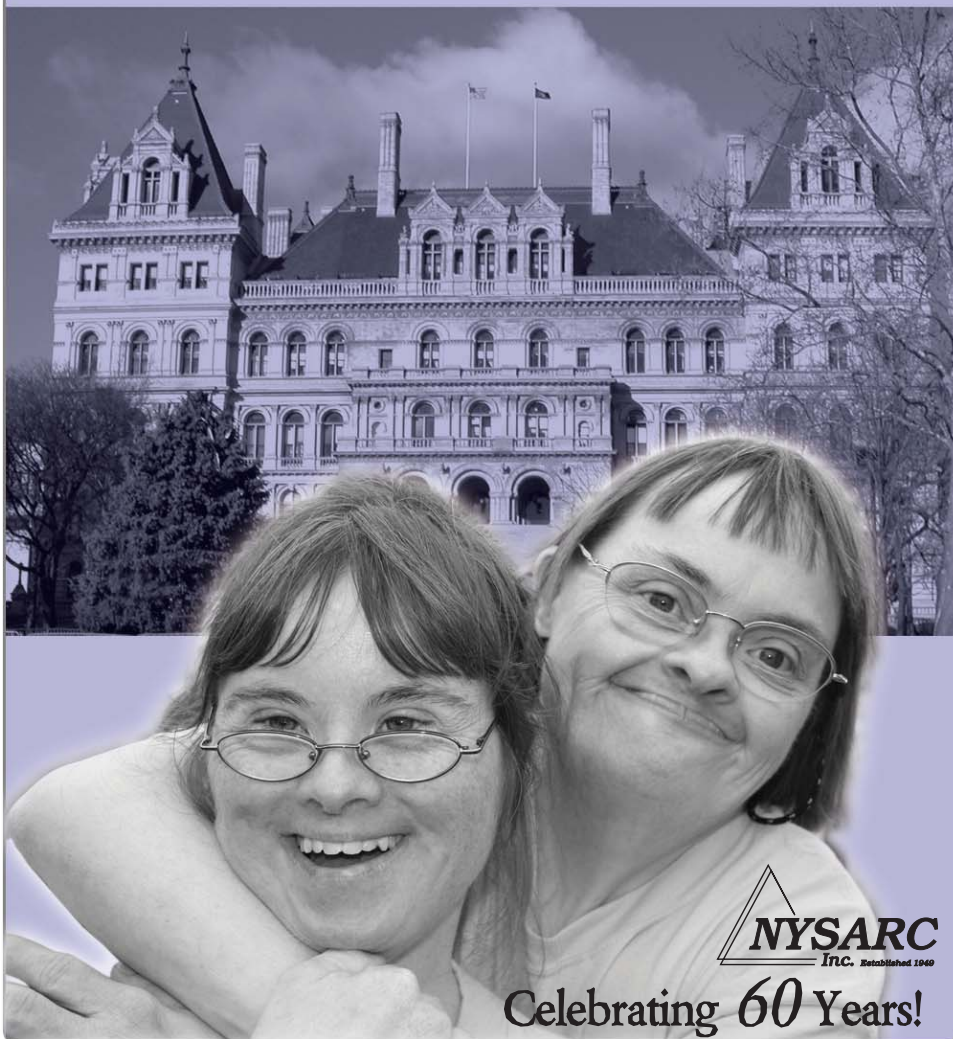


NYSARC, Inc. 2009 Legislative Platform

*A family-based organization working with and for
people with intellectual and other
developmental disabilities.*



NYSARC
Inc. Established 1949

Celebrating **60** Years!

NYSARC, Inc.

***Legislative
Platform
2009***



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Intellectual Disabilities

NYSARC, Inc. Implements Terminology Change

Over recent years, there has been a growing conviction among advocates that the term "mental retardation" has acquired a demeaning and derogatory connotation. NYSARC, Inc. has therefore adopted alternative language for this term. This language is used by other national organizations such as The Arc of the United States. We believe it enhances the dignity and respect accorded to the individuals we serve.

Accordingly, NYSARC, Inc. has transitioned from the use of the term, "people with mental retardation and other developmental disabilities", to "people with intellectual and other developmental disabilities". This change is incorporated in the NYSARC, Inc. Legislative Platform.

Since mental retardation is a type of developmental disability, for purposes of this platform we will use the term "intellectual developmental disability" to mean what was formerly meant by the term "mental retardation".

There will be instances when the Legislative Platform will retain the term "mental retardation" when it is, for example, part of the legal or formal name of a law or bill, such as the "Health Care Decisions Act for Persons with Mental Retardation".

Also, NYSARC, Inc. recognizes that the term "mental retardation" is readily understood by the Legislature and the public. Therefore, NYSARC, Inc. will continue to use the term in communications with the Legislature when the urgency and expediency of legislative activity makes it the most practical means of accomplishing important objectives.

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NYSARC, Inc. Affirmation Statement

We as parents, friends and advocates of people with intellectual and other developmental disabilities recognize that every person has value and should have the opportunity to be a productive citizen in his or her community.

We affirm our commitment to ensure that all individuals and their families be given a choice of resources which will maximize the potential for growth and independence.

We remain united as one Association in support of this mission.

What are Intellectual Disabilities (Mental Retardation)

According to the definition adopted by the American Association on Intellectual and Developmental Disabilities (formerly, the American Association on Mental Retardation), an individual is considered to have intellectual disabilities (mental retardation) based on the following three criteria:

Intellectual functioning level (IQ) is below 70-75; significant limitations exist in two or more adaptive skill areas; and the condition is present from childhood (defined as age 21 or younger).

People with intellectual disabilities (mental retardation) make up a significant constituency within the broader disability community.

Who Is NYSARC, Inc.?

NYSARC, Inc. is a voluntary organization of fifty-five Chapters consisting of parents, friends and volunteers serving thousands of New York residents with intellectual and other developmental disabilities. The Organization currently has over 71,000 members located in almost every county, community and developmental center. Collectively, the Organization employs more than 26,000 individuals and is able to provide direct services to over 60,000 persons daily. It is the largest organization of its kind in the nation.

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NYSARC, Inc. maintains a strong centralized presence in order to advocate on important statewide issues of concern for people with intellectual and other developmental disabilities throughout New York State.

From its headquarters located on the outskirts of the State's Capital, the Organization works closely with the Legislature, the Governor's Office, state agency personnel and other advocacy organizations on important areas of concern. This has become increasingly important as state deinstitutionalization policies have led to a mass exodus of people from institutional facilities into community based programs; a transition that has raised concern about the quality of life accorded to people with intellectual or other developmental disabilities to unprecedented levels.

NYSARC, Inc. continues to take pride in the leadership it has demonstrated in fostering a universal commitment to the dignity of people with intellectual and other developmental disabilities.

Development of Legislative Platform

NYSARC, Inc.'s Legislative Platform is a consequence of continuous input from the Organization at all levels. NYSARC, Inc. Chapters, committees and individuals recommend legislative goals to the NYSARC, Inc. State Office throughout the course of the year. Additionally, NYSARC, Inc. State Office staff make recommendations based on their knowledge of state and federal policy developments.

In August, all recommendations are forwarded to the NYSARC, Inc. Governmental Affairs Committee. The Governmental Affairs Committee develops a series of recommended legislative goals for consideration by the NYSARC, Inc. Board of Governors at its fall meeting, held during the NYSARC, Inc. Annual Convention. The Delegate Assembly gives its final approval at that Convention.

In January, final legislative goals are printed and distributed throughout the Organization, as well as to other advocacy organizations, the Legislature, Governor's Office and pertinent state agencies.

Legislative goals deal with all aspects of the Organization's mission,

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including guardianship, funding, health care, education, community development, worker pay and consumer protection. While much of the NYSARC, Inc. State Office's legislative activity is driven by the Organization's legislative goals, much is also driven by unforeseen developments created by legislation which the NYSARC, Inc. State Office believes works either for or against the interests of the Organization and the individuals it supports.

Overseeing State Policy

NYSARC, Inc. has long understood that there may be a huge discrepancy between public laws, policies and promises on the one hand and how people with intellectual and other developmental disabilities and their families are actually treated on the other. Thus, NYSARC, Inc. closely monitors the activities of state agencies and the thousands of regulations and activities they are charged with implementing. Based on this, NYSARC, Inc. provides continuous input to state officials to influence the direction of state policy.

NYSARC, Inc.'s aim is consistent with its mission: ***"To protect and advance the interests of all people with intellectual and other developmental disabilities and their families"***.

In addition, NYSARC, Inc. routinely intervenes, using its close ties with decision makers, to ensure that resources and policies are in place to support individuals with intellectual and other developmental disabilities and the families who depend upon the Organization's Chapters for those vital services.



Celebrating 60 Years!

Immediate Legislative Issues

These issues comprise NYSARC, Inc.'s highest priority for immediate action in the upcoming legislative session.

A) MENTAL HYGIENE LAW

ISSUE #1: Preserving Service Levels

Recommendation: Enact legislation protecting service levels for persons with intellectual and other developmental disabilities and expanding services for individuals in need, especially those in need of out of home residential care.

Background: Persons with intellectual and other developmental disabilities are our most vulnerable citizens. Many have multiple disabilities, are medically fragile and are totally dependent on day and residential programs for their well-being and even their lives. Without adequate services, their quality of life can rapidly deteriorate, their disabilities become worse and their lives are threatened. Active treatment, for example, recognizes that simply maintaining these individuals is not enough. They must be active, stimulated and involved in the life of their community as well as fed, clothed, housed and kept out of harms way.

It is for exactly these reasons that community based care replaced institutional care, leaving that horrific legacy behind. Making persons part of their community, giving them purpose and dignity, translated into an improved emotional and physical condition. This requires adequate resources without which the horrors of the institution can be easily replicated in the community.

Parents, family members and advocates fought for decades for a community based system so that their loved ones would not have to endure the horror of institutional life. They are equally determined to fight to ensure that institutional conditions are not recreated in the community.

Fiscal conditions should never, as a matter of State policy, endanger the well-being of our most vulnerable citizens or endanger the expansion of necessary out-of-home opportunities.

Immediate Legislative Issues

ISSUE #2: Wage Fairness

Recommendation: Promote legislation establishing wage fairness between voluntary and State employees working in programs serving persons with intellectual and other developmental disabilities. Wage fairness should be phased in over a 3 year period and focus on direct support professionals and other critical employees.

Background: For years, the huge pay gap - approximately 30% - between State and voluntary employees serving persons with intellectual and other developmental disabilities has underscored the fact that equal work for this vital job does not entail equal pay. As staff recruitment and retention problems have worsened, the State/voluntary pay gap has become increasingly unacceptable as a matter of practice and principle. Clearly, as pointed out in a NYSARC, Inc. study, adequate pay is the single most important factor in both recruiting and retaining staff. It is critical that workers in voluntary programs receive the same pay accorded their counterparts in State operated programs.



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Immediate Legislative Issues

ISSUE #3: NYS CARES II and III (New York State Creating Alternatives in Residential Environments and Services)

Recommendation: *Promote legislation adopting the seventh year of NYS CARES II and the third year of NYS CARES III to provide appropriate residential placements for all individuals waiting at home in need of out-of-home care. It is also intended to downsize larger, older residences into small, state-of-the-art residences where applicable.*

Ensure that NYS CARES II and III are implemented in accordance with principles pertaining to humane placement and in accordance with appropriate input from parents, residents and other concerned individuals. Finally, the plan must ensure that appropriate services are developed for persons with special needs (i.e., behavioral, medical, etc.).

Since this legislative initiative must be enacted each year as part of the State Budget it must be included as a regular part of NYSARC, Inc.'s legislative platform until NYS CARES II and III are complete.

Background: NYS CARES I came to an end in FY 03-04. That historic program was begun to meet the needs of individuals living at home who require out-of-home care. In FY 03-04 the Governor initiated NYS CARES II as a sequel to NYS CARES I. NYS CARES II is intended to make sure that no one is left behind. It is a 10 year initiative but must be approved by the legislature annually as part of the State Budget.

NYS CARES II is intended to serve 1,900 individuals in out-of-home residential placements while providing in-home supports for 4,000 individuals. It is also intended to downsize large, older, antiquated residences with smaller state-of-the-art residences.

Immediate Legislative Issues

ISSUE #4: Full Time, Independent Ombudsperson

Recommendation: Promote passage of legislation establishing a full time, independent Ombudsperson program for all persons with intellectual and other developmental disabilities in every DDSO. The Ombudsperson should be aimed at the needs of persons who currently have no parent, guardian, or correspondent to advocate for them; and families, guardians, and correspondents in need of, or requesting advocacy.

Background: At NYSARC, Inc.'s initiation, the Legislature passed and the Governor signed Chapter 57 of the Laws of 1987 establishing an Ombudsperson at each developmental center to advocate for developmental center residents. NYSARC, Inc. recognized that developmental center residents, especially during a period when those facilities were being consolidated and closed, had special needs requiring specialized advocacy.

However, since then, NYSARC, Inc. has recognized that persons with intellectual and other developmental disabilities living in the community and their families have unique needs which can require specialized advocacy services depending on a variety of factors such as place of residence, economic status, disability level and access to community resources. Furthermore, massive deinstitutionalization has brought many persons into the community who have no parent, guardian, or correspondent to advocate on their behalf. Finally, an increasing proportion of elderly individuals has created a greater demand for persons who can advocate on their behalf.

As a consequence, NYSARC, Inc. has supported extending the services of the Ombudsperson into the community.

Based on experience with the Developmental Center Ombudsperson program, NYSARC, Inc. also supported making Ombudspersons both full time and independent. It was clear that the demand for service required a full time position and that the lack of independence from the Office of Mental Retardation and Developmental Disabilities could constrain the ability of the Ombudsperson to act effectively.

Immediate Legislative Issues

ISSUE #5: Adequate Funding for Adequate Staffing

Recommendation: Promote funding legislation, pursuant to the State budget, to provide adequate funding for staffing necessary to provide individualized services and meet needs such as unanticipated hospitalization, behavioral crisis and other similar needs which current funding mechanisms do not adequately reimburse.

Background: As community based programming has expanded, strong emphasis has been placed on including individuals in all aspects - social, recreational and vocational - of the communities in which they reside.

Too often however, funding for staffing has not been sufficient to meet these goals, particularly when a crisis erupts. Therefore, the broader aim of community based care has not been realized. Unless adequate staffing for community based care, both state and voluntary operated, is funded - the full promise of community based care will never be fulfilled.

However, some believe - including OMRDD - that the current methodology for handling this issue is fair. That is, when an agency has a deficit in the residential program serving the individual who requires additional service, it can appeal the additional cost. But when it has a surplus in that program, it is expected to use that surplus to fund the additional cost of care. It should be noted that the funding involved is Medicaid.



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Immediate Legislative Issues

B) SOCIAL SERVICES LAW

ISSUE #6: Protection of Adults with Disabilities from Abuse

Recommendation: *Promote the passage of legislation to give the Commissioner of OMRDD the explicit authority to take custody of an adult individual - similar to authority now possessed by Adult Protective Services - living in a non-licensed or non-certified setting, whose health or safety the Commissioner believes is at risk due to their living situation.*

Background: Adults with intellectual and other developmental disabilities living at home with their families or in other non-certified settings may be subject to abuse or neglect. They may not receive appropriate medical care or other services necessary to meet their vocational, emotional, physical or financial needs.

Pursuant to regulations promulgated as a result of Chapter 356 of the laws of 2006, adults with intellectual and other developmental disabilities, living in non-certified settings who have allegedly been abused but who DO NOT receive services from OMRDD, are the responsibility of the Commissioner of the Office of Children and Family Services (OCFS). Those who do receive services from OMRDD are the responsibility of the Commissioner of OMRDD.

However, regardless of who has formal responsibility for these individuals, the Commissioner of OMRDD should be able to take custody of individuals in non-certified or non-licensed settings - as Adult Protective Services currently can - to protect them from an imminent risk to their health and safety.

Immediate Legislative Issues

C) EDUCATION LAW

ISSUE #7: Preschool

Recommendation: *Promote a viable funding methodology for preschools which is predictable, provides timely reimbursement of current costs, and funds capital commitments.*

Such methodology must support a continuum of services pursuant to IDEA, from integrated and itinerant services to full day center-based programming, consistent with the requirements of the child's Individualized Education Plan (IEP).

Background: Preschool programs provide services to children ages 3 to 5. The statewide preschool program is critical to transition youngsters to elementary education settings by minimizing developmental problems before school age. Responsibility for determining funding levels and allowable program types rests with the State Education Department (SED). As preschool programs diversify services to offer more itinerant, half-day and integrated options, the current funding methodology often undermines these efforts. Last year, legislation was passed to update the funding methodology, but was vetoed by the Governor. NYSARC, Inc. will continue to advocate for enactment of this measure.



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Immediate Legislative Issues

D) FEDERAL LAW

ISSUE #8: Direct Support Professional Fairness and Security Act of 2009

Recommendation: Promote introduction and co-sponsorship of "The Direct Support Professional Fairness and Security Act of 2009" to amend Title XIX of the Social Security Act and provide Medicaid funds to states, enabling them to increase wages paid to direct support professionals who provide services to individuals with disabilities.

Background: This legislation is the outcome of a campaign by national advocates to improve the wages for the nation's non-public direct support professionals providing services to persons with disabilities. During the 110th Congress it was introduced in the House of Representatives by Representatives Lee Terry (R-NE) and Lois Capps (D-CA) as HR 1279.

The legislation recognizes that substandard wages and benefits paid to non-public direct support professionals are a national crisis.

The "Direct Support Professional Fairness and Security Act of 2009" would, like prior versions of the bill, provide an option to states to eliminate the gap between public and private employees by providing states with enhanced federal Medicaid funding.

It should be noted that NYSARC, Inc. conducted a campaign to encourage New York State's entire congressional delegation to co-sponsor HR 1279. Of the 29 members of the New York delegation, 18 members became co-sponsors.

The "Direct Support Professional Fairness and Security Act" is considered to be a long term initiative by state and national advocates.

Immediate Legislative Issues

ISSUE #9: Preserving Medicaid Reimbursement

Recommendation: Promote legislation to suspend or, preferably, eliminate proposed federal regulations to limit federal Medicaid reimbursement. Specifically, the legislation should be aimed at stopping any attempts by The Centers for Medicaid and Medicare Services (CMS) from implementing regulations cutting, reducing or eliminating Medicaid funding for any service which is depended upon by persons with intellectual and other developmental disabilities.

Background: Last year the Bush Administration and CMS (The Centers for Medicaid and Medicare Services) began issuing a series of regulations aimed at cutting the nation's Medicaid program. A total of seven regulations were issued. They were aimed at a broad variety of Medicaid funded services. One would have destroyed New York State's system of financing its service system by limiting reimbursement to public facilities.

Congress responded to these regulations by passing a series of moratoriums holding implementation of CMS regulations in abeyance. However, the moratoriums initially enacted were slated to expire in April and May of 2008. Eventually Congress enacted a moratorium suspending implementation of 6 of the 7 regulations until April of 2009. The new Congress and President Obama must either extend the moratoriums beyond April 2009 or void the regulations altogether.

Continuing Legislative Issues

A) MENTAL HYGIENE LAW

ISSUE #1: Prohibiting Collocation

Recommendation: Promote legislation prohibiting the collocation of developmental centers and correctional facilities.

Background: Collocating correctional facilities with developmental centers places the vulnerable persons served by developmental centers at an increased risk of harm. Further, associating treatment of persons with intellectual and other developmental disabilities with treatment of prisoners reinforces the old stereotype that persons with intellectual and other developmental disabilities are outcasts from society.

ISSUE #2: Requiring a Plan for Closure of all Developmental Centers

Recommendation: Promote legislation that establishes an annual plan to address closure of Developmental Centers, and assures continued community based development.

The plan must ensure that Developmental Center closures proceed in accordance with laws pertaining to humane placement and with input from consumers, parents, advocates, and other concerned individuals. The development of appropriate services for individuals with special needs (i.e., behavioral, medical, etc.) must be clearly identified.

Individuals with intellectual and other developmental disabilities, who have been identified as having criminal and/or other behaviors, which put themselves or the community at risk, require highly structured environments. For the protection of these individuals and the community at large, NYSARC, Inc. acknowledges the need of OMRDD to operate specialized treatment units subject to strict oversight.

Continuing Legislative Issues

ISSUE #2: Requiring a Plan for Closure of all Developmental Centers (Cont'd)

Background: 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 the community. NYSARC, Inc. continues to support closure of Developmental Centers and the development of necessary community based services to accomplish this goal.



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2008-2009 NYSARC, Inc. Executive Committee Members

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2009 NYSARC, Inc. Governmental Affairs Committee

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