

2016 NYSARC Position Statement on Autonomy,
Decision-Making Supports and Guardianship



The Arc®

New York

GUARDIANSHIP PROGRAM

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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.

¹ Excerpted from The Arc draft Position Statement on Autonomy, Decision-Making Supports, and Guardianship 3-29-16

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- 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.

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.²

- 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.³
- 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.

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 3-29-16

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- 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.

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.

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- 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.

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