

# Elder Law Attorney

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

## Message from the Chair

As Section Chair, my predominant goal has been to build on the initiatives of our most recent Past Chairs, with whom I have had the pleasure of working. The members of our Executive Committee, Section Officers and I have sought to create and schedule high-quality CLE programs that offer exceptional legal education combined with opportunities for networking and entertainment. We have also sought to attract new members to the Section and to bring them into leadership roles as program speakers and eventually as Executive Committee members and Officers. I also believe that it is most important that our Section continue to have an active role in the legislative process and be advocates for our clients. Our legislative efforts have ranged from reviewing various Senate and Assembly proposals to participating in



**Timothy E. Casserly**

lobbying days, to initiating new, proposed legislation. For example, in the case of the “Compact,” we have created and proposed an innovative program that evolved from nothing more than a few creative ideas from the members and leaders of our Section.

I wish to take the opportunity to thank Howard Krooks for most immediately furthering these goals as the Program Chair of our recent Summer Meeting held in Baltimore. I wish also to thank Kathy Heider for arranging the perfect setting of Baltimore’s Inner Harbor for our meeting. Being in the Inner Harbor allowed us to attend our CLE sessions and then walk out of the front door of the hotel to be entertained by dozens of Baltimore’s best attractions, activities and delectable crab cakes.

In case you missed it, the Summer Meeting began with a meeting of our Executive Committee wherein 21 members are in new roles as Chairs and Vice-Chairs of various committees. We also presently have 9 members who are new to the Executive Committee. For the conference itself, we again saw a number of new faces

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and first-time attendees among the 200-plus guests which included over 130 attorneys. Our speakers included mostly new faces as 12 of our 16 speakers were presenting for the first time to our Section, but with the same high quality to which we are accustomed.

The first of the Meeting's presenters was Barbara Collins from the Centers for Medicare/Medicaid Services (CMS), Office of the General Counsel. Ms. Collins' remarks centered around the implementation of the Deficit Reduction Act (DRA) of 2005 and the policies of CMS. The perfect follow-up to this session was Lou Pierro's update, which included how CMS policies are affecting our clients with regard to the implementation of the DRA in New York State. Throughout the next two days the quality of the programs remained consistently high as we heard from nationally recognized speakers: Charles Sabatino (Director of the ABA's Commission on Law and Aging), Gene Coffey (from the National Senior Citizens Law Center), William Conway (of Wealth Council, LLC) and Thomas Forrest (President of Charles Schwab Bank); Section members Anthony J. Enea and Ira Miller presented on Medicaid and Estate Planning in the context of a Guardianship update and Rose Mary Bailly and Michael Davis (a member of the Maryland Bar) discussed cutting-edge issues relevant to powers of attorney. Other sessions included programs on Medicaid Litigation, Medicaid Waivers, Long Term Care Insurance and our closing session on investing, entitled "Are You Smarter than a Fifth Grader?" (which confirmed that many of us are not).

Another aspect of our Summer Meeting which not only helped our bottom line, but introduced new resources to our respective practices, was the 12 Exhibitors attending and sponsoring the meeting. Being able to review their various products and services in one location is a great benefit for us, so *Thank You* to the Exhibitors and *Thank You* to Sponsorship Chair Anthony J. Enea and Judy Grimaldi and Lisa DeKenipp for their assistance in arranging for the attendance of our sponsor. Hopefully, everyone who attended found the meeting as beneficial and enjoyable as I did, and will mark their calendars to attend next summer's Meeting, which will be Chaired by Anthony J. Enea and Michael Amoruso (Chair Elect) in Washington, DC at the Ritz Carlton, July 23–26, 2009.

As stated above, we fortunately have many new participants within our Section's Executive Committee, but there are still plenty of opportunities available. On page 30 of this issue, you will see a listing of all of our different committees. Please note that there are several newly established committees including Mental Health Law, Trust and Estate Administration, Special Needs Planning and Practice Management and Technology. Each of our committees is always looking

for new members, so feel free to contact the Chairs if you have any interest in working on programs, articles, legislation or any other activities of the respective committees. An example of some of the work being done by our committees includes the Financial Planning and Investments Committee, Chaired by Laurie Menzies and Walter Burke, which is working with New York State Chapters of the Financial Planning Association to give joint presentations to consumers entitled "Financial Literacy for Older Adults." The Special Needs Planning Committee, Co-Chaired by Joan Robert and Vince Russo with JulieAnn Calareso as Vice-Chair, is developing a booklet entitled "Guidelines for Trustees of Special Needs Trusts." The Health Care Issues Committee, Co-Chaired by Judy Grimaldi and Tammy Lawlor with Shari Hubner and Michael Haggerty as Vice-Chairs, is in the final stages of the publishing an Advanced Directives book, and are working on a statewide introduction of the MOLST tool to end-of-life issues.

The Legal Education Committee, Co-Chaired by Ellen Makofsky and Ami Longstreet, is working with me to develop a series of one hour Podcasts and Webinars on current developments and relevant topics in the area of Elder Law. It is our hope that we will attract some new speakers to give these presentations and expand the pool of speakers that we have available for the other programs presented by our Section.

Our Publications Committee, tirelessly Chaired by Anthony J. Enea as Editor-in-Chief of the *Elder Law Attorney*, has room available on the Committee for Associate Editors. Please contact Anthony if you are interested.

Also, several Committees, including our Client and Consumer Issues Committee, are working with Crystal Doolity and James Barnes of the Young Lawyers Section to update the *Senior Citizen Handbook* from its last revision in 1999. Ultimately, this joint effort will provide a valuable guide for consumers, which will be available in both hard copy and online.

Hopefully, the above-stated activities illustrate that there are numerous ways to be involved with our Section through our Committees.

In the legislative area, New York's session ended in June without much in the way of new law being signed by the Governor that might be relevant to our practices. Perhaps the most noteworthy item for us was the Governor signing into law *Paralegal Day*, which was July 20, 2008. Don't miss it next year. Otherwise, there was some legislation particularly relevant to our Section passed by both Houses of the Legislature but not signed by the Governor as of my summer deadline. Depending on when, or if, these items should arise again in the next session, our Legislative Committee,

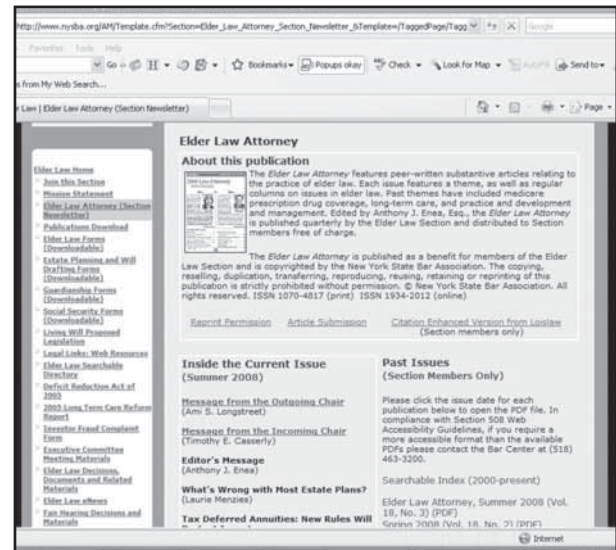
Co-Chaired by Michael Amoruso and Amy O'Connor, will reach out for assistance with comments and /or lobbying to relevant parties. Also, we will continue to work with the Bar Association in advancing the proposal for the Compact for Long Term Care, which remains among the Bar's legislative priorities for the coming year.

I would like to request that you set the time aside to attend our Fall Meeting, which will be held at the Otesaga Hotel in Cooperstown. Historically, our Section's Fall Meeting has been an opportunity for those who did not have the time and /or ability to make it to our Summer Program to attend and participate in a Section meeting within New York State. This year, Cora Alsante is Chairing the Fall Program, which will be followed by the Advanced Institute Co-Chaired by Robert Kurre and Amy O'Connor. The dates of the meetings will be Thursday, October 23rd and Friday, October 24th for the Fall Program with the Advanced Institute being held on Saturday, October 25th. Lisa DeKenipp is lining up another great group of exhibitors, and Cora has lined up a great panel of speakers covering topics ranging from drafting promissory notes to a guardianship panel featuring Justices Joel Asarch and Peter Wells. And for those of you who were unable to attend the past two Annual Meetings in New York City, we are reprising a popular program wherein we have a panel of attorneys from various Departments of Social Services, including Dan Tarantino from New York State, to answer questions from our Section members. Also, based on input from attendee evaluations of past programs, we will be having a session on practice management and time management. Finally, one new feature we are adding to our Fall Meeting is our First Annual Section Softball Game. The game is scheduled for Friday afternoon so as to allow anyone arriving for Saturday's Advanced Institute as well as those coming for our Fall Program to participate in the game. Depending on the mailing of this newsletter, you should have two to three weeks for practice and conditioning. Hopefully, you will be able to participate or, at least, sit in the bleachers and laugh at those who do. (Advil and ice packs will be available upon request.)

I look forward to seeing you in Cooperstown.

**Timothy Casserly**

## The *Elder Law Attorney* is also available online!



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## Editor's Message

As this edition of the *Elder Law Attorney (ELA)* was being readied for print, the lazy, hazy days of summer in the Empire State were in full swing. Sadly, summer's temptations have victimized the *ELA* with a small shortage of feature articles. No matter how many e-mails I sent and phone calls I made begging and pleading for articles, my pleas fell on deaf ears. Apparently, the sun, sand, golf, tennis and vacations have afflicted many with writer's block.

Fortunately, a good number of *ELA* devotees and contributing authors resisted the temptations of summer and submitted excellent pieces. To them I am forever grateful. For example, as feature articles we have an excellent submission from former Section Chair Lou Pierro, Esq. and Paul Gellert reviewing some creative options with respect to utilizing reverse mortgages as



an elder law and estate planning tool. Michael Pfeifer, Esq. has submitted an excellent piece extolling the virtues and practical benefits of a "pooled trust." David Goldfarb, Esq. has submitted a short piece informing our readers as to recent changes in the "Family Health Plus" Medicaid program. Leona Beane, Esq. has also submitted an interesting piece entitled "Incorporating Mediation Within the Guardians' Powers."

In keeping with the Guardianship theme, I have also included an article by yours truly entitled "How to Prevent Family Conflicts in the Event of Incapacity and Utilization of Article 81 of the Mental Hygiene Law When a Clash Is Inevitable."

Finally, our regular contributing authors Valerie Bogart, Esq. (with Robert Briglio, Esq.); Judith Raskin, Esq.; Ellen G. Makofsky, Esq.; Robert Kruger, Esq.; Lisa Friedman, Esq. and Adrienne Arkontaky, Esq. have all submitted exceptional articles.

I am confident that you will find this edition of the *ELA* to be excellent and informative reading.

**Anthony J. Enea**

## Request for Articles



If you have written an article you would like considered for publication, or have an idea for one, please contact Elder Law Attorney Editor:

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*Articles should be submitted in electronic document format (pdfs are NOT acceptable) and include biographical information.*

**[www.nysba.org/ElderLawAttorney](http://www.nysba.org/ElderLawAttorney)**

# Keeping the Castle: Reverse Mortgages and Forward Options

By Paul Gellert and Louis Pierro

Bubbles bursting, financial meltdowns and bank closings are not the prescription for restful nights for seniors who have long seen the equity in their real estate as the security blanket to help make later years more financially secure. Lenders have been tightening guidelines, making it more difficult to borrow against the captured equity. The strong emotional desire of most seniors who do not want to sell but want to continue to live in their homes has led to the development of the family of reverse mortgages and forward options. These financial products allow the monetizing of the equity without surrendering the home.



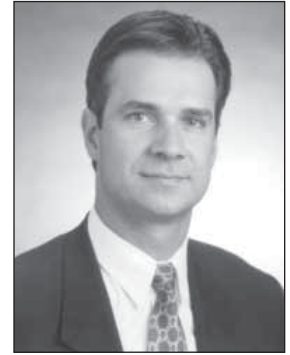
Paul Gellert

These products can also provide the means to pay for some things that everyone would agree should have been done years before but got put off for one reason or another, usually because they would create a current cost for a (too) distant benefit. Now, seniors need additional funds to live on or want to have long term care insurance, to establish an ILIT for estate planning or to give a helping hand to children or grandchildren. But they want to do these things without having to go out of pocket.

Reverse mortgages are the most commonly known form of equity release programs, familiar to many through ads on television or in magazines targeted at seniors. A traditional mortgage is a forward mortgage, only needing that adjectival distinction since the advent of the reverse mortgage 20 years ago. Money is borrowed based on a percentage of the value of the property and repaid to zero over time. (For purposes of this article, that overly simplistic definition will suffice.) A reverse mortgage is just the opposite of that. Instead of receiving a loan and paying down to zero, the homeowner receives an advance, which can be either as a lump sum, monthly payments, a line of credit, or a combination of them. When the loan becomes due, either through death, sale or because the home is no longer a primary residence, the advanced amount(s), upfront and monthly servicing fees and accumulated, compounded interest is payable—never more than the value of the property.

With the new Housing and Economic Recovery Act of 2008 (H.R. 3221) signed into law on July 30, the loan limit for FHA insured Home Equity Conversion Mortgages (HECM) will go to \$417,000 nationally with

a higher limit of \$625,000 in high cost county lending areas. This will now be available for co-op properties. Implementation should be in October or November, according to the National Reverse Mortgage Lenders Association. (Fannie Mae has discontinued its Home Keep program as of September 3.) There are some proprietary programs that have higher loan limits. They all have two important things in common that are specific to reverse mortgages as opposed to the option programs: the property must be a primary residence and the mortgage must be a first lien.



Louis Pierro

HECMs have an age requirement that all borrowers must be at least 62. This can lead to a conundrum. The algorithms for determining the loan amount, be it lump sum, line of credit or either advances for set time or for the life of the borrower, coupled with the Loan-to-Value limit, are based on the age of the youngest borrower. The calculation is the basic net-present-value formula with the number of periods determined by 100 (the end-of-life point) minus current age. The older the borrower is at the start point, the more money is advanced monthly. So, to get the highest monthly advance, the older person should be the only one on the reverse mortgage, and by guideline the only one on the deed. But, since typically the older spouse is the male and men have a shorter life span, if it is set up this way, on the death of the borrower, the younger spouse must sell the house or pay off the reverse mortgage. A choice has to be made between maximizing monthly distribution and minimizing the impact on the younger spouse. If the younger property owner is not yet 62, the choice is moot.

In response to this dilemma, a new program has been devised by World Alliance Financial Corp, which is in essence a “bridge” reverse mortgage. The minimum age is 60. The loan amount is from \$50,000 to \$150,000 and is like a line of credit. It, like its cousins, must be a first lien and on a primary residence. Its *raison d’être* is to carry seniors to the 62 years of age threshold.

The money received by the senior is considered an advance, and is not “income” and therefore not taxed, but the payments are counted as liquid assets if they are kept at the end of the month received, so care must be taken to make sure guidelines for Medicaid and governmental programs are not exceeded.

All of the programs are non-recourse, protecting the borrower, if the final loan amount, between principal and compounded interest, is greater than the value of the home at time the loan becomes due. The Mortgage Debt Forgiveness Act passed in 2007 doesn't really come into play here because the loan was non-recourse to start, unlike a traditional residential mortgage which is "guaranteed" by the note signed by the mortgagor. No forgiveness, no tax consequence.

All of these reverse mortgage programs are appropriate for people who need to supplement income or pay for health costs or insurance. The biggest pluses are that there is no health requirement, no credit requirement and no income requirement. So for people 60 or older who need the money and have health issues, reverse mortgages are usually the only option.

Cash-out traditional mortgages are useful for those to whom the extra monthly carrying costs are not a burden. Although traditional mortgages are available, they are not likely to be a viable solution except in some very extraordinary situations. The same is true for Home Equity Lines of Credit (HELOC), although a case can be made for using it as a reverse annuity, where you start with a line of credit of \$X and after ten years of principal withdrawals and interest payments on the rising outstanding balance, there is zero availability. Since the loan would either have to be paid out of then-available liquidity or refinanced using more of the equity in the property, it does not appear to be a useful strategy. Both in the case of cash-out and HELOC underwriting, many seniors would not qualify based on income, and non-income-verification loans are becoming scarcer and more expensive.

Another, more attractive, alternative to reverse mortgages is to sell an equity option on the future appreciation of the property. There is a relatively new (4-years) program available from EquityKey. It does not have the limitations inherent in reverse mortgages; current mortgages do not have to be paid off, two individual owners can each have a separate option and the property does not have to be a primary residence. Reverse mortgages are more advantageous where there are health issues, the owner is 62 but not yet 65 or the property is worth less than \$500,000.

The option premium received is 10–15% of the current value of the property in exchange for 50% of the future appreciation. For example, if the current value of the property is \$600,000 and it appreciates to \$1,000,000 when the client dies or sells the property, the \$400,000 increase in value is divided between the option holder and the client. The advantages of this over reverse mortgages is that it can be any type of real estate, primary or investment or even commercial.

There are no costs to the seller of the option (the client) and the option premium should be tax free until the option is exercised, at which point it will be subject

to long-term capital gains tax. David Sterlitz, counsel to EquityKey LLC, the company which purchases the options, believes that "for Federal income tax purposes, granting an option is an open transaction, the tax effect of which is determined at the time the option is exercised, sold or lapses. (Rev. Rul. 78-182, 1978-1 C.B. 265). Alternatively, the option may be treated as a forward contract, but the tax consequence would be the same as if treated as an open transaction. (A. Kramer, *Financial Products*, Section 60.04[A]; Rev. Rul. 74-223, 1974-1 C.B. 23)."

It is not a lien, and it does not prevent future financing. The requirements are: the individual must be 65–85 years old and insurable. (The company buys insurance as a hedge.) The property can have financing up to 70% of value (if the property appreciates, it can be refinanced to that 70% limit). If the property has lost value at the end point, the company does not exercise its option and the property owner owes nothing.

If the end point is the death of the client, there are three options: 1. The heirs receive 80% of the value of the property less transaction costs, which are actual, but capped at 8%; 2. the heirs buy the option back for 50% of the appreciated value; or 3. the non-participating survivor remains in the property and the option is extended. If both spouses qualify, they can sell 100% of the future appreciation for 20–30% of the current value of the property. The forward option cannot be used for purchase, but because there is no seasoning requirement, the client can sell the option on the property as soon as the two appraisals are done, assuming the health conditions have already been met.

What makes this a viable alternative to a reverse mortgage, in instances where property value (\$500,000 minimum value), health (must be insurable) or age (must be 65–85) are not factors, is the ability to use any type of real estate, even land valued at more than \$3,000,000 or property owned by closely held corporations. That last category would allow for key-man insurance to protect the corporation from having the drunken brother-in-law or trophy spouse become part of management. For clients who have relatively high-net-worth, the option payment can be used to purchase long-term care insurance, establish an ILIT or even to help out children or grandchildren without increasing monthly outflow.

There are other programs to consider, including both The Rex Agreement and My Equity Freedom, variations on the equity option concept which do not have age restrictions and have much different business models. As the population ages and the need grows to use the equity in real estate to help fund the lives of aging baby boomers, one thing is certain: there will be new reverse mortgage and forward option programs introduced.

# The Benefits of Using a Pooled Trust

By Michael Pfeifer

Parents who have a child with special needs face many challenges. One of those challenges is deciding how leave an inheritance to their child. Parents have a few sensible choices that they may make. They might set up a special needs trust on behalf of their child. This will allow the disabled child to enjoy the benefits of his or her inheritance while protecting the child's ability to access government programs such as SSI and Medicaid.



Rather than setting up a special needs trust, there is another choice that the parents might consider: they could have a pooled trust operated by a not-for-profit organization administer their child's inheritance. The purpose of this article is to discuss some of the advantages of choosing this option.

Most of the time in this article, we will be speaking about third-party trusts that hold assets contributed to the trust by third parties. Sometimes, we may refer to first-party trusts that hold the assets of the disabled individual.

## **The Trustee of a Pooled Trust Will Not Die, Become Incapacitated, Sick, Get Divorced, Etc.**

When parents set up a special needs trust, they will have to appoint a trustee to manage the trust. Very often, they will choose a sibling or other relative of the disabled child.

Life sometimes throws curve balls at us. Even the best-intentioned trustee cannot guarantee how long he or she will live, or avoid becoming sick or old. Divorce could be a distraction. If a trustee is unable to perform the duties of trustee for any reason, the child with special needs may suffer the consequences of not having a trustee who is attentive to her needs.

Pooled trusts are operated by not-for-profit organizations and are not dependent upon the health or other circumstances of an individual trustee. There is an organization managing the trust, and if one person can no longer manage his or her responsibilities, another person will take over. Thus, the needs of the disabled child are attended to and not dependent upon any one person.

## **The Sibling of the Special Needs Child Does Not Have to be Burdened with the Job of Managing the Trust**

Being a trustee is not easy. There are many responsibilities: properly investing the assets; avoiding distributions that will interfere with the receipt of governmental benefit programs; using the assets of the trust wisely to give maximum benefit to the disabled child; and determining the disabled beneficiary's needs. The sibling of the special needs child will also have his or her own family responsibilities, which at times will be pressing. There will be career pressures. Perhaps, there will be a move to a different area of the country—or a move out of the country.

By placing an inheritance in a pooled trust, you take the burdens—and perhaps resentments—away from family members who have multiple pressures on their time.

## **A Private Trustee Will Not Have the Expertise that the Pooled Trust Can Bring to the Table**

There are four areas of expertise the trustee will need to perform his or her duties appropriately: 1) legal; 2) financial/investment; 3) tax; and 4) personal.

### **Legal Expertise**

Can the trustee pay for the special need child's rent if she is receiving SSI? Can the trust own a home that the special needs trust beneficiary can live in? Can the trust pay a companion to accompany the beneficiary on vacation?

A trustee must answer many legal questions. A private trustee will have to pay for legal advice before making decisions about what expenditures can be made from a trust. Worse still, some trustees will make the expenditure and then ask for expert advice, causing liability to themselves and perhaps jeopardizing the trust beneficiary's continued eligibility for government programs such as Medicaid or SSI.

A pooled trust will have experts available who guide the trustees in making the appropriate legal decisions.

### **Financial/Investment**

Most states have enacted a Prudent Investor Act. New York's Prudent Investor Act requires the trustee to "exercise reasonable care, skill and caution to make and implement investment and management decisions as a prudent investor would for the entire portfolio, taking

into account the purposes and terms and provisions of the governing instrument.” EPTL 11-2.3 (b)(2).

Investing assets over a long period can be a hazardous undertaking, especially in uncertain times. A private trustee may not have the expertise to do this, requiring the hiring of a financial planner to create a plan of investment that is reviewed regularly. Although a trustee may delegate the investment functions, she must “exercise care, skill and caution” in selecting the delegee, establishing the scope and terms of the delegation, reviewing the delegee’s performance and controlling the cost associated with the delegation. EPTL 11-2.3 (c)(1)(A) through (D).

A pooled trust will alleviate the headache of a sibling trustee who may not have the expertise or acumen to enable him to perform these functions.

### **Tax**

Taxes are a fact of life for trusts as well as individuals. Taxes will have to be paid on behalf of the trust, and the trustee has the responsibility to see that the taxes are paid. The trustee can be held personally liable for taxes that are not paid. This headache can also be eliminated for the sibling trustee by placing the inheritance into a pooled trust.

### **Personal**

What type of wheelchair is most appropriate to purchase for this particular disability? If supplemental or catastrophic medical insurance is desired or sensible, what is the best policy? What are the best computer programs for someone who is sight impaired? What type of vocational program would be appropriate for the disabled person?

These are questions that even the best-intentioned sibling may have a problem answering but a pooled trust trustee will have experience in handling.

### **A Pooled Trust Will Accept Modest Size Contributions**

Most banks and trust companies will refuse to manage trust assets that are not well into the six-figure dollar range. Pooled trusts will accept much less. For instance, Life’s Worc of Garden City, NY, will accept a minimum of \$500 for its first-party trust and \$10,000 for its third-party trust. AHRC, Nassau of Brookville, NY, will accept a minimum of \$25,000 for its first-party and third party trusts. (You must make an initial payment of \$10,000 and pay the remainder within five years.)

### **Conflict of Interest of Family Members**

Upon the death of the disabled beneficiary, a third-party special needs trust usually gives the balance of the trust assets to surviving family members. A trustee who knows that he or his family will receive the remaining trust estate has a conflict of interest. This conflict of interest could affect him when he is deciding whether to make a distribution on behalf of the special needs beneficiary.

Of course, the trustee of a pooled trust has a conflict of interest as well since the remaining trust assets will be used toward programs for other disabled beneficiaries. However, the trustee of a pooled trust will not *personally* benefit by her decision whether to expend trust assets on behalf of the special needs beneficiary.

### **Lower Administrative Fees**

Pooled trusts charge much lower administrative fees than a bank or trust company. In addition, Life’s Worc and AHRC do not charge trustee fees, which can be a considerable expense of administering a trust. Thus, more money will be spent on the beneficiary and less on managing the trust.

### **Other Services**

As stated before, pooled trusts are run by not-for-profit organizations. They very often will offer other services to their trust beneficiaries, which may include clinical, medical, rehabilitative, accounting, legal, advocacy and service coordination (mobilizing the people necessary to provide a specific service) services.

### **Conclusion**

Being a trustee is hard work and complicated. Not everyone has the skills, knowledge, time, health or temperament to be an effective trustee. By using a pooled trust, disabled beneficiaries can have the advantage of having their assets administered by caring professionals who know what they are doing.

**Michael L. Pfeifer is the principal attorney of Michael L. Pfeifer, P.C. The firm concentrates in the areas of elder law, special needs planning and estate planning in Garden City, NY. Mr. Pfeifer has been practicing law since 1987. Mr. Pfeifer’s professional memberships include the Elder Law Section of the New York State Bar Association; the Trusts and Estates Law Section of the New York State Bar Association; the Elder Law Committee of the Nassau County Bar Association; and the Surrogate’s Court, Estates & Trusts Committee of the Nassau County Bar Association (former Chairperson of the Legislative Sub-Committee).**

# Recent Changes to Family Health Plus

By David Goldfarb

Family Health Plus is an expansion of Medicaid coverage for lower-income adults (aged 19 to 64) who do not have health insurance but have income or resources which disqualify them from Medicaid and other public health insurance programs. Its benefits are provided through managed care plans. The resource test for Family Health Plus is now the same as the Medicaid resource limit of 150 percent of the Medicaid annual income level. N.Y. Soc. Serv. Law § 369-ee(1)(i) and (2)(c); 05 OMM / ADM-5 (8 / 19 / 05).



In 2008, parents with income up to 150% of the Federal Poverty Level (\$31,800 for a household of four) are eligible for Family Health Plus. For purposes of determining income eligibility, depreciation of assets owned by a self-employed farmer are included as part of the gross family income. N.Y. Soc. Serv. Law § 369-ee(2)(d). Family Health Plus also covers uninsured adults without children whose income is at or below 100% of the Federal Poverty Level (\$10,400 for a single adult). Single individuals and couples without children (aged 19 to 64) with little or no income may be ineligible for Medicaid and other benefits because they have no unmet need, but they would still qualify for Family Health Plus. GIS 07 MA / 021 (11 / 01 / 07).

If an individual has access to cost-effective employer-sponsored health insurance, then they shall not be enrolled in, or shall be disenrolled from, Family Health Plus. If such person enrolls in the employer-sponsored health insurance, then Family Health Plus will pay the premium, co-insurance, any deductible amounts and other cost-sharing obligations for the person's employer-sponsored health insurance that exceed the amount of what would have been the person's co-payment obligation under Family Health

Plus. And Family Health Plus will pay for services and supplies that it covers to the extent that such services and supplies are not covered by the person's employer-sponsored health insurance. N.Y. Soc. Serv. Law § 369-ee added by 2007 N.Y. Laws ch. 58; 08 OHIP / ADM-1 (January 25, 2008). There are excepted benefits that an individual can have and still be eligible to enroll in Family Health Plus. These include prescription-only coverage. GIS 08 MA / 007 (3 / 13 / 08).

Beginning July 2008, prescription drugs will not be provided under Family Health Plus, but will instead be paid through eMedNY. Co-payments for Family Health Plus members will remain at \$3 for generics and \$6 for brand-name drugs. N.Y. Soc. Serv. Law 369-ee(2-b) added by 2008 N.Y. Laws ch. 58.

The FHPlus Web site is at <http://www.health.state.ny.us/nysdoh/fhplus/index.htm>.

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# Incorporating Mediation Within the Guardians' Powers

By Leona Beane

I am sure that many of us have faced situations wherein two (2) Co-Guardians don't always see eye-to-eye. Certainly both should be required to cooperate with the other more readily, and yet there are many situations wherein, for example, whatever Co-Guardian X suggests for the benefit of the IP, in response, Co-Guardian Y rejects that suggestion and makes another suggestion or stonewalls the entire process. This is extremely frustrating for the Co-Guardians but more so, it is certainly not beneficial for the IP's care and treatment.

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*"The Mediator does not render any decision; the Mediator does not decide who's right or wrong; the Mediator assists the parties in resolving their dispute(s) by encouraging discussions, considering options, problem solving, and creative solutions."*

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Thus, I am suggesting the use of Mediation to assist in resolving disputes and controversies whenever there are disputes or indecisions among the two (2) Co-Guardians and other family members.

Mediation is an informal alternative dispute resolution process. It has been found to be a very effective and successful form of dispute resolution for many reasons—it is a simplified, informal and flexible process and it is cost effective as far as the costs of the proceeding and the time entailed. Litigating a dispute in Court can be very, very expensive with resulting high costs of attorney fees, discovery, depositions, retaining experts to testify, and can be and generally is very time consuming, and also can be emotionally draining upon the parties and their families.

The Mediator does *not* render any decision; the Mediator does *not* decide who's right or wrong; the Mediator assists the parties in resolving their dispute(s) by encouraging discussions, considering options, problem solving, and creative solutions. The Mediator does *not* force something upon the parties. Mediation is a voluntary, consensual process.

There are many different possible definitions of mediation. For example, the Office of Court Administration defines Mediation<sup>1</sup> as: "A consensual dispute

resolution process in which a specially trained neutral third party helps disputants to identify issues, clarify perceptions and explore options for a mutually acceptable outcome."

There are many additional possible definitions of Mediation. This author is providing a definition which covers most situations: Mediation is an informal, voluntary, confidential process whereby a neutral, impartial third party (the Mediator) assists the parties to resolve their dispute(s) by means of facilitating discussions to consider different options so that the parties can craft an agreement that will be acceptable and agreeable to both parties.

Many attorneys mistakenly and erroneously believe that Mediation is the equivalent of a settlement conference in Court.<sup>2</sup>

With Mediation the parties have the opportunity to "craft" their own agreement with the assistance of a trained Mediator. The end result may not always be exactly what all parties want, but each will have had input in the end result, as the process requires give and take from all parties. If one of the parties is not satisfied with the final agreement, he or she is *not* forced or pressured to sign it. Mediation is a confidential process; whatever is discussed in Mediation is inadmissible.<sup>3</sup>

Mediation has proven to be very beneficial in all different types of proceedings. It is being utilized in the Court a great deal in more and more proceedings.<sup>4</sup> An article written by this author several years ago encouraged the Courts to incorporate and utilize Mediation in contested Guardianship proceedings.<sup>5</sup> Mediation is currently being utilized in the Model Guardianship Part in Suffolk County presided by Justice Leis.<sup>6</sup>

Included herein is a group of sample mediation provisions that can be incorporated within the Guardians' powers. These can also be utilized without a Guardianship where two (2) or more caretakers are having difficulty in fully communicating and cooperating to provide joint benefits for the disabled person. It might be useful for many other similar types of situations, whereby two (2) or more individuals are attempting to work together for the benefit of and as relating to the care of a parent or other relative.

These mediation provisions can be included within an agreement and within the powers of the Co-Guardians.

## Sample Mediation Provisions

1. The Co-Guardians of the person realize and acknowledge that on an ongoing basis there may be situations that arise wherein they both cannot agree, and they realize and acknowledge the benefits of Mediation. On an ongoing basis, the Co-Guardians agree that if any dispute arises between them (which might include by example, but not be limited to, the selection of a particular facility; selecting a professional to be utilized for an evaluation or particular treatment; issues and questions relating to the services to be provided for the IP; issues relating to the IP's treatment and numerous other issues), and if they are not able to resolve same between them within a relatively reasonable period of time, the Co-Guardians agree they shall proceed to attempt to resolve the dispute(s) via Mediation.

2. The Co-Guardians of the person have been presented with the names of two (2) Mediators to date, namely that of A and B. The Co-Guardians agree they shall submit their dispute(s) to be resolved by Mediation utilizing the services of either A or B or any other Mediator they both agree upon. Thus, the Co-Guardians may agree on utilizing the services of a different agreed-upon Mediator.

3. If they cannot agree on a specific Mediator, and if the matter cannot be resolved between them within a reasonable period of time, then either of the Co-Guardians has the right to submit a written notice (via e-mail plus letter) to the other Co-Guardian, indicating that said Co-Guardian intends to proceed with Mediation, and is requesting an agreement as to the selection of a specific Mediator within the next five (5) days.

4. If within ten (10) days thereafter they have not been able to agree upon the use of a particular Mediator (or there has been no response from the other Co-Guardian), then said Co-Guardian has the right to contact either of the suggested named Mediators for the purposes of scheduling a Mediation.

5. The other Co-Guardian, once contacted by the Mediator, agrees to fully participate in Mediation in good faith in the attempt to resolve the dispute(s) between them.

6. Once the matter is before the Mediator, both Co-Guardians agree they will each fully cooperate with the Mediator in scheduling and attending one or more Mediation sessions, and will cooperate in good faith in the Mediator's attempts to resolve the dispute(s), so as to provide the best possible treatment and care for the IP in the best interests of the IP.

7. The Co-Guardians have been informed that Mediation is a confidential process, and that the Mediator

is forbidden from breaching confidentiality regarding any matters discussed during the Mediation.

8. Notwithstanding confidentiality, each of the Co-Guardians agrees that the Mediator is authorized to provide the following information to the Court: (i) that a Mediation has been requested; (ii) that Mediation was held, and the dates that Mediation was held; (iii) whether any of the disputes were resolved, and if so, which dispute(s) were resolved; (iv) whether the dispute was not resolved, and in the opinion of the Mediator cannot be resolved at this time; and (v) if any Mediation agreement was executed between the Co-Guardians (resolving any of the disputes), in which situation a copy may be provided to the Judge presiding over this matter. The Mediator shall be authorized to also provide the above information to the Court Examiner appointed by the Court to oversee the Guardianship. In all other respects, the Mediator shall be required to adhere to full confidentiality.

9. The Co-Guardians agree that the cost of the Mediator's services shall be paid for out of the IP's Guardianship funds by the Guardian of the property.<sup>7</sup>

10. At any time should either of the Co-Guardians of the person contact the Court for a conference or submission of a motion or proceeding to the Court (other than relating to fees, compensation, or accountings), it shall be necessary that said Co-Guardian demonstrate to the Court that the Co-Guardians have already proceeded with Mediation and that the dispute(s) could not be resolved.

11. The Co-Guardian contacting the Court shall be required to specifically confirm that said Co-Guardian has participated in good faith in the Mediation.

I hope that many of you will find these sample mediation provisions useful. It must be stressed that a Mediator *does not* make decisions for the parties and *does not* require or force decisions upon them, but a well-trained, experienced Mediator discusses the matter with the parties, and through these discussions, the parties come up with the ultimate decision that they both agree upon—in effect, they craft their own agreement, with the assistance of the Mediator. There is a high compliance rate with mediated agreements—after all, the parties treat it as their own agreement.

These sample Mediation provisions hopefully will facilitate ideas for attorneys in the Elder Law area to think of incorporating Mediation in more Guardianship proceedings and more of their litigation involving the elder law practice.

The clients will be satisfied and receive great benefit from attorneys incorporating and utilizing Mediation in their practice to cover additional situations.

## Endnotes

1. [www.nycourts.gov/ip/ADR](http://www.nycourts.gov/ip/ADR). "In general, mediators do not offer their own opinions regarding likely court outcomes or the merits of the case. Instead, mediators offer the opportunity to expand the settlement discussion beyond the legal issues in dispute and focus on developing creative solutions, which emphasize the parties' practical concerns."
2. A settlement conference in Court provides assistance to the Court in reducing the number of cases on the Judge's docket. But the settlement conference does *not* provide all the benefits of Mediation. At a settlement conference, many times only the attorneys appear. In Mediation, the actual parties are required to be present and are encouraged to participate. At Mediation, nobody is pressured to agree, which occurs at many settlement conferences.  
  
Because the Courts have large caseloads and are understaffed, a settlement conference in Court generally provides a limited amount of time because of the Court's limited resources. In Mediation, generally several hours are set aside and the parties are generally instructed not to make appointments for the balance of the day so that there are no interruptions once the "momentum" for resolution gets underway.
3. See CPLR 4547.

4. See Ann Pfau and Daniel Weitz, "Court Annexed ADR on the Rise," N.Y.L.J., April 12, 1999, p. 1; *see also* current Reports of Office of Alternative Dispute Resolution Programs, Office of Court Administration.
5. "Should Mediation Be Available as an Option to Reduce Litigation in Contested Guardianship Cases?" NYSBA *Journal*, June 2002, p. 27, vol. 74, no. 5.
6. H. Patrick Leis, "The Model Guardianship Part" NYSBA *Journal*, June 2006, p. 10, vol. 78, no. 5.
7. That provision would have to be included within the Co-Guardians' powers, or if not in the powers, it should be approved by the Court.

**Leona Beane is a member of the Section, and handles wills, probate, trusts, estate and guardianship matters. She is an Arbitrator and Mediator for several different forums and was chair of the ADR Committee at New York County Lawyers Association for four years. She is currently Vice Chair of the newly formed Dispute Resolution Section of the NYSBA.**

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# How to Prevent Family Conflicts in the Event of Incapacity and Utilization of Article 81 of the Mental Hygiene Law When a Clash Is Inevitable

By Anthony J. Enea

Unfortunately in our litigious society, it has become commonplace for siblings, family members and friends to battle for control of the finances and care of their aging parents and loved ones. While the litigation superficially may be for the authority to make day-to-day financial and health care decisions, sadly, often at the root of the litigation is inheritance and monetary control.



It is anticipated that litigation involving aging parents, such as litigated Article 81 of the Mental Hygiene Law (MHL) guardianship proceedings, will rapidly grow in direct proportion to the aging population of the United States. Additionally, another relevant factor is that the largest transfer of inter-generational wealth, estimated to be approximately \$10 trillion, will be transferred from the World War II generation to the “baby boomers.” The transfer of such a great amount of wealth will inherently generate additional conflicts and controversies.

Unfortunately, the victim in these controversies is often the family unit. I have witnessed firsthand the bitterness, resentment and destruction of relationships among parents, siblings and loved ones. The effect is best described as a “family divorce,” the impact of which may be felt for generations.

Fortunately, there are steps that can be undertaken to minimize the risk of such controversies affecting families. As is often the case, it is imperative that the potential solutions be implemented well before the problems begin to manifest themselves. Some potential solutions are:

**(a) The execution of a general durable power of attorney, with broad powers being given to the agent.**

If the general power of attorney is durable, its efficacy will continue even after the subsequent disability or incompetence of the principal. It is best to utilize a customized durable general power of attorney form which grants the agent the broadest powers to act on behalf of the principal, including, but not limited to the powers to engage in various types of Medicaid and

estate planning. In my opinion the standard Blumberg Form Power of Attorney is too limiting and restrictive, especially as to the potential need to make transfers of assets for estate and Medicaid planning purposes. In drafting a power of attorney with broad gifting powers it is imperative that one be cognizant of the New York Court of Appeals decision in *In re Ferrara*, 7 N.Y.3d 244, 852 N.E.2d 138, 819 N.Y.S.2d 215 (2006). The Court of Appeals in *Ferrara* reversed the decision of the Appellate Division Second Department and revoked gifts that were made under a power of attorney. The Court of

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*“[T]he largest transfer of inter-generational wealth, estimated to be approximately \$10 trillion, will be transferred from the World War II generation to the ‘baby boomers.’”*

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Appeals in finding for the Salvation Army held that all gifting must be in the “best interest of the principal.” Additionally, with respect to the *Ferrara* case, it should be noted that on April 15, 2008, the Appellate Division Second Department 2008 NY Slip Op. 3455 affirmed the decree of the Rockland County Surrogate’s Court denying the request for a hearing on the issue of whether gifts of the decedent’s property made by one heir to himself were in the best interest of the principal under the power of attorney. Additionally, the Appellate Division Second Department remitted the matter to the Surrogate’s Court of Rockland County for the computation of prejudgment interest to be awarded to the Salvation Army. The Court opined that the Salvation Army’s possession of property as residuary beneficiary of the decedent’s estate was “interfered with” (CPLR 5001[a]).

The selection of the individual or individuals who will be the named agent(s) under the power of attorney is a decision of great importance. The individual selected must be someone the principal has a great deal of trust and confidence in. If the attorney-in-fact will have broad powers, including broad gifting powers, the principal should give serious consideration to the appointment of two (2) attorneys-in-fact who will be required to act jointly. In spite of the potential administrative difficulties it may cause by requiring that two (2) agents execute all documents, having at least two (2) agents will create a system of checks and balances, and

help reduce the likelihood of financial abuse, fraud and self-dealing.

(b) **Execute a health care proxy**, wherein a health care agent is selected. The individual selected is permitted by New York Law to make all health care decisions when the principal is no longer able to make these decisions. The health care proxy can specify which treatments and medical care one wishes and does not wish to have administered. Under New York Law only one health care agent at a time can be designated in the health care proxy. NYS Public Health Law § 2981. The principal should take the time to tell his or her agent exactly what his or her wishes are with respect to medical care and, specifically, end-of-life decisions, e.g., hydration and the use of ventilators and respirators. One should provide a copy of the health care proxy to his or her physician.

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*"The[se]. . . forms enable an individual to protect him or herself by enabling the individual to choose a family member or trusted friend to make financial and/or health related decisions if he or she is no longer able to do so."*

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(c) **Execute a living will**, wherein one is able to state his or her wishes not to be kept alive by extraordinary measures. While a living will is not statutorily recognized in New York, it is still additional written evidence of one's wish not to be kept alive by extraordinary measures.

(d) **Execute a Do Not Resuscitate Order (DNR)**, which is a document executed by the individual and his or her physician. The DNR can explicitly specify the circumstance wherein an individual does not want to be resuscitated. I often recommend that the client keep a pocket DNR in his or her wallet and purse, and on the refrigerator and to provide copies to loved ones. It is especially helpful in cases where the client suffers from a chronic and persistent life-threatening illness.

(e) **Execute a Burial Agent Designation Form** wherein you will be able to appoint an agent to dispose of your remains. In said form you will be also permitted to specify where you wish to be buried, any wishes regarding cremation and even the location of your wake and funeral. Public Health Law § 4201.

The execution of the aforesaid documents will go a long way in obviating the possibility of litigation regarding end-of-life and burial decisions.

The above-referenced forms enable an individual to protect him or herself by enabling the individual to choose a family member or trusted friend to make

financial and/or health related decisions if he or she is no longer able to do so.

However, if because of alleged financial, physical or emotional abuse it becomes necessary or inevitable that legal action be undertaken, in most instances, Article 81 of the Mental Hygiene Law for the appointment of a guardian will be the appropriate legal proceeding. Typically allegations are made that a physically or mentally incapacitated person is the victim of financial or physical abuse. The Petition in the Article 81 Guardianship proceeding will seek to obtain control over the person and property of the alleged victim of abuse by seeking a determination that the person is an incapacitated person as defined by Article 81. The Petition can also seek to void documents and contractual arrangements entered into by the alleged incapacitated person.

As part of an Article 81 proceeding the Courts have voided powers of attorney, health care proxies, Trusts, and Last Wills and Testaments executed by the incapacitated person and have also voided transfers of assets made by the incapacitated person. (See *In re Loretta I*, 34 A.D.3d 480 (2006); *In re Rita R*, 26 A.D.3d 502 (2006); *In re Shapiro*, N.Y.L.J., 4/19/01 (Supreme Court, Nassau County)). The Courts as part of an Article 81 Proceeding have also voided a marriage as a contractual arrangement pursuant to Article 81.29(d) of the MHL. (See *In re Sierra*, 15 Misc. 3d 1116A (2007, Supreme Court, Westchester County)).

In many cases, because of ongoing financial abuse and other alleged improprieties, it may be necessary as part of the Article 81 proceeding that a Temporary Restraining Order (TRO) be issued. Section 81.23(b)(2) of the MHL specifically authorizes the issuance of a TRO upon a showing that if a TRO was not issued, the property of the AIP would be dissipated to the financial detriment of the AIP. However, pursuant to the MHL the Court is not permitted to issue a TRO against the AIP. Section 81.23(b)(4) of the MHL further provides that where the TRO provides for a restraining notice, the person with custody or control over the person or property of the IP or the AIP is forbidden to make or suffer any sale, assignment, transfer or inheritance with any property of the IP or the AIP except pursuant to the Order of the Court.

Clearly, an Article 81 Proceeding with a properly drafted TRO will help put a halt to ongoing financial abuse during the pendency of the Article 81 proceeding. In fact, Section 81.23(b) of the MHL is sufficiently broad enough to be applied to restrain the use of a power of attorney during the pendency of the Article 81 proceeding. Additionally, a TRO as part of an Article 81 can be utilized to prevent the alleged abuser (both financial and physical) from having any contact with the IP or AIP during the pendency of the Article 81 proceeding. In a recently litigated matter I was able

to have the Court issue a TRO enjoining the alleged abuser from living at the home of his alleged victims and restraining him from visiting the home of his alleged victims.

An additional potential benefit of commencing an Article 81 proceeding is the possibility under Section 81.23(a)(1) of the MHL that the Court may appoint the Petitioners as Temporary Guardians for the AIP. Section 81.23(a)(1) specifically authorizes the appointment of a Temporary Guardian “upon showing of danger in the reasonably foreseeable future to the health and well being of the alleged incapacitated person, or danger of waste, misappropriation or loss of property of the alleged incapacitated person.”

The powers granted to the Temporary Guardian can be fashioned to address the exigencies and needs of each particular case and the AIP involved. In requesting the Court to appoint a Temporary Guardian, it is imperative to document the existence of an emergency and that the powers requested in light of the emergency are the least restrictive alternative.

From the above stated I believe it is sufficiently clear that taking appropriate steps to prevent clashes by family members over one’s assets is imperative. However, if a clash is inevitable, Article 81 of the Mental Hygiene Law will serve as a powerful vehicle to help rectify any wrongdoing.

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# Federal Settlement Expands Access to Medicaid Consumer-Directed Personal Assistance and Nursing Services

By Valerie J. Bogart and Robert Briglio



On June 12, 2008, the Protection and Advocacy for persons with Developmental Disabilities (PADD) program at Nassau/Suffolk Law Services (NSLS) obtained a federal court settlement that will expand access to two Medicaid home care programs in New York State—

the Consumer Directed Personal Assistance Program (CDPAP) and Private Duty Nursing (PDN) program. The case challenged policies and practices of the New York State Department of Health (DOH) effectively denying home care services to Plaintiff, Jeanette Leon, and threatening her with institutionalization in violation of the Americans with Disabilities Act (ADA) and the Medicaid law (*Leon v. Danes et al.* (CV 07-1674 E.D.N.Y.)). The settlement is posted on the Online Resources Center at [www.wnyc.net](http://www.wnyc.net).<sup>1</sup>

## Facts of Named Plaintiff

Jeanette is twenty-two years old and has lived with and been cared for by her mother, Veronica Leon, her whole life. Jeanette has been disabled since birth and suffers from Cerebral Palsy, severe developmental delays, a seizure disorder, glaucoma, severe allergies, and mental retardation. Jeanette's father abandoned the family long ago, leaving Veronica Leon to independently raise Jeanette.

In order for Jeanette to remain at home, she requires nursing and assistance with eating, dressing, toileting, and all other activities of daily living. Mrs. Leon has managed this intense level of care for her daughter with help from Medicaid home care programs, such as private duty nursing.<sup>2</sup> As a result, Jeanette has enjoyed an active life and completed high school. She engages in various recreational activities with her mother, such as trips to the park, shopping malls, restaurants, museums and concerts, among other activities.

Receipt of Medicaid nursing services has been problematic over the years, the result of a shortage of nurses willing to take Medicaid cases in Suffolk County because of the low Medicaid payment rate. A previous lawsuit brought by NSLS resulted in a settlement providing for a higher rate for home nursing services

for Jeanette for two years. However, after the settlement expired, problems finding nurses resurfaced.<sup>3</sup>

Veronica Leon was advised to apply on Jeanette's behalf for home care through the CDPAP.<sup>4</sup> CDPAP allows Medicaid home care recipients or a friend or relative to assume responsibility for directing their home care program. Either the consumer—or a "self-directing other" person on her behalf—hires and trains personal care aides to perform the necessary skilled tasks, which would otherwise have to be performed by a nurse. NYS Education Law § 6908, subd. 1(a)(iii). For Jeanette to be eligible, her mother, acting as the "self-directing other," would need to direct the program.

Jeanette was found eligible for CDPAP by the Suffolk County Department of Social Services (SCDSS) in May 2005, and the program was functioning well. CDPAP ensured Jeanette regularly received the home care she needed in contrast to the lapses experienced with Medicaid nursing. In addition, CDPAP was much less costly to the state and county than nursing care. With home care in place, Veronica Leon was able to work as a part-time teaching assistant to help pay the household's expenses.

In March 2006 SCDSS terminated Jeanette from CDPAP because Veronica Leon was occasionally leaving the house to work and was not present at all times to "supervise" the provision of CDPAP to Jeanette. The termination was made despite a backup plan created by Mrs. Leon to ensure her daughter was never without someone to assist with her needs. In December 2006, the State DOH affirmed SCDSS's termination of CDPAP pursuant to a recent DOH policy that prohibits CDPAP assistance for non-self-directing patients like Jeanette who require nursing assistance, unless a self-directing other is home at all times to supervise the CDPAP personal assistant.<sup>5</sup> Additionally, DOH failed to provide any alternative Medicaid home care for Jeanette, such as private duty nursing services, to prevent Jeanette's institutionalization. Veronica's only options were to care for Jeanette 24 hours a day or place her in a nursing home.

## The Settlement

The settlement of this case provides for new policies and procedures to be implemented by the State DOH and local districts in both the Medicaid CDPAP and Private Duty Nursing programs.

The revised CDPAP policies amend and clarify a 2006 directive on CDPAP, called DOH 06 OMM / LCM-1. Question 8 in this directive required that the CDPAP aide be “supervised and directed while performing” a skilled task, by the friend or family member who directs care for a CDPAP recipient (“a self-directing other”). The settlement clarifies that the a self-directing other does *not* have to be present at all times in which skilled nursing tasks are administered by a CDPAP aide to a non-self-directing recipient of CDPAP. The settlement specifically amends Question 8 of the LCM.

The revised policy also provides guidance to local Department of Social Services (DSS) districts statewide regarding the assessment process for the receipt of CDPAP by non-self-directing recipients. The guidance clarifies how a district determines which consumers are “self-directing,” and for those who are not, the level of involvement required of the “self-directing other.”

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*“Significantly, the settlement establishes statewide procedures for obtaining Medicaid private duty nursing services if there is difficulty finding a provider.”*

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The settlement also establishes procedures for the receipt of Medicaid private duty nursing services where previously there had been a vacuum, except in the few local DSS districts that still process these applications.<sup>6</sup> The new DOH policies and procedures describe private duty nursing services, inform applicants (and their representatives) as to who can provide the services, describe how to apply for services, and require decisions to be made within 21 days of a fully documented application. The guidelines require that applicants be informed of how to obtain a list of Medicaid private duty nurses in their area by calling the Medicaid helpline at 1-800-541-2831 and online at [www.homecare.nyhealth.gov](http://www.homecare.nyhealth.gov).

Significantly, the settlement establishes statewide procedures for obtaining Medicaid private duty nursing services if there is difficulty finding a provider. One of the options established is the right of clients or their representatives to apply at the local DSS for a DOH case-specific enhanced payment rate. The enhanced rate is applicable in *all* DSS districts in the state pursuant to the settlement.<sup>7</sup>

The settlement provides that the Private Duty Nursing procedures will be issued and available at all local DSS districts and will be posted on the state’s Web site.

Finally, the settlement provides compensation to Jeanette for services paid out of her trust while left without any home care services from DOH, and attorney’s fees for plaintiff’s counsel.

For information regarding settlement, see the documents posted at the WNYLC.com Online Resource Center, or contact Robert Briglio at the NSLS PADD program, [rbriglio@wnylc.com](mailto:rbriglio@wnylc.com) or (631) 232-2400.

## Endnotes

1. Registration is required, which is free.
2. Soc. Serv. L. § 365-a(2)(l), 18 N.Y.C.R.R. § 505.8. Services are authorized using prior approval procedures under 18 NYCRR § 513.
3. Subsequent litigation establishing an enhanced rate for PDN in Nassau and Suffolk Counties, *Scholtz v. Novello et al.*, CV-02-4245 (E.D.N.Y.) and *Bacon v. Novello et al.*, CV-02-4244 (E.D.N.Y. 2004), was of no benefit to Ms. Leon because the counties no longer processed applications for PDN by 2006. (Settlements posted at the Online Resource Center at <http://www.wnyc.net>).
4. Soc. Serv. L. § 365-f, DOH 06 OMM / LCM-1.
5. DOH 06 OMM / LCM-1.
6. The settlement recites that the following seven districts process applications for private duty nursing: Broome, Chemung, Erie, Oneida, Schenectady, Tompkins and Westchester (Settlement, Exh. B). For all other districts, applications are processed directly by the State Department of Health in Albany.
7. The Coalition for Medically Fragile Children developed legislation that was effective January 1, 2007, creating an enhanced private duty home nursing rate for medically fragile children under age 21. Medically fragile children are defined as those needing continuous home nursing services. That law will sunset in 2011. The *Leon* settlement establishes a case-by-case procedure for adults and children who are not “medically fragile” to obtain a case-specific enhanced rate, subject to the approval of the Division of the Budget.

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# Advance Directive News: DNRs Homeside

By Ellen G. Makofsky

As our clients age in place they often become anxious with the thought that a 911 call by a family member or home health aide will result in a furious attempt at unwanted cardiopulmonary resuscitation (CPR) as they lie on the kitchen floor.<sup>1</sup> Those fears are well founded. CPR can cause much physical trauma to the body, and statistics reveal that hardly any who receive CPR recover to resume their regular lives.<sup>2</sup> Few want to be cheated of a peaceful passing by spending their last moments in the traumatic throes of CPR.



## Presumption for Resuscitation

New York State law provides that where there is no direction from the individual or surrogate health care decision-maker, there is a presumption for resuscitation.<sup>3</sup> What this means is that where emergency medical services personnel respond to a 911 call, they are required to undertake all efforts, no matter how traumatic, to revive the person experiencing a cardiac or respiratory arrest. For the unconscious senior lying on the kitchen floor the presumption can be overcome only with a properly executed Do Not Resuscitate Order (DNR). Different types of DNRs are valid in different situations.

## The Non-Hospital DNR Order

A non-hospital DNR may be established for an individual living at home or in an assisted living facility. It directs emergency medical services and hospital personnel not to attempt cardiopulmonary resuscitation in the event an individual suffers cardiac or respiratory arrest.<sup>4</sup> It is not the attorney who prepares the non-hospital DNR but rather the attending physician who issues the DNR on a special standardized New York State form which becomes immediately effective. Where a non-hospital DNR is issued, it remains in force for a maximum of 90 days; however, the physician is charged with reviewing the appropriateness of the order in light of the individual's condition each time the physician examines the individual.<sup>5</sup> When the non-hospital DNR expires, another may be issued.

## Capacity Issues

There is a very strong presumption for capacity in regard to an individual's ability to make a DNR decision. The statute provides that every adult shall be presumed to have the capacity to make a decision regarding cardiopulmonary resuscitation unless determined otherwise. The determination of incapacity must be made by the attending physician in writing and requires a concurring written determination by a second physician regarding the lack of capacity.<sup>6</sup> Even when this standard is met, a surrogate<sup>7</sup> may not consent to a DNR order unless certain other additional criteria are met. A physician must further determine that: the patient has a terminal condition; or the patient is permanently unconscious; or resuscitation would be medically futile; or 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.<sup>8</sup>

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*"CPR can cause much physical trauma to the body, and statistics reveal that hardly any who receive CPR recover to resume their regular lives."*

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The criteria to be met for surrogate DNR decision making is formidable. No such criteria must be addressed however when the individual requesting the DNR possesses the requisite capacity. This leaves open the opportunity for those living at home in fear of that 911 call to request their own DNR. As the statutory presumption for capacity is so high, the request is difficult to challenge.

## Requirements for a Non-Hospital DNR

As the DNR is not an attorney-generated document, the individual requesting a DNR must seek out his or her physician. It is likely that at this point a full discussion will ensue between patient and physician as to the appropriateness of the issuance of a DNR. Once a decision is made it is an uncomplicated matter to set the required mechanism in place. An adult with capacity may consent to a non-hospital DNR simply by making an oral statement to the attending physician. Although no writing is required, a written statement can also be used to initiate a DNR if signed in the pres-

ence of two witnesses. Once the DNR is requested, a record of the issuance of the DNR must be made in the patient's medical chart. The actual DNR is issued on a standardized form which is then given to the individual. Once issued, the DNR should be readily available and displayed prominently at home so that should a triggering event occur, emergency medical services and hospital personnel will be on notice not to attempt cardiopulmonary resuscitation.

For those who seek the peace of mind in knowing that at the end of a life long lived, there will be a peaceful passing, the non-hospital DNR is worth considering.

## Endnotes

1. CPR refers to the medical procedures used to restore a patient's heartbeat and breathing in case of heart and respiratory failure. CPR may involve simple techniques such as mouth-to-mouth resuscitation and external chest compression, or may be more complex and involve the administration of electric shock, insertion of a tube to open the patient's airway, injection of medications into the heart and, in extreme cases, open chest heart massage.
2. When evaluating actual success rates for post-CPR survival without a diminished quality of life, the statistics are disheartening. Only 5 percent of hospitalized patients who receive CPR recover and resume their regular lives.
3. N.Y. Public Health Law § 2962.
4. N.Y. Public Health Law § 2977.
5. This is in contrast to a DNR issues for a hospital patient where the physician is required to review whether the DNR is appropriate in light of the patient's condition at least every seven days. N.Y. Public Health Law § 2970.
6. N.Y. Public Health Law § 2963.
7. The following persons chosen in order of priority listed may act as surrogate decision maker and sign a DNR: health care agent; 17-A guardian; the spouse; an adult child; a parent; an adult sibling; and a close friend. N.Y. Public Health Law § 2965.
8. N.Y. Public Health Law § 2965.

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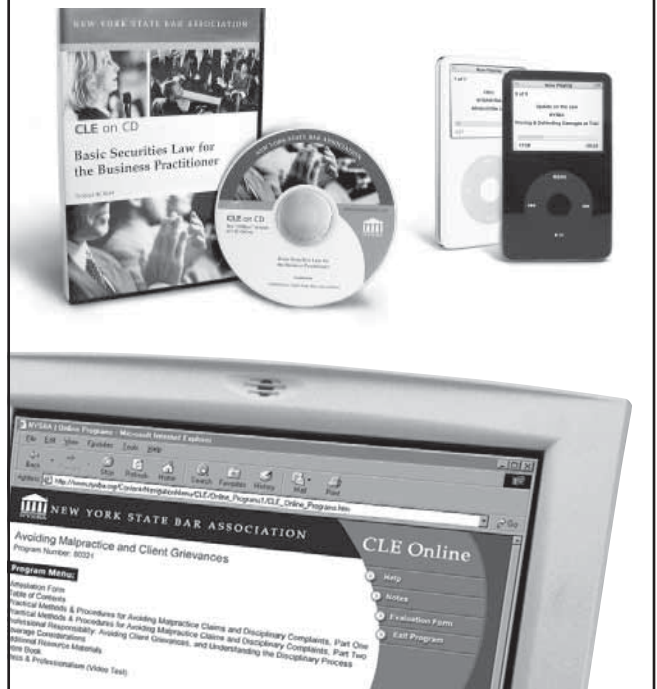
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# Recent New York Cases

By Judith B. Raskin

## Venue

**The Court transferred a new guardianship matter to a neighboring county where the incapacitated person was located. Case returned to court where originally filed. *In re Davis*, 2008 NY Slip Op. 51070U, 2008 N.Y. Misc. LEXIS 3107 (Sup. Ct., Queens County, May 30, 2008).**



Leonard Davis sought appointment as guardian for his brother Edward, who resided in a facility in Queens County. Mr. Davis filed the petition in Kings County on April 1, 2008. On April 28, 2008, the Supreme Court, Kings County, issued an order, *sua sponte*, transferring the matter to Queens County based on venue requirements set forth in MHL § 81.05(a). The Supreme Court, Queens County, signed the Order to Show Cause and made the petition returnable in Kings County. The Court in Queens cited both CPLR 510 and MHL § 81.05(a). Improper venue can be changed only upon motion.

**The Court that granted guardianship transferred an order to show cause seeking modification of the initial order to the county where the ward came to reside. The order to show cause was made returnable to the original court. *In re Fister*, 2008 NY Slip Op. 51169U, 2008 N.Y. Misc. LEXIS 3344 (Sup. Ct., Queens County, June 5, 2008).**

In 2004, the Supreme Court, New York County, appointed the Jewish Association for Services for the Aged (JASA) as guardian for Judy Fister for a period of three years. Prior to the termination of the three-year period, JASA moved to extend its appointment for an indefinite term. Shortly after its receipt of JASA's order to show cause, the Supreme Court, New York County, ordered, *sua sponte*, that the venue be changed to Queens County, where Ms. Fister was then located.

The Supreme Court, Queens County, signed the order to show cause and made it returnable in New York County, where the matter was originally heard. Pursuant to CPLR and MHL, venue cannot be changed except upon motion. The court was adamant that such change of venue is not only without statutory basis but would result in unnecessary delays and inefficiencies and would destroy continuity of oversight.

## Residency

**A Medicaid applicant appealed from a fair hearing decision confirming the agency finding that he was**

**not a New York resident. Appeal denied. *Jenkins v. Novello*, 2008 NY Slip Op. 3114, 50 A.D.3d 381, 855 N.Y.S.2d 456, 2008 N.Y. App. Div. LEXIS 3088 (App. Div. 1st Dep't, April 10, 2008).**

In 2004, William Jenkins' Medicaid application for institutional care was denied for the reason that he was not a New York resident. Mr. Jenkins unsuccessfully appealed the residency determination at a fair hearing. He then brought an Article 78 which was transferred to the Appellate Division.

The Appellate Division upheld the fair hearing decision. Evidence showed that Mr. Jenkins intended to return to his home in South Carolina upon his release from the nursing home. But his Benefits Coordinator testified that he then changed his mind and did intend to stay in New York. The Court said where the evidence was conflicting it could not override the fair hearing decision. Mr. Jenkins could have made his intent clearly known but failed to do so.

## Personal Jurisdiction in Article 81

**A guardian sought to extend its appointment where the ward had since been moved to an out-of-state facility. Granted. *In re Lillian*, NY Slip Op. 28155, 2008 N.Y. Misc. LEXIS 2447 (Sup. Ct., Delaware County, April 17, 2008).**

The Delaware County Commissioner of Social Services was appointed guardian for Lillian following a hearing that took place in her hospital room in New York. Thereafter, Lillian's caseworker was unable to place her in a New York facility due to Lillian's aggressive behavior. The guardian then transferred Lillian to a nursing home in Massachusetts.

In accordance with the Court's original order, the guardian brought an order to show cause one year later to extend the guardianship. At this proceeding, Lillian's court-appointed attorney argued that the Court lacked personal jurisdiction because Lillian's transfer to an out-of-state facility terminated her New York domicile. Lillian's attorney also argued that the hearing must take place in her presence.

The Court held that while an Article 81 guardian has no power to change the incapacitated person's domicile without court approval, the guardian does have the power to change her place of abode under MHL § 8122(a)(9). The Court found that although Lillian's abode had changed, she remained a domiciliary of New York and the Court continued to have personal jurisdiction. The Court also held that pursuant to MHL § 81.11(c), where a New York domiciliary resides in an out-of-state facility, her presence at the hearing can be waived. Because Lillian refused to participate in the

hearing and she was located out of state, she did not have to be present at the hearing. The Court extended the guardianship, finding evidence that Lillian was still incapacitated and in need of a guardian.

## **Temporary Medicaid**

**A class of inmates receiving mental health treatment sought temporary Medicaid upon their release.**

**Granted. *City of New York v. Novello*, 2008 WL 2130330 (App. Div. 1st Dep't, May 22, 2008).**

A group of inmates filed a class action in 1999 against the City of New York. The inmates were receiving mental health treatment while incarcerated and sought appropriate provisions for their continued care if needed upon their release.

The parties entered into a stipulation of settlement. The Court required a modification of the stipulation to include the availability of temporary medical assistance upon discharge pursuant to SSL § 133. The City requested this modification from the Dept. of Health (DOH). DOH refused to provide this temporary assistance. The City appealed.

In the interim, effective April 1, 2008, SSL § 366 was amended to provide that an inmate receiving Medicaid benefits immediately prior to incarceration would remain eligible while an inmate and upon release would not have to reapply. As to other inmates, the Court found that in rejecting the City's request the actions of DOH were arbitrary and capricious. DOH should have agreed to the proposed rule submitted by the City or offered an alternative to provide for temporary medical assistance for the inmates in need.

***This case was submitted by Aytan Belling. Aytan wrote the amicus brief on behalf of the New York Chapter of NAELA. He is now litigating the right of home care recipients needing personal care attendants to temporary Medicaid.***

## **Section 1983 Attorney Fees**

**Petitioner appealed from a denial of section 1983 attorney fees. Granted provided federal grounds were basis for relief. *Giaquinto v. Commissioner*, NYS DOH, 2008 NY Slip Op. 5350, 2008 N.Y. LEXIS 1492 (Ct. of Appeals, June 12, 2008).**

Petitioner Dominick Giaquinto's Medicaid application was denied for excess resources. At a fair hearing, he requested a raised CSRA for his wife as her income was below the MMMNA. The matter was referred back to the agency to determine the raised CSRA by calculating the amount needed to purchase a single premium annuity that would generate her income shortfall. He successfully appealed. The Supreme Court held that DOH could not use the single premium annuity method. It failed to follow its prior policy and changed the basis of the calculation without explanation. The Court granted attorney fees.

DOH then appealed on the merits and the fee award but then withdrew the appeal on the merits. The Appellate Division reversed the fee award. The Court found that while the petitioner may have a valid federal claim, 42 U.S.C. § 1983 permits suit against state officers in their official capacity only when the relief sought is prospective and the relief in this case was retrospective.

Petitioner appealed. The Court of Appeals held that the petitioner did receive prospective relief. The Court remanded the matter back to the Supreme Court to determine whether relief was awarded on federal grounds.

***Louis Pierro represented the appellant.***

## **CSRA Annuity Calculation**

**A community spouse with excess resources appealed from a determination that her raised CSRA would be calculated using the single premium annuity method. Denied. *Ekiert v. Daines*, Index No. 841-08 (Sup. Ct., Albany County, June 23, 2008).**

When Mr. Ekiert's Medicaid application was approved, Mrs. Ekiert had \$242,000 in excess resources. At a fair hearing, the DOH agreed that Mrs. Ekiert was entitled to a raised resource allowance to generate the difference between her income of \$508.24 and the MMMNA. DOH referred the matter back to the Albany County Dept. of Social Services to calculate the raised CSRA based upon the cost of a single premium annuity that would generate the income deficiency.

The couple appealed. They argued that the annuity method included a return of principal, that the statutory language required a straight interest calculation, that implicit in the annuity method is the requirement to purchase an annuity, that the agency did not explain its use of the new calculation method, that the annuity method is not actuarially sound and that DOH should be doing the calculation, not DSS.

The Supreme Court affirmed the fair hearing decision. The court found that CMS permits agencies to use any reasonable method to calculate the raised CSRA, that the annuity calculation is reasonable, that Mrs. Ekiert is not required to actually purchase the annuity and that the annuity method was sufficiently explained in the fair hearing decision. Although DOH should have calculated the CSRA, the couple was not harmed by the remand to DSS for the calculation.

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# End-of-Life Decision Making Under Article 17-A and Article 81

By Lisa K. Friedman and Robert Kruger

Guardianship for people who are mentally retarded or developmentally disabled may be obtained from the Surrogate's Court or the Supreme Court. When it comes to end-of-life decision making, the two are not necessarily equal. But it is possible to take advantage of both statutes in the best interest of the subjects of these proceedings.

In 1969, Article 17-A of the Surrogate's Court Procedure Act was created as the result of family advocacy in order to allow a family member to continue to make decisions and advocate for their child who is mentally retarded. Twenty years later, in 1989, Article 17-A was expanded to provide guardianship to the entire population of individuals with developmental disabilities, which includes people with mental retardation. The New York State Association of Retarded Citizens, now known as NYSARC, was a leader in advocating for the creation of a separate statute for people with mental retardation and, later, developmental disabilities.

Article 17-A guardianships are brought in the Surrogate's Court and usually are guardianships only of the person. Most individuals who are mentally retarded or developmentally disabled have no assets, since they must be eligible for Medicaid in order to receive services; thus, a guardian of person-only is usually sought under Article 17-A.

Article 81 of the Mental Hygiene Law was created in effect to reform the conservator and incompetency statutes. Unlike Article 17-A, Article 81 is based on a more adversarial approach in order to insure that the due process rights of the incapacitated person are protected. Most individuals who have Article 81 guardians, have guardians of the person *and* property from the outset. Often, personal needs issues are secondary to property issues. For example, applications are often brought pursuant to Article 81 to establish supplemental needs trusts for persons who are mentally retarded or developmentally disabled with funds received from a personal injury or medical malpractice actions, inheritances or some other source of assets which, if not addressed, would disqualify an individual from receiving benefits.

Article 81 guardians may exercise only those powers that they are granted. Section 81.29 of the Mental Hygiene Law provides that "nothing in this article shall be construed either to prohibit a court from granting, or to authorize a court to grant, to any

person the power to consent for the withholding or withdrawal of life-sustaining treatment, including artificial nutrition and hydration." The Article 81 guardian cannot make end-of-life decisions unless he or she has clear and convincing evidence as to the wishes of the incapacitated person.

Until March 16, 2003, like the Article 81 guardian, the guardian of the person of someone who is mentally retarded or developmentally disabled appointed under 17-A, while a plenary guardian, was able to make all medical decisions for his or her ward *except* for end-of-life decisions involving the withholding or withdrawal of life-sustaining treatment. If there was an Article 81 guardian, the same rule applied, unless the incapacitated person had explicitly expressed his or her wishes regarding end-of-life decisions. A person who is mentally retarded or developmentally disabled can rarely express her or his wishes regarding end-of-life care, therefore limiting the ability to withhold or withdraw life-sustaining treatment for that individual.

On March 16, 2003, after a number of reports regarding the suffering of terminally ill individuals with mental retardation resulting from the inability to withhold or withdraw life-sustaining treatment, the New York State Legislature added Section 1750-b to the Surrogate's Court Procedure Act (L. 2002, ch. 500) which provided for the "Health care decisions for mentally retarded persons." Chapter 500 provided that in spite of the inability of the person with mental retardation to communicate his or her wishes regarding end-of-life treatment, non-corporate guardians of people with mental retardation could withhold or withdraw life-sustaining treatment. Section 1750-b(4) addresses life-sustaining treatment or the withholding of the same. Section 1750-b(5) through (7) addresses objections to the implementation of end-of-life decisions and court challenges to such decisions.

There have since been a number of amendments to Section 1750-b that expanded who could make end-of-life decisions under 1750-b, notably:

- 1) 1750-b was expanded to cover corporate guardians of people who are mentally retarded, such as NYSARC, Inc. *See* L. 2003, ch. 232;
- 2) end-of-life decisions can now be made for people who are developmentally disabled as well as those who are mentally retarded. L. 2005, ch. 744;

- 3) non-guardian family members can now petition to make end-of-life decisions pursuant to SCPA 1750-b procedures. L. 2007, ch. 105; and
- 4) surrogate decision-making committees established under Article 80 of the Mental Hygiene Law will as of January 3, 2009 be able to make end-of-life decisions for individuals who have no family members. L. 2008, ch. 262.

Choice of forum is now an important consideration when preparing a guardianship for a person who is mentally retarded or developmentally disabled. In the future the Article 81 guardian may wish he or she had the authority to make end-of-life decisions in order to assure ease of medical decision making including withholding and withdrawing life-sustaining treatment.

If the individual who is mentally retarded or developmentally disabled has a personal needs 17-A guardian, end-of-life decisions can be made for him or her following the procedures set forth under section 1750-b of the Surrogate's Court Procedure Act. If the individual at some future point has assets from a personal injury, medical malpractice settlement or inheritance or a retroactive Social Security award, then a decision may be made to make an application for a supplemental needs trust under Article 17-A or Article 81, or bring a plenary application in Supreme Court.

The Article 81 guardian of a person who is mentally retarded or developmentally disabled may be unable to make such end-of-life decisions under Article 81. If, however, that guardian is a family member or a corporate guardian, then end-of-life decisions can be made non-judicially following the procedures set forth under section 1750-b(4) through 1750-b(7) of the Surrogate's Court Procedure Act.

The decision to withhold or withdraw life-sustaining treatment can be expressed either orally or in writing by the family member or guardian.<sup>1</sup> The attending physician must "determine to a reasonable degree of medical certainty" that the person who is mentally retarded or developmentally disabled must be incapable of making the medical decision."<sup>2</sup> The attending physician with the concurrence of another physician must confirm that "to a reasonable degree of medical certainty" the person who is mentally retarded or developmentally disabled 1) has a medical condition that is a terminal condition; or 2) is permanently unconscious; 3) or has a medical condition that is irreversible and will continue indefinitely; and 4) that the life-sustaining treatment will impose an extraordinary burden on such person in light of a) such person's medical condition and b) the expected outcome of the life-sustaining treatment; and, in the case of withholding or withdrawing artificial nutrition and hydration

1) there must be no reasonable hope of maintaining life or 2) the artificially provided nutrition or hydration must pose an extraordinary burden.<sup>3</sup>

Once the attending physician learns of the decision of the guardian, he or she must include that decision in the medical chart and either promptly issue the order to withhold or withdraw life-sustaining treatment or object to the decision as provided for in 1750-b(5).<sup>4</sup> At least 48 hours before implementing the decision, the attending physician must notify the person who is mentally retarded or developmentally disabled, unless it is determined that such individual would suffer immediate and severe injury from such notification; and, if the person does not live in a residence, either the chief executive officer of the residential provider; and the Mental Hygiene Legal Service (MHLS) or the Commissioner of the Office of Mental Retardation and Developmental Disabilities (OMRDD).<sup>5</sup> If there is no opposition, then the Article 81 guardian can make the end-of-life decision following the procedures set forth under 1750-b of the Surrogates Court Procedure Act.

An objection to withhold life-sustaining treatment can be made by the mentally retarded person, by the parent or adult sibling of said person who has maintained substantial or continuous contact with the mentally retarded person, by the attending physician, or by any other health professional providing services to the mentally retarded person, or by the chief executive officer of the residential facility and MHLS or the Commissioner of OMRDD.<sup>6</sup> Once an objection is lodged either orally or in writing,<sup>7</sup> the implementation of the decision is suspended and the persons entitled to notification are notified and the suspension must be noted in the medical chart.<sup>8</sup>

If there is an objection to the end-of-life decision, then<sup>9</sup> the guardian, the attending physician, the chief executive officer of the residence of the person who is mentally retarded or developmentally disabled and MHLS or the commissioner of the OMRDD may commence a special proceeding in a court of competent jurisdiction.

If, however, the Article 81 guardian is not a family member or a corporate guardian, then the end-of-life decision will need to be sought using the most recent amendment to Section 1750-b, which allows a Surrogate Decision Making Committee to make such a decision. Of course, this can be done only after January 3, 2009.

The Surrogate Decision Making Committee Law (SDMC), passed in 1985, provides that when there are no family members or guardians to make medical treatment decisions, Surrogate Decision Making Committees can make such decisions on behalf of individuals who are determined to be incapable of so doing. The

committees are made up of four individuals who volunteer to sit on the panels. The hearings are held after the process is commenced by the filing of a declaration and supporting documents including a declaration regarding capacity and a certification of Need for Major Medical Treatment. The Commission on the Quality of Care (CQC) processes the application and sets up a hearing. The patient and MHLS attend. The patient's parents, spouse, adult child(ren), committee, conservator, guardian or correspondent, the director of the residence, if any, are notified of the time and place of the hearing. The panel members personally interview the patient and take testimony from the participants. MHLS may be heard and may present witnesses and otherwise advocate for their client in regard to the proposed medical procedures. The panel must consider three questions: 1) Does the patient have the ability to consent or refuse the proposed medical treatment?<sup>10</sup> 2) Is there a family member or guardian who is legally authorized, available and willing to make the major medical treatment decision?<sup>11</sup> and 3) Is the proposed major medical treatment in the best interests of the patient?<sup>12</sup> Three of the four panel members must determine by clear and convincing evidence that the major medical treatment is necessary.<sup>13</sup>

It is also noteworthy that the only remaining potential decision maker who should be included as a non-guardian family member by way of one last amendment is the Consumer Advisory Board (the CAB) which is a quasi-independent entity charged under the Permanent Injunction, dated March 11, 1993, in *New York State Association for Retarded Children et al. v. Pataki et al.*, 72 Civ. 356, 357 (JRB), “*Willowbrook*” litigation. The Permanent Injunction integrated prior court orders that charged the CAB with the responsibility of monitoring all care and services of *Willowbrook* class members pursuant to the Permanent Injunction in the *Willowbrook* litigation. The CAB provides necessary and appropriate representation and advocacy services on an individual basis to all non-correspondent former *Willowbrook* class members as long as such class member shall live. It functions *in loco parentis* for *Willowbrook* class members who do not have an actively involved family member. Perhaps 2009 will result in one more amendment to 1750-b that will obviate the need to use Surrogate Decision Making Panel for a *Willowbrook* consumer in order to make an end-of-life decision.

In order to avoid a challenge to this approach in an Article 81 guardianship proceeding, it might be wise to simply seek a 17-A guardian of the person-only and, if desired, address property guardianship issues under Article 81 in the Surrogate's Court.

It is noteworthy that the recently enacted Chapter 210 of the Laws of 2008 provides for a two-year pilot program where a simplified health care directive form will be used by persons who are mentally retarded and developmentally disabled who are receiving services from OMRDD. The health care agent will be able to act immediately upon execution with the consent of the principal. Chapter 210 provides a useful option for medical decision making for high functioning individuals who are mentally retarded and developmentally disabled, obviating the need for a personal needs guardian.

## Endnotes

1. SCPA 1750-b(4)(c)(i) and (ii).
2. SCPA 1750-b(4)(a).
3. SCPA 1750-b(4)(b).
4. SCPA 1750-b(4)(c).
5. SCPA 1750-b(4)(d).
6. SCPA 1750-b(5)(a).
7. SCPA 1750-b(5)(b).
8. SCPA 1750-b(5)(b) and (c).
9. SCPA 1750-b(6).
10. MHL § 80.03(c).
11. MHL § 80.03(b).
12. MHL § 80.07(f).
13. MHL § 80.07(e).

**Robert Kruger is an author of the chapter on guardianship judgments in *Guardianship Practice in New York State* (NYSBA 1997) 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)).**

# Special Needs Forum: Waivers in New York

By Adrienne Arkontaky

Each year, families of children with severe disabilities struggle to meet the needs of their children. Families are faced with mounting health care costs, uncovered therapies and drug coverage. Families cannot find or afford nurses, aides or respite workers to help with the care of children with severe disabilities. Years ago, when it became difficult for families to care for their medically fragile children, in many instances, the only option was institutionalization. Today, fortunately, there are viable alternatives to residential placement. Many states, along with New York State, have developed "Waiver Programs" which allow children with severe disabilities to remain in the community. New York State provides many supports and access to health care coverage under "Medicaid Waiver" programs. A "waiver" is a federally approved deferral of the regular Medicaid rules to allow children with disabilities to remain at home and still obtain Medicaid coverage.



As a parent of a child with severe disabilities, I understand the importance of adequate health care coverage. My sixteen-year-old daughter, Jordan, has undergone nine orthopedic surgeries since birth. Her customized wheelchair cost over \$7,000, and the nursing coverage she receives would be unaffordable without the coverage under the Waiver program. The costs of Jordan's care are covered by a combination of private insurance coverage and a Medicaid waiver program known as the "Care at Home program." This program allows children with severe physical disabilities to remain at home with their families. The Care at Home Waiver is only one of many programs that assist families in caring for children with disabilities in the home. In this issue of the "Special Needs Forum," I decided to take a look at this important program available to families in New York who have children with severe disabilities. There are other programs such as the Home and Community Based Services (HCBS) Waiver and the Traumatic Brain Injury (TBI) Waiver. I believe Elder Law practitioners should have at least a basic knowledge of these programs as they offer supports to families who struggle with the everyday stresses of caring for children with severe physical and mental challenges. These programs also allow the families of children with disabilities to be an important

part of the decision making process when determining what type of care is needed.

## The Care at Home Waiver Program

The New York State Department of Health administers five Care at Home (CAH) Medicaid Waiver programs. Started in 1985, the program enables families to obtain Medicaid coverage in order to care for children with disabilities at home instead of in an institutional setting. When the CAH Waivers were first developed, there were many children in intermediate care facilities (ICF), hospitals and nursing homes. Many of the children could return home if there were support services available in the community to attend to their needs and the children could maintain their Medicaid eligibility. When a child is placed in an ICF, nursing home or hospital, their Medicaid eligibility is determined without parental income. However, once they leave the facility, they usually lose their eligibility because the child's parents' income is considered for Medicaid eligibility, often deeming the child ineligible. The waiver allows community access to Medicaid using the child's income. The CAH programs are designed for families who would not normally be eligible for Medicaid.

The Department of Health operates CAH I/II for children who require a very high level of care similar to nursing home or hospital care. These children may require frequent device-based respiratory, nutritional or other intensive support such as suctioning, g-tube feeding and/or oxygen support. CAH III, IV and VI are available for children who require an intermediate care facility level of care. All CAH programs provide case management, respite and home and/or vehicle modification services.

CAH I/II participants must be younger than 18 and have had a continuous 30-day hospital stay or 30 days within a 90-day period. The child must be physically disabled by the Social Security Act standards (if the disability is physical in nature). There must be a determination that the child can be cared for safely at home with supports. Also, the child must be 1) ineligible for Medicaid in the community because the income and resources of the responsible parent or guardian would be deemed to the child, and 2) the child would be eligible when not deemed, and 3) the cost of caring for the child in the community must not be more than the cost of caring for the child in an appropriate institutional setting.

CAH III, IV and VI participants have the same requirements as above except they do not have to have had the 30-day hospital stay. They must be developmentally disabled and have complex needs.

Many families learn about this waiver from the child's school, physician, social worker or Early Intervention Program (EIP). The application process usually includes completion of a Medicaid application, a level-of-care screening, a home assessment, a disability determination, physician orders, care plan and a budget.

The Care at Home Waiver provides case management services. A case manager is a very important source of information for families of children with disabilities. The case manager helps families gain access to the Medicaid and other support services in the community. The case manager usually develops a care plan for the families, taking into consideration the unique needs of the child with disabilities. There is no better advocate than a well-versed and passionate service coordinator. The case manager can assist families with respite, nursing, medical equipment, and adaptations in the home. It is important that the case manager be in regular contact with the family to ensure that the child and family feel well supported. A family can change case managers at any time.

CAH also pays for durable medical equipment such as wheelchairs, orthotic appliances, bath chairs, diapers and in many cases supplemental nutrition such as Ensure. The program may also cover the cost of therapies such as physical, occupational and rehabilitative therapies.

One benefit of the CAH programs is the option of home adaptation and vehicle modification. Many children can remain at home only if changes are made to the structure of the home to assure that the children are safe. These changes also allow the families to care for the children and provide a better quality of life for them. The budget of the specific waiver program must be evaluated to be sure that the adaptations fit into the budget accordingly. Vehicle modifications are also available to families. Once again, the budget must be considered. The parents must purchase the vehicle and the CAH Waiver pays for the adaptations. There are guidelines for modifying a vehicle and home that must be followed. It is important for families to discuss these needs with a service coordinator to be sure they are following the procedures. Some examples of adaptations that can be made are the purchase of a backup generator for needed medical equipment, installation of wheelchair ramps, widening of wheelchair ramps and bathroom renovations.

There is also a respite component to the CAH Waiver Program. Respite can be provided in the home

by a nurse or health care professional. These caregivers will care for the child while family members are out. This support gives family members a break from the challenges of caring for a child with disabilities. Children may also be cared for on a short-term basis in a hospital or skilled nursing facility. Usually the service coordinator will work the additional care needs into the child's care plan.

Nursing services are probably the most needed support service and may be the most difficult to access. This is due in part to the shortage of nurses available. Nursing services can be provided by different level professionals according to the child's needs. LPNs, RNs and agencies can provide the appropriate care depending on the needs of the child. When speaking with families of children served under the CAH program, one hears that the biggest problem is finding nurses to fill the hours. It becomes difficult to locate nurses who are available at odd hours such as weekends and holidays. Many families take ads in newspapers or use word of mouth to find nurses.

It is also important to remember that CAH should generally not be a substitute if private insurance is available for the child. Medicaid is always the payor of last resort and if possible should act as a supplemental insurance policy if families can access private insurance coverage. A family may still apply for CAH Medicaid for a child even if they have private insurance. Many families have private health coverage but often there is not sufficient coverage to pay all the costs of keeping a medically fragile child at home. Many times, Medicaid will pick up costs that insurance does not. At times, private insurance will pick up a portion of the cost of nursing coverage but Medicaid is needed to provide the additional hours that are needed to keep a child safe at home. Caring for a child with severe disabilities can be physically and emotionally challenging.

The application process is also not as complicated as one might think. The CAH coordinator obtains all the necessary medical and financial information about the child. The first step is for the child to be "Medicaid eligible." The child must be ineligible for Medicaid when the parental income and resources are considered and the child must be eligible for Medicaid using only income and resources belonging to the child. There is usually a home health assessment done. An agency usually visits the home to determine the needs of the child and assess whether the child can be managed at home. The Service Coordinator develops a care plan and lists all the services needed to keep the child at home including medical equipment and any other supports that need to be in place. The care plan usually lists how many hours of nursing are required and how often the services will be provided. The plan will include the names of all the service agencies and / or

providers that are available to the families. The Service Coordinator will also monitor the budget developed for the child to be sure that it is cost effective. All of the CAH programs have budget caps which are based on the type of care the child needs. It is also important that the child's physician provide documentation that reflects the medical necessity of the services listed on the care plan developed. It is important that the family review the Plan of Care carefully to make sure that the child's needs will be met.

Once an approval is received from New York State, the case manager usually meets with the family and reviews how the program is administered. The case manager should discuss the recertification process and the eligibility requirements to be sure that the family maintains the child's eligibility. Of course, it is important that the child maintain limited assets for the purpose of maintaining eligibility. Many times problems occur when the child is deemed eligible for CAH and subsequently receives a medical malpractice settlement. It is very important for the practitioner to consider establishing a Special Needs Trust for the purpose of protecting the government benefits.

It is also important to remember that a child can only be enrolled in one waiver at a time. However, if the child's needs change, a service coordinator should consider whether the child would be better served on a different program. It is also important to remember that CAH generally will not pay for private nursing care while a child is hospitalized. Twenty-four-hour nursing care is also not generally available.

This particular waiver also ends upon the child's 18th birthday. At least six months before the child turns 18, the case manager and the local social service agency should begin to transition the child out of the CAH program. At that time, the family should consider applying for Supplemental Security Income-related

Medicaid. Eligibility of course will depend on meeting both disability and financial criteria.

It is also important to remember that if a family has a problem with any determinations under the CAH program, the right to a fair hearing is available as with other Medicaid programs.

Each family's needs are very different. It is important to speak with the local department of social services about what program is correct for a family's needs.

This is a very unique and important program for families of children with severe disabilities. Parents who utilize the program are thankful that it is available. Parents must remember that once the child is enrolled in the program, there are frequent visits from outside agencies and caregivers in the home on a regular basis. This may be somewhat intrusive for some families but the benefit is that children remain in a warm, safe, loving environment where their families can provide a good quality of life for the child and entire family.

For more information on the Care at Home Waiver, families can call the New York State Department of Health or their local Department of Social Services.

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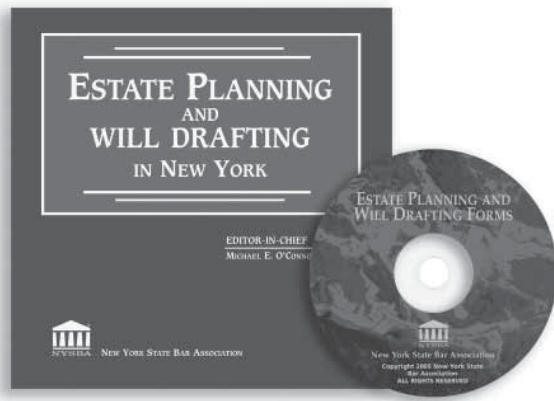
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