

AHRC NEW YORK CITY'S GUARDIANSHIP NEWSLETTER

AHRC's Guardianship Department is pleased to distribute our First Annual Guardianship Newsletter. In this issue, we provide a description and overview of the Guardianship Program, including the Guardianship Committee and staff. We also discuss 17-A guardianship, supplemental needs trusts and highlight several people for whom AHRC is guardian.

WHAT IS AHRC NEW YORK CITY'S GUARDIANSHIP PROGRAM?

AHRC's Guardianship Program consists of two key components that provide much needed services for people with developmental and intellectual disabilities and their families:

The Guardianship Department Legal Services Unit (LSU) provides help to the community in various ways, including:

- Full representation in all five boroughs to support families pursuing legal guardianship and assistance to families planning for the future for a loved one. The LSU works from a waitlist of hundreds of people seeking free legal services.
- Community outreach and trainings
- Brief advice and referrals
- If a guardian is no longer able to serve, and NYSARC/AHRC is the standby next in line, the LSU will file a successor guardianship petition on NYSARC/AHRC's behalf

The Department also acts as the primary and standby guardian for people with intellectual or developmental disabilities through the NYSARC Corporate Guardianship Program. AHRC's Guardianship Program is part of a network of chapter guardianship programs throughout the state that are administered by NYSARC, the appointed guardian, and is overseen by the New York State Guardianship Committee. The Guardianship Program steps in to provide guardianship services when guardians are no longer able to do so. In New York City, the Program is overseen by AHRC's local Guardianship Committee of seven volunteers, all of whom have or have had a family member with a disability. The Committee has regular meetings to provide oversight, review the needs of the people within the Program and advocate as needed. There are special and emergency meetings when

important healthcare, personal and end-of-life decisions need to be made.

As of Fall 2014, the Program currently acts as legal guardian for twenty-nine people and as standby guardian for an additional forty-six. We provide care, support and advocacy as primary guardian, while always encouraging the highest degree of autonomy possible, by:

- Enhancing quality of life for each person through birthday parties, outings, vacations, recreational activities, and holiday celebrations
- Attending meetings on the person's behalf
- Assisting each person to choose appropriate medical care, residential placement, day programs, and employment
- Responding to emergencies
- Making end-of-life decisions and futures planning arrangements

Every person for whom the Guardianship Program is primary guardian is visited at least monthly (more if there is a need). Guardianship staff also visit people for whom NYSARC/AHRC is standby guardian (excluding alternate standbys) on a yearly basis, so that the person and guardian are familiar with the Guardianship Program and vice versa.



The Guardianship Program organizes various group outings each year, which are financed by a range of sources, including a special fund that was created for the benefit of individuals within the Program. These events are great opportunities for all the people for whom AHRC is guardian to get together with each other, staff and committee members. The Program usually hosts a bowling event towards the end of the summer, where everyone is able to participate regardless of physical limitations. Everyone looks forward to the festive December holiday party with a DJ, dancing, and Santa giving out gifts for all.



STAFF PROFILES

Saletaire Adorno

Saletaire holds a bachelor's degree in psychology from Fordham University. She has had the pleasure of working with the Guardianship Program since 2003. Though Saletaire plays many roles in the department, her predominant duty is acting as a guardianship advocate. She has been amazed to see how the people for whom the Program is guardian of have changed and benefited from this valuable service. Saletaire has experienced loss, sadness, and happiness in this role, but takes on these struggles in order to properly advocate for others and provide the best quality of care.

Zhanna Kulshanova

Zhanna explains her role as Guardianship Advocate as incredibly satisfying because she is able to change peoples' lives for the better. She most enjoys making a positive impact on the lives of others. Zhanna Kulshanova is originally from Kazakhstan, where she worked as an English teacher. She speaks three languages and holds a bachelor's degree in literature. Zhanna has been with AHRC New York City for eight years, the past four working with the Guardianship Program.

Kara McGuinness-Hickey

Kara is a Staff Attorney and graduated from Brooklyn Law School in 2006. Kara has worked for AHRC for seven years. She previously worked for the New York State Attorney General's Office, the New York Public Interest Research Group, and at a respite house providing care to non-ambulatory people with developmental disabilities. What Kara enjoys most about her job is helping families and getting to know her clients. She lives in Brooklyn with her husband and their dog, a retired racing-greyhound.

Randi Rosenstein Vacca

Randi is the Director of Legal Services and supervises the Guardianship Program. While in school, she worked with Binghamton University's Children's Unit for Treatment and Evaluation, the Atlanta Volunteer Lawyer Foundation and the EEOC. She has also taught as an adjunct professor at New York Law School. She graduated from Emory University School of Law in 2004 and has worked at AHRC for the past nine years. Randi finds her work within the legal and corporate guardianship components of the Guardianship Program to be so rewarding because she sees the help it provides to the people and community it serves.

SELECTED PROFILES

Vito L.

Vito, who turned ninety years old in May, loves going to the movies, bowling, eating out and attending sporting events. Every year, he looks forward to AHRC's Dinner Dance and Recreation Dance, attends all of the Guardianship Program's events and goes to AHRC's Elaine Gordon and Katy Isaacson Camp for ten days. Vito is a very valued member of his community and is well known in his church and neighborhood, where he has lived for more than thirty years. He loves to meet new people, and is extremely close to his guardianship advocate, and all of his "buddies" within the Guardianship Program. Everyone in his life has either been introduced to Vito's guardianship advocate by him or has heard about her. To celebrate Vito's recent birthday, the Guardianship Program and his residence arranged a big celebration with all of his close friends. Vito had a wonderful time and he felt very special.



Alan C.

When the Guardianship Program first became involved, Alan had recently been removed from his mother's home by Adult Protective Services and placed in a nursing home. While living with his mother, who suffered from mental illness, Alan did not receive any services or medical care, and in the nursing home he was kept in bed almost the entire day. Guardianship Program legal staff secured a restraining order to protect Alan and worked with the judge to find appropriate supports. Today Alan, who is forty-six and has cerebral palsy and spastic quadriplegia, lives in a residence in Brooklyn. His complicated medical situation has vastly improved through numerous hospitalizations, Program medical advocacy and close attention from caring staff. He attends a stimulating day program during the week, enjoys weekend day trips, and goes to AHRC's Camp Anne each summer. Alan's guardianship advocate describes him as a sweet and gentle person who has overcome a very difficult past. He has learned to communicate his wants and needs with gestures, facial expressions, and vocalizations in ways he couldn't before becoming involved with the Guardianship Program.

LEGAL FAQs

What Is 17-A Guardianship?

Pursuant to Article 17-A of the Surrogate's Court Procedure Act, the Surrogate's Court can appoint a person or corporate guardian (such as the NYSARC/AHRC Guardianship Program), to act as guardian for an adult with developmental and intellectual disabilities in order to make essential life decisions for that person. The court can also appoint standby guardians. When appropriate, families can decide to have a corporate guardian, such as NYSARC, appointed as a primary, standby or alternate standby guardian.

What Is Standby Guardianship?

Standby guardianship allows the guardian to decide who will take over when they are no longer able to serve due to death or incapacity. Standby guardians have no authority during the lifetime of the guardian, and must petition the Surrogate's Court to be appointed guardian upon the death or incapacity of the prior guardian. When appropriate, families can request to have a corporate guardian, such as NYSARC, appointed as standby or alternate standby guardian. If NYSARC is the next appointed standby, AHRC's Guardianship Program will file a petition seeking confirmation from the Surrogate's Court as successor guardian. If not, it will be up to the next standby in line to petition the Surrogate's Court to name themselves as guardian.

What Happens if a Standby Guardian Does Not Petition for Guardianship after the Death or Incapacity of the Guardian?

Standby guardians must petition the court within 180 days of the death of the prior guardian; after this time frame, legal authority to make healthcare and other decisions regarding the wellbeing of the adult with

developmental or intellectual disabilities will end. Unfortunately, sometimes standby guardians fail to petition the Surrogate's Court to be appointed successor guardian, which leaves the adult with developmental or intellectual disabilities without an acting guardian. This is why it is very important to ensure that standby guardians in your guardianship succession understand their



responsibility to file for guardianship immediately with the Court. Under a new law, the failure of a standby or alternate standby guardian to assume the duties of guardianship by seeking court confirmation or renouncing the guardianship allows other standby guardians in the succession, including NYSARC via AHRC, to give 60 days notice, and then file for successor guardianship, thereby "jumping" the standby that refuses to act. This allows NYSARC via AHRC to respect the wishes of the primary guardian who made the original arrangements, while guaranteeing that a guardian is appointed to make healthcare decisions and decisions regarding the well being of the person with developmental or intellectual disabilities.

SUPPLEMENTAL NEEDS TRUSTS

Medicaid and Supplemental Security Income (SSI) are needs-based governmental entitlements which only cover the costs of basic needs, such as food, housing, and clothing. However, supplemental needs trusts (SNTs) allow families to provide additional funds for their loved ones with intellectual and/or developmental disabilities, without negatively affecting their eligibility for needs-based entitlements. SNTs allow people some access to personal financial resources after parents or family members have passed away and can be used to pay for supplemental needs, including vacations, camp, medical expenses beyond those funded through government benefits or assistance, one-to-one care that would not otherwise be covered, televisions, computers, birthday/holiday gifts, special equipment, additional clothing and support for a variety of recreational and

athletic activities and outings. Although the Guardianship Program can only act as guardian of the person and will not manage the finances of anyone for whom we are guardian, we work with trustees to purchase all of these items and services where appropriate and beneficial.

First-party SNTs are irrevocable trusts created for the sole benefit of the person with intellectual and developmental disabilities. First-party SNTs are funded by the assets of the person with intellectual and/or developmental disabilities. Third-party SNTs are also established for individuals with intellectual and developmental disabilities, but are instead funded by someone other than the individual (i.e. a parent or family member). Some key differences between third and first-party SNTs are described in the table below.

Third-Party SNT

Established for a person with intellectual and /or developmental disabilities, but funded by someone other than that person (usually a family member).

Can be funded during the family member's lifetime, and added to over time by family members.

A family member's will can allocate a portion of their estate into the SNT.

Families can name the SNT as beneficiary of an insurance policy.

A pension or settlement money can be used to fund the SNT.

First-Party SNT

A self-funded, irrevocable trust created for the sole benefit of the person with intellectual and/or developmental disabilities.

If establishing a private trust, the person with intellectual and developmental disabilities must be under the age of 65, and it must be funded with the beneficiary's own assets.

If private, the trust must provide that upon the beneficiary's death, Medicaid will be reimbursed to the extent possible.

A parent, grandparent, legal guardian, or court order must establish this trust if the person is not able to do so.

Commonly, a first-party trust is established because the individual receives an inheritance or lawsuit recovery.

SNTs can be created by families inter vivos (while they are alive) or testamentary (through their will). Families must also decide whether they would like to utilize a private or pooled SNT. Private SNTs are created and maintained by families, whereas pooled SNTs are managed by non-profit organizations.

TYPES OF SNTs

Private (Self-Settled) SNT

There is no minimum amount required.

If established with family funds, the remaining funds can be allocated to other individuals upon the beneficiary's death, without restrictions.

Families can appoint themselves, another family member, an attorney, a trusted friend, a bank or financial services to act as trustee to maintain control over the funds.

Families need a knowledgeable attorney to set up a private SNT and pay attorney's fees.

If the private SNT is set up with the individual's own funds, Medicaid will have a lien on any remaining funds after the individual's death.



Pooled SNT

Many non-profits require a minimum initial deposit

Pooled SNTs are managed by non-profit organizations; the funds are pooled together for investment and management purposes. The trustee is the non-profit, but the trust contains separate accounts for each beneficiary.

First-party pooled trusts can be established for individuals of all ages.

Families do not need an attorney to write a trust and only will complete a Sponsor Agreement to open an account with the non-profit agency.

The agency will have skill and expertise in this field, and can best understand the needs of the beneficiary over their lifetime.

Pooled trusts are not subject to the Medicaid payback rule. However, upon the individual's death, most non-profit agencies require that some or all leftover funds in the trust remain with the agency.

Information about the AHRC New York City Foundation Community Trusts is available at
<http://www.ahrcnycfoundation.org/special-needs-trusts>.

You may contact the Foundation to discuss trusts or to make a donation to help the Guardianship Program
by calling (212) 780-2682.

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Futures planning means thinking about what happens to your loved one when you are no longer able to take care of them; it is to ensure that their needs are met in a way that you would if you could.

Futures planning is not a one-time effort — getting all the elements of a plan in place is more difficult and/or time consuming the first time. It is then easier going back periodically to review arrangements related to guardianship, living and service arrangements, contingencies and emergencies, access to financial resources, health care and other critical life and end of life decision-making processes and burial plans.

Guardianship may not be appropriate for every situation and it is important to find

the best approaches to futures planning for a person with developmental and intellectual disabilities.

Futures planning — particularly looking for ways to provide a person with a developmental or intellectual disability to access to some financial resources — in our experience adds greatly to the choices, supports and comforts available for people, particularly years after family members are not around anymore to help.

Primary guardians are likely to have to periodically review the arrangements they make vis-a-vis providing for standby guardians as times go by and things change and people get older. It is important that primary guardians be sure standby guardians are clear about their roles and responsibilities and know how to take the next steps and who to consult for help if they are required to become primary guardian.



We hope that you found this overview of guardianship and the NYSARC Guardianship Program as delivered at AHRC NYC informative and thought-provoking! If you have any questions,

please feel free to reach out to us at (212) 780-4408.