

GUARDIANSHIP MATTERS

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NYSARC GUARDIANSHIP PROGRAM STATISTICS AS OF NOVEMBER 23, 2004

Court Appointed

Primary Guardianships:	258
Standby Guardianships:	194
Alternate Standby Guardianships:	264
Guardianships:	264

TOTAL: 716

Pending Court Decrees

Primary Guardianships:	70
Standby Guardianships:	32
Alternate Standby Guardianships:	24

TOTAL: 126

THE RIGHT TO VOTE

BY: PATRICIA W. JOHNSON, ASSISTANT COUNSEL, NYS COMMISSION ON QUALITY OF CARE FOR THE MENTALLY DISABLED



One of our fundamental rights and duties in our democratic society is the right to vote and people with disabilities may exercise that right if they understand what it means to vote. Article II, Section 1 of the New York State Constitution provides that "Every citizen shall be entitled to vote at every election for all officers elected by the people and upon all questions submitted to the vote of the people provided that such citizen is eighteen years of age or over and shall have been a resident of this state, and of the county, city, or village for thirty days next preceding an election." New York Election Law Section 5-106(6) sets forth the reasons for exclusions for voters and requires that the person not have been determined to be incompetent by a court of law.

Since an Article 17-A guardian pursuant to the Surrogate's Court Procedures Act is appointed for a person who is determined to be incapable of managing his/her self and his/her affairs, questions often arise regarding the ward's right to vote. As the ward has not been declared incompetent and, for example, maintains the right

to marry, if capable, to execute a Health Care Proxy or Do Not Resuscitate (DNR) order, if capable, there is no New York statutory exclusion of persons with guardians from voting when they understand what it means to vote and can sign their names or seek assistance. This is in keeping with the current trend to individualize the determinations of capacity relative to the decision at hand and the responsibility of the guardian as fiduciary to carry out the competent wishes of the individual.

Similarly, Mental Hygiene Law Section 33.01 assures that persons receiving mental hygiene services who are qualified and eligible shall not by the receipt of services be deprived of their civil rights including the right to vote.

The law does, however, preclude another person from casting a vote on behalf of an individual who does not understand what it means to vote.

- Election Law §17-132 makes it a felony to aid or advise another person to vote when the person is not qualified.
- Election Law §17-130 provides that it is a misdemeanor to request, in-

duce, or persuade a person within the voting booth to vote for a particular candidate or ballot.

- Election Law §8-306 requires an oath of the person assisting a voter before they enter the voting booth that s/he will not in any manner request or seek to persuade or induce the vote to vote for any particular ticket or candidate and authorizes enforcement of the oath.
- Election Law §17-132 makes it a felony to fraudulently sign the name of another upon an absentee voter's envelope or aid in doing or attempting to do a fraudulent act in connection with an absentee vote cast.

At the same time, both federal and state laws ensure that a person who understands what it means to vote has the right to have someone they trust to assist them in the voting booth. Thus, to the extent the guardian or other assistant is helping the ward in casting the ward's vote, the vote is valid in New York. Guardians, friends, and family members can assist people with diminished capacity to obtain the information and skill they need to make an informed decision to vote.

(Continued on page 3)

FUNDING GUARDIANSHIP FOR PERSONS IN NURSING HOMES

Persons in nursing homes often lack the ability to make their own medical care decisions. This may not be an issue if they are lucky enough to have a guardian to assist them in making choices on their behalf. If they don't have a guardian, but are financially well off, then their resources would be used to acquire the services of a guardian. However, many people in nursing facilities and intermediate care facilities (ICFs) lack both capacity and wealth. Almost all of their monthly income is being applied to the cost of their care. Under Medicaid, their payment is known as the NAMI (net available monthly income). The NAMI is paid to the nursing facility or ICF, which then credits Medicaid for the NAMI amount. At first glance, it would seem that there are no funds available to support a guardianship.

This is not necessarily true. Courts have held in New York State and other states that when a guardian is necessary to make medical decisions

for an incapacitated person, the cost of the guardianship (both petition costs and ongoing operating expenses) can be viewed as a necessary medical expense. Under Medicaid, necessary medical expenses are an exclusion from the person's income in a chronic care facility, such as a nursing facility. Procedurally, the Court would issue an order directing the nursing home to pay from the person's income an amount set by the court for guardianship services, either the petition costs, monthly guardianship services or both. Medicaid would reduce the NAMI by the amount ordered by the court and the nursing home's claim to Medicaid would go up by an amount equal to the reduction of the NAMI.

The Medicaid exclusion for necessary medical expenses is found in NYS Social Services regulations at 18 NYCRR Section 360-4.9(a)(4). It is defined as "expenses incurred for medical care, services or remedial care for the institutionalized individual, not paid by Medicaid or a third

party". Use of this phrasing in the petition and order will make it clear that the cost of guardianship for the incapacitated person residing in a nursing facility falls into the exclusion.

This was evidenced this past January, when the Arc of Oneida-Lewis County Chapter took the bold step of seeking Court approval for guardianship fees on behalf of an individual with developmental disabilities residing in a nursing home. With the critical assistance of James Moragne, District Manager of Revenue Support for OMRDD, and a great deal of perseverance demonstrated by the Chapter's Executive Director and Guardianship Program staff, the Chapter was successful in securing a monthly fee of \$250.00 to make decisions about medical treatment and health care as part of the overall guardianship services offered by the Guardianship Program.

PUBLICATION AVAILABLE ON MAKING FINANCIAL PLANS

Making Plans: A Financial Guide for People with Down Syndrome and Their Families is a new resource for individuals with Down Syndrome, their families and support people. The purpose of the booklet is to help families move toward independence by making plans for the future, managing money so that plans can become a reality, and learning how to use the resources and laws that enable people with disabilities to lead fulfilling lives.

Part I of Making Plans is a workbook that speaks directly to the individual with Down Syndrome.

Part II provides parents and caregivers with financial and other information to help guide their loved one toward independence. Both parts correspond so that families can read together as they plan for the future.

Families can use Making Plans to:

- Set financial goals;
- Plan how to manage money;
- Talk about post-secondary education, jobs, government assistance, housing, guardianships, trusts and other life-planning issues; and
- Prepare for a future in which your loved one has the opportu-

nity to reach his or her full potential.

Making Plans is a collaborative effort of the National Down Syndrome Society (NDSS), the National Endowment for Financial Education, and Mass Mutual Financial Group.

To order a copy, contact NDSS at (800) 221-4602 or info@ndss.org. Individual copies are offered free of charge. For bulk orders, you are requested to pay for shipping charges.

NYSARC POSITION ON GUARDIANSHIP



Individuals with disabilities who do not possess the cognitive, communicative or educational capacity to make autonomous decisions or to provide informed consent for personal and financial affairs may benefit from guardianship to assist them in: accessing appropriate services; receiving advocacy; promoting their quality of life; and participating as full members of their communities.

Individuals with disabilities who do not possess the cognitive, communicative or educational capacity to make autonomous decisions or to provide informed consent for personal and financial affairs may benefit from guardianship to assist them in: accessing appropriate services; receiving advocacy; promoting their quality of life; and participating as full members of their communities.

It is NYSARC's position that:

- A guardian is involved in an active continuous life-long relationship of trust with the individual.
- A guardian has the legal responsibility to advocate in assisting the individual at key decision points, in the same manner as would an ethical, competent, caring parent and family member.
- A guardian offers assistance and intervention as needed, based on the individual's capacities, while ensuring the individual has every opportunity to retain and exercise individual rights to the extent possible.
- A guardian works to strengthen the individual's capacity for independent decision-making by promoting self-reliance, participation to the maximum extent of his or her abilities in all decisions pertaining to the individual and autonomy.
- A guardian places the welfare of the individual over the welfare of any service provider.
- A guardian has the responsibility to understand and advocate for person-centered planning and the least restrictive alternative regarding the individual's rights and abilities to control his or her environment.
- A guardian should be guided by the wishes and preferences of the person for whom he or she is acting to the greatest extent possible.
- If the person's prior or current wishes are unknown, unclear or would cause substantial harm to the individual, the guardian must act in the best interest of the individual.
- A guardian has a responsibility to promote and monitor the individual's health and well-being and to ensure that all necessary medical, mental and dental care needed for the individual is appropriately provided.
- A guardian has the responsibility to see that a financial plan is in place for the individual's life and death.

*

Adopted October 20, 2001 at NYSARC, Inc. Delegate Assembly

THE RIGHT TO VOTE

(Continued from Front page)

The inspectors or a person of the ward's own choice shall assist the individual in the voting booth if s/he cannot read or is so physically handicapped that s/he needs assistance with the machine or ballot. Prior to entering the voting booth, the person who assists the voter completes the oath advising that s/he will not in any manner request, or seek to persuade or induce the

voter to vote for a particular ticket or candidate.

For additional information or assistance, contact the Commission on Quality of Care's Protection and Advocacy for the Help America Vote program (PAVA), which provides outreach and advocacy services to ensure the full participation of individuals with disabilities in the electoral process, at 800-624-4143.

Election Law §8-306

Sets forth the means for a guardian to assist the capable ward in the voting booth.

The ward advises the inspectors under oath that s/he needs assistance.

WHEN IT HAPPENS IN YOUR FAMILY

BY: BARBARA ELLIS, RN, BSN, CCM
FAMILY GUARDIAN

INTRODUCTION:

I recently had the good fortune of meeting Barbara Ellis at a Conference jointly sponsored by the National Guardianship Association (NGA) and the National Academy of Elder Law Attorneys (NAELA) in Colorado Springs where we were both attending as many workshops and plenary sessions as we could cram into a day. Barbara instantly impressed me with her friendly manner and her eagerness to learn as well as share her experiences as her sister's legal guardian. Although NYSARC, Inc. is the guardian and standby guardian for persons with a primary diagnosis of mental retardation and other developmental disabilities under Article 17-A of the Surrogate's Court Procedure Act, there are many individuals for whom NYSARC also serves who have dual mental health needs as well.

The following remarks by Barbara Ellis offer a rare insight and perspective on negotiating the unfamiliar territory of guardianship and the uncertainty a family member can feel in advocating for their loved one who requires support and assistance throughout their life.

Erica F. Berman
Associate Executive Director for Guardianship Services
NYSARC, Inc.

At a guardianship conference I attended recently, we had the opportunity to hear about guardianship from a personal viewpoint from one of the probate justices on the judicial panel. During the discussion, he shared with us his thoughts concerning the guardianship of his mother-in-law and what he went through with his wife during the proceedings. He, as a member of the court, knows exactly what to expect of the legal system, yet he was seeing this case from a different perspective. His black judicial robe was absent and he was not sitting on the bench in his usual courtroom. Instead, the impact was personal, and he was abiding by the courts ruling rather than making the ruling. Personally, not being involved in the legal system as a profession, I tried to imagine how difficult it was for him to shift roles so abruptly. Did his wife feel helpless like the rest of us? Did they have a conflict with the decisions made by the judge? Who did they turn to for support? He had at his disposal a network of professionals involved in guardianship that the novice family guardian would never have available.

With this 'view from within' comes an emotional toll that surfaces when the individual being protected is within your own family. I know because I am my sister's legal guardian. I could relate to him when he told us that he wished he had acquired this knowledge years ago without having to personally go through the experience. I thought this was a powerful statement considering the fact that he held the position of making critical decisions for others under guardianship and was, what most would consider, over-qualified for the responsibility as compared to the total unpreparedness of the typical family guardian. I wondered how this personal experience would have influenced his decisions in the past and how it is influencing his decisions in the present.

This protection, although necessary, comes with a price. One must learn how to live with a different set of rules and an invasion of privacy that requires us to document information and seek the approval of powerful strangers within the system. Separate from the legal system, although equally important, is the case man-

agement aspect of guardianship involving multiple agencies who also have their own set of rules and regulations regarding eligibility and benefits.

I told one of the professional guardians after the conference that I came to the conclusion that it was better for me not to have known the magnitude of the responsibility I was assuming at the onset of my appointment years ago. The total impact would have been overwhelming and yet, I had a background as a healthcare professional which was useful, but only to a point.

Since I have joined the local, state, and national organizations and have been attending guardianship seminars in hope of furthering my education on a professional level, while retaining my family status, I have stepped beyond my personal responsibilities as my sister's guardian. I am so impressed with the knowledge base, commitment level, and dedication the professional guardians have toward the most vulnerable in our society. Each, in their own unique way, is contributing to my education. I have also

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ARTICLE 17-A GUARDIANSHIP: SELF-HELP AVAILABLE ON CD ROM & ONLINE

WWW.CQC.STATE.NY.US/GUARDFRM.HTM

BY: BILL COMBES (BILLC@CQC.STATE.NY.US) OR (518) 388-2887

All of us, whether disabled or not, reach the age of majority at 18 years. This means, that under the eyes of the law, we are able to make decisions independent of our parents. However, this becomes somewhat complicated when we talk about some individuals with developmental disabilities who may not be able to decide matters for themselves.

In order to accommodate the fact that a number of adults with developmental disabilities might not be able to make decisions for themselves, Article 17-A of the Surrogate's Court Procedure Act was enacted in 1969 and amended in 1989. It permits parents, or any other concerned party, to petition the Surrogate's Court to be appointed guardian of the adult with the disability. By being appointed guardians, parents can legally continue their authority beyond their offspring's age of 18 years.

The process for being appointed guardian is a legal and formal one that traditionally has been initiated by an attorney. However, the law

does allow for a person to petition the court on his/her own behalf (pro se). By doing so, the parent only incurs the cost of the court filing fee and extraneous copying costs. To date, many parents and others have availed themselves of the Commission on Quality of Care's Pro Se Guardianship Training.

Now, parents and others can access the Commission's self-help instructions and Surrogate's Court forms at our website listed above. In addition to the online resource, the Commission has developed a CD ROM that incorporates all of the guardianship forms and instructions with a copy of the very popular Developmental Disabilities Planning Council's 90 page publication: [A Guide for Families and Friends of People with Developmental Disabilities 2003 Fifth Edition](#). This combination of materials, in an easily accessible format, gives parents and others all the information necessary for planning for the future.

When accessing the guardianship forms, the CD ROM permits the user to navigate from the directions to the actual form. As you proceed through

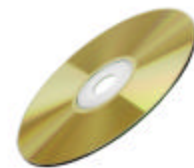
the directions, you may click onto the form, begin typing and then navigate back to the directions for the next steps. After completing each form, the individual can print the finished product in a format that has been accepted by all of the Surrogate's Courts. You will need to have Adobe Acrobat Reader™ loaded on your computer. There is a link at the CQC web site to download a free copy:

<http://www.adobe.com/>

Please feel free to call or e-mail for your free copy of the Commission's CD ROM [Guardianship and Planning for the Future](#). Consumers are encouraged to "burn" (copy) additional copies for other family members or to use for training purposes.

E-mail assistance for completing the forms is available at :

billc@cqc.state.ny.us or call toll-free 1-800-624-4143 or directly at (518) 388-2887.



"Each time a person stands up for an ideal, or acts to improve the lot of others...(she)/he sends forth a tiny ripple of hope, and crossing each other from a million different centers of energy and daring, those ripples build a current that can sweep down the mightiest walls of oppression and resistance."

Robert F. Kennedy
Day of Affirmation Address
Capetown, South Africa—1966

TRAIN THE TRAINER WORKSHOPS ON END-OF-LIFE CARE: SUPPORTING OLDER PERSONS WITH INTELLECTUAL DISABILITIES AND THEIR FAMILIES

As part of a unique project funded through the New York State Developmental Disabilities Planning Council, NYSARC, Inc., in cooperation with the New York State Office of Mental Retardation and Developmental Disabilities (OMRDD), has presented a series of statewide train the trainer workshops in order to develop additional resources for end-of-life care training. This training, which was offered in five (5) areas of the state in 2004, will be provided once again, in 2005 to individuals in five (5) additional regions. The training is scheduled to conclude in June 2005.

Workshop Objective:

The End-of-Life Care curriculum is designed to help transform death and dying from a critical incident to a natural end-of-life cycle for people with developmental disabilities and their families. The presentations are provided by distinguished and nationally recognized leaders and practitioners in areas ranging from end-of-life care; grief counseling and hospice care to aging, gerontology, medical care decision-making and advanced directives for persons with developmental disabilities.

Who Should Attend:

The Train the Trainer workshops are designed for people who have an interest in aging issues in the field of developmental disabilities. Once trained in this curriculum, participants and their sponsoring agency become a training resource in their area of the state. Prior attendance at NYSARC's previously sponsored End-of-Life Care Seminars is preferred, but is not required.

What issues does the Curriculum address and who serves on the Faculty:

Aging for People with Developmental Disabilities – Lawrence T. Force, Ph.D.

Presentation will address definitions, demographics, and concerns for end-of-life care.

Disenfranchised Grief- Kenneth J. Doka, Ph.D.

Presentation will look at recognizing and treating sorrow.

Emotional and Spiritual Concerns -Geraldine Abbatiello, Ph.D., APRN

Presentation will discuss the emotional and spiritual aspects of end-of-life.

Administrative Aspects- Lawrence R. Faulkner, Esq.

Presentation will address the ethical, legal and policy concerns.

Is There a Registration Fee:

There is no charge for this workshop, although pre-registration is required. Attendees will receive seminar materials including:

End-of-Life Care Manual
Resource Guide
End-of-Life Care Trainer's Guide

2005 Dates and Locations

March 17-18, 2005
Long Island

April 19-20, 2005
Staten Island

May 12-13, 2005
Binghamton

June 7-8, 2005
Buffalo

June 8-9, 2005
Rochester

For further information about registration and location of workshops, please contact:

Cindy Tracey
NYSARC, Inc.
(518) 439-8311

NYSARC CORPORATE GUARDIANSHIP TRAINING DELIVERED AND SCHEDULED

October 27, 2004: Livingston-Wyoming ARC

Presented training to Chapter Guardianship Committee and Board of Directors

October 28, 2004: Seneca-Cayuga ARC

Presented training to Chapter Guardianship Committee

November 15, 2004: Delaware ARC and Otsego ARC

Conducted a joint presentation to Chapters' Guardianship Committees

December 7, 2004: Yates ARC

Presented training to Chapter Guardianship Committee

January 4, 2005: Schenectady ARC

Will present training to Chapter Guardianship Committee

January 18, 2005: Jefferson ARC

Will conduct three (3) trainings for Chapter Guardianship Committee, Staff and Families

January 20, 2005: Orange AHRC

Will present training to Chapter Board of Directors

March 23, 2005: Niagara ARC

Will conduct two (2) trainings for Chapter Board of Directors and Guardianship Committee

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

IMPROVING THE LIVES OF PERSONS WITH DISABILITIES

In response to the needs and concerns of parents, advocates and individuals with developmental disabilities, NYSARC, Inc. established The NYSARC Trust Services and the NYSARC, Inc. Community Trusts to assist individuals in safeguarding their personal and financial future. Monies in both the Trust Services and the Community Trusts, are pooled for investment purposes, and both programs qualify as Supplemental Needs Trusts. In the Community Trust program, upon the death of the Beneficiary (or person with a disability for whose benefit the trust has been established), all funds remaining in the sub-account shall remain with the Community Trusts to further its purposes.

In early Spring 2005, the Trustees of the NYSARC Trust will be awarding up to \$10,000 in grants from its Remainder Fund Grant Program to assist individuals with disabilities throughout New York State who have limited resources. The application packets with specific guidelines will be distributed to all Chapter Executive Directors the week of January 4, 2005, in order to meet the deadline due date of February 10, 2005. Grants will be awarded based upon the need of the individual, and the ability to meet the application guidelines.

For further information on this innovative grant program, please contact Heidi Flatt, Assistant Executive Director for Fiscal Management and Trust Administrator at the NYSARC, Inc. State Office at: flatth@nysarc.org or (518) 439-8311.

INFORMATIVE WEBSITES

National Down Syndrome Societywww.ndss.org**Volunteer Match**www.volunteermatch.org

An internet service which helps to find a volunteer opportunity in your community.

New York State Bar Associationwww.nysba.org**Disability Information**www.disabilityinfo.gov

Services as a gateway to the federal government's disability-related information and resources.

Social Security Program Operations Manual System<http://policy.ssa.gov/poms.nsf/aboutpoms>

This is the website for the Social Security Program Operations Manual System (POMS) and is the primary source of information used to process claims for Social Security benefits.

ADA Watchwww.adawatch.org

A project of the National Coalition for Disability Rights.



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

WHEN IT HAPPENS IN YOUR FAMILY

(Continued from page 4)

observed the close relationship the professional guardians have with some of the judges and attorneys and who in turn, respect the professional guardians, as well.

I recently chose to attend the family guardianship course offered in my area for newly appointed guardians. This eight hour class was taught by a group of dedicated and caring professionals who shared their knowledge, expertise, and patience with a diverse group of individuals who share a common bond and who were trying to accept the responsibility now before them. I'm not sure what I expected of the group composition but found myself empathizing with the emotional and fiduciary dilemmas they all faced.

The course focused on the legal obligations and responsibilities expected of them by the court. Specific family problems were addressed because of the individual questions asked, so as a result, we all learned from each other. Within the allotted time, our educators did a good job, but I was looking beyond the information provided, to the case management aspect of guardianship that the legal system does not address and the emotional and sometimes physical toll guardianship places on a family guardian. Listening to the stories of these newly appointed guardians and their hunger for advice and guidance to help them make sense of the situations they found themselves

in, took me back to the beginning of my guardianship and the problems I faced, all alone, with the exception of the support of my attorney. One young lady with an optimistic attitude and a calmness that covered for the reality she was now facing, told me her story. Her husband was killed in a helicopter crash abroad after September 11th, leaving her with a one year old and a three year old. I kept thinking, we were all focusing our grief on those who died because of September 11th and yet, she was going through her ordeal without the collective support of the nation. The insurance policy left to her minor children was the reason for her appointment. Another couple desperately seeking information was in charge of their granddaughter's assets. The little girl's father had been killed in a car accident and their daughter was less than responsible. How to take care of their granddaughter without alienating their daughter was just one of their dilemmas separate from the legal issues. I kept thinking, not exactly what they planned to do at this stage of their lives. Another gentleman had moved his parents in with his family because his father was under guardianship. He had difficulty, as did the rest, comprehending all of the rules and restrictions in trying to be good parents and grandparents to their family members. There was no reasonable explanation as to why petitioning the court, through

their attorney, for expenses to redecorate the granddaughter's room would cost more than the items themselves, and why the letters of guardianship and power of attorney papers were causing problems with agencies who recognized one instead of the other despite the official ruling in our state. For this gentleman, he was just trying to be a good son to his parents and abide by the law.

Guardianship is difficult enough for the professionals who are educated, experienced, have a network of resources to draw from, and are comfortable with the legal system and the case management aspect of guardianship. Imagine how overwhelming this responsibility is for us family guardians without these support systems built in and who lack the comfortable, objective distance that we can never really achieve.

As I attend the seminars and conferences, I hear a reoccurring theme: to educate others, both professional and non-professional, about the responsibilities we all share as guardians, whether professional or family, and to find some common ground for us to share in this world of guardianship which seems to function quite silently and insulated from the rest of society and whose laws are administered so differently throughout our country.