

About NYSARC, Inc.

In 1949, NYSARC, Inc. (formerly the New York State Association for Retarded Children, Inc.) was formed by parents who were determined to change forever society's traditional disregard for the needs of their children.

The establishment of the Association marked a turning point for all citizens with mental retardation and their families in the United States. As a parent-based organization dedicated to action on behalf of their children, the Association became a unique and effective organizational model which has been duplicated across the nation.

In the years to follow, the Association grew rapidly as a service provider and as the leading advocacy organization in the State. Its founders and leaders were responsible for landmark legislation that secured the rights and dignity of people with intellectual and other developmental disabilities which is the birthright of every other citizen.

NYSARC, Inc. is a voluntary organization of 55 county wide chapters consisting of parents, friends and volunteers. The Association currently has over 71,000 members located in almost every county and community in New York State. Collectively, NYSARC, Inc. employs 26,000 individuals and is able to provide direct services to over 60,000 people daily. NYSARC, Inc. is the largest organization of its kind in the nation.

“While there may be some doubt as to how much we may be able to change our children for the world's sake, there can be no doubt about how much we must change the world for our children's sake.”

Joseph T. Weingold

POSITIONS OF NYSARC, INC.

PREFACE

NYSARC's mission is to advocate for persons with intellectual and other developmental disabilities in every manner possible. In its advocacy role, NYSARC 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, NYSARC 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. The environment where people live, study, work, recreate and worship must reflect affirmation of each person's strengths, wants, needs and desires. Services, supports and resources should be individually tailored to enhance each persons's ability to achieve self-identified goals and aspirations in every aspect of life.

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.

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ADVOCACY

NYSARC views advocacy as vital in improving and sustaining quality of life for people with intellectual and other developmental disabilities. To be successful, advocacy must take place at both the individual and system levels.

It is NYSARC's position that:

- Families can be the best advocates for their family members. To be successful, they must have access to family support services, parent groups, information and referral, network and advocacy assistance and training.

- \$ Advocates must be knowledgeable about how to access protection under federal, state and local laws and regulations in the matter of abuse or neglect of any person with intellectual and other developmental disabilities.

- \$ Individuals with intellectual and other developmental disabilities can advocate for themselves and be encouraged through informative communication from families, service providers, et al to be able to do so.

- \$ Advocacy systems must be designed, adequately funded, staffed and implemented to ensure that services and remedies are available to all individuals who need them.

- \$ Acceptable advocacy includes the following:
 - \$ Training in rights and advocacy skills;
 - \$ Information and counseling on how to solve problems;
 - \$ Referral of individuals to services agencies;
 - \$ Mediating between and with a person and an agency;
 - \$ 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.

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

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AGING

The need for advocacy for persons with intellectual and other developmental disabilities spans a person's life time. People with intellectual and other developmental disabilities must be afforded the opportunity to age with dignity and respect. People in the general population are living longer, so too are people with disabilities. This longevity creates an increased need for specialized services for the aging population with intellectual and other developmental disabilities.

It is NYSARC's position that:

- People with intellectual and other developmental disabilities have the right to live in their community through their entire life span in an appropriate and supportive residential option connected with and supported by family, friends, advocates and natural supports.
- People with intellectual and other developmental disabilities have the right to be supported by staff with appropriate training, skills and competencies necessary to support them throughout their life span.
- People with intellectual and other developmental disabilities 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.
- People with intellectual and other developmental disabilities should have the respect of their supporting provider organization through clear policies and planning to provide guidance in developing services, supports, physical space and resources throughout the life span of the individual.
- People with intellectual and other developmental disabilities should have an individualized personal plan that guides the service provider, staff, family and advocates and reflects personal life choices, including end-of-life decisions.
- Appropriate services developed by staff with professional expertise must be provided for people with intellectual and other developmental disabilities who are aging that meet their unique needs in every aspect of their lives.

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

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

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ASSISTIVE TECHNOLOGY

Assistive technology is the term used to describe external devices that are used by children and adults with intellectual and other developmental disabilities to enhance and increase independence, mobility, communication, environmental control and choice. It also refers to direct services that assist individuals in selecting, acquiring or using such devices.

It is NYSARC's position that:

- Assistive technology must be readily available and affordable throughout the life span of children and adults with intellectual and other developmental disabilities to facilitate inclusion in the community.
- 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.
- Individuals knowledgeable about people with intellectual and other developmental disabilities and current technology must be involved in assessing the needs of the person to ensure the selection of appropriate technology.
- Professionals in the field must be knowledgeable of funding and resources for assistive technology and provide information and assistance in how to acquire technology to persons we serve and their families.

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AUTISM

NYSARC was formed by parents of children and adults with intellectual and other developmental disabilities to advocate for services where none were available. Over time, the need to advocate for groups of people with disabilities who have emerging needs that are not adequately met has been the cornerstone of NYSARC and its membership.

During the past decade, individuals with Autism Spectrum Disorder have been documented as a critically emerging group, with a suggestion that it may affect one in every 150 births in the United States. These individuals are in need of services to assist them to be included in education and work environments. Individuals with autism and/or those on the spectrum represent an increasing segment of people with disabilities that require specific advocacy for services to assist them fully participate in their communities. However, they often cannot access these services due to complex and restrictive definitions related to eligibility under education and Medicaid rules.

It is NYSARC's position that:

- Individuals with autism spectrum disorder require the same early intervention services and life span services currently available to individuals who are developmentally disabled, as defined under eligibility rules of education and Medicaid services.
- Chapters and members of NYSARC advocate to establish demonstration programs to provide evidence-based services, treatments, and interventions for individuals on the spectrum.
- Service interventions typically provided to individuals with intellectual and other developmental disabilities, such as early intervention, inclusionary education, housing, day services and employment must be made available to individuals on the spectrum.
- The service networks in New York State must be encouraged and supported to develop strong diagnostic resources to accurately identify those individuals on the spectrum in need of services, treatment and interventions.
- People with autism spectrum disorder should be able access the protection and advocacy services currently available to people with developmental disabilities.
- Research must be funded to study the diagnostic and service interventions opportunities which would support individuals with autism spectrum disorder.

Adopted October 17, 2008 NYSARC, Inc. Delegate Assembly

BEHAVIORAL SUPPORTS

People with intellectual and other developmental disabilities function best under conditions that promote and reward social and emotional relationships. These relationships are characterized by mutual trust, positive regard, caring-respectful-considerate relationships and an environment that fosters active involvement and encourages learning. If challenging behaviors emerge and persist in spite of changes made to the environment in which the person functions, then the person must have access to individualized positive behavioral supports.

It is NYSARC's position that:

- \$ Every person has the right to humane effective treatment for changing dysfunctional behaviors that uses positive reinforcement and refrains from using aversive procedures.*
- \$ The most effective and desirable supports and services are those that focus on the person rather than on the behavior, on preventing rather than reacting to maladaptive behavioral episodes, and on helping the individual develop effective skills and coping strategies rather than on the use of external controls to manage dysfunctional behaviors.
- \$ Supports and services must be developed in collaboration with the individual in a respectful and sensitive manner.
- \$ Many challenging behaviors can be reduced or eliminated by engaging the person in activities that encourage choice.
- \$ Medical and psychological conditions, communication difficulties, and environmental factors that may be potential sources of behavior difficulties must be considered to ensure the best possible plan for effective behavior change.
- \$ Training in effective methods of behavior change technology such as ABC (Antecedents, Behavior, Consequences) charting, functional assessments, and positive reinforcement must be provided for family and staff.
- \$ Supports and services must be provided in a manner that maximizes access to and participation in the full range of opportunities available in the home, school, and community.
- \$ Inappropriate behaviors can often be reduced or eliminated when accurate, comprehensive information is collected, analyzed and used for planning prior to initiating services.
- \$ Services provided by staff who have developed effective, caring relationships will result in reduction of inappropriate behavior.
- \$ Properly applied, positive approaches like those described above, can eliminate the need for physical interventions and result in more respectful and humane interactions.

***Aversive procedures are defined as those which utilize physical or emotional pain stimuli in response to behaviors deemed unacceptable by their caregivers.**

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

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

COMPREHENSIVE HEALTH CARE

Persons with intellectual and other developmental disabilities, regardless of the severity of their disability, have the right to comprehensive, appropriate, timely, affordable and accessible medical, dental, habilitative and rehabilitative treatment services throughout their lives. Regulations, rate calculations, or licensing requirements should not be factors that determine the delivery of comprehensive health care services.

It is NYSARC's position that:

- **Comprehensive Treatment must:**
 - Include quality primary care and specialty medical care, dental, clinical, rehabilitative and habilitative services consistent with the person's medical and developmental diagnosis.
 - Preserve and/or improve the person's health, physically, mentally, emotionally and socially.
 - Facilitate the health and habilitative growth of persons receiving services.
 - Include clinical and service coordination that will serve to integrate comprehensive health care services and enhance health care outcomes.
 - Be available, accessible, affordable and timely.
 - Be provided only with the informed consent of the individual or legal guardian or 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 individual 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, 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 persons with intellectual and other developmental disabilities, providers and caregivers must educate the medical community on research based best practices.

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

Adopted with Revisions November 4, 2005, NYSARC, Inc. Delegate Assembly

DEVELOPMENTAL CENTER CLOSURE

For years, development of community-based residential and day programs has been essential in order to assure persons with intellectual and other developmental disabilities their rightful place in society. NYSARC, Inc., 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 live and work successfully as participating members of their communities. With appropriate training and support, individuals living in Developmental Centers can be fully integrated into community settings.

It is NYSARC's position that:

- Developmental Center closure efforts must continue to move forward.
- Developmental Center closures must be in accordance with principles pertaining to humane placement.
- Downsizing must continue as quickly as possible until closure is accomplished.
- Providers must be guaranteed the financial resources to provide the proper training, services and supports in order to maintain challenging individuals in community settings.
- Closure plans must ensure that appropriate services are developed for persons with special needs.
- Developmental Centers must never again be an acceptable place to live!
- **DEVELOPMENTAL CENTERS MUST NEVER AGAIN BECOME A WAY OF LIFE!**

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

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

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.

It is NYSARC's position that:

- Direct Support Professionals must receive wages and benefits sufficient to attract and retain the workforce to fully support people with intellectual and other developmental disabilities living in the community.
- Relevant funding sources must support provider agencies in delivering high quality, certificate based training covering the essential knowledge, ethical principles and practices, and skills necessary for effective direct care support that promotes continued development and meets with the needs of persons with intellectual and other developmental disabilities.
- Providers must foster the professional and personal development of Direct Support Professionals by providing access to continuing education and training.
- 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.
- 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.
- 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.

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

EDUCATION

Education is a life-long process for individuals with intellectual and other developmental disabilities. Educational systems and programs should value all individuals and their families and include them in all aspects of education. 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.

NYSARC's position on education is evidenced when:

- The legal rights of students with intellectual and other developmental disabilities are protected and enhanced.
- Educational systems comply fully with the spirit and intent of the Federal law IDEA (Individuals with Disabilities Education Act) and State Education Department regulations.
- Appropriate resources must be made available so that with proper supports students with intellectual and other developmental disabilities have the choice to be educated within their own neighborhood school where their friends and siblings are educated.
- State and federal governments conduct effective monitoring of IDEA. Sanctions are used by federal and state governments to ensure compliance by state and local education agencies.
- Students with intellectual and other developmental disabilities are educated with appropriate supports and services in a least restrictive environment and in an age-appropriate classroom with non-disabled peers.
- Children with intellectual and other developmental disabilities (Early Intervention 0-3, Preschool 3-5) are provided from birth with free and appropriate services which address their individual needs in settings with typical children.
- Individuals with intellectual and other developmental disabilities and their families have access to advocacy support and services. They receive training and guidance from local, regional and statewide advocacy networks and become effective advocates for children within the educational system.
- Certification requirements for regular education teachers at preschool, elementary and secondary levels require teachers to demonstrate ability to work with students with intellectual and other developmental disabilities.
- Students with intellectual and other developmental disabilities are entitled to the services of teachers with certification in special education in the area of their disability and/or need.
- Students with intellectual and other developmental disabilities and their parents or guardians are part of the decision-making process regarding educational placement and programming.

- Individual Education Plans consistently reflect a person-centered focus in educational goals and action plans.
- All students in special education are provided transition plans that reflect appropriate future goals in employment and community living.
- Local NYSARC Chapters form strong partnerships with local school systems to provide for an appropriate transition to the adult world for students who are graduating from special education programs.

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EMPLOYMENT

A vast majority of individuals with intellectual and other developmental disabilities can be employed given the knowledge, insight and technology available. With appropriate education, training and support, individuals can be productive and fully integrated into work settings and can receive equitable wages and benefits.

It is NYSARC's position that Employment:

- Be considered as a natural part of the lifelong process of self-determination.
- \$ Be governed by policy (federal, state, local) that fosters competitive employment in inclusive settings with funding for necessary supports, such as transportation, service coordination, and child care.
- \$ Includes efforts to forge the development of partnerships with business, government, public and private education and labor to provide meaningful training opportunities from school age through adulthood in a variety of work settings with emphasis on the use of natural supports.
- \$ Provides for a wide range of employment opportunities including sheltered, supported and competitive work to serve a diverse group of individuals.
- \$ Ensures that every individual has access to employment, continuing education, and career development, based on abilities and desires.
- \$ Ensures access to professional vocational assessments and training for general job skills and social skill development leading to job placement.
- \$ Opportunities are enhanced through volunteer activities utilized to provide training and experiences that may become future paid positions.
- \$ Include volunteer work that may be an appropriate alternative for those persons not able to work in traditional employment.

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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

FAMILY SUPPORT

NYSARC believes that the ability of families to attain a normal lifestyle for themselves and their family member with intellectual and other developmental disabilities should be maintained and continually strengthened. Their unmet needs should be addressed in a variety of ways.

It is NYSARC's position that:

- The family is usually the best source of support for an individual with intellectual and other developmental disabilities.
- In addition to family, other supports and services must be available throughout the life of this individual.
- The support necessary for the individual should be determined by the family.
- Families must be provided with sufficient information to make informed decisions and to coordinate services for their family member.
- These supports must assist families in the promotion of inclusion of children and adults with intellectual and other developmental disabilities in their life in the community.
- There must be a community based support network of interested citizens and family members as part of the community that helps facilitate access to community resources.
- Advocates for local, state and national policy be family centered.

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

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

GUARDIANSHIP

Individuals with disabilities who do not possess the cognitive, communicative or educational capacity to make autonomous decisions or to provide informed consent for personal and financial affairs may benefit from guardianship to assist them in: accessing appropriate services; receiving advocacy; promoting their quality of life; and participating as full members of their communities.

It is the position of NYSARC, Inc. for all individual and corporate guardians that:

- A guardian is involved in an active continuous life-long relationship of trust with the individual for whom he or she is the guardian.
- A guardian is legally responsible for assisting the individual at key decision making points, in the same manner as would an ethical, competent, caring parent and family member.
- A guardian offers assistance and intervention as needed, based on the individual's capacities, while ensuring that the individual has every opportunity to retain and exercise individual rights to the extent possible.
- A guardian works to strengthen the individual's capacity for independent decision-making by promoting self-reliance and participation to the maximum extent of his or her abilities in all decisions pertaining to the individual.
- A guardian places the welfare of the individual over the welfare of any service provider.
- A guardian shall advocate for person-centered planning to serve as a guide for the preferences of the person to assure that services are provided in least restrictive environments.
- If the person's prior or current wishes are unknown, unclear or would cause substantial harm to the individual, the guardian must act in the best interest of the individual.
- A guardian plays a life-long essential role in ensuring that the individual receives appropriate health, mental, dental, and end-of-life care and treatment.
- A guardian is responsible for seeing that a financial plan is in place for the individual during his/her lifetime and at his/her death.

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

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

INCLUSION

In the past 30 years extraordinary changes have occurred in the lives of people with intellectual and other developmental disabilities. Prior to that they lived in institutions and/or homes which segregated them from society. They were often denied the opportunity to enrich their daily lives through mainstream involvement in the community.

It is NYSARC's position that:

- Inclusion is a primary goal of people with intellectual and other developmental disabilities. However, community education and understanding are prerequisites for inclusion to be achieved.
- An inclusive environment must be provided which allows opportunities for people with intellectual and other developmental disabilities and their families to have choices in where they live, learn, work and play. Public and private resources must be readily available to make this inclusive environment a reality.
- Children and adults with intellectual and other developmental disabilities must be included in all aspects of the community, including, but not limited to, recreation, education, vocation, healthcare, social, cultural, and spiritual activities enjoyed by persons without disabilities.
- Inclusion choices must be based on the interest and desires of the individuals with intellectual and other developmental disabilities and they must have maximum control over these choices.
- Adults with intellectual and other developmental disabilities must have the right to engage in relationships that range from friendships to choice of life partners.

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

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

INDIVIDUAL SERVICE COORDINATION

Children and adults with intellectual and other developmental disabilities must have access to services and resources that are available to all other citizens. Finding, 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 is not an easy task.

It is NYSARC's position that:

- Such services and resources should be controlled by individuals and their families through an organized process.
- Such services should include the active involvement of the individuals and their families.
- Individual service coordination can/should go beyond the current available services and resources where so indicated.
- Individuals and families must be aided in their planning and activities by individual service coordination, who help them find, use and coordinate resources and opportunities in their community.
- Individual service coordinators must be competent, sensitive and committed to representing the interests, preferences and visions of the individual and, when appropriate, their families.
- Individual service coordinators must provide reliable information, help explore options, guide individuals, families and friends in making informed decisions.
- Service Coordinators should use formal and informal supports.
- Service Coordinators should have arms-length latitude to enhance objectivity and eliminate any appearance of a conflict of interest when employed by the consumer's provider of service.
- Service Coordination provided by the consumer's provider of service must be person centered to ensure that all service options within and outside of the service provider agency are available and accessible to the individual.
- Funding should be available that supports individual service coordination that is of high quality, as measured by effectiveness, responsiveness, continuity, reliability, and acceptability to the user.

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INDIVIDUAL SUPPORTS

Individuals with intellectual and other developmental disabilities shall be afforded the individual supports and other resources necessary to enable them to lead a fulfilling and self-directed life. This includes the elements of personal relationships, meaningful activities and community participation.

It is NYSARC's position that:

- The role of the family and community must be accentuated as the most essential source of support for an individual with intellectual and other developmental disabilities.
- Children, adults, and families must be involved in decisions about who will provide for their personal needs and care.
- All individuals must have individual service coordination available to them to help in identifying, coordinating, and utilizing resources and opportunities in their communities.
- All individuals must have access to assistive technology, which is necessary to allow them to be self sufficient and engage in activities that are meaningful to them.
- A variety of necessary supports and services must be provided to develop relationships and be accepted citizens in the community.
- Individual supports must not be denied for any reason, including but not limited to, severity or type of developmental disability, maladaptive behaviors, motor or sensory limitations, or personal finances.
- Supports must be planned for in accordance with the principles of person-centered planning.

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

JUSTICE AND FAIR TREATMENT UNDER CRIMINAL LAW

All individuals with intellectual and other developmental disabilities are protected under the U.S. Constitution and Bill of Rights and are entitled to fair treatment in the criminal justice system.

It is NYSARC'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 must be informed about intellectual and other developmental disabilities as it affects 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 available to confer with individuals with intellectual and other developmental disabilities prior to and during questioning by law enforcement 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 appropriate support is 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, by definition, raises issues of miscommunication, misinformation and providing an adequate defense to the extent that imposition of the death penalty is unacceptable.
- \$ When an individual has been court ordered to the custody of the Office of Mental Retardation and Developmental Disabilities, the individual must be provided with appropriate clinical treatment and opportunities for re-introduction into society.

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MANAGED CARE

Managed health care organizations and managed health care plans must be totally responsive to the health care needs of persons with intellectual and other developmental disabilities.

It is NYSARC's position that managed health care plans best serve the health care needs of individuals when:

- There is guaranteed access to comprehensive health care services including primary care, specialty care and the full range of ancillary services.
- Services are provided by health care practitioners knowledgeable and with expertise in intellectual and other developmental disability health issues.
- Member services and health care services are timely and responsive to the health care needs, questions and concerns.
- Enrollment into the managed care plan is voluntary and does not discriminate based on disability, health status including pre-existing conditions, race, color, religion, gender, national origin or sexual orientation.
- Assistance is offered as needed to understand options for enrolling or not enrolling in the plan and understand benefits and services provided.
- Their rights and interests are respected regarding medical, behavioral, health and dental treatment decisions.
- They receive comprehensive, understandable information about the health services covered by the plan.
- They have a right to access services either within the plan's benefit package, or if not covered as part of the plan's package, outside the plan.
- They have a choice among health care practitioners, specialty services, durable medical equipment vendors and pharmacies.
- They can choose specialists to serve as their primary care providers when health conditions warrant.
- Health care services reflect personal respect and consideration and are provided in a clean and safe environment free of unnecessary restraints and compliant with ADA standards.
- They receive complete information about their diagnosis, treatment options and prognosis including information about all known possible risks and benefits of a proposed procedure or treatment.

- Privacy and confidentiality of all information and records regarding their medical care is upheld.
- Requests are honored for reconsideration of a medical care decision by professionals in the plan or independent from the plan, knowledgeable of the particular health condition as it relates to intellectual and other developmental disabilities.
- A distinction is made and preserved between health care and long term care.
- Health care and long term care services are coordinated and integrated as appropriate to enhance positive outcomes for the individual.
- There is the opportunity for persons with intellectual and other developmental disabilities to have an advocate of their choice involved in their decision-making process.

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NEW TERMINOLOGY

Labeling terminology has been used historically to identify and categorize diagnostic characteristics of clinical disabilities for the purpose of professional interventions and access to entitlements, in support of persons with disabilities. The definition of the term “mental retardation” has evolved over the years. In more recent times, the term “intellectual and other developmental disability” now encompasses disabilities attributable to mental retardation, cerebral palsy, autism and other neurological impairments.

The use of the term “mental retardation” in day to day parlance is unacceptable. NYSARC has taken steps to move away from the use of the term “mental retardation”. In 2004, the celebration of Mental Retardation Awareness Month was renamed Developmental Disabilities Awareness Month. The vast majority of NYSARC Chapters do not use the term “mental retardation” in describing the people they serve. New terminology must be adopted to describe disabling conditions.

It is NYSARC’s position that:

- # All individuals with disabilities are people first. People first language that is respectful of the person should be used when referring to them.**
- # All persons be portrayed for their talents and skills, not their limitations.**
- # The terminology “intellectual and other developmental disabilities” should be adopted in all internal and external communications. ****
- # All Chapters of NYSARC be encouraged to conform to this position and use people first terminology and “intellectual and other developmental disabilities” in internal and external communication.**
- # All appropriate NYSARC documents be revised to reflect the above.**

****This position does not negate the use of the term “mental retardation” for purposes of public policy and legal entitlements.**

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

PREVENTION

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

It is NYSARC's position that prevention 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 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 and dental services during pregnancy.
- # Mandatory newborn screening programs done within a time frame that guarantees accurate results and treatment for metabolic disorders such as phenylketonuria, galactosemia and hypothyroidism.
- # Education policies and programs to prevent 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 for education, intervention programs and other supports that can prevent the occurrence of a disability or diminish the extent of impairments that lead to disability.
- # 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 to sustain their family unit.

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PROTECTION

Children and adults with intellectual and other developmental disabilities are significantly more likely to be mistreated by the general public, service providers, and even their families. They must be protected from harm and injury throughout their lives while also being provided with the tools and supports necessary to protect themselves.

It is NYSARC's position that:

- # Family and friends of people with intellectual and other developmental disabilities and the community are the best sources of protection from harm. If for any reason the above groups are unable 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.
- # Individuals with intellectual and other developmental disabilities must be given the opportunity to learn to protect themselves and be able to seek appropriate assistance.
- # Service organizations must ensure that all staff have the training and competence to work effectively and appropriately with children and adults with intellectual and other developmental disabilities.
- # Service organizations must screen all applicants to eliminate those with a history of perpetrating abuse, neglect, or criminal record and evaluate all employees in accordance with NYS OMRDD and NYS Education Department standards on a regular basis to ensure appropriate job performance.
- # Service organizations must immediately investigate allegations of abuse or neglect and take immediate corrective action when warranted.
- # In accordance with OMRDD 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.

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PUBLIC RECOGNITION OF PERSONS WITH MENTAL RETARDATION AND OTHER DEVELOPMENTAL DISABILITIES

Recognition of the contributions made by people with intellectual and other developmental disabilities is important if they are to become fully participating members of the community. The public, at large, must be made aware of their abilities and how they contribute to improving the quality of life for everyone in the community.

It is NYSARC's position that every effort should be made to:

- ! Enlist the support of the media to continue to use its resources to increase public awareness and understanding of the abilities of people with intellectual and other developmental disabilities.
- \$ Encourage the identification of positive and meaningful news stories that recognize the accomplishments of people with intellectual and other developmental disabilities.
- \$ Encourage universal use of people-first language to describe people with intellectual and other developmental disabilities. Eliminate the pejorative use of any version of the words retarded or mentally retarded.
- \$ Promote persons with intellectual and other developmental disabilities in a manner which reinforces their value as accepted and productive members of the community.
- \$ Demonstrate the commitment of NYSARC and all of its Chapters by employing and recognizing people with intellectual and other developmental disabilities.
- \$ Promote NYSARC and its chapters as the preferred source of information on issues relating to people with intellectual and other developmental disabilities.

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QUALITY

A standard of high quality must be reflected throughout the full continuum of services and supports for people with intellectual and other developmental disabilities. Quality is attained through: inclusion in all components of community living; developing independence with options and informed choices; personal satisfaction with services and supports meeting wants and needs; continuous dedicated planning and development of services based on individual needs instead of program availability.

It is NYSARC's position that supports and services are of high quality when they:

- # Assure that people clearly understand how to explore options and make informed decisions.
- # Afford full access to what individuals want and need in a timely, safe manner, both in the community and for those who remain in institutional settings.
- # Are person-centered and reflect an integrated process regardless of the person's diagnosis.
- # Recognize that family can be the best support a person has.
- # Allow individuals and their families to drive the design of services and supports.
- # Are available in the individual's home community.
- # Build upon a person's strengths and talents in a positive, least restrictive and non-aversive approach.
- # Respond to changes in a person's life, using best practice standards provided by qualified, competent individuals who are committed to growth and development.
- # Respect the rights, dignity and privacy of individuals.
- # Are provided by people experienced, knowledgeable and open to the most appropriate settings and methods for positive outcomes.
- # Are funded at a level that meets individual needs and expectations without categorical limits, waiting lists or any other barriers that would prevent or limit meaningful options.

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RECREATION

Participation by persons 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.

It is NYSARC's position that:

- # Access to recreational and leisure times 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 playgrounds, recreational facilities and outdoor recreational areas are appropriate and accessible to people with intellectual and other developmental disabilities.
- # Assistive technology must be used to increase participation in inclusive recreation and leisure activities.
- # Information and education must be provided to people with intellectual and other developmental disabilities and their families to ensure they are aware of the opportunities and benefits of inclusive recreation and leisure activity.

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RESEARCH

Research must provide accessible and relevant information to people with intellectual and other disabilities and their families, professionals, the general public and public officials to provide the knowledge to create, sustain and improve services which support an enhanced quality of life for people with intellectual and other developmental disabilities.

It is NYSARC's position that:

- \$ Research priorities must reflect input from a broad spectrum of stakeholders (people with intellectual and other developmental disabilities, their family members, academics from many disciplines, service providers, advocates, policy makers). Priorities should 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.
- \$ Researchers must follow generally accepted professional standards of research design and reporting, including protection of the subject's rights to informed consent, confidentiality, privacy and rights for health and safety.
- \$ Research must include a variety of quantitative and qualitative methodologies to achieve the multiple goals of research.
- \$ Researchers must 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.
- \$ Research must contribute to quality of life outcomes for people with intellectual and other developmental disabilities and their families.
- \$ Research must be used to identify exemplary practices and study the issues involved in expanding policy and practices beyond pilot sites.
- \$ Research must identify and support practical applications to address the daily needs of people with intellectual and other developmental disabilities and their families.
- \$ Research must provide validated evidence-based results to identify and build public support for promising programs.
- \$ Research must increase public understanding and support for local, state, and national policies that provide for community based living opportunities, programs, and services for people with intellectual and other developmental disabilities and their families.
- \$ Research findings must be disseminated in a manner that clearly communicates the essence of the findings to those who plan and implement programs and services, using all appropriate communication vehicles.
- \$ Research must be used to determine whether the desirable program outcomes established by appropriate bodies are being met.

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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. It should be recognized that they may need some accommodations and supports to enable them to exercise these rights.

It is NYSARC'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 special 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 when the individual's life, health, safety or general well being are compromised.

\$ To membership, employment and leadership in NYSARC, Inc.

\$ To any and all other rights enjoyed by all citizens.

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

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SELF-ADVOCACY ROLE IN LEADERSHIP

Self Advocacy plays an important part in promoting the values and mission of NYSARC and its Chapters. Individuals with intellectual and other developmental disabilities are increasingly participating on boards of directors, advisory boards and board committees. Appropriate training and supports must be provided so that they can participate fully and meaningfully in these leadership groups.

It is NYSARC's position that:

- Individuals with intellectual and other developmental disabilities must have direct input into Chapter management planning and decision making.
- Individuals with intellectual and other developmental disabilities must have every opportunity through either paid or volunteer positions in promoting the development of self-advocacy programs and supports.
- A full opportunity must be given to individuals with intellectual and other developmental disabilities to cultivate leadership in all aspects of services and supports.
- Service Providers must provide financial and administrative support for self-advocacy activities including participation at self-advocacy meetings.
- Service Providers must encourage and support individuals with intellectual and other developmental disabilities by providing a full array of supports that foster individual choice, inclusion and personal empowerment.
- Service Providers must promote and guide public policies to support individuals with intellectual and other developmental disabilities in their journey for personal choice, empowerment, planning and inclusion.
- A positive image of people with intellectual and other developmental disabilities as valued members of the community must be promoted.
- Service Providers must promote the use of people first language so that individuals with intellectual and other developmental disabilities are recognized as people first, rather than as consumers, participants or clients.
- Service Providers must promote best practices as they relate to self-advocacy.
- Continuous commitment to public education about self-advocacy must be demonstrated through use of all forms of media, public forums and on-going community education.

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

SELF-DETERMINATION

People with intellectual and other developmental disabilities can be helped to improve the quality of their lives by being given greater control and responsibility for themselves. There is a dignity of risk factor inherent in self-determination. 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 NYSARC's position that people with intellectual and other developmental disabilities must:

- # Be provided with 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 be given opportunities to pursue those dreams and desires in their lives.
- # Be provided opportunities to acquire and develop meaningful skills and confidence that enable them to ensure a greater degree of control of their lives and environments.
- # Be provided a wide range of experiences to help all persons understand their community so that they may make informed and individualized decisions.
- # Be provided with necessary supports, which will enable persons to develop, maintain, and further meaningful relationships.
- # Be provided with opportunities to make informed choices regarding their use of personal financial resources, their acquisition of desired services and their choice of supports.
- # Be provided with access to assistive technology, personal assistance, and necessary supports to promote optimal communication and have unlimited opportunities for independence.
- # Be provided with appropriate training, accommodation, and support so that persons may become active members of groups, clubs and organizations, including NYSARC.

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SEXUALITY

Individuals with intellectual and other developmental disabilities are people with sexual feelings, needs and identities. Sexuality should be acknowledged as part of the total context of human relationships. Informed consent in sexual expression protects the rights and dignity of the individual.

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 NYSARC's position that people with intellectual and other developmental disabilities have fundamental rights commensurate with their abilities to:

- \$ Convey informed consent both through verbal expression and responsible interpersonal behavior.
- \$ Privacy.
- \$ Love and be loved in a caring, nurturing relationship.
- \$ Develop friendships and emotional relationships.
- \$ Learn about and be protected from sexual exploitation, sexual abuse, unsafe sexual behavior, sexually transmissible diseases; and learn about other issues regarding sexuality and expressions of sexuality.
- \$ Be informed about other sexuality issues and expressions of sexuality.
- \$ Exercise their rights and responsibilities in regard to privacy and sexual expression for themselves and others.
- \$ Full information and access to HIV counseling, testing and protection from sexually transmissible diseases, HIV and unwanted pregnancy.
- \$ Full information and access to options in the event of an unwanted pregnancy.
- \$ Marry and make informed decisions concerning having children.
- \$ Develop expressions of sexuality reflecting age, social development, cultural and religious values and social responsibility.

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SPECIALIZED TREATMENT UNITS

NYSARC recognizes that a growing 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 require other residential settings.

It is NYSARC's position that:

- # Specialized treatment units for these individuals may require a more secure, highly structured environment as an alternative to the prison system.
- # OMRDD must address the ever increasing needs of this growing population by providing proper financial and environmental supports.
- # OMRDD must ensure properly trained clinical personnel to provide intensive therapeutic treatment.
- # As with all placements, proper planning with input from family and/or advocates must occur.
- # The civil and legal rights of all persons with MR/DD 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.
- # OMRDD needs to develop an emergency treatment/crisis intervention.
- # Exclusion and segregation from community must never be the norm, we must always work towards a return to community living.
- # The state shall remain the provider of last resort.

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

SPIRITUAL OPPORTUNITIES FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES

In addition to the social, economic, psychological and health concerns of every person, individual planning should also address the spiritual dimension of persons with intellectual and other developmental disabilities. While local congregations can be a tremendous resource in assisting in full inclusion in community life for persons with intellectual and other developmental disabilities and their families, these congregations require assistance in fulfilling this role.

It is NYSARC's position that:

- # Spirituality, spiritual growth and religious expression that a person's history, tradition and current preference or choice are rights that must be honored by supports from service systems and religious communities, as should the choice not to participate.
- # Information on the right of every individual to choose to participate or not in any spiritual activity must be fully explained and information on the availability of such opportunities must be provided.
- # Every effort must be made to provide consumers transportation, personal assistance or other access to spiritual activities of their choosing.
- # The desires and interests of families must be accommodated when assisting individuals to participate in spiritual activities when not in conflict with the individual's personal choice including 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.
- # 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.

Adopted October 25, 2003 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. This population is unable to fully comprehend the negative affects on their health, the addictive properties of these substances and the illegality of their use of the street drugs. The use of these substances often causes behavior that is disruptive to the family and the community and results in confrontations with law enforcement personnel. When arrested and sentenced to jail or ordered to receive treatment in traditional substance abuse programs, they receive either no treatment or treatment inappropriate to their level of functioning. Upon reentering their community, the substance abuse is often resumed leading to further elevation of negative behaviors.

It is NYSARC's position that:

- \$ Education on the nature and effects of the use of alcohol and illegal drugs should be presented in public schools at a pre-adolescence stage of development. Education should be on a level of understanding appropriate to the abilities of the people with intellectual and other developmental disabilities and should be repeated on a yearly basis as part of a students' IEP until academic education is completed.
- \$ Education should include the pitfalls of the association with other people who use street drugs or alcohol to excess and afford the individual with the opportunities to engage in peer mentoring programs with same age developmentally typical peers.
- \$ 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 how to address the problem.
- \$ Special substance abuse treatment programs should be developed to treat individuals with intellectual and other developmental disabilities. If traditional programs are used treatment should be in collaboration with programs for people with intellectual and other developmental disabilities.
- \$ Parents and significant others in the addicted individual's life should be involved in the treatment process including appropriated modified programs such as Alanon (A support group for families of people with chemical dependencies).

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

USE OF MEDICATIONS

Medications are 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 for a full and valued life.

It is NYSARC's position that:

- \$ Medications should 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 are prescribed only by licensed, qualified medical professionals who are familiar with the individual.
- \$ The person with intellectual and other developmental disabilities will be included in discussions and decisions regarding the use of pharmaceutical treatment for a target behavior and/or medical situation.
- \$ Before medication is started, the individual, if capable, parent or individual legally authorized to give consent, will be consulted and must give consent, as appropriate, and 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 determined by the physician in consultation with the family, staff, individual with intellectual and other developmental disabilities, 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.
- \$ All prescribed medications must be approved by the Federal Drug Administration. No experimental, non-qualified pharmaceuticals will be used in the course of normal medication use.

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

WHERE PEOPLE LIVE

People with intellectual and other developmental disabilities have the right to live in the community of their choice and to choose with whom they reside. Given the appropriate supports and services, they can grow, develop and become contributing members of the community. The days of institutional living for people with intellectual and other developmental disabilities have ended in New York State.

It is NYSARC's position that:

- \$ Individuals with intellectual and other developmental disabilities, both children and adults, have the right to be integrated in their communities.
- \$ Fully funded individualized supports and services, including appropriate accommodations, must be available to meet the needs of the individual and must be of high quality.
- \$ Funding for supports and services must follow people with intellectual and other developmental disabilities and not be tied to a facility or a location.
- \$ Individuals with intellectual and other developmental disabilities or their advocates must be able to choose where they live.
- \$ The family of the person with intellectual and other developmental disabilities must have the choice of working with a range of provider agencies to help find the appropriate residence for their family member.
- \$ The health and safety of people with intellectual and other developmental disabilities must include the option of remaining in their residence of choice as long as possible with appropriate supports and funding.
- \$ People with intellectual and other developmental disabilities have the right to receive the necessary supports and services to remain at home with their families, including ready access to high quality medical and psychiatric care as needed.

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Allegany	Oneida-Lewis
Benevolent Society (Staten Island D.C.)	Onondaga
Bronx D.C.	Ontario
Broome-Tioga	Orange
Cattaraugus	Orleans
Chautauqua	Oswego
Chemung	Otsego
Chenango	Putnam
Clinton	Rensselaer
Columbia	Rockland
Community League (Wassaic D.C.)	Rome Tri-County
Delaware	St. Lawrence
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Nassau	Westchester
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New York City	Wilton D.C. *
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