follow patient's prior oral or written directions ⁴	Follow: (i) patient's prior written directions, or (ii) patient's prior oral directions if made during hospitalization before two witnesses ⁵	
2	Patient, previously when capable, appointed health care agent*	Health care agent decides per PHL 29-C ⁶	Health care agent decides per PHL 29-C ⁷	
3	Patient has a court-appointed guardian per SCPA Art. 17-A*	Guardian decides per SCPA §1750-b ⁸	Guardian decides per SCPA §1750-b ⁹	
4	Patient resides in community (and not an OPWDD-licensed residence) and has involved family*	Surrogate decides per FHCDA ¹⁰	Involved family member decides per SCPA §1750-b. ¹¹ The prioritized list of qualified family member is set forth in 14 NYCRR §633.10(a)(7)(iv) (c). Note—A domestic partner or close friend would not qualify. ¹²	
5	Patient resides in community (and not an OPWDD-licensed residence) but has no involved family*	Surrogate Decision Making Committee (SDMC) decides per MHL Art. 80 ¹³	SDMC decides per SCPA §1750-b ¹⁴	
6	Patient resides in OPWDD- licensed or operated facility, is temporarily in a hospital or NH, and has involved family*	Involved family member decides per 14 NYCRR §633.11 ¹⁵	Involved family member decides per SCPA §1750-b. The prioritized list of qualified family member is set forth in 14 NYCRR §633.10(a)(7)(iv)(c). ¹⁶ Note—A domestic partner or close friend would not qualify.	
7	Patient resides in OPWDD- licensed or operated facility, is temporarily in the hospital or NH, but has no involved family*	SDMC decides per 14 NYCRR §633.11	SDMC decides per SCPA §1750-b. ¹⁷	

* Applies only if no row above it applies.

Surrogate Decision Making for Incapable Adult Patients with Mental Illness¹⁸

A Chart of Applicable Laws and Regulations¹⁹

	Follow the rules in the first row that applies:	Decisions in Hospitals (excluding MH unit) and Nursing Homes	
		A Consent to Treatment	B Decision to withdraw or withhold life-sustaining treatment (including entering a DNR Order)
1	Patient, previously when capable, left prior written or oral directions	Follow patient's prior oral or written directions	Follow: (i) patient's prior written directions, or (ii) patient's prior oral directions if made during hospitalization before two witnesses
2	Patient, previously when capable, appointed health care agent*	Health care agent decides per PHL 29-C	Health care agent decides per PHL 29-C
3	Patient has court-appointed guardian per MHL Art 81 with health care decision- making authority.*	Guardian with health care decision-making authority decides per the FHCDA ²⁰	Guardian with health care decision-making authority decides per the FHCDA ²¹
4	Patient resides in community (including an OMH-licensed residence) and has family or close friend*	Surrogate decides per FHCDA ²²	Surrogate decides per FHCDA ²³
5	Patient resides in community (including and OMH-licensed residence) but has no family or close friend*	 (i) Surrogate Decision Making Committee (SDMC) decides per MHL Art. 80 if the patient is eligible²⁴ (ii) Otherwise, attending physician decides per FHCDA²⁵ 	Attending physician or court decides, per FHCDA ²⁶
6	Patient brought to hospital or NH from OMH-licensed or operated psych hospital or unit. Patient has family or close friend.*	 (i) If patient was discharged from the OMH-licensed or operated psych hospital or unit, then surrogate decides per FHCDA²⁷ (ii) If patient was not discharged, then spouse, parent or adult child decides per 14 NYCRR §27.9 	(i) For DNR, surrogate decides per PHL Art 29-B (ii) For other decisions, surrogate decides per FHCDA ²⁸
7	Patient brought to hospital or NH from OMH-licensed or operated psych hospital or unit. Patient has no family or close friend*	Decision by either (i) SDMC per MHL Art. 80 (ii) Court per §27.9 ²⁹	 (i) For DNR, attending phys'n decides per PHL Art. 29-B (ii) For other decisions, attending physician or court decides, per FHCDA³⁰

*Applies only if no row above it applies

Endnotes

- 1. This document is the January 12, 2010 version of a document that appears on the NYS Bar Association Family Health Care Decisions Act Information Center, www.nysba.org/fhcda. It is reprinted here with the permission of the NYS Bar Association.
- 2. The relevant clauses of the FHCDA are PHL § 2994-b.3-4, which state:

3. Prior to seeking or relying upon a health care decision by a surrogate for a patient under this article, if the attending physician has reason to believe that the patient has a history of receiving services for mental retardation or a developmental disability; it reasonably appears to the attending physician that the patient has mental retardation or a developmental disability; or the attending physician has reason to believe that the patient has been transferred from a mental hygiene facility operated or licensed by the office of mental health, then such physician shall make reasonable efforts to determine whether paragraphs (a), (b) or (c) of this subdivision are applicable:

(a) If the patient has a guardian appointed by a court pursuant to article seventeen-A of the surrogate's court procedure act, health care decisions for the patient shall be governed by section seventeen hundred fifty-b of the surrogate's court procedure act and not by this article.

(b) If a patient does not have a guardian appointed by a court pursuant to article seventeen-A of the surrogate's court procedure act but falls within the class of persons described in paragraph (a) of subdivision one of section seventeen hundred fifty-b of such act, decisions to withdraw or withhold life-sustaining treatment for the patient shall be governed by section seventeen hundred fifty-b of the surrogate's court procedure act and not by this article.

(c) If a health care decision for a patient cannot be made under paragraphs (a) or (b) of this subdivision, but consent for the decision may be provided pursuant to the mental hygiene law or regulations of the office of mental health or the office of mental retardation and developmental disabilities, then the decision shall be governed by such statute or regulations and not by this article.

4. If, after reasonable efforts, it is determined that a health care decision for the patient cannot be made pursuant to subdivision two or three of this section, then the health care decision shall be made pursuant to this article.

3. The chart review group was convened by Lorraine Ryan, Senior Vice President, Legal, Regulatory and Professional Affairs Greater NY Hospital Association and Sara Kaplan-Levenson, Project Manager, Regulatory and Professional Affairs, Greater NY Hospital Association. Participants included John V. Campano (NY Presbyterian), Joan Hauswald (NY Presbyterian), Deborah Korzenik (Continuum Health Partners); Lynn Hallarman, M.D. (SUNY Stony Brook Health Science Center); Jonathan Karmel (NYS Department of Health); Karen Lipson (NYS Department of Health); Carolyn Wolf (Abrams Fensterman). Paul Kietzman (NYSARC) also commented independently. I am very grateful to these reviewers—their work has improved these charts greatly.

- 4. It would seem that the designation of a surrogate (whether under SCPA §1750-b, 10 NYCRR §633.11 or the FHCDA) is not necessary if the incapable person, previously when capable, personally consented to the treatment.
- 5. It would seem that the designation of a surrogate (whether under SCPA §1750-b, 10 NYCRR §633.11 or the FHCDA) is not necessary if the incapable person, previously when capable, left clear and convincing evidence of a wish to forgo treatment under the circumstances presented. The FHCDA, in PHL §2994-d.3(a)(ii), provides guidance as to the type of evidence that would suffice.
- 6. NY PHL §2982.
- 7. NY PHL §2982.
- 8. NY SCPA §1750-b.1.
- 9. NY SCPA §1750-b.1.
- 10. NY SCPA §1750-b is inapplicable because its non-court process for authorizing an involved family member, Consumer Advisory Board or SDMC to act as a "guardian" is limited to decisions to withdraw or withhold life-sustaining treatment. See §1750-b.1(a). When a health care decision for the patient cannot be made pursuant to the SCPA or Mental Hygiene Law or regulations, the FHCDA becomes applicable. NY PHL §2994-b.4. Accordingly, the FHCDA becomes applicable, and a FHCDA surrogate can consent to such treatment per PHL §2994-d.
- NY SCPA §1750-b(a) applies because its non-court process for authorizing a family member to act as guardian applies to decisions to withdraw or withhold life-sustaining treatment. See §1750-b.1(a). Qualified family members are identified in 14 NYCRR §§633.10(a)(7)(iv)(c).
- 12. The OPWDD surrogate list promulgated pursuant to NY SCPA §1750-b(a) does not provide for the authorizing of a "close friend" to act as "guardian." See 14 NYCRR §633.10(a) (7)(iv)(c). However, NY SCPA §1750-b.1(a) provides that when no other surrogate is available, the MHL Article 80 SDMC may act as guardian for purposes of making the withdrawal or withholding of treatment decision.
- 13. Most patients with developmental disabilities and who do not a have a guardian or family will qualify for decisions by an SDMC. See MHL §80.3(b).3 (definition of "patient in need of surrogate decision-making"). Moreover, once a person is eligible for decisions by an SDMC, the person remains eligible regardless of a change in residential status. MHL §80.03(b). As a result, the FHCDA provisions on consent for patients without surrogate generally are not applicable. See §2994-b.3(c). In the relatively rare event where SDMC lacks jurisdiction for a patient, the FHCDA would apply.
- 14. Per NY SCPA §1750-b.1(a), when no other surrogate is available, the MHL Article 80 SDMC may act as guardian for purposes of making the withdrawal or withholding of treatment decision.
- 15. 14 NYCRR §633.11 provides surrogate decision-making rules for persons who are "residents of a facility operated or certified by OPWDD." Such persons, when hospitalized, are still residents of OPWDD facilities and subject to this regulation.
- 16. 14 NYCRR §633.10 implements SCPA 1750-b for residents of OPWDD-licensed and operated facilities.

- 17. See n.11.
- 18. Per PHL §2994-a.21: "Mental illness" means a mental illness as defined in subdivision twenty of section 1.03 of the mental hygiene law, and does not include dementia, such as Alzheimer's disease, or other disorders related to dementia. Per MHL §1.03(2): "Mental illness" means an affliction with a mental disease or mental condition which is manifested by a disorder or disturbance in behavior, feeling, thinking, or judgment to such an extent that the person afflicted requires care, treatment and rehabilitation.
- This chart points to the applicable law or regulation, but does not provide a complete summary of the applicable law or regulation.
- 20. PHL §2994-d.1(a).
- 21. Id.
- 22. Id.
- 23. Id.
- 24. PHL §2994-b.3(c) provides that if a health care decision can be made pursuant to the Mental Hygiene Law, then the decision is governed by such statute. Accordingly, if the decision can be made pursuant to MHL Art. 80 then the decision is governed by MHL Art. 80. Under MHL Art. 80, a decision can be made by an SDMC for a person who is "a resident of a mental hygiene facility including a resident of housing programs funded by an office of the department [of mental hygiene] or

whose federal funding application was approved by an office of the department or for whom such facility maintains legal admission status therefor; or receiving home and community-based services for persons with mental disabilities provided pursuant to section 1915 of the federal social security act; or receiving individualized support services " Also, note that MHL Art. 80 and the FHCDA have some differences in the scope of major medical treatments that can be authorized pursuant to their procedures.

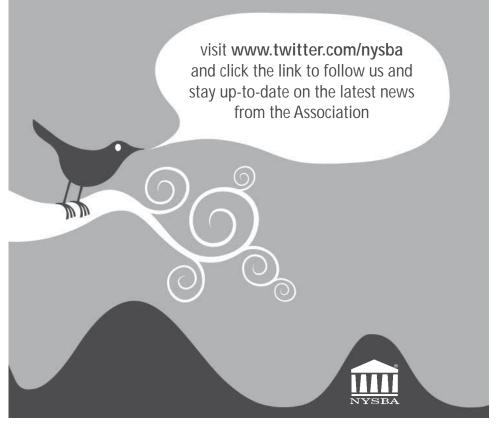
- 25. PHL §2994-b.4 provides that "If, after reasonable efforts, it is determined that a health care decision for the patient cannot be made pursuant to subdivision two or three of this section, then the health care decision shall be made pursuant to this article." Accordingly, if MHL Art. 80 is inapplicable, then the FHCDA, and specifically PHL §2994-g, becomes applicable.
- 26. There is no applicable Mental Hygiene Law or OMH regulation. Accordingly, PHL §2994-g.5 applies.
- 27. If the patient was discharged from the OMH-regulated facility or unit, then OMH regulations become inapplicable, and the FHCDA applies.

- 28. If the patient was discharged from the OMH-regulated facility or unit, then OMH regulations become inapplicable, and the FHCDA applies. But even if the patient was not discharged, there still is no applicable Mental Hygiene Law or OMH regulation. (MHL Art. 80 is inapplicable because it does not authorize the SDMC to make decisions to withdraw or withhold life-sustaining treatment). Accordingly, per PHL§2994-b.4, the FHCDA becomes applicable.
- 29. Both provisions are available as a means to secure consent to treatment.
- 30. There is no applicable mental hygiene law or regulation. (MHL Art. 80 is inapplicable because it does not authorize the SDMC to make decisions to withdraw or withhold lifesustaining treatment). Accordingly, PHL §2994-g.5 applies.

Robert N. Swidler is General Counsel, Northeast Health, Troy NY. Mr. Swidler is also Editor of the NYSBA *Health Law Journal* and Editor of the NYSBA FHCDA Information Center.

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Honoring Patient Preference at the End of Life: The MOLST Process and the Family Health Care Decisions Act

By Karen Lipson and Jonathan Karmel

Introduction

Patient self-determination and informed consent are fundamental elements of medical care in the United States. When a patient loses the capacity to make medical decisions, securing informed consent and carrying out the patient's wishes raise complex legal and ethical issues. These issues are particularly challenging when the patient is near the end of life and decisions must be made about whether or not to provide life-sustaining treatment. Advances in medical care in the last fifty years have enabled us to prolong life where death was once imminent, but often cannot promise an acceptable quality of life. As a result, patients and family members today face difficult choices about how they will live and die.

Since the late 1980s, New York State and the federal government have sought to encourage patients with advanced, life-limiting conditions to make decisions concerning life-sustaining treatment in advance so that, in the event that they lose decision-making capacity, their wishes can be honored. Enacted in 1990, New York's health care proxy law provides a mechanism for competent adults to appoint health care agents to make medical decisions on their behalf in the event that they lose the capacity to make those decisions. The federal Patient Self-Determination Act, enacted in 1991, requires hospitals, nursing homes, hospice programs and home health agencies to inform patients upon admission about their decision-making rights, ask them about advance directives, such as health care proxies and living wills, and document those directives in their medical records.¹

Despite these efforts, studies have shown that the majority of seriously or terminally ill patients lack advance directives.² Moreover, the evidence suggests that the treatment people receive at the end of life is different from the treatment they would have requested, and often the care received is more aggressive than they would have wanted. Opinion polls indicate that a sizeable majority of patients would prefer to die at home.³ Yet, approximately one in five Americans dies in an intensive care unit, and almost one-third die in a hospital.⁴ Another 22 percent die in a nursing home.⁵ According to the Dartmouth Atlas on Health Care, Medicare beneficiaries in New York have the highest rate in the U.S. of inpatient days during the last six months of life—15.5

days per deceased patient.⁶ Even among Medicare beneficiaries with advanced cancer, the rate of hospital deaths is surprisingly high. About 29 percent die in a hospital, and only about half receive hospice care.⁷ The rate of hospital deaths for these patients was the highest in the Manhattan hospital referral region, while hospice use in that region was significantly lower than the national average.⁸



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In the absence of advance care planning and an advance directive, when a patient loses decision-making capacity, health care providers and family members often struggle mightily to make treatment decisions consistent with the patient's wishes and values and with New York's laws governing informed consent. Often these difficult decisions are made in the midst of a crisis with little opportunity for reflection. Futile and burdensome treatment may be provided, or life-sustaining treatment may be withheld, without a clear understanding of what the patient would have wanted, causing distress and guilt for family members.

Until June 2010, when an adult patient in New York lacked capacity to make medical decisions and had not appointed a health care agent or executed a living will, family members were legally authorized to consent only to a do not resuscitate (DNR) order. Decisions to withhold other life-sustaining treatment, such as artificially administered nutrition or hydration, could be made only with clear and convincing evidence of the patient's wishes or pursuant to a court order. As a result, patients near death sometimes languished in hospitals receiving futile treatment that family members knew the patient would not want. With the enactment of the Family Health Care Decisions Act (FHCDA),⁹ effective June of 2010, family members and close friends can be surrogates with authority to make any treatment decision on behalf of a patient who lacks capacity. While FHCDA facilitates health care decisions for vulnerable patients, it will not succeed in promoting patient autonomy un-

less prospective surrogates are familiar with their loved one's goals for care, treatment preferences, and values. This can be accomplished through effective advance care planning.

Even when an advance directive is completed, if it does not transition with the patient between health care settings, it may be ineffective in assuring that the patient's care reflects his or her wishes and values. Between 25 and 30 percent of dying patients are cared for in three or more settings in the last months of life.¹⁰ In addition, advance directives may not be implemented properly if they are not discussed with the patient's family members in advance of a crisis. Absent these discussions, an advance directive may be too vague to provide effective guidance to clinicians and family members when the need for a decision arises. In a 2008 report to Congress, the U.S. Department of Health and Human Services concluded that many of the barriers to effective advance care planning could be addressed through adoption of the POLST (Physician Orders for Life-Sustaining Treatment) process:

> Encouraging additional POLST efforts that translate chronic care patient's [sic] care goals into easily identifiable, portable and renewable medical orders that follow the patient across settings would go a long way toward enhancing advance care planning in this country.¹¹

POLST, known in New York as "MOLST" (or Medical Orders for Life-Sustaining Treatment), is a national model for advance care planning that supports shared, informed decision making, portability of advance directives across health care settings, and continuity of care.

This article will discuss how the MOLST process works, the law governing decisions to withhold and withdraw life-sustaining treatment in New York State, and the legal basis for the MOLST process. It will describe how the enactment of FHCDA has affected MOLST. Finally, it will describe the MOLST legal checklists developed by the New York State Department of Health (DOH), and the applicable law for patients in facilities licensed by the Office for People With Developmental Disabilities (OPWDD) and the Office of Mental Health (OMH).

The MOLST Process

New York's MOLST process is based on the POLST Paradigm Program initiated in the mid-1990s. Approximately 25 states have active or developing POLST programs. In another seven states, POLST has been adopted at the local or regional level.¹² With the goal of providing patient-centered care and shared decision making, POLST provides a structured framework for conversations between physicians and their patients (or the patient's authorized decision-maker) concerning prognosis, the benefits and burdens of the life-sustaining treatment and the patient's personal goals for care. The product of the dialogue is concrete, actionable orders recorded on a portable, easily identified form. Studies have shown that POLST is useful in initiating conversations about end-of-life care, in preventing unwanted resuscitations and hospitalizations, and in documenting a range of treatment options.¹³

Ideally, a completed MOLST form is the culmination of a conversation or series of conversations between a competent patient and his or her physician and family members.¹⁴ Although health care agents and FHCDA surrogates may consent to MOLST orders on behalf of patients who lack medical decision-making capacity, the best way to assure patient self-determination is for the patient to make these decisions while he or she has capacity to do so. Family members and/or close friends are typically included in these discussions so that they develop an understanding of the patient's goals for care and values and, in the event that the patient loses capacity, will be able to make decisions consistent with their loved one's wishes and beliefs.

After discussing the patient's prognosis, goals for care, values, options, and any prior advance directives with the patient, his or her family members, and/or close friends, the physician reviews the MOLST form (DOH-5003) with the patient and family and completes and signs it. In some physician practices and facilities, a portion of the conversation may be facilitated by a nurse or social worker; however, a licensed physician must always, at a minimum: (i) confer with the patient and/or the patient's health care agent or surrogate about the patient's diagnosis, prognosis, goals for care, treatment preferences, and consent by the appropriate decision-maker, and (ii) sign the orders derived from that discussion.

The form is bright pink so it can be found and identified easily by emergency medical services personnel responding to a call and by health care facility staff when it is placed in a medical record. The form includes specific orders concerning resuscitation, intubation, future hospitalization, artificially administered hydration and nutrition, administration of antibiotics and general treatment guidelines, such as "comfort measures only," "limited medical interventions," and "no limitations on medical interventions." The form requires the signature of the physician. Either the name or the signature of the person consenting to the orders must be included on the

form. In addition, the name(s) of the witness (es) to the consent must be included on the form as well. 15

The MOLST form is effective in the community and in health care facilities and is intended to accompany the patient as he or she transitions from one setting to another. Under FHCDA, rules governing the implementation of orders to withhold or withdraw life-sustaining treatment upon inter-institutional transfer between hospitals or nursing homes also govern non-hospital orders upon transfer to a hospital or nursing home from the community.¹⁶ Such orders remain effective until an attending physician examines the patient, and either continues the prior orders or determines that they are no longer appropriate or authorized and cancels them.¹⁷ Before canceling them, the attending physician must make reasonable efforts to notify the person who consented to the orders and the hospital staff directly responsible for the patient's care. If the notice cannot be made prior to the cancellation, it must be made as soon as practicable afterwards.18

Although this article focuses on decisions to withhold or withdraw life-sustaining treatment, due to the complex laws surrounding such decisions, the MOLST process does not presume an outcome that limits interventions. The form includes a range of options from "attempt CPR" and "no limitations on medical interventions" to "allow natural death" and "comfort measures only." The process is not intended to limit in any way the choices of patients and families, but rather to empower them to make choices consistent with the patient's wishes, values and goals.

The Law Governing Decisions to Withhold or Withdraw Life-Sustaining Treatment in New York State

Decisions to withhold or withdraw life-sustaining treatment may be made in several different ways in New York State. A person with capacity to make medical decisions may consent to a specific medical order prior to losing capacity.¹⁹ Or, under New York common law, health care providers may withhold or withdraw life-sustaining treatment from a patient who is dying and currently lacks the capacity to make his or her own decisions, if doing so is based upon clear and convincing evidence of the patient's wishes.²⁰

Under New York's health care proxy law (Public Health Law Article 29-C), health care agents can make decisions to withhold or withdraw life-sustaining treatment even where patients have not left clear and convincing evidence of their wishes. The agent must make decisions in accordance with the principal's wishes, or if the principal's wishes are not reasonably known and cannot with reasonable diligence be ascertained, in accordance with the principal's best interests.²¹

The agent's authority to make decisions concerning the withholding or withdrawing of artificial nutrition and hydration is somewhat limited. If the principal's wishes concerning artificial nutrition and hydration are not reasonably known and cannot with reasonable diligence be ascertained, the agent does not have authority to make decisions regarding these measures.²² However, it is not necessary to have clear and convincing evidence of a patient's wishes to satisfy the health care proxy law's standard of "reasonably knowing" the patient's wishes. Patients may explicitly state their treatment wishes on their health care proxy, in which case the health care proxy is also functioning as a living will.

When patients lack capacity, have not left clear and convincing evidence of their wishes and do not have a health care proxy, New York law authorizes specified individuals to serve as surrogates to make decisions to withhold or withdraw life-sustaining treatment discussed in more detail below. New York has allowed surrogate health care decision making for DNR orders since Public Health Law (PHL) Article 29-B was enacted in 1987. In 1991, Article 29-B added provisions for non-hospital DNR orders. DOH created the "standard form" to issue a non-hospital order not to resuscitate (DOH-3474), which is still in use today. With the enactment of FHCDA, surrogates may make any health care decision on behalf of a patient in a hospital or nursing home, including decisions to withdraw or withhold lifesustaining treatment.

The Legal Basis for the MOLST Process

In 2005, the Public Health Law was amended to give DOH authority to issue "alternative forms" for issuing non-hospital orders not to resuscitate in Monroe and Onondaga Counties. This established MOLST as a pilot program. In 2006, the law was amended to allow such "alternative forms" to be used to issue non-hospital do not intubate (DNI) orders. This was necessary because the Public Health Law makes a distinction between a DNR order and a DNI order. Under the letter of New York's Law, a DNR order only applies when a patient is in cardiac or respiratory arrest, i.e., when a patient has no pulse and/or is not breathing. Even if a patient has a non-hospital DNR order, emergency medical services personnel will still intubate a patient who has a pulse or is breathing, unless the patient also has a non-hospital DNI order.²³ In 2008, the law was amended to authorize MOLST as a non-hospital DNR and DNI order statewide.²⁴ MOLST is the only authorized mechanism in New York to put in place a non-hospital order that includes both DNR and DNI.25

Life-Sustaining Treatment Orders and MOLST Under FHCDA

Chapter 8 of the Laws of 2010, the legislation that included FHCDA (PHL Article 29-CC), made significant changes to the process for consenting to DNR orders and other orders to withhold or withdraw life-sustaining treatment. In addition to authorizing surrogate decision making in general hospitals and nursing homes for any type of health care decision, including DNR orders, it also amended PHL Article 29-B (the old DNR law) to make it applicable only to DNR decisions in certain mental hygiene facilities. It also moved the provisions for non-hospital DNR orders to a new PHL Article 29-CCC.

Under current law, the legal requirements for issuing medical orders to withhold or withdraw lifesustaining treatment differ depending on the patient, the decision-maker, and the setting where the patient is located. These requirements can be divided into eight different categories:

1. Adult Patients with Medical Decision-Making Capacity (Regardless of Setting)

Adults are presumed to have capacity to make medical decisions, unless a contrary determination has been made by a court or by the requisite health care professionals pursuant to FHCDA.²⁶ Adults with medical decision-making capacity have a right to consent to or decline life-sustaining treatment.²⁷ Prior to the enactment of FHCDA, there was a therapeutic exception to the rule that a DNR order for a patient with capacity must be based upon the patient's consent. FHCDA eliminated that exception.²⁸

As explained above, adults with capacity also have the right to execute advance directives, such as a living will, to avoid getting life-sustaining treatment that they do not want after they lose capacity. A living will may not be fully effective in accomplishing this goal, because a living will may not be written with sufficient specificity to provide clear and convincing evidence of the patient's wishes. In order to provide greater assurance that their wishes will be carried out, patients can consent to medical orders for life-sustaining treatment. With the informed consent of the patient, the patient's physician can issue a variety of medical orders using DOH's MOLST form-from provide comfort measures (palliative care) only; do not attempt resuscitation (allow natural death); do not intubate (DNI); do not hospitalize; no feeding tube; no IV fluids, do not use antibiotics; to no limitations on medical interventions. Physicians may also issue other medical orders related to other lifesustaining treatments (e.g., dialysis) in the space on the form available for "other instructions."

Under FHCDA, surrogate consent is not required if the decision was expressed by the patient before the patient lost capacity "either orally during hospitalization [including during residency in a nursing home] in the presence of two witnesses eighteen years of age or older, at least one of whom is a health or social services practitioner affiliated with the hospital, or in writing."²⁹ The phrase "in writing" includes any legally executed non-hospital DNR order or MOLST form, even if the form was completed prior to hospitalization with the oral consent of the patient to just one witness who was the attending physician who signed the order(s).³⁰ However, two witnesses are recommended.

2. Adult Patients Without Medical Decision-Making Capacity Who Have a Health Care Proxy (Any Setting)

A patient without medical decision-making capacity is still presumed competent to appoint a health care agent, unless such person has been adjudged incompetent or otherwise adjudged not competent to appoint a health care agent, or unless a committee or guardian of the person has been appointed under the Mental Hygiene Law or Surrogate's Court Procedure Act (SCPA).³¹

The health care agent named in the health care proxy can consent to medical orders relating to life-sustaining treatment. If the patient's wishes are reasonably known, the health care agent must make decisions in accordance with those wishes. When there is evidence of the patient's wishes, the health care agent should still be asked to consent to the medical orders and given the opportunity to provide additional evidence of the patient's wishes. So long as the health care agent represents that he or she is acting in accordance with the patient's wishes, the health care provider should generally follow the decisions of the health care agent, unless a court has determined otherwise under PHL section 2991.

Under current law, if the principal's wishes regarding the administration of artificial nutrition and hydration are not reasonably known and cannot with reasonable diligence be ascertained, the health care agent does not have authority to make decisions regarding these measures. Health care providers may presume that patients' wishes regarding the administration of artificial nutrition and hydration are reasonably known when health care proxies state that the patients have discussed their wishes with their health care agents, and the agents know their wishes about artificial nutrition and hydration. Even if the patient's wishes regarding artificial nutrition and hydration are not known, the person named as health care agent may still have authority to make the decision as a FHCDA surrogate. It is likely that the health care agent is also highest in priority on the

FHCDA surrogate list or could be designated as surrogate by a person higher in priority.³²

Health care agents can consent to decisions to withhold or withdraw life-sustaining treatment in any setting and therefore have authority to consent to the medical orders on a MOLST form no matter where the form is completed.

3. Adult General Hospital or Nursing Home Patients Without Medical Decision-Making Capacity Who Do Not Have a Health Care Proxy, and Decision Maker Is FHCDA Surrogate

Decisions to withhold and withdraw life-sustaining treatment in a general hospital or nursing home are governed by FHCDA. Unlike PHL Article 29-B, FHCDA does not explicitly state that patients are presumed to consent to life-sustaining treatment.³³ However, FHCDA requires a number of conditions to be satisfied before life-sustaining treatment may be withheld or with-drawn. These include patient-centered decision-making standards for surrogates and clinical standards that must be verified by two physicians.³⁴ Unless these conditions are satisfied, life-sustaining treatment, including cardiopulmonary resuscitation (CPR), presumably must be provided.³⁵

Under FHCDA, the rules for issuing orders to withhold or withdraw life-sustaining treatment in general hospitals or nursing homes have changed in a number of ways. As noted above, FHCDA authorizes surrogate decision making for all medical decisions, not just DNR decisions. Surrogate consent to a DNR order is now governed by the FHCDA rules for decisions to withhold or withdraw life-sustaining treatment. Before FHCDA, a surrogate could consent to a DNR order if the patient had a "terminal condition," which was defined as "an illness or injury from which there is no recovery, and which reasonably can be expected to cause death within one year." By contrast, FHCDA requires "an illness or injury which can be expected to cause death within six months, whether or not treatment is provided." FHCDA like the prior law, also allows surrogate consent when the patient is permanently unconscious. Under prior law, a surrogate could consent to a DNR order if resuscitation would be "medically futile," but FHCDA contains no equivalent standard for surrogate decision making. Before FHCDA, a surrogate could consent to a DNR order when resuscitation would impose an "extraordinary burden on the patient in light of the patient's medical condition and the expected outcome of resuscitation for the patient." The parallel provision of FHCDA is that "the provision of treatment would involve such pain, suffering or other burden that it would reasonably be deemed inhumane or extraordinarily burdensome under the circumstances *and the patient has an irreversible or incurable condition*" (emphasis supplied).³⁶

Since it is no longer sufficient that resuscitation is an extraordinary burden, and the patient must also have "an irreversible or incurable condition" under the extraordinary burden standard, hospitals and nursing homes will have to determine whether any of a patient's conditions can be considered "irreversible or incurable." Presumably, this term was not intended to include conditions that are literally irreversible and incurable, but are in no way debilitating. On the other hand, consider the patient who is over 100 years old and has lost medical decision-making capacity, but has no "irreversible or incurable" condition (other than the frailty that naturally accompanies old age). The application of the law to this patient is not entirely clear.

Although the law defines CPR as a type of lifesustaining treatment, it distinguishes between DNR and other orders to withdraw or withhold life-sustaining treatment, in certain circumstances. One significant difference between DNR orders and other orders to withhold or withdraw life-sustaining treatment in FHCDA is that ethics committee review is not automatically required to issue a DNR order in a nursing home under the "irreversible and incurable condition" standard, whereas ethics review committee approval is required in a nursing home to issue other orders to withhold or withdraw life-sustaining treatment under that standard.³⁷

4. Adult General Hospital or Nursing Home Patients Without Medical Decision-Making Capacity Who Do Not Have a Health Care Proxy, and for Whom No FHCDA Surrogate Is Available

In limited cases, facilities may withhold or withdraw life-sustaining treatment from patients who lack medical decision-making capacity, have no health care agent, and for whom no surrogate is available. In these cases, treatment is being withheld or withdrawn without consent. A court of competent jurisdiction may make this decision. Alternatively, FHCDA provides that the facility may withhold or withdraw life-sustaining treatment if the decision is consistent with the patient's wishes, if known, or in the patient's best interests, and two physicians determine that treatment "offers the patient no medical benefit because the patient will die imminently, even if the treatment is provided," and "the provision of life-sustaining treatment would violate accepted medical standards."³⁸ Before FHCDA, a general hospital or nursing home could issue a DNR order for a patient for whom no surrogate was available if CPR was "medically futile," a term that does not appear in FHCDA. Although the law now uses different words,

there are probably few, if any, cases in this fourth category where a DNR order legally could have been issued before FHCDA but could not be issued under FHCDA.

5. Adult Patients Outside of a General Hospital or Nursing Home Without Medical Decision-Making Capacity Who Do Not Have a Health Care Proxy (Except Patients in Categories Seven and Eight)

Non-hospital DNR and DNI orders are now governed by the new PHL Article 29-CCC, which is derived from former PHL section 2977.³⁹ One difference between PHL Article 29-CCC and former PHL section 2977 is that now home care services agencies and hospices are explicitly required to honor non-hospital DNR and DNI orders. A non-hospital DNR order may be issued on the "standard form," which is DOH-3474, or the "alternative form," which is DOH-5003 (the MOLST form).⁴⁰ Nonhospital DNI orders can only be issued on the MOLST form, not on the standard form.

FHCDA surrogates have authority to consent to non-hospital DNR and DNI orders.⁴¹ They do not have legal authority to consent to other orders to withhold or withdraw life-sustaining treatment outside of a general hospital or nursing home. Nevertheless, DOH allows the issuance of other orders to withhold or withdraw life-sustaining treatment based upon clear and convincing evidence of the patient's wishes. This is based on patients' common law and constitutional rights, as recognized in case law,⁴² as well as the federal statutory right to self-determination.

6. Minor Patients

FHCDA defines a minor as an unmarried individual under eighteen years of age.⁴³ In general, a parent or legal guardian may consent to medical services for a minor.⁴⁴ Under PHL section 2504 and common law, parents can consent to medical orders issued by a physician that withhold or withdraw life-sustaining treatment from their children.⁴⁵ Some attorneys may be concerned that a decision to withhold or withdraw life-sustaining treatment from a terminally ill child could be construed as neglect under the Family Court Act. However, in cases involving terminally ill children and burdensome medical interventions, courts have considered parental consent to a physician's order to withhold or withdraw life-sustaining treatment, while providing palliative care to optimize the child's quality of life, a reasonable decision, not an abandonment or medical neglect of the child.⁴⁶ Indeed, the New York State Legislature has recently affirmed the legitimacy of palliative care in appropriate circumstances.⁴⁷

FHCDA provides specific procedures that must be followed when a parent or guardian of a minor makes decisions about life-sustaining treatment in a general hospital or nursing home. Most of the provisions for a health care decision for an adult patient by a surrogate also apply to a decision by a parent for a child who lacks capacity, except that the decision only takes into account the child's wishes as appropriate under the circumstances. The attending physician must determine whether the minor has capacity, and if so, the minor must consent to the decision. Only one parent's consent is required, but health care providers must make diligent efforts to notify a second parent who has maintained substantial and continuous contact with the minor.48 The second parent so notified has an opportunity to object to the decision before it is implemented.⁴⁹

FHCDA does not address parental consent to the withholding or withdrawing of life-sustaining treatment outside of the hospital and nursing home settings. However, the common law provides some guidance. Before the enactment of FHCDA, in *Matter of AB*,⁵⁰ the court held that the most relevant statute should govern decisions by parents to withhold or withdraw lifesustaining treatment from minor children. Accordingly, the court applied the standards in section 1750-b of the Surrogate's Court Procedure Act, which governs surrogate decision making for persons with developmental disabilities. Now that FHCDA provides a statutory framework for decisions made by parents for children in general hospitals and nursing homes, that framework should be applied to decisions on behalf of children in the community. Just as *Matter of AB* used the standards in SCPA section 1750-b, the most relevant statute in effect at that time, decisions by parents or legal guardians of minors in the community to withhold or withdraw life-sustaining treatment should incorporate the FHCDA procedures and standards. Thus, physicians should only issue orders to withhold or withdraw life-sustaining treatment from children in the community under circumstances in which those orders would be permitted in nursing homes or hospitals.

Since the standards for nursing homes are the most stringent (specifically regarding the need for ethics committee review when decisions other than DNR are made for a patient who is neither terminally ill nor permanently unconscious), those standards should be used in the community as well. Note that in cases where ethics review committee review is needed in the community, the physician will have to find an ethics review committee willing to review the case even though the patient is neither a hospital inpatient nor a nursing home resident. In these cases, the physician would presumably have

privileges at a local hospital, and that hospital's ethics review committee may be willing to review the case.

FHCDA also gives an "emancipated minor" authority to decide about life-sustaining treatment in a general hospital or nursing home.⁵¹ An emancipated minor is a minor who is the parent of a child or is age 16 or older and living independently.⁵² Although there are other instances in which a minor may consent to health care without a parent's permission or knowledge, neither FHCDA nor any other New York statute gives minors living independently general authority to make health care decisions for themselves. Also, it should be noted that FHCDA does not allow surrogates on the surrogate list to make decisions for emancipated minors who lack capacity; it only provides for health care decisions for adult patients by surrogates. Under FHCDA, however, a person under 18 years old who is married is an "adult." 53

7. Patients with a Developmental Disability Who Lack Decision-Making Capacity and Who Do Not Have a Health Care Proxy

FHCDA does not apply to decision making for patients with developmental disabilities who lack medical decision-making capacity. Surrogate decision making for patients with developmental disabilities who lack capacity is governed by the Surrogate's Court Procedure Act (SCPA).⁵⁴ Decisions to withhold or withdraw life-sustaining treatment may be made by surrogates as provided in SCPA section 1750-b and 14 NYCRR section 633.10. Decisions by surrogates pursuant to the SCPA may be recorded in the MOLST form.⁵⁵ To assure compliance with this process, OPWDD requires that a special checklist be attached to the MOLST form.

8. Patients in a Psychiatric Unit of a General Hospital or a Psychiatric Institution Licensed by OMH Without Decision-Making Capacity Who Do Not Have a Health Care Proxy

FHCDA applies to patients with mental illness in a "general hospital," as defined by FHCDA. FHCDA, however, does not apply to decision making for patients in a ward, wing, unit or other part of a general hospital operated for the purpose of providing services for persons with mental illness pursuant to an operating certificate issued by OMH or a "hospital" as defined in Mental Hygiene Law section 1.03(10). DNR orders for such patients are still governed by the provisions of PHL Article 29-B.⁵⁶ In compliance with Article 29-B and any other applicable laws, MOLST may be used for patients with mental illness in any setting.⁵⁷

Legal Requirements Checklists

As described above, decision-making standards and procedures for decisions to withhold or withdraw lifesustaining treatment vary depending on who makes the decision and where the decision is made. Accordingly, DOH has developed checklists that summarize these requirements in six different scenarios, along with general instructions and a glossary:

- MOLST Checklist 1—Adult with capacity (any setting)
- MOLST Checklist 2—Adult with health care proxy (any setting)
- MOLST Checklist 3—Adult with FHCDA surrogate (hospital and nursing home)
- MOLST Checklist 4—Adult without FHCDA surrogate (hospital or nursing home)
- MOLST Checklist 5—Adult without capacity in the community
- MOLST Checklist for Minor Patients and Glossary (any setting)

These checklists are not mandatory; they are intended as a tool to assist health care providers in complying with the complex laws governing decisions concerning life-sustaining treatment when completing MOLST forms.⁵⁸

In addition, OPWDD has developed a checklist for people with developmental disabilities who lack medical decision-making capacity and do not have a health care proxy.⁵⁹ This checklist is mandatory and must be attached to the MOLST form. The use of this checklist assures that any medical decisions involving the withholding or withdrawing of life-sustaining treatment from individuals with developmental disabilities comply with the process set forth in the Surrogate's Court Procedure Act.

The DOH checklists for adults share a number of common elements. For example, they remind providers to ask patients about executing a health care proxy, if the patient has not done so and has capacity to execute one. DOH Checklists 2 through 5 set forth the appropriate process for the capacity determination, depending on whether a health care agent or an FHCDA surrogate is the decision-maker. And, they direct the physician to notify the patient of the determination of incapacity if there is any indication that the patient is able to comprehend the determination. All summarize the statutory standards for medical decision-making capacity and informed consent to life-sustaining treatment orders. And, all of the checklists remind providers of the witness requirements and the need to notify the director of the

patient's correctional facility or mental hygiene facility and Mental Hygiene Legal Services, where applicable.

The DOH checklists also specify the unique requirements applicable to specific decision-makers and settings. For example, Checklist 2 (for adults with a health care proxy) alerts the provider to the two-physician capacity determination process for decisions by health care agents. It also points out the limits on the health care agent's ability to consent to the withholding or withdrawal of artificial hydration or nutrition. Checklist 3 includes both the patient-centered standards and clinical standards that must be met under FHCDA to justify the withholding or withdrawal of life-sustaining treatment when a surrogate makes that decision. Checklist 3 also points out the required ethics committee determination for decisions to withhold or withdraw life-sustaining treatment (other than CPR) in a nursing home under the "irreversible or incurable condition" standard. Checklist 4 sets forth the two alternative processes for decisions to withhold or withdraw life-sustaining treatment from a patient who lacks capacity and has neither a health care agent nor an FHCDA surrogate: (i) a court proceeding; or (ii) a determination by two physicians that treatment offers the patient no medical benefit because the patient will die imminently, even if the treatment is provided, and the provision of life-sustaining treatment would violate accepted medical standards.

DOH Checklist 5 delineates in detail the complex requirements for adults in the community who lack capacity and do not have a health care proxy. Checklist 5 makes clear that the authority of the FHCDA surrogate in the community is limited to DNR/DNI decisions. It also indicates that decisions concerning other lifesustaining treatment may be made based on clear and convincing evidence of the patient's wishes. "Clear and convincing evidence" is defined in the glossary accompanying the general instructions.⁶⁰

Finally, the DOH checklist for minor patients applies to patients under age 18 who are not married. However, it also notes that special considerations and requirements apply to decisions concerning life-sustaining treatment for emancipated minors. The checklist does not go into detail about the various considerations that apply to life-sustaining treatment decisions by or concerning emancipated minors. Instead, it directs physicians to consult with counsel regarding such decisions. As discussed above, the checklist for minor patients imports into the community setting the FHCDA requirements for withholding or withdrawing life-sustaining treatment, other than DNR, in a nursing home. It requires ethics committee review for such decisions, if the patient is neither terminally ill nor permanently unconscious. The checklist sets forth the requirements

to assess the minor's capacity and secure his or her consent, if he or she has capacity. It also describes the requirements concerning notification and participation of a non-consenting parent.

It is undoubtedly challenging for busy health care providers to juggle all of these different checklists with disparate requirements. However, the checklists merely reflect the complexity of the law. And, that complexity is largely driven by a desire to protect the rights of vulnerable patients—a paramount consideration in our society. Clearly, health care providers should appreciate and consider the legal and ethical implications when issuing an order to "allow natural death."

Conclusion

MOLST and FHCDA together provide an opportunity to honor the wishes of patients and to improve the quality of end-of-life care. Widespread completion of health care proxies and MOLST forms by patients with capacity will reduce the need for decision making by FHCDA surrogates for patients approaching the end of life and will provide guidance for surrogates when needed. MOLST empowers patients in two ways. It provides a structured framework for discussions between clinicians and patients and their families about end-of-life options, so that patients have the information they need to make informed decisions. And, it provides a vehicle for patients to make clear their wishes concerning life-sustaining treatment. MOLST enables patients to communicate across care settings their desire to receive life sustaining treatment. It also makes it possible to honor the wishes of a patient to spend his or her last days comfortably at home, instead of in a hospital receiving futile and invasive interventions.

Endnotes

- 1. See 42 U.S.C. §§ 1395cc(f), 1396a(w).
- Kass-Bartelmes, BL, Hughes, B, "Advance Care Planning: Preferences for Care at the End of Life," Agency for Healthcare Research and Quality, March 2003.
- 3. According to a 1999 Harvard Public Opinion Poll, 71 percent of Americans would prefer to die at home. A 2002 Harris Interactive Poll found that 86 percent of Americans believe that people who have a terminal illness would most like to receive end-of-life care at home. See also Yankelovich Partners/TIME/ CNN Survey, available at http://www.libraryindex.com/ pages/3165/Public-Opinion-About-Life-Death-CONCERNS-ABOUT-DEATH.html.
- 4. Angus, DC, Barnato, AE, Linde-Zwirble, WT, Weissfeld, LA, Watson, RS, Rickert, T, Rubenfeld, GD, "Use of intensive care at the end of life in the United States: An epidemiologic study," *Critical Care Medicine*, 32(3):638-643, March 2004. Zhao, Y, Encinosa, W, "The Cost of End-of-Life Hospitalizations 2007," HCUP Statistical Brief #81, Agency for Healthcare Research and Quality, Nov. 2009, http://www.hcup-us.ahrq.gov/reports/statbriefs/sb81.pdf.

- 5. Centers for Disease Control and Prevention, Nation Vital Statistics System, Deaths by place of death, age, race, and sex: United States, Worktable 309, 2005, available at: http://www. cdc.gov/nchs/nvss/mortality/gmwk309.htm.
- 6. Dartmouth Atlas on Health Care, End of Life Care, http://www. dartmouthatlas.org/data/region/profile.aspx?loc=34&tab=22.
- Goodman, DC, Fisher, ES, Chang, CH, Morden, NS, Jacobson, JO, Murray, K, Miesfeldt, S, "Quality of End-of-Life Care for Medicare Beneficiaries, Regional and Hospital-Specific Analyses," Dartmouth Atlas Project, Nov. 2010, at 4.
- 8. Id. at 28.
- 9. L. of 2010, ch. 8, § 2.
- "Advance Directives and Advance Care Planning: Report to Congress," U.S. Dept. of Health and Human Services, Aug. 2008, at 14, citing Brock, D, Foley, DJ. "Demography and Epidemiology of Dying in the U.S. with Emphasis on Deaths of Older Persons," in Harold, JK, Lynn, J, eds., A *Good Dying: Shaping Health Care for the Last Months of Life*, NY, NY: 1998, at 49-60.
- 11. Id. at 42.
- 12. Oregon State Health & Science University, Center for Ethics in Health Care, POLST, http://www.ohsu.edu/polst/.
- Hickman, SE, Nelson, CA, Perrin, NA, Moss, AH, Hammes, BJ, Tolle, SW, "A Comparison of Methods to Communicate Treatment Preferences in Nursing Facilities: Traditional Practices Versus the Physician Orders for Life-Sustaining Treatment Program," *Journal of the American Geriatrics Society*, 58(7): 1241-1248, Jul. 2010; Hammes, BJ, Rooney, BL, Gundrum, JD, "A Comparative, Retrospective, Observational Study of the Prevalence, Availability, and Specificity of Advance Care Plans in a County that Implemented an Advance Care Planing Microsystem," *Journal of the American Geriatrics Society*, 58(7): 1249-1255, Jul. 2010; Hickman SE, Nelson CA, Moss AH et al., "Use of the Physician Orders for Life-Sustaining Treatment (POLST) Paradigm Program in the Hospice Setting," *J Palliat Med*. 12:133–141, 2009.
- 14. As discussed more fully below, if the patient lacks medical decision-making capacity, an appropriate FHCDA surrogate can provide consent to MOLST orders, based on specified standards, on behalf of a patient in a hospital or nursing home. In the community, surrogates may consent only to DNR and DNI orders.
- 15. Information for providers and consumers concerning the MOLST process is available on the Department of Health's website at http://www.nyhealth.gov/professionals/patients/ patient_rights/molst/ and on the Compassion and Support website at http://www.compassionandsupport.org/index.php.
- 16. PHL § 2994-ff (orders pertaining to a patient admitted to a mental hygiene facility are governed by Article 29-B).
- 17. PHL §§ 2994-l, 2994-ff.
- 18. PHL § 2994-l(2).
- 19. See PHL §§ 2964, 2994-d(3)(a)(ii), 2994-cc(1).
- 20. Matter of Westchester County Med. Ctr. on Behalf of O'Connor, 72 NY2d 517.
- 21. PHL § 2982(2).
- 22. Id.
- DOH Bureau of Emergency Medical Services Policy 11-02 (http://www.nyhealth.gov/nysdoh/ems/pdf/11-02.pdf).
- 24. L. 2008, ch. 197.

- 25. PHL § 2994-dd(6).
- 26. PHL § 2994-c(1).
- 27. Matter of Storar, 52 NY2d 363, 376.
- Cf., former PHL section 2964(3), repealed by l. 2010, ch. 8, §
 9. The legislature intended to prohibit health care providers from issuing DNR orders without the informed consent of the patient, and PHL section 2805-d(4)(d) should not be interpreted to allow the "therapeutic exception." L. 2010, ch. 8 did not eliminate the principle that patients are presumed to consent to the administration of CPR in the event of cardiac or respiratory arrest. *See* PHL § 2962(1).
- 29. PHL § 2994-d(3)(a)(ii).
- 30. See PHL § 2994-cc(1).
- 31. PHL § 2981(1).
- 32. See PHL § 2994-d(1).
- 33. Cf., PHL § 2962(1).
- The patient-centered standards require that decisions are made 34. "in accordance with the patient's wishes, including the patient's religious and moral beliefs" or "if the patient's wishes are not reasonably known...in accordance with the patient's best interests." The patient's best interests include: "consideration of the dignity and uniqueness of every person; the possibility and extent of preserving the patient's life; the preservation, improvement or restoration of the patient's health or functioning; the relief of the patient's suffering; and any medical condition and such other concerns and values as a reasonable person in the patient's circumstances would wish to consider.' PHL § 2994-d(4). The clinical standards require a determination that (i) treatment would be an extraordinary burden, and either the patient has a terminal condition that is expected to cause death within six months, regardless of whether treatment is given, or the patient is permanently unconscious; or (ii) the treatment would be inhumane or extraordinarily burdensome and the patient has an irreversible or incurable condition. PHL § 2994-d(5).
- 35. See PHL § 2994-d; see also, PHL §§ 2805-d(2), 2504(4), 3000-a, and generally Article 30.
- 36. PHL § 2994-d(5).
- 37. PHL § 2994-d(5)(b).
- 38. PHL § 2994-g(5).
- 39. Former PHL § 2977 was repealed by l. 2010, ch. 8, § 20.
- 40. See PHL § 2994-dd(2) and 2994-dd(6).
- 41. PHL § 2994-cc(3).
- Cruzan v. Director, Missouri Dept. of Health, 497 US 261; Matter of Storar, 52 NY2d 363.
- 43. PHL § 2994-a.
- 44. PHL § 2504.
- 45. Matter of AB by Her Mother, CD, 196 Misc.2d 940, 959 ["Pursuant to Matter of Hofbauer and Public Health Law § 2504(2), CD is authorized to make this choice for her daughter"]). Unlike former PHL section 2977, PHL section 2994-cc contains no specific provisions regarding consent by a parent to a nonhospital DNR order for a minor child. There is nothing, however, in the legislative history of l. 2010, ch. 8, to suggest any intent to take away the ability of the parent or legal guardian of a minor to consent to a nonhospital DNR order for a minor.
- 46. See Matter of Hofbauer, 47 NY2d 648, 656.
- 47. See l. 2010, ch. 331, adding PHL § 2997-c.

- 48. PHL §§ 2994-a(24), 2994-e.
- 49. PHL §§ 2994-a(26), 2994-m(2)(a).
- 50. 196 Misc.2d 940, 959.
- 51. PHL § 2994-e(3).
- 52. PHL § 2994-a(8).
- 53. PHL § 2994-a(1).
- 54. PHL § 2994-b(3).
- Memo from Eileen Zibell to DDSO Directors, Voluntary Provider Agency Executive Directors regarding approval of MOLST form (January 21, 2011), http://www.omr.state.ny.us/health/ hp_MOLST.jsp.
- 56. PHL §§ 2961(9), 2994-a(10).
- 57. Letter from Commissioner Michael Hogan, NYS Office of Mental Health, to Commissioner Richard Daines, NYS Dept. of Health (August 23, 2010), http://commons.wikimedia.org/wiki/ File:MOLST_OMH_approval.JPG.
- The checklists are available on the DOH website at: http://www. nyhealth.gov/professionals/patients/patient_rights/molst/.
- 59. The OPWDD checklist is available at: http://www.omr.state. ny.us/health/hp_MOLST.jsp.
- 60. "Clear and convincing evidence" is evidence that the patient held a firm and settled commitment to the withholding of life-sustaining treatment in the event of circumstances like the patient's current medical condition. The evidence may be in a written living will, and/or previous oral statements indicating the patient's wishes, considering the circumstances under which such statements were made and to whom. In order to decide whether the evidence of the patient's wishes is clear and convincing, consideration should be given to:
 - whether the statements were general or specific;
 - whether the statements were about specific circumstances (for example, terminal illness, persistent vegetative state) that are similar to the patient's current medical condition;
 - the intensity, frequency, consistency, and seriousness of such statements;
 - whether the statements tended to show that the patient held a firm and settled commitment to certain treatment decisions under circumstances like those presented;
 - whether the strength and durability of the patient's religious and moral beliefs make a more recent change of heart unlikely; and
 - whether the statements were made to one person only or to more than one person close to the patient.

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Making the Family Health Care Decisions Act Apply to Hospice Patients

By Kathy McMahon

Introduction

The Family Health Care Decisions Act (FHCDA), first introduced in 1993, went through many iterations before it was passed and signed into law in 2010. This landmark piece of legislation sets forth a framework for surrogate decision making for patients who lack capacity and have not designated a health care proxy or estab-



lished advance directives. New York is no longer one of the only states in the nation that had neither surrogate decision-making statute or case law. However, as enacted, the FHCDA authorizes surrogate decision making only in hospital and long-term care facilities.¹

For 17 years New York State's hospices advocated for passage of the Family Health Care Decisions Act (FHCDA). Hospices regarded passage of the Act as an access issue—without FHCDA terminally ill patients who lack capacity are denied access to the hospice benefit. When FHCDA was passed and signed into law in 2010 it was a momentous event. However, FHCDA does not address surrogate decision making in hospice or for someone lacking capacity in a community-based setting to elect hospice.

Background—Hospice

Hospice is a unique model of care—it provides case management and patient-centered care using an interdisciplinary team. Patient choice is one of the hallmarks of the program, which has been a Medicare benefit since 1985. Patient choice—medical decision making—is clear cut when the patient has capacity and/or has an advance directive. However, when the patient lacks capacity, and there is no health care proxy, what happens to the patient in the community who could benefit from hospice care? Since the FHCDA is inapplicable to such patients, it ordinarily means that the patient is denied access to hospice care, which clearly was not the intent of the FHCDA.

Hospice:

• Embraces all patients coping with advanced illnesses,

- Focuses on comfort rather than cure,
- Emphasizes quality of life,
- Promotes personal choice and individual dignity,
- Respects the traditions and wishes of the patient and the patient's family,
- Most often provides care in the patient's home, but when necessary, can also provide care in the nursing home and inpatient setting,
- Utilizes current treatments and medications,
- Addresses physical, social, emotional, and spiritual needs, and
- Provides care and support to the bereaved.

In hospice the *family* is the unit of care. Each patient/ family has an interdisciplinary team, comprised of: physician, nurse, home health aide social worker, pastoral care (if they wish), volunteers (if they wish) and bereavement counselors.

The process for acceptance into the hospice program is comprehensive: 1) the patient is referred to the hospice; 2) the hospice completes an evaluation to determine eligibility (6 months or less terminal diagnosis; two physicians must certify the 6-month prognosis); 3) the patient (or health care proxy) elects the hospice benefit; 4) comprehensive assessment of the patient's/family's need is completed; and 5) a Plan of Care (which is changed as needed to meet the needs of the patient and family) is developed.

The diagnoses of hospice patients include: cancers; chronic obstructive pulmonary disease (COPD), such as emphysema; cardiac diseases, e.g., congestive heart failure (CHF); Parkinson's disease; Alzheimer's and other dementias.

Challenges Faced by Hospice

The case study below clearly demonstrates why FHCDA should apply to hospice:

Patient, a 75-year-old man, was dying from brain cancer. His doctor, an oncologist, first raised the issue of hospice care with the patient's wife when the patient was at home and receiving home health care. At that time, the patient

no longer had decision-making capacity. The patient's wife immediately recognized the value of electing hospice. She knew that her husband would prefer to die at home with palliative care, and she very much wanted to start to receive the case management and multidisciplinary support services that hospice could offer.

Accordingly the physician referred the wife to the local hospice, and she promptly contacted that organization. However, the hospice administrator reluctantly informed the wife that she did not have the authority either to elect hospice for her husband, or to authorize a plan of care at home that limited life-sustaining treatment. He suggested that the wife either go to court for a guardianship, or wait until her husband was hospitalized, and then use her authority as surrogate under the FHCDA to elect hospice. The wife was dismayed, and did not take further steps to secure hospice services. Her husband died about two weeks later with far less than optimal end of life care.

If the FHCDA applied to decisions relating to hospice patients (including the decision to elect hospice), it would have been possible for care to be provided in accordance with the patient's wishes. Instead, currently this wife and many others like her do not have authority as surrogate decision-maker, and are constrained from fulfilling what they believe would have been the patient's wishes.

How Hospice Fits Within the FHCDA Structure

Hospices, like hospitals and nursing homes, are highly regulated. Hospices are Medicare-certified by the Center for Medicare & Medicaid Services (CMS)² and licensed by the State of New York.³ They must operate in compliance with CMS's Hospice Conditions of Participation (COPs). New York's hospices are periodically surveyed by the NYS Department of Health's Bureau of Home Care and Hospice Surveillance and Quality Indicators/Evaluation to assure that they are in compliance with the COPs:

Quality matters! New York's hospices are committed to providing quality end-of-life care. All hospices are mandated by CMS to have a Quality Assessment and Performance Improvement (QAPI) program in place.⁴ Seven New York State Hospices and palliative care providers participated in the recently completed CMS AIM (Assessment, Intervention and Measurement) grant, which charged IPRO with developing a set of recommended quality measures for hospice. Phase 2 of the NYS Department of Health's (DOH) Hospice Quality Initiative will be implemented in the near future.

Amendments to allow surrogate decision making for hospice will be an easy "fit" within the structure already established by FHCDA. Specifically, hospices can meet the FHCDA standards with respect to:

- use of ethics committees,
- process for determining capacity,
- process and procedures for end-of-life decision making, and
- decision making for the "isolated patient," i.e., a person who lacks capacity and who has no one in the hierarchy listed in FHCDA.

Next Steps

The statute that enacted the FHCDA charged the Task Force for Life and the Law with examining whether the FHCDA should be amended to apply to decisions for health care in community-based settings.⁵ The Task Force's report, issued on December 22, 2010 (see Appendix A on p. 51) recommended: "...that the Legislature amend the FHCDA to include decisions regarding hospice care."⁶ This is a big "win" for patients in community-based settings who are eligible for the hospice benefit but lack capacity and do not have a health care proxy. The next step is to translate the Task Force's recommendation into draft statute for introduction in the New York State Assembly and Senate.

Conclusion

State law must protect the rights of all patients, ensuring that they can live with dignity and receive care consistent with their own wishes and beliefs. It is crucial that all New Yorkers—including those being cared for outside hospital or nursing home settings—should be offered protection by the law and compassion by the courts.

Without the protections afforded by the Family Health Care Decision Act, many New Yorkers are denied access to the quality end-of-life care offered by hospice. Most family members incorrectly assume that they do have the legal right to make decisions on behalf of the patient who lacks capacity. Unfortunately, that is not the case.

We are now in year eighteen of the struggle for a health care decision-making process that supports access to hospice. Will 2011 be the year? We certainly hope so. The Task Force on Life and the Law is to be commended for their comprehensive report and thoughtful consider-

ation of the issues. The Legislature should act quickly to adopt the Task Force's recommendations, and apply the FHCDA to decisions relating to hospice.

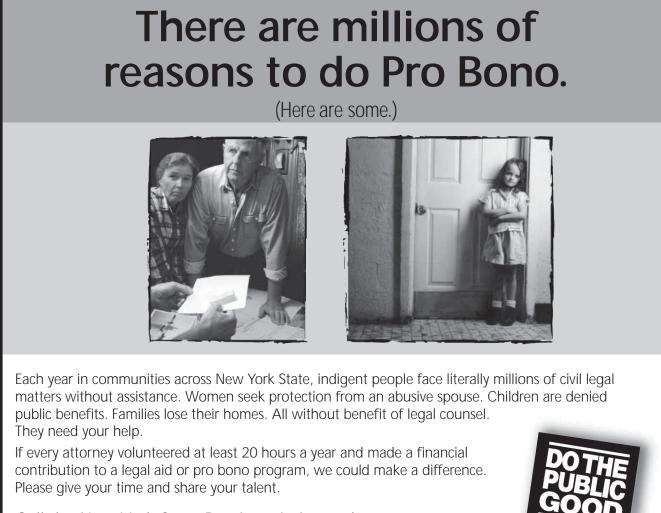
Endnotes

- 1. Public Health Law §2994-b.1.
- 2. See 42 CFR Part 418. CMS approves hospices for participation in Medicare after a survey by either the State or a recognized accreditation agency. The survey examines this hospice's compliance with CMS conditions of participation. See CMS State Operations Manual, chapter 2.
- 3. NYS Public Health Law Article 40.
- 4. 42 CFR §418.58.

- 5. NY Laws of 2010, Ch.8, §28.2.
- NYS Task Force on Life and the Law, Recommendations Regarding the Extention of the Family Health Care Decisions Act to Hospice, Nov. 30, 2010. The recommendation can be found on p. 51 (Appendix A) or at http://www.health.state.ny.us/regulations/task_force/ docs/2010-12-22_extension_of_family_health_care_decisions_act. pdf.

Kathy McMahon is President and CEO of the Hospice and Palliative Care Association of New York State.

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APPENDIX A



Richard F. Daines, M.D. Chairperson

Beth E. Roxland, J.D., M.Bioethics Executive Director

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December 22, 2010

Honorable John L. Sampson Majority Conference Leader, New York State Senate Legislative Office Building 188 State Street, Room 409 Albany, New York 12247

Honorable Dean G. Skelos Minority Leader, New York State Senate Legislative Office Building 188 State Street, Room 907 Albany, New York 12247

Honorable Sheldon Silver Speaker, New York State Assembly Legislative Office Building 188 State Street, Room 932 Albany, New York 12248

Honorable Brian M. Kolb Minority Leader, New York State Assembly Legislative Office Building 188 State Street, Room 933 Albany, New York 12248

Dear Senators Sampson and Skelos, and Assembly Members Silver and Kolb:

On behalf of the New York State Task Force on Life and the Law (the "Task Force"), I am pleased to submit for your consideration, "*Recommendations Regarding the Extension of the Family Health Care Decisions Act to Include Hospice*."

The Task Force was created by Executive Order in 1985 to develop public policy on issues arising at the interface of law, medicine, and ethics. Since then, the Task Force has issued influential reports on a variety of bioethics issues, including genetic testing, assisted reproductive technologies, allocation of ventilators in the event of a pandemic influenza outbreak, and organ donation.

The Task Force commends the Legislature on the passage of the Family Health Care Decisions Act ("FHCDA") in March 2010, which provides New Yorkers with an invaluable tool to facilitate surrogate decision-making for health care. Prior to the FHCDA, families and close friends of patients did not have the authority to make even routine health care decisions on a patient's behalf, and were required to satisfy an extremely high evidentiary burden when the decision concerned the withholding or withdrawing of life-sustaining treatment. The FHCDA greatly improved this situation by authorizing surrogates to make health care decisions for loved

ones in hospitals and residential health care facilities. However, it still leaves thousands of New Yorkers who receive care in other settings and who cannot speak for themselves without the benefit of a surrogate decision-maker.

The Legislature directed the Task Force to examine whether the FHCDA should be amended to apply to decisions for health care provided in settings outside of hospitals and residential health care facilities. *See* 2010 N.Y. Laws Ch. 8, § 28 (2). Over the past several months, the Task Force has deliberated over the ethical and legal issues raised by extending the FHCDA, and is prepared to make an initial recommendation that the FHCDA should be amended to provide surrogates with authority to make decisions on behalf of incapable patients for hospice care.

In order to be eligible for hospice, a patient must suffer from a terminal illness and have a lifeexpectancy of six months or less. These patients' conditions often affect their ability to make choices or express wishes, precisely at a time when they face many important health care decisions. Accordingly, surrogate decision-making for these vulnerable patients is crucial to ensuring that their rights and welfare are protected, and that they live the remainder of their days in dignity and with appropriate care.

As is set forth in further detail in the accompanying document, the Task Force hereby recommends that the Legislature amend the FHCDA to include decisions regarding hospice care. In the coming months, the Task Force will continue to explore the legal and ethical dimensions of extending the FHCDA's surrogate decision-making authority to other care settings and will provide additional recommendations on these issues to the Legislature.

Thank you for your attention to this matter, and for entrusting the Task Force with this important project. We look forward to working with you in the future.

Sincerely,

Beth Rodland

Beth E. Roxland, J.D., M.Bioethics Executive Director New York State Task Force on Life and the Law

Enclosure

cc: Richard F. Daines, M.D., Commissioner, New York State Department of Health Honorable Thomas K. Duane, Chair, New York State Senate Health Committee Honorable Kemp Hannon, Ranking Member, New York State Senate Health Committee Honorable Richard N. Gottfried, Chair, New York State Assembly Committee on Health Honorable James G. Bacalles, Ranking Member, New York State Assembly Committee on Health

APPENDIX A (continued)

Recommendations Regarding the Extension of the Family Health Care Decisions Act to Include Hospice

New York State Task Force on Life and the Law

November 30, 2010

I. Introduction

The enactment of the Family Health Care Decisions Act ("FHCDA") in March 2010 reflects the culmination of seventeen years of advocacy and support from the health care community in New York State, and represents a landmark legislative achievement. The law establishes a framework to allow surrogate decision making for patients without capacity when they have not chosen a health care proxy or left other instructions to direct their care. The Task Force on Life and the Law ("Task Force") proposed the legislation in its 1992 report titled *When Others Must Choose: Deciding for Patients Without Capacity* and welcomed with enthusiasm its passage.

The FHCDA was designed to fill a longstanding gap in New York law by providing an invaluable tool for surrogate decision-makers to honor the wishes of patients when they cannot speak for themselves, or to act in the best interests of these patients when their wishes are unknown. Prior to the passage of the FHCDA, families and close friends of patients did not have the authority to make even routine health care decisions on a patient's behalf, and were required to satisfy an extremely high evidentiary burden when the decision concerned the withholding or withdrawing of life-sustaining treatment. As a result, surrogates did not have the ability to consent to ameliorative treatments or to object to procedures, regardless of the degree of invasiveness, which may have run contrary to their loved one's previously expressed wishes or best interests.

II. FHCDA Issues for Task Force Consideration

The scope of surrogate authority under the FHCDA currently is limited to decisions about health care provided in two specific settings: hospitals and nursing homes.¹ The Legislature explicitly assigned² to the Task Force the project of considering whether the FHCDA should be amended to apply to decisions for health care provided in other settings, such as hospice, home care, or doctor's offices.³

The Task Force began its deliberations by identifying: (1) the settings where surrogate health care decisions are likely to be necessary, and (2) the procedural safeguards required to ensure proper oversight of health care delivery and protection of patient rights in these additional sites. For the reasons discussed below, surrogate decision making in hospices emerged as a priority for early legislative action. In the coming months, the Task Force intends to continue its deliberations and issue further recommendations on the extension of the FHCDA, but is making an initial recommendation that the FHCDA be amended to include surrogate decision making in the context of hospice care.

III. Provision of Hospice Care

A. The Provision of Hospice Care in New York State

Hospice is an interdisciplinary approach to end-of-life care that emphasizes palliative treatments and comfort care rather than curative care, while simultaneously providing comprehensive support to patients and their families. Hospice care is often provided in hospitals and nursing homes, but also is routinely provided in the home and other community-based settings. Patients are not eligible for hospice care until it is determined that their condition is incurable and that they have a life expectancy of six months or less.

In order to receive hospice care, an eligible patient must "elect" to enroll in hospice.⁴ Once the hospice election is made, a detailed care plan is created by the hospice team and the patient, which includes preferences and directions for withholding or withdrawing care. Therefore, health care decisions must be made both

to elect hospice and to direct the care of the patient once he or she is enrolled in hospice. When a patient lacks decision-making capacity, the family or other decision-maker must step in to make these decisions.

B. Barriers to Surrogate Decision Making Regarding Hospice Care

Patients who qualify for hospice care are an extremely vulnerable population who, by definition, are at the end of their lives. Due to complications resulting from terminal illness, many of these patients lack decision-making capacity and therefore must be able to rely on surrogate decision-makers and clinicians to ensure that they live out their final days in comfort and with dignity.

The current wording of the FHCDA creates a barrier to the utilization of hospice by terminally ill individuals because the authority it bestows upon surrogates is limited to care provided in hospitals or nursing homes. The FHCDA does not permit a surrogate to elect hospice care for a loved one who is being cared for outside of a covered facility at the time of the election decision. Even when a patient is successfully enrolled in hospice, a surrogate lacks the ability to make decisions about on-going care so long as that care is to be provided outside of a covered facility, for example, where hospice care will be provided in a stand-alone hospice facility or in the home. Therefore, the ability of a patient without decision-making capacity to access hospice care will depend upon where care is currently provided or will be provided going forward. Instead, the focus should be solely on ensuring that the individual's known preferences or best interests are honored at this crucial time.

IV. Task Force Conclusions

The limited applicability of the FHCDA maintains the status quo prior to its passage for hospice care outside of hospitals and nursing homes, which creates confusion and inequity. Without extending the authority bestowed by the FHCDA, would-be surrogates will continue to face the obstacles to decision making historically inherent in New York State, especially with respect to end-of-life care. Accordingly, the FHCDA should be amended to provide surrogates with authority to make health care decisions for hospice care outside of hospitals and nursing homes.

Promoting access to hospice, as well as supporting family participation in hospice care, is consistent with the intent of the legislature and overall regulatory approach to hospice care in New York State. The legislative declaration accompanying Article 40 of the Public Health Law, which governs hospice, states in pertinent part:

In recognition of the value of hospice and consistent with state policy to encourage the expansion of health care service options available to New York state residents, it is the intention of the legislature that hospice be available to all who seek such care and that it becomes a permanent component of the state's health care system.⁵

Furthermore, the regulations governing hospice care envision family involvement and surrogate consent, stating, "if a patient is not capable of giving informed consent, written informed consent must be obtained from any individual who is legally authorized to give such consent on behalf of the patient."⁶ The regulations also regard the patient and family as a unit, repeatedly referring to the "patient/family" when describing patient rights, the plan of care, and recordkeeping.⁷ Extending the surrogate authority in the FHCDA to hospice care outside hospitals and nursing homes will help to ensure consistency in the application of associated laws and regulations.

The addition of hospice also fits well into the structure of the FHCDA as it currently stands, without requiring extensive changes. Hospices are federally certified and highly regulated at the state level. The safeguards and oversight mechanisms in the FHCDA, including the procedures for determining capacity, the procedures for end-of-life decision making, and the requirements of ethics review committees will translate into hospice settings. Hospices have physicians and other interdisciplinary professionals on staff to fulfill the statutory requirements in these areas, and most hospices have their own ethics committee, or have access to an ethics committee (*e.g.*, through an affiliated institution or other agreement).

V. Recommendations

Because the needs of hospice-eligible patients are immediate and compelling, and because hospice programs are regulated and structured in ways that generally would allow application of the FHCDA's standards and procedures, the Task Force recommends that the FHCDA should be amended to:

- Allow patients who meet the criteria for hospice, but cannot make decisions on their own, the ability to have a surrogate appointed for them pursuant to the FHCDA for decisions relating to hospice care.
 - When patients have no surrogate reasonably available, willing or competent, decisions should be made on a patient's behalf in accordance with standards and mechanisms already set forth in the FHCDA.⁸
- Apply similar presumptions and procedures currently in the FHCDA to the determination of whether a potential hospice patient lacks capacity, and to the selection of the individual who will serve as surrogate.
- Enable surrogates to elect hospice care on behalf of patients, regardless of where the patients reside at the time of the election.
- Authorize surrogate decision making for all care while in hospice, including creation of the hospice plan of care and decisions to withholding and withdrawing life-sustaining treatment, using similar standards for decision making and oversight mechanisms that the FHCDA currently requires in hospital and nursing home settings.

Beth E. Roxland, J.D., M.Bioethics Executive Director

On Behalf of the New York State Task Force on Life and the Law

Endnotes

- 1. N.Y. Pub. Health Law Art. 29-CC § 1 (2010); *see also* N.Y. Pub. Health Law § 2994-b (applicability). More specifically, the FHCDA applies only to decisions regarding care provided in "hospitals," which is defined to include "general hospitals" and "residential health care facilities." *Id.* § 2994-a (18). A "residential health care facility" is "a nursing home or a facility providing health-related service." *Id.* § 2801 (3). Hereinafter, the terms "nursing home" and "residential health care facility" will be used interchangeably, and "general hospital" will be referred to as "hospital."
- 2. 2010 N.Y. Laws Ch. 8, § 28 (2).
- 3. The original Task Force proposal envisioned that surrogate authority would extend to all treatment decisions, without regard to where they were made, so long as appropriate safeguards were in place. However, the delivery of health care has changed significantly since the proposal was developed and it is prudent to reevaluate the effectiveness of the safeguards outside of the institutional settings of hospitals and nursing homes.
- 4. 42 C.F.R. § 418.24 (a) (2010); see also N. Y. Comp. Codes R. & Regs. tit. 10, § 793.6 (3) (2010).
- 5. N.Y. Pub. Health Law § 4000.
- 6. N.Y. Comp. Codes R. & Regs. tit. 10, § 793.6 (3).
- 7. See, e.g., id. §§ 794.1-4.
- 8. Patients who do not have an individual available to act as a surrogate similarly stand to benefit from hospice care as their counterparts with surrogates, and therefore should have equal access to such care. While there are legitimate concerns about the vulnerability of these individuals, the safeguards required by the FHCDA, such as oversight by an Ethics Review Committee, will ensure that only patients who are eligible—and for whom such care is in their best interests—will have decisions regarding hospice care made on their behalf.

Extending the Family Health Care Decisions Act to Home Care

By Alfredo D. Cardillo, M.S.W.

This article reviews some of the issues that would need to be considered in a potential extension of the Family Health Care Decisions Act (FHCDA) to the home care setting. To properly appreciate these issues and indeed the larger context of surrogate health care decision making in the home care setting, the article provides an overview of home care



in the evolving health care system, a review of New York's home care infrastructure, compelling reasons why FHCDA should be made applicable to home care, issues to consider in a potential extension, and options for bringing the FHCDA home.

Overview—Home Care and the Evolving Health Care System

The health care system is becoming increasingly integrated, encouraged by advancement in clinical practice, innovations in care management and technology, outcome/value based imperatives, incentives for efficiency, buy-in to integration by providers and payors, and progressive governmental policies.

In this context in which traditional modalities of care are being reexamined and opened to change, home health care has assumed an ever-deepening role in the delivery and coverage of care.

Home health agencies serve the gamut of patients, from new mothers and their infants to individuals over 100 years old, providing the range of preventive, preacute, post-acute, therapeutic, high-tech and chronic care. For a growing number of patients, home care is a core and collaborating component of their "medical home"—that "place" to which patients turn for their basic medical management needs and to which government and payors are further turning to bring the elements of the system together in a patient-centered, customized manner of care.

Home care has evolved to where it now flows to and between all of the various parts of the system; it is vitally connected to and with all levels of care. It is a prehospital intervention and a preventer of trips to the emergency room. In some models it is being directly substituted for acute inpatient stays. It has taken the place of the far end of hospital episodes, shifting this care to the home. It is the preferred setting for patient rehabilitation, and the choice for long term care over institutionalization.

The Home Care Infrastructure in New York State

The principal infrastructure of the New York's comprehensive home care system consists of Certified Home Health Agencies, Long Term Home Health Care Programs and Licensed Home Care Services Agencies.

Certified Home Health Agencies (CHHAs) are certified by the state under article thirty-six of the public health law to provide nursing, therapeutic and home health aide services under the Medicare and Medicaid programs.¹ CHHAs must meet the federal Medicare Conditions of Participation² along with an array of additional New York State regulations³ for operation of their services, management of the patient's care and quality assurance. CHHAs may be free-standing agencies—such as a Visiting Nurse Association—or may be sponsored by hospitals, nursing homes or county/municipal health departments. CHHAs are responsible for developing, managing and providing the plan of care for an individual in his or her home. CHHAs cover a wide range of patients, and often provide the short-term skilled and rehabilitation services needed following hospitalization. CHHAs have many roles in the delivery of services in the community, ranging from preventive, public health and therapeutic services, to the management of chronic disease, to the care of individuals at the end of life. CHHA services are available statewide.

Long Term Home Health Care Programs (LTHH-CPs), often referred to as the "Nursing Home Without Walls Program," are also agencies certified to participate in Medicaid and Medicare, but are specialized in the care of individuals who are otherwise medically eligible for admission to a nursing home.⁴ LTHHCPs are sponsored by hospitals, nursing homes and CHHAs which receive specific state certification to provide a Long Term Home Health Care Program. LTHHCPs provide, coordinate and are responsible for managing a comprehensive plan of care for medically fragile adults and children, individuals with chronic illness and persons

with disabilities. LTHHCPs are authorized to provide an extensive range of diverse and interdisciplinary services similar to the health, social and environmental supports provided in a nursing home. LTHHCPs must also meet the federal Conditions of Participation⁵ as well as the array of state regulatory requirements⁶ for operation, care management and quality assurance. LTHHCP services are available throughout the state, except in a few of the most rural counties, where development continues to be explored.

Licensed home care services agencies (LHCSAs) are licensed by the state to provide paraprofessional and nursing services, often as subcontractors in the delivery of CHHA or LTHHCP services.⁷ LHCSAs are not direct participants in Medicaid or Medicare, but subcontract with CHHAs, LTHHCPs or county departments of social services to provide services paid for by governmental plans. Under these subcontract arrangements, responsibility for the patient, the services and the plan of care rests with the CHHA and the LTHHCP. Like CHHAs and LTHHCPs, LHCSAs may also provide care to patients on a private pay basis or as covered by insurance or other third-party plans.

More and More Decisions Applicable to and Made Within the Home Setting

With the expanding role of home care and increasing integration of the system, more and more patient health encounters will be occurring in the home setting. Hence, more and more will a person's health care decisions be applicable to, and made within, the home.

As an example, emerging technologies are increasingly permitting through CHHAs and LTHHCPs daily monitoring and treatment decisions/interventions for patients with unstable or high risk conditions. Home telehealth allows for the daily monitoring of patient vital signs and other key health indicators, permitting diagnosis, decision making and intervention for patients without ever leaving the home. Thus is the case for patients suffering congestive heart failure, the most frequent cause of repeat hospitalizations. Increasingly, congestive heart failure patients can avoid hospitalization and emergency room use by being monitored at home by a home care agency. Among other vitals, agency staff are able to monitor the principal indicator of weight-gain (revealing likelihood of fluid retention) and address any necessary intervention with the patient and/or the patient's family and the physician, all in a diagnosis and decision making process without dislocation from the home.

Even apart from the growth and change in the field, all patients and providers in home health must routinely

make decisions with regard to care and treatment for an infinite array of needs and circumstances; and, many patients, especially those in an advanced, medically fragile state, face highly critical decisions. As home care increasingly becomes a venue for individuals with advanced or potentially life-threatening conditions, it is increasingly the venue in which such decisions are faced.

Need to Extend the Family Health Care Decisions Act to the Home Setting

Although critical health care decision making is necessary in the home, state laws do not currently provide in home settings the same, clear structure recently provided for such decision making in hospitals and nursing homes when a patient loses health decision making capacity and no proxy or other legally authorized representative is available.

From the time that the Family Health Care Decisions Act was first introduced, in the early 1990s, until near to its final version in 2010, the proposed law applied to decisions made in virtually all health care settings. However, the complex and volatile concerns associated with the assignment of a surrogate decision maker which took the Legislature the better part of two decades to resolve, led the Legislature in its final agreement to start with a narrower law that applied only in hospital and nursing home settings.

While this approach helped secure an agreement on the law and provided a secure starting point for implementation, the Legislature recognized the necessity to right away begin work toward researching the extension of the FHCDA to additional settings.

With new procedures and clarity for hospitals and nursing homes, the new law simultaneously creates a cliff in applicability to other settings, like home care. Under the FHCDA, in order for surrogates to be appointed and/or for decisions to be made for patients at home, home care patients have to be hospitalized or placed in a nursing home, or the home care provider or family must seek "workarounds" and be faced with inconsistency of procedure, such as what existed for hospitals and nursing homes prior to the FHCDA.

Case in point #1: Patient "A" suffers from dementia. While hospitalized, the patient is determined to have lost capacity for health care decision making. The patient's spouse is appointed surrogate during the hospitalization. The patient is then discharged home. A home care plan is instituted to provide care for the patient. The dementia progresses and the patient loses the ability to swallow and is at risk of aspiration, pneumonia and possible death. Under the existing FHCDA, the surro-

gate cannot make a decision to forgo medical treatment for this life-threatening condition for this patient while the patient is at home—because the FHCDA is not applicable to the home setting. In order for the surrogate to be able to make this decision, the patient would have to be hospitalized or admitted to a nursing home, where the decision to forgo treatment would be made and the patient subsequently returned home.

Case in point #2: A diabetic patient with severely and rapidly deteriorating health, and without a surrogate, is determined to have a gangrenous leg, which without treatment/amputation will hasten death. Various members of the patient's family claim that the individual, if able to make his or her own decision, would never choose the amputation and would prefer to pass without this additional suffering. Under the FHCDA, neither the appointment of one of the family members to be surrogate, nor the decision to forgo amputation, could be made in the home environment. For these decisions to be made, the current law would require the patient to be hospitalized for the appointment of a surrogate and for the surrogate to decide on behalf of the patient to forgo the treatment and return the patient home.

Case in point #3: Assume the same diabetic patient in Case #2, but this time the patient's physician is offering, as an alternative to amputation, a powerful medication with possible serious side effects, to be administered by IV at home. The closest family wants to consent to the treatment on behalf of the patient, but the physician questions the family member's authority to decide. Here again, for the family member to have clear authority to decide, it would appear necessary to hospitalize the patient, whereupon the family member would become an FHCDA surrogate.

The lack of the extension of the FHCDA to the home setting and the consequences as described above are improper for both the patient and the system.

Issues to Address in Extending the FHCDA to the Home

In implementing the Legislature's directive to explore the extension of the FHCDA to other settings,⁸ in fall 2010 the New York State Task Force on Life and Law reached out to the Home Care Association of New York State (HCA) to engage the Association in researching home care. To facilitate this research, HCA convened a workgroup of home care clinicians and administrators to review the provisions of the FHCDA and, considering the parameters, protections and other provisions of that law, identify what issues would have to be addressed

to feasibly and properly extend the law to home care. Several of these issues are next discussed in this section.

1. What Should Constitute "Home Care" for Purposes of FHCDA Extension to the Home?

In extending the FHCDA to home care, it will have to be determined whether "home care" should mean only the general setting in which the patient resides or, more specifically, a patient at home under the care of a formal home care program (a CHHA or LTHHCP).

As the FHCDA is currently constructed, the patient's "care setting"—i.e., a general hospital or nursing home—functions as the patient's principal health care provider, through which the FHCDA's procedural and quality assurance mechanisms are established and ensured for the patient.

Thus, if the Act were to be extended to patients at home, the closet parallel to the existing FHCDA would be to extend its provisions through the patient's principal provider in the home setting, and thus to patients at home under the care of a CHHA or LTHHCP. In this scenario, the FHCDA would ostensibly provide that CHHAs and LTHHCPs, in conjunction with the patient's physician, ensure for patients the same (or appropriately modified for the home) types of protections as the FHCDA requires of hospitals and nursing homes, including clinical determinations, ethics reviews and decision-making standards.

In the case of patients cared for at home by family or others but without connection to the formal home care system, the FHCDA's protections and protocols, which revolve around the participating provider and provider setting, would need a connection to some other provider base. Without a link to formal home care, this may be a quandary for the FHCDA and these patients. One suggestion may be that, unless there is an interest or plan for a such a patient to engage with a home care agency, the FHCDA provider connection may be most practically established with the patient's primary physician. Thus, a possible route for FHCDA coverage of such patients living at home, but not in home care, may be through eventual FHCDA extension to physician offices and the categorization of these patients as "under the care of a physician's office" instead of as "home care" patients.

2. The Home Environment Versus an Institutional Setting

An important issue in considering and navigating the FHCDA's extension to home care is the varied, personalized and comparatively dynamic nature of the home environment—vastly distinct from the institu-

tional care settings in which the Act currently applies and operates.

Hospitals and nursing homes are a relatively tightly controlled environment, whereas the home is an open and personal setting, ultimately shaped by the patient and other household members.

In institutional environments, the clinical staff is present 'round the clock, including physician access. The total environment is under the purview of the facility's administration and the facility is subject to an array of regulatory standards.

The very essence of home care is that service is provided in the personalized environment of the patient's home. In home care, the patient and/or family determine the environment, which is filled with autonomous personal and critical health choices. Professional assistance (i.e., contact with agency staff) is available 'roundthe-clock in CHHAs and LTHHCPs; however, except in very limited cases, patients in home care are not accompanied by twenty-four hour on-site staff, as they are in institutions.

Patient care in an institution is provided in a provider-driven and controlled environment. Home care is the opposite; it is patient-driven and patient/family controlled. Within this characteristic of home care also lies the essence of the comfort and desire of individuals to receive health care at home, and for those at the end of life, makes it their vastly preferred place to live out their final days.

It is important, therefore, that the would-be operation of the FHCDA in home care be duly considerate of such distinguishing factors from institutional care. At a minimum, the extension of the Act should contemplate the relevant considerations and adaptations—from the law's current institutional focus—to make it compatible with and properly accommodating for both home care patients and providers.

3. FHCDA Key Features Will Require Adaptation for Home Care

Certain features which are fundamental to the FHCDA in its current institutional settings are not mandated for, and may not be present in the same way, in home care. In this regard, extension of the FHCDA to home care would require a thorough examination of these features and their capacity to be provided for or properly adapted for the home care field.

Attending Physician: The presence of and access to physicians and medical directors in hospitals and

nursing homes, which are pivotal requirements in the current FHCDA, differ in the world of home care.

In institutions, "attending physicians" have primary responsibility for the care and treatment of patients. Attendings are responsible for the orders and on-site care of the patient.

Home care's "equivalent" of an attending physician is the "ordering physician." In home care, this physician issues the orders for the plan of care which is then implemented and managed by the home care provider. All home care is provided pursuant to physician orders. In home care, a physician orders the start of care, and these orders must be renewed at least every sixty days. The physician must otherwise approve changes in the plan of care.

Continuity with physicians can be challenging for Medicaid patients and hospital dischargees, whose orders for home care may be issued by a hospitalist and then shifted to a physician in the community, who for some Medicaid patients may be a physician in a clinic group. This dynamic, which is in contrast to the institutional sectors, must be acknowledged in designating or translating the "attending physician's" responsibilities in a potential FHCDA extension to home care.

Another area of variance in applying the current FHCDA to home care involves the FHCDA's specification of various roles for a Medical Director. Home care agencies are not required to have Medical Directors. However, some home care agencies have contractual or other organizational relationships with physicians, including the Medical Directors of the agency's parent sponsor if it is a hospital- or nursing home-based home care agency. In these cases, either the parent facility's Medical Director or other affiliated physician could perhaps serve in the prescribed roles required by the FHCDA, and indeed would need to be retained for such if the FHCDA were to be eventually extended to home care.

Ethics Committees: Unlike institutions under the FHCDA, home care agencies are not required to have the FHCDA's prescribed Ethics Committees. However, some home care providers either already have their own Ethics Committees or utilize the Ethics Committee of their parent hospital or nursing home if part of the same system.

Convening Ethics Committees would be a new mandate for home care agencies if the FHCDA were to be extended to home care. While a potentially good practice to have such committees in home care regardless of the FHCDA, requiring home care Ethics Committees at this

time in an already well-overburdened field necessitates careful consideration. The issue of mandates in home care will be further discussed later in this article.

4. Determinations of Capacity/Incapacity

Under the FHCDA, determinations of incapacity are made by the attending physician; in nursing homes there must be an independent determination of incapacity by a health or social services practitioner employed by or otherwise formally affiliated with the facility.

In an FHCDA extension to home care, it is contemplated that determinations of incapacity could be made by the *ordering* physician (the physician who has ordered the home care plan of care) or by the patient's primary physician if other than the ordering physician. Recently implemented federal requirements for home care patient "face-to-face" encounters with physicians may facilitate such determinations, especially in startof-care situations. As is the case in nursing homes, the added FHCDA protection of securing concurring opinions by a health or social services practitioner could be provided in the same way by the staff of the CHHA or LTHHCP.

5. Health Care Decisions for Patients Without Surrogates

The FHCDA establishes a framework for making routine medical decisions, major medical decisions and decisions to withhold or withdraw of life-sustaining treatment for patients *without* surrogates.

In home care, routine and major medical decisions need to be able to be made in a timely manner in the context of the patient's care and the home care agency's general operations. The current FHCDA authorizes a hospital or nursing home patient's attending physician to decide about routine medical treatment, and nothing in the Act requires health care providers to obtain specific consent for treatment where specific consent is not otherwise required by law.

It is contemplated that a parallel provision for home care could authorize the ordering physician in conjunction with the home care provider to be the sources for routine medical decisions.

Under the FHCDA, making a major medical treatment decision (such as the use of psychoactive medications, physical restraints, invasion of bodily integrity requiring incision, producing substantial pain, discomfort, debilitation or having a significant recovery period) requires the attending physician and a concurring opinion of at least one other designated physician, or Medical Director if the patient is in a nursing home. A health or social services practitioner may provide the concurring opinion if the decision is about the use of physical restraints.

If a parallel provision were to be established for home care, it is contemplated that the ordering physician could make the medical decision. However, in providing for the concurring opinion of a Medical Director (or other physician), the previously discussed issue that home care providers do not currently routinely have a Medical Director would need to be addressed. While many of the major medical decisions that meet the criteria of the FHCDA would be more apt to be applicable in a hospital than in a patient's home, as the system evolves and more and more complex care is provided in the home, more and more of these treatment decisions will likewise be made in the home.

Under FHCDA, decisions to withhold or withdraw life-sustaining treatment would require either a court of competent jurisdiction or a decision by the attending physician, with independent concurrence of a second physician designated by the hospital or nursing home, that to a reasonable degree of medical certainty (i) life-sustaining treatment offers the patient no medical benefit because the patient will die imminently, even if the treatment is provided; and (ii) the provision of lifesustaining treatment would violate accepted medical standards.

If the FHCDA were to be extended to home care, it is contemplated that the same process and protections would be required of the provider and accorded the patient.

6. New Mandates

Home care agencies are currently besieged by new and mounting state and federal mandates. HCA has estimated that in just past several years, these mandates have resulted in \$75 million in unfunded obligations. Moreover, the state and federal budget processes have unleashed unprecedented cuts to the health care system, home care included. New requirements which might be imposed on home care agencies as a result of a possible FHCDA extension must be carefully and thoughtfully evaluated in this context.

Potential Options for FHCDA Extension to Home Care

Considering the aforementioned issues, one suggested option for allowing FHCDA extension to home care is to provide legislative authority for a provider opt-in process, beginning with CHHAs and LTHHCPs. While an opt-in would not bring FHCDA authority

to initially nonparticipating providers, it would indeed allow for a tested and gradual period of FHCDA implementation in home care through the participating agencies, with issues able to be identified and addressed on the front end. Given the important and fundamental goal at stake for the patients, as well as the integrity of the health care decision making process outside of the institutional sector, such a proposed opt-in merits serious consideration.

Indeed, "home is where the heart is." Home is where people in need of care overwhelmingly prefer to be and the direction in which health care continues to move. Our laws, rules and opportunities should similarly follow that course.

Endnotes

- 1. NY Public Health Law §§3606, 3608.
- 2. 42 CFR Part 484.
- 3. 10 NYCRR Part 761.
- 4. NY Public Health Law §§3610, 3616.
- 5. 42 CFR Part 484.
- 6. 10 NYCRR Part 761.
- 7. NY Public Health Law §3605; 10 NYCRR Part 766.
- 8. NY Laws of 2010, Ch. 8, §28.2.

Al Cardillo is the Executive Vice President of the Home Care Association of New York State.

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Introducing—

The NYSBA Family Health Care Decisions Act Information Center

The NYSBA Health Law Section has launched a web-based resource center designed to help New Yorkers understand and implement the Family Health Care Decisions Act—the new 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.



www.nysba.org/fhcda

A Bridge for People with Developmental Disabilities: The FHCDA and HCDAPMR Need Some Reconciliation

By Paul R. Kietzman

Several years before New York adopted the Family Health Care Decisions Act (FHCDA), it adopted a surrogate decision-making law for persons with intellectual disabilities, the Health Care Decisions Act for Persons with Mental Retardation (HCDAPMR).¹ As undeveloped and inadequate as the statutory end-of-life law of New York was for persons without intellectual disabilities, the Courts and ultimately the legislature acknowledged in the passage of HCDAPMR that the law of this State was a particular hardship on its citizens with intellectual and other developmental disabilities ("ID/DD").²

Subsequent to its enactment in 2003, the HCDAPMR was widely and successfully implemented across the State's system of care overseen by the Office for People With Developmental Disabilities (OPWDD), but not without broad legal challenges to its constitutionality and purported retroactivity as to guardians appointed prior to its effective date.³ The statute was incrementally amended to confer end-of-life decisionmaking authority to corporate guardians, to guardians of persons with developmental disabilities, to "qualified" family members of persons with ID/DD who had no appointed guardian, and ultimately to add the Willowbrook Consumer Advisory Board and Surrogate Decision-Making Committees⁴ to the list of non-guardian surrogates who could consent to the withholding/ withdrawal of life-sustaining treatment. NYSARC, as Article 17-A primary corporate guardian for well over 300 individuals and as residential service provider for tens of thousands of aging persons with ID/DD, uses this statutory scheme on a weekly basis.

As the window of opportunity for passage of the FHCDA opened a crack in the Spring of 2010, there was a great deal of give and take among the legislative committee chairs, their staff, and advocates and service providers of all persuasions, including NYSARC, over the issue of how the statute would deal with health care decisions for persons with ID/DD. Having mid-wifed and wet nursed the SCPA 1750-b, NYSARC was vigilant for any traces of baby in the FHCDA bathwater. The outcome of that final dialogue was largely satisfactory to the ID/DD advocacy community, with a few exceptions, which will be the subject matter of this article.

There is much to like about the FHCDA, most notably for the OPWDD provider and advocacy community the fact that SCPA 1750-b, as well as the OPWDD medical consent,⁵ health care proxy,⁶ and perhaps other related regulations were preserved.⁷ It is not clear to me that the OPWDD DNR regulations survive at this point.⁸ Hospital and nursing home patients with a diagnosis of ID/DD, patients with a history of OP-WDD services, or patients admitted from an OPWDD system facility will have health care decisions, which they might currently lack capacity to make themselves, made pursuant to familiar statutory and regulatory processes, including SDMCs. Also, a new definition of "life-sustaining treatment" was added by the FHCDA to the HCDAPMR,⁹ so that the authority of guardians and other surrogates to make end-of-life decisions now includes decisions to forgo cardiopulmonary resuscitation.

In recognition of the legislature's unique opportunity to enact the FHCDA after more or less twenty years of effort, some unresolved matters relating to the Mental Hygiene system of care were referred to a special committee of the Governor's Task Force on Life and the Law,¹⁰ which as of this writing has not been formally constituted. Other matters seem to have simply gotten lost in the midst of twenty years of drafting, negotiating and re-drafting.

In addition to the new and expanded SCPA definition of life-sustaining treatment in SCPA 1750-b, the bill made some major modifications to Public Health Law Article 29-B. which had, since its enactment in 1987. addressed "orders not to resuscitate" in a broad range of facilities including general hospitals, nursing homes, psychiatric centers and "schools" listed in Mental Hygiene Law 13.17.11 The FHCDA created a new PHL Article 29-CC ("Nonhospital Orders Not To Resuscitate"), which, at new section 2994-cc 5, states that consent by a patient or by a surrogate of a resident of a "mental hygiene facility" shall be governed by newly amended PHL article 29-B.¹² However, the amended definition of "hospital" in the new PHL article 29-B is outdated in referring to "school(s) named in section 13.17 of the mental hygiene law." The term "attending physician" was re-defined as a physician selected by or assigned to a "patient in a hospital." More to the point, there were

and are no "schools" named in MHL 13.17 at the time of FHCDA enactment, and even interpreting intent in some uncomfortably broad way, all of MHL article 13 applies only to State-run facilities. Residential facilities operated by private non-profit providers like NYSARC presently serve significantly larger numbers of ID/DD New Yorkers than State facilities.

Also, any person presently or previously served in the OPWDD care system (State-operated or voluntary operated) would be eligible for end-of-life decision making under SCPA 1750-b, which now includes DNRs. There was no reason for the amended PHL Article 29-B to address any need of OPWDD consumers, and, I believe, the OMH provider and advocacy community agrees that the Article should be repealed and/or replaced. However, the purpose of this piece is to argue that before the work of the Governor's Task Force results in...whatever it results in, there is a need for a few matters (as to which there is believed to be no significant disagreement) to be resolved. I would start with the repeal of PHL Article 29-B, and a nip and a tuck to the other involved statutes.

What's to like about SCPA 1750-b? In the first place it more than survived its trip through the appellate courts of the State. Justice Graffeo, writing for the Court of Appeals in *Matter of MB*,¹³ affirming the basic constitutionality and retroactive effect of SCPA 1750-b, stated:

In the wake of Storar, a distinction arose between the common-law rights of competent adults, who could make their wishes concerning end-of-life care known to family and friends, and mentally retarded persons who had never been competent to make their own health care decisions and for whom life-sustaining treatment could not be refused. When these mentally retarded individuals became irreversibly, terminally ill they were, in effect, ineligible for hospice or other palliative care because their guardians were unable to refuse more intrusive, acute medical treatments aimed at extending life for as long as possible.

This was the situation the Legislature sought to remedy when it enacted the Health Care Decisions Act for Persons with Mental Retardation (HCDA)...."

In this technically moot case (MB died while the matter was before the Staten Island Surrogate), the Court of Appeals went on to note approvingly that the 1750-b process, among other things, requires: that the guardian/surrogate "advocate for the full and efficacious provision of health care, including life-sustaining treatment";¹⁴ a de novo two physician certification of the person's lack of capacity to make the end-of-life decision at hand;¹⁵ as well as providing a "...notification and objection process...[which]...provides substantial protection to mentally retarded patients."¹⁶

Among the entities entitled to both object to and seek administrative and judicial review of a guardian or other surrogate decision are the Mental Hygiene Legal Service (MHLS) for persons served residentially in the OPWDD system, OPWDD itself where a person is not currently residentially served in its system, and State and private (like NYSARC) providers of residential services to the patient. The responsibilities of MHLS to advocate broadly for persons with ID/DD are set forth succinctly in statute at MHL Article 47. The duty of the OPWDD service provider is more subtly spread throughout the MHL.¹⁷ Probably the clearest demonstration of the obligations of OPWDD facility directors is found in the very framework of the *Storar* decision referenced in *Matter of MB*.¹⁸

As the dissenters in *Storar* accurately put it: "(u)ntil today, however, this court has never recognized the standing of a medical care provider to seek authorization to continue medical care against the wishes of a patient or one who stands in his stead."¹⁹

In 1986, when the Legislature undertook the enactment of the former PHL Article 29-B it could have ignored the *Storar* majority's finding that "the peculiar facts of this case" justified not only the filing of the petition but the continued party participation by Director Soper through all three Courts. Instead, it embraced that right/duty in numerous sections of Article 29-B,²⁰ conferring a plethora of rights concerning notification, objection, and the seeking of administrative and judicial review of surrogate DNR decisions. Arguably, these directors, generally entrusted with the life-long care of their residents, can be said to be exercising the State's *parens patriae* power in this statutory scheme.

Among the things that remain troubling about the FHCDA-amended PHL Article 29-B is the removal of virtually all rights of facility directors which formerly existed in the sections enumerated above.²¹ SCPA 1750-b recognizes at all stages of the decision-making process that the State (through OPWDD facility directors and MHLS) as well as non-profit facility directors, like NYSARC's, have the right to be informed and to object to matters of both substance and process as to each end-of-life decision.

Also, assuming that PHL Article 29-B can't apply to persons with ID/DD outside State facilities (if at all...), the "presumption in favor of resuscitation"²² no longer applies to anyone anywhere under the FHCDA, except as the presumption is embodied in the guardian's duty to "advocate."²³ Bear in mind that SCPA 1750-b applies regardless of setting—even in three-bed rural community homes. Whatever caused the legislature to abandon the presumption in new PHL Articles 29-C and 29-CC, the State's long, unhappy history of patients with ID/DD being under-treated militates in favor of the presumption in 1750-b 4.

A few other more mechanical problems arise under the FHCDA. As currently formulated the HCDAPMR²⁴ refers objecting parties to hospital "dispute mediation system(s)" established pursuant to PHL section 2972 (part of Article 29-B). Since the definition of hospital in 2961 9, no longer means "general hospital" or nursing home, the appropriate reference in the HCDAPMR²⁵ should be to "ethics review committee(s)" established pursuant to new PHL 2994-m.

Probably the most common basis for the entry of a DNR for a person with ID/DD is that CPR would be "medically futile"²⁶—that "cardiopulmonary resuscitation will be unsuccessful in restoring cardiac and respiratory function or that the patient will experience repeated arrest (sic) in a short time period before death occurs." That finding, "to a reasonable degree of medical certainty," by a physician who has personally examined a patient will in and of itself suffice as a basis for a DNR. That standard was not embodied anywhere in SCPA 1750-b by the FHCDA. It should be borrowed from PHL Article 29-B and inserted both in PHL Article 29-C and in the HCDAPMR.²⁷

These and a minimal number of other minor language tweaks to SCPA 1750-b would, it is submitted, put the application of the FHCDA to patients with ID/ DD on a firmer, clearer foundation while we await the work of the Governor's Task Force on Life and the Law. A bill containing these provisions is drafted and being shared with appropriate NYSBA committees, legislators and staff, other stakeholders, and the GTFLL staff.

Endnotes

- 1. Surrogate's Court Procedures Act section 1750-b, which became part of SCPA Article 17-A, "Guardians of Mentally Retarded and Developmentally Disabled Persons, SCPA sections 1750 through 1761."
- 2. The term "mental retardation" is being incrementally stricken from the lexicon.
- 3. See Matter of MB, 6 NY3d 437 (2006).
- 4. "SDMCs"—see Mental Hygiene Law, Article 80.

- 5. 14 NYCRR 33.11.
- 6. 14 NYCRR 633.20.
- 7. See Public Health Law section 2994-b, subsection 3.
- 8. See 14 NYCRR 633.18.
- 9. SCPA 1750-b 4.
- 10. See FHCDA, L.2010, Ch. 8, section 28.
- 11. PHL Article 29-B is now called "Orders Not to Resuscitate for Residents of Mental Hygiene Facilities."
- Mental hygiene facility is appropriately defined in new PHL 2994-aa 12 as a residential facility "operated or licensed by" OMH or OPWDD.
- 13. Supra note 3, 6 NY3d at 439.
- 14. 6 NY3d at 442, quoting from SCPA 1750-b 4.
- 15. 6 NY3d at 451.
- 16. Id. at 454.
- But see MHL Article 33, and, in particular, sections 33.01 and 33.03 (b) 4, requiring facility directors to ensure the obtaining of informed consent for surgery or other major medical treatment.
- 18. *Matter of Storar*, 52 NY 2d 363 (1981), another technically moot case that the Court of Appeals elected to hear because of the significance of the legal subject matter.
- 19. 52 NY 2d at 388. John Storar's mother was his SCPA 17-A guardian, and it was her difficult decision to deny her son blood transfusions that was overridden by the courts, on the petition of the State's facility director, Charles Soper, who expressly relied upon his "duty" under MHL 33.03.
- 20. Including subsections 2964 4, 2965 4(c), 2966 2, 2972 2, and 2973 1.
- 21. See FHCDA L.2010, Ch. 8, sections 12, 14, 18 and 19, e.g.
- 22. The partial title of PHL 2962.
- 23. Found in SCPA 1750-b 4, quoted fully in the MB decision, supra.
- 24. SCPA 1750-b 5(d).
- 25. Id.
- 26. As that term is defined in PHL Article 29-B at 2961 12.
- 27. SCPA 1750-b 4(b)(i).

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The Palliative Care Information Act and Its Applicability to Cases Subject to the Family Health Care Decisions Act

By David C. Leven

Introduction

The Palliative Care Information Act,¹ which became effective on February 9, 2011, requires the attending health care practitioner of a patient who is terminally ill to offer information about palliative care and end-of-life treatment options. The Palliative Care Information Act and the Family Health Care Deci-



sions Act will often apply simultaneously to the same clinical cases. Therefore, it is important for health care attorneys and health care practitioners not only to be familiar with both of these laws, but to understand the connection between them. Health care attorneys should play a prominent role in ensuring that their clients are aware of and comply with the Palliative Care Information Act and with the Family Health Care Decisions Act when these laws intersect.

Pursuant to the Family Health Care Decisions Act (FHCDA), a surrogate has the right to receive medical information and medical records necessary to make informed decisions about health care for the patient. Specifically, health care providers must provide information including the diagnosis, prognosis and the risks and benefits of alternative treatment options.²

When a determination is made that the patient has a terminal illness or condition and death can be reasonably expected within six months, whether or not treatment is provided, the Palliative Care Information Act (PCIA) becomes operative. It is applicable to surrogates when a patient with a terminal illness or condition who does not have a health care agent lacks capacity to reasonably understand and make informed choices related to palliative care.³ After a determination has been made that the patient lacks decision making capacity, in accordance with the FHCDA, the surrogate is entitled, under the PCIA, to receive important relevant information and counseling that would otherwise have been offered to a patient with capacity.

Summary of the Palliative Care Information Act

The key provision of the law states:

If a patient is diagnosed with a terminal illness or condition, the patient's attending health care practitioner shall **offer (emphasis added)**⁴ to provide the patient with information and counseling regarding palliative care and end-of-life options appropriate to the patient, including but not limited to: the range of options appropriate to the patient; the prognosis, risks and benefits of the various options; and the patient's legal rights to comprehensive pain and symptom management at the end of life.⁵

Additionally,

- a. The obligation to provide such information and counseling can be fulfilled by the attending physician or nurse practitioner or by referral or transfer to another appropriate health care practitioner.⁶
- b. Information can be provided verbally, or in writing.⁷
- c. A surrogate may decline the offer to receive the information and/or counseling.⁸

Comment: If an offer to provide information and counseling is declined, the practitioner should renew the offer, as appropriate, when the patient's condition changes and different treatment options may be available (see section on counseling on p. 86).

Definitions:

- "Appropriate" means consistent with applicable legal, health and professional standards; the patient's clinical and other circumstances; and the patient's reasonably known wishes and beliefs.
- "Attending health care practitioner" means a physician or nurse practitioner who has primary responsibility for the care and treatment of the patient. Where more than one physician or nurse

practitioner share that responsibility, each of them has responsibility under this section, unless they agree to assign that responsibility to one of them.

- "Palliative care" means 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 under article forty of [the Public Health Law].
- "**Terminal illness or condition**" means an illness or condition which can reasonably be expected to cause death within six months, whether or not treatment is provided.⁹

The Need for the Palliative Care Information Act

The PCIA, a model for the nation, was needed for many critically important reasons despite the well established right of patients to have information sufficient to make informed decision about their treatment.

First, at the end of life, physicians have often been unwilling to have discussions with their patients about their diagnosis, prognosis and treatment options or those discussions have been inadequate. One study involving 332 advanced cancer patients who were followed from the time they were enrolled until they died (an average of 4.4 months) found that only 123 of those patients had end-of-life discussions with their physicians.¹⁰

The lack of physician-patient communication is one reason why hospice referrals have been made so near death or not at all. In New York State 33% of patients were enrolled for only 7 days or less and 32% were enrolled for 31 days or less in 2008, the last year for which figures are available, http://www.nyhealth.gov/statistics/facilities/hospice/utilization_and_cost/2008/ 11. Since patients are eligible for hospice when it is likely that they will die within six months and hospices generally provide excellent end-of-life care and have been extremely beneficial for the vast majority of patients and their families, referrals should be made much earlier for most patients. Compliance with the PCIA will result in more and earlier referrals to hospice.

Secondly, the vast majority of dying patients in fact want to know their diagnosis and prognosis. In one study of 214 persons aged 60 and older with a limited life expectancy secondary to cancer, congestive heart failure, or chronic obstructive pulmonary disease, 83% of those believing they had 1 year or less to live wanted to discuss prognosis. $^{12}\,$

And, in a recent survey 95% of patients with 3 different forms of cancer wanted their oncologist to be honest about their expected survival.¹³

Thirdly and most importantly, when discussions take place between physicians and their dying patients, quality of life is improved, decisions are made for less aggressive interventions, lives are extended, patient's wishes are more likely to be respected, and hospice referrals occur sooner.¹⁴ One recent study found that patients with terminal lung cancer who began receiving palliative care immediately upon diagnosis as compared to patients receiving standard care not only were happier, more mobile and in less pain as the end neared—but they also lived nearly three months longer.¹⁵

In addition, patients with cancer are more likely to receive end-of-life (EOL) care that is consistent with their preferences when they have had the opportunity to discuss their wishes for EOL care with a physician.¹⁶

Finally, cost savings result when end-of-life discussions take place. According to a 2009 study, patients with advanced cancer who reported having EOL conversations with physicians (only 31% of the patients had such discussions) had significantly lower health care costs in their final week of life. Higher costs were associated with worse quality of death. Additionally the study found that patients who had EOL discussions with their physicians "were more likely to receive outpatient hospice care and be referred to hospice earlier."¹⁷

Implementation of the Palliative Care Information Act

It is important that the PCIA be effectively implemented. Affected patients are dying and this will be a very difficult time for them and surrogates who are empowered to make decisions for them. Health care attorneys should be helpful in working with their health care professional colleagues, as well as their clients, to ensure successful implementation.

The new law only requires the provision of information and counseling concerning palliative care to patients with an illness or condition that is reasonably expected to cause death within six months. However, this of course does not bar the provision of information and counseling to surrogates where the patients are outside the terminal diagnosis—i.e., patients who are seriously or chronically ill. In fact it is often clinically

appropriate to do so earlier. Health care attorneys can help facilitate compliance with the strict requirements of the law and recommend that earlier conversations take place with their institutional clients. Attorneys who have individual clients who are seriously or terminally ill can act similarly.

Informing Health Care Professionals About the Palliative Care Information Act

Health care professionals need to know about the content of the FHCDA to ensure compliance and they need to understand its connection, when applicable, to the Family Health Care Decisions Act. Physicians, nurse practitioners, nurses, and social workers all perform key roles in helping patients at the end of life so they will need to know what is required by the law and where they can assist patients and surrogates to effectively implement it. The New York State Department of Health has reached out to physicians and nurse practitioners but it will not be able to reach all who are affected by the law. Additionally, students in medical, nursing and social work schools need to be educated about the PCIA, preferably during courses, which should be required, on palliative and end-oflife care. Health care attorneys who have affiliations with hospitals, nursing homes, health care professional schools, etc., are urged to assist to ensure that the PCIA has been brought to the attention of health care professionals and that they have or will receive appropriate training.

NYS Department of Health Information on the Palliative Care Information Act

The New York State Department of Health has information (DOH) on its website on the PCIA. This includes Questions and Answers about Palliative Care, Hospice, and the Palliative Care Information Act and a list of Resources for Practitioners, http://www.health. ny.gov/professionals/patients/patient_rights/palliative_care/. It provides a good deal of useful information and should be a helpful guide to health care and legal practitioners. DOH has informed hospitals and nursing homes about the law and has sent the information on its website to them and to a mailing list of associations and societies. However, it is likely that many individual health care practitioners will not be informed or timely informed about the PCIA. Health care attorneys are urged to find out whether your health care practitioner colleagues know about the PCIA and the information available from the DOH and to inform those who do not.

Counseling

The PCIA definition of attending health care practitioner is clear. One or more physicians or nurse practitioners might have primary responsibility for the care and treatment of the patient so that each of them would have responsibility to provide information and/ or counseling to the surrogate who agrees to accept it. Physicians having different specialties might equally be involved with a patient's care. There is no bar to the involvement of any practitioner or specialist who is acting as an attending practitioner whom a surrogate wishes to access for the counseling and information under the PCIA. Any such bar would run counter to the legislative goals and intent of the PCIA and may result in a contraction of information on palliative care and end-of-life options to surrogates of patients who are terminally ill.

In most situations there probably will and should be more than one information/counseling meeting. For example, the practitioner may offer to provide information and counseling during one conversation and, if the surrogate agrees, they may jointly decide to have a second meeting to discuss specific options. The surrogate, who will usually be a family member, may wish to have others family members attend.

Best practice will normally require continuing conversations as the patient's disease worsens and condition changes. Appropriate options to discuss initially with a surrogate may be different than appropriate options to discuss later as the trajectory of the disease or illness progresses. As a patient's condition changes and worsens, surrogates who have initially declined should again be offered information and counseling.

If one health care professional has had a discussion with the surrogate, another health care professional now involved as an attending may still be obligated to have a discussion with the surrogate. If a physician asks "have you had a conversation about this" and the surrogate responds affirmatively, the physician should ask if the surrogate would like to discuss anything relevant to palliative care and end-of-life options. The surrogate could agree or decide to have continued discussions only with the health care professional with whom the surrogate first talked.

Documentation

Documentation of the provision of any information and/or counseling should always be placed in the patients' medical record under the PCIA so that all practitioners working with patients will be informed of what has transpired. Where more than one health

care practitioner is involved in providing the information/counseling, documentation is essential so that each practitioner knows and understands what others have done and said and that, where possible, there is consistency.

Documentation by a health care professional of a meeting with the surrogate to discuss palliative care/ end-of-life options does not diminish the obligation of that same health care professional to have continuing discussions, as appropriate with the surrogate, all of which are properly documented.

Conclusion

The need for and the importance and benefits of the Palliative Care Information Act, a model for the nation, are clear. Physicians are not spending enough time having discussions with their patients about end-of-life care and explaining fully the options available to patients early enough in the course of illness. Yet patients generally do, and presumably surrogates will, want to know the diagnosis, prognosis, treatment alternatives and the risks and benefits of those options so that they can make informed decisions. When physician-patient communications do take place, the quality of lives of patients improves, patients are referred to hospice earlier, patients live longer, their wishes are more often respected and costs are reduced. If the PCIA is implemented as intended, surrogates should be able to make informed decisions about palliative care and end-of-life options for patients who lack decision making capacity.

Health care attorneys can and should play an important role to ensure successful implementation of the Palliative Care Information Act generally, and particularly in conjunction with the Family Health Care Decisions Act.

Endnotes

- 1. 2010 Laws on NY, Ch. 331; NY Public Health Law §2997-C.
- 2. NY Public Health Law, Article 29-CC, §2994-d3(c).
- 3. NY Public Health Law, Article 29-D, §2997-c2.
- 4. NY Public Health Law, Article 29-D, §2997-c2. There has been some confusion about what the attending health care practitioner must do. The attending health care practitioner must offer to provide information and counseling, which is not the same as being required to provide it, unless the patient or here the surrogate wants it. The patient, or here the surrogate,

may and usually will want the information and counseling but has the right to refuse it.

- 5. NY Public Health Law, Article 29 D, §2997-c2.
- 6. NY Public Health Law, Article 29 D, §2997-c2, c3.
- 7. NY Public Health Law, Article 29 D, §2997-c2.
- 8. Id.
- 9. Id.
- Alexi A. Wright, et al., "Associations Between End-of-Life Discussions, Patient Mental Health, Medical Care Near Death, and Caregiver Bereavement Adjustment," JAMA, 2008;300(14):1665-1673.
- http://www.nyhealth.gov/statistics/facilities/hospice/ utilization_and_cost/2007/.
- T.R. Fried, et al., "Prognosis communication in serious illness: Perceptions of Older Patients, Caregivers, and Clinicians. Journal of the American Geriatrics Society. 2003. 51:1398-1403.
- A. Bhatnagar, et al., "What do Patients want from Their Radiation Oncologist? Final Results from a Prospective Randomized Trial," Radiation Oncology Volume 75, Number 3, Supplement, 2009.
- Alexi A. Wright, et al., "Associations Between End-of-Life Discussions, Patient Mental Health, Medical Care Near Death, and Caregiver Bereavement Adjustment," JAMA, 2008;300(14):1665-1673.
- Jennifer S. Temel, et al., "Early Palliative Care for Patients with Metastatic Non–Small-Cell Lung Cancer," New England Journal of Medicine, 363; 8, 2010.
- Jennifer W. Mack, et al., "End-of-Life Discussions, Goal Attainment, and Distress at the End of Life: Predictors and Outcomes of Receipt of Care Consistent With Preferences," J. Clin. Oncol. 28:1203-1208 (2010).
- Baohui Zhang, et al., "Health Care Costs in the Last Week of Life Associations With End-of-Life Conversations," Arch. Intern. Med. 2009; 169(5):480-488.

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