

SIB

Sibling Information Bulletin

Vol. 8 Number 1

AHRC New York City

Winter 2008

Guardianship - The precise laws of guardianship vary with each state, this bulletin is based upon the laws of New York State as of January 2008.

What Is Guardianship?

By law, a parent is considered the natural guardian of his/her child until that child reaches the age of eighteen, regardless of the extent of the child's capacity or diagnosis of a disability. Once the child reaches the age of eighteen, a parent, sibling or other family member must petition the court to be granted legal guardianship in order to be granted authority to continue making decisions on behalf of a person with a disability. If you become a guardian in New York State under Article 17-A of the Surrogate's Court Procedure Act, you are granted legal authority to make decisions on behalf of the best interest of your sibling (legally your ward), and to advocate for their best interests. The precise laws of guardianship vary with each state, so guardianship should be obtained in the state (county) in which the disabled person resides.

Remember: The function of a guardian is to make decisions on behalf of the disabled person...decisions that the court has determined cannot be made by the person. Sibling guardians (and other guardians) are most likely to be called upon to make decisions concerning an individual's residential, educational, medical, and/or financial needs.

Under a New York State law that became effective in March of 2003 (known as the Health Care Decisions Act or "HCDA"), guardians appointed for a person pursuant to Article 17-A are granted the authority to make all medical decisions, including decisions regarding life sustaining treatment, which is treatment without which the patient is likely to die. End of life decisions include withdrawing or withholding artificial nutrition (feeding tube) and hydration (water) and respirator connections (ventilators and breathing assistance). Previously, a person born without capacity to make his wishes known regarding end of life medical treatment was forced to undergo all life sustaining measures resulting in sometimes painful and agonizing deaths. Fortunately the HCDA now allows persons born without capacity to die with dignity when there is a legal guardian to act on their behalf. Notably, as of December 30, 2008, the HCDA was amended to expand the authority to make end-of-life decisions to non-guardians. A prioritized list of actively involved family members who can be considered as qualified in the particular circumstance of a decision to withhold or withdraw life-sustaining treatment has been promulgated by OMRDD. The hierarchy of this list is as follows: (1) actively involved spouse, (2) actively involved parent, (3) actively involved adult child, (4) actively involved adult sibling, and (5) actively involved family member (that did not fit into the prior categories).

*to avoid being awkward, the male gender pronoun will be used throughout this bulletin.

What is Guardianship Not ?

Legal guardianship does not mean that you must take your sibling into your home or that you are financially responsible for them. You do not take on the obligation to support your sibling or become the caregiver. In fact, guardians are not expected to use their own funds on behalf of their ward with a disability. In addition, guardians are not legally or criminally liable for the actions of their wards.

A 17-A guardian is granted plenary (full) authority to protect the interests and rights of the person with the disability and to make decisions on his behalf. However, certain fundamental rights are not taken away from a person with a disability even though a legal guardian has been appointed, like the right to vote. For persons with disabilities who are higher functioning, there are less restrictive alternatives to guardianship, such as appointing a health care proxy for those individuals who may not require assistance making decisions in every aspect of their lives, but do need help making informed medical decisions.

Is Guardianship Necessary?

First, consider whether your sibling can make decisions on his own behalf and manage his daily affairs. There will almost certainly be critical decisions regarding residential, medical, and financial situations during your sibling's lifetime when a surrogate decision-maker will need to make the final determination on their behalf. To help you decide how necessary it is for your sibling to have a guardian, take a moment to consider the following questions:

Financial: Can your sibling make change of a dollar or change of \$20? Can he understand basic banking transactions? Can he pay his own bills? Does he give money or other things away? Can merchants, landlords, con artists, etc. easily exploit him?

Medical: Does your sibling know what illness is? How to take medicine as directed by a physician? Can he determine when he needs to go to the doctor? Can he understand between alternatives in medical procedures, or understand the risks/benefits of a procedure? Can he understand when pain or suffering requires medication, which might have serious side effects?

Would guardianship assist your sibling in the management of his life?

MOST IMPORTANTLY, does your sibling want you to be his guardian?

In addition, are you concerned about future planning, including who will make decisions for your sibling/ward if something happens to you? If so, guardianship allows you to plan for the future by designating a "standby guardian" to protect your sibling when you are no longer able to do so.

The Guardianship Procedure

There are two different statutes in New York State under which a person may apply to become the guardian of a person with intellectual disabilities. These are Article 17-A of the Surrogate's Court Procedure Act, and Article 81 of the Mental Hygiene Law.

Article 17-A of the Surrogate's Court Procedure Act is a plenary statute, which grants the guardian authority over the person or the person's property or both. Article 17-A is specifically for persons with mental retardation and/or developmental disabilities. When you are the guardian of the person, you have the legal authority to make decisions regarding the ward's personal needs (i.e. . . .residential, medical, educational, etc.). This proceeding is brought in the Surrogate's Court in the county in which the disabled person resides. If your sibling resides in a residence, Mental Hygiene Legal Services will be appointed to represent your sibling in the guardianship proceeding. When you are

the guardian of property, you have the legal authority to make financial decisions on behalf of the ward in conjunction with the Clerk of the Surrogate's Court.

It is important to note that when you bring an Article 17-A petition, you have the opportunity to name a standby guardian(s). Standby guardians take over when the primary guardian becomes incapacitated or dies. You can name an alternate standby to take over when the standby guardian becomes incapacitated or has died; a second alternate standby to take over after that one, and a third alternate standby and so on. You may also name a Corporate Guardian (a non-profit agency guardian) to take over at some point within the guardianship succession, but corporations can serve as guardian of the person only, not property. Article 17-A proceedings are brought in the Surrogate's Court and the filing fee at the time of this publication is \$20.00. If you engage an attorney to help with the process, those fees would be in addition to the court-filing fee, however you are not required to have an attorney to file for guardianship. AHRC Legal Services can provide assistance with filing for 17-A Guardianship and does have a lengthy waitlist of individuals who would like this level of representation.

Article 81 Guardianship is available to anyone whose capacity is called into question, whether due to age or mental impairment.

Under Article 81 of the New York State Mental Hygiene Laws, a person may be appointed guardian for a specific purpose. Article 81 Guardianship is available to anyone whose capacity is called into question, whether due to age or physical or mental impairment. The powers of the guardian would be specified in the order granting the guardianship authority. These are tailored guardianships whereby a person is appointed guardian for only those particular needs where the proposed ward needs assistance. This proceeding is brought by an Order to Show Cause in Supreme Court in the county in which the incapacitated person resides and the filing fee at the time of this publication is \$210.00. Legal representation is required, and attorney's fees and other related costs can be substantial.

A Note about 17-A Standby Guardians.

- 1. If your parents are alive and are the Primary Guardians, you may be asked to be the Standby Guardian.*
- 2. If the Primary Guardian becomes incapacitated (temporarily or permanently), or dies, the Standby Guardian will need to bring a Successor Petition in the court where the proceeding initiated to have yourself declared Primary Guardian (it is not automatic).*
- 3. When the Primary Guardian passes away, the Standby Guardian has 60 days (in NYS) to file a Successor Guardianship petition for Primary Guardian status. During those 60 days, the standby guardian is automatically given full authority to make decisions.*

A SITUATION FOR STANDBY GUARDIANSHIP

Dan, who is 59 years old and his wife Sara, have been caring for his brother Jacob since their parents died. Dan became the legal guardian for Jacob, but now Dan and Sara are getting older and they are concerned about who would oversee his care if Jacob should outlive them. Their daughter has indicated an interest in stepping into their role, but they don't want to unduly burden her or have her make promises she will have difficulty keeping. While they explore the many options for Jacob's continued care, they wonder if they should pursue Standby Guardianship status for their daughter.

Standby guardianship should be considered in this situation. This is a family decision that should be addressed prior to a particular crisis. In general, Standby Guardianship should always be investigated when the Primary Guardian is nearing senior years. Remember, guardianship does not require financial obligation from the primary or standby guardian.

AN OUT-OF-STATE CAREGIVING SITUATION

Maria's brother Jose is doing well in his new supported work placement, and is being screened for a supportive apartment. He currently lives at home with his parents. Maria lives in another state, and does not anticipate returning to her hometown to live. While she applauds her brother's accomplishments, she knows that he will continue to rely on his parents for making important decisions; especially those related to chronic health issues. She worries about the day when her parents are no longer around, and wonders if guardianship would be a way for her to oversee and advocate for her brother.

Her parents should begin the guardianship process, and consider standby guardianship status for Maria. Guardianship would allow Maria to have a say in medical and residential decisions for Jose after the parents become incapacitated or die, even if Jose remains in New York and Marie lives in another state. However, if Jose leaves New York State to live with Marie, guardianship should be pursued in the new state.

JUST TURNING 18

Roseanne just turned 18, is moderately retarded and has multiple disabilities. She had been attending a special education class in the local high school, but with budget cutbacks the school district is talking about concentrating all special education students in one high school on the other side of the district. Sara, Roseanne's 15-year-old sister, desperately wants Roseanne to stay in the high school so that she can be close and keep an eye on her. The guidance counselor told her that Roseanne's guardian is the only one who can make a formal request on Roseanne's behalf. Neither she nor her parents are Roseanne's guardians.

Right! The education law does not recognize the rights of parents once the child reaches the age of eighteen, unless they have become legal guardians. Sara cannot be a guardian until she is of legal age (18), but her parents should become Roseanne's guardians now, to assist Roseanne in her educational decisions, and to advocate on her behalf.

FROM DEVELOPMENTAL CENTER/INSTITUTION TO GROUP HOME

Sergio's 26-year old sister Natasha was placed in a distant developmental center years ago due to her unmanageable behavior. The family has maintained contact with Natasha through regular visits. The state now intends to close the institution and plans to move Natasha to a group home in a nearby town. Sergio's widowed mother is upset at the change, but feels the state knows best. Sergio thinks that Natasha should be placed in a residence closer to the family, so they can more easily monitor her care. He wonders what legal right he has to make the state comply with his wishes, and has heard that his mother is not his sister's legal guardian solely by being her parent.

Neither Sergio nor his mother has legal authority to decide where Natasha is placed unless one or the other is granted legal guardianship! Under OMRDD regulations, which govern residential placements, a parent or sibling can act as the 'correspondent' to participate in the decision-making process. So Sergio and his mother would be able to advocate in this process, but perhaps could not have the final say that she would have if she was the legal guardian. In addition, Sergio needs to explore the Guardianship process and see how it may apply to his situation.

INDEPENDENCE ISSUES

Arnold's brother Willie is mentally retarded, but as Arnold says, "it is hard to tell unless you get to know him on a more familiar basis." Willie is employed as a shipping clerk and lives at home with his parents. As soon as he gets his paycheck he spends all the money on gifts and extravagant things for himself that have to be returned for store credit. Twice he had been with his friends when they were pulled over for speeding, and once, all of them were drinking too much. Arnold and his parents wrestle with the need to balance their support and guidance for Willie with his need for independence and a chance to grow and choose how he wants to live his life. They wonder whether Willie needs full guardianship although they are unsure of what other alternatives exist that would legally allow him to make whatever decisions and choices he can. And what will Arnold do when his parents cannot "manage" Willie and/or when Willie has to live some place other than in his parents' home?

Guardianship is designed to authorize Arnold to help his brother when his brother cannot make his own safe and appropriate choices. However, guardianship is not a means of controlling an individual with a disability who may be making choices in his life that the family disapproves of. A health care proxy or an Article 81 Guardianship could possibly be explored here, to appoint someone for Willie to meet his specific needs so that he retains the independence he deserves.

A NEW RESIDENCE

Anita's sister Myra has Down's Syndrome. She is in an assisted employment program, attends recreation programs, has a boyfriend and is on a waiting list for a community residential alternative, which she has visited and is eager to move into. Anita's parents, who are her guardians, are concerned about this transition and increasingly worry aloud that Myra "may not be ready for this". Anita, who is the standby guardian for Myra, thinks Myra is capable of doing many things, and wants to be supportive. She knows Myra is beginning to lose her confidence and excitement about the possibility of a new home, and is concerned about being overprotective of Myra, who has demonstrated great capabilities for growth.

This is not a guardianship issue per se. The problem seems to be overprotective parents, who are fearful about letting Myra move out and become more independent. A legal guardian has an obligation to make decisions in the best interest of the disabled person, taking into consideration the ward's own wishes.

Remember:

The function of a guardian is to make decisions in the best interest of the person with the disability – decisions that the court has determined cannot be made by the person himself.

A HOMECARE SITUATION FOR ELDERLY PARENTS

Jamal's parents have provided the primary support to Kesha, Jamal's 40-year-old sister with multiple disabilities. Kesha has a pleasant life at home, but has rarely been cared for by anyone outside the immediate family. Jamal's mother has now developed some health problems, which make things difficult. She will not tolerate discussion of changes in Kesha's care, despite pressure from her husband. They did place Kesha's name on a residential waitlist years ago, "just in case" but have made it known that they wish for Kesha to live with their son, Jamal. Jamal's wife is totally opposed to this plan. Jamal has heard that it is important to pursue legal guardianship, and wants to discuss this with his parents. How does he begin to broach this important topic?

Avoid delaying guardianship decisions until a crisis arrives! The guardianship process can take time, and there are expectations in this situation that are, perhaps, unrealistic. One good source of support to begin the process of planning for the future would be a family lawyer, financial planner or social service agency caseworker. Guardianship is not the only issue in this scenario and the family needs to communicate. Jamal and his wife need to be educated about guardianship and understand that guardianship does not impose the obligation to directly care for the individual with disabilities.

SHARING RESPONSIBILITIES

Emily has two sisters: Susan and Rita. Their brother Ted is moderately retarded and living in a group home near Susan and Emily. Emily has always been close to Ted and is his legal guardian. Susan and Rita are, successively, next in line as standby and alternate standby guardians. Ted has significant health problems and a communication difficulty, which makes it important for someone to be with him when he has to “deal” with the health service providers. He’s been in the hospital four times this year already. Because Emily is the guardian, and has always been able to communicate best with Ted, she is finding herself committing the most to him – in time, money and energy. Her work is beginning to suffer and her husband is resenting that Emily is “spending” so much time and money on Ted. He feels that her two sisters can, and should be willing to help with the activities and needs. How does Emily find ways to share the responsibility of helping to look after Ted?

Together, the siblings should work out what each can contribute and “share the wealth” as well as the responsibility. All tasks should be detailed and the sharing should be negotiated with the siblings. It is possible one sibling has money but no time, and another has more time with less financial resources. This can be the beginning of a new means of sharing the care giving responsibilities for their brother, Tom.

IS GUARDIANSHIP NEEDED FOR SENIORS?

Ever since their father died, Hank, who has Down’s Syndrome and is functioning on a very high level, has lived with his brother Joe, who is not Hank’s legal guardian. For twelve years, Hank has been a messenger for a local financial institution. In the past two months, his supervisor has called Joe every week. At first it was to ask if Hank was sick because his behavior was erratic: he was showing up late for work, his deliveries were often slow and his generally excellent performance had deteriorated. Hank recently spent his entire paycheck in the grocery store, his next one on clothes, and last week, he missed work for two days without calling and then lost his paycheck. Joe is worried as he sees Hank’s behavior becoming increasingly inappropriate and sometimes dangerous to himself. Hank’s doctor says that it may be time for Hank to retire. He tells Joe that Hank is aging, possibly more rapidly than the calendar would show. He says that Hank is experiencing some memory loss and should be more carefully “watched”. Should Joe try to become Hank’s guardian?

Joe needs to investigate guardianship in light of Hank’s difficulty in functioning. Guardianship is a legal proceeding in which a determination is made about Hank’s competence to make decisions and ability to handle his own affairs. In light of Hank’s deteriorating condition, guardianship may be the best option to help advocate for his needs.

QUALITY OF LIFE

Carlos, a 27 year old man with profound mental retardation, non-verbal and living in a group home for 8 years, was found unresponsive in his bed. Taken to the hospital, Carlos went into cardiac arrest and CPR was performed and they were able to get his heart beating again. When Carlos's brother Nick arrived, the physician met with him and said he should sign a DNR (Do Not Resuscitate Order) to prevent any further CPR because it was "medically futile to continue resuscitating him". Can Nick, who is not Carlos's legal guardian, sign a DNR Order?

Yes. If a person is determined to be incapable of making a decision regarding CPR, then a surrogate decision-maker can provide consent when certain medical conditions are met. Authorized surrogate decision-makers are, in priority order, a health care agent, a legal guardian, a spouse, a son or daughter, a parent, a brother or sister, or a close friend. The person must be deemed to have a terminal condition, be permanently unconscious, CPR would be medically futile, or CPR would cause extraordinary burden. Due to the sensitive nature of these decisions, the incapacitated person's beliefs should be ascertained to the extent possible, including moral, ethical and religious beliefs.

AHRC

NEW YORK CITY SIBLING COMMITTEE

CHAIRPERSON: Ruth Pickholz

VICE CHAIRPERSON: Victoria Liska

MEMBERS: Randy Rosen, Lee Slonimsky, Steven Atamanchuk,
Pearl Basch, Marsha Heiman, Nilsa Santiago, Selma Miller,
Jack Gorelick

AHRC STAFF:

Judy DeLasi, Associate Executive Director

Annette Spallino, LMSW Sibling Services Coordinator

SIB

SIBLING INFORMATION BULLETIN

IS PUBLISHED BY THE SIBLING
COMMITTEE OF AHRC NEW YORK CITY

83 MAIDEN LANE

NEW YORK, NY 10038

www.ahrcnyc.org

