The Arc
New York
GUARDIANSHIP PROGRAM
Achieve with us.
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Welcome Letter for Executive Directors and Board of Directors

Welcome to the NYSARC corporate Guardianship Program. We want to provide you with an overview and orientation on the role and responsibilities of our Chapters’ Guardianship programs. Each Chapter’s Program is comprised of a voluntary standing Guardianship Committee and Guardianship Staff. They are charged with providing supports, advocacy and oversight services on behalf of NYSARC, Inc., which is appointed the corporate Primary and Successor Guardian of the Person for over 600 individuals with intellectual and developmental disabilities.

The Chapter’s Executive Director and Board of Directors play an important and integral role in the success of the Chapter’s Guardianship Program. It is your understanding, commitment and leadership that is necessary to ensure that the Program receives the appropriate allocation of staff and financial resources for the Guardianship Committee and staff to fulfill their fiduciary responsibilities as required by the organization’s Guardianship Policies and Procedures. It is also important to understand the primary responsibilities of the volunteer committee members who serve as the decision-making body in consultation with the Guardianship Coordinator for the individuals for whom NYSARC is Guardian. They must be allowed to freely advocate for an individual’s expressed and/or best interests, if not known, and always place the wellbeing of the person above the interests of the Chapter or other agency providing services to the individual in the Guardianship Program.

The NYSARC Guardianship Program is one of the most unique models of its kind in the country since it depends on both staff and volunteer Committee members’ dedication to work in partnership in providing supports that are determined least restrictive but necessary to enable people with intellectual and developmental disabilities (I/DD) to live as independent and self-directed lives as possible.

We hope that this welcome packet containing background information on the NYSARC corporate Guardianship Program will be useful in understanding the important role that everyone at the Chapter plays in carrying out our commitment to individuals in our Guardianship Program and their families.

Thank you.

Katharine Wilson Conroy
Chairperson, NYSARC Guardianship Committee

Erica F. Berman
Assistant ED for Guardianship Services
The NYSARC, INC. Corporate Guardianship Program

Our Mission
The NYSARC Corporate Guardianship Program offers a continuum of services for individuals with intellectual and developmental disabilities who require different levels of advocacy and supports for decision-making. This is done in the least restrictive manner while promoting their individuality, autonomy, dignity and self-worth. The Guardianship Program honors the personal wishes, preferences and beliefs that afford each person the independence and participation in all decisions affecting their lives.

Our Vision
An individual with developmental disabilities has their VOICE heard and respected in every life decision.

A Brief History
The Corporate Guardianship Program was established in 1970 by NYSARC, Inc. as a service to its members and to individuals with intellectual and developmental disabilities and their families in New York State. The program offers a commitment to parents, relatives and friends of individuals with intellectual and developmental disabilities that someone will always be available, through guardianship under Article 17-A, to provide advocacy and support for those people with I/DD who need assistance in managing their life affairs.

NYSARC, Inc. is a tax-exempt 501(c)(3) charitable not-for-profit membership corporation that was formed in New York State in 1949. Providing
guardianship services is very much in line with the purposes for which NYSARC, Inc. was formed.

From the beginning, the fundamental purpose of the guardianship program has been to ensure that upon the inability of the primary guardian to serve, the corporate Guardianship program through the local Chapter’s volunteer Guardianship Committee would always be available to provide ongoing advocacy and support for those in need of this level of assistance in managing their personal life affairs.

The NYSARC, Inc. Guardianship Program endeavors to offer families a seamless and smooth transition when it is required to move up in the guardianship succession upon the death or disability of the guardian. The NYSARC, Inc. blends professional corporate oversight with dedicated volunteerism to operate its guardianship program based on “family and self-determined values and needs.” In addition to being mission driven, with benchmarks, outcomes and standards of practice, our guardianship expertise helps to clearly promote the least restrictive intervention while focusing on the person’s ability for self-directed living: autonomy, independence, and decision-making.

In particular, the Guardianship Program works to ensure that the expressed wishes of every individual are considered and addressed. As most caring parents do for their adult children, our program strives to promote independence, autonomy, choice making and quality of life initiatives that include the person’s full participation as a citizen and member of his or her communities.

NYSARC, Inc. takes its role as guardian seriously; we do not view corporate guardianship as a substitute for other available and less restrictive community resources. We always encourage other suitable family members to serve as guardian. Thus, NYSARC, Inc. will serve only as a “guardian of last resort.” When no other supports or family members are available, interested or suitable, NYSARC, Inc. will consider a request to serve as the primary, standby or alternate standby guardian. NYSARC, Inc.’s Corporate Guardianship Program operates under Article 17-A of the Surrogate’s Court Procedures Act, which provides the guardian with authority to fulfill his or her fiduciary duties. NYSARC, Inc.’s Corporate Guardianship program exercises only the degree of authority necessary to appropriately meet the individual’s unique needs. Our guardianships under Article 17-A offer the greatest amount of independence and autonomy possible. Where support and assistance are needed, the guardianship program facilitates participation by the person under guardianship in all areas of decision-making affecting his or her life.
NYSARC’s Guardianship Policies and Procedures

Every individual, including both volunteers and staff, involved in the administration of the Corporate Guardianship Program shall follow the policies and procedures adopted by NYSARC, Inc., as well as all laws and regulations pertaining to guardianship under Article 17-A.

These policies and procedures include the following key principles:

- Guardianship is a continuous life-long relationship of trust.

- Guardians have the legal responsibility to advocate like ethical, competent and caring parents and families in assisting the individual at decision points.

- Guardians offer assistance and intervention in relationship to the individual’s capacities for Independent decision-making.

- Guardians place the welfare of the individual over the welfare of any service provider.

- Guardians encourage autonomy in seeking quality of life through personal relationships with the individual.
So, You’ve been Appointed as a Standby Guardian . . . Now What?
You have been asked by your parents, family member, or friend, to serve as the Standby Guardian for your loved one. What does that mean? What are your responsibilities?

Legal Definition of Guardianship
In New York State, the rules of guardianship for people with intellectual and other developmental disabilities are defined in Article 17-A of the Surrogate’s Court Procedure Act (SCPA). If you were appointed the Standby Guardian of the Person and/or Property of an individual with intellectual or developmental disabilities under this Act, then should anything happen to the Primary Guardian that makes them unable to provide guardianship, you will take over the responsibility of becoming the Primary Guardian for that individual.

Why Guardianship May Be Beneficial
Many family members and friends of those individuals with intellectual and developmental disabilities ask the following questions: Why is guardianship necessary? What does it involve? What are my responsibilities? It is not an option that every family must pursue, since there are other less restrictive alternatives available to those who have capacity to take care of themselves and make their own decisions regarding their medical and other personal care as well as finances.

To help answer some of these questions The Arc New York has identified many reasons why guardianship can be a crucial support for those with intellectual and developmental disabilities.
The Role of a Guardian:

- Give voice to a person who is unable to fully represent his/her wishes, preferences, beliefs, values, desires and needs
- Act as a legal advocate and provides legal protections in decision-making; has legal standing to challenge treatment decisions and access medical records. Helps to access and negotiate service delivery systems and medical and dental services
- If appointed guardian, most likely authorized to provide informed consent for medical treatment and dental care in a thoughtful, proactive and timely manner; may make decisions about life sustaining treatment, including admission to hospice and palliative care
- Help to promote decision-making alternatives for person with disabilities, fosters choice making and understands potential consequences; helps person to exercise independence and autonomy in the least restrictive manner and environment
- Serve as a decision maker when necessary
- Provide oversight and serves as a safety net when needed
- Provide a continuous lifelong relationship of trust, further enriching the lives of persons with I/DD
- Offer permanency, continuity of care, oversight and added value above and beyond what is already being provided to the person in programs and residence
- Offer peace of mind

While serving as the Standby Guardian, although there is no legal responsibility given to you under the law until you actively assume the responsibility following the death, incapacity, or voluntary withdrawal by the Primary Guardian, you are encouraged to follow these steps should the need ever arise for you to assume the responsibilities of the Primary Guardian.
Responsibilities of a Standby Guardian

Know the Individual

To be an effective guardian at some point in the future, it is advised that you keep in touch with the individual supported by guardianship services.

Personal visits are often the most helpful and effective way to learn about the individual and his or her lifestyle, including strengths, needs, wishes, preferences, beliefs, including religious and spiritual, etc.

It is not unusual for Standby Guardians to live out of the state, and it is difficult to make personal visits. Therefore, it is important to keep in contact with the Primary Guardian. You may want to discuss with the Primary Guardian issues regarding the person’s medical, dental, residential, education, employment or day program needs as well as the person’s financial resources.

Essentially, the more familiar you are with the needs and issues of the individual now, the easier the transition can be should you assume the responsibilities of the Primary Guardian.

Keep the Court Informed

When you are Standby Guardian, it is important that you keep the Surrogate’s Court, in the county where you were named the Standby Guardian, informed of changes in name (e.g. through marriage) or addresses.

Ask the Primary Guardian to provide you with the County of the Surrogate’s Court, which issued the Letters of guardianship, and the file number of that guardianship case. You should also have copies of the Court Degree and Letters naming you as the Standby Guardian.

What happens when the time comes for you to become Primary Guardian?
Although the Court named you the Standby Guardian a number of years ago, this does not mean that you automatically become the Primary Guardian upon the death, incapacity or removal of the Primary Guardian without also returning to the Surrogate’s Court within 180 days to confirm your Guardianship Appointment.

Here are the steps for you to follow for your appointment to be Primary Guardian:

Legal Confirmation
When the Primary Guardian dies, becomes incapacitated or renounces guardianship, you must file a petition with the Surrogate’s Court confirming your authority to assume the role of successor guardian. This MUST be done within the 180 days following the death or removal of the Primary Guardian. This is called a Confirmation Petition. If this is not done within the
prescribed time, the person would be without a guardian and you would have to reapply to the Court in the form of petition or, Court application.** (**This rule varies from county to county).

Most courts will require either a certified copy of the death certificate, affidavit of renunciation, or decree showing adjudication of incapacity of the Primary Guardian. In some instances, you may be asked to be fingerprinted once again by the Surrogate’s Court, depending on the date of the initial decree naming you as Standby Guardian. The Surrogate’s Court also has the right to require a hearing and may require updated medical certifications.

The Confirmation process may be completed on a pro se basis (without the assistance of an attorney), although you may wish to retain legal counsel to assist you with this process.

**Naming the New Standby Guardian**
In many cases, the initial Primary Guardian has not named an alternate Standby Guardian. If this is the case, please consider your successor when petitioning to be the Primary Guardian. Just as you were named Standby Guardian, you should seriously consider who you would like to care and advocate for your person should the time come when you can no longer carry out the responsibilities of Primary Guardian.

For more information, please contact the Guardianship Program at your local Chapter of The Arc New York, or NYSARC, Inc. Guardianship Department at (518) 439-8311. We would be happy to provide you with additional assistance.

NYSARC (The Arc New York)
Guardianship Program Services
29 British American Blvd., 2nd Floor
Latham, NY 12110
(518) 439-8311

Celebrating 70 Years of Advocacy, Support, and Empowerment
Sample Guardianship Application Letter

Dear Applicant:

We recognize your desire to honor and foster the well-being, expressed wishes, and best interest of your family member throughout his or her life. The Arc New York, together with its chapters, offers a unique lifetime commitment to relatives of individuals with developmental disabilities through its corporate guardianship program.

Typically considered “the guardian of last resort,” meaning no family members and/or close friends are able to fulfill the role of guardian, The Arc NY offers a back up to your family’s planning ensuring the care, advocacy and quality of life that you have provided for your family member thus far will continue for the rest of his/her life. The attached application includes many in depth questions in order to provide the Guardianship Committee and Chapter with vital information.

Expectations of guardianship staff include: maintaining training, attending regional meetings, completing an Annual Status Report for each individual, attending Life Plan meetings, maintaining open lines of communication, providing oversight and advocacy for support staff (residential, nursing and day), reviewing requests for consents for medical needs and/or other life changing decisions (change of residence or day program) and providing consent when appropriate. Alternate options will be provided by the Guardianship Coordinator, and we recommend working with an attorney who is knowledgeable in these areas. Information regarding The NYSARC Trust Services or other financial planning alternatives will be made available to you, or your attorney, upon request.

There is no current public or dedicated funding for guardianship services in New York State at this time. The Arc New York and its chapters are dependent on private contributions to insure the future of its corporate guardianship program. Costs incurred by the guardianship program include the cost of staffing the program in order to meet the needs of the individuals benefitting from guardianship services. Expenses also include, but are not limited to, providing those receiving guardianship services with visits and gifts for birthdays and holidays in addition to regular visits from guardianship staff/committee members, and costs associated with amending the guardianship succession and burial expenses. Where funds are available, it is our expectation that you will make financial provisions to help the operation of the Arc Chapter Guardianship Services.

Please note your application will not be turned down based on your inability to provide funds. However, when you have the resources it is a requirement to provide some financial support to the Guardianship program.

We ask you to complete the application, providing as much information as possible. The information provided will be vital in supporting your family member going forward. If a question does not apply to you or your family member, please provide a brief explanation where necessary.

Information provided will be held in confidence and only shared as necessary to advance the application. Please feel free to contact Chapter staff for assistance in completing the guardianship application. Thank you for considering The Arc New York in this very important matter.
Special Needs Trusts: Financial Tools to Protect Benefits for People with Disabilities

A person with a disability can only have a certain amount of money in their name to qualify financially for the essential services they receive through means-tested government benefit programs such as Supplemental Security Income (SSI) and/or Medicaid. This can make it challenging for people with disabilities to save money and support their daily living needs. When planning for the future, a special needs trust (SNT) can play a critical role in protecting a person’s eligibility for benefits while helping to provide the financial means to improve a person’s quality of life.

What is a special needs trust?

A special needs trust (SNT), also referred to as a supplemental needs trust, is a special type of trust which, under Federal statute and New York State law, allows a trustee such as NYSARC, Inc., to manage funds for the benefit of a person with a disability while preserving that person’s eligibility for government benefits.

Funds deposited into a valid SNT are disregarded when determining a person’s financial eligibility for benefits, thereby allowing a person to get the services they need while setting money aside for uncovered medical expenses and life-enhancing purchases that their benefits do not provide.

Why create a trust?

- Primarily used to help a person qualify and/or maintain financial eligibility for means-tested government benefits, such as Medicaid and/or Supplemental Security Income (SSI)
- Secure a better financial future for a loved one with a disability without jeopardizing benefits or financial assets he or she is entitled to receive
- Allows a person to set aside funds for purchases not covered by benefits and life-enhancing items and services
- Avoid having to spend-down funds quickly and, all-too-often on frivolous purchases, to maintain benefit eligibility

Who can fund a trust?

A SNT can be funded with money that belongs to a person with a disability as a first party trust or by someone other than the beneficiary as a third party trust, such as a parent, grandparent, sibling or other interested third party.

Understanding the Types of SNTs and Other Financial Tools

The Donor, person funding the trust, can establish an individual SNT if the trust beneficiary is under the age of 65. Individual SNTs require an attorney to draft a trust document and someone to serve as trustee. The trustee has a fiduciary responsibility to administer the trust in the best interest of the trust beneficiary and must follow the regulations set by the Social Security Administration.

A pooled SNT is another option for people with disabilities of any age. A pooled trust offers an affordable alternative to an individual trust by pooling the funds for investment management and administrative cost savings. The trust documents are already in place, therefore, it does not require an attorney to set up and a not-for-profit organization serves as trustee.

For capable individuals whose qualifying disability was prior to age 26, an ABLE Account may also be an option to set aside funds for qualified disability expenses without putting a person’s benefits at risk.
**First-Party Funded Special Needs Trust** – A person with a disability may need to set up a first party SNT if he or she receives or is entitled to receive money that will put them over the financial limits for benefits. For a person receiving SSI, having any more than $2,000 in their name could jeopardize their benefit eligibility. Common funding sources include a direct inheritance, proceeds from a lawsuit deposited in a lump sum or structured payments, a retroactive Social Security award, resources accrued from Disabled Adult Child (DAC) benefits or excess monthly income. Funds in a SNT can be used to enrich a person’s quality of life by making purchases that are for the sole benefit of the trust beneficiary and for goods and services that a person’s benefits do not provide.

Upon the death of the trust beneficiary, any balance in the trust is typically subject to a payback to the State(s) that provided Medicaid services throughout that person’s life before any money can go to remainder beneficiaries.

**Third-Party Funded Special Needs Trust** – A third party can set up a SNT to leave money or real property to a loved one with a disability who receives government benefits or is expected to need benefits later in life. For a parent or relative of a person with I/DD, there is nothing more important than knowing that their loved one is happy and safe both now and in the future. Life happens, which makes planning early critical. Third party SNTs are most often set up in a Will as part of an estate plan where the Donor names the trust as the beneficiary of an inheritance, life insurance policy, other asset/s or monetary gifts. The Donor can also create and fund a SNT during their lifetime if they have money available now to provide to a loved one. If there is money left in a third party SNT upon the death of the trust beneficiary, the trust is not required to repay the State(s) that provided services to the trust beneficiary. Any remaining funds will go to the remainder beneficiaries named in the trust document, such as other children and family members.

**Pooled Special Needs Trust** – Pooled trusts are administered by not-for-profit organizations, offering the benefits of a professional trustee at a significantly lower cost, which makes setting up a trust more accessible for people with disabilities. These trusts are easy and inexpensive to establish because an attorney is not required to draft the trust document, although it is always a good idea to consult with a legal professional. The funds are pooled into one account for investment and management purposes, however, each person’s activity is tracked in separate sub-trust accounts, much like a checking account. With funds pooled, the administrative costs are lower and a person can benefit from greater investment power. A pooled trust closes upon the death of the trust beneficiary and—unless the remaining funds exceed the person’s Medicaid lien—the not-for-profit will typically retain the funds, or a portion of the funds, to benefit other people with disabilities.

**ABLE Accounts (529A)** – An ABLE account could also be an option if the person's onset of disability was prior to age 26 and they are capable of maintaining some level of financial independence. ABLE Accounts are tax-advantaged savings accounts designed to help people with disabilities set aside money for qualified disability expenses while maintaining their eligibility for Medicaid and/or SSI benefits. Account holders must maintain a record of expenses and payment receipts to show that purchases were made for qualified disability expenses. Deposits into an ABLE account can come from any source up to a maximum total annual contribution limit of $15,000. Once the account exceeds a balance of $100,000, the overage could impact a person’s SSI benefits. Any funds left in an ABLE account upon the death of the account holder are subject to Medicaid payback, even funds deposited by a third party.

Do you have questions? To learn more, contact NYSARC Trust Services at (518) 439-8323 or visit www.nysarctrustservices.org. NYSARC Trust Services has administered SNTs since 1972, helping thousands of people protect benefit eligibility and improve quality of life.

NYSARC Trust Services
518-439-8323
www.nysarctrustservices.org
Role and Responsibilities of the Chapter Board of Directors

- Ensure that the Chapter has enough financial and staff resources to support the necessary infrastructure and operations of the guardianship program.

- Ensure that the Chapter has established a diverse and appropriate number of community-based, volunteer members comprising the Guardianship Committee, who functions as the representative and legally empowered guardian of the “person”, on behalf of NYSARC, Inc.

- Review, consider, approve and sign off on each Guardianship application. Including requests for transfers from another Chapter that meets the Corporate Guardianship Program eligibility requirements, and that is recommended by the Chapter’s Guardianship Committee.

- Document accepted corporate applications and accepted or disapproved transfers from other Chapters in minutes of each board meeting.

- Monitor and oversee the activities of the Chapter Guardianship Committee to ensure compliance with the program’s Policies and Procedures.

- Avoid any appearance or actual conflict of interest, or manage a potential conflict involving the affected board member by recusing him/herself from voting on an application where he/she may be related to the individual.

- Ensure that the Guardianship Committee and Coordinator must be free to advocate in the best interests of the individual in the chapter’s Guardianship Program.

- Ensure that the Guardianship Committee is recognized and supported as the independent decision-making body for individuals in the Chapter’s Program.

- Ensure that the Chapter Guardianship Program serves as a resource to families, agencies and CCOs in the community, and it offers a range of least restrictive alternatives to guardianship and tools for decision making.
Role and Responsibilities of the Executive Director

- Ensure that the Chapter has enough resources to support the necessary infrastructure and operations of the guardianship program.
- Establish and maintain a diverse and appropriate number of community-based, volunteer members comprising the Guardianship Committee who function as the representative and legally empowered guardian of the “person”, on behalf of NYSARC, Inc.
- Ensure that the Guardianship Committee is comprised with a majority of non-board members.
- Designate an appropriate Guardianship Coordinator and alternate, to serve as a liaison to the Guardianship Committee & provide support and oversight to that individual.
- Ensure that the Guardianship Committee and Coordinator are recognized by Chapter staff as the legal representative of the individuals in the Chapter’s Guardianship Program.
- Ensure that the Guardianship Committee and Coordinator are free to advocate in the best interests of the individuals in the chapter’s Guardianship Program.
- Review and move to approve or disapprove with an explanation each Guardianship application that is being considered by the Guardianship Committee and Board of Directors.
- Ensure that the Guardianship Committee/Coordinator are informed of all issues affecting a person who has been involved in a serious incident or event.
- Ensure that authorization is obtained from the Guardianship Committee when consenting to a person’s major medical/dental procedures.
- Ensure Chapter’s Guardianship Program Committee and staff participate in Regional Guardianship meetings, annual Training Symposium, core and other webinar trainings and other educational opportunities.
- Ensure Chapter’s participation in Regional Guardianship Sub-Committee meetings and activities.
- Ensure Chapter’s completion of and annual self-assessment of the Guardianship Program as assigned.
- Ensure that the Chapter Guardianship Program serves as a resource to families, agencies and CCOs in the community, and further offers a range of least restrictive alternatives to guardianship and tools for decision making.
Role & Responsibilities of NYSARC Guardianship Staff

Administrative, Operations and Oversight

- We work as a team!
- Serve as liaisons to State Guardianship Committee and Chapter Guardianship Programs
- Assist State Committee members in oversight duties and responsibilities on behalf of Board of Governors
- Provide administrative support to Corporate & Chapter Guardianship Programs
- Maintain electronic records/database systems
- Process applications submitted by Chapters requesting NYSARC to serve as Guardian of the Person and of “last resort”
- Review annual status reports and provide ongoing oversight/monitoring of the Corporate Guardianship Program
- Review and follow-up on Incidents/Events
- Assist Chapters/Legal Department with holding End-of-Life care meetings - (1750-b)
- Provide ongoing technical assistance and information and referral

Policies and Procedures – Program Compliance

- Develop, implement and evaluate the highest standard of practices for providing guardianship services
- Offer guidance as well as an operational understanding of fiduciary responsibilities to effectively administer NYSARC’s Corporate Guardianship Program
- Ensure that Chapters are following prescribed policies and procedures adopted by the Board of Governors
- Prepare and provide program reviews (audits) and assistance when necessary to Chapters for all active Guardianship programs when new applications are submitted, any recognitions are considered, or issues/concerns arise
- The State office staff assist the Chapters in understanding the mission and benchmarks/guiding principles of the Guardianship Policies and Procedures manual

Education and Training

- Develop and implement ongoing training sessions and opportunities for Chapter Guardianship Committee members and Coordinators required upon assumption of duties/responsibilities and throughout tenure
- Promote and distribute information on surrogate decision-making alternatives, Supported Decision-Making and other less restrictive continuum of supports for professionals and families
- Coordinate and Sponsor conferences and educational forums
- Disseminate relevant, cutting edge information on Guardianship, the Corporate Guardianship Program, and other less restrictive alternative supports and tools for decision making through the development of literature and publications on guardianship
- The State Guardianship Committee and Staff are responsible to help identify and recommend topics for training, discussion, and strategies for implementation at Regional Guardianship Subcommittee meetings
Role and Responsibilities of the Chapter Guardianship Coordinator

The Guardianship Coordinator will be responsible for serving as the staff liaison to the Chapter’s Guardianship Committee. As the Guardianship Coordinator, you will be responsible for supporting and assisting the Guardianship Committee in fulfilling its duties and responsibilities. The Policies and Procedures for the corporate guardianship program will provide you with in-depth guidance about your specific responsibilities. That said, some of the more important aspects of your new position can be found below.

A Chapter Guardianship Coordinator:

- Is appointed by the Chapter’s Executive Director to serve as liaison to the Guardianship Committee
- Provides support and advocacy in conjunction with the Guardianship Committee to the program participants, carries out the decisions, and fulfills the responsibilities of the Chapter Guardianship Committee
- Communicates with, supports and provides guidance to families on the topics of guardianship and least restrictive alternatives before family considers pursuing guardianship
- Ensures appropriate completion (or assists with the completion) of the internal application process when considering NYSARC corporate guardianship
- Visits program participants in guardianship program a minimum of eight (8) times annually
- Attends various meetings on behalf of the program participant and advocates for their needs, supports and services
- Ensures that Annual Status Reports (ASRs) are prepared for each person in the guardianship program and submits them to the NYSARC Guardianship Program staff
- Ensures that holidays, birthdays and other special occasions are acknowledged and celebrated
- Stays current on guardianship related issues and receives ongoing education and training to support decision making
- For primary guardianships, shall become familiar with the individuals ISP/Life Plan and keep the committee informed of their progress in achieving goals
- Is responsible for contacting the Care Coordinator/Manager, Chapter staff and/or other agencies, about the appointment of NYSARC, Inc. as the Primary Guardian
- Informs NYSARC, Inc. State Office of any changes to the guardianship succession
- Attends and participates in one to two Regional Sub-Committee Meetings annually
• Attends and participates in the annual Guardianship Training Symposium

• Is responsible for maintaining ongoing communication with The Arc New York State Office Guardianship and Legal staff on matters of importance, including issues relating to conflicts of interest, end of life, placement of individuals in skilled nursing facilities, etc.

• Maintains individual records on each person for whom NYSARC, Inc. is appointed Primary, Standby and Alternate standby Guardian

• Is responsible for submitting and following up on Serious Incident Reports (OPWDD/Justice Center requirements) each time a Primary Guardianship participant is involved in an incident/event in one of the categories below:
  
  o Reportable Incidents – Abuse/Neglect (14 NYCRR 624)
  
  o Reportable Incidents – Significant Incidents (14 NYCRR 624)
  
  o Serious Notable Occurrences (14 NYCRR 624)
  
  o Minor Notable Occurrences 14 NYCRR 624)
  
  o Other Incidents/Events Required by NYSARC Guardianship Policies and Procedures

• Participates in all core Training and Education requirements for Guardianship Coordinators/Staff in order to increase your knowledge and enhance understanding of your role and responsibilities. Training areas include but are not limited to: Guardianship 101, end-of-life care, management of incidents/events, less restrictive alternatives to Guardianship, SDM, consent and capacity, supplemental needs trusts, health care proxies, etc.
Role of the Chapter Guardianship Committee Member

The selection of a volunteer member to serve on a Chapter’s Guardianship Committee is one of the most vital and impactful responsibilities in promoting the quality of life and wellbeing of individuals in the guardianship program. Volunteers represent the heart and soul of the Guardianship Program. They serve as the ultimate decision maker and advocate, and their diverse backgrounds, experiences, commitment and mission to support people with intellectual and developmental disabilities are essential to the success of the program.

The chapter will designate the Guardianship Coordinator to serve as staff liaison to the Guardianship Committee. The committee will receive ongoing support and guidance from the Guardianship Coordinator. The NYSARC Policies and Procedures for the corporate guardianship program will provide further guidance and go into greater detail about specific responsibilities.

The first and foremost responsibility of a committee member is to become familiar with the individuals being served, the history and current agenda of the Committee, and to attend all meetings. Other responsibilities include:

- Oversight and monitoring of the Chapter’s Guardianship Program
- Protecting the personal interests of individuals in the guardianship program by establishing the highest degree of trust, loyalty and fidelity in relation to the person
- Familiarizing themselves and refer to the NYSARC Guardianship Policies and Procedures for guidance, expectations and understanding of one’s role and responsibilities, to ensure compliance with all requirements
- Reviewing, discussing and considering new requests for guardianship in the form of an application prescribed by NYSARC, and help to determine the appropriateness of the request according to the eligibility requirements established in the Policies and Procedures Manual, and whether less restrictive supports and services may be considered for the individual
- Staying informed about the overall wellbeing of everyone for whom NYSARC is appointed primary and successor guardian through the review of annual status reports (ASRs), updates provided by the Guardianship Coordinator, chapter staff and other committee members with knowledge of the individuals
- Expecting notifications about any serious incidents or events involving each person for whom NYSARC is appointed Primary or successor guardian and discussing any recommendations for care and advocacy to ensure the individuals wellbeing
- Becoming knowledgeable about each person’s strengths, abilities, preferences, choices, and wishes, including about end of life, as well as their need for supports and advocacy, in order to help make informed decisions and live self-directed lives.
The Arc New York Guardianship Program Position Statement
2016 NYSARC Position Statement on Autonomy, Decision-Making Supports and Guardianship

All individuals with intellectual and developmental disabilities (I/DD) have the right to be recognized as persons before the law and to enjoy legal capacity on an equal basis with individuals who do not have disabilities in all aspects of life. The personal autonomy, liberty, freedom, and dignity of each individual with I/DD must be respected and supported. Legally, each individual adult or emancipated minor is presumed competent to make decisions for him or herself, and each individual with I/DD should receive the preparation, opportunities, and decision-making supports to develop as a decision-maker over the course of his or her lifetime.¹

Providing a continuum of supports from least restrictive to greater levels of assistance that include advocacy, supported decision making and guardianship are the principle underpinnings of the NYSARC guardianship program, and each of these decision-making alternatives foster consideration of risks, benefits and alternatives.

Advocacy

To make decisions for oneself is a core human and civil right. When someone needs help with making decisions, assistance should be tailored to that individual’s unique needs. Advocacy is essential for promoting and protecting the civil and human rights of people with I/DD and for establishing, maintaining or improving their quality of life: exercising their rights, making choices, contributing to society and living independently.

- The principles and practices of Person Centered Planning are supported to promote and encourage self-determined lives.
- All persons have legal capacity; all persons have the right to assistance in exercising that right.
- When a person has a guardian, or even a strongly vocal family member or other advocate, the organization providing services must maintain its focus on the person receiving supports. Support staff are critical in maintaining this focus on the person. (CQL)
- The guardian should take action to assist the person to petition the court to remove a guardian where guardianship is not appropriate, or where a guardianship should be tailored or where a guardian is acting against the individual’s wishes and desires. The court can be petitioned to remove the guardian completely, to restrict the guardian’s scope or to appoint another guardian if necessary.
- All persons assisting individuals with I/DD with advocacy and decision making, (including participants in supported decision making, family members and guardians) should have access to education, training and other resources.

¹ Excerpted from The Arc draft Position Statement on Autonomy, Decision-Making Supports, and Guardianship 329-16
2016 NYSARC Position Statement on Autonomy, Decision-Making Supports and Guardianship

Supported Decision Making

Supported decision-making is a process by which a person with an intellectual or developmental disability can be supported in making his or her own decisions. Supported decision-making draws on our common experience of consulting or seeking assistance from others when we make decisions or choices in our own lives. Whether it is renting an apartment, buying a car, or choosing to get married, we do not make decisions in a vacuum, but rather with “support” from friends, family and/or experts of some kind.

People with intellectual or developmental disabilities also have a right to make their own choices and decisions, but may need more or different kinds of support to do so. Supports may include help with accessing information that is useful or necessary for a decision; help with weighing the pros and cons, assisting in communicating the decision to third parties, and/or in carrying out the decision. But the decision should always be the person’s decision and not the supporter’s.  

- A person with intellectual or developmental disabilities should receive the preparation, opportunities, and decision-making supports to develop as a decision maker over the course of his or her lifetime.
- Support may come from one or more individuals, possible family, friends, peers, neighbors or service providers.
- The individual may need assistance to identify the person or persons to assist him/her in making decisions.
- Supported decision-making can be evidenced in a written document, a “supported decision-making agreement.”
- Issues surrounding “acceptance” of decisions by medical staff, banks, etc. need to be addressed.
- Support of the individual in making his/her own decisions must be insured. Supported decision making does not substitute the decision of others For the decision of the person supported.
- Supported decision-making provides part of a tailored guardianship structure, providing supports in areas of decision making where a guardian decision maker is not needed.
- Need for legislative authorization and framework.

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2 Excerpted from material in the grant discussion of the SDM grant received by Hunter College and NYSACRA from the DDPC.

3 Excerpted from The Arc draft Position Statement on Autonomy, Decision-Making Supports, and Guardianship 329-16
2016 NYSARC Position Statement on Autonomy, Decision-Making Supports and Guardianship

Guardianship

Individuals with disabilities who do not possess the cognitive 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 the position of NYSARC, Inc. for all individual and corporate guardians that:

- A guardian is involved in an active, continuous life-long relationship of trust with the individual for whom he or she is the guardian.
- A guardian is legally responsible for assisting the individual at key decision-making points.
- A guardian offers assistance and intervention as needed, based on the individual’s capacities and expressed wishes, while ensuring that the individual has every opportunity to express preferences and have them honored to the extent possible.
- A guardian works to strengthen the individual’s capacity for independent decision-making by promoting self-reliance and participation to the maximum extent of his or her abilities in all decisions pertaining to the individual.
- A guardian places the welfare of the individual over the welfare of any service provider.
- A guardian shall advocate for individualized planning with the person in accordance with his/her wishes, preferences and desires to ensure that services are provided in accordance with those standards.
- If the person’s prior or current wishes cannot be ascertained or would cause substantial harm, the guardian will make every effort to act in the best interest of the individual.
- A guardian plays an essential role in advocating that the individual receives a high standard of care in all aspects of his/her life, including health, mental, dental, and end-of-life care and treatment.
- While a guardian is not financially responsible or obligated to expend his/her own funds for the benefit of an individual, a guardian should take appropriate steps, to secure public or private benefits and, if there are available funds, to see that there is a financial plan in place to address the individual’s needs and/or desires during his/her lifetime; and ensure there are arrangements in place for the funeral and burial of the individual or other specified provisions have been made.
• The guardian has the moral and ethical responsibility to ensure that appropriate and dignified funeral and burial arrangements or other specified arrangements are made for the individual, taking into consideration his/her religious, spiritual and cultural beliefs and practices.

• Guardianship will only be considered when other less restrictive options have been explored: (e.g. designating a health care agent, appointing an agent under a Power of Attorney, or appointing a power of attorney or rep payee, using service coordination, or utilizing supported decision making committees or supported decision-making models).

• A guardian will only be appointed after there has been an independent review of the need for guardianship or if the individual is represented by Counsel.

• The need for continued guardianship should be reviewed at least annually at planning meetings with the team or other appropriate party including the guardian. (CQL)

• The authority of the guardian will be tailored to the meet the specific needs of the individual in the least restrictive manner.
Alternatives to Guardianship and Tools for Decision Making

It is important to understand that Guardianships in New York State are divided into Guardianship of the Person and Guardianship of the Property. While the standard for both are generally the same, there are alternatives that should be considered that may limit or eliminate entirely the need for a Guardian of the Person or the Property.

Guardianship of the Person includes responsibilities that are focused on the health, welfare and person of the individual in question; while Guardianship of the Property is directed at the oversight and management of the individual’s personal assets (money, real estate, etc.).

It is important to understand these differences when considering alternatives to Guardianship.

Alternatives to Guardianship of the Person

There are legal ways to give someone else authority to make certain decisions for you other than guardianship. In particular, the level of capacity required to execute advance health care directives is quite low, allowing a person the opportunity to direct who and how their care will be handled should they lose capacity to make health care decisions themselves.

Advanced Health Care Directives – (i.e., Health Care Proxy, Living Will and MOLST) used to memorialize the individual’s health care preferences. Advance Directives detail the person’s preferences with respect to certain medical interventions, should they become unable to communicate them to a doctor and appoint a person to make those decisions.

Health Care Proxy – A legal document that allows a person with capacity to appoint an “agent” to make health care decisions, should that person’s doctors determine they are not capable of understanding the nature and consequences of the health care decisions they are being asked to make at some point in the future.

Living Will – can provide the agent appointed by an individual with the clarity they need to fulfill their charge and to be protected while they do so. The living will serves as a declaration of the individual’s wishes as to health and end of life care. It can list procedures the individual does or does not want and is generally considered acceptable evidence of the individual’s wishes.

Supported Decision-Making (SDM) – A model for supporting people with disabilities (often cognitive disabilities) to make significant decisions and exercise their legal capacity. Specific decisions are addressed, weighted and concluded by the person with the disability, while drawing on the support of a network of people or an individual. While this model is offered throughout the country, it is not a legal decision-making method in the State of New York. Information about New York State’s pilot project on Supported Decision Making in New York can be found at https://sdmny.org/.
Alternatives to Guardianship of the Property

Durable Power of Attorney – This is a document that, under New York law, is effective when signed and allows a person to designate an agent or agents to make personal and financial decisions on his/her behalf. These documents are comprehensive and grant significant authority over one’s assets, and one’s ability to contract for services or for entrance into a residential health care facility. These, unlike Health Care Proxies, should only be executed under the supervision of an attorney licensed to practice in New York State.

Tools for Decision Making

Surrogate Decision Making Committee (SDMC) – New York State offers an alternative to the court system for individuals who lack capacity to provide informed consent for those individuals with I/DD or with mental illness who do not have a legally authorized decision maker to act on their behalf and are in need of non-emergency, major medical procedures, i.e., a colonoscopy or dental extractions under general anesthesia. This program also handles end-of-life decision making for qualifying individuals.

Actively involved family members – An actively involved family member is someone 18 years of age or older and who has demonstrated significant and ongoing involvement in an individual’s life and sufficient knowledge of his/her needs.

MOLST (Medical Order for Life Sustaining Treatment) - This is not a document that an individual can execute on their own, it is a medical order that is issued by a doctor that allows a person to elaborate on their wishes for end of life care and various medical procedures after consultation with a Doctor.

The Office for Individuals with Developmental Disabilities has developed a checklist for the review of a MOLST with a person with I/D or I/DD, as well as other resources for healthcare decisions, which can be found at the links below.

- MOLST Checklist
- Healthcare Decision Resources

Court Order – A legal action can be commenced in the County or Supreme Court for a court order. Papers supporting the need for the medical procedure are filed with the Court. The individual has legal representation (usually through the Mental Hygiene Legal Service) and a hearing can be held on the issues presented. This is typically a last resort when there are no other available options.

Restoration of Rights

Because guardianship is created by a court, it must be dissolved in court. People seeking help should contact DRNY at (518) 432-7861, or online at www.drny.org. An Intake Specialist will collect some confidential information and the case will then be referred to an attorney. The attorney will explain the restoration process, identify the client’s goals and concerns, help
collect documents and, with the client’s consent, talk to people who might support the restoration. All information shared between the client and the attorney is confidential. The attorney will review the case and make recommendations to the client. If the client and attorney agree that there is enough evidence to dissolve the guardianship, the attorney will prepare legal documents to file with the court. The judge will want to hear from all parties and will review all papers submitted before deciding. The judge may decide to hold a hearing and take sworn testimony from witnesses. The attorney will involve and support the client through the entire process, which could take several months. More information on this process for people under guardianship can be found in What to Expect if I Want to Terminate My Guardianship on the DRNY website.

Disability Rights New York (DRNY) is a non-profit law office and advocacy agency that protects and advances the rights of people with disabilities. These efforts include assisting people who are under guardianship who wish to end the guardianship and have their rights restored. DRNY also helps people for whom guardianship is being sought who wish to retain the right to make decisions. DRNY can provide assistance in both SCPA 17A and MHL Article 81 guardianship proceedings.

All of DRNY’s services are free.

The Mental Hygiene Legal Service (MHLS) is another resource for individuals residing in residential settings, or people eligible to reside in a certified setting. The MHLS is a New York State agency responsible for representing, advocating, and litigating on behalf of individuals receiving services for a mental disability. MHLS operates pursuant to Article 47 of the New York State Mental Hygiene Law and is an agency of the judicial branch of government. The law allows the MHLS to provide legal representation to an individual and can inform residents and their families of other available legal services if they are unable to provide direct representation in a case.

The MHLS has designated offices for every county in the State. Legal assistance can be obtained by contacting the closest regional office. Advise the office of the county of the person’s residence, the issue at hand and that assistance is requested. Regional Office contact information can be found here.

The MHLS office in Albany, NY can also be contacted at (518) 451-8710 and given the same information. The person will then be referred to the MHLS office that would handle the matter. An attorney can meet with the person, review records, investigate claims, advise them of their rights and help make a plan to move forward. The MHLS can be appointed by a Court to represent someone but can also initiate any legal action to safeguard individual’s rights. This can include a legal action to enforce the terms of a guardianship, modify a guardianship order or remove a guardian in appropriate circumstances.
Conclusion

We want to thank you for taking the time to review and consider the background materials provided in this welcome packet. It is our greatest hope that it serves to sufficiently orient you to this unique and special corporate Guardianship Program. Your understanding of the fiduciary duties assumed by the Chapter’s Guardianship Committee and Coordinators/Staff as well as the oversight duties of the Chapter’s board of directors and executive director is integral to successfully supporting and meeting the needs of the individuals in the Guardianship Program.

We hope that you find your participation to be a rewarding and enjoyable experience. Should you have any questions, please feel free to contact the NYSARC Guardianship Program Staff. Welcome and thank you!

NYSARC Guardianship Program Staff

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Celebrating 70 Years of Advocacy, Support, and Empowerment