

Elder and Special Needs Law Journal

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

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Message from the Chair

“It is not the strongest of the species that survives, nor the most intelligent, but the one most responsive to change.”



The above quote is often attributed to Charles Darwin. Whether this is an accurate quotation, or merely a paraphrase, isn't so important, as is the fact that it seems to be an accurate statement relating to all forms of life.

This quote comes to mind as I look back over my years in the practice of Elder Law, particularly the last six. This area of practice is

constantly in a state of flux. Every time you pick up the kaleidoscope there is a different picture. Over those six years, we have had to adapt to four major changes: the Deficit Reduction Act, two revisions of the statutes governing Powers of Attorney, and, most recently, the issuance of Emergency Regulations concerning Medicaid Estate Definition. Just as we were completing our adjustment to earlier changes, we now have been subjected to dramatic changes regarding both Estate Recovery, and the less publicized changes relating to home care and newly required Managed Care Programs. Since we have so much change imposed upon us, we had better be able to respond and adapt, if we expect to survive.

This is where the role of our Section takes on such importance. It has made a concentrated effort to keep its members up-to-date on these changes, and to provide educational forums to help us all better understand and respond appropriately to those changes, including CLE programs, a dynamic Listserve, quarterly meetings, Webinars and Webcasts.

Section Highlights

Fall Meeting. The historic Fall Meeting in Buffalo, jointly held with the Trusts and Estates Law Section, was extremely successful, and very well attended. There are so many overlapping practice issues that the substantive programs produced a real synergy benefiting both Sections. My thanks and admiration for the exceptional effort put forth by **Laurie Menzies** of the Elder Law Section and **Victoria D'Angelo** of the Trusts and Estates Law Section to make the event the success it was; and a special commendation to **Steve Silverberg** who did a masterful job pinch hitting for a presenter on a little over 24 hours notice.

The utilization of the Round Table format provided for lively and informative interaction, and the Program

presenters covered important issues, such as the new regulations and ADM, updates, and planning strategies for both sections.

Kathy Heider and Lisa Bataille did a marvelous job coordinating all the arrangements, Section meetings, and agendas, with the able assistance of Lori Nicoll. I have no idea how they were able to keep it all straight and on track.

Enhanced Estate Recovery Regulations. The long-awaited and much maligned Emergency Regulations arrived on our doorstep September 8. These regulations have created a “sea change” in the practice of Elder Law, and several other areas of practice, such as T&E and Real Estate. There is a serious issue of unfairness in its retroactivity as applied to life estates. Legitimate estate and asset preservation planning techniques when implemented are now deemed available to recovery.

The regulations also present serious legal issues that will produce a logjam of litigation across the state. In order to bring some uniformity to our approach in defending and challenging these regulations, I have appointed an **Estate Litigation Task Force**, Co-Chaired by **David Goldfarb** and **Rene Reixach**, with members **Aytan Bellin**, **Ira Salzman**, and **Lou Pierro**. They will be available to share and coordinate the most recent and successful approaches to assisting our clients.

The Legislation Committee, Co-Chaired by **Amy O'Connor** and **David Goldfarb**, has been extremely active conducting a continuous effort to modify, if not repeal, these regulations by meeting with and lobbying the executive and political machinery.

Jeannette Grabie was inspired to write a letter to her state senator about the fallout from these regulations. The letter was well received, and started a groundswell of letter writing and other activities. At the time of this writing, it appears that the Senate will be holding hearings, at which we hope to present, and further, that the Senate will be sending a letter to the Governor expressing a willingness to revisit this issue. This sequence of events confirms what I've always known: never stand between a woman and her objective.

Webcast. The Section conducted a Webcast utilizing the exceptional talents of **David Goldfarb**, **Anthony Enea** and **Lou Pierro**, together with a pretty good moderator, to present the “known, knowns” and the “known, unknowns” of the new Estate Recovery Regulations. Aside from some technical difficulties, it was very successful. The materials themselves were worth the price of admission. I realize that the entire

“landscape” of estate recovery may change by the time you read this, but the Webcast will remain available on the Bar website for at least six (6) months from the date of its presentation.

Mentoring Committee. **Joan Robert** and **Tim Caserly** are Co-Chairing this committee with the assistance of **Anne Dello-Iacona**. It is always difficult to create and implement a new program, but they have done a masterful job. Practicing in the constantly churning waters of Elder Law is daunting enough as it is, but is even more so for the newly initiated. This program will provide a reassuring resource in the form of a Mentor to guide the beginning Mentee with 5 years or less enrollment in the Section. If you have the experience, please consider signing up to serve as a Mentor. Many of us serve in an ad hoc mentoring role now, but this will provide a structure and mechanism for matching up the inexperienced with the more experienced. Maybe this program should be called MentorMatch.Com.

Elder and Special Needs Law Journal: It is with great sadness, but with equally great appreciation for their accomplishments, that we have experienced the resignation of our Co-Editors of this *Journal*. **Andrea Lowenthal** and **David Okrent** have asked that they be allowed to pass the baton to a new team of Co-Editors. After putting out a request at the last Executive Committee meeting and reviewing the applications, I have appointed **Adrienne Arkontaky** and **David Kronenberg** as the new Co-Editors. Due to the fact that there is always an issue in development, this appointment required immediate attention, so Adrienne and David have had to take the reins quickly. Fortunately for all concerned, Andrea and David have agreed to remain in a mentoring role during the transition phase. This issue is the first fruits of that transition. Our very best wishes to Adrienne and David as they embark on their new adventure.

Andrea and David deserve our commendation and gratitude for a marvelous contribution to the *Journal* and our Section. They have done a great deal to continue to elevate the quality of the *Journal* and to make it the hallmark of our Section. They have accomplished this through their dedication, talent and sacrifice. The

Section and the publication have been greatly enhanced by their efforts, and we are extremely grateful for their contribution. At the same time we are reassured that Adrienne and David are the right team to build on the great tradition of this *Journal*.

Ethics Committee: This committee, chaired by **Judith Raskin** with **Vice-Chair Natalie Kaplan**, has developed a very creative way to help us focus on the ethical issues we frequently encounter. They utilize a survey format to present a fact situation with questions for us to answer regarding the appropriate response to the issues presented. Thereafter, we find out the correct answer. The approach is fun, challenging, and instructive, so please participate.

Another way to participate is to provide Judy and Natalie with issues you have faced in your practice. They will then build a scenario for presentation, so we can all participate in your challenge. It was interesting to hear Judy report at the Fall Executive Committee meeting that the opinions of the New York State Ethics Board are rarely unanimous. So don't fret if you're unsure about the correct answer, or if your response differs from the reported “correct” answer.

Our thanks to Judy and Natalie for this creative approach to assist us in fine-tuning our sensitivity to the ethical dilemmas present in our practice.

Conclusion

My thanks to all of our dedicated officers and members of the Executive Committee for their efforts in serving the Section and its membership. They do so much in developing the programs that help to keep us current regarding recent developments in our area of practice. It is through their efforts that we are able to continually adapt and be “responsive to change.” Let me leave you with what might be called our Section Beatitude:

“Blessed be the flexible, for they shall never get bent out of shape.”

T. David Stapleton

Message from the “Newly Appointed” Co-Editors in Chief



After getting over the initial exhilaration of being appointed co-editors, we realized that with this extraordinary opportunity comes incredible responsibility. After our appointment, we decided to immediately meet to discuss how we would “conduct business” and produce a publication dedicated to providing both our new and experienced

colleagues with interesting, important, and timely articles relevant to the practice of Elder Law and Special Needs Planning.

Bracing ourselves for the task at hand, we knew there would be many challenges. What would those challenges entail? Well, the first challenge we encountered was to simply follow in the footsteps of the prior co-editors in chief, David Okrent and Andrea Lowenthal. Together, Andrea and David produced an amazing *Journal* read and respected by the entire Elder Law Section. Under their leadership, the design of the *Journal* was revamped, the title was changed to reflect the true spirit and practice of elder law and special needs planning, and articles were obtained from a vast number of professions, capturing a number of different issues.

We hope to build upon their efforts, mindful of the fact that our predecessors, along with the Chair of our Section, T. David Stapleton, believed enough in our capabilities to bestow upon us the title of “Co-Editors in Chief.” We thank them for this opportunity, and pledge to provide our readers with a valuable resource that we hope will prove useful, thought provoking and appealing. So here we go...

This Winter 2012 issue is devoted to several issues that are important within the area of special needs planning and advocacy. Whether you are raising a child with special needs, caring for a loved one with disabilities, or advocating for the rights of a disabled individual, it is extremely important for practitioners to be aware of the many challenges that exist. We believe that it is enormously important to use a holistic approach when it comes to planning.

If we are truly advocates, then we must analyze *all* of the needs of the client, and make suggestions accordingly. If a family has a child with special needs, perhaps we should ask whether the child is receiving special education services, or if the child is a recipient

of services from the Office of Persons with Developmental Disabilities (OPWDD)? It is imperative that practitioners planning for a child with a disability approaching 18 years of age question whether the child needs a supplemental needs trust (SNT), and/or a transition plan to facilitate his or her future endeavors. Perhaps individuals request information on the process of purchasing a home with guardianship or SNT funds. Knowledge of what to do if you are the trustee of an irrevocable trust is vital; whether it pertains to a reverse mortgage or creative ways to increase an income, we as practitioners should be familiar with a range of topics and concerns.

In addition, we must look at situations where, despite our best advocacy efforts, an individual with a disability is denied needed benefits and services, or perhaps nursing home care. If it is necessary to appeal the decision through a fair hearing, how does a practitioner prepare? What's more, since many practitioners assist clients in exploring various government benefits, from prescription drug coverage to financial eligibility and pooled trusts, it is important for practitioners to make appropriate recommendations. For example, the use of pooled trusts is growing, and thus we must obtain up-to-date information on how they are utilized. And, as more and more persons with disabilities are exploring employment options that permit individuals to retain their government benefits, programs like the Ticket to Work program, through the Social Security Administration, are becoming more popular.

It is by being well versed in the above topics that we as practitioners are able to better assist an individual with a disability gain independence and self confidence, thereby increasing his or her quality of life. Cover to cover, this edition provides information needed to help you make appropriate recommendations and advocate more zealously on the issues raised above, adding to your Special Needs Planning arsenal.

We must not forget that life beyond Special Needs Planning does exist. So, in other news, and as this issue goes to press, we face expanded estate recovery and the mandatory enrollment of individuals who receive personal care and other community-based long-term services in Managed Long Term Care (MLTC). Advocates, including leading members of our Section, have been working to try to slow down the implementation of



these changes. Regarding estate recovery, we include in this issue a Memorandum from the Legislation Committee on the proposed regulation. Regarding the mandatory transition to MLTC, we include a recent letter from a group of advocates to the Centers for Medicare & Medicaid Services, which highlights major concerns with this plan. We owe a debt of gratitude to all of these individuals and organizations for their amazing work.

Additionally, with Recent New York Cases, Advance Directive News, and our E-News Submission, we are keeping you updated on what is happening in the courts and in our practices.

In closing, we are very thankful to all of the authors for their submissions. We recognize the commitment of time and energy that it takes to write. Also, we are

thankful to our editorial board, production editors and student editors who volunteered their time. In the short time since our appointment, it has become evident that Andrea and David, along with other past editors, chose an incredibly talented group of professionals who value the integrity and recognize the importance of this publication. Our commitment to the Elder Law Section, our readers, the editorial board, and staff, is to work hard, listen to your suggestions, and produce a publication everyone will be excited to read.

Dave Stapleton, David Okrent and Andrea Lowenthal, we thank you for your confidence and we are truly honored to be a part of this effort.

Good reading!

David and Adrienne

NYSBA Guidelines for Obtaining MCLE Credit for Writing

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

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

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

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

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

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

Court Evaluator Creativity in the Distribution of Justice: Providing a Voice to the Voiceless

By Andrea F. Blau



In Article 81 guardianship proceedings, the appointment of a Court Evaluator (CE) is mandatory.¹ Courts select CEs from lists maintained by the Office of Court Administration (OCA).² Nearly anyone who has attended the requisite live or self-study certification program³ may apply for appointment (UCS-870R), pursuant to Part 36 of the Rules of the Chief Judge.

Applications for appointment are renewable every two years from the date of eligibility. Currently, no additional training is required.

"Our esteemed colleague, Robert Kruger, has been quite outspoken about the critical role the CE plays in the guardianship appointment process, noting the importance of experienced CEs, especially in difficult cases."

The qualifications of the certified CE, as noted in MHL §81.09(b)(1), are rather broad:

[T]he court may appoint as court evaluator **any person** including, but not limited to, the mental hygiene legal service in the judicial department where the person resides, a not-for-profit corporation, an attorney-at-law, physician, psychologist, accountant, social worker, or nurse, **with knowledge of** property management, personal care skills, the problems associated with disabilities, and the private and public resources available for the type of limitations the person is alleged to have...

Each court or chambers has its own protocol for selecting names from its county's eligibility lists, the only "official" criteria concern disqualifications due to the Part 36 income cap rules or conflicts of interest. For example, Mental Hygiene Legal Services (MHLS) is ineligible to serve as Court Evaluator if MHLS is also representing the Alleged Incapacitated Person (AIP) as counsel.⁴ Our esteemed colleague, Robert Kruger,

has been quite outspoken about the critical role the CE plays in the guardianship appointment process,⁵ noting the importance of experienced CEs, especially in difficult cases. Indeed, finding the right "match" may make a significant impact on the proceeding's outcome.

The role of a well-chosen CE is especially important in the "dual Part" cases. In June 2008, the authority of the Supreme Court over Article 81 proceedings under the Mental Hygiene Law (MHL) was combined with that of the Housing Court, creating a special "dual Part," affording one court, and therefore, one judge, jurisdiction over eviction proceedings involving tenants for whom guardianship petitions had also been filed.⁶ The reported actual outcome of this integrated Part has a remarkably efficient handling of hundreds of integrated cases involving extremely vulnerable tenants, many of whom are elderly or have mental and/or physical disabilities.

Judge Shlomo Hagler, who currently presides over the above integrated Part in New York County, notes the following:

In each case, the court appoints both counsel for the alleged incapacitated person and an **appropriate** court evaluator (otherwise called **the eyes and ears of the court**) to **investigate** and **report** his or her findings on whether a guardian is appropriate and to identify **and address** any underlying problems.⁷

The role of the CE in this innovative Part is therefore extremely important, and potentially quite powerful. The appointment of an experienced or skilled CE can translate into effective legal outcomes for both tenant AIPs and their landlords.⁸ To illustrate this point, three very brief examples of "unique solutions to real problems"⁹ as promoted within this Part, follow.

Case One involved eviction and guardianship petitions for two AIPs, an elderly mother and her 55-year-old daughter, both with mental and physical disabilities, living in a small walk up apartment subsidized and managed by a not-for-profit corporation. The mother and daughter were unable to work, had lived together for decades, rarely left the apartment except for food shopping, and were extremely codependent. Due to their "Colliers brothers" hoarding behavior and paranoia, they refused to allow entry for inspection, and subsequently failed their Section 8 recertification. Their rent rose from an affordable \$340 to nearly \$1200 per month, and after two years of arrears they faced imminent eviction. Human Resource Administration

(HRA) filed petitions for guardianship for both the mother and daughter based on the recommendations of Adult Protective Services (APS). Simultaneously, TROs staying the evictions were filed, and the cases were assigned to the dual Part.

At the time the CE was assigned, the AIPs were no longer willing to speak to their APS caseworker, and rejected his attempts to assist them in relocating. Additionally, the psychiatrist from HRA who had assessed them recommended separating them, placing the mother in a nursing home, due to what was perceived as destructive codependency. The end result was an increase in paranoia by the AIPs. When they were served notice of their guardianship petitions with the “laundry list” of all encompassing guardianship powers being requested,¹⁰ as the list by HRA is not typically tailored to the individuals being served, they dug in their heels even further.

The CE appointed to this case was a veteran clinician and attorney who had been customizing intervention programs for individuals with complex disabilities for decades. The CE communicated with both the APS case worker and the assigned counsel from MHLS to coordinate a plan. While the AIPs did not possess a phone, the CE was able to contact them via their neighbor, whom they trusted, and arranged for a home visit. Due to her clinical skills, the CE was able to successfully gain entry into the AIPs’ home to both inspect the premises and interview them. She noted that the apartment, while in need of deep cleaning, was not a hazard and could indeed pass a Section 8 inspection for recertification once entry was allowed. Additionally, while the mother and daughter were clearly codependent, they appeared no more mutually reliant than many elderly couples who had been together for 55 years, as they had indeed been together since the daughter’s birth. In their own way, they took care of one another and, if separated, it seemed unlikely either would thrive. Once inside the apartment, the CE was able to better assess the AIPs’ functional skills, as well as review the guardianship petition with the AIPs and explain their rights to them. Prior to the CE’s visit, they had been aware of the eviction proceedings but were unable to distinguish between the eviction and the guardianship proceedings and felt extremely vulnerable. By the end of the interview, the AIPs agreed to meet with their assigned counsel and attend their scheduled Article 81 hearing. While rejecting their case worker’s offer to pick them up and bring them to the Court, they did indeed appear, insisting on sitting near the CE as well as their MHLS counsel, who had subsequently also gained their trust. At the hearing, the AIPs each agreed to the appointment of a guardian with limited, specific powers to assist them, but without dramatically changing their independence or lifestyles. The guardian was not given power to relocate the AIPs without further petition to the Court. The landlord was content with the AIPs remaining in their

apartment pending their successful Section 8 recertification, which was ultimately obtained—a successful outcome for all parties.

Case Two, while having a less “storybook” happy ending, also demonstrates the creative ways a CE might be used in addressing underlying problems in difficult Article 81 cases. The AIP was a 37-year-old man living in a lovely studio in Manhattan. Although his employment history was extremely erratic, at the time he had signed his lease he was employed in his family’s business and was able to pay his rent. However, as his mental disabilities were not being treated, his Borderline Personality Disorder, Post Traumatic Stress Disorder (PTSD), Attention Deficit Hyperactivity Disorder (ADHD), and lifelong marginal functionality ultimately resulted in his loss of both employment and the good graces of his family, who refused to continue to assist him financially. APS stepped in when he was faced with eviction, owing over \$70,000 in rent arrears. As he appeared incapable of making any plans for relocating, HRA filed a petition for guardianship, along with a TRO staying his eviction until the Article 81 preceding was resolved. The case was summarily assigned to Judge Hagler’s dual Part.

In addition to interviewing the AIP, the appointed CE interviewed the various members of the AIP’s family. A suggestion was put forward in which some type of accommodation might be made to assist the AIP in paying back an acceptable portion of the arrears in a compromise settlement with the landlord, after which the AIP’s rental would be significantly reduced, as 20% of the building was, in fact, subsidized. However, while the family did have the financial means to assist the AIP, the parents were long divorced and combative, and the family dynamics between the AIP, his father, and his brothers, in combination with the AIP’s long history of self-destructive behaviors, made it very difficult for the family to come together to support the AIP in any constructive manner. A range of alternatives to a city-based agency guardianship was proposed by the court at several status conferences, but the family was unable to reach an agreement. As a result, a city agency was ultimately assigned the commission to assist the AIP in relocating.

The CE was successful, however, in helping the AIP deal with an important underlying problem. The AIP had refused to take medication for his psychiatric disorder because he had suffered an extreme reaction to Ativan, which greatly reduced his ability to function. Various psychiatrists whom he had seen believed that without medication, he would not regain the stability he needed to function independently. The CE discovered, when interviewing the psychiatrist who had most recently evaluated the AIP, that the AIP was an excellent candidate for a new behavioral approach toward treatment, Dialectical Behavioral Therapy, which might result in his gaining functional independence without

medication. This option was highlighted in the CE's, report which was then transmitted to the agency commissioned to assist the AIP.

Case Three is truly an example of providing a voice for the voiceless, as the title of this article suggests. The AIP was a 75-year-old woman who, at the time the case reached Judge Hagler's chambers, was receiving palliative care, and her ability to communicate had been severely compromised. She had been living in a two-bedroom, rent controlled apartment for thirty-five years until her recent hospitalization, with the hopes of returning to her home. She had a two year history, however, of significant physical and mental deterioration due to Multiple Infarct Dementia as well as Traumatic Brain Injury following a fall. She was divorced with two adult daughters who were raised in the apartment. The younger of the two returned to their "family home" three years prior to the Article 81 petition.

The reason this case landed in the dual Part was because of a holdover petition filed by the management of the AIP's rent controlled apartment. Due to the AIP's deterioration and increased hospitalizations over a two-year period, the management refrained from signing the AIP's standard lease renewal, stating that she was no longer a full-time resident. They additionally claimed that her daughter who was living in the apartment had no legal right to remain in the rent controlled apartment. The two petitions, the holdover and Article 81, were assigned to the dual Part with the holdover action placed off calendar while the guardianship petition was heard.

The AIP was in a semi-conscious state when the appointed CE went to visit her in the hospital, as she had deteriorated since the Article 81 filing. Judge Hagler's Principal Court Attorney, Aaron Hauptman, who selected the CE for this and the above cases, clearly has the expertise in matching Court Evaluators with AIPs. In point of fact, had a different CE been appointed without the extensive clinical experience of working with severely communicatively impaired people, it is highly unlikely that the AIP's interview would have revealed anything beyond verifying the AIP's inability to manage her own affairs or attend the court proceedings. However, the CE was able to successfully ascertain by interview with the AIP and her elder daughter that while the AIP hoped to return to her apartment, she realized it was unlikely. What was additionally revealed, which was most poignant, was that the AIP was simply "holding on" to life so that she could be assured that her younger daughter would not be unfairly evicted from her home. As there was no challenge as to the need for a guardianship or the suitability of the elder daughter to serve, the guardianship petition was quickly granted. When the AIP passed away a few months later, it was with the comfort of knowing that her "voice" was indeed heard and that the subsequent

holdover proceeding would remain with Judge Hagler and be dealt with fairly.

"[H]ad a different CE been appointed without the extensive clinical experience of working with severely communicatively impaired people, it is highly unlikely that the AIP's interview would have revealed anything beyond verifying the AIP's inability to manage her own affairs or attend the court proceedings."

Endnotes

1. M.H.L. § 81.09(a) ("At the time of the issuance of the order to show cause, the court shall appoint a court evaluator."). In practice, courts sometimes appoint Mental Hygiene Legal Services as counsel to the alleged incapacitated person in lieu of appointing a court evaluator.
2. M.H.L. § 81.09(b)(1) ("...the name of the court evaluator shall be drawn from a list maintained by the office of court administration").
3. M.H.L. § 81.40(b).
4. M.H.L. § 81.09(b)(2).
5. Robert Kruger, *Guardianship News: Court Evaluator's Redux*, ELDER L. ATTY. Vol. 20, No. 3, 45-46, Summer 2010.
6. Shlomo Hagler, *Innovative Part Integrates Guardianship and Housing Matters*, N.Y.L.J., Wed., June 22, 2011, at 4, 9.
7. *Id.* at 4.
8. Andrea Blau, *The Interplay between Legal Policy and Clinical Practice*, TRANSLATIONAL SLP-A: ESSAYS IN HONOR OF SADNAND SINGH 13, (2012).
9. *See supra* note 5 at 9.
10. HRA traditionally lists an all-inclusive range of recommended powers in its guardianship petitions, leaving the narrowing and tailoring of these powers to the AIP's counsel to design with their clients to present at the Article 81 Hearing.

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Can the Trustee of an Irrevocable Trust Obtain a Reverse Mortgage?

By Wayne R. Bodow



Reverse mortgage (HECM) law originates from federal statutes and regulations.¹ Without the preemption clause included in these statutes the uniform lien priority would fail.² The authority for HUD to allow an irrevocable trust to hold a reverse mortgage comes from the *Mortgagee Approval Handbook 2060.1 REV-2*,³ published by HUD (*Handbook*). The most im-

portant source is the mortgagee letters issued by HUD⁴ (letter(s)), which detail the substantive requirements. The mortgagee letters are searchable. The controlling letter, 93-22, published July 19, 1993 details the insurance and underwriting requirements and establishes the specific guidelines related to trusts that hold a reverse mortgage. This letter clarifies that inter vivos trusts, also known as living trusts, are eligible. Perhaps this letter was issued to verify that the reference in the *Handbook* does not limit acceptance for reverse mortgage funding only to the irrevocable trust.⁵ Nevertheless, it is this letter that defines the qualifications for both revocable and irrevocable trusts that will hold a reverse mortgage. The underwriting conditions derived from the *Handbook* and letters established by MetLife Home Loans (MLHL) are:

1. A natural person must establish the trust by a written document during the lifetime of the individual establishing the trust, to be effective during his or her lifetime. It may be established solely by one individual or jointly by more than one individual.
2. All current beneficiaries of the trust must be "eligible HECM borrowers" and meet the minimum age requirements for eligible borrowers (age 62) from the time of closing until the mortgage is released (i.e. borrower/current beneficiary must occupy the property as a principal residence and new beneficiaries may not be added to the trust). Contingent or successor beneficiaries receiving no benefit from the trust without possessing any control over the trust assets until the beneficiary is deceased need not meet eligibility requirements.
3. The trust document must name one or more trustee(s) to hold legal title to manage the property that has been placed in trust.

4. The trustee(s) must have the power to encumber the subject property for the purpose of securing the loan for the party or parties who are the "borrower(s)" under the note.
5. The lender must be satisfied that the trust is valid and enforceable, providing the lender with a reasonable means to assure it is notified of any subsequent change of occupancy or transfer of a beneficial interest. The trust must ensure each borrower/current beneficiary has the legal right to occupy the property for the remainder of his or her life.
6. If title is to be held in a trust, the full title to the secured property must be vested in the trust. There may be no other owners. The title insurance policy must assure full title protection to the lender and must state that title to the secured property is vested in the trustee(s). It should be noted, Texas properties are ineligible.
7. Each trustee (in all instances) must separately execute the Note, Truth-in-Lending, Right to Cancel, HUD-1, the Security Instrument and any applicable riders necessary to create a valid first mortgage lien under state law. *Note:* Trustee(s) are specifically prohibited from signing the *Loan Agreement*.
8. Each borrower/current beneficiary/grantor must sign all documents including the Note, Security Instrument and any applicable riders necessary to create a valid first mortgage lien under state law.
9. The trust must be one in which the individual establishing the trust has reserved, to himself or herself, the right to revoke the trust during his or her lifetime.

Note: Irrevocable trusts are eligible on an exception basis only. The standards 1-8 above apply to irrevocable trusts. The irrevocable trust documents must be submitted to an MLHL-approved trust review attorney for preliminary review. If the irrevocable trust does not allow for principal distribution, secondary approval is required by MLHL legal counsel. The purpose of the attorney review is to ensure that the trust is valid, complies with the laws of the state in which the property is located, and that the trustee(s) can legally enter into the transaction and meet HUD guidelines.⁶ An attorney opinion letter and trust review letter must be provided to the lender prior to the closing documents being drawn. The title company must issue the Trust Mortgage Endorsement. The cost of the trust review

cannot be charged to the borrower. The HUD-1 must reflect POC by MLHL. MLHL does not charge any fees for reviewing a trust document or for providing an attorney opinion letter.⁷ The mortgage commitment letter given to the trustee(s) of an irrevocable trust requires that any funds received be deposited into a segregated account controlled exclusively by the trustee(s).

As part of Medicaid planning, most attorneys are using an irrevocable sprinkle trust with income-only distributions to the borrower/current beneficiary/grantor(s). This trust document should include language that specifically gives the irrevocable right of the borrower/current beneficiary/grantor(s) to reside in the property as his or her principal residence during his or her lifetime and include specific powers to enable the trustee(s) to mortgage the real property held in the trust. Additionally, the borrower/current beneficiary/grantor(s) must have either a right to receive income or principal from the trust. However, if the borrower/current beneficiary/grantor(s) has no lifetime use of the property specified within the terms of an existing trust the alternative without modification of the trust would be to record a deeded life estate, remainder to the trust; or modify the trust by following the principles detailed under the NYS Decanting Statute and EPTL 10-6.6(b). Creative discretionary distribution of income remains a gray area for analysis. But as the drafter of a new trust you have the option of a free eligibility review of your work product from MLHL, wherein suggestions can be made (if necessary) to enable the trust to be eligible for reverse mortgage funding. Because the document must be read in its entirety, I was not able to obtain pre-approval for the following creative language:

(Borrower/current beneficiary/grantors) give discretion to the trustee to distribute income to (borrower/current beneficiary/grantors) from the reverse mortgage credit line provided that in the trustee's opinion that the distribution will not reduce the value of (borrower's/current beneficiary's/grantors') residence below the value as determined when the property was deeded to the trust. When it is clear that such distribution will not reduce the principal value below the value as determined at the time the property was deeded to the trust the trustee(s) shall be required to make a distribution to (borrower/current beneficiary/grantors) equal to the prior year's credit line growth accumulation.

Approval of a pre-formatted irrevocable trust document should not be assumed. There is no tribunal available to interpret documents. To my knowledge, MLHL is the only lender that submits an irrevocable trust to HUD seeking insurance approval underwriting. Before

reaching the submission stage, the application must first pass MLHL's scrutiny. The administrators look only at the clear language and the supporting documents to stamp approval. The Handbook authorizes that the trustee of an irrevocable trust may obtain a reverse mortgage to encumber the borrower's/current beneficiary's/grantor(s)' principal residence but there are no substantive specific "letters" detailing the approval process for the eligibility of an irrevocable trust to hold the reverse mortgage. Clarity should prevail. But pre-approval does not guarantee that a new "letter" will again change the landscape.

Are the distributions of funds from the reverse mortgage considered income or principal distributions? This is a fact-intensive analysis and was the subject of my presentation at the 2011 NYSBA Elder Law Section meeting held in Manchester, Vermont. The key to this analysis is to carefully review the amortization schedule that is part of the reverse mortgage application and closing documents. A line of credit option is a unique feature of a reverse mortgage in that the credit line is guaranteed to grow at the same rate as the loan. Drawing out the credit line growth generally leaves the principal value of the home unaffected. Yet, for taxation purposes, the funds received are considered return of principal and result in no taxation to the estate. A trust may hold assets that generate non-taxable "income."

A compelling argument that distributions from a reverse mortgage are income-only distributions occurs if the home value that can be realized from sale is equal or greater than the appraised value of the residence when the deed transfer to the trust occurred. The assumptions made to compile the amortization schedule enable a guided conservative withdrawal of funds from the reverse mortgage. The assumptions include two variable factors: 1) the growth rate of the line of credit which is equal to a variable interest rate of the loan; and 2) the real property appreciation rate. Also, the trustee will be guided by the receipt of a detailed monthly statement showing the loan balance and availability of funds. Assuming the property was free and clear, and the only sums financed are the closing costs, the credit line value will exceed the starting point value of the home in one year. The credit line growth is not tied to the changing value of the property and therefore is analogous to a "put" in the stock market, guaranteeing the value of the property, if the funds are drawn before the reverse mortgage becomes due and payable.⁸

Conclusion

When the trustee is guided to immediately obtain a reverse mortgage at the creation of the trust using the new "Saver" no load option,⁹ the clients' objectives are generally enhanced. The results are potential release of trapped equity (that will be received tax free), the establishment of an emergency source of funds and potentially an increased wealth transfer to the next

generation realized by the guaranteed growth in the line of credit. Today's reverse mortgage offers numerous options. In general, the more equity that is tapped, the higher the cost of the loan. Conversely, the lower equity tap results in a lower cost loan.¹⁰ The irrevocable trust was designed to protect assets with guided long term planning. The new options now available with reverse mortgage products should be evaluated at the initial planning stages to determine if, together with the irrevocable trust, the client's objectives will be better served. Finally, an existing trust can always be amended to meet the HUD guidelines through the use of the NYS Decanting Statute.

Endnotes

1. The legislative history on the origins of reverse mortgages can be found in *The Housing and Community Development Act of 1987* (P.L. 100-242, 1/2/88). See 12 U.S.C. 1715z-20 et al. (2002); 24 CFR 206 et al. (2011).
2. 24 CFR § 206.8. (2011). "(a) Lien priority. The full amount secured by the mortgage shall have the same priority over any other liens on the property as if the full amount had been disbursed on the date the initial disbursement was made, regardless of the actual date of any disbursement. The amount secured by the mortgage shall include all direct payments by the mortgagee to the mortgagor for any purpose including loan advances permitted by the mortgage for interest, taxes and servicing charges and costs of collection, regardless of when made. The priority provided by this section shall apply notwithstanding any State constitution, law or regulation. Second mortgage. If the Secretary holds a second mortgage, it shall have a priority subordinate only to the first mortgage (and senior liens permitted by paragraph (a) of this section.)" *Id.*
3. HUD HANDBOOK, <http://www.hud.gov/offices/adm/hudclips/handbooks/hshg/4060.1/index.cfm>. See Page 98 of this Handbook in release 7610.1 (05/2010) ("Properties held in

trust...[do] not require a trust to be irrevocable for the property to be eligible for a HECM.").

4. HUD HANDBOOK, <http://www.hud.gov/adm/hudclips/letters/mortgagee/files>.
5. See HUD HANDBOOK, *supra* note 3.
6. 24 CFR § 206.45 (2011). "Eligible properties (a) Title. A mortgage must be on real estate held in fee simple, or on a leasehold under a lease for not less than 99 years which is renewable, or under a lease having a remaining period of not less than 50 years beyond the date of the 100th birthday of the youngest mortgagor." *Id.*
7. All referrals for attorney opinion letters will be sent to MLHL approved attorneys. There will be no charge for the opinion letter issued. Please email your trusts to wbodow@metlife.com or fax to 1-518-953-1545.
8. See HUD HANDBOOK, *supra* note 3, at 154. "The loan becomes due and payable when the last surviving borrower: 1. Passes away; 2. The property is no longer the primary residence of the borrower; 3. The last surviving borrower has been unable to occupy the home for more than 12 consecutive months; 4. The borrower sells or otherwise transfers ownership of the property; or 5. The borrower fails to perform an obligation under the mortgage." *Id.*
9. Effective October 4, 2010, a HECM saver option became available, under which up-front costs were reduced through near-zero insurance premiums. Additionally, loans are now available without any mortgage origination or servicing fees. Program, rates, fees and terms and conditions are not available in all states and are subject to change. All loans are subject to property approval. Certain conditions and fees may apply.
10. The Saver option reduces the loan pay out by 10-18%.

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The NYSBA Family Health Care Decisions Act Information Center

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

www.nysba.org/fhcd

New York State's People First Waiver for Developmental Disabilities Services: Crafting a Plan for Delivering Comprehensive, Person-Centered Care¹

By Courtney Burke

The New York State Office for People With Developmental Disabilities (OPWDD) and the New York State Department of Health (DOH) have begun discussions with the Federal Centers for Medicare & Medicaid Services (CMS) regarding an 1115 research and demonstration waiver that will be called the "People First Waiver" (Waiver).² An 1115 Waiver³ provides states the opportunity to create and test service system improvements while retaining Federal Medicaid support for needed services to individuals.⁴ The Waiver will allow New York State to design significant programmatic, administrative, and fiscal improvements to its service system for people with developmental disabilities. These reforms are needed to support OPWDD's continued progress in providing community-based services for greater numbers of people, reducing the role of institutional care within the service system, and to support the development of a sustainable fiscal platform for long-term care services. In addition, the Waiver will allow New York State to make these service system changes while redesigning its Medicaid program to meet federal expectations and implementing provisions of the Federal Affordable Care Act.

The Waiver will eventually replace the existing 1915(c) waiver⁵ that currently supports the delivery of community-based services to approximately 70,000 individuals. The Waiver will ensure that New York's developmental disabilities service system is aligned with and functioning as smoothly as an important component of an integrated, reformed and comprehensive system of Medicaid-funded services.

A. Why the People First Waiver and Why Now?

1. Meeting More Complex Needs

The Waiver is the mechanism through which OPWDD can redesign its system to better meet the needs of individuals with developmental disabilities. In recent years, the percentage of people served by OPWDD who have two or more medical conditions has grown to more than 22 percent. Similarly, the number of people served who are diagnosed with autism



spectrum disorders (ASDs) has increased to more than 17 percent. Furthermore, over the past 20 years, the percentage of people receiving OPWDD services who have a psychiatric diagnosis and a developmental disability has almost doubled, from 16 percent in 1989 to more than 30 percent in 2010. Two other notable trends are that people with developmental disabilities are now living longer, and a greater percentage of individuals who receive OPWDD services have complex service needs. Hence, it has become clear that the needs this system is called upon to meet are much more complex than they were when the system was created.

"The Waiver will allow New York State to design significant programmatic, administrative, and fiscal improvements to its service system for people with developmental disabilities."

The Waiver will support development of a service menu that appropriately responds to these heightened complexities and a coordinated system for planning, delivering, and funding comprehensive care that responds to the full range of service needs of people with developmental disabilities. For the first time, New York State will be able to offer individuals "no wrong door" to all the Medicaid services they need, whether these are long-term supports and services (traditionally provided by the OPWDD system), mental health services, or acute health care services.

2. Meeting More Needs in Community Settings

The current service system's fiscal platform was developed to support the provision of care in institutional settings. In the years since its inception, OPWDD has successfully responded to the needs and desires of individuals and families, and transitioned the system to one focused primarily on supporting people in community settings. Today, OPWDD serves the vast majority of its service population in community settings. To continue this trend away from institutional services and toward a system that relies only minimally on institutional care to provide short-term preparation for living in community, OPWDD must develop new services that can meet higher levels of support and care in community settings.

As this programmatic system enhancement occurs, the new Waiver will also require a needed modernization of the service system's fiscal platform so that reimbursement rates no longer encourage the provision of institutional services, but instead support individuals to live, work, and grow in community settings with appropriate supports to meet their needs. The Waiver will correct the outdated institutional services foundation of the fiscal platform and allow New York State to create a modern infrastructure to deliver new levels of support in community settings.

3. Improving Cost Effectiveness by Targeting Service Needs

New York State's per capita Medicaid expenditures for people with developmental disabilities far exceed the national average and those of other comparable states. In 2007, New York State accounted for more than 20 percent of the total national Home and Community-Based Services Waiver⁶ expenditures. From 2005 to 2010, these expenditures in New York State grew at a rate of 6.2 percent, faster than the rate of inflation for the same period, which was 3.3 percent. This data reflects the fact that New York State provides a great deal of Medicaid-funded services to individuals with developmental disabilities and their families. However, in light of the increasing demands on the service system, this data also suggests the need to ensure that OPWDD's service system is operating with efficiency—that its service providers are delivering the most effective services at the level of care people truly need.

The Waiver will allow OPWDD to design new methods of assessing individuals' needs and using those assessments to allocate resources that will support more targeted service delivery. In turn, greater efficiency in our use of resources will be achieved. At the same time, the Waiver will support development of a new quality assurance and oversight system which will promote and reward excellence, while measuring success at both the individual and system levels. The Waiver will also incorporate quality management reforms that will transparently monitor agency performance related to both their effectiveness at meeting individuals' needs and fiscal accountability, thereby incentivizing cost efficiency and further ensuring the best, most appropriate use of Medicaid funding.

4. Establishing a Safety Net

New York State currently provides a wide range of safety net services through different state agencies: the Department of Health, the Office of Mental Health, the Office of Alcoholism and Substance Abuse Services and OPWDD. These services help people to remain in their home settings and receive services through commercial insurance without enrolling in the Medicaid program, thereby avoiding or delaying the need for more costly care. The Waiver will establish a safety net care pool

that will support "early touch." These are preventive services that can cost effectively meet people's needs, so that those needs do not grow and require more costly services such as hospital stays or emergency room visits later on. The Waiver will allow New York State to continue to offer these important services that support more desirable outcomes for people and allow the state to maximize the reach of its services.

B. Customizing Healthcare Reform to Support People with Developmental Disabilities

As New York State reforms its entire Medicaid program to achieve enhanced performance and cost-effectiveness, the Waiver assures focused attention to creating an infrastructure that aligns with the larger reforms and respects the unique needs of individuals with developmental disabilities. One critical and defining aspect of the Waiver is its focus on providing services only to individuals with developmental disabilities. This fact alone makes this 1115 waiver unique among the many 1115 waivers in existence in New York State and other states, and is important because of what it means for New Yorkers with developmental disabilities.

The OPWDD has a well-established partnership with the families and individuals it serves, and its service providers will directly inform and support the development of the many reforms that will be accomplished through this new Waiver. While the Waiver will result in coordinated comprehensive care, the new system, its services and their delivery will be developed, planned, and implemented by parties with a finely honed understanding of the needs of this population. This makes the Waiver a unique opportunity to ensure coordinated, high-quality care specifically for individuals with developmental disabilities and their families.

In particular, the Waiver design progress to date suggests that the transformation to a managed care model of service delivery and funding may result in managed care organizations known as Developmental Disability Individual Support and Care Coordination Organizations (DISCOs) with unique systems for delivering person-centered planning and services and measuring the effectiveness of their service providers, the DISCOs' own fiscal integrity and accountability, and their ongoing quality improvement. For each individual it serves, the DISCO would receive a monthly capitation payment based on an independently administered needs assessment tool and augmented by other adjustments. In turn, the DISCO is responsible for coordinating comprehensive services (long-term care, acute and specialty health care, behavioral health care, etc.) directly or through subcontracts with qualified providers. In addition, DISCOs will offer opportunities for self-direction, including opportunities for individuals to have budget and employer authority for their services.

The current thinking is that over time, the DISCO will assume full financial risk for meeting enrollee service needs within its capitation revenue. This new platform (as opposed to the current fee-for-service system) will encourage more flexible, person-centered service delivery as DISCOs work to identify and meet each individual's exact needs for support, while providing incentives for cost-efficient service delivery and care with greater customer satisfaction. Development of the DISCO model for service planning and delivery will be accompanied by prescriptive parameters that ensure adherence to the principles of providing individuals and families the ability to make informed choices, provide individualized needs-based service planning and equity of service access, and promote integrity, public transparency, and accountability.

"One of the largest tasks within development of the Waiver has been fulfilling OPWDD's commitment to a transparent and inclusive public process."

C. Waiver Design Process and Timeline

1. Working with Stakeholders to Initiate System Reform

The Waiver initiative began with New York State's submission of a concept paper to the Federal CMS in April 2011. Upon receiving a positive response from CMS, OPWDD, with the support of Governor Andrew Cuomo and other state agencies, launched a process of gathering public input that would inform development of the waiver and also a structured waiver design process rich with the voices of key stakeholders—individuals with developmental disabilities, family members, service provider agencies and agency associations, and outside experts in areas such as long-term care, behavioral health care, services for the aging, and home care.

In June 2011, a steering committee with this diverse representation chartered five separate design teams that worked throughout the summer to explore key design aspects of the new waiver: 1) access and choice; 2) care coordination; 3) benefits and services; 4) quality; and 5) fiscal sustainability. The teams researched and analyzed information from other states and expert sources. In some cases, the teams called for focused work groups to examine in even greater detail critical topics, such as system needs related to supporting employment outcomes, identifying an appropriate needs assessment tool, and supporting self-direction. In late August 2011, the design teams reported the results of their work by submitting team reports that articulated their recommendations, identified the next steps to

take, and described related key issues that must be resolved.

2. Next Steps: Gathering Feedback, Developing Pilot Projects and Securing CMS Support

In the months ahead OPWDD will use the recommendations of the design teams to give shape to its 2011 comprehensive annual plan, known as the 5.07 Plan, and hold public hearings on the recommendations as a plan for action and reform. Comments received will help to finalize the plan that will guide OPWDD in the next steps of preparing for waiver implementation. Many details remain to be worked out, and stakeholder voices will be essential to getting them right.

One critical aspect of the Waiver is its distinction as a research and demonstration waiver, and the requirement for New York State to demonstrate the effectiveness of the waiver reforms to the federal government. Developing the Waiver is a process of identifying needed reforms, strategizing the means to achieve those reforms, and then testing and evaluating their implementation—all of which will take several years. Following finalization of the 5.07 Plan, OPWDD will initiate two key activities: 1) issuing a Request for Information; and 2) subsequently, submitting a Request for Applications. Together, these two activities will launch pilot projects that will effectuate the system reforms of the new waiver and evaluate their results. These pilot projects will demonstrate the managed care model of service delivery and funding. Also, the projects will provide for the programmatic reforms related to increasing the system's focus on individualized needs assessments, enhanced quality of services, and improved coordination of care. The pilot projects will be the critical step in linking the initial waiver design work to the realization of the waiver reforms system-wide.

At the same time, OPWDD is engaging in ongoing discussion with the federal CMS about details of the waiver design and implementation. The process of arriving at a satisfactory plan for implementing the many reforms identified by the design teams requires extensive planning and system analysis. CMS must approve the reform plans prior to the start of the Waiver in April 2012. As the conversation continues, details emerge which provide the necessary operational parameters to move the Waiver from conceptual design to a true plan for testing, improving, and executing reform.

3. Staying Informed and Involved

One of the largest tasks within development of the Waiver has been fulfilling OPWDD's commitment to a transparent and inclusive public process. Development of the Waiver is an extensive process, and OPWDD is counting on its longstanding partners—self advocates, family members, and service providers—to work with us as we add definition and details to its plans and to

Medicare Prescription Drug Coverage: Barriers to Access at the Pharmacy Counter

By Doug Goggin-Callahan

In 2006 Congress added to the Medicare program a prescription drug benefit. Unlike other Medicare benefits, it requires the beneficiary to opt in by purchasing a Medicare Part D prescription drug plan. This article will review the complex methodology of appealing the refusal by a Medicare Part D insurer to pay for a prescription drug.



Since its inception in 2006, Medicare Part D, Medicare's voluntary outpatient prescription program, has grown to include 35 million of the total 49 million Medicare beneficiaries in the United States.¹ In addition to increased enrollment, the Part D market has developed considerably both in terms of plan selection and price range. In 2012, Medicare's administrative agency, the Center for Medicare & Medicaid Services (CMS), expects 29 stand-alone prescription drug plans to be offered in New York State, with premiums as low as \$15.10 per month.² Despite a relatively robust plan landscape and high rates of enrollment, people with Medicare Part D may experience difficulty obtaining prescribed medications at the pharmacy.³ In order to overcome these obstacles, beneficiaries must understand Medicare's drug utilization controls and appeals process.

Medicare Part D insurance plans must develop both a formulary and a prescription utilization management program.⁴ As part of their utilization management programs insurers may require the following: 1) prior authorization for medications; 2) that a beneficiary try a particular medication on the plan's formulary before paying for the prescribed medication; or 3) limit the dosage or amount of medication that may be covered.⁵ And unlike in the Medicaid program, prior authorization may be required before a beneficiary can access a medication that is on the formulary.⁶ Therefore, a medication's presence on a plan formulary and a prescription in hand is not a guarantee that the insurance plan will cover the drug at the pharmacy counter.

Consequently, many Medicare beneficiaries first become aware of a barrier to accessing their medication at the pharmacy counter.⁷ At this point the beneficiary has already seen his or her doctor, been prescribed a medication and brought the prescription to the pharmacy, only to find that there is a stop on the plan's coverage. Utilization restrictions not known to the beneficiary or

the doctor at the time the prescription was written frequently account for these coverage denials.⁸

At present, pharmacies are required only to post a generic notice that instructs beneficiaries to contact their plan if they disagree with the stop on their coverage. The pharmacist is not required to, and often cannot, provide detailed information as to why the medication is not covered by the insurer.⁹ Beginning in 2012, beneficiaries will be provided with a generic notice instructing them they have a right to request a coverage determination from their plan if they believe the medication should be covered by their insurer.¹⁰ It will not, however, contain detailed information as to why the coverage is being withheld (e.g. prior authorization requirement, dosing above the quantity limit, etc.). The lack of specific information may leave beneficiaries confused as to the necessary next steps to obtaining coverage of the medication.

At this juncture, no appeal rights have been triggered; the only right that exists is the right to request a coverage determination from the insurance carrier.¹¹ A plan's decision not to provide or pay for a Part D drug, which triggers appeal rights, is defined as a "coverage determination."¹² Surprisingly, a coverage denial at the pharmacy counter is not considered a coverage determination under Medicare law.¹³

Instead, the beneficiary must contact his or her plan and proactively request a coverage determination if he or she wishes to pursue an appeal. Beneficiaries may request coverage determinations orally or in writing from their plan.¹⁴ CMS has recently adopted regulations that would allow for the electronic submission of coverage determination requests beginning January 1, 2012.¹⁵

Before filing a coverage determination request, a beneficiary may need to contact his or her plan to determine what utilization tool is being applied to the medication. If the utilization tool being applied is step therapy, a quantity limit, or a higher pricing tier, the coverage determination must include a supporting statement from the prescribing physician.¹⁶ The statement must tell the plan that a substituted medication would be less effective or harmful—or both—to the beneficiary.¹⁷ Because of these exacting language requirements, the prescription itself does not satisfy the requirement of physician support.

In practice, regardless of the reason coverage is being withheld, it is useful to have the support of a prescribing physician. The coverage determination is usually made by computer algorithms based on the answers to a series of yes or no questions.¹⁸ Decisions that cannot be made by the algorithm or require more technical ex-

pertise are forwarded to clinical staff.¹⁹ Because plans have only 72 hours to make a non-expedited coverage determination, there is an increased likelihood that plan staff will simply deny the request if information is missing or incomplete.²⁰ Physician information that is tailored to the particular utilization denial will thus increase the likelihood of a plan approving the coverage request.

If a beneficiary receives an unfavorable coverage determination, he or she may continue to appeal the decision, first through the plan's internal appeals process, then through an independent adjudicator, and ultimately through the Federal Courts. One of the most critical junctions for beneficiaries, however, is the coverage denial at the pharmacy counter. It's important for beneficiaries and their attorneys to understand the rights that are triggered by this denial, the parties that need to be involved in the appeal, and the steps that are necessary to obtain coverage of the medication.

Endnotes

1. 2011 Ann. Rep., THE BDS. OF TRS. OF THE FED. HOSP. INS. AND FED. SUPPLEMENTARY MED. INS. TR. FUNDS, <https://www.cmus.gov/ReportsTrustFunds/downloads/tr2011.pdf>.
2. 2012 CMS Fact Sheet, THE CENTER FOR MEDICARE AND MEDICAID SERVICES, <http://www.cms.gov/Partnerships/downloads/statefact-sheets-all-2012.pdf> (Medicare beneficiaries who qualify for the Federal subsidy, Extra Help, may pay no monthly premium for their prescription drug plan).
3. U.S. GOV'T ACCOUNTABILITY OFFICE, GA0-08-47, MEDICARE PART D: PLAN SPONSORS' PROCESSING AND CMS MONITORING OF DRUG COVERAGE REQUESTS COULD BE IMPROVED (2008) [hereinafter *GAO Report 2008*] (finding that 11.3% of surveyed beneficiaries reported utilization controls were placed on medications they were taking).
4. See generally, DEP'T OF HEALTH & HUMAN SERVS., MEDICARE PRESCRIPTION DRUG MANUAL, Ch. 7, MEDICATION THERAPY MGMT AND QUALITY IMPROVEMENT PROGRAM, Section 60, DRUG UTILIZATION MGMT. PROGRAM, <https://www.cms.gov/PrescriptionDrugCovContra/Downloads/R3PDBv2.pdf>.

5. *Id.* at § 60.1.
6. See VICKI GOTTLICH, BENEFICIARY CHALLENGES IN USING THE MEDICARE PART D APPEALS PROCESS TO OBTAIN MEDICALLY NECESSARY DRUGS (Kaiser Family Found., Sept. 2006).
7. *Id.*
8. GAO Report 2008, *supra* note 3, at 22 (finding 34% of appeals to the independent external adjudicator were in regards to utilization restrictions).
9. See Gottlich at ii.
10. Uniform Exceptions and Appeals Process for Prescription Drug Plans and MA-PD Plans, 76 Fed. Reg. 7,321,471 (April 15, 2011) (to be codified at 42 C.F.R. pt. 423).
11. MEDICARE PRESCRIPTION DRUG BENEFIT MANUAL, Ch. 18, Section 10.1 (the presentation of a prescription at the pharmacy counter does not need to be considered a coverage determination).
12. 24 C.F.R. § 423.566.
13. MEDICARE PRESCRIPTION DRUG BENEFIT MANUAL, Ch. 18, Section 10.1.
14. 42 C.F.R. § 423.568(a)(1).
15. Uniform Exceptions and Appeals Process for Prescription Drug Plans and MA-PD Plans, 76 Fed. Reg. 7,321,471 (April 15, 2011) (to be codified at 42 C.F.R. pt. 423).
16. 42 C.F.R. § 423.578.
17. *Id.*
18. GAO Report 2008, *supra* note 3, at 12.
19. *Id.*
20. *Id.* at 13.

Doug Goggin-Callahan is the Medicare Rights Center's Director of Education and New York State Policy Director. Most recently he was the Client Services and Program Counsel at the Medicare Rights Center. Before joining Medicare Rights, Mr. Goggin-Callahan worked as an attorney at Ropes & Gray, where he worked on antitrust and securities matters. Mr. Goggin-Callahan received his law degree from Fordham Law School, and his B.A. from New York University. He is admitted to the New York State Bar and the Southern District of New York.

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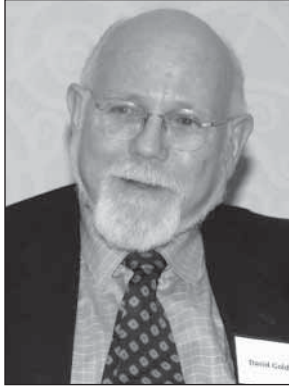
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New York Law Provisions Impacting Elder Law in 2011

By David Goldfarb

As I am sure you are all aware, New York State enacted enhanced Medicaid estate recovery legislation in 2011, whereby an individual's "estate" includes all of the individual's real and personal property and other assets passing under the terms of a valid will or by intestacy. Enhanced Medicaid estate recovery also includes any other property in which the individual has any legal title or interest at the time of death, including jointly held property, retained life estates, and interests in trusts, to the extent of such interests.¹



A. Enhanced Medicaid Estate Recovery

The enhanced recovery of assets passing outside probate or intestacy is only pursuant to regulations adopted by the Commissioner, which may be promulgated on an emergency basis. A claim against a recipient of such property by distribution or survival shall be limited to the value of the property received or the amount of medical assistance benefits otherwise recoverable pursuant to this section, whichever is less. At the time of this writing, emergency regulations and an Administrative Memorandum (ADM) have been published, but a final regulation has not been promulgated.

Despite the fact that the emergency regulations and ADM appear to impact vested property interests such as life estates, it should be noted that the Chapter Law "effective date" provision states the following:

[T]his act shall not be construed to alter, change, affect, impair or defeat any rights, obligations, duties or interests accrued, incurred or conferred prior to the effective date of this act;....²

The law became effective April 1, 2011.

B. Other Medicaid Provisions

Medicaid and FHPlus applicants, who do not have a resource test, may attest to the amount of interest income generated by resources if the amount of such interest income is immaterial to eligibility. This provision was enacted in 2010, but implemented by a 2011 ADM.³

Eligibility for the Medicaid Buy-In Program for the Working Disabled was changed so that a recipient

must have non-exempt resources of less than \$20,000 for an individual or \$30,000 for a couple. Since these are working individuals, their retirement accounts were usually not in pay-out status and therefore not exempt. However, the amendment will now exempt all retirement accounts.⁴

By either an amendment to the State Medicaid Plan or by a federal waiver, the state may exempt an amount of income for housing expenses for persons being discharged from a nursing home into the community who are enrolled in Medicaid Managed Care and are not considered an Institutionalized Spouse of another Medicaid recipient.⁵

"The Marriage Equality Act became effective July 24, 2011, and provides equal treatment and recognition for all otherwise valid marriages entered into by same or different-sex couples."

Level I Personal Care Services (sometimes called Housekeeping) are now limited to eight hours per week for individuals whose needs are limited to nutritional and environmental support functions.⁶ Level I Services are limited to the performance of "nutritional and environmental support functions" such as: making beds, dusting and vacuuming, light cleaning, dish-washing, shopping, laundering, and preparing meals.

Bed hold payments for temporary hospitalizations will only be paid to nursing homes by Medicaid if at least fifty percent of the facility's residents eligible to participate in a Medicare managed care plan are enrolled in such a plan.⁷

C. The Marriage Equality Act

The Marriage Equality Act became effective July 24, 2011, and provides equal treatment and recognition for all otherwise valid marriages entered into by same or different-sex couples. It will protect spouses of same-sex marriages for all Medicaid purposes, including, but not limited to, protection against spousal impoverishment. Same-sex couples that were validly married in other jurisdictions will continue to be recognized for Medicaid purposes.⁸

D. Trust Decanting Provisions

An authorized trustee with unlimited discretion over principal in any trust, or an authorized trustee

with the power to invade trust principal but without unlimited discretion, may appoint the principal into another trust for a beneficiary. Such an authorized trustee may exercise this power without obtaining the consent of the parties interested in the trust and without a court order.⁹ The 2011 law repealed EPTL 10-6.6 (b), (c), (d), (e), (f) and (g) and added new provisions EPTL 10-6.6 (b)-(s).¹⁰ Prior to that, a trustee needed court approval unless the interested parties to the trust consented. This power is commonly referred to as “trust decanting.”

“Under the 2011 amendments, a trustee may pay over the principal of a trust to a new trust even if the trustee does not have absolute or unlimited discretion to invade the principal of the trust.”

Under the 2011 amendments, a trustee may pay over the principal of a trust to a new trust even if the trustee does not have absolute or unlimited discretion to invade the principal of the trust. With respect to an inter vivos trust, there is no requirement to file the instrument with a court as long as the trust has not been the subject of a proceeding in the Surrogate’s Court.¹¹ An authorized trustee is one with authority to pay trust principal to beneficiaries other than the creator, or a beneficiary to whom income or principal must be paid currently or in the future, or who is or will become eligible to receive a distribution of income or principal in the discretion of the trustee.¹² A power to pay principal that includes words such as best interests, welfare, comfort, or happiness is not considered a limitation or modification of the right to distribute principal.¹³ The decanting provision has been used to achieve tax savings and protect a beneficiary’s entitlement to government benefits.

Under the 2011 provisions, an authorized trustee may not use the provision to reduce, limit or modify a beneficiary’s right to a mandatory distribution of income or principal, a mandatory annuity or unitrust interest, a right to withdraw a percentage of the value of the trust or a right to withdraw a specified dollar amount, if the mandatory right has come into effect with respect to the beneficiary. However, this restriction

would not prevent the trustee from decanting to a supplemental needs trust that conforms to the provisions of EPTL § 7-1.12.¹⁴ The decanting instrument must be signed and acknowledged by the trustee, and a copy served on all interested parties by registered or certified mail, or by personal delivery.¹⁵

Endnotes

1. N.Y. SOC. SERV. LAW § 369(6) (as amended by 2011 N.Y. LAWS 59).
2. 2011 NY LAWS Ch. 59, Part H, Section 111 (u).
3. 2010 N.Y. LAWS 58 (amending N.Y. SOC. SERV. LAW §§ 366-a(2) and 369-ee(2)); see 11 OHIP/ADM-1 (Mar. 11, 2011).
4. 2011 N.Y. LAWS 59 (amending N.Y. SOC. SERV. LAW § 366(1)(a) (12)).
5. 2011 N.Y. LAWS 59 (adding N.Y. SOC. SERV. LAW § 366(14)).
6. N.Y. SOC. SERV. LAW § 365-a(2)(e)(iv) (added by 2011 N.Y. LAWS 59; GIS 11 OLTC 007 (June 3, 2011)).
7. 2011 N.Y. LAWS 59 (adding N.Y. PUB. HEALTH LAW § 2802(25)(b) (iv)).
8. 2011 N.Y. LAWS 95 (adding N.Y. DOM. REL. LAW §§ 10-a, 10-b); See also GIS 08 MA/023 (Aug. 20, 2008).
9. 2011 N.Y. LAWS 451 (amending N.Y. EST. POWERS & TRUSTS LAW 10-6.6) (effective Aug. 17, 2011).
10. Previously, 2001 N.Y. LAWS 204, amended N.Y. EST. POWERS & TRUSTS LAW 10-6.6 (effective Aug. 20, 2001).
11. N.Y. EST. POWERS & TRUSTS LAW 10-6.6(c),(j).
12. N.Y. EST. POWERS & TRUSTS LAW 10-6.6(s)(2).
13. N.Y. EST. POWERS & TRUSTS LAW 10-6.6(s)(9).
14. N.Y. EST. POWERS & TRUSTS LAW 10-6.6(n)(1).
15. N.Y. EST. POWERS & TRUSTS LAW 10-6.6(j).

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Guardianship News: Buying a House

By Robert L. Kruger

I decided to write on this subject when it dawned on me that I was spending egregious amounts of time dealing with the maintenance of guardianship-owned houses. Moreover, the subject goes far beyond maintenance issues: I began to question my willingness to support, either as a fiduciary or as counsel, house purchases in many situations.



Buying the House

Let us assume that there is a guardianship for an infant (someone under the age of 21) belonging to a family that is considered poor or marginal. Furthermore, in this hypothetical, the family is a single parent household, living in substandard housing. In addition, the family income is comprised of the product of public entitlement programs, supplemented with undeclared and “off the books” income.

Moreover, let’s imagine that the guardianship estate is \$1,000,000 or less. If there is no structure, in this interest rate climate, the guardianship income is unlikely to reach 4% or \$40,000, much less exceed it. Because the family is financially struggling, the guardianship will almost assuredly be paying homeowners insurance, real estate taxes, fuel and most repairs. For our purposes, we may err on the side of optimism, hoping that the family can afford to pay the gas and electric, as well as the phone, cable and internet bills.

Obviously, the annual cost of real estate taxes and other major expenses varies with each location, but fuel does not. However, homeowners insurance differs, and repairs are likely to be higher, since the cost of the house is lower. I usually put an arbitrary cost estimate of \$2,000.00 per month on these items. If the costs run close to that, then I have spoken for \$600,000.00 of the recovery (4% of \$600,000.00 is \$24,000.00).

There are administrative costs...commissions and fees...and I have not mentioned the particular needs of the Incapacitated Person (IP). This family, described above, is unlikely to be able to afford a house. If expenses exceed estimates, the guardian will be invading the principal to cover costs, and in this interest rate climate, the invasion of principal will be all the greater as the interest rates are lower.

If there is a structure in place, the income will at least continue and renew the balance sheet. Except, there will be less principal on hand, since a significant

portion will be tied up in the annuity. This seems to me to be a positive...the guardianship estate may be reduced, but it will not be altogether depleted. In these circumstances, I view the structure as a life preserver. The annuity usually has a fixed term—say, 30 years and life, and it often has a cost of living increase component. Consequently, this income can always be counted on to replenish the guardianship account. What’s more, if costs exceed income, then you must cut costs, for the simple reason that cannot spend what you don’t have.

Nevertheless, if the family is a working family, or the guardianship estate is quite substantial, then you have far greater flexibility in the cost of the purchase and carrying costs.

But if you don’t have that degree of flexibility, I try to steer the family in question towards a condominium, because monthly maintenance costs include the real estate taxes, fuel and exterior repairs. The condo owner does not pay separately for landscaping, and the costs can usually be contained, though not always. To illustrate, the mother of one of my wards caused a fire in the condo apartment. Damages were substantial and the insurance recovery was significantly less than the cost of repair. Furthermore, since a condo purchase does not require board of directors approval, as a co-op does, the process itself favors a poorer and less sophisticated purchaser. If the money is there, a condo will work.

Ability to Live in a House

When I was younger, and my faith in people was greater, I learned a hard lesson—not everyone who purchases a house knows how to live in a house. Some people are simply not stewards of property. In actuality, some can be quite destructive. My poster child—the mother who started the fire mentioned above—often neglected to walk the dog, with predictable results. Also, cigarettes were put out on the cushions of a new sofa.

More frequent, however, are parents who don’t want to spend their child’s money. Many of these parents attempt to make home repairs themselves, and due to a lack of education and skill, they end up making a simple repair an extensive one, costing the guardianship a lot of money unnecessarily. For example, during the late October snowstorm and subsequent blackout, one family heated a portion of the house by boiling water on the stove. Inevitably, this weakened the ceiling and caused the need for significant and extensive repairs to the ceiling.

The best illustration of this theme came many years ago, when a father began to call me to replace his appliances, failing to recognize that these items could be

repaired. In that case, I actually hired a de facto super, a building maintenance manager, to freelance and make repairs. Eventually, the family understood that repairs come before any replacement request.

Steering unsophisticated families toward condos, rather than houses, might have saved the guardianship estate money and the undersigned grief.

Repairs and Rehab

When I purchase a home for a guardianship, I order an engineer's inspection, as most attorneys do. In addition, I send my architect out with the engineer, because I lack confidence in the thoroughness of the engineers, whose reports are often canned. I want to know more than the generic phrases stating that the plumbing system is "fairly good" to "good." In truth, I want to receive a more nuanced report, and occasionally a prospective purchase is killed because both the architect and the engineer spot problems down the road.

Before I used the architect in this manner, I purchased houses that had been previously repaired on the cheap, with second rate materials and third rate workmanship. This necessitated applications to the court for permission to repair or rehab the house in extensive ways, and these applications are costly. Yet, if the architect and engineer can anticipate potential rehabilitation issues, the cost is miniscule compared with the potential savings.

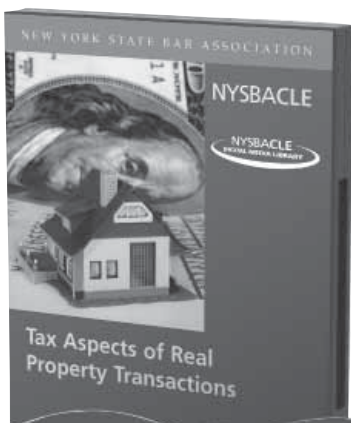
Presently, I have a six-figure rehab job judicially approved, and one of comparable size completed. The

finished job involved a sizable estate (\$2,300,000.00); however, there were heavy demands on the income. In that instance, prior to approving the work, the court appointed a general contractor to review the architect's recommendations. While the scope of work was not significantly modified, we had already dealt with the inevitable accompaniment to these requests.

It is here that I am referring to the inevitable wish list of the mother. I present these requests to court as one of necessity; the mother's wish list is usually decorative and optional. One need only mention that a request must be made to court to invite a laundry list of suggested improvements. The guardian has to scrutinize that list with a gimlet eye. That is precisely what a court should, and usually does, do.

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

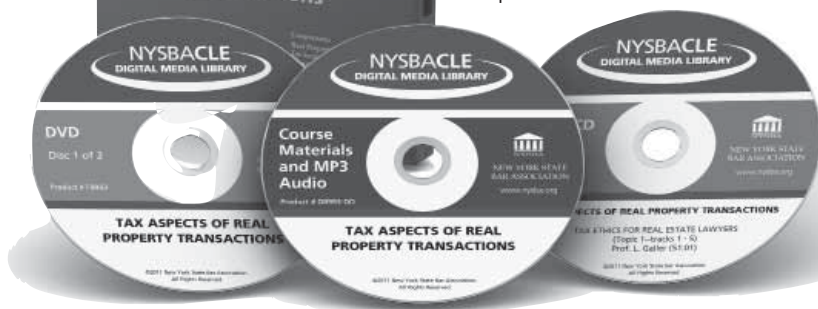
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The People First Waiver and Children With Disabilities

By Allison Landwehr

As many of you know, Governor Andrew Cuomo is working to restructure New York State's Medicaid program with the help of the Medicaid Redesign Team (MRT); however, what remains less visible are the changes likely to occur within the Medicaid Waiver program. While efforts of transparency exist, Medicaid recipients, advocates



and practitioners remain nervous and confused regarding the implementation of a new waiver, the People First Waiver (PFW). A separate and distinct effort, apart from the MRT, the PFW, if approved by the Center for Medicare & Medicaid Services (CMS), will assuredly impact all who are eligible to receive services under the Office of People with Developmental Disabilities (OPWDD). Due to the exponential growth of children with developmental disabilities, this article will focus on children with disabilities who are currently receiving health care under the Medicaid Waiver program, and how the PFW may affect their care.

A. An Overview of the New York State Medicaid Waiver Program

Administered by the federal government, the Medicaid program is within the purview of CMS, an agency within the Department of Health and Human Services (HHS).¹ The Medicaid Waiver program allows the HHS Secretary to waive various federal statutory and regulatory requirements, such as financial eligibility, to provide Medicaid coverage for those who would not ordinarily be eligible.² The Social Security Act endows states with three basic waiver opportunities, each with its own purposes and requirements: section 1115, section 1915(b), and section 1915(c).³ However, section 1115 permits applications of Medicaid research and demonstration projects, endowing states with the flexibility to request to CMS that certain Medicaid restrictions be waived.⁴ Nevertheless, "[t]he Secretary cannot waive constitutional requirements or other federal laws, such as the Americans with Disabilities Act (ADA)."⁵ Allowing for an infinite number of project possibilities, section 1115 can, by default, be unpredictable, causing many receiving Medicaid coverage to wonder what will happen to their health care.⁶

Sections 1915(b) and (c) are more rigid, specifying particular Medicaid provisions to be waived regarding particular types of care. Section 1915(b) pertains to

managed care and freedom of choice waivers.⁷ Section 1915(c) focuses on home and community-based services (HCBS), granting states the ability to offer long-term care services within the community, rather than an institutional setting.⁸ Each of these three waivers is utilized by the New York State Medicaid program; however, the bulk of them are from sections 1115 and 1915(c) of the Social Security Act.⁹

Currently, the New York State Medicaid Waiver program has four main waivers which apply to children with disabilities. While the four programs are administered by different agencies, all of the programs are under the Department of Health's (DOH) control. The four main waiver programs are as follows:

1. NY Care at Home I, II: "Provides case management, bereavement services, expressive therapies, family palliative care education (training), home and vehicle modifications, massage therapy, pain and symptom management, respite for *physically disabled ages 0-17*."¹⁰ This waiver program is pursuant to section 1915(c) of the Social Security Act and is administered by the *DOH*.¹¹
2. NY Care at Home III, IV, and VI: "Provides case management, respite, assistive technology to *individuals with autism, and [developmental disabilities]...ages 0-17*."¹² This waiver is pursuant to section 1915(c) of the Social Security Act and is administered by the *OPWDD*.¹³
3. NY B2H: "Provides day habilitation, health care integration, skill building, special needs community advocacy and support, crisis respite, accessibility modifications, adaptive and assistive equipment, crisis avoidance and management and training, family/caregiver supports and services, immediate crisis response services, intensive in-home supports and services, vocational services for *individuals with autism, developmental disabilities ages 0-20, and individuals with mental illness ages 19-20 and w/SED ages 0-18, as well as the medically fragile ages 0-20*."¹⁴ This waiver program is pursuant to section 1915(c) of the Social Security Act and is administered by the *Office of Children and Family Services (OCFS)*, because it applies solely to children in its care and custody or that of a Local Social Services District (LDSS).¹⁵
4. NY OMH SED: "Provides for crisis response, family support, individualized care coordinator (case management), intensive in-home, respite,

skill building for *individuals w/mental illness SED ages 5-21*.”¹⁶ This waiver program is pursuant to section 1915(c) of the Social Security Act and is administered by the *OMH*.¹⁷

If CMS approved New York State’s PFW, lots of children currently receiving support and services under the above Medicaid Waiver programs are likely to experience a change in coverage during the year 2012.¹⁸ Drafted under the authority of section 1115 of the Social Security Act authorizing research and demonstration projects, both the New York State DOH and the OPWDD have proposed alterations to the current Medicaid Waiver program via the PFW.¹⁹ Consequently, it is imperative that we as practitioners stay up-to-date on the progress of New York State’s proposal, and inform our clients of the prospective modifications.

B. The People First Waiver Explained

The details concerning the PFW are outlined in a “Concept Paper” produced and submitted by the New York State DOH and OPWDD to CMS. The aspects of the PFW presented within the “Concept Paper” reveal very little, though it contains a general overview explaining its intended goals and purposes.²⁰ Elasticity is common regarding section 1115 projects, since states typically work with the CMS to formulate the particulars of the project subsequent to receiving its approval.²¹ Totalling only eight pages, the “Concept Paper” fails to provide a thorough description of the PFW, though it features these major propositions: 1) revised care coordination through systems of managed care and coordination for people with developmental disabilities with extreme medical and or behavioral needs; 2) a transformation of the long-term care system of delivery; and 3) the establishment of a safety net care pool to enhance the delivery of essential mental hygiene services.²²

According to the “Concept Paper,” only those eligible to receive services under the OPWDD will be affected by the PFW if it is approved.²³ At first glance, this population could seem easy to detect, but it is far broader than one initially assumes. As a case in point, one might examine the above list of Medicaid Waivers and determine that only those receiving Medicaid through Care at Home III, IV and VI will be affected by the PFW, because it is the only program run by the OPWDD. However, that would be incorrect.²⁴ As a result of eligibility criteria under the Medicaid Waiver program, many children with disabilities meet the criteria for both an OPWDD waiver and a waiver administered by another New York agency. Therefore, there are several hundred children with disabilities who have opted to obtain health care under a non-OPWDD waiver who are nonetheless still considered OPWDD eligible by the DOH, and as a result, they too would be affected by the PFW.²⁵

The PFW is slated to affect around 100,000 New Yorkers currently enrolled in the state’s Medicaid program, “eighty percent of whom have been assessed to need an institutional level of care.”²⁶ Currently, it is estimated that the OPWDD provides health care to about 80,000 people with developmental disabilities.²⁷ According to the OPWDD, the PFW was designed by New York State as a result of several demographic factors, ranging from a longer lifespan for people with disabilities, to an increase in people being served by the OPWDD, as well as a spike in the diagnoses of autism, up five-hundred percent.²⁸ In addition, the “Concept Paper” cites a three-decade-old infrastructure, along with archaic programmatic mechanisms, as reasons for the PFW.²⁹ And lastly, the 1115 project seeks to restructure community-based service options, since much of the long-term care inevitably needed for children who are eligible under the OPWDD is administered by the DOH.³⁰ The PFW objectives are written very generally, since the project is in its nascence, but the language indicates that there will be sweeping changes in the Medicaid coverage for children with developmental disabilities in the year 2012, the details of which, unfortunately, remain unknown.³¹

C. The People First Waiver and Budgetary Constraints

Like most states, New York is experiencing a budget crisis, with expenditures for Medicaid increasing by \$2.18 billion between April 2005 through March 2010, and as the OPWDD accounts for \$2.16 billion of this ninety-nine percent jump, fiscal concerns are evident.³² While the OPWDD has explained that the PFW will attempt to provide for greater fiscal sustainability, the office has also stated that “[t]he PFW is *not* a means to address ongoing budget needs.”³³ Nevertheless, simply looking at the seventy-four percent of people receiving services under the label of developmentally disabled, with close to ten percent designated as autistic, it is clear that cost played a role in the design of the PFW.

The concern by practitioners, advocates, and Medicaid recipients stems in part from the fact that no additional amount of money can be acquired to achieve the goals of the PFW. The Social Security Act retains strict guidelines regarding all section 1115 demonstrations and projects, mandating budget neutrality.³⁴ As a result, the PFW cannot increase the money New York State currently receives from the federal government to achieve its aims.³⁵ Thus, for many, the glaring question is how the PFW will create new reimbursement models, better care via a managed care system, greater self-determination for Medicaid recipients, and decrease overhead?³⁶ A critic of the PFW, Stephen Sano, Executive Director of the Handicapped Children’s Association (HCA), has stated that the DOH and OPWDD are essentially asking “...how you’re going to take your cut...”³⁷ The “Concept Paper” nonetheless

maintains that New York State will work in conjunction with CMS to revise the Medicaid program and ensure that per diem rates reflect the actual cost of services, focusing on individual need, rather than provider cost.³⁸ Such assertions, however, have failed to assuage concerns regarding the potential stripping of Medicaid services and supports to children with disabilities.

D. The Effect of the People First Waiver

Throughout May, June, and August of 2011, stakeholders expressed their fears. However, with a growth rate of three percent annually in the OPWDD budget, and an inflation rate for Medicaid expenditures reaching almost three percent above average, it is evident that the program requires modification.³⁹ According to the “Concept Paper,” the PFW will ensure greater efficiency and accountability, thereby reducing fees.⁴⁰ It also continues vital mental hygiene services via the establishment of a “safety net care pool,” providing “lower-cost services that meet individuals’ needs....”⁴¹ In addition, the PFW claims to offer “[b]etter care coordination for developmentally disabled individuals with extremely complex medical [and/or] behavioral needs,” through care coordination and management, yet the lack of information as to how and when remains disconcerting.⁴²

While distinct from the efforts of the MRT, the “Concept Paper” states that the DOH and OPWDD will implement the recommendations of the MRT, and consequently, the PFW will develop managed care models for Medicaid recipients with developmental disabilities for medical and long-term care.⁴³ Despite the fact that many children with developmental disabilities presently receive care via waivers set to expire at adulthood, these waivers are still susceptible to managed care, especially if in time they are merged with those receiving long-term care.⁴⁴ Even though the PFW is split up into separate plans regarding its execution, one over the next five years, including the shift to managed care, and another beginning immediately after CMS’ approval, many are nervous about the flexibility a section 1115 project affords New York State.⁴⁵ Still others remain anxious about the move to managed care, suggesting that it is a pseudonym for managed cost, likely to lead to inadequate services for those with the most significant developmental disabilities.⁴⁶

Conclusion

In New York State, Medicaid is the primary funding source for services to children with developmental disabilities, yet with a growth in population and financial constraints, an overhaul is gravely needed.⁴⁷ At first glance, the PFW appears to be a potential problem-solving mechanism for the DOH and OPWDD; however, its future remains uncertain. Many practitioners, advocates, and Medicaid recipients have expressed

warranted feelings of unease regarding the section 1115 project, and thus, it is our job to quell these anxieties, while keeping our clients informed, and watching for the upcoming updates.

Endnotes

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Advance Directive News: A Melody Requiring Reflection

By Ellen G. Makofsky

Sometimes the same old song keeps repeating and repeating. I am having that problem, although I am not remembering that same old melody; instead I am thinking of the case I discussed in my last column, *Matter of Zornow*.¹ I find this case very troubling. After contemplating the Zornow case and completing my last column, I spoke with Dr. Patricia



A. Bomba, a tireless advocate for Medical Orders for Life Sustaining Treatment (MOLST). Dr. Bomba was also distressed with the outcome of the case and was especially concerned because in rendering his opinion, Judge William P. Polito summarily dismissed the MOLST for lack of statutory authority. An examination of the Public Health Law, however, tells another story.

The facts of the case are interesting. Joan Zornow, a 93-year-old nursing home resident, suffered from advanced Alzheimer's disease. Mrs. Zornow never executed a health care proxy and a dispute arose among her seven children concerning a directive to withhold food and water. Two successive MOLSTs were executed by Mrs. Zornow indicating that artificial nutrition and hydration were not to be initiated and that Mrs. Zornow was not to be hospitalized unless she suffered from pain or severe symptoms which could not otherwise be controlled.² There was a dispute among family members about Mrs. Zornow's care and these directions. On the one hand, Douglas Zornow, one of her seven children, contended that his mother had verbally instructed him and other siblings that she did not want artificial nutrition and hydration if she were unable to orally ingest food and water.³ On the other hand, Carole Zornow, one of her daughters, stated that her mother indicated to her that she wanted to receive artificial nutrition and hydration. According to Carole Zornow, her mother repeated this directive to her nurse who then recorded the direction in the nursing facility's health care records.⁴ The dispute precipitated a guardianship proceeding in which Carole Zornow sought the power to make end of life health care decisions for her mother.

The Court held that the statements made by Douglas Zornow and his siblings about Joan Zornow's wishes "did not comply with the clear and convincing standards required by the Court of Appeals"⁵ because the Court found the wishes to be too vague and too general in nature. Judge William P. Polito, the presiding

judge in this matter, also revoked both of the MOLSTs created by Mrs. Zornow, stating that "it could not identify any statutory authority or immediate basis for such directives."⁶ The Court appointed Carole Zornow and Catholic Family Services as co-guardians, and the Court turned to the Family Health Care Decisions Act⁷ (FHCDA) as the controlling statute in regard to surrogate health care decision-making for Mrs. Zornow.⁸ That done, Judge Polito determined that Mrs. Zornow's wishes had to be "those of her Roman Catholic religious belief."⁹ Therefore she was "obligated by her religious beliefs to continue to receive artificially administered food and water...."¹⁰

The Court set aside Mrs. Zornow's wishes by stating that the MOLSTs lacked legislative authority. This is clearly wrong.

Contrary to the finding in *Zornow*, legislative authority for the MOLST is found in N.Y. Pub. Health Law § 2994-dd(6).¹¹ Codification of the MOLST goes back to 2005 when subdivision 13 was added to section 2977 of the Public Health Law pursuant to Chapter 734 of the Laws of 2005. Subdivision 13 authorized a pilot project in Monroe and Onondaga counties to allow for the use of "alternative forms" for issuing nonhospital orders not to resuscitate. Although the generic term "alternative forms" was used in place of the word MOLST, the legislative history clearly indicates that subdivision 13 was passed specifically to authorize the use of the MOLST.¹²

In 2006, subdivision 13 pursuant to Chapter 325 of the Laws of 2006 was amended to expand the authority of the MOLST to allow "alternative forms" to be used to issue nonhospital "do not intubate orders" as well as do not resuscitate orders. Again, the legislative history indicates that "alternative forms" means the MOLST.¹³

In 2008, the Legislature again amended subdivision 13 pursuant to Chapter 325 of the Laws of 2006 to allow for the statewide use of alternative forms. Legislative history again includes a description of "alternate forms" as the MOLST.¹⁴

In 2010, subdivision 13 was recodified verbatim as N.Y. Pub. Health Law § 2994-dd(6) as part of the FHCDA. Also in 2010, the New York State Department of Health approved a revised version of the MOLST form and issued the form as a Department form.¹⁵

Conclusion

Mrs. Zornow executed two MOLSTs. These documents clearly stated Mrs. Zornow did not wish the administration of artificial nutrition and hydration and

that she did not want to be readmitted to a hospital. For Judge Polito to dismiss and disregard not one but two MOLSTs because the Court “could not identify any statutory authority or immediate basis for such directives”¹⁶ is hard to understand. Judge Polito’s substituted end-of-life Catholic doctrine for the previously expressed wishes of Mrs. Zornow is not resting well with me, so the melody just goes on and on.

Endnotes

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5. *Id.* (citing *Matter of Westchester County Med. Ctr.*, 72 N.Y.2d 517, 531 (N.Y. 1988)).
6. *Id.* (citing *In Re Nimon*, 789 N.Y.S.2d 596 (N.Y. App. Div. 2005)).
7. See L.2010, Ch. 8.
8. N.Y. PUB. HEALTH LAW § 2994-d (Consol. 2010).
9. *Zornow*, 919 N.Y.S.2d at 276.
10. *Id.*
11. Section 2994-dd(6) is a recent re-codification of N.Y. PUB. HEALTH LAW § 297-dd(13) which was first enacted in 2005 specifically for the purpose of authorizing the use of the MOLST form.
12. See Introducer’s Memorandum in Support of S5785, 2005–06 Reg. Sess. (N.Y. 2005), available at <http://image.iarchives.nysed.gov/images/images/82721.pdf> (stating, “Under existing law, the Department of Health may only approve one standard non-hospital order not to resuscitate. A new form, known as the Medical Orders for Life Sustaining Treatment (MOLST) has been developed by those in the field. This form allows the patient to have more say in treatment decisions and has been introduced in Monroe and Onondaga counties as a standardized form that is authorized for use in non-hospital settings. This legislation will allow for the use of the MOLST form as a demonstration program in Monroe and Onondaga Counties.”).
13. See Introducer’s Memorandum in Support of S6365A, 2006 Reg. Sess. (N.Y. 2006), available at <http://image.iarchives.nysed.gov/images/images/79356.pdf> (stating, “[B]ecause this form also permits an individual to instruct that he or she is not to be intubated... this legislation permits alternative non-hospital DNR forms, such as MOLST, to specifically include ‘do-not intubate orders.’”).
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15. See N.Y.S. Dept. of Health Form 5003 (June 2010), available at <http://www.health.state.ny.us/forms/doh-5003.pdf>.
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Housing Options for Adults With Intellectual and Developmental Disabilities in New York

By John Maltby

What Crisis?

In the 1930s, the average life expectancy for a person with what we now refer to as an Intellectual and Developmental Disability (I/DD) was 20 years. Today, people with I/DD are living almost as long as the typical population.¹ Changes in medical knowledge have led to a reduction in some sources of I/DD, as well as increases in other types of diagnoses. For example, brain damage caused by phenylketonuria has been almost eliminated in the western world due to the testing of newborns, introduced in 1963. Whereas autism, on the other hand, first described in 1943 but not in the Diagnostic Statistical Manual (DSM) until 1974, is now diagnosed in roughly 1 out of 110 children.²



New York's institutional and "group home" congregate care systems are among the most expensive in the nation. The annual cost of an institutional bed in New York in 2009 was \$1,237 per diem—at the time there were 1,492 people in such settings for an annual cost of \$1.85 billion.³ The cost of the least supervised (24/7) certified settings in New York begins at \$348 per day.⁴ Long-term care is labor intensive, requiring mostly part-time limited skill labor. Demand for people to work in the field is increasing as the general population ages. However, the supply of people prepared to do the work for the pay offered is limited.⁵

Beginning in 1975, children with disabilities became entitled to a "free and appropriate" education under PL 94-142. The path to inclusion has been slow. Thirty-six years later, there is now a generation of young adults with disabilities graduating from high school who are expected to be included in society. They want to work in jobs, not programs, and live in homes, not group homes. The housing options offered by the state are simultaneously unappealing and, because of current fiscal nervousness, unavailable.

The transformation of disability issues into civil rights issues is a process that has been under way for many years. It has changed public perceptions of people with disabilities generally, as well as those with I/DD. Many families no longer feel as stigmatized or isolated as in the past and they are prepared to advocate and lobby as citizens rather than as supplicants.

Taken altogether, this combination of demographic pressure, high costs, labor constraints and cultural

change, highlights the lack of sustainability of New York's current housing model. Coming at a time when New York is under a spotlight because of allegations of abuse in State homes, and misuse of Medicaid funds, these trends have created a concatenation of factors that represent an opportunity and occasion for fundamental change.⁶

Recent History

This year will mark the fortieth anniversary of a suit by parents of children at the state-operated Willowbrook School on Staten Island in New York. The case *ARC v. Rockefeller* (later *Carey*), stirred public outrage because of the conditions exposed by a then young TV reporter, Geraldo Rivera. Almost forty years later, we can still read reports in *The New York Times* citing abuse of adults in state-operated group homes.⁷ In some ways not much has changed, but in fact we are in a vastly different world.

Willowbrook was one of several catalysts that sparked the deinstitutionalization movement. Institutions which had been established in the late 18th century as well-intentioned models of "Moral Treatment," and later of the "Mental Hygiene"⁸ movement of the late 19th century, had degenerated into "snake pits"⁹ of appalling squalor and overcrowding by the 1960s. Similar outrages had been exposed in other states. As a result, since the 1950s and increasingly under the Kennedy administration, the Federal government had been taking a more active role in requiring and incentivizing states to improve conditions for people with disabilities including those with I/DD living in institutions. Federal funding and concomitant regulation increased with the introduction of Medicaid. While social pressure certainly led to fundamental changes in public perception, funding incentives changed much of the design of systems and the nature and size of state-operated or certified facilities.

Certified Congregate Care and Other Housing

By 1972, non-profit agencies, (also known as "voluntaries" in state parlance), were providing day and residential support to people with I/DD, funded by parent fees.¹⁰ In the post-Willowbrook era, the state contracted with such agencies to assist in housing people moving out of institutions and included funding for the people they were already serving.¹¹ Gradually, a system of "certified" housing evolved, run by non-profit "voluntary" agencies as well as the State, and funded primarily and now almost exclusively through Medicaid and Social Security Administration sourced funding.¹² Certified "group homes" were required to abide

by specific regulations, and in exchange were funded at a higher rate than non-certified settings.¹³ Parent fees were no longer required and for-profit companies were excluded from providing services.¹⁴

“Group homes” often encountered community opposition when first planned. Some opposition arose from outright prejudice, others were concerned about abuse. Many worried that non-profit housing would be left for the community to subsidize once it was taken off the local tax rolls.¹⁵ In 1978, New York State passed the Padavan Law, allowing the state’s zoning laws to override local laws.¹⁶ As a result of Padavan, the final decision as to where to locate a certified home remains in the hands of the Commissioner of the Office of People with Developmental Disabilities (OPWDD).¹⁷

There are four primary categories of certified housing in New York State:¹⁸

1. **Institution:** The most segregated setting is a large institution, which has more than 16 beds (and up to 100-plus beds). These are the vestiges of the 1,000-plus bed institutions that formed the primary settings for long term care until the 1970s. Approximately 4% of the 64,000 people housed in “out of home” placements in New York are in either state institutions or nursing facilities;¹⁹
2. **ICF:** People with high level needs but who are not institutionalized are housed in Intermediate Care Facilities (ICFs).²⁰ State operated ICFs average 10 beds and house some 29% of the population, with a further 4% housed in private institutions;²¹
3. **IRA:** Less restrictive but still 24/7 are “Supervised” Individualized Residential Alternatives (IRAs). “Supported” IRAs operate with less than 24/7 support and are typically houses with less than six beds. These house some 26% of the population, and;²²
4. **Supported Living:** Funding is provided to people living with their parents, their own families, with other unrelated people, or on their own. This funding supports some 37% of the housed population. While these settings receive state and federal funding support, they are generally not “certified.”²³

The structure of housing that evolved to replace institutions has served New York well in the forty years since Willowbrook. However, for the reasons cited above, it is no longer sustainable. Through the years, we have learned that people with I/DD have an improved quality of life, at a lower cost, in smaller settings than the ICF-MR model. Nevertheless, the system we have created locks them in. Simultaneously, the high cost of certified settings limits availability of beds and locks out people in need. Statewide, the waiting

list for people seeking a placement in a group home is more than 4,000, most of whom are the adult sons and daughters of parents who are themselves aging.²⁴ At the same time, it is not clear that the settings the wait list is rationing are even desired by or appropriate for those who are waiting.

In an authoritative work on the history of services in New York State, entitled *From Snake Pits to Cash Cows*,²⁵ Paul J. Castellani, Ph.D., cites the fundamental “cleavages” that run through the history of the Mental Disability community—“Institution versus community, upstate versus downstate, Democrat versus Republican, mental retardation versus DD, operation versus advocacy, along with racial, ethnic and class issues.”²⁶ One could add the generational gap between the families that saw the downside of deinstitutionalization, and whose primary focus is safety and security, in contrast to the more entitled younger generation who view risk differently. All of these cleavages help explain why the move from a system built on mini-institutions is finding it hard to adapt to an integrated world. Still, the most difficult obstacle is a combination of funding and culture.

Voluntaries are paid a significant amount per bed to run certified settings. Given a higher resident-to-staff ratio, the residents become more compliant. The residents then become more integrated into other services the voluntary provides, thereby increasing the revenue of the voluntary. Removing an individual from that vertically integrated model significantly alters the profitability.²⁷ Fixed costs remain the same while revenue declines. Agencies have come to depend on the operating surpluses certified residences provide and are incentivized to restrict the movement of residents out of such settings. Some of them have acquired substantial real estate portfolios that they would be obliged to convert to other non-profit usage or surrender.²⁸ At the same time, a substantial accumulated body of regulation that is institutionally derived limits flexibility for the voluntary providing certified residential facilities, and makes small scale operations almost impossible to operate. While history, in addition to financial and regulatory incentives, are all aligned to perpetuate an institutional bias, best practice, consumer preference, demographics, financial constraints and labor constraints argue for reformation. Pressures both within and outside the system have been building for many years and now we are on the verge of historic change.

Time for a Change

The legal support for changes in the housing system is derived from the case of *Olmstead v. L.C. and E.W.* In 1999, Justice Ruth Bader Ginsburg, delivering the opinion of the Supreme Court, wrote:

States are required to place persons with mental disabilities in community settings rather than in institutions

when the State's treatment professionals have determined that community placement is appropriate, the transfer from institutional care to a less restrictive setting is not opposed by the affected individual, and the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities.²⁹

Olmstead created a legal foundation for people who wished to live in non-institutional settings and sparked the creation of New York's "Most Integrated Setting Coordination Committee" (MISCC), which is comprised primarily of seven state agencies.³⁰

Preparing people for work and adult life is important. Since the passage of PL 108-446, the Individuals with Disabilities Education Act of 2004, states have been required to ensure that schools provide transition services. In New York State, these services are set out as part of the State Performance Plan (SPP). The relevant items in the SPP are Indicators 13 and 14, which require significant effort be devoted to supporting transition services that "further education, employment, and independent living."³¹ While not specific about housing, any worthwhile transition should address where a person will live and whether he or she will need support. Unfortunately, school district compliance is spotty and penalties for noncompliance are light.³²

While not requiring states to provide services, the "Money Follows the Person" (MFP) program (established in the Deficit Reduction Act of 2005) provides states with funds to move residents from institutions into the community, and to "backfill" the resulting empty nursing home bed, keeping the nursing home financially whole.³³ In New York State, the program initially only applied to people with Traumatic Brain Injury (TBI) who wanted to leave nursing homes.³⁴ Progress has been slowed by resistance from the nursing home industry, nursing home unions, and complex regulations governing the process.³⁵ The MFP may pick up some further impetus as the fiscal constraints of long term care begin to bite even further.

The principal funding source for long-term care in New York is Medicaid, and the State is subject to the policies set by the Center for Medicare & Medicaid Services (CMS). CMS has supported individualized housing for many years. CMS requires states that offer Consumer Directed Services (CDS) to provide each consumer with: 1) person-centered planning where the consumer is not simply shown or assigned an agency's product menu, but is able to plan his or her own future (unimplemented in New York for the last twenty years); 2) an individualized budget (i.e. MFP); 3) information and assistance, including a support broker and financial management services; and 4) quality as-

surance and improvement. In October 2009, New York introduced its 1915 Waiver,³⁶ which provided for consumer choice through a funding mechanism referred to as "Consolidated Supports and Services" (CSS). This was eagerly anticipated by consumers, but provider agencies have been slow to adopt and the state slow to fund.

New York State is currently planning a 1115 waiver (i.e., it will ask CMS to "waive" section 1115 of the Social Security Act). The OPWDD prospectus for the 1115 waiver is very clear that CDS are at the core of how services will be shaped for the future:

A transformed long term care delivery system that places person centered planning, individual responsibility and self determination at the forefront [which will] enhance care and individual satisfaction and lower Medicaid costs.³⁷

[That will] "prioritize services that adapt to the individual rather than asking individuals to adapt to the service" [and that] "financial support will be directed to individuals not to programs or institutions."³⁸

Once funding is attached to and directed by the persons with I/DD, or their family or advocate, they are free to purchase housing and support resources as they see fit. They might choose to live in one of the existing congregate settings, but they can also choose to stay in their family home with support, live with friends, or live alone.³⁹ They can choose who works for them, and what resources they obtain from the public or private sector. The fundamental change is that they now have choice of where, with whom and how to live as independently as they are capable of living.⁴⁰ Instead of a rationed system of congregate care, they can access the same housing and labor market as everyone else.⁴¹

In addition to the changing legal, regulatory and fiscal environment, the labor force is changing. Public outrage at the apparent toleration by the civil service union in New York of abusive behavior by its members has led to challenges to the hold that union employees have on the lives of the people they "support," especially those in more isolated settings.⁴² The National Alliance for Direct Support Professionals⁴³ has created a credentialing system and is collaborating with self advocacy organizations, including the Self Advocacy Association of New York State, to provide professional education, and to create a career path for people who support those with I/DD. These efforts and resources such as the College of Direct Support,⁴⁴ which seeks to provide a career path and accreditation simultaneously, address the impending labor shortage and the problems created by lack of skills and training in the current labor force.⁴⁵

As little as five years ago, “text to voice to text” technology for people who could not speak cost thousands of dollars and came with a bulky keyboard. Today—“there’s an app for that.”⁴⁶ The pace of change in technology is something we all experience. Technology that once had to be custom designed and built for people with I/DD has become generic and widely used. Tracking technology, movement sensors, warning or prompting devices and safety alarms all help to reduce the dependency on support personnel and provide individuals with more control over their lives. However, Medicaid regulations have yet to catch up with the shift to generic technology. “Durable Medical Equipment” (which Medicaid will pay for) can be used to purchase traditional equipment, but not more recent generic and cheaper resources.⁴⁷

Remote health monitoring—“telehealth” and “telemedicine”—are proven resources for improving the health of people with chronic conditions (often the case with people with I/DD) and for reducing hospital stays and E.R. visits.⁴⁸ Under IDEA, access to Assistive Technology (AT) was mandated where appropriate. Advocates now look to the Fourteenth Amendment to support provision of AT to help adults be integrated in to the workforce and to live in the most integrated setting.⁴⁹ Certainly the economics of AT facilitated empowerment can be compelling.

Technology can also help with the regulatory overload. For example, current practices (even more so than official regulations) covering the provision of services in small group settings require reports to be generated in 15 minute intervals.⁵⁰ A simplified online compliance and regulatory tool would provide more timely, relevant, and useful information than the current systems.

What Is the Role of the Attorney in This Change?

1. People with I/DD need support to enforce existing laws like *Olmstead*, the ADA, and IDEA. Attorneys can help prod the state to adhere to its own stated policies such as Most Integrated Settings, Money Follows the Person, and Person Centered Planning, most of which are derived from Federal regulations attached to funding matches;
2. Vigorously prosecute cases of abuse and neglect in state- and voluntary-operated housing and day programming;
3. Use the ADA to gain entry to the workplace for people with I/DD who want to work; and,
4. People with I/DD who seek to live independently encounter a maze of programs, entitlements and unforeseen hurdles to eligibility. Negotiating and maintaining coverage requires trained and independent support.

Conclusion

Taken together, the federal and state laws that require a more integrated setting, the impetus from CMS to promote Consumer Directed Services, advances in technology, an enhanced workforce and significant changes in public attitudes towards disability since the 1990 passage of the Americans with Disabilities Act, all provide a setting for change. The dismal state of New York’s finances and the current abuse scandals which have led to significant changes in management at OPWDD have provided the catalyst. We are at a point where we can move from a “planned economy” model wherein non-profit corporations provide a restricted menu of costly yet indifferent services at the direction of a highly regulatory focused state agency, to a “free market” economy where people with I/DD purchase their services from providers who are competing for their business based on quality and service.

Endnotes

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31. The Individuals with Disabilities Education Improvement Act of 2004 (IDEA) requires each state to have in place a State Performance Plan (SPP) that evaluates its efforts to implement the requirements and purposes of Part B of IDEA and describes how the state will improve such implementation. NY State's is available at <http://www.p12.nysed.gov/specialed/spp/> (last visited November 28, 2011).
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50. OPWDD regulations: “The unit of service for OPTS Community Habilitation is an hour of service with payment issued to your agency for each 15 minute time period. For each continuous service delivery period (or “session”), a minimum of one Community Habilitation service must be delivered and documented. When determining the “billable service time,” only face-to-face service delivery by Community Habilitation staff actively providing a habilitation service “counts.” Staff can be “regular” payroll staff or paid contract staff. A full 15 minutes of service must be documented in order for your agency to be paid for a billing unit. There is no “rounding up,” i.e. no payment will be issued if your agency only delivers 12 minutes of Community Habilitation service,” available at http://www.opwdd.ny.gov/wt/memoranda/images/wt_comm_hab_apendixb_072810.pdf. (last visited November 28, 2011).

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How to Prepare for and Win an Administrative Fair Hearing

By Richard A. Marchese, Jr.

As former Chief Counsel to the Monroe County Department of Human Services, I had many opportunities to both observe and advocate at Fair Hearings on behalf of the Department in cases which the Department's denial or discontinuance of Medicaid benefits was at issue. During the course of my fifteen years as counsel to the Department,



I came across several instances (actually, more than several) that left me perplexed and bemused by both the appellant's counsel's performance during the Fair Hearing and the lack of preparation for the hearing itself. I came away from many of these hearings with the same thought—my opposing counsel had not treated the matter as seriously as he or she should have treated it. In these cases, the generally relaxed attitude of counsel toward the preparation and conduct of the Fair Hearing inevitably resulted in mistakes and errors of judgment that could have easily been prevented. Now that I have joined private practice and have an opportunity to represent and litigate on behalf of clients in need of Medicaid services, I would like to pass on some words of wisdom, if you will, as to how I believe one should prepare for and conduct oneself at an Administrative Fair Hearing.

A. Carefully Review the Notice Sent to Your Client

The regulations governing Fair Hearings are set forth in 18 N.Y. COMP. CODES R. & REGS. (NYCRR) Part 358. All Medicaid applicants and recipients are entitled to written notice of any agency action which results in a denial or discontinuance of Medicaid benefits.¹ A Medicaid applicant is entitled to *adequate* notice of any action taken in accepting or denying the application. Medicaid recipients are entitled to *timely and adequate* notice of any agency action to discontinue, suspend, reduce or restrict Medicaid benefits. Timely notice means a notice which is mailed at least ten days before the date upon which the proposed action is to become effective.² "Adequate notice" means a notice that, among other things, sets forth the following:

1. The action that the agency proposes to take or is taking, and the effect of such action;
2. The effective date of the action (except in the case of a denial);
3. The specific reasons for the action;

4. The specific laws and/or regulations in support of the action; and
5. A recitation of the client's right to an agency conference, the procedure for requesting such conference, an explanation of the time frame in which the client must request a hearing, and an explanation of how to request the hearing.³

The notice requirements are usually strictly construed by the Administrative Law Judge (ALJ). As a practitioner you must carefully review the adequacy of the notice. Did the agency cite any regulation or statute as justification for the intended action? If so, was the correct regulation cited? Did the notice provide any explanation whatsoever for the intended action? If the notice appears to be deficient, this should be immediately brought to the attention of the ALJ right at the commencement of the hearing. ALJs are required to conduct an on-the-record assessment of the notice, and "must determine whether to find a notice void, require the social services district to provide additional information, or grant a recess or adjournment on the appellant's behalf."⁴ Very often you will find in busy districts that notices lack the proper citations to the laws and regulations in support of the intended action and/or the notice is confusing in its explanation of the intended action. Please make sure that this argument is made on the record in case of appellate review.

The timeliness of the notice must also be closely scrutinized. Make sure that the notice was mailed at least ten days before the date upon which the proposed action is to become effective.⁵ Again, in busy districts it is often a case that case examiners send out notices that take effect immediately, or within five days of the intended action. In the case of a discontinuance of Medicaid benefits, any notice that does not provide at least ten days notice is defective and will result in the ALJ voiding the agency's action and directing that the agency issue a new timely and adequate notice to the client.⁶

B. Request a Fair Hearing and, if Appropriate, Aid Continuing

The request for a Fair Hearing must be made within 60 days after the Social Services agency's "Determination, Action, or Failure to Act About which you are complaining...."⁷ The notice itself will contain the date by which the client must request the Fair Hearing. The request may be made by telephone or by mail to the number and address cited in the notice. Such a request can also be made via e-mail through the website offered by the Office of Temporary and Disability

Assistance.⁸ In cases in which the agency is required to issue timely notice because of a discontinuance of Medicaid benefits and/or services, if the client requests a Fair Hearing before the effective date of a proposed action as contained in the notice, the recipient will be entitled, in most instances, to aid continuing until the Fair Hearing decision is issued.⁹ Obviously, the provision of continued aid is critical to clients who have received notices indicating that their benefits will be discontinued or changed. Therefore, it is imperative that a client request a Fair Hearing before the deadline (i.e., the effective date of the notice) or else the client's Medicaid case will be closed or modified pursuant to the language indicated in the notice.

C. Review the Case Record and Evidence Packet of the Agency

As the representative of your client, you have the right to examine and receive copies of documents in your client's case record, which you will need to prepare for the Fair Hearing.¹⁰

This examination of the case record may take place at any reasonable time before the date of the Fair Hearing.¹¹ Exercise this right. The packet of evidence that the agency will introduce at the hearing contains documents that support only the agency's action or contention. The *case record* may very well be replete with documents, bank records, etc. that not only help to negate the agency's argument, but that serve to prove your contention that the agency is in error. Furthermore, upon an oral written request, the agency must provide you, as representative, with copies of any documents in the case file that you request for the purposes of hearing preparation. This must be done without charge to the client, and these documents must be provided by the agency at a reasonable date and time before the hearing, as long as the request is made five or more business days before the date of the hearing.¹² Litigating at an Administrative Fair Hearing on behalf of your client without looking at the case record is like walking into a darkened alley without a flashlight.

The same right to examine the case record applies to the documents and records that the agency will submit into evidence at the Fair Hearing. In this respect, the regulations afford your client the ability to fully see all of the evidence that will be offered by the agency in support of his or her position, a right that does not exist for the agency with respect to any records that your client will submit. The due process rights to examine the case record and records that will be offered into evidence at the hearing are for the benefit of your client and provide you with a distinct advantage when arguing your position at the hearing.

The only exceptions to the document discovery provisions cited above are records from Child Protective Services and files that are maintained by the County Attorney (or Welfare Attorney) for the agency.

Besides these exceptions, the right to examine both the case record and agency evidence packet should be exercised as a standard step in your preparation for the hearing.

D. Request an Agency Conference

18 NYCRR § 358-3.8 provides that a client may request an agency conference at "any reasonable time before the date of your Fair Hearing." The agency *must* hold the conference when such is requested by the client.¹³ The agency must bring the necessary information and documentation to the conference (including a telephone conference) to explain the reason for the agency's determination and to provide a meaningful opportunity to resolve the problem.¹⁴

There seems to be a split of opinion on whether an agency conference is necessary and/or helpful. I have always been of the opinion that one should request a conference if only because it can be to your advantage to meet with the case examiner and perhaps the examiner's supervisor who will be presenting on behalf of the agency at the Fair Hearing. You may also be able to glean information ahead of the hearing that will be helpful to you in the presentation of your case. The best reason for holding an agency conference is that many times these conferences will result in a resolution of the issues, thus obviating the need for a Fair Hearing. Obviously, there is a cost factor with both requesting and participating in a conference, but I look at it more as a discovery proceeding with an added benefit that you get to "know your enemy" and perhaps convince the other side before the Fair Hearing that you are indeed correct.

E. Prepare Documents for Submission at the Fair Hearing

There is nothing that an ALJ likes more than having the relevant laws, regulations and policy directives provided in a packet at the time of the Fair Hearing. It just makes the judge's life a lot easier. Providing these citations saves the judge the time and effort needed to pull down the relevant regulations when he or she gets around to writing his/her decision, and also serves to clearly focus the judge on the issues at hand. If in your review of the case record you find documents that are helpful to your client, by all means submit those as well. It is best to have all of these documents numbered sequentially (just as the agency does) for easy reference, not only at the Fair Hearing, but for reference by the ALJ when writing his or her decision.

If you have witnesses who are unable to come to the hearing and give testimony, consider drafting an affidavit for their signature and submission as part of your evidentiary presentation. ALJs will usually accept affidavits into evidence, and their submission will help fill out the record in the event of a subsequent Article 78 proceeding (see section J below).

Finally, conduct a search for prior Fair Hearing Decisions on point and submit these as well. The Western New York Law Center has a wonderful database of Fair Hearing decisions that is searchable by word (www.wnylc.net). Also, the State Office of Temporary and Disability Assistance has recently developed its own database of decisions going back to November 2010 that is very extensive and also searchable by word.¹⁵

F. Prepare Your Witnesses

This is the number one mistake that I have seen counsel make at Fair Hearings. Again, for reasons that I can only attribute to the fact that these are proceedings conducted with less formality than those in a courtroom, time and time again witnesses who were not prepared by their attorney blurted out information unfavorable to their case or, even worse, failed to address issues that were vital to their position and which could have resulted in a favorable decision. Also, talk to your client about how to dress for the hearing. Appearing at the hearing in a fur coat with a large diamond ring will not help the client's cause. Prepare your witness. If you do so, you will stand a much better chance of winning your case.

For example, if you will be asking for an increase in the community spouse minimum monthly maintenance allowance, citing "exceptional circumstances causing significant financial distress" (the "Gomprecht" standard¹⁶) as justification for the increase, you must sit your client down well before the hearing and go over his/her testimony. Certain things that your client believes constitute financial distress (i.e., not being able to dine out five times a week) obviously will not help the client's cause at the hearing, and such statements will inevitably be blurted out by your client if you have not spent the necessary time going over the facts of the case and the applicable legal standards. This means conducting a mock cross examination prior to the hearing, and "playing the devil's advocate" with your client.

G. Treat the Matter as a Trial in a Court of Law

Yes, the rules of evidence are relaxed (hearsay is admissible). Yes, you are appearing in a conference room instead of a courtroom without a stenographer and without a bailiff. And yes, the ALJ has no robes to wear. However, this is still critical litigation and probably represents your one and only shot at convincing a tribunal that the agency has acted in error. A relaxed atmosphere does not mean you should relax yourself. Arrive on time, dress for court, and above all, give the ALJ the deference that he or she deserves—use phrases such as "may it please the court" and "your honor." Sloppiness begets sloppiness. You cannot expect the ALJ to treat the matter with the seriousness it deserves if you are treating the case as a walk in the park. Let the ALJ know through your body language and through your words that this case is vitally important to your client and that the agency has acted incorrectly and

contrary to the laws and policies of the state of New York.

The ALJs I know usually perk up if an attorney will be presenting on behalf of a client, as this is not the norm. Remember, ALJs hear all types of cases, from food stamps and housing denials, to calculations of cash grants. Most of these cases are rote applications of the regulations to the facts. The ALJs assume that if counsel is present, the case must be different and that important issues will be discussed. Don't disappoint them with lackluster performance.

H. Make an Opening Statement

It does not have to be a soliloquy, but by all means prepare and give an opening statement at every Fair Hearing. This essentially lets the judge know what the issues are, what the evidence will show in support of your contention, and what laws and regulations apply. Look the judge in the eye and let the judge know why you are correct and that the agency is wrong. Remember that the ALJ has heard many cases before yours and will hear many afterward. It is your job to make sure that the ALJ remembers your case and will afford it the serious time and deliberation necessary to render a decision in your favor.

I. Relate the Client's Story

Personalize your client. How did he/she end up in this situation? What is your client's background? What did he/she do for a living prior to his or her health diminishing? While such information may not be germane to the legal issue at hand, it is important for the ALJ to put the matter in dispute in context. Too often we as practitioners get caught up in this arcane area of Medicaid rules and regulations, and in our eagerness to make a legal point we neglect to paint a full picture of our client for the judge's consideration. Relating the client's story through testimony of the client, spouse, children, etc., will serve as an appropriate introduction to the legal issue in dispute, and will help the ALJ to get to know your client in a way that is normally not addressed in the myriad of hearings over which he/she presides.

J. Make a Complete Record for Article 78 Purposes

This point is critical. Because the proceedings are tape recorded, it is important that everyone testifying speaks up and enunciates clearly, or else you run the risk of a transcript that comes back with the dreaded word "unintelligible" on it. Make sure that you "shoot all of your bullets" (i.e., produce all of your evidence and all of your arguments) and make sure everything gets on the record. The worst feeling when reviewing a transcript of a hearing for a possible Article 78 appeal is to find that a certain document was never submitted, or that a critical policy directive was not brought to the attention of the ALJ.

K. Submit a Memorandum of Law

The best practice is to always request at the end of the hearing an opportunity to submit a memorandum of law for the judge's consideration. This will allow you an opportunity to digest what occurred at the hearing and gives you the freedom of time to cogently get your arguments down on paper. I always submit my memos in letter form and make it brief (no more than three pages) and to the point.

If for some reason you forget to cite a regulation or ADM favorable to your case, do not hesitate to include this in your memo, with a request that the judge please consider the cited law/policy directives in rendering a decision.

L. Don't Leave the Administrative Law Judge Hanging Out on a Limb

The seven words that every ALJ hates to hear are "this is a case of first impression." I have not met an ALJ yet who wants to be a hero and make trail blazing new law for the State of New York. Even if it is a new issue, let the judge know that the law is on your side and that any decision that he or she renders will have a sound legal basis in the laws of the state of New York. Believe me—the opportunity to make new law, which may excite you, will not excite the ALJ.

M. Appellate Review of Adverse Decisions

In the event of an adverse decision, the client has four months in which to seek appellate review by way of an Article 78 proceeding.¹⁷ The respondent in such a proceeding will be both the local agency and the state of New York. The state will be represented by the New York State Attorney General's office, and will usually take the lead in the defense of the appeal.

There is an interim step that a practitioner may wish to consider in the event of an adverse Fair Hearing decision. Department regulations provide that: "The Commissioner (i.e. of the State Office of Administrative Hearings) may review and issue fair hearing decisions for purposes of correcting any error found in such decision."¹⁸ After such review, "The Commissioner may correct any error of law or fact which is substantiated by the fair hearing record." The trigger for this review process is informally known as a Request for Reconsideration. The request is made by letter to the Office of Administrative Hearings on notice (of course) to the agency and counsel for the agency. Please note that during the pendency of this review the original decision is still binding and must be complied with by the agency. Also, please note that such a request does not toll the time in which the client is to request an appeal of the decision via Article 78, unless the state so stipulates.

It is my experience that such a request for reconsideration should be used judiciously. Such a request

should also be made only in cases where it is readily apparent that the ALJ "got it wrong," and where the agency was acting without any legal justification or authority in taking the action at issue.

Conclusion

I hope that these pointers are helpful to you as an Elder Law practitioner, and that your next opportunity to litigate at a Fair Hearing will result in a positive result for your client.

Endnotes

1. N.Y. SOC. SERV. LAW § 22, N.Y. COMP. CODES R. & REGS. tit. 18, § 358-3.3.
2. N.Y. COMP. CODES R. & REGS. tit. 18, § 358-2.23.
3. N.Y. COMP. CODES R. & REGS. tit. 18, § 358-2.2.
4. See *Memorandum DSS-524EL*, RESOURCE CENTER OF THE WESTERN NEW YORK LAW CENTER, available at <http://www.wnyc.net/web/welfare-law/main.htm> (December 11, 1996) (From Russell J. Hanks to all hearing officers and supervising hearing officers, addressing the issue of inadequate notices, Office of Temporary Disability Assistance, Office of Administrative Hearings).
5. N.Y. COMP. CODES R. & REGS. tit. 18, § 358-2.23.
6. N.Y. COMP. CODES R. & REGS. tit. 18, § 358-3.3.
7. N.Y. COMP. CODES R. & REGS. tit. 18, § 358-3.5(b)(1).
8. See *Fair Hearings*, OFFICE OF TEMPORARY DISABILITY ASSISTANCE, available at www.otda.state.ny.us/oah/ (last visited November 4, 2011).
9. N.Y. COMP. CODES R. & REGS. tit. 18, § 358-3.6.
10. N.Y. COMP. CODES R. & REGS. tit. 18, § 358-3.4(b).
11. N.Y. COMP. CODES R. & REGS. tit. 18, § 358-3.7.
12. N.Y. COMP. CODES R. & REGS. tit. 18, § 358-4.2(c).
13. N.Y. COMP. CODES R. & REGS. tit. 18, § 358-4.2(f).
14. N.Y. COMP. CODES R. & REGS. tit. 18, § 358-4.2(g).
15. See *Fair Hearing Decision Archive*, OFFICE OF TEMPORARY DISABILITY ASSISTANCE, available at <http://otda.ny.gov/oah/FHArchive.asp> (last visited November 4, 2011).
16. *Gomprecht v. Gomprecht*, 652 N.E.2d 936 (1995).
17. CPLR 217.
18. N.Y. COMP. CODES R. & REGS. tit. 18, § 358-6.6.

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Pooled Trusts and the Preemption Doctrine

By Robert P. Mascali

In the Fall 2011 edition of the *NYSBA Elder and Special Needs Law Journal*, there was an article that discussed remainder funds and pooled trusts and contained the following statement:

It remains an open question as to what requirements a particular state may or may not impose in connection with the distribution of remainder funds in a pooled trust upon the death of the beneficiary, the underlying issue being the applicability of the preemption doctrine which may be a subject for a future article in this series. Suffice it to say, some states will only approve a pooled trust to operate within the state provided the trust directs that all or a specified portion of the remainder funds are used to reimburse that state for Medicaid paid on behalf of the deceased beneficiary.¹



As if on cue, this past August, the United States District Court for the Eastern District of Pennsylvania has provided us with a decision in the case of *Lewis v. Alexander*,² which reviews a Pennsylvania statute³ and gives guidance for state officials and elder law practitioners on this issue. This case is relevant to New York practice as both New York and Pennsylvania are “1634” states. Essentially there are three major testing areas of criteria that an individual would need to satisfy in order to be eligible for Medicaid, based on state criteria. New York, Pennsylvania and thirty other states and the District of Columbia are considered to be “1634” states, which are generally required to provide Medicaid to all Supplemental Security Income (SSI) recipients and also utilize a medically needy test for those not receiving SSI.⁴

Pooled trusts are a particular type of a supplemental needs trust and are specifically authorized by federal law.⁵ While the statutory requirements are similar to those governing first party, self-settled supplemental needs trusts,⁶ there are significant differences. In particular, pooled trusts need to be established and managed by non-profit entities and the non-profit entities are

permitted to retain funds that remain upon the death of the pooled trust participant.⁷

The Pennsylvania statute at issue established a number of requirements that are somewhat more restrictive than, and not contained in, the federal law. Briefly, Section 1414 establishes the following additional requirements:

- (a) The “Special Needs” requirement which goes beyond the federal requirement that the beneficiary of such a pooled trust account be “disabled” as defined by the Social Security Act and crafts a further requirement dealing with the individual’s condition and ability to otherwise pay for special needs;
- (b) The “Age” requirement which limits the availability of pooled trusts to disabled individuals who are younger than 65 years of age;
- (c) The “Expenditure Restrictions” adding a “reasonable relationship to the needs of the beneficiary” requirement to the **sole benefit** requirement in federal law;
- (d) The “Fifty Percent Payback” provision, in effect limiting the amount that can be retained by the nonprofit upon the death of the beneficiary to only one half of the remainder funds and directing the other half to be used to reimburse the state for Medicaid provided during the lifetime of the beneficiary.

The District Court summarily dealt with the issue of the impact of Supremacy Clause,⁸ and determined that the various plaintiffs have standing and that the issues raised were ripe for decision. The plaintiffs contended that Section 1414 was preempted by federal law on two separate counts, 1) as regards the entire statute based upon the “no-more-restrictive rule” established in the Social Security Act,⁹ and 2) as to certain provisions as they conflict with the “no-more-restrictive rule” and the specific trust counting rules enacted by Congress in the enabling legislation. On the other side, the state defendants contended that their statute was only in furtherance of their right to regulate trusts operating within their state and that the federal law does not require states to recognize either self-settled or pooled trusts and that in any event, the federal law was not mandatory. While the court in *Lewis* acknowledged that there have been some contrary decisions which have held the federal law to be permissive rather than mandatory (including the dicta contained in the Second

Circuit decision in *Wong v. Doar*¹⁰), Judge DuBois concluded that in this case the federal law was mandatory. From that point, the court proceeded to an examination of the preemption doctrine. The court concluded that since certain provisions of the Pennsylvania statute established a more restrictive standard than Medicaid and SSI law, and were in direct conflict with the federal statute that deals with pooled trusts, there was a preemption and those conflicting provisions were rendered invalid.

Few areas in the law deal so clearly with the intersection of federal and state laws and the concept of federalism as in the administration of the Medicaid program. Unlike Medicare, which is both established and administered by the federal government, Medicaid is a federally established program that is administered by the various states which can elect to administer their programs in different ways subject to certain requirements. In that regard, it has been said:

While Medicaid is a system of cooperative federalism, the [preemption] analysis applies; once the state voluntarily accepts the conditions imposed by Congress the Supremacy Clause obliges it to comply with the federal requirements.¹¹

As the efforts to reform the Medicaid system continue in New York State and elsewhere, it is necessary to keep this basic constitutional precept in mind.

Endnotes

1. NYSBA *Elder and Special Needs Law Journal*, Fall 2011, page 48.
2. *Lewis v. Alexander*, No. 06-3963, 2011 U.S. Dist. Lexis 95109 (E.D. Penn. Aug. 22, 2011).
3. 62 PA. CONS. STAT. ANN. § 1414 (2005).
4. See POMS SI 01715.010. The remaining states are either “209 (b)” states or “SSI criteria” states.
5. See 42 U.S.C. § 1396p(d)(4)(C) (2010).
6. See 42 U.S.C. § 1396p(d)(4)(A) (2010).
7. See 42 U.S.C. § 1396p(d)(4)(C) (2010).
8. U.S. CONST. art. VI, cl. 2. The Supremacy Clause of the U.S. Constitution provides as follows: “This Constitution, and the Laws of the United States which shall be made in Pursuance thereof; ...shall be the supreme Law of the Land; and the Judges in every State shall be bound thereby, any Thing in the Constitution or Laws of any State to the Contrary notwithstanding.”
9. See 42 U.S.C. § 1396a(a)(10)(C)(i)(III) (2010).
10. See *Wong v. Doar*, 571 F.3d 247, 258 (2d Cir. 2009) (“[W]e discern no inconsistency in a statute that provides that an individual may create a Special Needs Trust with SSDI income, but leaves it to the agency to determine how to treat the income contained in such a trust—whether from SSDI or any other source—or purposes of Medicaid eligibility.”)
11. *Lewis*, 2011 U.S. Dist. LEXIS 95109 at *67 (citing *Lankford v. Sherman*, 451 F.3d 496, 510 (8th Cir. 2006)).

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The views and opinions contained in this article are those of the author and do not represent the view or opinion of NYSARC, Inc.

Seeking Reimbursement for Private School Tuition

By Lauren I. Mechaly

When the 2011-2012 school year began, nearly 500 students with disabilities were without a kindergarten placement in New York City.¹ This means that the Committee on Special Education (CSE) convened to develop an Individualized Education Program (IEP) for each of these students, and then failed to make a recommendation for an appropriate placement for September.



Although kindergarten is not a mandatory school year for students in New York,² many parents feel that in addition to the natural continuation of the preschool program, kindergarten is a necessary foundation for the transition to first grade. In these tough economic times, parents are faced with a very difficult decision—send their son or daughter to a general education classroom, or place him or her in a private school. For a parent with a special needs child, the answer is very clear. The question simply becomes, who pays for the private school tuition?

Under federal and state regulations, a student with a disability is entitled to a free appropriate public education (FAPE).³ The purpose of the Individuals With Disabilities Education Act (IDEA) is “to ensure that all children with disabilities have available to them a free appropriate public education that emphasizes special education and related services designed to meet their unique needs and prepare them for further education, employment, and independent living....”⁴

In general, the local educational agency (LEA) where the private school is located is responsible for equitable participation,⁵ and must spend an amount “equal to a proportionate amount of Federal funds made available” under the IDEA to meet its obligations to parentally placed private school children with disabilities.⁶ The same does not apply to students who have been parentally placed as a result of the LEA’s failure to provide FAPE in the public school.

A child’s IEP must be implemented on the first day of the school year.⁷ Failure to do so is a denial of the student’s right to FAPE. Implementation of the IEP includes placement in an appropriate program designed to meet the student’s unique educational needs.

In New York City, if it is determined that the public school cannot provide an appropriate educational environment, the CSE may defer the child to the Central

Based Support Team (CBST) for placement in a state-approved non-public school (NPS).⁸

In a case now referred to as simply “*Jose P.*,”⁹ it was affirmed that the Board of Education must “take all actions reasonably necessary to accomplish timely evaluation and placement in appropriate programs of all children with handicapping conditions.”¹⁰ A Nickerson Letter, named for Eugene P. Nickerson, who was appointed to hear the case in the United States District Court for the Eastern District of New York, must be issued to a student in New York City if the CSE fails to recommend a placement within thirty days of the CSE review meeting that established the student’s program for the upcoming school year.¹¹ Although a Nickerson Letter authorizes tuition funding for an NPS,¹² it passes the burden onto the parent to first and foremost to find an appropriate school for the student, and then find an appropriate school with an available seat. While this may be a viable solution in theory, practically it often poses more difficulty to the parent than it is worth, especially when the Nickerson Letter is presented to a parent in August.

If the LEA, such as the New York City Department of Education (NYCDOE), denies a child’s right to FAPE, the parents’ recourse is to request an impartial hearing by filing a Request for Due Process.¹³ This administrative proceeding, held before an Impartial Hearing Officer (IHO), sets forth any and all violations alleged against the LEA,¹⁴ and requests certain relief for the student for the LEA’s failure to provide a FAPE.

It is important to remember that a child with a disability who has been parentally placed in a private school does not have an individual right to receive special education and related services that he or she would receive if enrolled in a public school.¹⁵ If, however, the parent is seeking tuition reimbursement from the LEA, the child with a disability shall continue to receive special education and related services that he or she would receive in the public school system. It is also important to note that the Supreme Court has held that “IDEA authorizes reimbursement for the cost of private special-education services when a school district fails to provide a FAPE and the private-school placement is appropriate, regardless of whether the child previously received special education or related services through the public school.”¹⁶

It is well settled that parents may be entitled to tuition reimbursement despite the unilateral withdrawal of their child from the public school¹⁷ for failure of the public school to provide a FAPE. The factors a parent must prove in such a case, hereinafter referred to as the

“*Burlington* factors,” include 1) the public school placement is inappropriate; 2) the private school placement is appropriate; and 3) the equities favor the parent.¹⁸ There are two sources of funding available to parents who unilaterally place their child in a private school setting.

The Supreme Court unanimously held that if a public school fails to provide an appropriate education to a student with a disability, and the student receives an appropriate education in a private placement, the parents are entitled to be reimbursed for the child’s education.¹⁹ Through this “Carter funding,” the Supreme Court has created the ability to unilaterally place a student in a private school, and to seek reimbursement through the impartial hearing process. However, although this case presents the parent with the opportunity to seek reimbursement for tuition following a unilateral placement in a private school, this case does not provide for families who cannot afford to pay for private school tuition.

The Northern District in New York identified that a conflict arises between a student’s right to FAPE and the state’s approval process “when a parent does not have the financial means to front the cost of a non-approved private school. Without external support, the child would have no chance at what has already been determined to be his or her opportunity to receive an appropriate education.”²⁰ The Court held that if the *Burlington* factors have been met, and if a parent can demonstrate that he or she is unable to afford unilateral placement in a private school, “the public school must pay the cost of private placement immediately.”²¹ Through this “Connors funding” the court created the ability for parents to unilaterally place a student in a private school and seek prospective payment.

During the pendency of the impartial hearing, the parent has the right to invoke a “stay-put,” meaning that the last agreed-upon IEP will be in place during the pendency of the proceeding.²² For the parents of the 500 students in New York City without kindergarten placement, the conflict arises whether to implement the child’s preschool IEP during the pendency of the proceeding, and place the child back in a preschool program, or to withdraw the child from the public school system and unilaterally place him or her in a private school for the kindergarten year. In *Burlington*, the court recognized the conflict parents face between maintaining their child in an inappropriate placement and finding the funding for a private school. Accordingly, the court held that a unilateral withdrawal from school prior to an administrative hearing does not waive the child’s right to such an equitable remedy at the end of the review process.²³

Conclusion

It is important for parents to know that their child’s right to a free appropriate public education should not be affected by the inability of the school district to provide an appropriate public school setting. Whether the school district has recommended an inappropriate placement, or has failed to recommend any placement, the parents of a special needs child should always remember that they are entitled to seek reimbursement for private school tuition. Most importantly, a parent should know his or her rights, and should seek the advice of counsel if those rights are being violated.

Endnotes

1. Corinne Lestch and Ben Chapman, *Hundreds of NYC students still without seats as school year begins*, DAILY NEWS, Sept. 8, 2011, available at http://www.nydailynews.com/ny_local/2011/09/08/2011-09-08_no_seat_cant_stand_it_frustrated_irate_parents_rip_ed_dept_after_about_500_kids_.html?print=1&page=all.
2. NY Educ. L. § 3205.
3. 20 U.S.C. § 1412(a)(1); 8 NYCRR § 200.4(c)(5) (2011).
4. 20 U.S.C. § 1400(d).
5. 34 C.F.R. § 300.132(a); 20 U.S.C. § 1412(a)(10)(A)(i).
6. 34 C.F.R. § 300.133(a); 20 U.S.C. § 1412(a)(10)(A)(i)(I)-(II).
7. 8 NYCRR § 200.4(e)(1)(i-ii).
8. *Approved Private, Special Act, State Operated and State Supported Schools in New York State*, NYSED.GOV June 30, 2010, available at <http://www.p12.nysed.gov/specialed/privateschools>.
9. *Jose P. v. Ambach*, 669 F.2d 865 (2d Cir. 1982).
10. *Id.* at 867.
11. 8 NYCRR § 200.4(e); NY Educ. L. § 3206-c.
12. The reader should note that only schools on the state-approved list will accept Nickerson Letters as a source of funding. For placement in private schools not on the list, the parent must consider “Carter” funding and “Connors” funding, discussed later in the article.
13. 8 NYCRR § 200.5(i); 20 U.S.C. § 1415(b)(7) and 1415(c)(2); 34 CFR 300.508.
14. The statute of limitations in these cases is 2 years. 20 U.S.C. § 1415(f)(C).
15. 34 C.F.R. § 300.137.
16. *Forest Grove Sch. Dist. v. T.A.*, 129 S. Ct. 2484, 2496 (2009).
17. *Burlington Sch. Comm. v. Dept. of Educ.*, 471 U.S. 359 (1985).
18. *Id.*
19. *Florence County Sch. Dist. Four v. Carter*, 510 U.S. 7 (1993).
20. *Connors v. Mills*, 34 F. Supp. 2d 795 (N.D.N.Y. 1998).
21. *Id.* at 806.
22. 20 U.S.C. § 1415(j); 8 NYCRR 200.5(m).
23. *Burlington*, 471 U.S. at 370.

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Guardianships and Supplemental Needs Trusts (SNTs) as Planning Tools for Parents of Adult Disabled Children: A Case Study

By Sara Meyers

Many couples and individuals come to our office for an estate planning consultation. We review their estate plan and long-term care needs and ask about their age, health, finances, and family. Only later do they tell us about their adult disabled child. This article focuses on children with special needs who are over the age of 18, and, using a few case examples, provides an overview of Guardianships and Supplemental Needs Trusts (SNTs) as planning tools for their parents.



The typical scenario is as follows: a couple in their mid-seventies with three children, one of whom is in his or her late forties with a disability limiting his or her capacity. Often, many people with disabilities who are currently this age have lived at home their entire lives, were in school until age twenty-one, and have not received any support services or job training. The parents have not done any special needs or long-term care planning for their child. As part of the parents' estate plan, we would discuss planning for their child both during their lifetime and upon their death, as she will need support services in place once her parents can no longer care for her, such as life skills training, a place to reside, and protection of assets.

We advise the parents to commence a Mental Hygiene Law Article 81 Guardianship proceeding so that they may be appointed the child's guardian, both of person and property. This will grant them the legal authority to make medical and financial decisions for their child. If the child is a Medicaid recipient and has surplus income, or if the child is not on Medicaid, but may be in the future, we request that the Court authorize the creation and funding of a pooled income only trust. For example, the NYSARC, Inc. Community Trust II, for the deposit of the individual's Medicaid surplus income.

In terms of estate planning for the parents, we recommend that their Last Wills contain a Supplemental Needs Trust (SNT) if they have a beneficiary with a disability. An SNT is a Trust created for the benefit of a

disabled individual, either inter vivos or testamentary. The funds are exempt for both Medicaid and SSI purposes. By depositing their inheritance into an SNT, the money will not affect Medicaid or SSI eligibility. Congress, in 1993, created an exception under the amendments to the Omnibus Budget and Reconciliation Act¹ to specifically authorize the use of Supplemental Needs Trusts for the benefit of individuals who are under the age of sixty-five and disabled according to Social Security standards. Social Security defines disability as a mental or physical impairment expected to last at least 12 months and prevents the person from engaging in substantial gainful activity.²

Another familiar instance revolves around a child with a disability who has recently turned eighteen, who lives at a school which provides specialized instruction catering to his needs, providing life and vocational skills training. In addition, usually the parents and grandparents in this scenario have given the child money, and for explanatory purpose let's say that he has accumulated over \$100,000 in a Uniform Transfers to Minors Act (UTMA) account at a local bank. The UTMA gives the child a right to these assets. A transfer under the UTMA "is irrevocable, and the custodial property is indefeasibly vested in the minor."³ Accordingly, the property belongs to the child, and the parent and/or custodian cannot prevent him from accessing same.

In this case, the parents did not want their child to have access to the funds, now that he turned 18. They were concerned that their child, who is unable to understand simple math, could not manage these funds. We filed an Article 81 Guardianship Petition for the parents to be appointed guardians of both person and property, and requested court approval to create and fund a first-party/self-settled SNT with the child's assets and to appoint the parents the Trustees thereto. Self-Settled Trusts are SNTs funded with a disabled beneficiary's own funds, or funds to which he is entitled such as a personal injury award or inheritance. Such trusts also must have a Medicaid payback provision. Upon the death of the disabled beneficiary, all remaining trust principal and accumulated income must be paid back to Medicaid to reimburse Medicaid for all benefits paid to the disabled beneficiary during his or her lifetime. Any funds left over may be paid to the named beneficiary of the Trust.

The SNT we drafted and submitted to the Court, and to the Department of Social Services (DSS) for approval, is a First Party/Self Settled SNT with a Medicaid payback provision. DSS must approve the SNT. In many jurisdictions, the Court will not sign the guardianship judgment until it has received a letter from DSS approving the SNT. Additionally, the guardianship Judgment was tailored for flexibility in terms of the Guardian of the Person. The guardians of the person, the parents, are to consult with their child in relation to decisions regarding their abode and medical needs. Also, to give their child some independence, the guardians are to establish a checking account for their son or daughter, independent of the guardianship account, depositing \$200 a month for their child to use at his or her discretion. This provides their child some autonomy and helps him or her develop a sense of ownership and independence.

We also advised the parents not to deposit other monies into the UTMA account, which was re-titled to the name of the SNT. We also recommended that they create a Third Party SNT pursuant to EPTL 7-1.12 and deposit any gifts or monies that they or others wish to give to their child to an account in the name of the Third Party SNT. A Third Party SNT is a Trust created and funded by someone other than the disabled beneficiary with funds that are not those of the disabled person. The SNT can be "inter vivos" or "testamentary." For inter vivos third-party SNTs, the creator can be a person or entity other than the beneficiary's spouse or a person with a legal obligation (a parent of a disabled child under the age of 18) to support the beneficiary. A parent of a minor child can fund and create a testamentary trust for the disabled beneficiary.

EPTL 7-1.12 codifies *In Re Escher*,⁴ wherein the Bronx County Surrogate's Court held that a testamentary trust, established by the parents of a disabled child, allocating the principal solely for the beneficiary's "necessary support and maintenance" was protected from a State claim for reimbursement on the

amount it had paid on behalf of the daughter. The court found that the testator had intended the principal to be used for the daughter during her lifetime.

It should also be noted that the funding of a Third Party SNT has Medicaid planning benefits for the Grantor of the Trust. The transfer of assets to the SNT is considered an exempt transfer by the transferor, and no period of ineligibility is created.

We had a case recently that illustrates what can happen if estate planning is not done, or if a parent's estate plan fails to take into consideration the needs of an adult disabled child: Mom died with a Last Will leaving all of her assets to her son, an adult with a disability who resides in a group home and receives SSI and Medicaid. If he were to receive the bequest outright, then he would lose his SSI and Medicaid. A Guardian Ad Litem was appointed for him in Surrogate's Court to represent him and his best interests. The court agreed to have the executor of the estate hold the son's bequest pending a guardianship petition in Supreme Court, as well as the approval of a First Party SNT for the deposit of the inheritance. If the mother's Last Will had a provision for a disabled child, his bequest would have gone into a Third Party SNT, with no payback provision and the Guardianship and the need for a First Party SNT would have been obviated.

Endnotes

1. See generally Pub. L. No. 103-66, 107 Stat. 312 (1993).
2. 42 U.S.C. § 423 (2006).
3. See Uniform Transfers to Minors Act (2005).
4. 94 Misc. 2d 952, affirmed 75 A.D. 2d 531, 426 N.Y.S. 2d 1008.

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Recent New York Cases

By Judith B. Raskin

Medicaid: Fraudulent Conveyance

Dept. of Social Services (DSS) objected to the accounting in the estate of a refusing spouse, claiming assets fraudulently conveyed were available for recovery. Granted in part.¹

DSS appealed from a dismissal of its objections to an accounting in the estate of a Medicaid recipient's refusing spouse. The value of the estate was less than the claims of creditors, including DSS.

DSS argued that three conveyances made by the refusing spouse were fraudulent under Debtor Creditor Law and should be available to creditors. The spouse had purchased an annuity and received fair consideration in return; gifted a camp to his children retaining a life estate; and gifted a car to his caregiver.

The Third Department held that only the car was a fraudulent conveyance. It was the only gift made at a time when the value of the gift reduced decedent's assets to less than his total debts. The decision cites Debtor Creditor Law § 273, which states: "any conveyance made without fair consideration that renders a person insolvent at the time of the transfer is considered fraudulent as to creditors without regard to intent." DSS could recover, to the extent available, an amount equal to the excess resources available at the time of application plus the excess income for each of the 39 months that decedent received medical assistance.

Medicaid: Uncompensated Transfers

Petitioner appealed from a Medicaid denial due to uncompensated transfers. Denied.²

Petitioner facility submitted a Medicaid application for its resident, Bernadette Jordan. The application was denied because the applicant had transferred assets from her revocable trust to her daughter. The facility appealed. The denial was upheld at a fair hearing. In the Article 78 proceeding, petitioner facility argued that the transfers were not gifts. The documented expenses were advanced by the daughter with the expectation of mother and daughter that the daughter would be reimbursed.

The court held that the decision was rational and not arbitrary and capricious. On further appeal, the Second Department affirmed, as there was no contem-

poraneous written agreement showing the intention of repayment.

Medicaid: Spousal Income Allowance

Medicaid recipient appealed from fair hearing decision directing her to pay her excess income to the nursing home and not to her spouse.³

A nursing home resident and Medicaid recipient brought this Article 78 proceeding. She appealed from a fair hearing decision directing her excess income be paid to the facility and not to her spouse. Relying on *Balzarini v. Suffolk County Dept. of Social Services*,⁴ she argued that her spouse's living expenses such as mortgage payments, real estate tax, credit card payments, and utility costs qualified as exceptional circumstances resulting in significant financial distress pursuant to state and federal Medicaid law. Subsequent to the filing of the petition, *Balzarini*, was reversed. The Appellate Division held in the Article 78 proceeding that spousal living expenses were not exceptional circumstances. The appeal was denied based on the reversal in *Balzarini*.⁵

Article 81: Bond

*Matter of Karen T.*⁶

Kim T. was appointed guardian for her daughter and ordered to obtain a bond in the amount of \$800,000. She petitioned to reduce the amount of the bond as the ward's assets under a ladder settlement would not exceed \$310,000 in the first year. In addition, the bonding company would not issue a bond greater than the value of the ward's assets.

The court lowered the bond amount to \$310,000 for one year, at which time the guardian would submit an accounting to determine the amount of the bond requirements thereafter.

Article 81: Fees

Petitioner in a withdrawn Article 81 proceeding appealed from an order directing him to pay counsel fees. Granted.⁷

When this Article 81 proceeding was withdrawn, the court ordered petitioner to personally pay \$825 to Mental Hygiene Legal Service for its fee as counsel to the AIP. The petitioner appealed.

The Second Department reversed. When an Article 81 proceeding is withdrawn or dismissed the court may, in its discretion, order payment by the petitioner.



In this case, the petitioner did not bring this proceeding in bad faith and was not held responsible for the fee.

17-A Fees

17-A guardians petitioned for fees. Denied.⁸

Parents of Jonathan EE were their son's 17-A guardians for several years before they were replaced in 2009. They petitioned for guardianship fees. The Surrogate's Court, Broome County, awarded them \$41,872 to be paid from Jonathan EE's supplemental needs trust. The trustee appealed. Petitioner parents cross appealed.

The Appellate Division, Third Dep't, reversed, dismissing the petition on the grounds that there is no statutory provision in Article 17-A of SCPA authorizing fees to a 17-A guardian.

Article 81: Penalty Period

Article 81 guardian argued that a three-year look back should be applied to property transferred in 2005. Denied. No gift was made.⁹

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

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

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

Article 81: Health Care Decisions

Petitioner sought appointment as Article 81 personal needs guardian to override her mother's MOLST and authorize artificial feeding. Granted.¹⁰

The petitioner, one of seven children of the Alleged Incapacitated Person (AIP), Joan Zornow, sought appointment as Article 81 guardian with the authority to make medical decisions for her mother with advanced Alzheimer's disease. Joan Zornow had not executed a health care proxy but had executed several Medical Orders on Life-Sustaining Treatments (MOLSTs), directing no artificial feeding and no hospitalization. The court appointed petitioner and her brother, Douglas Zornow, as temporary co-guardians. Douglas Zornow supported the directions in the MOLST and testified to his mother's wishes to forgo artificial feeding. His sister testified to their mother's expressed desire for artificial feeding. The court found the request for artificial feeding to be clear and convincing evidence of the AIP's wishes in her specific situation.

The court appointed the petitioner and Catholic Family Services as co-guardians. As Joan Zornow was a Roman Catholic, the court extensively reviewed Roman Catholic beliefs regarding artificial feeding. It directed the guardians to follow the Roman Catholic position to provide artificial feeding with few exceptions and to disregard any directions in the MOLST to the contrary.

Probate: Undue Influence v. Duress

Named executor and sole beneficiary moved for summary judgment in action to set aside will. Denied on claim of duress. Granted for all other claims, including undue influence.¹¹

Decedent left a \$2.8 million estate. The surviving co-executor grandnephew, who was also the sole beneficiary, submitted the will for probate. The will named him as contingent beneficiary but he became the sole beneficiary due to the prior deaths of the decedent's sisters. Four nieces and nephews contested the probate on several grounds, including undue influence and duress. The proponent moved for summary judgment. His sister testified to the decedent's fear and distrust of the proponent. In considering the motion, the court extensively reviewed the evolving legal issues of undue influence and duress.

The court denied summary judgment on the claim of duress but granted it for all other claims including undue influence. It held that there was insufficient evidence to support undue influence but it remained an issue of fact as to whether the decedent felt threatened by the proponent to the extent that she was afraid to make changes to her will.

Article 81: Attorney Fees

Attorney guardian sought legal fees for preparation of annual accounts. Denied.¹²

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

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

Article 81: Appointment

Brother petitioned for appointment as personal needs guardian where his children were remainder beneficiaries of the AIP's significant trust. Independent guardian appointed.¹³

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

The evidence and court evaluator's report detailed the AIP's need for assistance and supported keeping her at home. A neighbor testified that the brother was not fully addressing the AIP's needs and that he was protecting the trust assets for his children.

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

his appointment but the court saw an actual conflict in this case.

Endnotes

1. *Estate of Steele*, 85 A.D.3d 1375, 925 N.Y.S.2d 250 (3d Dep't 2011).
2. *Komanoff Center v. Daines*, 85 A.D.3d 1183, 926 N.Y.S.2d 629 (2d Dep't 2011).
3. *Zickl v. Daines*, 83 A.D.3d 1582, 921 N.Y.S.2d 761 (4th Dep't 2011).
4. 55 A.D.3d 187, 863 N.Y.S.2d 706 (App. Div. 2d Dep't 2008), rev'd by, in part, petition dismissed by, certified question answered by, 16 N.Y.3d 135, 944 N.E.2d 1113 (2011).
5. *Id.*
6. *Matter of Karen T.*, 91755/10, N.Y.L.J. 1202500683817, N.Y.L.J. p. 34, vol. 246 No. 10 (Sup. Ct. Bronx Co., June 14, 2011).
7. *Matter of Marjorie T.*, 84 A.D.3d 1255, 923 N.Y.S.2d 870 (2d Dep't 2011).
8. *Matter of Jonathan EE*, 86 A.D.3d 696, 927 N.Y.S.2d 171 (3d Dep't 2011).
9. *Matter of Abrams*, 31 Misc. 3d 830; 921 N.Y.S.2d 485 (Sup. Ct. Kings Co. 2011).
10. *Matter of Zornow*, 31 Misc. 3d 450, 919 N.Y.S.2d 273 (Sup. Ct. Monroe Co. 2010).
11. *Matter of Rosasco*, 31 Misc. 3d 1214A, 927 N.Y.S.2d 819 (Sur. Ct. New York Co. 2011).
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13. *Application of A.M.*, 917XX10, N.Y.L.J. 1202493613803 (April 25, 2011).

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The Proper Purpose of Assessments in the IEP Process: It's a Lot More Than Reporting a Score

By Anthony Rifkin

Tests and the Perceptions They Create

We've all experienced not quite being able to remember something. Whether it's a word, fact, etc.—it's on the tip of our tongue, but just won't come out.

We are lucky because there is a very good chance we'll be able to retrieve that piece of information. Simply by doing something else, the lost information will probably pop out. But what about those that can't remember, and are challenged by a bottleneck in that very same channel? We are able to "stay on top of" things because we can remember. But what happens to those that face such a challenge? Should it be assumed they don't know, or that they are less intelligent?

I use this as a simple example to show how and why testing must be so much more than scoring "yay" or "nay" on a set of test items. As the above example demonstrates, what is the meaning of such a score, if it reflects only that the right answer came out? Is it an honest assessment of the individual? If it is us, then we can show what we are able to retrieve, and how we are able to perform. But with those that face challenges, the same score may only indicate that that retrieval or performance is not forthcoming. But that score tells us nothing about *why*. If an individual requires a customized educational program that focuses on his or her needs, then an answer to *why* is needed.

For starters, it is also important to note how many such challenges may exist. There are broad categories, of course: problem solving, memory, attention, perception, language. But within each of these there are a multitude of possibilities. Secondly, it is important to remember what those scores on intelligence and educational tests actually reflect: the norms for individuals the same age. In other words, just as we can perform well in relation to our peers and can score well on these tests, those with challenges don't. But again, that is all that the scores are indicating—these individuals don't perform well in comparison to others, in general.

A. The Importance of Individual Testing for Designing a Program

We may have the responsibility to design a program for these individuals, which must not only ad-



dress their reality, but also help them to deal with it. Such a program should address their challenges to help them to learn and develop, so that they may participate in the world as fully as possible. It is the challenges themselves that therefore must be assessed.

This is a tricky business, but also not beyond our purview, as it can be done with those very same tests. We can even use those very same scores in doing this, using those scores as part of a larger interpretive and exploratory process. They become means to map out a terrain, showing the client's high and low spots, strengths and weakness. However, that is just a first step, as one must then try to discern why the terrain is shaped in the way that it is. The terrain of an individual's mental, emotional and social makeup is a very subtle thing. Additionally, one must account for his or her experiences up to that time as well.

The task is, at the very least, daunting. It can be easily understood why educational systems fall back upon normed scores to place and position individuals. Thankfully we can examine our clients' performances on those tests, item by item. In that we can start to see what may underlie their performance, test further, and then eventually find what underlies that terrain. This is an ongoing process. For the individual's subsequent program can be structured to test that terrain too. The initial key is to first perform a decent assessment. With that, we can start to open the door for them.

B. The Process Approach to Testing: Exploring the Whole Terrain

Luckily, the modes for testing such as terrain have been explored, and have been shared for some time now, using the same tests that standardized scores are reported from. One of the primary approaches to this mode of testing is called the Process Approach.¹ Via the Process Approach, one examines how the individual arrived at his or her answers on a test. In fact, on some tests, alternative means are provided for testing the same content. For example, if one cannot retrieve a name, one may be able to recognize it, thus testing for the blockage mentioned earlier. Regrettably though, an individual's issues are often not that simple. In fact, the combination of two or three challenges can provide quite a knot to be untied. That is why testing across the whole terrain becomes so important. This is the cornerstone of neuropsychological testing, of which the Process Approach is a part. Obviously, on one hand, schooling in terms of brain functions can play an important part in the interpretive process. With head inju-

ries and conditions leading to insults of the brain, one can see specific impairments in function and in the performances that result from localized damage. However, the parts of the brain are not organized in isolation of each other. Instead, the brain normally performs its functions via connections made between multiple areas of the brain, so that multiple processes can occur simultaneously. When you hear something, there is an order and partitioning to processing what you hear. Multiple systems, including cognitive, mnemonic, linguistic and perceptual, may be brought to bear on the processing of a single piece of information. An additional full set of processes may in turn be brought to bear on one's reaction to it, which can include a response, motoric or linguistic, and/or seeking further information, thus involving perceptual, attentional or linguistic processes.

If a brain insult occurs to one of the areas responsible for a part of one of these processes, then an isolated impairment may be seen, which will be visible when testing these individuals. In fact, they can be very similar to our "tip of the tongue" example, with all else functioning normally. The rest of their language and thinking may be in place, with their not being able to perform that one piece. It's as if that piece just dropped out. Or, depending on the injury, there may be multiple such pieces. Or worse, there may be qualitatively different complexes. Still, there can be an identifiable, "localized" sense to what processes are missing.

1. Neurological Challenges of Children

However, with the neurological challenges that children face, the situation is different. The subtle contributions of development are so strong that isolatable functions and performances are less likely, especially in terms of how we know those functions in our fully-developed, "adult" terms. Kids are still putting the pieces together. Even the functions that naming or remembering serve can be different for a child than they are for an adult. This is so because development is the core focus of children's lives. For example, it is not just that piece that is lost when trying to retrieve a piece of information, but access to structures of knowledge and ways of knowing, which a child is actively building, for which he or she needs those "pieces of information." By comparison, we have already "built" our knowledge bases, so we only need the information in the moment. And for the child, each of the sub-systems, e.g., attentional, perceptual, linguistic, and motoric, play a part in development that must be coordinated with the others. If one of them does not play its part, a broader set of issues may arise. These are like the complexes I mentioned for adults above, but their ramifications go even further. For they affect the ground that is being built by the child, through their development. With kids, one is assessing a dynamic terrain, and having to judge occurrences yet to come.

2. Examination of a Single Test Item

Before we start feeling too phenomenally intimidated by all this, let's drop back and look at a single test item to see how we may tackle it. Part of what is so interesting about the standardized tests is how many systems may come into play within one test item. This is obviously the case, given the description a few paragraphs back of how multiple systems must be coordinated for processing a single piece of information, much less our having to respond to it. There is seldom an item that is a solely "verbal" or solely "perceptual." Like anything else, an item will be made of parts. A test with a set of such items may be similar. But caution must be taken here too, for new processes may be added on with later items, so that they are "harder." For example, with an arithmetic problem, there's a qualitative difference between addition of single digits versus addition of double digits, the addition of two numbers and the addition of three or more numbers, etc. Therefore, our basic unit must be the single test item, noting exactly what the task demands are for *each* item.

Within a single such item one can see how an assessment can account for the above. A single item, with its multiple processes, is like a microcosm of the larger whole, with the larger whole operating by the same principles. A single item is made of parts, so examine how those parts are dealt with and you will be able to see how the whole operates.

Take a standard arithmetic word problem. "If Mary has 6 tomatoes and sells 3...." You've already solved it, without my even having completed the statement. Interesting, eh? You did it in your head, mentally. And you did it automatically. I didn't need to tell you to do it. Six minus three equals three. You used memorized "math facts." Still, a child counting on his or her fingers could solve it. There is a strong linguistic component too. How did you and the child arrive at subtraction? A linguistic convention indicated by the word "sells" tells us this, plus the concepts behind "If Mary has....," so that we're looking for some alteration in that amount.

That is an example of just a small piece of the mental terrain that is your life, that you don't even think about. Yet the child must build a terrain like that which you now stand on. However, our judgments of a child and their performance are not always so lenient. Even if transferred to paper, written down and solved, these are clearly mental manipulations. But what if a child can't do it without writing it down? Is he or she unable to perform the mental manipulation? Hardly, especially if he or she did all the steps of translating and transferring the problem, performing the calculation, and arriving at the solution. No, rather, that child may be burdened by some other aspect of short term retention, of not being able to hold on to the information *and* perform the mental manipulation at the same time. Now we are starting to get at something.

Whereas this single item is probably not making you feel comfortable with this world of assessment yet, let me expand to show you where it fits. What if that single item, just the mental arithmetic problem alone, with its answer scored as “right” or “wrong,” is all the information gotten from the testing? Then all that underlies there is missed. For those of us who can “pop out” our answer, this is not a problem. For a child that is struggling with some *aspect* of this, it is a problem. Luckily, in this case, it is likely that our child will be given a sheet of written problems to solve too. But if he or she does well with those, then it may be said “good with calculations, but not good with mental manipulations.” Even worse, that mental arithmetic score may be entered into an overall verbal score for the child, as they are “word” problems, thus lowering that score too. Of course, any test worth its salt and the testers who administer them will note the significant difference of this test from others within that “verbal” domain. But in the process of getting those scores reported, and meeting the demands for the classification and placement decisions for all students, are these differences really noted?

C. Comparing Single Items Across Tests

So we stop for a moment, and start with our single item again. If we at least have it as a snapshot of the student, that may give us an honest starting point, before all else is swept under the rug. While our single item is still no less intimidating, it at least gives us something: something real.

The trick for using it, though, is in using it in combination with other test items—across tests—but doing so in terms of those parts I illustrated. If two test items on different tests, share two parts, but differ on a third part, and the child’s performance is different on these two items, then what? This is why so many tests are administered during neuropsychological testing. Only in this way can you get a true picture of this child’s terrain, for his or her particular strengths and weaknesses. For example, that very subtle difficulty in retaining and comparing information when problem solving mentally may show up elsewhere. Of course, with experience you know what tests those may be, so you use them. As now you are looking at the terrain itself, and testing it. The scores are secondary. Though you calculate them too, so that when writing about your findings you can say “the child fell below the norms on X,” but then with your comparison of items you can say “but here appears to be the reason why.” It is the combination of elements within particular tasks that you are now looking at, or more precisely, that you are looking at to see how the child responds. A similar task with just perceptual combinations may not give the child a problem. But that may be because the perceptual problem is seen, and can be solved by using mental manipulations of visually present materials, such as in puzzles. Or,

because the child got to perform the task motorically. So you look at tests that require the manipulation, juxtaposition and selection of visually presented materials without motor manipulation—quite a mouthful, but you know the tests, and what is done with them. Or maybe it’s the retention of linguistic information, which must then be manipulated, that is giving the child a hard time. So you look to see if they can handle other types of verbal materials that require inferences and prediction. Or is there something in the word/arithmetic problems themselves? Or is the problem in the character of number, and how the child relates to that?

In this way, all the single items are like atoms, bouncing off of each other. The sets they come from may have similarities and differences within them. So you can see whether the atoms do or don’t bond to make molecules. One watches their behaviors, and performs tests to see how they behave. And in this way one can come to know a child’s terrain—by closely examining it with these special tools, tools that one becomes familiar with, and with which one is able to see the nuances of an individual.

Finally, with a view of the child, one must then approach the dynamic of his or her development. As noted, a child’s purpose and place with all of this is very different from ours. Children are testing and trying things. They are learning and coming to be. But as we are viewing them, there is another point we should remember. We have values that we bring to this picture, much like the judgments I mentioned above. But is it the child we see, or our judgments? For we see a low score in mental arithmetic, or his need to use paper to solve the problem, but is that the end of the world? Our view says something is wrong. But have we looked at its meaning for the child and, most importantly, for his or her development? For, what is the effect of something being declared “wrong”? With that, and our normative scoring systems, we become as much of an “effect” upon development as anything else!

I express the idea in this way to suggest what our role is at this point, as we head toward setting out a program for the child—one that hopefully relates to his or her educational needs. So let’s say we find that there’s a mix, right there at the point where the linguistic aspect of the problems meets the arithmetic itself. To overcome this impasse, the child has to write down the problem. We find that this enables him or her to make the transition. Hypothetically, what if the other children aren’t allowed to do that, and there is a very stringent rule at the child’s school about this? Should our child be allowed to? Will he/she be given an unfair advantage thereby? Or do we look at our child as a developmental whole, as a child who could well use that aid, to open and ease his or her way in the world?

Now obviously, I'm being a bit simplistic with this example, but it's to make a point. To bring that point home, we are only talking about a single, easily imagined aid and solution, for a problem that does not appear that severe, and a solution that few would object to. But what if the linguistic gap is much larger? For example, our child has been found to have a real difficulty dealing with abstractions, exactly of the type found in word problems. Our testing led us down a path that showed those aspects to be malfunctioning. Now what are our responsibilities, and how can they be met? What compensations will be allowed? Will the child be allowed to use a calculator, even though he/she can perform the operations sufficiently without one? But what if this aids the child's linguistic challenge in this case, which can be tested and shown? Here we are starting to cross over a line, out of the land of our familiar, conventional knowledge and judgments. Here we are moving into that land above, the terrain of the brain systems themselves. And this is the child's brain, the one that child needs to build his or her mental world with.

This is still only scratching the surface. We may be helping to get the child by, but greater educational questions may need to be addressed as well. What "compensations" may be needed if a part is not fully functioning, or potentially even "missing"? In terms of the IEP process, can the child receive an appropriate education if these challenges are not adequately identified and the necessary compensatory strategies not provided? Again, with the brain-injured adult, that piece might be taken out, and a function lost. It is noted, and it is seen. Of course, such an occurrence, in and of itself, may seem devastating, and means for compensating for the loss may be sought. With the child, though, the distinct "piece" is not as visible, because it has not as yet contributed to the whole. And the child may present as being "of this character or that," and may even seem fine. For example, in our world where "I'm not good at math" is heard all the time, it may be easy to pass the problem by.

However, we have identified a problem. We have looked further than the initial "word problem" and the situation with arithmetic. We are not satisfied with the global test score that simply suggests that the child is a bit "slow," if that is where this is leading. There is a reason why they child is not performing well, and on a set of very specific types of problems. So before the labels can be made to stick, what can be done? If the child has talents and strengths, those should be accentuated. How can they be given a better balance, as that is what we would feel, and hopefully seek for the brain-injured adult above. So why not for our child too? Even if those stronger parts are not of an accelerated type, they must be supported and enabled to flourish, rather than the "whole" simply receiving a label. This is where the parts that have been identified by our initial test items

can come into play. Work with those parts should always continue. Even if it is never complete, ways may be found for the child to compensate, just as we would think about our brain-injured person who has "lost" something. Yes, in the case of our child, it requires looking into the future, which is harder than noting something that was there and is suddenly gone. But we are looking at how they may grow, not weighed down by that part that they didn't have, and by finding a way to live and work with it. Again, it is those parts that we can "see" in our tests.

In this way, an IEP should be sculpted to meet a child's needs. And that should be an ongoing process over the years, tracking progress in the identified areas, and noting changes as they are needed. Of course, the challenges that may need to be faced, for and by any specific child, may be far more than portrayed above as well. The above picture was drawn to show a single thread. In actuality, a combination of linguistic, attentional, perceptual and motoric problems can result in a rather complex terrain. The challenge for us, as well as the child, is the same. Identify the problem, and deal with it. Scores and classifications mean nothing if they simply "place" a child. That placement must be for the child's identified needs. And the educational program for that child, including placement and support services, must be for the same purpose. So the proper use of an assessment will be to tell us what those needs are. It is only at that point that the work then begins, i.e., that which needs to be done to best facilitate and assure appropriate, measurable educational growth, leading to the achievement of the student's independent functioning.²

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Ticket to Work—Support Services for People Who Live With a Disability and Want to Work

By Adrienne Arkontaky

Now forty years old, Jack has suffered from severe seizures since he was eleven years old. He is on a variety of different anti-seizure medications. The combination of drugs leaves him tired and, at times, unable to concentrate. He worked for various companies over the years, earning enough to qualify for Social Security Disability (SSDI) benefits and as a result, he was able to utilize Medicare to cover his health care costs. However, he could not maintain his employment because he suffered from seizures on a regular basis.



For the last year, Jack's new team of physicians has been able to control his seizures and Jack has now been seizure free for more than nine months. Jack wanted to return to the work force but he feared that if he were to accept a job, he would lose his SSDI and access to health care benefits. Jack contacted the local Social Security Administration (SSA) office and spoke to a worker who suggested that Jack apply for the "Ticket to Work" program.

The purpose of the Ticket to Work program is to expand the universe of service providers available to individuals who are entitled to Social Security benefits based on disability or eligible for Supplemental Security Income (SSI) benefits based on disability or blindness in obtaining the services necessary to find, enter and retain employment. Expanded employment opportunities for these individuals also will increase the likelihood that these individuals will reduce their dependency on Social Security and Supplemental Security Income (SSI) cash benefits.¹

This program will help Jack develop work skills and return to work without an immediate loss of benefits. The SSA worker referred Jack to a Work Incentives Planning and Assistance Project ("WIPA"). WIPA projects are SSA-approved organizations that help SSA beneficiaries explore work opportunities. The WIPA staff discusses the Ticket to Work program and work incentives and how the programs will affect Social Security benefits. The staff works with beneficiaries to find proper resources and information to help achieve employment goals. The WIPA projects also host work incentive seminar events (WISE). The best part about WIPA is that the services are generally free to beneficiaries.

There are several Social Security Disability benefit programs. Individuals may receive SSI or SSDI or a combination of both benefits.

Recipients of these benefits are often concerned that SSI or SSDI monetary benefits will be reduced or even cancelled if the recipient gets a job. Beneficiaries are also worried that health care coverage (Medicare and/or Medicaid) associated with these benefits will be jeopardized if they return to the work force and if they go back to work and are unable to sustain employment, must they apply for benefits again. Because of the many concerns beneficiaries have regarding the possible loss of benefits, many do not attempt to look for work. In part, because of these concerns, the SSA developed the "Ticket to Work" program.

A. What Is the Ticket to Work Program?

The Ticket to Work program is a free and voluntary program developed to assist SSI and SSDI beneficiaries who live with a disability return to work or increase work hours if they are already employed.

Most individuals with disabilities ages 18 through 64 who receive SSDI and/or SSI may participate in the program. The program was developed to assist SSI/SSDI beneficiaries improve their earning potential, retain eligibility for benefits if a job does not work out and provide beneficiaries with supports and resources necessary for the beneficiary to be successful.²

B. How Does the Ticket to Work Program Work?

A referral is made to a WIPA project benefits counselor. The benefits counselor assists the beneficiary in finding an Employment Network (EN) and "assigns a ticket." The beneficiary works with the EN to explore work options.³ To get started, beneficiaries should call the Ticket to Work Help Line at 866-968-7842 or 866-833-2967 (TTY). Also, beneficiaries may visit www.socialsecurity.gov/work to find a WIPA. It is important to note that while an individual is utilizing the Ticket to Work program, Continuing Disability Reviews are exempted as long as the individual is demonstrating progress towards work goals.⁴

EN teams may help individuals prepare resumes and develop interview skills, explore employment accommodations and provide referrals to other resources. The Employment Networks may also help with employment leads and develop an employment plan.⁵

Individuals may also use a "Ticket" to access Vocational Rehabilitation services (VR). A VR counselor assists the beneficiary in developing employment goals and implementing a plan.⁶

Established under Part C Title 1 of the Developmental Disabilities Assistance and Bill of Rights Act, the Protection and Advocacy Beneficiaries of Social Security (PABSS) services are located throughout the United States and are free to all SSDI and SSI beneficiaries and anyone who receives Medicare and/or Medicaid based on a disability.⁷ PABSS assists advocating for employment accommodations and vocational services, provides information to beneficiaries regarding benefits and even helps with any overpayment issues.

The Ticket to Work program also establishes “work incentives.” Work incentives provide beneficiaries with a safety net so that beneficiaries can receive job training, improve work skills, pursue an education, and explore different jobs or careers.⁸

C. Examples of Work Incentives

The Trial Work Period (TWP) is available for SSDI beneficiaries only. This incentive allows the beneficiary to explore work options for at least nine months. During the trial period, the beneficiary will continue to receive full SSDI benefits as long as the recipient continues to have a disabling impairment and reports the work activity. There is no limit on how much income the beneficiary earns during this time.⁹

The Extended Period of Eligibility (EPE) for only SSDI beneficiaries allows beneficiaries to re-qualify for SSDI benefits without a new application, disability determination, or waiting period. This provides a sense of security to recipients doing well in their work positions.¹⁰

An Earned Income Exclusion (EIE) for only SSI recipients provides that less than half of the earnings are counted by Social Security as earned income, which may allow some working SSI recipients to continue to receive an SSI check while working.¹¹

The Ticket to Work program also provides for an Expedited Reinstatement (EXP) of benefits. Under this incentive, if benefits are stopped because of the recipient’s earning level, the beneficiary can request to have the benefits reinstated without the need to complete a new application. The beneficiary can also receive temporary benefits for up to six months. The Expedited Reinstatement is available to both SSDI and SSI recipients.¹²

The program also provides protection from medical Continuing Disability Reviews (CDR) for both SSDI and SSI recipients. The beneficiary will not have to undergo a medical Continuing Disability Review while participating in the Ticket to Work program.¹³

In addition to the above incentives, there are earned income tax credits available (EITC). These tax benefits are special tax benefits for working individuals with limited income. The EITC is not counted as income in most benefit programs. Eligible individuals

from age 25 to 64 must earn less than the qualifying amount set by the SSA.¹⁴

Individuals participating in the Ticket to Work program may also establish an Individual Development Account (IDA). An IDA is a savings program where the beneficiary saves part of his or her income for a home, higher education or a business. Savings may be matched up to \$2.00 for every \$1.00 saved. There is a maximum allowable savings of \$4,000 allowed. The funds are not counted as an asset for both federal and state programs.¹⁵

As evident in this article, the Ticket to Work program is designed to get people working without fear of loss of benefits. It has assisted many SSI and SSDI beneficiaries to enhance their lives, earn more income, gain independence, explore new careers and achieve a better quality of life.

For more information on this and other programs offered by the SSA, call the Ticket to Work Help Line at 866-968-7842 or visit the SSA website at www.SSA.gov.

Endnotes

1. Title 20, Chapter III, §411.100.
2. Title 20, §411.125.
3. §411.115(e), POM-DI55060.001.
4. POM-DI55050.010.
5. §411.115(f).
6. §411.115(m), POM-DI26520.001.
7. POM-DI55001.005.B.
8. POM DI 13010.0D1.
9. POM DI 13010.035.
10. POM DI 13010.210.
11. POM HI 030 20.030.
12. POM DI 13050.060.
13. §411.160, §411.165.
14. POM SI 00830.60.
15. POM DI 60060.20.

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VIA FIRST CLASS & ELECTRONIC MAIL

December 27, 2011

Victoria Wachino
Director, Family and Children's Health Program Group
Centers for Medicare & Medicaid Services
7500 Security Boulevard, MS S2-01-16
Baltimore, Maryland 21244-1850

Dear Ms. Wachino:

We are disability rights and seniors rights advocates, consumers, community advocacy organizations, and lawyers representing people with disabilities and older New Yorkers. We write to express concerns about the expansion of the 1115 waiver in New York State to include mandatory enrollment of Dual Eligibles who receive Medicaid personal care and other community-based long-term services in Managed Long Term Care ("MLTC") plans, as set forth in the letter to you from Jason Helgeson (letter dated April 13, 2011,) and in the documents accompanying that letter.

The MLTC plans, providers, and consumers all want a system that achieves the common goal of providing adequate and necessary services to enable people to live in the community, in furtherance of the goals of the ADA and *Olmstead*. However, the State proposes to rush into implementing a monumental change in how at least 85,000 individuals now receive Medicaid community-based services in New York City, to be followed later statewide, without sufficient safeguards to ensure that enrollees will receive the services they need in the community to avoid institutionalization. We are particularly troubled by anticipated problems with capacity, enrollment, gaps and interruptions in coverage, as well as with the program's lack of proper incentives, due process protections, oversight, and ability to absorb special programs currently providing critically important services. Our concerns and our recommendations are set forth in detail below.

SUMMARY OF RECOMMENDATIONS

1. **Timing and Capacity -- Mandatory enrollment should not begin until other systemic concerns described below are addressed, and then solely with new applicants --** over 1,000 persons per month in NYC alone, which would provide an opportunity to work out and test the new systems. **Enrollment of current personal care and other program recipients should not begin until at least six months later**, after the State, in consultation with stakeholders, has monitored the impact of mandatory enrollment upon new applicants and adjusted the capitation rates and other systems as necessary.
2. **Adequate Information Must be Provided to Consumers for Informed Choice in Enrollment, and the Network of Community Partners Must be Educated About the Sweeping Changes.**
3. **Increased Consumer Protections & State Oversight Are Needed to Ensure Compliance with Olmstead.**
 - A. **MLTC Plans must be at risk for nursing home costs as well as community-based services costs**, and must not be permitted to dis-enroll members whom they determine require nursing home placement. Plans must incorporate risk adjustments or other mechanisms that incentivize community-based services.
 - B. **Plans must be given uniform standards for determining medical necessity that are consistent with established policy and precedent.** Mandatory enrollment must be postponed at least until the State has tested, revised, solicited input from consumers and other stakeholders, and conducted the necessary training for a new **Uniform Assessment Tool** that will be used by MLTC plans.
 - C. **When a plan determines that community-based services are not appropriate and that nursing home placement is necessary, the plan must give notice of such proposed placement both to the consumer, with appeal rights, and to an outside review entity**, such as an independent living center, who will be funded to ascertain whether the member voluntarily agrees to placement based on an informed choice, and whether community-based services could be provided.
 - D. **More robust state oversight is needed, including expansion of Quality Assurance Reporting Requirements (QARR)** to include additional metrics applicable to members who need long-term care.
 - E. **The State must ensure that an MLTC member has the due process right to continue receiving services unchanged, as “aid continuing” pending a hearing, before an MLTC plan reduces or terminates services** that were previously authorized by the plan or by the prior-approval procedure for the services that the individual previously received before mandatory MLTC enrollment.

F. **DOH must create, in partnership with consumers and their advocates, an Americans with Disabilities Act Compliance Appendix to the contract,** and monitor its implementation as a step towards disability literacy.

4. **Access to Special Program Services -- Long-Term Home Health Program (LTHHP) and Consumer-Directed Personal Assistance Program (CDPAP) recipients should be excluded from mandatory managed long term care.** LTHHP recipients are already enrolled in a 1915(c) waiver with cost neutrality requirements and care management, and stand to lose spousal impoverishment protections as well as waiver services. CDPAP recipients and applicants also should be exempted until the State develops adequate requirements to preserve the CDPAP model as developed in New York State.

5. **A new point of entry that is accessible for NYC residents with disabilities seeking community-based long-term care services to apply for and renew Medicaid is not yet developed, tested or publicized, threatening to disrupt care and deny access.** It is critical that mandatory enrollment not commence until procedures are established to ensure that no vital Medicaid home care will be discontinued during temporary lapses in Medicaid pending resolution of renewal errors, and to ensure that Medicaid applications and requests for home care services are processed expeditiously in ways that reasonably accommodate the disabilities of the applicants.

DETAILED RECOMMENDATIONS

1. TIMING AND CAPACITY

The State's recent *Draft Enrollment Plan* proposes to implement mandatory MLTC much more rapidly than originally proposed. Beginning April 2012, all new applicants for personal care in NYC -- about 1170 per month¹ -- will be required to enroll in a Managed Long Term Care plan, and within only six months -- instead of the original 36 months -- all 45,000 current personal care recipients² -- will be enrolled in MLTC. The transfer of current personal care recipients alone will increase by 150 percent the number now voluntarily enrolled in MLTC -- 29,000 in NYC. Similarly, the State does not specify the numbers of individuals to be enrolled in the second phase, when the draft plan proposes to enroll *all* CHHA recipients, Long Term Home Health Plan (1915 waiver) recipients, adult day health care and private duty nursing recipients in NYC during only two months—November and December 2012. We estimate that these enrollees will number at least 40,000 – 60,000 in New York City alone.³

The rushed enrollment challenges not only the plans' capacity to absorb large numbers of enrollees, but also their ability to serve enrollees with more extensive needs for home care and

¹ NYC HRA Home Care Services Program, "Screen, Intake & Pending (SIP) Unit CASA by CASA REPORT" (average 1170 applications filed per month for the six months ending January 2010, of which about 250 new cases per month approved for service)(provided in April 2010 to Selfhelp Community Services, Inc. in response to Freedom of Information request.)

² An average of 50,410 people received personal care in NYC per month in the First Quarter 2010. NYS Dept. of Health, Medicaid Quarterly Reports of Beneficiaries, Expenditures, and Units of Service by Category of Service by Aid Category by Region, posted at <http://www.health.ny.gov/nysdoh/medstat/quarterly/aid/quarterly.htm>; scroll to 2010 – First Quarter, direct link at http://www.health.ny.gov/nysdoh/medstat/quarterly/aid/2010/q1/docs/2010_q1_aid.xls. (Note that the number receiving personal care services for First Quarter 2010 has been reduced by about 5,000 to reflect the number of mainstream Medicaid managed care recipients whose personal care services were newly carved into their managed care benefit package on August 1, 2011.)

³ This is based, in part, on an estimated 49,989 people receive long-term CHHA services in NYC. (This is 69% of the 59,405 people receiving CHHA services per month in NYC in Q1 2010, excluding 31% estimated by the United Hospital Fund to be short-term users). See NYS DOH Medicaid Quarterly Reports, *supra*, n 2; and Alene Hokenstad et al., *An Overview of Medicaid Long-Term Care Programs in New York* (United Hospital Fund 2009)(p. 9), posted at <http://www.uhfnyc.org/publications/880507>. In addition to the CHHA recipients, in Calendar Year 2008 the following numbers of NYC residents received other long-term care services: Long Term Home Health Care Program --16,289; Adult Day Health Care --10,524; Assisted Living Program -- 1,932; private duty nursing -- unknown. NYS DOH, *Interim Report Home Health Care Reimbursement Work Group* (Dec. 2009)(Table 2-A: NYS Medicaid Recipient Counts for Long Term Care Services – NYC)(posted at http://www.health.ny.gov/facilities/long_term_care/reimbursement/docs/hcrw_interim_report.pdf). The total potential non-personal care enrollees, then, are 69,734. Even a reduction by 30% to eliminate any duplication and short-term usage still leaves 50,000 people to enroll in two months.

other services. We question the State's claim that the current voluntary MLTC plans are equipped to serve the influx of new members because they already serve members with a "high level of impairment." The State admits that the current population served by MLTC "...is less impaired than the nursing home population," yet it fails to compare the MLTC population to the Medicaid personal care population about to be enrolled *en masse*. According to the United Hospital Fund, "...two-thirds of New York City's personal care beneficiaries had comparable levels of need [to nursing home residents] on key indicators, such as functional and cognitive status, as indicated by resource utilization group ("RUG") scores...."⁴ Moreover, we firmly believe that in the last six years of voluntary MLTC enrollment, many of the MLTC plans have "cherry-picked" a lower need population, in effect siphoning off people from the low end of the bell curve of personal care and CHHA recipients, and thereby leaving a higher-acuity population in the personal care and CHHA programs.

The personal care services provided to the New York City residents who will be mandated to enroll in MLTC plans were authorized under a tightly regulated prior authorization procedure that strictly limits services to those that are *medically necessary* under state law – any reduction by the MLTC plans threatens their health and safety. These strict utilization controls, which entail an onerous multi-assessment regime conducted by the local Medicaid offices (the Human Resources Administration, or "HRA," in New York City) and subject to review by the State when consumers request administrative hearings, already ensure that only "medically necessary" services are provided. This strict prior approval mechanism prevents any excessive usage that might occur in other "fee for service" systems. A sense of the rigor of this process—and the vulnerability of this high-need population—can be gleaned from sampling the thousands of hearing decisions issued by the State, finding that HRA *denied* adequate services. *See, e.g.*, Hearing No. 5874576L decision dated Oct. 14, 2011.⁵ Therefore, any reduction by MLTC plans in the personal care services that have been determined to be medically necessary is potentially life-threatening. Over 40 percent of personal care recipients have been receiving personal care services for at least seven years due to long-term chronic conditions.⁶ Therefore, any reduction by MLTC plans in the personal care services that have been determined to be medically necessary is potentially life-threatening.

⁴ Alene Hokenstad et al., *An Overview of Medicaid Long-Term Care Programs in New York* (United Hospital Fund 2009), posted at <http://www.uhfnyc.org/publications/880507>; *see also* S. Samis & M. Birnbaum, *Medicaid Personal Care in New York City: Service Use and Spending Patterns* (United Hospital Fund 2010), posted at <http://www.uhfnyc.org/publications/880720> (Over 70 percent of New York City personal care recipients in a 2003 cohort had at least one chronic disease, and over half had multiple chronic diseases, with one in four recipients having a mental health diagnosis.)

⁵ Decision posted online at http://www.otda.ny.gov/fair%20hearing%20images/2011-10/Redacted_5874576L.pdf.

⁶ S. Samis & M. Birnbaum, *Medicaid Personal Care in New York City: Service Use and Spending Patterns* (United Hospital Fund 2010), *supra*, at pp. iii-iv, 6-8.

The capacity of these MLTC plans to receive and serve an influx of at least 85,000 new members in--many of whom have higher level needs—is not clear, especially not on the implementation timeline proposed. The risk-adjusted capitation rates that have been calculated for plans currently are based on the acuity of their current voluntary enrollees – the State has not projected whether the acuity of the anticipated increased enrollment will require adjustment of these rates – without adequate rates or risk adjustments such as outlier payments or stop-loss mechanisms, both plans and consumers are at risk.

In the summer of 2011, some MLTC plans in New York City were backlogged in processing the influx of a few thousand clients transitioned from fee-for-service CHHA care resulting from reimbursement cuts enacted by the State that became effective in April 1, 2011.

Considering the delays in absorbing this relatively small influx of new members, we are fearful of the delays to come when tens of thousands of new members are enrolled. The State should obtain from the MLTC plans the information that is needed to assess the respective plans' capacity to process and initiate service on cases referred since April 1, 2011, and to meet the enrollment demand under the mandatory transition timeline.

RECOMMENDATION: Mandatory enrollment should begin solely with new applicants -- over 1,000 persons per month in NYC alone, which would provide an opportunity to work out and test the new systems. **Enrollment of current personal care and other program recipients should not begin until at least six months later,** after the State, in consultation with stakeholders, has monitored the impact of mandatory enrollment upon new applicants and adjusted the capitation rates and other systems as necessary.

2. ADEQUATE INFORMATION MUST BE PROVIDED TO CONSUMERS FOR INFORMED CHOICE IN ENROLLMENT, AND THE NETWORK OF COMMUNITY PARTNERS MUST BE EDUCATED ABOUT THE SWEEPING CHANGES.

With mandatory enrollment slated to begin in only three months, to date there are no stated plans for informing consumers of their choices, or for educating the huge network of community-based social services and health care providers who assist consumers in accessing Medicaid home care services. Nor is it clear how auto-assignment will work where the existing plans have very different capacities and different specialties (e.g. Guildnet specializes in visually impaired, while Independence Care Systems specialized in physical disabilities.)

The State claims that consumers will receive a description of the types of plans available to make an informed choice. However, the State has *not* circulated drafts of this information for input from stakeholders, including consumers. Information provided to consumers about their choices must include information about the track record of each plan in authorizing services. Consumers need to know the information set forth in Exhibit A (a copy attached hereto) – now available only through Freedom of Information requests. This includes the percentage of members receiving 700+ hours per month (meaning continuous 24-hour care, i.e. 168 hours/week) and other ranges of hours. Exhibit A shows that four MLTC plans in NYC ranged from 0.2% to 8% in the number of members provided 700+ hours per month. For someone who had

been receiving that amount of personal care services for years through the NYC personal care program, this is certainly crucial information in selecting a plan. Similarly, consumers have the right to know the percentage of the capitation rate spent on nursing home care, home care, durable medical equipment, and transportation (*See* Exhibit A.)

Additionally, statewide consumer and professional education and training are needed; consumer advocacy organizations should be funded to provide such training to the myriad grassroots neighborhood-based organizations that provide services to the aging and disabled.

3. LACK OF CONSUMER PROTECTIONS & STATE OVERSIGHT TO ENSURE COMPLIANCE WITH OLMSTEAD

We have the following critical concerns, all of which raise serious implications under the Americans with Disabilities Act (ADA) as interpreted in *Olmstead v. L.C.*, 527 U.S. 581 (1999). Terms and conditions of the waiver must incorporate these elements:

- A. MLTC plans must be at risk for nursing home costs as well as community-based services costs, and must not be permitted to dis-enroll members whom they determine require nursing home placement.** Risk adjustments or other mechanisms must be incorporated into the capitation rates and contracts that incentivize community-based services and offset incentives for nursing home placement for high-need individuals who are “outliers” in terms of need.

Currently, MLTC plans may dis-enroll a member on the basis that he or she requires long-term nursing home placement; this creates an incentive to place higher-cost members into nursing homes rather than to provide adequate community-based services to prevent institutionalization. Moreover, for the small number of recipients for whom nursing home care is less costly than community-based care – roughly two percent of the current personal care population -- there are no mechanisms to counter the financial incentive for the MLTC plans to institutionalize them, in violation of *Olmstead* and the ADA. There are about 1,200 people in NYC who now receive continuous 24-hour services (2 – 12-hour shifts/day), out of about 50,000 personal care recipients. In addition, an unknown but presumably small number of the 59,000 home health recipients receive 24-hour care because they need round-the-clock assistance with toileting, ambulation, turning and positioning and other (activities of daily living (“ADLs”)) because of dementia, stroke, multiple sclerosis, or other severe chronic conditions. *The State has proposed no mechanism to counter the incentive created by capitation for the plans to institutionalize these individuals*, despite its articulation of the need for such mechanisms in “care coordination principles.”⁷ Under the current “voluntary” MLTC system, some MLTC plans already have informed prospective members that they have a

⁷ See http://www.health.ny.gov/health_care/medicaid/redesign/docs/2011-11-15_care_coord_model_guidelines.pdf at p. 8 (providing no explanation for how rates will “incentivize community-based services.”)

limited number of “slots” for 24-hour care. The State has not responded to our requests to consider risk adjustments such as stop-loss mechanisms or outlier payments to ensure access to community-based care.

- B. **Plans must be given uniform standards for determining medical necessity that are consistent with established policy and precedent.** Mandatory enrollment must be postponed at least until the State has tested, revised, solicited input from consumers and other stakeholders about, and conducted the necessary training for a new **Uniform Assessment Tool** that will be used by MLTC plans.

Unlike much of the primary and acute medical care authorized under traditional managed care plans, the authorization of long-term care, particularly home care services, must take into account myriad factors that are not solely medical – e.g. the individual’s available social network of informal caregivers, his or her housing situation, the logistics needed for basic housekeeping, shopping, and other tasks. **Mandatory enrollment must be postponed at least until the State has tested, revised, and solicited consumers’ and other stakeholders’ input about, a new Uniform Assessment Tool that will be used by MLTC plans.**⁸ The State has said this tool will not be ready for implementation until October 2012. Until then, MLTC plans may simply make up their own rules and guidelines, which will result in inconsistent and arbitrary determinations.

In addition to a uniform assessment tool, the standards used to assess the amount of services necessary must comply with standards set by regulation, litigation and administrative precedent in New York State over decades. In just one example, the MLTC model contract requires involuntary dis-enrollment by the plan when a consumer is hospitalized for 45 days or longer.⁹ This requirement potentially violates several court decisions and settlements which have been incorporated into State directives.¹⁰ Similarly, state regulations restrict the use of “task-based assessment” for people determined to have 24-hour a day needs (18 NYCRR 505.14(b)(5)(v)), and a State directive prohibits the denial of personal care services needed to assist a consumer to safely perform basic activities of daily living –a policy that is vital to protect people who have dementia. See NYS Dep’t of Health GIS 03 MA/003, http://www.health.state.ny.us/health_care/medicaid/publications/docs/gis/03ma003.pdf. The fair hearing decision example provided on page 5 above cites this directive in reversing the City’s denial of personal care services. The same clear authority must control when MLTC plans determine eligibility and need for services.

- C. **When a plan determines that community-based services are not appropriate and that nursing home placement is necessary, the plan must give notice of such proposed placement, with appeal rights, both to the consumer and to an outside review entity,**

⁸ The State also must conduct training in order to effectively implement such a uniform assessment tool.

⁹ See www.nyhealth.gov/health_care/managed_care/mltc/pdf/mltc_contract.pdf at p. 14, par. D.4(c) (2007).

¹⁰ *Granato v. Dowling*, 74 F.3d 406 (2d Cir. 1996), *Burland v. DeBuono*, NYS Dept. of Health Local Comm’r. Mem. 99-OCC-LCM-2 (4/20/99); *Catanzano v. Dowling*, *supra*, App. II to 18 NYCRR 505.23.

such as an independent living center, who will be funded to ascertain whether the member voluntarily agrees to placement based on an informed choice, and whether community-based services could be provided to maintain the individual in the community.

There are insufficient procedural and oversight mechanisms to prevent MLTC plans from utilizing excessive nursing home services instead of community-based care. Even now, with a lower-acuity voluntary enrollment population, some MLTC plans spend as much as 11.4% of their capitation on nursing home care.¹¹ We question how and why the State currently permits such high usage of nursing home service, and we are extremely concerned that this usage will only increase when the pool of consumers entering MLTC programs expands to include those now receiving high hours of personal care or CHHA services. The MLTC model contract gives MLTC plans total discretion in determining when to utilize nursing home services that are included in the capitation rate. The State has not proposed any safeguards to ensure access to community-based care.¹² In addition to possible risk adjustments as described above, the SDOH should also implement mandatory reporting requirements, so that an external review entity must first review—and approve—any proposed placement in a nursing home, for services other than short-term rehabilitation services.

D. More robust state oversight is needed, including expansion of Quality Assurance Reporting Requirements (QARR) to include additional metrics applicable to members who need long-term care.

The State must do more pro-active monitoring than simply obtaining reports from MLTC plans on the numbers of grievances or hearings filed, or conducting consumer satisfaction surveys. The vast majority of consumers, who by definition are elderly and/or disabled, many with mental illness, will not utilize the grievance and hearing systems. As the court found in *Mayer v. Wing*, 992 F. Supp. 902 (S.D.N.Y. 1996):

...Although some Medicaid recipients are able to successfully challenge reductions at fair hearings, such hearings are not enough to assure Plaintiffs due process... 'The administrative appeal process is not a substitute for proper prior procedures at the agency level. Whatever its value in individual cases, the administrative appeal process may not regularly be used as a vehicle to conduct a requisite inquiry which the agency continually fails to institute'....

¹¹ See Personal Care Aid Utilization Comparison in MLTC Plans in NYC, page 2 (Based on MLTC Cost Reports filed with State DOH for 2009 Q4)(Two-page summary attached as Exhibit A.) Note that this data was obtained in a Freedom of Information request, and is not readily available to consumers.

¹² See www.nyhealth.gov/health_care/managed_care/mltc/pdf/mltc_contract.pdf at p. 14, par. D.4(c).

992 F. Supp. at 912. Initially, for the at least 85,000 people currently receiving services that are being transferred to MLTC plans, the State must require MLTC plans to report every decision to reduce services from the amount previously authorized under the regulated prior approval system, and every decision to terminate community-based services. The State must then arrange for an independent oversight entity to review such cases to ensure that MLTC plans are not improperly denying services and/or placing people in institutions. Additionally, the State must sample, randomly, approvals and denials for other services – i.e. motorized wheelchairs and other durable medical equipment, transportation for medical care, dental care and eye care, and other services covered in the package. Oversight is also needed to ensure timely authorizations for services.

Quality Assurance Reporting Requirements (“QARR”) reporting data must be expanded to include additional metrics that are applicable to members who need long-term care (e.g. ability to perform activities of daily living, prevalence of decubitus conditions, usage of incontinence pads as opposed to assisting with toileting, incidence of falls and other accidents, temporary and permanent nursing home placement.)

- E. **The State must ensure that a MLTC member has the due process right to continue receiving services unchanged, as “aid continuing” pending a hearing, before an MLTC plan reduces or terminates services** that were previously authorized by the plan or by the prior-approval procedure for the services that the individual previously received before mandatory MLTC enrollment, regardless of when any authorization period for such services expires.

The proposed procedures deny Medicaid beneficiaries due process protections of advance notice and a hearing before any adverse changes by the MLTC plan in the long-term-care services plan.¹³ Reduction or termination of Medicaid services must comply with the rights established in *Goldberg v. Kelly*, 397 U.S. 254 (1970), including advance notice and a right to a pre-termination hearing before any change in services is implemented. In this context, this means that before an MLTC plan can change a service plan previously authorized by the former utilization review system, the MLTC plan must provide advance notice and the individual must have a right to a pre-termination hearing, with Aid Paid Pending (known as “aid continuing” in NYS) pending the hearing. The State has indicated that now it is interpreting the federal Medicaid managed care regulations at 42 CFR §438.420(b)(4) to mean that the MLTC plan must only continue the enrollee’s benefits if the original period covered by the original authorization has not expired. The end result for this fragile population is that the MLTC plan may reduce hours sharply or even terminate services altogether after the standard six-month authorization period expires, with no advance notice and no right

¹³ Exemplifying the lack of consumer input in the development of the MLTC system, the State Medicaid Redesign Team Subcommittee on Managed Long Term Care designated a Workgroup charged with developing and recommending Fair Hearing and Due Process procedures. The State convened this Workgroup to meet only one time, precluding it from adequately addressing these key issues.

for the consumer to receive aid pending a hearing, even for an individual who was found by the NYS Department of Health after an administrative hearing to need 24-hour/day care.

The State incorrectly relies on this federal regulation, promulgated almost a decade ago, which was written for short-term primary and acute medical services, where the individual would have no expectation that services would continue once that medical condition has been treated. At the time, Medicaid-managed care benefit packages did not include *long-term* home care services. Since an individual's chronic conditions rarely will improve, the need for ongoing long-term home care services likely will continue for an indefinite time period. Indeed, the average period of receiving Medicaid personal care services in NYC was found to be 4.75 years in December 2008, with over 40 percent of personal care recipients receiving personal care services for at least seven years.¹⁴

Failure to accord consumers the right to aid continuing pending a hearing on proposed adverse changes in their service plan would violate due process, as interpreted in *Mayer v. Wing, supra* (holding due process prohibits arbitrary reductions in Medicaid personal care services previously approved, even where beneficiary receives advance notice with the right to receive services unchanged as aid-continuing pending a pre-reduction hearing.)

Even if the MLTC plans are not required to pay for services during the "aid continuing" period pending the hearing, the State cannot be absolved of its constitutional duty to provide due process, and must establish a mechanism to pay the MLTC plans or the providers directly to provide services pending the hearing. As is true with fee-for-service Medicaid, the beneficiary may be liable to repay the cost of services provided pending the hearing if the proposed reduction is upheld by the hearing decision.

F. DOH must create, in partnership with consumers and their advocates, an Americans with Disabilities Act Compliance Appendix to the contract, and monitor its implementation as a step towards disability literacy.

With its emphasis on interdisciplinary care coordination and avoidance of inappropriate reliance on institutional settings, MLTC presents some opportunities to improve the care of people with disabilities. However, MLTC will only achieve this promise if it attends to the disability literacy of MLTC plans. Disability literacy for MLTC plans may be defined as the capacity to understand, communicate, and partner with people with disabilities with demonstrated understanding of their perspectives and beliefs concerning health behavior. An example would be recognition of the preference for self-direction and informed choice. Lack of training on disability literacy issues and problem-solving to

¹⁴ S. Samis & M. Birnbaum, *Medicaid Personal Care in New York City: Service Use and Spending Patterns* (United Hospital Fund 2010), *supra*, at pp. iii-iv, 6-8.

remove barriers for health plan administrators, staff and care practitioners creates a very significant barrier to effective health care.

Disability literacy is critical to the success of the MLTC program. New York State recently has observed that people with disabilities requiring significant assistance have a lower health quality of life, engage in behaviors such as smoking that present health risks and engage in fewer health promoting activities such as exercise. They experience chronic conditions at a higher rate than people without disabilities.¹⁵ They also experience health disparities and face significant problems accessing health services. For example, adults who are deaf report poor health with greater frequency than people who are not deaf, lack interpreters in health settings and fail to receive health information and instructions from practitioners. Adults with developmental disabilities are at higher risk of obesity, cardiovascular disease and hypertension than people without developmental disabilities. They encounter problems working with providers who do not give them enough time to undress, communicate or understand instructions.¹⁶

Managed long-term care can fulfill its promise of coordinating care and avoiding expensive and overly restrictive institutional placement, only if it addresses disability literacy issues.

An *Americans with Disabilities Act Compliance Appendix* to the contract would make provision for eradication of physical, communications-related, programmatic and attitudinal barriers. For example, MLTC Plans must be required to have and/or develop an experience and knowledge base to serve people with significant disabilities. Among issues to be considered are:

- A. the physical accessibility of administrative and provider facilities;
- B. willingness and capacity to provide written materials in alternate, accessible formats;
- C. expertise in assessing needs for adaptive equipment and environmental modifications, including wheelchair fitting and seating and home modifications, with policies and practices for approval of durable medical equipment and transportation that are consistent with applicable laws and promote independent living;
- D. understanding of, and the capacity to address, the housing and social service needs of participants;
- E. a proven and documented commitment to maintaining people in the most integrated setting;
- F. policies that facilitate the provision of reasonable accommodations to people with disabilities; and

¹⁵ New York State Department of Health, Disability and Health Program, "Chartbook on Disability in New York State, 2007, Results from the Behavioral Risk Factor Surveillance System." 2008.

¹⁶ National Council on Disabilities, "The Current State of Health Care for People with Disabilities," 2009.

- G. provision of opportunities for plan participants to participate, in a significant manner, in the development of plan policies and practices.

4. **ACCESS TO SPECIAL PROGRAM SERVICES:**

A. Long-Term Home Health Plan (“LTHHP” 1915(c) waiver)

This 1915(c) waiver was renewed on Sept. 1, 2010 with new quality assurance and service package enhancements, along with new data collection and analysis requirements. See NYS DOH, 11 OLTC-ADM-1, *Long Term Home Health Care Program Waiver Renewal* (April 26, 2011) http://www.health.ny.gov/health_care/medicaid/publications/docs/adm/11oltcadm-1.pdf. The State has announced that MLTC plans will provide state plan services only. Thus LTHHP participants forced to enroll in MLTC will lose valuable waiver services. Additionally, married participants would lose spousal impoverishment protections approved in this waiver that are not available in MLTC programs.

RECOMMENDATION: Participants in this waiver should be excluded from mandatory managed long term care, since this 1915(c) waiver already has *cost neutrality* requirements and care management.

B. Consumer Directed Personal Assistance Program (“CDPAP”) Services

The State law authorizing DOH to submit this waiver expansion request requires MLTC plans “to offer and cover Consumer-Directed Personal Assistance (CDPAP) services for eligible persons who elect such services pursuant to Soc. Serv. L. 365-f.” Part H, § 41-a. This provision holds the promise that consumers will continue to have the guaranteed option to self-manage their services through the CDPAP, as required by state law. However, we have concerns about how this requirement will be implemented. There is an inherent conflict in the notion of having a nurse manage a care plan for a consumer who is directing his or her own care. The recent release of CDPAP regulations¹⁷ recognizes the unique self-management attribute of the model which is contradictory to nurse management and supervision of the consumer’s care needs as delivered by consumer employed and trained Personal Assistants.

Other potential conflicts are inherent in the question of who will determine whether the consumer is self-directing or has a designated representative who is available and willing to direct his or her care plan. The MLTC plan may have a conflict of interest in being the decision maker on this issue. Consumers must receive notice of and the opportunity to appeal denial of eligibility for CDPAP services at a fair hearing, as they do now. DOH must consider the serious implications under the state and federal regulations discussed above as to whether the entity that provides such notice is the MLTC plan, the LDSS or another entity designated by DOH.

We also question whether MLTC plans will be required to contract with an independent CDPAP provider, or whether they or their existing sub-contractors of home care services

¹⁷ NYCRR Title 18 Section 505.28 (g)(1).

will be allowed to develop in-house CDPAP programs. In the case of the latter, we would have serious concerns about the legal, regulatory, and values-based barriers that may impede traditional agencies that provide home care--whether licensed home care services agencies, CHHAs, or MLTC plans,--from fully embracing the idea of and providing consumer-directed personal assistance services. A specific balance of responsibility must be achieved between the consumer and the provider in order to maintain both the consumer's empowerment and to mitigate the provider's exposure to liability.

RECOMMENDATION: Until the State develops adequate requirements to preserve the CDPAP model as developed in New York State, consumers enrolled in, or who wish to apply for the CDPAP program, should be exempted from mandatory enrollment in MLTC.

5. A NEW POINT OF ENTRY THAT IS ACCESSIBLE FOR NYC RESIDENTS WITH DISABILITIES SEEKING COMMUNITY-BASED LONG-TERM CARE SERVICES TO APPLY FOR AND RENEW MEDICAID IS NOT YET DEVELOPED, TESTED OR PUBLICIZED, THREATENING TO DISRUPT CARE AND DENY ACCESS.

Mandatory MLTC fundamentally alters the 30-year old system and entry point for 1,170 NYC residents to file Medicaid applications each month and 50,000 recipients to process annual Medicaid renewals. For over 30 years, New York City's Human Resources Administration (HRA) has maintained between one and three "one-stop" offices in each borough called "CASA offices," (also known as "CASAs") at which frail homebound seniors and people with disabilities can both apply for Medicaid and initiate a request for personal care services, and then annually renew eligibility for Medicaid.

These CASAs accommodate the disabilities of many applicants by having a caseworker visit the applicant at home to complete the applications for both Medicaid and home care. By simultaneously processing the dual applications for Medicaid and for personal care services, the CASA system is efficient and can approve Medicaid and home care within 45 -60 days. The State has not yet specified whether the CASAs will still accept and process the Medicaid applications through this system oriented for homebound people. If not, applications will have to be filed through the other Medicaid offices that serve all ages and populations. These offices do not have a reliable system for promptly accommodating the needs of people whose disabilities make travel difficult. If applicants are required to wait until Medicaid is approved—a period of at least 45 days—before they can apply to an MLTC plan, then such a waiting period will delay delivery of services significantly.

Systems are not developed or ready to ensure continuity of home care when inevitable bureaucratic glitches occur in routine renewals for Medicaid after April 1, 2012. Until now, NYC HRA CASAs handled the routine Medicaid renewals for personal care recipients to demonstrate continuing financial eligibility for Medicaid, accommodating their disabilities by assisting them with collecting documents via home visits. Given the huge volume of Medicaid renewals in NYC, errors commonly happen, with vulnerable clients experiencing lapses in

Medicaid coverage due to renewal paperwork that was lost in the mail or was never processed. *The current NYC HRA policy ensures that vital personal care services are not disrupted during any temporary lapse in Medicaid due to such renewal errors.* HRA has exercised its contractual authority with personal care providers to direct them to continue providing services while the problem is being corrected. Under managed care, however, if the managed care plan does not receive their monthly capitation payment because Medicaid eligibility erroneously has lapsed due to a bureaucratic error, plans may and have been known to discontinue home care services, leaving vulnerable seniors and people with disabilities at risk of severe harm.

RECOMMENDATION: It is critical that mandatory enrollment not commence until procedures are established to ensure that no vital Medicaid home care will be discontinued during temporary lapses in Medicaid pending resolution of renewal/ recertification errors, and to ensure that Medicaid applications and requests for home care services are expeditiously processed in ways that reasonably accommodate the disabilities of the applicants.

* * *

Thank you for the opportunity to voice these concerns. We would welcome the opportunity to meet to discuss these issues.

Very truly yours,



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ARISE Independent Living Center, Oswego NY

Bronx Independent Living Services

Brooklyn Center for Independence of the Disabled

Center for Independence of the Disabled, NY

Coalition of Institutionalized Aged and Disabled

Commission on the Public's Health System in New York City

Goldfarb Abrandt Salzman & Kutzin LLP

Home Care Council of New York City

Independent Living Center of the Hudson Valley, Inc.

JASA/Legal Services for the Elderly in Queens

Legal Aid Society

Legal Service NYC

Legal Services NYC – Brooklyn Branch

Lenox Hill Neighborhood House

Medicaid Matters NY

Metropolitan Council on Jewish Poverty

MFY Legal Services, Inc.

Morningside Retirement and Health Services (MRHS)

New York Association on Independent Living (NYAIL)

New York Lawyers for the Public Interest

New York Legal Assistance Group

Queens Legal Services

Self-Advocacy Association of New York State

Selfhelp Community Services, Inc.

Southern Tier Independence Center

United Jewish Council of the East Side, Inc.

United Spinal Association

Westchester Disabled on the Move, Inc.

Yad HaChazakah-The Jewish Disability Empowerment Center Inc.

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Demonstrations & Waivers
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Mark Kissinger, New York State Dep't. of Health
Vallencia Lloyd, New York State Dep't. of Health

Senator Kirsten Gillibrand
Senator Charles Schumer

EXHIBIT A

Personal Care Aid Utilization Comparison in MLTC Plans in NYC

Based on MLTC Cost Reports filed with State DOH for 2009 Q4

Data obtained through Freedom of Information Request

Personal Care Aide Utilization Comparison in MLTC Plans in NYC

2009 Q4

Exhibit A5 - Personal Care Hours Year-to-Date	ICS		Guildnet		HomeFirst		VNS	
	Avg Hours PMPM	% of Members	Avg Hours PMPM	% of Members	Avg Hours PMPM	% of Members	Avg Hours PMPM	% of Members
Member Breakdown by Category and Use Category Based on Hours per Month								
700+ hours per month	723.7	8.0%	727.2	6.0%	720.0	1.1%	735.3	0.2%
480-699 hours per month	610.6	3.7%	578.4	2.5%	573.5	0.4%	606.1	0.3%
320-479 hours per month	366.8	8.2%	358.6	5.2%	397.1	12.1%	360.0	3.5%
240-319 hours per month	260.6	10.0%	269.7	8.7%	272.0	10.4%	268.6	8.6%
160-239 hours per month	193.8	21.2%	183.5	18.6%	194.3	21.0%	194.6	21.7%
80-159 hours per month	116.2	27.7%	104.7	40.4%	102.6	38.3%	116.0	41.1%
1-79 hours per month	39.8	21.0%	50.0	18.6%	40.5	16.7%	44.8	24.6%
TOTAL	218.8		186.0		173.6		140.2	
Avg Hrs per Week (PMPM x 12 / 52)	50.5		42.9		40.1		32.4	
Unit Cost	\$15.51		\$13.26		\$13.89		\$19.37	

MLTC Cost Report data for the period ending 12/31/09. Source: NYSDOH

Independence Care System

**INDEPENDENCE CARE SYSTEM
PCA, HHC, NURSING FACILITY, TRANSPORTATION & DME/SUPPLIES COST AS PERCENTAGE OF TOTAL MEDICAL EXPENSE
BASED ON 4TH QUARTER 2009 MMICOR FILINGS**

Provider	Personal Care Aides	Home Health Care	Nursing Facility	Transportation	DME & Supplies/Other
Expense PMPM					
ICS	\$ 3,394.03	\$ 130.42	\$ 83.19	\$ 230.21	\$ 302.90
Guildnet	\$ 1,983.25	\$ 299.34	\$ 54.69	\$ 117.54	\$ 67.88
HomeFirst	\$ 2,342.60	\$ 56.76	\$ 107.27	\$ 100.69	\$ 42.11
VNS	\$ 2,468.44	\$ 339.70	\$ 397.40	\$ 93.34	\$ 41.44

Expense/Revenue PMPM	Total Medical	
	Expense	Premium
ICS	\$ 4,400.03	\$ 5,187.48
Guildnet	\$ 2,675.91	\$ 3,239.41
HomeFirst	\$ 2,692.47	\$ 3,079.89
VNS	\$ 3,393.71	\$ 3,960.81

Provider	Personal Care Aides	Home Health Care	Nursing Facility	Transportation	DME & Supplies/Other
Expense as Percentage of Total Medical Expense					
ICS	77.1%	3.0%	1.9%	5.2%	6.9%
Guildnet	74.1%	11.2%	2.0%	4.4%	2.5%
HomeFirst	87.0%	2.1%	4.0%	3.7%	1.6%
VNS	72.7%	10.0%	11.7%	2.8%	1.2%
Expense as Percentage of Medicaid Premium Income					
ICS	65.4%	2.5%	1.6%	4.4%	5.8%
Guildnet	61.2%	9.2%	1.7%	3.6%	2.1%
HomeFirst	76.1%	1.8%	3.5%	3.3%	1.4%
VNS	62.3%	8.6%	10.0%	2.4%	1.0%

MEMORANDUM ON PROPOSED REGULATION ON MEDICAID ESTATE RECOVERY

3. *See* Uniform Transfers to Minors Act (2005).

ELDER LAW SECTION REAL PROPERTY LAW SECTION TRUSTS AND ESTATES LAW SECTION

Elder, RPLS, T&E - #6

January 6, 2012

PROPOSED REGULATION ON MEDICAID ESTATE RECOVERY

The Elder Law, Trusts and Estates and Real Property Sections express their appreciation to the New York State Department of Health and the Executive chamber for providing an open and collaborative process, and seeking input from the Sections regarding the proposed estate recovery regulation.

We support the change that the new definition of estate will only affect estates of persons dying on or after July 1, 2012. Additionally, changing the definition of an interest in property immediately prior to death from “includes” to “means” will go a long way to assist people in knowing in advance the consequences of their actions. The changes provide fair warning, and, as was pointed out at our meeting, “time to take corrective action.”

However, we continue to have a number of concerns with the proposed regulation. This memorandum will discuss six areas of concern: retroactive effect, life estates, spousal claims, retirement plans, annuities and liens. We have not repeated our policy concerns or why we feel that many of these changes will actually cause an increase in Medicaid expenditures. We have focused here instead on why we feel this proposed regulation is in conflict with the amended estate recovery legislation and other New York State laws. For our other concerns please refer to our prior correspondence.

Retroactive Effect:

We continue to be perplexed by the fact that the proposed regulation affects vested interests despite the clear language of the enabling legislation prohibiting this. The proposed regulation applies to Medicaid recipients who die on or after July 1, 2012, even if the enumerated transactions occurred prior to such date. This is in conflict with the enabling provision of the statute, 2011 NY Laws Ch. 59, Part H, § 111 (u), which states: “(u) this act shall not be construed to alter, change, affect, impair or defeat any rights, obligations, duties or interests accrued, incurred or conferred prior to the effective date of this act;...”

Opinions expressed are those of the Section/Committee preparing this memorandum and do not represent those of the New York State Bar Association unless and until they have been adopted by its House of Delegates or Executive Committee.

The import of § 111 (u) of the statute is to make it clear that any definition of “estate” established by the Department cannot impair interests in property that vested prior to April 1, 2011. These vested interests would of necessity include remainder interests in real property which under the Estates, Powers and Trusts Law are vested, alienable and not subject to defeasance by any action of a life tenant. See EPTL §§ 6-4.7, 6-5.1 and 6-5.10. In addition, retroactive effect of the regulation would constitute a taking in violation of the U.S. Constitution.

Life Estates:

The proposed regulation expands the definition of estate to include the value of a retained life estate immediately prior to death. Specifically, 18 NYCRR § 360-7.11 (a)(2)(ii) states:“(a)(2)(ii) a retained life estate, based on the actuarial life expectancy of the life tenant;” and 18 NYCRR § 360-7.11 (a)(3) states: "(a)(3) Retained life estate means: (i) a life estate created by a person or the person's spouse in property in which the person or spouse held any interest at the time the life estate was created; or (ii) a life estate created for the benefit of a person or the person's spouse in property in which the person or spouse held any interest within five years prior to the creation of the life estate."

The proposed regulation conflicts with existing New York law, which provides for the indefeasible vesting of a remainder interest and will result in competing claims to property of a deceased Medicaid recipient. In particular, see EPTL §§ 6-4.7 and 6-5.1.

We have raised with you a couple of examples where there would be clear title problems if this proposed regulation went into effect. In the first example, an elderly homeowner sells his house at a discount in exchange for retaining the right to live there for life. The arms-length purchaser paid fair market value for the remainder interest in the property based on the IRS tables valuing a remainder interest. Subsequently after the funds from the sale are exhausted, the life tenant goes on Medicaid for a couple of years before his death. In the second example, a mother transfers her home to a child but retains a life estate; the child later sells his remainder interest to a third party. Subsequently the life tenant goes on Medicaid before dying. In both cases Medicaid’s claim would conflict with the rights of the remaindermen.

Spousal Claims:

The proposed regulation confuses estate recovery from a Medicaid recipient and from a legally responsible spouse of a Medicaid recipient. Estate recovery under Social Services Law § 369, both before and after the amendment, applies to estate recovery from the estate of the Medicaid recipient. As was recently pointed out by the Appellate Division 2nd Department, these rules and exclusions do not apply to recoveries against the estate of a legally responsible relative, such as a spouse. *Matter of Schneider*, 70 A.D. 3d 842, 894 N.Y. 2d 162 (2d Dep’t 2010). In *Schneider* the Court pointed out, “Moreover the

limitation on recoveries from a Medicaid recipient's estate where the recipient is survived by a permanently disabled child (see 42 USC § 1396p [b] [2]; Social Services Law § 369 [2] [b] [ii]; *Matter of Andrews*, 234 AD2d 692, 692-693, 650 NYS2d 470 [1996]; *Matter of Samuelson*, 110 AD2d 187, 192-197, 493 NYS2d 784 [1985]; *Matter of Burstein*, 160 Misc 2d 900, 901-902, 611 NYS2d 739 [1994]) is inapplicable here, where the DSS does not seek recovery from the estate of the institutionalized spouse for medical benefits that it furnished to her pursuant to Social Services Law § 366 (3); but, rather, seeks recovery from the estate of the community spouse (see Social Services Law § 369 [2] [b] [ii]).”

It could not be any clearer that the statute refers to "the individual's estate." However, the proposed regulation when it discusses "Retained life estates" at § 360-7.11 (a)(3) refers to "a life estate created by a person or the person's spouse in property in which the person or spouse held any interest at the time the life estate was created;...." The proposed regulation clearly indicates there would be a claim against a retained life estate by a spouse as part of estate recovery against the estate of a spouse. Yet, there is no similar authority in the statute.

Retirement Plans:

The proposed regulation at § 360-7.11 (a)(2)(viii) has added estate recovery against “the amount the person could have withdrawn from an individual retirement account or other retirement fund, taking into account any penalty for early withdrawal.” The statute does not list retirement accounts, nor could it, since this is specifically prohibited by EPTL § 13-3.2(a) which states: “(a) If a person is entitled to receive (1) payment in money, securities or other property under a pension, retirement, death benefit, stock bonus or profit-sharing plan, system or trust ... the rights of persons so entitled or designated and the ownership of money, securities or other property thereby received *shall not be impaired or defeated by any statute or rule of law* governing the transfer of property by will, gift or intestacy.” [emphasis added]

Three courts have applied EPTL § 13-3.2(a) to the claims of a decedent’s creditors. New York County Surrogate Preminger interpreted section EPTL §13-3.2 as prohibiting creditors from reaching the proceeds of several types of retirement plans payable to a revocable trust as beneficiary. The Surrogate said: "The court infers that the Legislature intends that the assets enumerated in EPTL 13-3.2 are exempt from creditors' claims after death, as they are in life.” *Matter of Gallet*, 196 Misc. 2d 303 at 309, 765 N.Y.S.2d 157 at 162 (Sur. Ct. N.Y. County 2003). Broome County Surrogate Peckham held that a IRC § 403(b) retirement annuity should be exempt from claims of creditors after death, stating: “Either by statute or case law virtually every type of retirement plan is exempt from the claims of the decedent's creditors. Anti-alienation applies to Employee Retirement Income Security Act, 29 U.S.C.S. § 1001 et seq., plans (29 U.S.C.S. § 1056(b)), New York State employees' retirement plans (N.Y. Retire. & Soc. Sec. Law § 110), New York State teacher's retirement plans (N.Y. Educ. Law § 524), individual retirement accounts (N.Y. C.P.L.R. § 5205(c)), federal thrift savings plans, and life insurance and annuities (N.Y. Ins. Law § 3212).” *Matter of King*, 196 Misc. 2d 250 at 255, 764 N.Y.S.2d 519 at 523 (Sur. Ct. Broome County 2003).

The Appellate Division, Third Department held in reliance on another provision in EPTL § 13-3.2(a) that an annuity is not subject to the claims of creditors. *Matter of Clotworthy*, 294 A.D.2d 720, 742 N.Y.S.2d 168 (3rd Dept. 2002). Since *Clotworthy* deals with a part of the EPTL provision dealing with annuities we will discuss it below.

Furthermore the proposed regulation has not taken into consideration the tax consequences to the retirement plan's intended beneficiary. Since these are pretax funds, the beneficiary must pay income tax on the funds. However under the regulation the funds will be claimed by the Medicaid Program. You analogized this to Medicaid's budgeting gross income. However, this is very different from that situation; the beneficiary here is not a Medicaid recipient, yet he is being taxed on funds he will never receive.

Annuities:

Claims against annuities are affected by two of the points discussed previously.

Sub provision (2) of EPTL § 13-3.2(a) would likewise prohibit recovery against certain annuities as proposed by the regulation at § 360-7.11 (a)(2)(vii). EPTL § 13-3.2 (a) provides "If a person is entitled to receive ... (2) money payable by an insurance company or a savings bank authorized to conduct the business of life insurance *under an annuity or pure endowment contract* or a policy of life, group life, industrial life or accident and health insurance, or if a contract made by such an insurer relating to the payment of proceeds or avails of such insurance designates a payee or beneficiary to receive such payment upon the death of the person making the designation or another, the rights of persons so entitled or designated and the ownership of money, securities or other property thereby received shall not be impaired or defeated by any statute or rule of law governing the transfer of property by will, gift or intestacy." [emphasis added]. Again, the Third Department specifically held in reliance on this section that an annuity is not subject to the claims of creditors. *Matter of Clotworthy*, 294 A.D.2d 720, 742 N.Y.S.2d 168 (3rd Dept. 2002).

In discussing claims against an annuity in § 360-7.11 (a)(2)(vii) the proposed regulation includes an annuity purchased by or with the assets of a person's spouse. But as we have pointed out Social Services Law § 369 applies only to the estate of the Medicaid recipient. *Matter of Schneider*, 70 A.D. 3d 842, 894 N.Y. 2d 162 (2d Dep't 2010).

Liens

The proposed regulation § 360-7.11 (b)(2) states: "Liens shall be imposed on property and assets described in subparagraph (ii) of paragraph (1) of subdivision (a) of this section as soon as practicable after the person's death. Liens asserted against real property, including cooperative apartments, will be effective upon the filing of a notice of lien in the office of the clerk of the county in which such property is located."

There is no statutory authorization to impose such liens. No provision of Social Services Law §369, either as it existed before or after the amendment expanding the definition of an estate, authorizes the imposition of post-death liens on real property to secure such claims. It is black letter law that a lien on real property may only be created by agreement (an equitable lien), or by statute. Clearly the regulation does not deal with cases where there was an express or implied agreement of the parties to assign a property interest. Indeed, as you have pointed out, some of these transfers may have historically occurred to avoid a lien or recovery. Therefore the lien sought to be imposed must arise from statutory authority. However, no such authority exists.

Subdivision 2 of §369 authorizes the imposition of pre-death liens on the property of Medicaid recipients in certain enumerated circumstances. For example, a pre-death lien may be imposed pursuant to a court judgment on account of Medicaid incorrectly paid, or a pre-death lien may be imposed on the recipient's home if no one is residing in the home. Such pre-death liens are the only ones so authorized by statute.

Review of the Medicaid recovery statutes of other States shows that other State legislatures have clearly given their Department of Social Services an enforcement mechanism to implement recoveries against life estates formerly held by deceased Medicaid recipients. The New York legislature chose not to do so. In the absence of legislative authority to impose a post death lien on real property, the State Department of Health may not create such authority by regulation.

Conclusion:

We appreciate the opportunity to comment on the draft regulation and we appreciate some of the changes that you have made from the previous emergency regulation. However, we continue to be concerned, not only because of the many policy concerns and negative effects that we have enumerated in the past, but because it appears that the proposed regulation is as we have pointed out here in direct conflict with the amended statute and with various other New York laws. Yet, when we have raised these issues, we have heard no explanation in response.

We look forward to your response, and our continuing dialogue.

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