



2023-24 Position Statements

The Arc New York's mission is to advocate for persons with intellectual and other developmental disabilities in every manner possible. In its advocacy role, The Arc New York is committed to a full quality of life for every person, as it recognizes the challenges of the present and has a clear vision for the future.

In this twenty-first century, The Arc New York continues to be dedicated to a primary goal that all persons with intellectual and other developmental disabilities and their families should have access to services, supports and resources that will foster the unique growth and development of every person. To this end, The Arc New York is committed to standards of excellence in service design and delivery in every life domain.

The environment where people live, study, work, recreate and worship must reflect an affirmation of each person's strengths, wants, needs and desires. Services, supports and resources should be of the highest quality, individually tailored to result in positive outcomes that will enhance each person's ability to achieve self-identified goals and aspirations in every aspect of life. Overarching quality standards in person-centered service planning and delivery, protection and safety, community inclusion, workforce performance, quality improvement plans and governance and leadership reflect the core values of The Arc New York and all of its Chapters.

We, as parents, friends and advocates of people with intellectual and other developmental disabilities, recognize that all persons have value and should be able to develop to the fullest extent of their individual capacities. The Position Statements that follow represent the collective thought of all members of this Association and are presented as an evolving framework for present and future advocacy effort.

Table of Contents

Introduction.....	1
Advocacy.....	4
Advocacy at the End of Life.....	5
Aging.....	7
Autonomy - Decision Making Supports - Guardianship.....	9
Assistive Technology.....	12
Autism Spectrum Disorder.....	13
Behavioral and Medical Research	15
Care Coordination.....	18
Comprehensive and Integrated Health Care	19
Data and Transparency.....	20
Developmental Center Closure.....	22
Direct Support Professionals.....	23
Diversity, Equity, and Inclusion.....	25
Early Intervention.....	26
Education.....	28
Employment.....	31
Family Support.....	32
Inclusion and Community Participation.....	33
Justice & Fair Treatment Under Criminal Law.....	34
Managed Care.....	35
Medicaid.....	37
Medical Aid in Dying.....	39
Pandemic/Public Health Emergency Response.....	40
People with I/DD and Co-Occurring Mental Illness.....	42
Positive Behavioral Supports.....	44
Public and Media Recognition of Persons with Intellectual and Other Developmental Disabilities.....	45

Quality Improvement.....	46
Recreation, Leisure, and Social Engagement.....	47
Rights.....	48
Safety & Protection.....	50
Self-Advocacy Role in Leadership.....	51
Self-Determination.....	52
Sexuality.....	53
Specialized Treatment Units.....	55
Spirituality.....	56
Substance Abuse.....	57
Use of Medications.....	59
Where People Live.....	60
Individuals with Intellectual and Developmental Disabilities Who Have Been Convicted of a Sexual Offense.....	61

Advocacy

Advocacy is vital to ensuring the quality of life for people with intellectual and other developmental disabilities. Advocacy must take place at both the individual and system levels, including entities critical to the achievement of positive outcomes for people with intellectual and other developmental disabilities.

It is The Arc New York's position that:

- Individuals with intellectual and other developmental disabilities have the right to participate in decisions about their lives and advocate for public policy which provides the systems and supports they need to participate fully in society.
- All self-advocates must be supported, educated, and provided with the information and tools necessary for effective advocacy efforts.
- Families can be effective advocates for their family members. To be successful, they must have access to family support services, parent and sibling groups, information and referral, network and advocacy assistance and training.
- Any advocate must be knowledgeable about how to access protection under federal, state and local laws and regulations.
- Advocacy must be designed, adequately funded, staffed and implemented to ensure that services and supports are available to all individuals and their families who need them.
- Advocacy efforts include the following:
 - Training in rights and advocacy skills,
 - Information and counseling on how to solve problems, including:
 - Referral of individuals to service agencies,
 - Appropriate mediation where necessary, and
 - Collaborating with community partners within and outside of the state.
 - Taking legal and other action, including class action litigation, to assert the rights of an individual or group;
 - Initiating investigations as needed; and
 - Influencing public policy decisions through direct education and information sharing with elected officials and governmental regulatory and funding entities.

Adopted October 21, 2000 at NYSARC, Inc. Delegate Assembly

Adopted with Revisions October 16, 2004 at NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 27, 2006 at NYSARC, Inc. Delegate Assembly
Adopted with Amendments October 18, 2013 at NYSARC, Inc. Delegate Assembly
Adopted with Amendments October 17, 2014 at NYSARC, Inc. Delegate Assembly
Adopted with Amendments October 21, 2021 at The Arc New York Board of Governors Meeting

Advocacy at the End of Life

All persons with intellectual and other developmental disabilities are valuable and deserve respect consistent with human dignity throughout their life. The value of a person's life is not related to the type, degree, or severity of disability. Attitudes related to care at the end of life may vary based on clinical experience, medical practice, religious beliefs and an understanding of the legal rights of individuals with intellectual and other developmental disabilities.

It is The Arc New York's position that:

- All Chapters providing services must be knowledgeable and well-versed of all laws, regulations, statutes and policies that apply to end of life decisions.
- The end of life is defined as the last year of life, consistent with the current standard in the public health law. Individuals may be considered to be at the end of life when:
 - they have a terminal condition that is progressive, irreversible, or incurable such as late-stage Alzheimer disease or terminal cancer,
 - expected to cause death in less than one year or
 - they are permanently unconscious; and
 - treatment would impose an extraordinary burden, other than intellectual or developmental disability.
- Individuals are not at the end of life when they are living in a stable condition that requires significant life-sustaining treatment (such as a mechanical ventilator or a feeding tube) and wish to continue receiving such treatment.
- Discussions about care at the end of life should occur, if possible, prior to being at the end stage of life. These discussions should include statements about what care the person would like to receive if he or she were in one of the end of life conditions described above. Those who are closest to the person (ordinarily the family, legal guardian, trusted caregivers, nurses, friends, and others) are best

able to identify the person's preferences when the person is unable to express them directly.

- Legal or other professional assistance should be used to develop living wills, health care proxies, and other such statements about personal preferences. These statements should be updated periodically taking into account the individual's wishes, medical advances, technological improvements, and changing perspectives during one's lifespan.
- Withdrawing or withholding care may be appropriate in some situations, consistent with legal authority granted by New York State, but should not itself imply lack of respect for the importance of that person's life. Withholding or withdrawal of life-sustaining treatment (including nutrition and hydration) should be consistent with the current public health law noted above.
- The principles of informed consent, as contained in statute, require that decision-makers have:
 1. the legal authority to provide consent if the person does not have the capacity to provide consent,
 2. all of the information needed to make a decision;
 3. the ability to assess the information adequately; and
 4. freedom from undue influence by others. Guardians and healthcare proxy representatives must always seek to determine the uncoerced, authentic voice of the person with an intellectual or other developmental disability, and failing that, what is in the person's best interest, and provide all of the information the person needs to express his or her preferences.
- Instructional strategies and training materials should be developed that will assist individuals with intellectual and other developmental disabilities to access relevant information, analyze it effectively, and utilize it to assess options and make choices.
- Religion and spirituality of the person are important and must be respected. Their religious or spiritual preferences should be made identified or articulated by the individual or his or her loved ones. Spiritual or pastoral care should be provided when it is desired.
- Needed treatment should be available in the most appropriate context, taking into account the person's preferences and health care needs. People should not be required to live in a nursing home in order to receive care that could be provided in a more natural setting such as the person's home. Needed treatment

includes (but is not limited to) provision of home health care, nursing, medications, nutrition, hydration, and social interaction.

- Hospice care at the end of life shall be available when it is appropriate. Adequate pain relief is essential to alleviate and prevent suffering at the end of life.
- The wishes of persons who have clearly and competently expressed them should be honored by caregivers and health care providers.
- Persons who are “permanently unconscious” should only have treatment withheld or withdrawn in the event that such treatment is found, under the standards and processes of the surrogates’ court procedures act, to be an “extraordinary burden on such persons, in light of” the person’s condition and the expected outcome of the treatment, both exclusive of such person’s intellectual or developmental disability.
- The legally determined surrogate (parent, spouse, etc.) or court-appointed guardian is authorized to make treatment decisions when the person is not able to make these decisions directly in accordance with the Health Care Decisions Act for Persons with Mental Retardation and the Family Health Care Decisions Act.
- Prompt hospital ethics committee and/or judicial review is appropriate and necessary when application of this policy is unclear or in dispute among health care providers, family members, guardians, friends and other significant caregivers. All other avenues such as the use of internal Ethics Committee, Guardianship Committee or Surrogate Decision-Making Committee should be exhausted.

Adopted October 21, 2011 at the NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 19, 2012 at NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 22, 2016 at NYSARC, Inc. Delegate Assembly

Aging

For the first time in history, Americans living in the 21st century will experience millions of people with intellectual and developmental disabilities living into their senior years. These Americans want to enjoy their older years in the same manner as others their age and have a right to the same opportunities, including full access to community supports from those agencies that serve all older people. However, many community-based services for senior citizens are not prepared to meet the special needs of older adults with IDD. Likewise, many disability-focused organizations have not planned for the challenges faced by these individuals. The discrimination that

older people often experience in accessing community activities, housing, services and supports is experienced to a much greater extent by people with IDD as they age.

Advocacy for and on behalf of people with intellectual and other developmental disabilities spans a lifetime. It is critical that advocates ensure that resources are dedicated to providing older adults with IDD the means to remain and thrive with dignity and respect as a vital part of their community.

It is The Arc New York's position that:

As they age, people with IDD must have every opportunity to be recognized as respected members of the community. Community services and supports that are geared to older community members must accommodate the supports needed by those who have also experienced lifelong disabilities.

People with IDD who are aging should:

- Be afforded the same rights, dignity, respect and opportunities as other older people in their communities;
- Be empowered, together with their families if asked, to advocate for themselves and be free from discrimination on the basis of disability and/or aging;
- Have access to appropriate community-based social services, transportation, legal services, the full array of affordable housing services appropriate to their age and physical and mental condition, and the full array of health care services appropriate to their age and physical and mental condition, including preventive health care, ongoing habilitation and rehabilitation services for as long as they are needed, including appropriate end-of-life care;
- Receive the supports they need to live, work, play, and retire when, where, and how they prefer, including supports for family members who can assist them in the pursuit of a quality and self-determined aging experience;
- Be free from the fear of inappropriate institutionalization, elder abuse and neglect by family members, providers or community members;
- Have access to financial supports that will provide them with retirement opportunities like those that are available to other older persons

- Have the right to be supported by staff with appropriate training, skills and competencies necessary to support them through their life span
- Have the right to be supported by service providers who exercise moral and ethical responsibility as they advocate for appropriate, competent and caring services in the community throughout the individual's life span
- Have the respect of their supporting provider organization through clear policies, services and supports, physical space and resources to help prevent falls, functional decline and to improve their quality of life throughout their life span
- Have the right to be active participants in developing an individualized personal plan that guides the service provider, staff, family and advocates that reflects their personal life choices, including health, wellness, recreation, and end-of-life decisions

Adopted October 25, 2003 at the NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 27, 2006 at NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 19, 2007 at NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 15, 2010 at NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 24, 2015 at NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 27, 2023 at The Arc New York Board of Governors Meeting

Autonomy - Decision Making Supports - Guardianship

All individuals with intellectual and developmental disabilities (I/DD) have the right to be recognized as full 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 himself 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.

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 Arc New York 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.

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.^[1]

- 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.^[2]
- 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 ensured. 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.

Adopted October 22, 2016 at NYSARC, Inc. Delegate Assembly

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

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

Assistive Technology

Assistive technology, sometimes termed Supportive Technology, refers to devices and services that are used by children and adults with intellectual and other developmental disabilities throughout the country which can lead to increased choice over day and residential placements. These devices provide supports to promote an individual's independence, mobility, communication, environmental control, health and wellness, life skills management, employment skills, and choice. Assistive technology helps the individual with daily life functions and facilitates inclusion in the community. Assistive technology also includes evaluations, direct services and training that assists the individuals with selecting, acquiring or using such devices and the software applications which are most appropriate and available.

It is The Arc New York's position that:

- It endorses the Coleman Institute's Declaration on The Rights of People with Cognitive Disabilities to Technology and Information Access and encourages passage of this declaration in New York State;
- New York State should maximize technology where it can benefit the lives of the people we support;
- Assistive technology must be readily available and affordable throughout the life span of individuals with intellectual and other developmental disabilities;
- Assistive technology should seek to include upgraded versions which remain actively supported by their vendors so that people with intellectual and developmental disabilities can expand their knowledge, their educational opportunities, and lead an inclusive and integrated life;
- The term "assistive technology" should be considered to include everyday personal technology like smart phones and tablets, which are universally accepted in society, thereby lessening the stigmatization that may come from the use of more disability-specific and more costly traditional AT devices;
- Technological innovators, designers and manufacturers must be educated to the needs of individuals with intellectual and other developmental disabilities to ensure the design and development of useful products. The best method of this education process is to include people with intellectual and other disabilities in the identification of their needs and to include them in the design and testing of assistive technology devices;

- Much of the focus of traditional assistive technology has been applied to the sensory and motor needs of individuals. We now believe there needs to be new research done on developing assistive technologies that address the complexity of cognitive disabilities that prevent many individuals to be fully included in the daily activities of life in their community;
- People with intellectual and other developmental disabilities, their families, educators and support professionals must be educated about the benefits of assistive technology;
- Individuals knowledgeable about people with intellectual and other developmental disabilities and familiar with current technology must be also become well versed in person-centered approaches and practices, so that their technology assessments take into consideration the global lifestyle needs of the person to ensure the selection of the most appropriate and comprehensive technologies;
- Professionals in the field must be well informed of funding and resources for assistive technology. It is essential that information and assistance in how to acquire and sustain assistive technology be provided to persons with intellectual and other developmental disabilities and their families, especially through life milestones, as in the transition of an individual from school to adult systems, where the ensured portability and transferability of personal technology is critical. There should be relevant public policy for funding access to technology as well as training and support.

Adopted October 21, 2000 at NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 27, 2006 at NYSARC, Inc. Delegate Assembly

Adopted Friday, November 15, 2019 by The Arc New York Board of Governors

Autism Spectrum Disorder

Intellectual and other developmental disabilities is a general classification which includes the classification of Autism Spectrum Disorder (ASD). ASD is a general term used to describe a group of complex development brain disorders which cause significant, life-long social, communication and behavioral challenges. With the right services and supports, individuals diagnosed with ASD can lead full, healthy and meaningful lives. There is an urgent need to address concerns about access to services given that the need for services is rapidly increasing.

It is The Arc New York's position that:

- Individuals diagnosed with ASD are included in the general category of “Intellectual and Developmental Disabilities” and must be provided the same services such as early intervention, inclusionary education, housing, day services and employment opportunities equally in the way that is appropriate and accessible to their specific needs such as those typically provided to individuals who have intellectual and other disabilities.
- The rules, definitions and regulations under the New York State Education Laws, the Insurance Laws and Medicaid eligibility related to individuals diagnosed with ASD must provide eligibility and accessibility to such services.
- The education and service networks in New York State must be encouraged and supported to develop strong diagnostic resources to accurately identify those individuals with ASD and their needs for services, treatment and interventions.
- The Arc New York Chapters must establish demonstrated evidenced-based treatment interventions for these individuals, especially supports for appropriate behavioral interventions.
- People who have been diagnosed with ASD must be able to access the advocacy and protection services currently available to people who have other developmental disabilities.
- Research must be provided to study the diagnostic and treatment models which most effectively help individuals on the ASD.
- Programs and initiatives to support individuals with ASD must be adequately funded to meet the growing demand for appropriate supports and services.
- Supports and services created for individuals with ASD must be person-centered and address the unique needs of each individual.
- Educational and supportive services must be available to local law enforcement first responders to appropriately recognize and intervene with individuals with ASD when involved as a victim or alleged target of a criminal investigation.
- Individuals with I/DD should have access to identification cards issued by OPWDD which include their name, address and additional information – including diagnosis – which could help first responders interact with and communicate with people with ASD.

Adopted October 17, 2008 at NYSARC, Inc. Delegate Assembly

Adopted October 15, 2010 at NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 21, 2011 at NYSARC, Inc. Delegate Assembly
Adopted with Amendments October 24, 2015 at NYSARC, Inc. Delegate Assembly
Adopted Friday, November 15, 2019 at The Arc New York Board of Governors

Behavioral and Medical Research

Basic and applied research on the causes, challenges and treatment of intellectual and developmental disabilities, as well as research on interventions and services which could improve the lives of people with intellectual and/or developmental disabilities, must be adequately financed, well designed, focused on relevant topics, conducted with the highest ethical standards, presented in formats accessible to multiple audiences, and have a positive impact on people's lives.

Issue:

Between 1% and 3% of persons in the general population are estimated to have some degree of intellectual disability and/or developmental disability. The exact number of people affected by intellectual and/or developmental disabilities is unknown, because individuals with intellectual and/or developmental disabilities cover a wide range of conditions, many of which are diagnosed several years after birth.

A variety of government agencies are responsible for undertaking vital research and data collection activities regarding the impact of disability and to improve the quality of life for children and adults with intellectual and/or development disabilities. Government and private funding is insufficient to support the broad research agenda that includes issues most important to people with intellectual and/or developmental disabilities and their families. Through basic and applied research, scientists and researchers can learn about causes of intellectual and/or developmental disabilities, address its preventable causes, improve the quality of life of people with intellectual and/or developmental disabilities and their families, and address policy and service-delivery enhancements. Researchers can identify the most promising educational, social and clinical interventions that help people live meaningful lives.

Historically, most people with intellectual and/or developmental disabilities and their families have not had input into the design, methodology, dissemination, use, and evaluation of research. Moreover, most research results have not been presented in ways which are accessible, understandable and useful for multiple audiences, including people with intellectual and/or developmental disabilities and their families.

While clinicians play an essential role in the evaluation, treatment of associated medical conditions and preventive care, and in facilitating and coordinating consultative services and community-based care, their awareness of the latest research findings and standards of integrated care vary, often leaving it to families to advocate and become the point of integration for their loved one. In addition, recent studies unknown to many (including clinicians), and in particular the availability of agnostic techniques such as genome-wide association studies, have identified new variants in a variety of genes which contribute to the risk of individuals with intellectual and/or developmental disabilities.

Advances in medical and behavioral science and research that relates to intellectual and/or developmental disabilities can be of great interest and benefit to individuals, their families, guardians and services providers. In turn, science & research organizations can benefit from broad awareness of these individuals and their families, however these organizations often have limited knowledge of or connection to these individuals and their families and vice versa.

It is the position of The Arc New York that:

- Government and private entities must provide adequate funding to support research on individuals with intellectual and/or developmental disabilities;
- The Research priorities set by funding sources, public policy setting bodies, and academic and professional associations must reflect the research needs and interests of people with intellectual and other developmental disabilities;
- Advances in medical/behavioral research which can provide for an earlier diagnosis (and potential treatment) of individuals with intellectual and/or developmental disabilities and/or the associated symptoms will allow for early intervention and better clinical management, thus improving the quality of life of the individuals and their families;
- In addition to causation and prevention research, priorities must promote and encourage basic and applied studies that focus on and help to enhance the quality of life for people with intellectual and other developmental disabilities;
- In parallel policies, practices and supports for people with intellectual and/or developmental disabilities must keep pace with developing knowledge. Promote translation of research findings into practice;

- Data based studies using relevant criteria, must be used to assess the effectiveness of a program or service in achieving its desired outcomes, and/or to compare the relative effectiveness of alternative programs or services;
- The Research must identify and support practical applications to address the daily needs of people with intellectual and other developmental disabilities and their families. Researchers must also consider the cultural, ethnic, racial, geographical and other differences that affect people's access to and ability to benefit from programs and services designed to serve them;
- Disability status should be incorporated in federally funded research;
- Advocacy, services providers and professional organizations, government agencies, the research community, and people with intellectual and/or developmental disabilities and their families must work together in defining, evaluating, and promoting a research agenda;
- Research on emerging interventions within properly regulated clinical trials and ensure must ensure that people with IDD are not excluded from benefitting from effective healthcare, and that those who can give informed consent are not categorically excluded;
- Results of research must be available in multiple formats, easily accessible and understandable for a wide audience, including people with intellectual and/or developmental disabilities and their families;
- Stringent scientific and ethical standards must be enforced to safeguard individual dignity, protect confidentiality, ensure efficient and effective use of research funds, and prevent exploitation or harm of people with intellectual and/or developmental disabilities and members of their families;
- For all basic and applied research involving persons with intellectual and/or developmental disabilities:
 - Specific procedures must be implemented to ensure full voluntary, informed, initial, and ongoing agreement and consent to participate
 - All research must be conducted by qualified researchers, in adequately monitored settings and reviewed for potential risk and benefit by qualified, competent scientific review boards

- Persons with intellectual and/or developmental disabilities should not be excluded from research that might benefit them as members of the general population
- Entities involved in conducting and financing basic and applied research should ensure that policies and standards with specific guidelines and safeguards are in effect to protect persons with intellectual and/or developmental disabilities and their families
- The ethical use of data and computerized forms of analytical computations must be overseen and guaranteed by federal, state, educational, and other entities involved with research

The Arc New York is committed to identifying and promoting research-based best practices, setting high standards for direct services and measuring outcomes.

Adopted January 19, 2023 at The Arc New York's Board of Governors Meeting

Revised and adopted October 27, 2023 at The Arc New York's Board of Governors Meeting

(note: revised statement combines former position on Research)

Care Coordination

People with intellectual and other developmental disabilities must have access to services and resources that are available to all other citizens. Identifying, obtaining and coordinating these services and resources to meet the entire range of personal needs and preferences necessary to assure quality of life in the community can be challenging.

It is The Arc New York's position that:

- Such services and resources should be available to individuals and their families through an organized process.
- Such services should address the needs and wishes of the individual and their family or guardian through a person-centered needs assessment interview process.
- Care Coordinators must be competent, sensitive and committed to representing the interests, preferences and visions of the individual and their family or guardian and assist them in making informed decisions.

- Care Coordinators need initial and ongoing training and supervision to ensure knowledge of all appropriate program and opportunity choices available to individuals and their families. Care Coordinators should identify and facilitate formal (day hab) and informal (family) supports as well as be aware of other options more suitable for an individual rather than the existing programs including schools.
- Care Coordinators should exercise confidentiality and neutrality and seek out services identified using all providers available in the community.
- Adequate funding must be available to support care coordination that is of high quality, and responsive to meeting the positive quality outcomes of the individual served. As a foundation for any future transition to managed care for people with I/DD, resources must be sufficiently allocated to ensure successful outcomes.

Adopted October 19, 2002 at NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 27, 2006 at NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 17, 2008 at NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 21, 2011 at NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 17, 2014 at NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 21, 2021 at The Arc New York Board of Governors Meeting

Comprehensive and Integrated Health Care

People with intellectual and other developmental disabilities have the right to comprehensive, appropriate, timely, affordable, and accessible medical, dental and habilitative services throughout their lives. Comprehensive health care must be provided, regardless of a person's ability to pay.

It is The Arc New York's position that:

- **Comprehensive Health Care must:**
 - Include quality primary care, specialty medical care, dental care, oral health, clinical, behavioral health, and habilitative services based on the person's medical and developmental diagnosis;
 - Preserve and/or improve the person's physical or psychological health and overall well-being;
 - Include care coordination that will integrate comprehensive health care services, enhance health care outcomes, and avoid duplication of services, which may reduce costs;
 - Be available, accessible, affordable and timely;

- Be provided only with the informed consent of the person receiving services, legal guardian, surrogate decision making committee or, any other legally authorized person.
- **The Health Care Decision Maker must:**
 - Have the legal capacity to give consent;
 - Be given sufficient information to understand the benefits and risks of the proposed treatment;
 - Be offered the opportunity to ask questions and receive complete answers in a manner understandable to the decision maker;
 - Never be forced to accept or reject a particular treatment through deceit, threat or for reasons that relate to the convenience of the provider.
 - Be selected by the person receiving services as a collaborative partner to the fullest extent possible.
- Properly obtained and documented advance directives must be honored for persons with intellectual and other developmental disabilities;
- Public policy must guarantee that health insurance coverage for persons with intellectual and other developmental disabilities is comprehensive in scope covering all physical and behavioral health issues, has a competitive rate structure with flexibility that allows for integrated service delivery, covering all health and health related services, equal in every respect to that afforded to the general population;
- In the delivery of health care services to people with intellectual and other developmental disabilities, providers and caregivers must educate the medical community on research based best practices;
- Direct Service Providers who accompany people with intellectual and other developmental disabilities in health care settings should receive training in how to effectively navigate those encounters;

Adopted October 20, 2001 at the NYSARC, Inc. Delegate Assembly as Medical/Dental Treatment

Adopted October 24, 2015 at the NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 27, 2023 at The Arc New York Board of Governors Meeting

Data and Transparency

Data collected by New York state agencies such as DOH, OMH, OPWDD, and the NYS Comptroller can offer insights into the I/DD population in myriad ways. This

Information is vital for understanding who is seeking access to services, what supports they seek, and how long they might wait to achieve their stated goals. Additionally, this information can provide a metric for tracking the efficacy of policies, particularly when it comes to residential placements.

True transparency accomplishes two goals. First, it maintains access to the information collected on a continual basis from providers, people, and other front-facing organizations and, second, it builds trust among all parties as long as the information distributed is accurately and fairly presented.

New York state offers many platforms for data access, but they do not fully illuminate the data of people with I/DD and in ways that are easily accessible.

It is the Position of The Arc New York that:

- OPWDD must, on a rolling basis, collect and share data on the full waitlist, which they maintain for emergency, substantial, current, and other residential supports
- Data must be accessible to people and stakeholders in a way that offers:
 - Insight into the need
 - Demographics of the current population being supported
 - The ways people are being supported
- Results and analysis of survey data that OPWDD collects from service providers must be shared with the providers in a timely fashion
- Costs associated with state operations must be accessible to people and stakeholders transparently and proactively
- OPWDD must partner with providers in the design of data definitions and collection methods wherever possible to maximize provider participation and the effectiveness of the survey process

Adopted October 13, 2022 at The Arc New York's (NYSARC, Inc) Board of Governors Meeting

¹ <https://health.data.ny.gov/>

¹ <https://omh.ny.gov/omhweb/statistics/>

¹ <https://opwdd.ny.gov/data>

¹ <https://www.osc.state.ny.us/>

Developmental Center Closure

Community-based residential and day programs have been essential in ensuring people with intellectual and other developmental disabilities their rightful place in society. The Arc New York continues to support closure of all Developmental Centers and the development of appropriate community-based services to accomplish that goal.

Individuals with intellectual and other developmental disabilities living in Developmental Centers can be fully integrated into community settings with appropriate training and support.

It is The Arc New York's position that:

- Developmental Center closure efforts must continue to move forward;
- Developmental Center closures must be in accordance with principles pertaining to person-centered placement;
- Downsizing must continue as responsibly and appropriate as possible;
- Providers must be guaranteed the financial resources to provide the proper training, and supports for individuals to successfully transition in to community settings;
- Closure plans must ensure that appropriate supports are developed for persons with special needs;
- Developmental Centers must never again become an accepted way of life.

Adopted October 19, 2002 at NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 19, 2007 at NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 15, 2010 at NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 24, 2015 at NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 27, 2023 at The Arc New York Board of Governors Meeting

Direct Support Professionals

A stable workforce of caring, competent, creative, well compensated, and qualified Direct Support Professionals is essential to providing safe, high quality and effective supports and services for people with intellectual and other developmental disabilities. Simply stated, DSPs are incredibly talented professionals who form the foundation of all The Arc New York provides. We cannot do what we do without them.

Provider agencies have consistently high vacancy rates for direct care staff. In addition, the National Core Indicators showed that Direct Support Professionals have a high turnover rate. Without a robust and stable workforce we are not able to consistently meet the high standards that people receiving services in our care deserve.

A lack of sound data compounds the problem. Federal agencies use data collected through the Bureau of Labor Statistics Standard Occupational Classification system to analyze workforce trends, but this system does not provide an accurate picture of current Direct Support Professional workforce challenges. This system classifies Direct Support Professionals under the broader category of “home health care aide,” which includes all home health care occupations. As a result, it is impossible to accurately track and report workforce trends for Direct Support Professionals, often resulting in the underreporting of workforce needs and regional workforce shortages.

It is The Arc New York’s position that:

- A living wage and benefits sufficient for economic security are vital in order to attract and retain a qualified workforce to fully support people with intellectual and other developmental disabilities;
- All Direct Support Professionals (DSP) deserve competitive pay and equivalent pay for the same work across the industry;
- New York State Department of Labor (DOL) and the federal Bureau of Labor Statistics (BLS) must revise the Standard Occupational Classification system to establish a separate code for Direct Support Professionals, ensuring better data on these pressing workforce challenges;
- Relevant funding sources must support provider agencies in delivering high quality, certificate based training which covers the essential knowledge, ethical principles and practices, and skills necessary for effective direct care support;

- Training must ensure that Direct Support Professionals be educated in the philosophy and values that persons with intellectual and other developmental disabilities are members of the community and should have every opportunity for choice and control over their lives;
- Providers must foster the professional and personal development of Direct Support Professionals by providing access to continuing education, training, genuine career roadmaps, and professional advancement opportunities;
- Continuation, expansion, and funding of professional certification programs must be supported and funded by local, state, and federal policy makers and agencies;
- National, state and local private and public entities must engage in policy initiatives that facilitate employment placement and offer financial supports as needed to increase the number of people employed in direct support work;
- Implement a statewide BOCES High School Program to introduce the direct support profession to new potential workforce candidates as has been done for Nurse Assistants, Home Health Aides and Personal Care Aides;
- Strong regional relationships with 2 and 4 year colleges and universities, BOCES, high schools and civic association agencies should be cultivated to develop a solid pipeline for DSP recruitment and professional development;
- Staff assignments of Direct Support Professionals must be thoroughly evaluated in order to minimize unnecessary transfers and prevent the resulting disruption of the continuity of service to persons with intellectual and other developmental disabilities;
- A work environment must be provided that will foster optimum employee satisfaction;
- We monitor factors contributing to DSPs' working environment including availability in their communities of public transportation, child and elder care, health care, and affordable housing;
- We maintain awareness of competitive forces in the labor market including trends in employee benefits (e.g., sick time, personal time off, health care and retirement) and minimum wage.

Adopted October 25, 2003 at NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 19, 2007 at NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 15, 2010 at NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 18, 2013 at NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 21, 2021 at The Arc New York Board of Governors Meeting

Adopted with Amendments October 27, 2023 at The Arc New York Board of Governors Meeting

Diversity, Equity, and Inclusion

Our mission to provide supports and advocate in every manner possible for people who have intellectual and other developmental disabilities is best fulfilled when we embrace diversity, equity and inclusion as a value and a practice throughout The Arc New York. The value of diversity, equity and inclusion extends beyond the people we support to their families, our employees, our leadership, our management and our governing bodies. The Arc New York will make it part of its mission to take appropriate measures and actions to move positively towards achieving diversity, equity and inclusion in all that we are and do.

It is The Arc New York's position that:

- We must foster a diverse, equitable and inclusive environment that is responsive to the interests, and needs of the diversity of people who reside in New York. This may include but is not limited to race, ethnicity, national origin, religion, age, marital status, sexual orientation, gender identity and expression, disability, language spoken or method of communication;
- No person should be defined by a single attribute or characteristic, but rather by the sum or combination/ intersection of their unique qualities and life experiences;
- Every effort will be made to incorporate culturally and linguistically competent policies, structures, and practices in all components of the organization (e.g. supports, programs, operational structure, leadership, staff, and governance);
- Individualized supports require the capacity to respond to cultural diversity. This may include but is not limited to race, ethnicity, national origin, religion, age, marital status, sexual orientation, gender identity and expression, disability, language spoken or method of communication;
- Culturally and linguistically competent (the ability to understand difference across cultures and languages) approaches, procedures, and assessments are used to determine supports and services;

- We respect, value, and celebrate the unique attributes, characteristics, backgrounds and perspectives of all our members and recognize that historically marginalized viewpoints enrich the entire organization;
- We are committed to expand the cultural competence of leadership and staff with regard to difference in cultures, languages, and other methods of communication.

Adopted October 27, 2023 at The Arc New York Board of Governors Meeting

Early Intervention

Early childhood, including the prenatal period, is a critical time for brain and organ development. Early intervention identifies and provides effective early support to young children who are at risk of poor outcomes. Effective early intervention works to address diagnoses of IDD and implement evidence based interventions as appropriate. Early interventions not only give children the best start possible, but also the best chance of developing to their full potential. Intervention is likely to be more effective when it is provided earlier in life rather than later. Though intellectual and development disabilities are life long, children can still make progress and thrive.

Education, research and advocacy reduces the incidence and limits the consequences of intellectual and other developmental disabilities. Every person has the right to grow and develop in nurturing environments that are free from abuse and neglect, free from disease and safe from injury regardless of their social or economic status.

It is The Arc New York’s position that early intervention efforts must include:

- Prenatal, perinatal and postnatal care, including frequent physical/developmental checks and adequate nutrition, as well as available and accessible support services, including genetic testing and counseling to high-risk populations;
- Education on the risks of exposing the fetus to X-rays, smoking, alcohol and drugs, prescription and non-prescription medications, and sexually transmissible diseases;
- Immunization against contagious diseases prior to pregnancy;
- Access to primary medical, dental and mental health services during pregnancy;

- Access to services for all infants and toddlers who need help, regardless of family income. Services should not be denied to a child just because his or her family is not able to pay for them;
- A concerted effort to provide services in home and community environments to the maximum extent possible for the child;
- Mandatory newborn screening programs done within a time frame that guarantees accurate results and treatment for metabolic disorders such as phenylketonuria, galactosemia and hypothyroidism;
- Advocating for public policies that improve public health and foster education, research and advocacy, reducing the incidence and limits the consequences of intellectual and other developmental disabilities;
- The prevention of childhood injuries resulting in intellectual and other developmental disabilities, including mandatory use of seat belts, safety seats and helmets;
- Removal of contaminants, which are known contributors to intellectual and other developmental disabilities;
- Enforcement of existing public policy designed to prevent intellectual and other developmental disabilities;
- Recognition of the importance of prevention and the responsibility to take a proactive role in educating the public about the known causes of intellectual and other developmental disabilities and ways in which they may be prevented;
- Advocacy to ensure that families in which one or both parents have an intellectual and other developmental disability receive all of the supports and services necessary;
- Infants and toddlers, birth through age three years, must have access to early intervention services administered and funded through the NYS Department of Health, for evaluation, eligibility determination, and if found eligible, appropriate intervention services to improve child and family development.

Adopted October 21, 2000 at NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 16, 2004 NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 21, 2011 at NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 24, 2015 at NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 27, 2023 at The Arc New York Board of Governors Meeting (note: revised position replaces former statement on Prevention)

Education

The most significant law pertaining to education for students with disabilities is the Individuals with Disabilities Education Act (IDEA)¹, which requires a free appropriate public education (FAPE), appropriate evaluation, an individualized education plan, least restrictive environment, parent participation, and procedural safeguards.

Students and children with intellectual and other developmental disabilities must be educated with appropriate supports and services in the least restrictive environment with free and appropriate services, which address their individual needs. However, these educational institutions have historically and inequitably been underfunded, which has caused teachers to be underpaid for their contributions and making it difficult to retain these valuable and critical educators.

Education is a life-long process for people with intellectual and other developmental disabilities (I/DD). Educational systems and programs must value all students and their families and include them in all aspects of education. Students with I/DD face significant additional challenges including baseline study skills, ability to self-advocate, and inadequate academic preparation due to lacking financial support for teachers and specialized educational institutions. The following guiding principles will significantly and positively enhance the education of individuals with intellectual and other developmental disabilities as well as all other individuals.

It is The Arc New York's position that:

- The legal rights of students with intellectual and other developmental disabilities are protected and enhanced when educational systems comply fully with the spirit and intent of the IDEA and State Education Department regulations;
- Students with intellectual and other developmental disabilities must be educated with appropriate supports and services in the least restrictive environment;
- State and federal governments must conduct effective monitoring of IDEA. Technical assistance and, when necessary, sanctions are used by federal and state governments to ensure compliance by state and local education agencies;
- Appropriate resources must be made available so that with proper supports students with intellectual and other developmental disabilities have the opportunity to be educated in the most person-centered way;

- Parents and families must be supported as essential partners in the education and transition to adult life of their children;
- School districts, parents, and families should work together to ensure that we are holding all children with disabilities to high standards and providing access to challenging academic content and achievement standards;
- Restraints, seclusion and isolation are not acceptable substitutes for positive behavioral supports for students who experience challenging behaviors, partnerships with Behavioral Health support should instead be advocated for the student;
- Ensure safe school environments, which provide mental health supports and protection against bullying;
- Assure that school personnel provide timely explanations that are understandable and use functional descriptive language for special education and related services being proposed for the student;
- Children with intellectual and other developmental disabilities (including Early Intervention 0-3, Preschool 3-5) must be provided, from birth, with free and appropriate services, which address their individual needs in natural and least restrictive environments;
- The efficacy of preschool intervention to enhance the lives of children with disabilities has been repeatedly confirmed by studies¹. Preschools are facing a deteriorating situation, threatening preschool closings and systemic collapse. Despite rising costs, preschools have not received a funding growth that meets the current need and pays teachers an equal wage with public schools;
- Special education 853/4410 schools need predictable and consistent growth factors, tuition rate increases, and other fiscal support to bring reimbursement in line with the cost of operations;
- The federal government, New York state and county governments must provide adequate and sustainable funding so that New York's most at-risk children are provided a chance for a life of independence and fulfillment;
- Individuals with intellectual and other developmental disabilities and their families must have access to advocacy support and services. Families must receive training and guidance from local, regional and statewide advocacy networks to become effective advocates for children within the educational system;

¹ <https://live-penn-impact.pantheon.io/wp-content/uploads/2016/2015/06/Why-Invest-High-Return-on-Investment.pdf>

- Schools and providers must give parents of children in transition (from early intervention to preschool to school age to post-secondary) information and the necessary supports to ensure a timely, seamless transition;
- There is a significant shortage of certified special education teachers and related personnel such as physical therapists, speech and language therapists, Occupational therapists, classroom aides and assistants. Special education programs must be fully funded by the federal government and New York state to correct these shortages;
- Students with intellectual and other developmental disabilities and their parents or guardians must be part of the ongoing decision-making process regarding educational placement and programming;
- The Arc New York Chapters must form strong partnerships with local school systems and other governmental agencies to provide an appropriate person-centered transition to the next phase of life for students who are graduating from special education programs;
- The general education curriculum must include age appropriate history, understanding, acceptance and contributions of people with disabilities throughout the K-12 grades;
- People with intellectual and other developmental disabilities have a right to lifelong learning including academic and personal enrichment classes;
- As adults, people should be encouraged to pursue educational and vocational opportunities including, but not limited to:
 - post-secondary programs;
 - non-credit and for-credit courses online;
 - fully integrated competitive or other employment;
- Individuals who choose these educational options have a right to appropriate supports.

Adopted October 25, 2003 at NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 27, 2006 at NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 19, 2007 at NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 15, 2010 at NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 21, 2011 at NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 24, 2015 at NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 27, 2023 at The Arc New York Board of Governors Meeting

Employment

People with intellectual and other developmental disabilities can and should be productively employed in their communities. Supports must be provided to assist with making informed choices about opportunities to utilize each person's talents and skills.

It is The Arc New York's position that Employment:

- Is a natural support of the lifelong process of human maturity and self-determination;
- Includes a full professional assessment of job, technical supports, and social skills development;
- Includes the opportunity for the person to participate in a comprehensive plan for learning and structuring employment and career exploration;
- Is natural when it is fully included and supported in community settings;
- Is successful when individualized supports include appropriate transportation, travel training, job coaching, service coordination, child care and necessary technology sufficiently adapted to accommodate the each person's needs throughout their lifetime;
- Is developed through knowledgeable partnerships with education, business and government to provide meaningful training opportunities from school age through adulthood in a variety of work settings with natural supports;
- Is responsive to person-centered choice and goals when a full range of options are offered including internships, a full range of fully included and inclusionary supported environments, competitive employment, volunteer positions, agency owned businesses and micro-enterprises (self-owned businesses);
- Recognizes each person's contributions and value with compensation which reflects a market driven wage for the work;
- Be responsive to individual choice and goals when the options include continued and ongoing exploration, educational opportunities and new work situations to encourage career development;

Adopted October 21, 2000 at NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 16, 2004 at NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 27, 2006 at NYSARC, Inc. Delegate Assembly
Adopted with Amendments October 19, 2007 at NYSARC, Inc. Delegate Assembly
Adopted with Amendments October 15, 2010 at NYSARC, Inc. Delegate Assembly
Adopted with Amendments October 24, 2015 at NYSARC, Inc. Delegate Assembly
Adopted with Amendments October 27, 2023 at The Arc New York Board of Governors Meeting

Family Support

The Arc New York believes that the ability of families to attain a desirable lifestyle for themselves and their family member with intellectual and other developmental disabilities should be maintained and continually strengthened.

It is The Arc New York's position that:

- We strive to address unmet needs on every level in whatever way is most effective.
- When properly resourced, the family is usually the best source of support for an individual with intellectual and other developmental disabilities. No family or caregiver should be under strain or duress as they strive to provide for the basic needs of their loved ones.
- Family opinions, concerns and interest must always be listened to and be included in service planning and in every facet of the individual's life.
- In addition to family, other supports and services must be available throughout the life of the individual. In some instances, appropriate support for the family of an individual with I/DD may be some level of residential placement (e.g., respite care, summer camp, supportive apartment, or group home). As individuals and their families age, residential resources take on increasing importance.
- A full array of supports and services must be available and maintained. The Arc NY encourages innovative methods for supports and services, which must be proven and well-established prior to replacing existing services.
- The support necessary for the individual should be determined by the individual and the family when appropriate and not in conflict with the individual's wishes.
- Families must be provided with sufficient information to make informed decisions and to advocate for services that will best meet the needs of their family member.

- These supports must assist families in the promotion of inclusion of children and adults with intellectual and other developmental disabilities in every aspect of their life in the community.
- A community-based support network of interested citizens and family members should be encouraged as part of the community that helps facilitate access to community resources.
- Advocates for local, state and national policy must be family centered and reflect the principles and goals of person-centered and self-determination strategies in all of their advocacy efforts.

Adopted October 19, 2002 at NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 19, 2007 at NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 18, 2013 at NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 27, 2017 at The Arc New York Board of Governors Meeting

Adopted with Amendments October 21, 2021 at The Arc New York Board of Governors Meeting

Inclusion and Community Participation

Extraordinary changes have occurred in the lives of people with intellectual and other developmental disabilities since the founding of The Arc New York in 1949. Prior to that people lived in institutions and/or homes that segregated them from society. They were often denied the opportunity to enrich their daily lives through mainstream involvement in the community. At the same time, the rest of the community was equally cut off and denied the opportunity to enrich their own lives through knowing and being in relationship with these people. The full presence and inclusion of people with intellectual and other developmental disabilities enriches the entire community.

Disability inclusion means understanding the relationship between the way people function and how they participate in society, making sure everyone has the same opportunities to participate in every aspect of life to the best of their abilities, and desires. Community inclusion encompasses: housing, employment, friends, education, health and wellness, religion and spirituality, family, and intimacy.

It is the Position of The Arc New York that:

- People with intellectual and other developmental disabilities are our family members and friends in the community. Community inclusion cannot be dependent on “community education.” The more that people with intellectual and other developmental disabilities are present and participating as citizens in their community, the fuller it becomes for everyone.
- An inclusive community must be provided which allows opportunities for people with intellectual and other developmental disabilities and their families to have choices in where they live and in all aspects of community life. Public as well as private resources must be readily available to them.
- People with intellectual and other developmental disabilities need access to all aspects of community life. The supports to access their choices need to change as the person’s life changes
- Children and adults with intellectual and other developmental disabilities must have the right to access and be supported in recreation, lifelong learning, work, healthcare, sports, social, cultural, and spiritual activities.
- Adults with intellectual and other developmental disabilities must have the right to engage in relationships that range from friendships to choice of life partners.

Adopted October 25, 2003 at NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 27, 2006 at NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 19, 2007 at NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 21, 2011 at NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 13, 2022 at The Arc New York Board of Governors Meeting

Justice & Fair Treatment Under Criminal Law

The Constitution and Bill of Rights protect and guarantee fair treatment in the criminal justice system to all individuals, including those with intellectual and other developmental disabilities.

It is The Arc New York’s position that:

- Fair treatment requires consideration of all aspects of the individual and his or her circumstances, including the presence of intellectual and other developmental disabilities.
- It is essential that defense lawyers, prosecutors, judges, court personnel, forensic evaluators, law enforcement personnel, victim assistance providers and criminal justice policy makers be informed about intellectual and other developmental disabilities as they affect the behavior of an individual, in order to ensure fair treatment.
- Advocates who understand intellectual and other developmental disabilities and the criminal justice system must be made available to confer with individuals with intellectual and other developmental disabilities prior to and during questioning by law enforcement personnel.
- The local chapter, The Arc New York and The Arc are the preferred sources of information on issues relating to people with intellectual and other developmental disabilities for the purpose of education, training and support with the criminal justice system and related personnel.
- The criminal court system must recognize that the presence of intellectual and other developmental disabilities does not necessarily affect the credibility of a witness if the necessary and appropriate supports are provided.
- Sentencing, treatment, habilitation or other services for individuals with intellectual and other developmental disabilities must take the disability into consideration.
- Opportunity for treatment or services shall not be denied to people with intellectual and other developmental disabilities, solely on the basis of criminal charge or background.
- The presence of intellectual and other developmental disabilities may raise issues of miscommunication, misinformation and a challenge to providing an adequate defense to the extent that imposition of the death penalty is unacceptable.
- We acknowledge that in 2004, the death penalty was declared unconstitutional by the New York Court of Appeals. We are ever watchful of any changes that might occur and stand in solidarity with individuals with intellectual and developmental disabilities who may be subject to the death penalty in other states and territories.

- When an individual has been court ordered to the custody of the Office for Persons with Developmental Disabilities, the individual must be provided with appropriate clinical treatment and opportunities for re-introduction into society.

Adopted October 21, 2000 at NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 16, 2004 at NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 21, 2011 at NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 21, 2021 at The Arc New York Board of Governors Meeting

Managed Care

Managed care may provide states and the federal government with the opportunity to reduce healthcare expenditures and better manage utilization, while improving quality and outcomes. Understanding what New York state intends to achieve by transitioning people with intellectual and other development disabilities to managed care is key to informing design decisions. Meaningful stakeholder engagement and education are vital for the program success.

The overarching goal for people with intellectual and other developmental disabilities supported in a managed care system must be quality driven and person/family centered. The supports offered must be integrated and coordinated, blending needed medical services with habilitation services in all life domains, without barriers for opportunity or access. Managed care payment models must provide sufficient resources and flexibility to both the person and the larger population, and must also allocate adequate administration payments to providers.

Regardless of the service delivery/payment strategy developed, a seamless “no wrong door” philosophy and practice, coupled with person-centered outcome measures aimed at enhancing quality of life, must be actionable in every life domain.

It is the Position of The Arc New York that managed care will best serve the health and habilitation needs of people with I/DD when:

- There are meaningful opportunities for stakeholder feedback during the design phase of the program.
- Care management roles are clearly defined

- Funding for the implementation and operation of managed care cannot come from the operating budgets of providers delivering supports and services to people with intellectual and other developmental disabilities or from the existing resources of the OPWDD system. Any attempt to do so would exacerbate the financial crisis faced by all voluntary providers already facing hardship.
- I/DD providers receive dedicated training and communication resources before, during, and after transition to managed care.
- Educational materials and notices relating to the transition to managed care are written in a way that people with I/DD and their families can easily understand, so as to ensure people understand what is changing, what is staying the same, that they have choices and rights, how to exercise their rights, and where to go for help.
- Once managed care is operational, ongoing engagement is key to ensuring Managed Care Organizations (MCOs) are complying with program standards delivering on the promise of managed care.
- Services and supports are delivered in a quality manner that maximizes personal wellbeing.
- Protections, health and safety, and rights are addressed in the determination of supports offered.
- Financial constraints are not the prevailing factor driving the system.
- Quality metrics are meaningful and reflect the unique needs of the I/DD population, including personal outcome measures, and need to reflect long-term care, as well as acute healthcare needs of people with intellectual and other developmental disabilities.
- No one is denied access to needed supports and services and everyone receives them in a timely fashion.
- Services and supports are offered and coordinated within the person's community.
- MCOs have significant expertise in serving the I/DD population and their needs
- Provider networks account for longstanding relationships between members and their providers.
- State oversight of MCOs is strong in order to ensure continued access to services and compliance with consumer and provider protections.

- The payer agencies and the agencies delivering supports, work together for the common good of the person being supported.
- Independent Ombudsman programs are in place to ensure that enrollees can both navigate the system and have continued access to the services they need.

Adopted October 18, 2013 at NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 17, 2014 at NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 14, 2022 at The Arc New York Board of Governors Meeting

Adopted with Amendments October 13, 2022 at The Arc New York Board of Governors Meeting

Medicaid

Since the late 1970's, the Federal/State Medicaid program has ensured that, nationally, at least 2 million people with intellectual and other developmental disabilities have access to health care and/or long-term services and supports.

Since 2010, federal and state policymakers have critically examined and curtailed Medicaid funding, resulting in compromising desired individual goals and quality of life for people with developmental disabilities. We must continue to educate and advocate with key decision makers at the state and federal level to ensure that Medicaid remains responsive to the critical needs of people with intellectual and other developmental disabilities.

It is The Arc New York's position that to address the present and emerging needs of people with intellectual and other developmental disabilities:

- The New York State Medicaid program should assist people with intellectual and other developmental disabilities to live full lives in the community, experience a high quality of life, and achieve economic security and personal independence to the extent possible for the individual;
- People with intellectual and other developmental disabilities are entitled to a full range of Medicaid-financed health care and long-term services across their lifespan;

- Families should not be required to impoverish themselves, use personal funds, nor be required to keep an individual at home to receive the essential health and social supports the individual needs to live;
- Services should be received with reasonable promptness and with sufficient quality and quantity to meet their individual needs;
- Funding should prioritize the least restrictive alternatives possible for each person;
- Medicaid must afford individuals and families opportunities to design and direct their own services to the extent that they wish and with the assistance they need;
- Services should be portable across all geo-political jurisdictions;
- Any effort to change or otherwise reform the Medicaid program must take into account the impact of such change upon individuals with intellectual and other developmental disabilities, in order to prevent unintended harmful consequences;
- The quality and effectiveness of health and long-term services and supports for persons with intellectual and other developmental disabilities depends upon qualified service providers with necessary skills and training. Federal and state responsibility for service quality, therefore, should include assuring sufficient recruitment, retention, and training of, as well as appropriate pay for, the personnel who provide needed services and supports;
- Medicaid-based provider reimbursement systems must provide for fiscal sustainability for organizations. This would include enough funding to give sufficient compensation for staff, but minimally a living wage and competitive fringe benefits;
- There must be timely reimbursement for all actual and reasonable costs;
- Medicaid-based provider reimbursement systems for the non-profit sector should be funded at an adequate level that provides the providers the flexibility necessary to navigate business requirements yet provide quality programs, support and services;
- Medicaid reform should address having flexibility in how wait lists are accessed and managed, the quality of service of providers and staff, and increased availability of quality health care services for individuals with intellectual and other developmental disabilities;

Adopted by the Arc of the United States, August 4, 2008.

Adopted October 23, 2009 at the NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 17, 2014 at NYSARC, Inc. Delegate Assembly

*Adopted Friday, November 15, 2019 at The Arc New York Board of Governors
Adopted with Amendments October 27, 2023 at The Arc New York Board of Governors
Meeting*

Medical Aid in Dying

Individuals with intellectual and developmental disabilities are, first and foremost, citizens, and are entitled to all the fundamental rights, both explicit and implied, that are guaranteed and enjoyed by all people under federal and state laws. Therefore, The Arc New York asserts that any rights included in any laws legalizing medical aid in dying should be guaranteed to people with intellectual and developmental disabilities.

It is The Arc New York's position that:

Mentally competent adults capable of making decisions for themselves who are dying of a terminal illness (typically 6 months or less to live) should have the option to obtain a prescription from their physician for medication if end-of-life suffering becomes unbearable so they can bring about a peaceful death.

- Additional protections must be in place for individuals with intellectual and developmental disabilities, beyond requiring two physicians to sign off and a mental health referral if mental capacity is in doubt.
- Prior to providing a prescription medication, physicians should be required to confirm that terminally ill, mentally competent adults are fully informed about all end-of-life options, including comfort care, hospice care, pain control, and medical aid in dying.
- Giving mentally competent, terminally ill adults the choice to end their own life is the same as allowing competent, terminally ill adults the choice to decline other treatments, like CPR, intubation, and artificial nutrition.
- The wishes of mentally competent adults who have clearly and competently expressed them should be honored by caregivers and health care providers.
- All persons with intellectual and developmental disabilities are valuable and deserve respect consistent with human dignity throughout their life. The value of a person's life is not related to the type, degree, or severity of disability.
- The personal autonomy, liberty, freedom, and dignity of each individual with intellectual and developmental disabilities must be respected and supported.

Pandemic/Public Health Emergency Response

People with intellectual and other developmental disabilities must be recognized as a priority during all public health emergencies (PHE), especially epidemics and pandemics. People with I/DD have the right to the availability of medical care and treatment, as well as essential and required supplies, including first tier access for vaccinations and pharmaceuticals.

As a practical example of this issue, the COVID-19 pandemic presented significant challenges for people with I/DD and providers of supports and services. The lacking accessibility to appropriate medical care and severely limited supplies exacerbated the fear of many that COVID-19 posed a graver threat to this vulnerable population. This fear was well-founded.

In New York state, people with I/DD living in residential group homes were nearly four times as likely to contract COVID-19 and twice as likely to die.² Another study took into consideration the national impact of those with I/DD across various residential models and found that people with I/DD were potentially six times more likely die from the virus as compared to the general population.³⁴

These studies illuminate some of the unique health uncertainties and access to care faced by people with I/DD upon the onset of a PHE. However, disruption to the continuum of supports and services also contribute to other negative health outcomes, such as the upending of progress towards greater community integration. This can affect numerous aspects of their lives, including but not limited to their employment via state-funded employment support, private employment, volunteering, day services, and other activities of their choosing that are vitally necessary.

It is the Position of The Arc New York that:

² S.D. Landes, J.M. Finan and M.A. Turk, COVID-19 mortality burden and comorbidity patterns among decedents with and without intellectual and developmental disability in the US, *Disability and Health Journal* <https://doi.org/10.1016/j.dhjo.2022.101376>

³ <https://www.aamc.org/news-insights/terrible-toll-covid-19-people-intellectual-disabilities>

⁴ <https://catalyst.nejm.org/doi/full/10.1056/CAT.21.0051>

- People with intellectual and other developmental disabilities must not be overlooked and be a priority to policy makers at all levels of government. It must be recognized that people with I/DD are more likely to have preexisting conditions, co-morbidities, and are more apt to live in congregate settings such as group homes, which places them at a higher risk of infection
- OPWDD must seek out and create service delivery, billing, and hiring flexibilities upon declaration of a PHE, which must be inclusive of but not limited to remote service delivery options for day, vocational and employment, including prevocational services.
- Telehealth services for all medical diagnoses is essential, especially for mental health care. This ensures that no person is without access to care, regardless of where care is administered
- Direct Support Professionals and all other staff working for provider organizations who support people with I/DD, must be immediately designated as essential workers alongside other frontline healthcare workers. This must include all hazard pay and additional benefits provided to essential healthcare workers in recognition of the work they do during a pandemic or similar PHE
- Local, state, and federal governments, medical practitioners, and facilities must provide and support full, equal, and priority access to medical care including vaccines, boosters and advanced treatment
- Providers of supports and services must ensure that all staff have the proper training, access to supplies, and competence to work during a pandemic or public health emergency
- OPWDD and NYS DOH must provide regular access to up-to-date data relating to the impacts of a PHE on people with I/DD, staff, and families to all stakeholders
- Monitoring the short- and long-term effects on people with I/DD throughout and following a pandemic or similar PHEs will assist future preparation response and prevention of negative health outcomes

Adopted October 13, 2022 at The Arc New York's (NYSARC, Inc) Board of Governors Meeting

People with I/DD and Co-Occurring Mental Illness

The response to support and service needs of all people with I/DD and co-occurring mental illness (MI), also known as dual diagnosis, is of deep concern. New York state I/DD and mental health (MH) authorities, responsible for funding and monitoring vital services are uneven in how they fund and support the service needs of people. At times, publicly funded programs are hard pressed to provide the levels of assistance, therapy, primary care, long-term medical oversight and individualized supports that people with these co-occurring conditions need to live, work, and lead lives in the community.⁵

According to a National Core Indicators data brief, almost half of people with I/DD meet the criteria for dual diagnosis.⁶ Despite the prevalence of mental health needs among people with I/DD, little is known about the best approaches for supporting the needs of people with I/DD and co-occurring mental health challenges and their families. This uncertainty has led to the dependence on outdated and potentially poor approaches to mental health care, such as seclusion, restraint, and psychotropics. Given the lack of support resources and services available for people and their families,⁷ the use of the aforementioned options may cause people with dual diagnosis to increasingly struggle with poor mental health.

Some people with dual diagnosis are not able to access the treatment they need because they are effectively excluded from inpatient services. People have been turned away from inpatient treatment because the facilities opined that people were not able to benefit from psychiatric treatment. People, finally admitted after prolonged periods of suffering, were able to benefit from treatment, establish a psychiatric regime that was effective, and go on to live their lives in a safer and happier fashion.

OPWDD and OMH have worked to develop specialized, multi-disciplinary, inpatient psychiatric units for children ages 5 to 21 who are dually diagnosed and the expansion of Crisis Services for Individuals with Intellectual and Developmental Disabilities (CSIDD). While these units have proven to be successful in transitioning children with psychiatric support needs into their communities, gaps exist for the adult population with similar support needs.

⁵ <http://thenadd.org/wp-content/uploads/2013/10/NADD-Position-Statement-on-Letterhead.pdf>

⁶ https://www.nationalcoreindicators.org/upload/core-indicators/NCI_DualDiagnosisBrief_Oct072019.pdf

⁷ <http://thearc.org/wp-content/uploads/2019/11/Training-Needs-of-Professionals-who-Serve-People-with-I-DD-and-Mental-Health-Needs-and-their-Families.pdf>

It is the Position of The Arc New York that:

- Appropriate funding and attention to comprehensive supports and services provides the most person-centered and cost-effective way of supporting this substantial population.
- Comprehensive training and education for staff, clinicians, first responders, and all professionals who support people with I/DD in the community is needed to support people with complex needs.
- Greater access must be provided to CSIDD and specialized, multi-disciplinary, inpatient psychiatric units and crisis services for people of all ages with dual diagnosis.
- The state must designate an existing psychiatric hospital as a regional center for excellence, equipped with advanced training in dual diagnosis and necessary telecommunication tools for consultation purposes.
- Alternative services must be readily available to providers who have exhausted all other options in their due diligence to meet the needs of people with highly complex needs and for the safety of other people and staff
- The state must support the 988 Suicide and Crisis Lifeline through continued and adequate state funding and training focused on the support of people with I/DD and dual diagnosis.
- Comprehensive instruction across all medical professions and in every setting must include awareness on how to address the needs of people with a dual diagnosis, particularly during medical emergencies.

Adopted October 13, 2022 at The Arc New York's (NYSARC, Inc) Board of Governors Meeting

Positive Behavioral Supports

People with intellectual and other developmental disabilities enjoy the most satisfying and productive lives under conditions which promote and reward positive social relationships and emotional wellbeing. When challenging behaviors occur that prevent any person from enjoying a satisfying and productive life, the supports provided shall be individualized and respectful of the person. Supports and services must be developed in collaboration with the person and the support network in a respectful and sensitive manner. Positive behavioral supports and interventions is a framework for assisting staff in adopting and organizing evidence-based behavioral interventions which enhances social behavior outcomes while increasing and maintaining positive relationships with others.

It is the Position of The Arc New York that:

- Every person has the right to compassionate and effective behavioral supports for managing challenging behaviors through the use of positive reinforcement.
- Challenging behaviors may be caused by medical, psychological, communications and/or environmental difficulties. All efforts must be made to understand the etiology of the behavior and appropriate ways to ameliorate the cause.
- Challenging behaviors can be reduced or eliminated when accurate, comprehensive information is collected, analyzed and used for planning prior to initiating a plan. Properly applied positive techniques can influence long-term behavior change and eliminate the use of physical interventions.
- Treatment, management and prevention of challenging behaviors is the responsibility of all support providers and must be overseen by qualified professionals who are certified and/or experienced in proven methods, such as applied behavior analysis.
- The use of any kind of intervention by staff that restricts a person's personal rights must be reviewed on a regular basis by the Human Rights Committee.
- The person must be engaged in activities that encourage choice and successful experiences. Supports must focus on providing valued and valuable activities which counteract boredom, coercion and lessen the restriction of freedoms.
- Ongoing training for staff and families in effective and positive methods for managing challenging behaviors is an important part of providing a supportive environment and long-term changes for the person.
- Supports and services must be provided in a manner that maximizes access and participation in the full range of opportunities available in the home, school and community.
- Total organization commitment requires an investment in staff training to develop specific competencies which promote person centeredness and positive practices.

Adopted on October 16, 2004 at the NYSARC, Inc. Delegate Assembly.

Adopted with Amendments on October 19, 2007 at the NYSARC, Inc. Delegate Assembly

Adopted with Amendments on October 23, 2009 at the NYSARC, Inc. Delegate Assembly

Adopted with Amendments on October 21, 2011 at the NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 17, 2014 at NYSARC, Inc. Delegate Assembly

Adopted with Amendments January 19, 2023 at The Arc New York Board of Governors Meeting

Public and Media Recognition of Persons with Intellectual and Other Developmental Disabilities

People with intellectual and other developmental disabilities are fully participating members of society and their community. Recognizing a person with I/DD is equally as valuable as any other member of the community that has made an important contribution.

It is the Position of The Arc New York that every effort must be made to:

- Promote and support people with intellectual and other developmental disabilities to speak, advocate and represent themselves publicly.
- Promote and encourage the presentation of stories with positive and meaningful news that recognize the accomplishments of people with intellectual and other developmental disabilities.
- Seek to identify, correct and/or eliminate the use of terms which are pejorative and can devalue people, including any version of words which are historical, dated or arcane, such as “retarded or mentally retarded”.
- Support and promote the development and presentation of educational curricula across all grade levels in New York state schools, which explains the history and accomplishments of people and systems in the field of disabilities.
- Use any and all public means and forms of media to promote persons with intellectual and other developmental disabilities in a manner which celebrates and reinforces their talents, skills and value as productive members of our communities.
- Serve as an example, through a Chapter commitment, to employ and recognize people with intellectual and other developmental disabilities in valued employment and leadership roles.

Adopted October 21, 2000 at NYSARC, Inc. Delegate Assembly

Revision Adopted October 16, 2004 at NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 27, 2006 at NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 21, 2011 at NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 17, 2014 at NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 13, 2022 at The Arc New York Board of Governors Meeting

Quality Improvement

High quality standards must be reflected throughout the full continuum of services and supports for people with intellectual and other developmental disabilities and within the work environment of the people who support them. Quality is reflected in high levels of personal satisfaction with life situations and *evidenced by measurable outcomes and a continuous improvement process*. Person-centered service planning and delivery, community inclusion, protection, and safety are an essential part of The Arc New York's core values.

It is the Position of The Arc New York that quality supports and services can be enhanced when the following occur:

- Quality is defined by the person and their support network.
- The person, their family, and their support network, drive the design of the supports and ensure that these supports are available in the person's home community.
- Providers respect the rights, dignity and privacy of people and provide supports in the least restrictive manner.
- People and their support network have the ability to explore options and make informed decisions.
- Supports are person-centered and reflect an integrated process regardless of the person's diagnosis and build upon the person's strengths and talents in a positive manner.
- Appropriate levels of resources are offered to the person, to include quality staffing and a broad array of supports, in a timely fashion.
- Providers of supports and services must be in compliance with all regulatory authorities.

Adopted October 21, 2000 at NYSARC, Inc. Delegate Assembly

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

Adopted with Amendments October 17, 2008 at NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 19, 2012 at NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 17, 2014 at NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 13, 2022 at The Arc New York Board of Governors Meeting

Recreation, Leisure, and Social Engagement

Participation by people with intellectual and other developmental disabilities in the same leisure, recreational and social activities that are offered to all citizens in their communities is an essential aspect of their quality of life. Recreational and leisure activities facilitate the development of community connections and can have significant benefits to physical and emotional health and well-being.

It is The Arc New York’s position that:

- Access to recreational and leisure activities appropriate to one’s interest and age level is a necessity and has the same level of importance for resource allocation as education, employment and living arrangements;
- Integrated leisure, recreational and social activities are an essential and legitimate component of a good quality of life for persons with intellectual and other developmental disabilities;
- Local communities and school districts have a responsibility to ensure that parks, playgrounds, recreational facilities and other outdoor recreational areas are accessible to people with intellectual and other developmental disabilities;
- Support must be provided and if needed, assistive technology, should be used to increase participation in inclusive recreation and leisure activities;
- Information and education must be provided to people with intellectual and developmental disabilities and their families to ensure they are aware of the opportunities and benefits of inclusive recreation and leisure activity.

Adopted October 21, 2000 at NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 24, 2015 at NYSARC Inc. Delegate Assembly

Adopted with Amendments October 27, 2023 at The Arc New York Board of Governors Meeting

¹ <https://sites.ed.gov/idea/>

Rights

Individuals with intellectual and other developmental disabilities are first and foremost citizens and as such are entitled to all of the fundamental rights, both explicit and implied, that are guaranteed to, and enjoyed by all people under the Constitution of the United States. They have the right to opportunities that enable

them to make choices for themselves and to exert a measure of control over their physical and social environment, without regard to race, gender, sexual orientation, national origin or incarceration. It should be recognized that they may need some accommodations and supports to enable them to exercise these rights and inherent responsibilities.

It is The Arc New York's position that fundamental rights include but not be limited to the right:

- To choose a place to live to do productive work, engage in leisure time activities, and to worship.
- To acquire and maintain adequate financial resources for independent living.
- To marry and have children.
- To full information and access to appropriate childcare and parenting skills while the decision to have children is being considered and access to ongoing supports and services once the decision to become a parent has been made.
- To receive appropriate education and training, rehabilitation, guidance, and counseling.
- To access all governmental programs in concert with all people.
- To receive individualized services and technologies designed to meet specific needs and help ensure optimal functioning.
- To receive appropriate, affordable and accessible wellness services, medical, dental and mental health care.
- To enhance quality of life through respite care, personal assistance, specialized training, individualized family assistance, retirement and old age planning.
- To be free from discrimination and the right to receive fair and equal treatment in the criminal justice system.
- To vote in fully accessible polling places.
- To protection and advocacy services during all stages of life.
- To be protected through the application of federal, state and/or local protection laws and regulations, from decisions or lack thereof, made by parents or guardians or service providers when the individual's life, health, safety or general well-being are compromised.
- To membership, employment and leadership in The Arc New York, Inc.
- To any and all other rights enjoyed by all citizens.

Adopted October 21, 2000 at NYSARC, Inc. Delegate Assembly

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

Adopted with Amendments October 19, 2002 at NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 16, 2004 at NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 17, 2008 at NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 19, 2012 at NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 22, 2016 at NYSARC, Inc. Delegate Assembly

Safety & Protection

People with intellectual and other developmental disabilities have the same rights and basic safety and protection needs as others. At the same time, they face numerous additional barriers, including protection risks, heightened risk of violence, exploitation and abuse by the general public, service providers, and even their families.⁸ People with disabilities are not a homogenous group and safety plans must address the unique needs of each person. Those plans must include protection from harm and injury throughout their lives, while also being provided with the tools and supports necessary to protect themselves.

It is the Position of The Arc New York that:

- A supportive network of family, friends, and advocates of people with I/DD and other disabilities are oftentimes the first line of protection from harm. However, if for any reason the above groups are the cause of harm, or unable and/or unwilling to provide the necessary protections, the appropriate protective agencies, support, and advocacy groups must be accessible and available to ensure that local, state, and federal laws are adequately enforced.
- People with intellectual and other developmental disabilities must be given the opportunity to learn to live safely in their community, protect themselves, and be able to seek appropriate assistance.
- Safety and fire drills must be designed with sensitivity to people's unique needs and capabilities, particularly when activities occur unexpectedly and quickly.

⁸http://www.thearc.org/wp-content/uploads/forchapters/NCCJD%20White%20Paper%20%231%20Violence%20Abuse%20Bullying_5.pdf

Drills must be planned with sufficient frequency to be realistic and without the possibility for “opting-out.”

- In accordance with OPWDD regulations and Mental Hygiene Law, parents and/or guardians must be informed of any investigation of abuse and neglect as required and be provided a statement of the final disposition of the investigation.
- Providers of supports and services must:
 - Screen all applicants to eliminate those with a history of perpetrating abuse, neglect, or a criminal record and evaluate all employees in accordance with NYS regulations, including those regarding the Justice Center, OPWDD and NYS Education Department, on a regular basis to ensure appropriate job performance
 - Ensure that appropriate safety and emergency management plans are in place, and that all staff have the associated training and competence to work effectively and appropriately with people with intellectual and other developmental disabilities.
 - Train staff to report allegations of abuse and neglect directly to the Justice Center to ensure the proper procedures are followed to address the allegations.
 - Immediately investigate allegations of abuse or neglect and take immediate corrective action when warranted
 - Take steps to limit access to Personally Identifiable Information (PII) and Protected Health Information (PHI), acknowledging the potentially grave consequences imposed by breaches and a person’s right to privacy. Access must be on a need-to-know basis and safeguards must include use of administrative, physical, and technical means

Adopted October 25, 2003 at NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 27, 2006 at NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 17, 2008 NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 21, 2011 at NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 17, 2014 at NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 13, 2022 at The Arc New York Board of Governors Meeting

Self-Advocacy Role in Leadership

People with intellectual and other developmental disabilities have the right to participate in decisions about their lives and advocate for public policy that provides the systems and supports they need to participate fully in society.

It is The Arc New York's position that this requires that people with intellectual and other developmental disabilities have the following opportunities and rights:

- To receive training and/or mentoring so they may participate fully and meaningfully on boards, committees, taskforces and other decision-making bodies that provide oversight and resource allocation in support of their lives.
- To be selected and/or elected to boards, committees and task forces of local organizations that serve support their lives, including The Arc New York Chapter Boards, Committees and Task Forces.
- To organize a chapter-level self-advocacy initiative, which informs the board and administration about quality of services and lives of their peers in the organization.
- To provide input into The Arc New York management, planning and decision making, including representation on The Arc New York Board of Governors, Committees and Task Forces.
- To receive financial and other supports from service providers and other advocacy organizations to participate in local chapter boards, local and statewide self-advocacy groups, governmental and statewide public policy organizations and national groups they choose and/or are elected to represent themselves and their peers.
- To have a partnership among people who receive supports, and administrators and agency personnel to reduce barriers to independence and individualization for people with disabilities.
- To have a partnership among people who receive supports, and administrators and agency personnel to educate the community and others regarding the importance of self-advocacy in our society.

Adopted October 19, 2007 at NYSARC, Inc. Delegate Assembly

Adopted October 23, 2009 at the NYSARC. Delegate Assembly

Adopted with Amendments October 19, 2012 NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 12, 2016 at NYSARC Inc. Delegate Assembly

Self-Determination

People with intellectual and other developmental disabilities can improve the quality of their lives by having control and responsibility for themselves. Inherent in this is the need to take prudent risks that result in personal growth. The nature and extent of that risk must be evaluated and shared with people with intellectual and other developmental disabilities when planning their activities and goals.

It is The Arc New York's position that people with intellectual and other developmental disabilities must:

- Have access to environments where they will be treated with dignity and respect and will also have opportunities to express preferences and have those preferences honored.
- Have sincere and active acknowledgment of their dreams and desires and have opportunities to pursue those dreams and desires in their lives.
- Have opportunities to acquire and develop meaningful skills and confidence that enable them to ensure the highest degree of control of their lives and environments.
- Have a wide range of experiences to help them understand their community so that they may make informed and individualized decisions.
- Have necessary supports, which will enable persons to develop, maintain, and further meaningful relationships, including personal friendships.
- Have opportunities to make informed choices regarding their use of personal financial resources, their acquisition of desired services and their choice of supports.
- Have access to assistive technology, personal assistance, and necessary supports to promote optimal communication and have unlimited opportunities for independence.
- Have appropriate training, accommodation, and support so that they may become active members of groups, clubs and organizations, including The Arc New York.

Adopted October 21, 2000 at NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 16, 2004 at NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 23, 2009 at the NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 19, 2012 at NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 22, 2016 at NYSARC, Inc. Delegate Assembly

Sexuality

People with intellectual and other developmental disabilities have inherent sexual feelings, needs and identities which must be affirmed, defended and respected. Sexuality must be acknowledged as part of the total context of human relationships. Informed consent in sexual expression protects the rights and dignity of the person. The presence of intellectual and other developmental disabilities regardless of severity, must not in itself, deny a person his or her right to sexual expression, justify involuntary sterilization, or cause denial of sterilization to those who choose it for themselves.

It is the Position of The Arc New York that:

- Disability has nothing to do with a person's ability to love and be loved. Every person must have the opportunity to be in a loving and consensual relationship if they so choose.
- The presence of an intellectual or developmental disability, regardless of severity, does not, in itself, justify loss of rights related to sexuality. Every person has the right to exercise choices regarding sexual expression and social relationships. Informed consent in sexual expression protects the rights and dignity of the person.
- With respect to sexuality, people have a right to:
 - Sexual expression of their choosing
 - Individualized education and information to encourage informed decision-making. Education may include issues such as reproduction, marriage and family life, abstinence, safer sexual practices, sexual orientation, sexual abuse, gender identity, and sexually transmitted diseases. The education must be reflective of the person's cultural, religious and moral values and of social responsibility.
 - Education must be provided by persons who demonstrate a positive attitude towards the expression of sexuality in people who have I/DD, and who are trained to provide information in a non-judgmental manner. Such personnel must be willing and trained to offer accurate and unbiased information related to human sexuality.

- Protection from sexual harassment and from physical, sexual, and emotional abuse
- All people have the right within interpersonal relationships to:
 - Develop friendships and emotional and sexual relationships where they can love and be loved, and begin and end a relationship as they choose
 - Dignity and respect
 - Privacy, confidentiality, and freedom of association
- With respect to the potential for having and raising children, people with intellectual or developmental disabilities have the right to:
 - Education and information about having and raising children that is individualized to reflect each person's unique ability to understand.
 - Make their own decisions related to having and raising children with supports as necessary.
 - Make their own decisions related to using birth control methods within the context of their personal or religious beliefs.
 - Have control over their own bodies
 - Be protected from sterilization solely because of their disability

Adopted by The Arc of the United States, August 4, 2008.

Adopted October 23, 2009 at the NYSARC, Inc. Delegate Assembly.

Adopted with Amendments October 19, 2012 at NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 22, 2016 at NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 13, 2022 at The Arc New York Board of Governors Meeting

Specialized Treatment Units

The Arc New York recognizes that a number of people who have intellectual and other developmental disabilities have been identified as having criminal, high risk and unacceptable behaviors. These individuals are not able to remain at home with their families and may require a more secure, highly structured environment as an alternative to the prison system.

It is The Arc New York's position that:

- OPWDD must address the ever-increasing needs of this growing population by providing proper financial and environmental supports.
- OPWDD must ensure properly trained clinical personnel to provide intensive therapeutic treatment.
- Proper planning with input from family and/or advocates must occur for all placements.
- The civil and legal rights of all persons with intellectual and other developmental disabilities must not be compromised because of the need for specialized environments.
- Legal rights and the right to due process should not be abridged when placement or referrals to specialized treatment units are made.
- OPWDD needs to develop a clear and consistent process for an emergency treatment/crisis intervention response.
- Exclusion and segregation from community must never be the norm; return to community living, where possible, must remain the goal.
- The state shall remain the provider of last resort.
- When an individual has been assessed and determined appropriate for movement to a less restrictive community setting, it is imperative that necessary supports and resources are in place prior to returning to a community setting.

Adopted October 19, 2002 at NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 23, 2009 at the NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 19, 2012 at NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 21, 2021 at The Arc New York Board of Governors Meeting

Spirituality

People with intellectual and other developmental disabilities have the right to choose their own expressions of spirituality, to practice those beliefs and expressions, and to participate in the religious community or other spiritual activities of their choice. The person also has a right to choose not to participate in religious or spiritual activity.

It is The Arc New York's position that:

- Spirituality is an important part of human experience that may be expressed both through religious practice and through expressions of personal meaning and values. Thus, spirituality and religious preference should be part of all assessments of individual and family needs, interests, and strengths.
- Spirituality, spiritual growth, and religious expression that respect a person's history, tradition, and current preference or choice are rights that should be honored by service systems and religious communities, as should the choice not to participate.
- The desires and interest of individuals and their families must be accommodated when assisting individuals to participate in spiritual activities of their choice including reading of religious material, playing religious music, and consideration for special dietary needs of individuals due to religious affiliations.
- Protections must be provided to assure that individuals are free from undue influence, proselytizing, direction or coercion to participate in any spiritual activity, religious group or sect.
- Faith communities should receive assistance from provider agencies and advocacy organizations to build their capacity to support and welcome people with intellectual and other developmental disabilities and their families.
- Advocates must collaborate with local congregations to assure the availability of a wide variety of spiritual opportunities, including both integrated and specialized community services, social activities of congregations, at-home services and specialized on-site services.
- Funerals and memorial services on behalf of the deceased in provider agencies are encouraged and should be in accordance with the individual's religious preference, whether clearly expressed or assumed by their regular attendance at a particular faith community. Memorial Services are also encouraged for the spiritual health of the deceased's friends, family and staff.

Adopted October 23, 2009 at the NYSARC, Inc. Delegate Assembly.

Adopted with Amendments October 19, 2012 at NYSARC, Inc. Delegate Assembly Adopted with Amendments October 22, 2016 at NYSARC, Inc. Delegate Assembly

Substance Abuse

An increasing number of people with intellectual and other developmental disabilities are becoming addicted to alcohol and other substances. Due to cognitive disabilities and other factors, some members of this population are not prepared to fully comprehend the harmful effects of such substances on their emotional and physical health, nor the addictive properties of these substances or the legal and social consequences of their use. Substance abuse often causes behavior that is disruptive to families and the community and may result in unwelcome confrontations with law enforcement personnel. When arrested and sentenced to jail or ordered to receive treatment in traditional substance abuse programs, persons with intellectual and other developmental disabilities often receive either no treatment or treatment inappropriate to their level of functioning. As a result, a return to substance use with all of its devastating consequences is likely upon re-entry into the community.

It is The Arc New York's position that:

- Education on the nature and effects of the use of alcohol and illegal drugs should be required to be presented to persons with intellectual and other developmental disabilities in middle school or at a comparable grade and developmental level. Education should be tailored to the cognitive and other abilities of people with intellectual and other developmental disabilities and should be repeated annually as part of students' IEP until their education is completed.
- Education should include the targeted strategies to help individuals with intellectual and other developmental disabilities to recognize and manage risks associated with environments and individuals likely to involve them in substance abuse behaviors.
- Professionals and direct service personnel working with people with intellectual and other developmental disabilities should be trained to recognize the behavior associated with substance abuse and to address the problem with evidence-based strategies specific to this population.
- Treatment should be made available to individuals with intellectual and developmental disabilities commensurate to the general population who experience substance abuse.
- If traditional programs are used, treatment should be in collaboration with providers who are experienced and skilled in working with persons with intellectual and other developmental disabilities. Treatment should also afford the individual with opportunities to engage in peer mentoring programs

commensurate with their developmental capacity. Specialized substance abuse treatment programs may need to be developed to treat individuals with intellectual and other developmental disabilities.

- Parents and significant others should be involved in the treatment process, including appropriate support programs such as Al-Anon (a support group for families of people with chemical dependencies.)

Adopted October 16, 2004 at NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 23, 2009 at the NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 19, 2012 at NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 22, 2016 at NYSARC, Inc. Delegate Assembly

Use of Medications

Prescription and non-prescription medications may be used to assist people with intellectual and other developmental disabilities to experience a full and rewarding life. The prescribing of medications should be considered a serious matter and guided by principles that assure the safety of the individual and attainment of a desired state that will allow a full and valued life.

It is The Arc New York's position that:

- Medications may be considered only after any other non-pharmaceutical measures have been exhausted in the control or remediation of the target behavior or medical situation.
- Medication should not be assumed to be a permanent solution.
- Medications must be prescribed only by licensed, qualified medical professionals who are familiar with the individual.
- The person with intellectual and other developmental disabilities must be included in discussions and decisions regarding the use of pharmaceutical treatment for a manifest or an underlying psychiatric condition and/or medical situation.
- Before medication is started, the individual, if capable, and/or parent or individual legally authorized to give consent, must be consulted and give consent, as appropriate, and be clearly informed about any prescribed pharmaceutical treatment, expected positive results and possible side effects.

- Medication regimens and prescriptions must be reviewed on a regular basis. Continuation of such medication regimens and prescriptions is to be determined by the physician in consultation with the individual with intellectual and other developmental disabilities, and/or family, staff, and advocates.
- The person with intellectual and other developmental disabilities must be given every opportunity to receive training to qualify for “self-medication” status.
- In cases where the person with intellectual and other developmental disabilities does not qualify for “self-medication” status, every assurance must be made to provide proper oversight by a knowledgeable individual certified in medication use and distribution.

Adopted October 27, 2006 at NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 23, 2009 at the NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 19, 2012 at NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 22, 2016 at NYSARC, Inc. Delegate Assembly

Where People Live

All people with intellectual and other developmental disabilities have the right to live in the communities of their choosing and be fully included with people who do not have intellectual or other developmental disabilities. The right to rent or own their home represents a basic foundational aspect of their independence and inclusion in the community.

It is The Arc New York's position that:

- Adults should control where and with whom they will live, with increasing affordable opportunities to rent or buy their own homes.
- Individuals with intellectual and other developmental disabilities have the right to be integrated in their communities.
- Necessary individualized supports, adaptations and choices regarding living arrangements should be of their choosing and under their control or the control of their surrogate.
- Children belong with their families. When this is not possible, a family environment that provides love, safety and security must be provided.

- The health and safety of individuals must be safeguarded wherever they live.
- Fully funded and high-quality, individualized supports and services, including appropriate accommodations, must be available to meet the needs of the individual.
- Funding for supports and services must follow people with intellectual and other developmental disabilities and not be tied to a facility or a location.
- The individual with intellectual and other developmental disabilities, and family members when necessary, must have the choice of working with a range of provider agencies to help find the appropriate residence for their family member.
- People with intellectual and other developmental disabilities who choose to live at home with their families have the right to receive the necessary supports and services, including ready access to high quality medical and psychiatric care as needed.

Adopted October 21, 2000 at NYSARC, Inc. Delegate Assembly

Revisions Adopted October 16, 2004 at NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 27, 2006 at NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 23, 2009 at the NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 19, 2012 at NYSARC, Inc. Delegate Assembly

Adopted with Amendments October 22, 2016 at NYSARC, Inc. Delegate Assembly

Individuals with Intellectual and Developmental Disabilities Who Have Been Convicted of a Sexual Offense

The provision of services and supports for individuals with intellectual and developmental disabilities (I/DD) who have been convicted of a sexual offense is a complex issue. Solutions must balance the rights and safety and security of the individual, other individuals receiving support and the community-at-large.

Every individual with I/DD is, first and foremost, a citizen who is entitled to all of the fundamental rights, both explicit and implied, that are guaranteed to and enjoyed by all individuals under federal and state constitutions, laws and regulations. This is true when a person with an intellectual and developmental disability is a convicted sexual offender as well.

One of the goals of working with an individual with I/DD who has been convicted of a sexual offense should be the provision of supervision, professional treatment and supports necessary to reduce the risk of future sexual offenses. Comprehensive evaluations must be conducted on an individual basis to ensure appropriate linkages to services with agencies that have the requisite capacity and experience.

It is The Arc New York's position that:

- Individuals with I/DD should be free from discrimination and have the right to receive fair and equal treatment under state and federal laws and regulations in the criminal justice system. Fair treatment requires consideration of all aspects of the individual and his or her circumstances including the presence of intellectual and developmental disabilities. It is essential that defense lawyers, prosecutors, judges, court personnel, forensic evaluators, law enforcement personnel, victim assistance organizations and criminal justice policy makers be aware of the needs of an individual with I/DD and how that disability may affect the behavior of the individual in order to ensure fair treatment.
- With available and appropriate supervision, supports, accommodations, treatment and education, individuals with I/DD, including those who have been convicted of committing sexual offenses, should be better able to lead lives as contributing members of their communities. In addition, supervision of these appropriate supports and services helps ensure the safety and wellbeing of other individuals, including those with I/DD.
- Individuals with I/DD who have been convicted of committing sexual offenses require supervision and treatment that focuses on addressing mental health, developmental and behavioral issues.
- Not every organization that provides supports and services to people with I/DD has the expertise and resources necessary to safely and effectively support individuals who have been convicted of committing a sexual offense. Similarly, not every organization is equipped to protect the safety of other individuals receiving support, as well as the general public, if asked to serve a person who may have been convicted of committing a sexual offense.
- An organization must have the opportunity to assess the individual with I/DD who has been convicted of committing a sexual offense to determine whether this individual can be supported safely and effectively in an environment with other vulnerable individuals. No organizations should be pressured to support or penalized for refusing to support a person who has been convicted of committing

a sexual offense when the organization feels it cannot reasonably and responsibly support such a person.

- When an organization is able and willing to provide services to a person who has been convicted of committing a sexual offense, the following guidelines must apply:
 - Each individual with I/DD who has been convicted of a sexual offense must be assessed on an individual basis to develop a comprehensive individualized plan.
 - Individuals, including individuals who have been convicted of committing a sexual offense, should be provided with services and supports that relate to and, where possible, support an increase in their capacity and ability to express themselves sexually in a way that is respectful of self and others; receive appropriate sex education; provided with assistance in overcoming difficulties in processing the concepts of consent; support and assist with exercising healthy expressions of sexuality; and receive education and counseling to assist in understanding the nature and consequences of their actions.
 - A Risk Assessment Plan (RAP) must be created and regularly reviewed for each individual which provides a framework for all of the supports, services and expected duration of services provided by professional and para-professional staff.
 - The RAP must be designed to increase the individual's responsibility and skill and behavioral acquisition while providing for the safety and wellbeing of the individual and others served.
 - Organizations which are capable and willing to serve individuals with I/DD who have been convicted of committing a sexual offense must ensure that all staff have the proper initial and ongoing training and competence to work effectively and implement the goals and objectives of the RAP.
 - Organizations must be provided with the appropriate financial resources to support the higher needs generally associated with providing services to individuals who have been convicted of committing a sexual offense.

Adopted by The Arc New York Board of Governors May 4, 2019

¹ <https://sites.ed.gov/idea/>