

GUARDIANSHIP MATTERS

SOMETIMES YOU NEED TO THINK OF YOURSELF FIRST...

PREPARED BY: KIMBERLY STRAUCHON VERNER, ESQ.
SENIOR ASSOCIATE WITH TULLY, RINCKEY & ASSOCIATES, P.L.L.C.

INSIDE THIS ISSUE

Guardianship Program is Committed 24/7	2
Policies and Procedures Sent to Chapters	2
When Roles are Reversed	4
Medication Information	5
Legislative Update	6
Regional Updates	7
NYSARC Guardianship Training	8

NYSARC GUARDIANSHIP PROGRAM STATISTICS AS OF MARCH 1, 2005

Court Appointed

Primary Guardianships:	257
Standby Guardianships:	193
Alternate Standby Guardianships:	262
TOTAL:	712

Pending Court Decrees

Primary Guardianships:	71
Standby Guardianships:	34
Alternate Standby Guardianships:	23
TOTAL:	128

When a new guardianship client comes to my office for assistance, I ask a lot of questions. The client is often surprised that many of the questions focus on the needs of the guardian and not on the needs of the person with a disability. However, I strongly believe that a guardian cannot wholeheartedly take care of another individual until the guardian has properly taken care of him or herself. I don't mean getting a massage or an annual physical. In this context, I mean taking care of your own legal affairs and making a plan for the possibility that one day, you, the guardian, may no longer have the ability to make decisions for yourself. Specifically, I mean signing Advanced Directives.



Advanced Directives are the documents a competent adult signs to appoint another person to make decisions for him or her in the event the adult signor (also known as the "principal") is unable to act. You would sign a Durable Power of Attorney to appoint one or more people to make

business and financial decisions on your behalf. In New York, you would sign a Health Care Proxy to appoint someone to make health care and end of life decisions for you. (In other states, this document may be called a Durable Power of Attorney for Health Care or it may be combined with the Durable Power of Attorney.) Some individuals also choose to execute a Living Will or include Living Will language in the Health Care Proxy.

The Durable Power of Attorney is a powerful document which permits the agent to make *any* financial or business decisions that the principal could make; including signing checks, making withdrawals from bank accounts, or completing an estate plan. This document is beneficial because the agent steps into the shoes of the principal and keeps his or her finances flowing smoothly. It is also potentially dangerous because the principal could be open to financial abuse by the agent. When choosing a possible agent, drafting attorneys always caution our clients to name only those family members or friends that could be trusted with all of their money and a blank

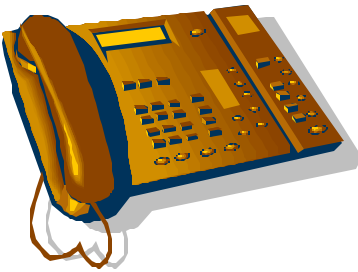
check because this is the power given under the Durable Power of Attorney.

The principal has two choices when deciding when the Durable Power of Attorney should go into effect. Under the standard Durable Power of Attorney, the agent may start acting as soon as the document is signed. This does not take away the authority of the principal, it just adds another person who can sign for the principal. If the principal prefers, he or she can sign a "Springing" Durable Power of Attorney, which does not allow the agent to act until a doctor signs a statement that the principal is no longer able to make decisions for him or herself.

The Health Care Proxy never goes into effect until the agent is unable to communicate his or her wishes to a health professional. Unlike the Durable Power of Attorney, in which you may name co-agents, you may **only name one** person at a time to act under the Health Care Proxy. From experience, I know that if the Health Care Proxy is needed, it is usually a trying and stressful time for a family. It is very easy for two children, two siblings, etc. to have different opinions or

(Continued on page 3)

THE NYSARC CORPORATE GUARDIANSHIP PROGRAM IS COMMITTED 24/7



The Corporate Guardianship Program has developed an internal policy to ensure that someone from the State Office is always available to assist the Chapters' Guardianship Programs should an end-of-life situation emerge with an individual for whom NYSARC, Inc. is serving as primary guardian.

If a situation requiring an end-of-life decision, or the possibility of such a decision, emerges after normal business hours (Monday - Friday 8:00 a.m. to 5:00 p.m.) the Chapters' Guardianship Coordinators, or other staff and members of the Guardianship Committee, will be able to contact the on-duty State Office staff by paging them at 518-448-6881.

Should the Chapters' Guardianship Program need to contact the State Office staff after hours concerning the health care needs of those persons for whom NYSARC, Inc. is Primary Guardian, the Chapters are asked to leave a message as well as a call back number. This pager is dedicated to the sole purpose of enabling Chapter staff and volunteers to get in touch with a NYSARC, Inc. State Office staff person to provide immediate and necessary assistance. The staff person who is on-call and paged will coordinate the necessary State Office resources.

—Muriel J. Doyne

NEW NYSARC, INC. GUARDIANSHIP POLICIES AND PROCEDURES MANUAL SENT TO CHAPTERS FOR IMPLEMENTATION

The Guardianship Policies and Procedures manual, adopted by the Board of Governors on October 15, 2004, has been sent this past December to the chapters for immediate implementation. Although the policies have an effective date of January 1, 2005, the Board of Governors has provided the chapters with a six (6) month grace period before full compliance is expected. The NYSARC, Inc. Guardianship Committee and State Office Staff are committed to working with the Chapters' Guardianship Committees and Staff in order to support and strengthen the corporate program on behalf of persons with mental retardation and other developmental disabilities and their families.

In his written remarks to the Board of Governors this past Fall, James M. Hayes, Chairperson of the State Guardianship Committee, spoke of operating an effective Guardianship Program as one significant area where we must depend on many of the elements that make us a strong organization statewide. "We must ensure that the vibrant and strong partnerships between volunteers and professionals; the shared responsibilities among the various stakeholders; the multiple levels of involvement and participation from the Chapter to regional to state level; and the diverse sources of resource support are strengthened." In essence, this manual provides the detail as to what we have committed to do as a statewide system, and what families and the courts can expect. This commitment, and a program based on a lifelong caring family voice of advocacy for each other's loved ones with mental retardation and other developmental disabilities and their families embodies our organization's founding principles and values, and surely sets us apart from others in the guardianship arena.

The summary of the NYSARC, Inc. Guardianship Policies and Procedures can be obtained by contacting Erica Berman at: bermane@nysarc.org

SOMETIMES YOU NEED TO THINK OF YOURSELF FIRST...

(Continued from page 1)

interpretations of the principal's wishes. This law is set up so that the principal names one primary family member or friend to speak on behalf of the principal to avoid this conflict. Adding "Living Will" language to the Health Care Proxy may help to clarify your wishes to both your agent and your physicians.

The big question for many people is "Do I need to see an attorney to sign these documents?" The biased answer from an attorney is yes for the Durable Power of Attorney and maybe for the Health Care Proxy - but let me explain why. You can get blank Durable Power of Attorney forms from your local business supply store or in a software kit, but these are usually generic forms, not State specific. If you see an estate planning attorney, this attorney will draft a Durable Power of Attorney based on New York statute and the document will be far more powerful and provide broader authority than a generic form. If you seek the assistance of an experienced elder law attorney, this document will most likely contain additional language granting the agent(s) broader authority to make decisions related to tax planning, estate planning and planning for long term care.

As for the Health Care Proxy, you can download a copy of this form from the New York State Department of Health's website (www.health.state.ny.us) and click on "forms". The Health Care Proxy is a straight-forward document which includes excellent, easy-to-follow instructions. However, I have two pieces of advice about signing the form. First, make sure that you have added language to the Health Care Proxy stating that your agent knows your wishes about artificial nutrition and hydration. If you do not include

this language and your family cannot prove your wishes by other means, by law, a hospital *must* insert a feeding tube, if medically necessary. Second, you should never have family members act as witnesses to your Health Care Proxy.

So, why do you need Advanced Directives? Guardians for persons with a disability are more aware of the consequences than the general public. If an adult does not have a Durable Power of Attorney and/or Health Care Proxy, and he or she suddenly becomes ill, is involved in an accident, or over time develops dementia, and is no longer competent to manage his or her affairs, someone will need to go to court to have a guardian appointed for this adult. If the person in need of a guardian does not have mental retardation, a developmental disability or a brain injury, this will have to be an Article 81 Guardianship through the Supreme Court. An Article 81 guardian is generally more complicated and much more expensive than the Article 17-A guardianships that most of you are familiar with. If given a choice, most adults I know would rather spend a few hundred dollars on these Advance Directives and control who will act for them in the future, then spend thousands of dollars on a guardianship and let the courts have the final say as to who should act and what powers the guardian should have.

If you have accepted the challenge of acting as the guardian for a person with a disability, I commend you for dedicating your time and energy to the needs of another person. Please arrange to sign a Durable Power of Attorney and Health Care Proxy, so you can have peace of mind with respect to your own affairs and can concentrate your energies on the person who is relying on you. And, getting an annual physical and a

massage couldn't hurt, too.

Kimberly Strauchon Verner, Esq.
Senior Associate
Tully, Rinckey & Associates, PLLC
Attorneys & Counselors at Law
3 Wembley Court
Albany, New York 12205
518-218-7100 Phone
www.tullylegal.com

Kimberly Strauchon Verner, Esq., is a Senior Associate with the general practice law firm of Tully, Rinckey and Associates, LL.P., of Colonie, New York, where she manages their trusts, estates and real property group. Her practice is focused in elder law, future care planning for persons with disabilities and their families, guardianships, general estate planning, estate administration, and residential real estate.

Prior to law school Kim worked at the Center for the Disabled coordinating grant-funded, innovative independent living programs for persons with developmental disabilities. Kim is the Co-Chair of the Albany County Bar Associations Elder Law and Trusts and Estates Committee and is also a member of the Elder Law and Real Property Sections of the New York State Bar Association. Currently, she serves as President of the Board of Directors of the Capital District Center for Independence.

Kim speaks frequently educating other professionals and the public on the topics of guardianship, disability law issues, estate planning, and residential real estate. She also conducts New York State Bar Association Continuing Legal Education seminars, educating the public at Albany Law School's Senior Law Days, and Disability Law Days.

WHEN THE ROLES ARE REVERSED AND ADULT CHILDREN BECOME GUARDIANS FOR THEIR PARENTS

Joan Kennedy has been an advocate for persons with mental retardation and worked for causes such as cancer research. She has been active in the Joseph Kennedy Jr. Foundation for Mental Retardation, and a supporter of several causes, including the Pine Street Inn, a Boston organization helping the homeless, and Children's Hospital in Boston.

Now she is in need herself of medical treatment and assistance due to reoccurring difficulties with alcoholism. According to several reports, including an Associated Press article on February 24, 2005, the Kennedy brothers and sister sought and were granted guardianship by the Probate Court on Cape Cod of their mother and former wife of Massachusetts Senator Ted Kennedy in the Spring of 2004, in order for the siblings to legally advocate for their mother's medical care and needs which were apparently being disregarded.

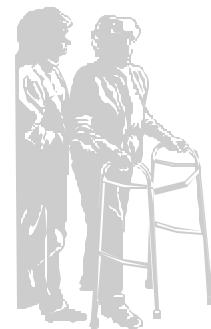
Under Massachusetts law, a person is presumed to be a competent adult and can only be awarded a guardian if the individual is determined to be unable to care for herself as a

result of mental illness, mental retardation, or because she is incapacitated and unable to communicate, such as being in a coma. Mental illness can be defined in broad terms for the purposes of awarding guardianship, and it can be any form of mental illness that requires treatment by a mental health professional, including anything from depression to schizophrenia to bipolar disorder. The petitioner(s) seeking the guardianship must be a parent, two or more relatives or friends of the respondent of the proceedings, the Department of Mental Health, or a non-profit corporation whose charter enables it to act as guardian. In this matter, there must be a preponderance of the evidence that the subject of the guardianship proceeding is mental illness, and she is unable to care for her basic needs, such as; food, clothing, shelter, or refuses treatment of her mental illness. In Massachusetts, there is a requirement that a medical certificate be completed along with the court application which also needs to be signed by a psychiatrist who examined the individual within the previous 30 days, and declares that the subject is unable to care for herself by

reason of mental illness.

Although the siblings, including Patrick Kennedy, Edward Kennedy Jr., and their sister Kara Kennedy Allen refused to elaborate on specific details about the guardianship order or Joan Kennedy's current health condition, it was disclosed that the guardianship was sought in order to ensure that their mother would receive on-going supervision in her daily affairs as routine as running errands. In the past, it has been noted that Joan Kennedy has been able to celebrate some triumphs over her drinking after seeking treatment, only then to encounter relapses from this disease. The Kennedy children have indicated through the media that they are committed to ensuring their mother's well-being and safety. Isn't that what guardians are suppose to do for their loved ones?

—Erica F. Berman



“The only limit to our realization of tomorrow will be our doubts of today.”

Franklin Delano Roosevelt

MEDICATION INFORMATION FOR CONSUMERS

Project MED which stands for Medical Education for Consumers, has created a way to provide information to patients in a consumer friendly manner that they can understand about the medications they are taking. The Nisonger Center at the Ohio State University received financial support from the U. S. Administration on Developmental Disabilities to fund Project MED, which consists of a series of eight booklets. The purpose of these booklets is to educate readers about classes of psychotropic drugs, mood and behavior medicines, as well as issues relating to a patient's rights and responsibilities. What makes them unique is that they are specifically designed for a broad group of people with limited reading ability who regularly take medication; such as persons with autism, mental retardation and other developmental disabilities, severe mental illness, child and adolescents, and people whose first language is not English.

Although these booklets were written for individuals with special needs, families of people with chronic illnesses, health care professions, and advocacy organizations are finding these booklets to be useful educational tools as well and have a wide appeal. They are written in large type, and with liberal use of illustrations. Currently, these booklets are in English, however the Spanish version will be made available in the near future.

BOOKLETS ARE NUMBERED AND TITLED AS FOLLOWS

1. **Patients' Rights and Responsibilities**—*An easy to read guide for people who take these medicines*
2. **Anticonvulsant Medicines**—*Medicine for people with epilepsy*
3. **Antipsychotic Medicines (Neuroleptics)**
4. **Antidepressant Medicines**
5. **Antimanic Medicines**—*Medicine for people with mood problems*
6. **Antianxiety Medicines**—*Medicine for people with too much worry*
7. **Stimulant Medicines**
8. **Other Behavior Medicines**—*This includes Blood Pressure medicine, Naltrexone, Vitamins and over the counter medicines.*

The booklets average 20-30 pages in length. Each publication covers at a minimum:

- a) The names of the medicines including brand and generic
- b) The uses of the medicines, including what is or is not "proven"
- c) Common side effects
- d) Common doses
- e) Common interactions
- f) "How long will I take this medicine"

By providing this information, Project MED hopes to increase a patient's participation in his or her own health care. These may be a valuable resource for individuals in our Guardianship Program, families and other persons being provided services by our Chapters.



The cost for each booklet is \$1.50 plus shipping and handling, and the order form can be found and printed from the Project MED website by going to <http://www.project-med.org/>. If you have any questions, you may also call the Research Coordinator at the Nisonger Center at (614) 688-3375.

—Erica F. Berman



LEGISLATIVE UPDATE—

NYSARC GETS BILL SPONSORED FOR CONTINUING AUTHORITY OF SDMCS

According to Ben Golden, Associate Executive Director for Governmental Affairs, multi-sponsored companion bills were just introduced on March 1, 2005 by the State Assembly and Senate to expand the medical services provided by the Surrogate Decision Making Committees (SDMC) Program, to persons with mental disabilities who move to nursing homes and other residential settings. Bills A. 5794, by Brennan, and S. 2751 by Morahan would amend Mental Hygiene Law Article 80 to enable anyone with a mental disability who at one time received services through the mental hygiene system continue to receive such services from the SDMCs regarding major medical treatment regardless of their change in residence.

Existing law has been interpreted to forbid continued decision making for an individual with mental disabilities by the SDMC operated under the auspices of the New York State Commission on Quality of Care for the Mentally Disabled, in the event the individual is no longer an “active” resident of a mental hygiene facility.

The SDMC program was originally established in the late 1980’s to make critical medical decisions for individuals with mental disabilities who do not have the capacity to make their own health care decisions, or another authorized individual, i.e. a guardian, to make such decisions for them. Without SDMCs, such individuals must rely on courts, often waiting months for medical decisions to be made for them by a court, despite facing painful or life threatening situations.

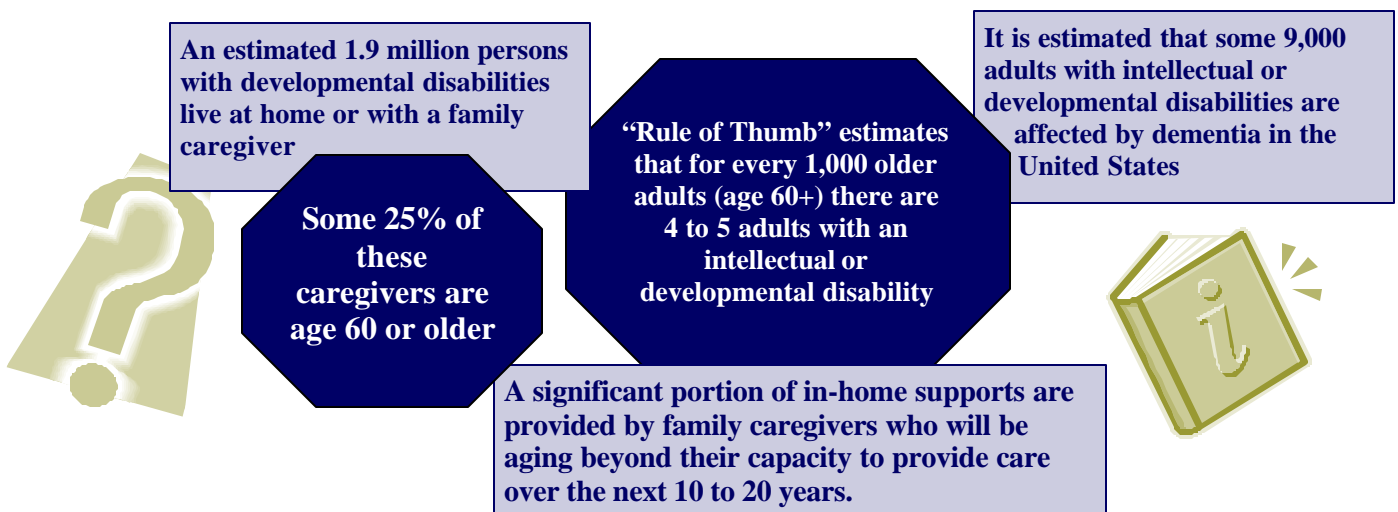
The SDMC has proven to be invaluable in making these critical medical decisions for persons residing in residences licensed or

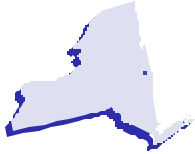
operated by OMRDD or the Office of Mental Health.

However, advocates and providers are alarmed by the increase in elderly individuals with mental disabilities who lose the benefit of expert medical decision-making by these Committees as a result of being placed outside the mental hygiene system, especially in nursing homes. SDMC loses jurisdiction for persons who move to nursing homes and these facilities then have to scramble to find other alternative means of making health care decisions. This can result in costly delays, both in providing appropriate and expeditious care and treatment, and considerable expense if the courts are petitioned to provide authority to grant these medical procedures or appoint temporary guardians.

We will continue to keep you informed on the progress of this important bill in the next issue of *Guardianship Matters*.

—Erica F. Berman





REGIONAL UPDATES—A VIEW ON REGIONAL GUARDIANSHIP COMMITTEE MEETINGS

Pursuant to previous policy of the Board of Governors and in accordance with NYSARC, Inc.'s Guardianship Policies and Procedures, the Guardianship Coordinators and others representing the Chapters' Guardianship Programs are required to attend and participate in regional meetings held throughout the year and share best practices and peer partnering with other Chapters located anywhere in the State.

The following represents a summary of the meetings attended by the Chapters in their respective Regional Sub-Committees.

Region # 1- Southeast Region –

Facilitated by Nancy Succoso - (Westchester Chapter)

January 27, 2005 –Regional Meeting was held at the Rockland County Chapter.

- ◆ Thirty (30) people representing six (6) chapters participated in the meeting with presentations provided by James C. Moragne, District Manager for Revenue Support, OMRDD, and Heidi Flatt, Assistant Executive Director for Fiscal Management, NYSARC, Inc.
- ◆ A brief presentation was made by Laurie Stride, Esq. on the Chantel Rutledge Decision.
- ◆ **Next Meeting:** Scheduled at the Rockland County Chapter for April 14, 2005.

Region # 2- Western /Finger Lakes Region—

Facilitated by Barbara Wale (Monroe Chapter)

December 10, 2004 -Regional meeting was held at the Monroe County Chapter.

- ◆ Twenty-six (26) people representing fourteen (14) chapters participated in the meeting with presentations provided by James C. Moragne, District Manager for Revenue Support, OMRDD, and Heidi Flatt, Assistant Executive Director for Fiscal Management, NYSARC, Inc.
- ◆ Erica Berman provided an update on NYSARC Inc. Guardianship activities and discussed the May 2005 Conference on Future Care Planning and End-of-life Care.
- ◆ **Next Meeting:** Scheduled for April 27, 2005 at the Monroe County Chapter.

Region # 3 –

Facilitated by Steve Ramos (Ulster-Greene Chapter)

December 17, 2004–Regional meeting was held at the Rensselaer County Chapter.

- ◆ Seven (7) people representing six (6) chapters participated in the meeting to discuss NYSARC's changes to the new Guardianship Policies and Procedures; recent End-of-Life care situations involving NYSARC, Inc. Wards receiving services from the Ulster-Greene and Rensselaer County

Chapters; the May 2005 Conference on Future Care Planning; and the need to have training for the Guardianship Coordinators in the near future.

- ◆ **Next Meeting:** Scheduled for March 11, 2005 from 10:30-3:30 p.m. at the Ulster-Greene Chapter in Catskill with invited Guest Presenters, James C. Moragne and Heidi Flatt.

Region # 4 – Central Region –

Facilitated by Debra Gallagher (Onondaga Chapter)

December 9, 2004 – Regional meeting held at the Onondaga County Chapter.

- ◆ Eleven (11) people representing eight (8) chapters participated in the meeting, and discussion included end-of-life decisions involving NYSARC, Inc. Wards; available guardianship training for Chapter Board of Directors, Guardianship Committees and families; the new Guardianship Newsletter; and the status of MHLs with NYSARC Guardianships.
- ◆ Training was provided by Mike O'Brien, Esq. who presented the module for Chapter Guardianship Committees.
- ◆ **Next Meeting:** Scheduled from 11:00-2:00 on March 10, 2005 at the Arc of Onondaga in Syracuse. Barb Wale has been invited to present on Peer Partnering at this meeting.

Region # 5 – Northeast Region –

Facilitated by Patty Paduano (Saratoga Chapter)

February 25, 2005-Regional meeting was held at the Saratoga County Chapter.

- ◆ Eight (8) people representing four (4) chapters participated in the meeting and discussion focused on the NYSARC Guardianship Policies and Procedures, including how new requirements will be addressed by each of the chapters. Warren-Washington Counties Chapter discussed their internal Policies and Procedures manual that incorporates additional information on how the guardianship services will be carried out by the Guardianship Program.
- ◆ **Next meeting:** Scheduled for June 3, 2005 at the Saratoga County Chapter.

INFORMATIVE WEBSITES

American Mental Health Counselors Associationwww.amhca.org

The AMHCA enhances the profession of mental health counseling through licensing, advocacy, education and professional development.

Guardianship Services, Inc.www.guardianshipservices.org

Guardianship Services recruits, screens and trains volunteers to serve as court-appointed guardians.

National Family Caregivers Associationwww.nfcacare.org

NFCA supports, empowers and educates Americans who care for a chronically ill, aged, or disabled loved one.

National Council on Disabilitieswww.ncd.gov

The NCD is an independent federal agency making recommendations to the President and Congress to enhance the quality of life for all Americans with disabilities and their families.

National Association of Protection and Advocacy Systemswww.napas.org

NAPAS is the voluntary national membership association of Protection & Advocacy (P&A) providers and Client Assistance Programs (CAPs).



A family-based organization working with and for people who have mental retardation and other developmental disabilities

393 Delaware Avenue
Delmar, New York 12054
Phone: 518-439-8311
Fax: 518-439-1893
www.nysarc.org
E-mail: nysarc@nysarc.org

On-line Shopping:
www.shopfornysarc.org

NYSARC, Inc. CORPORATE GUARDIANSHIP TRAINING



- February 8, 2005:** **Orange County Chapter of NYSARC, Inc.**
Training to Chapter Guardianship Committee
- February 15, 2005:** **Albany County Chapter of NYSARC, Inc.**
Guardianship training to Chapter Board of Directors
- February 17, 2005:** **Dutchess County Chapter of NYSARC, Inc.**
Training to Chapter Guardianship Committee
- March 8, 2005:** **Westchester County Chapter of NYSARC, Inc.**
Training to Chapter Guardianship Committee
- March 9, 2005:** **Franklin-Hamilton Counties Chapter of NYSARC, Inc.**
Training to Chapter Guardianship Committee
- March 14, 2005:** **Saratoga County Chapter of NYSARC, Inc.**
Training to Chapter Guardianship Committee
- March 15, 2005:** **Nassau County Chapter of NYSARC, Inc.**
Training to Chapter Guardianship Committee
- March 16, 2005:** **Ulster-Greene Counties Chapter of NYSARC, Inc.**
Training to Chapter Guardianship Committee
- March 23, 2005:** **Niagara County Chapter of NYSARC, Inc.**
Joint training to Chapter Board of Directors and Guardianship Committee
- April 26, 2005:** **Westchester County Chapter of NYSARC, Inc.**
Guardianship training to Chapter Board of Directors
- April 29, 2005:** **Wayne County Chapter of NYSARC, Inc.**
Training to Chapter Guardianship Committee
- May 25, 2005:** **Herkimer County Chapter of NYSARC, Inc.**
Joint Guardianship training to Chapter Board of Directors and Guardianship Committee, and Guardianship Training to Families.

Chapters are encouraged to contact Michael O'Brien, Esq., at the NYSARC, Inc. Office to schedule future trainings for their Board of Directors, Guardianship Committees, program staff and families. Mike can be reached at (518) 439-8311 ext: 228 or obrienm@nysarc.org.