



***NYSARC, Inc.***  
***2012***  
***Legislative Platform***

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

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**393 Delaware Avenue  
Delmar, New York 12054**

Telephone: (518) 439-8311

Fax: (518) 439-1893

E-mail: [nysarc@nysarc.org](mailto:nysarc@nysarc.org)

Website: [www.nysarc.org](http://www.nysarc.org)

# 2012 LEGISLATIVE PLATFORM

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**NYSARC, Inc.**  
**LEGISLATIVE AND POLICY PRIORITIES**

NYSARC supports the necessity of overhauling the current developmental disabilities system in New York State in order to achieve efficiencies necessary to adapt to a prolonged period of fiscal austerity. The well-being of our State's most vulnerable people depends on successfully undertaking this task.

To this end New York State is seeking federal approval for a system wide 1115 Medicaid Waiver. This will 1) eliminate current controversial rate setting methodologies and 2) pave the way to replace the existing fee for service system with a system based on principles of managed care. NYSARC supports the need to adapt to the current fiscal reality but reserves judgment on how that should be accomplished.

NYSARC believes that the Waiver must create a politically defensible and financially sustainable system that affords appropriate opportunities for all people with developmental disabilities in need.

Building this new system will require a mix of legislative and non-legislative strategies. The exact mix of strategies will be dictated by rapidly changing circumstances including very real political, financial and economic constraints on policy makers at every level of government.

**I. The New Waiver and Managed Care Environment**

The Waiver constitutes the financial context within which the entire developmental disabilities system may, according to current State plans, operate according to managed care principles. Within this environment, NYSARC will pursue key objectives. These include the following:

1. ***NYSARC Objective:*** Promote an 1115 Waiver that protects existing federal funding levels and provides additional funding to support necessary growth. The Waiver must recognize the lifelong needs of people with developmental disabilities. It must embrace their rights as full citizens of their community and reject a return to the substandard custodial care which their families fought to eliminate decades ago.

***Background:*** The Waiver will eliminate current controversial funding methodologies. Instead funding levels for New York State's developmental disabilities services will be negotiated between the State and federal government.

There is a risk that the federal government will use this opportunity to reduce funding to New York State's developmental disabilities system based on what it regards as questionable practices by the State. Nonetheless, these practices are all legal and approved by the federal government to meet legitimate, sometimes federally mandated, policy objectives. However, NYSARC agrees that the current funding methodologies represent an enormous political liability to the system of developmental disabilities and the people who depend on it.

Without the benefit of the current funding methodology, NYSARC must, as appropriate, advocate to preserve the current level of federal funding. NYSARC has been the leading advocate in Washington on this issue, a fact which has been strongly recognized by the State.

Further, NYSARC should, as appropriate, advocate for an adequate growth factor to support additional opportunities for people in need, including out-of-home residential placements. People must not be allowed to languish at home either for lack of services or because aging parents find themselves in a situation where they can no longer provide adequate care.

- 2. NYSARC Objective:** Promote a system that creates a sustainable and comprehensive array of services during a period of prolonged fiscal uncertainty.

**Background:** A new fiscal reality will require a service system that can generate efficiencies essential to providing quality services during a period of prolonged fiscal austerity.

In the event that, as planned, managed care does become the basis for New York's developmental disabilities services system, NYSARC must organize and position itself to provide the most benefit to the people it serves within the new environment. However, many details on the new environment are unresolved. As these details are clarified NYSARC must be ready to advocate where appropriate at an administrative or legislative level in either Washington or Albany.

- 3. NYSARC Objective:** In the event that managed care becomes the basis for a "reformed" services system, it must continue the current emphasis on enabling people with developmental disabilities to acquire, retain and enhance lifelong skills necessary to fully participate in society.

**Background:** Traditional managed care is based on a medical model which treats people for a curable illness. Developmental disabilities are not an illness but rather are a lifelong condition which, without ongoing help and intervention, diminishes the quality of an individual's life robbing them of the ability to play a meaningful role in their community and lead a fulfilling life. Without such support and intervention services become merely custodial. That is what parents and advocates fought for years to get away from.

NYSARC must ensure that any managed care system continue to promote employment, community integration, social and physical skills which are critical to full, lifelong participation in society. Any outcome measures used in managed care must be appropriate to the needs of people with developmental disabilities.

- 4. NYSARC Objective:** In the event that managed care becomes the basis for a "reformed" system, it must continue to emphasize rewarding Direct Support Professionals with adequate salaries, benefits and other strategies to promote their fulfillment and commitment.

**Background:** Ensure that direct support professionals are adequately compensated for work which is difficult, challenging and the foundation of all services provided by NYSARC and other organizations serving persons with developmental disabilities.

This has always been at the core of NYSARC's legislative efforts since the ability of our chapters to perform their central mission will rise and fall on our ability to recruit and retain a committed and qualified workforce.

Budget advocacy is central to the ability of non-profit agencies to pay decent wages and benefits. In concert with other groups advocating for and serving people with developmental disabilities, NYSARC has been a leader in the effort to advocate with the Governor and NYS Legislature to protect funding for voluntary operated services in order to provide the resources for direct support professionals.

5. **NYSARC Objective:** In the event that managed care becomes the basis for a "reformed system" it must provide services and residential placements for persons on the waiting list. Along with more traditional models, opportunities for shared-living and enhanced family care should be included in such development which must recognize the lifelong needs of people with developmental disabilities.

**Background:** A shortage of services exists for people with developmental disabilities and their families. In particular new residential development for people needing out of home care but living at home has either been terminated or cancelled. For many families it means that aging parents who have cared for their child throughout their life are forced to somehow continue providing that care. Not only is this contrary to State policy as firmly established through NYS-CARES, but it is also contrary to NYSARC's longstanding belief that in such situations families must have access to out of home placement. To meet this objective, NYSARC supports the adequate development of appropriate residential models. NYSARC also recognizes that without an adequate transportation system to tie residential and non-residential services together, the notion of comprehensive care that ensures people with developmental disabilities a meaningful role as full citizens of their community becomes meaningless. Adequate transportation is indispensable.

## II. Medicaid/Federal Entitlements

Medicaid funds approximately 90% of services to people with developmental disabilities in New York State. Nationally, it is seen as a "lifeline" for people with developmental disabilities. At both the State and federal level, Medicaid is seen as a major factor contributing to unsustainable spending and thus is under pressure from both levels of government. Protecting Medicaid is a top priority for all advocates throughout the nation. In the absence of an adequate Medicaid program, almost all other priorities become unattainable.

1. **NYSARC Objective:** Advocate to protect Medicaid on the State and especially the federal level.

**Background:** The Debt Ceiling bill enacted by Congress requires a bipartisan commission to propose \$1.5 trillion in savings. Medicaid, among many other programs, will be closely examined. While it is not clear that Congress will be able to accomplish this task, working closely with the Arc US we will take whatever advocacy steps are necessary to protect Medicaid during this process. The commission's proposal is due to Congress on November 23<sup>rd</sup>.

However, it is very unlikely that the assault on Medicaid will end with whatever decision is reached by the bi-partisan commission. Cutting Medicaid and other entitlements are seen by many as essential to deal with the federal deficit. As long as concern about the federal deficit remains, advocates must be concerned with protecting the Medicaid program.

2. **NYSARC Objective:** Advocate to protect SSI and SSDI on the State and especially federal level.

**Background:** SSI and SSDI provide critical monthly cash benefits to support people with developmental disabilities independently and in programs across New York State. For example, in New York State, SSI provides \$360 million to supplement persons in 24 hour programs. SSDI on the other hand is critical to persons with disabilities who have worked and have lost their jobs due to the ongoing strain on the economy. Other SSDI recipients may never have worked but receive SSID due to the death, retirement or disability of their parents. Both entitlement programs are at risk in the continuing battle over the federal budget deficit. Further, these programs depend on discretionary funding for various administrative functions. Discretionary funds are especially at risk during the fight over the deficit. While the importance of Medicaid has largely eclipsed SSI and SSDI they too are at risk and play a critical role in the lives of tens of thousands of people with developmental disabilities.

### III. Enhancing Quality and Curbing Abuse

Over the past year quality of care and abuse has emerged as a major issue. The New York Times wrote a major expose on abuse in State operated programs. Clarence Sundram, former head of the CQCAPD is heading up an effort by the Cuomo Administration to propose major systemic overhauls, including possible legislation, to fight abuse in both State and voluntary programs. Last session NYSARC proposed its own bill the substance of which may be incorporated into the new State contract with CSEA. Abuse and quality are tightly linked to the availability of funding to provide adequate resources to maintain a quality environment and to recruit, retain and train staff who can be trusted to provide high quality care.

1. **NYSARC Objective:** Promote legislation terminating employees with substantiated allegations of serious physical or sexual abuse.

**Background:** In response to the March 2<sup>nd</sup> *New York Times* story, NYSARC initiated legislation to terminate employees with substantiated allegations of physical or sexual

abuse. The *Times* reported on repeated instances in State operated group homes of employees with serious substantiated allegations of physical or sexual abuse who were given minor penalties only to return to work to repeatedly commit the same offense. NYSARC proposed its own legislation to resolve this matter. The legislation applied to both State and voluntary programs. Senate 5257 by Carlucci and Assembly 7670 by Weisenberg was held in Committee pending resolution of the CSEA contract. Subsequently the contract was finalized and may be implemented to achieve the purpose of NYSARC's bill. A decision is due shortly.

2. ***NYSARC objective:*** Promote legislation to create a dedicated state unit to conduct investigations into allegations of serious physical and sexual abuse; require that serious physical and sexual abuse be defined; and, require timeframes for completing investigations and any resulting due process.

***Background:*** Currently, investigations of allegations of serious physical or sexual abuse are performed by agencies across the state often using inexperienced investigators, different methods and standards for arriving at a determination. This leads to inconsistent results that may be unfair to employees alleged to have abused an individual and may open an agency up to legal action for an arbitrary finding. The perception of a conflict of interest created by agencies conducting their own investigations further undermines the process. The use of an independent State government unit with the sole responsibility for investigating such serious allegations would ensure the presence of experienced, well-trained investigators applying the same standards across the State. It would eliminate the threat of litigation to voluntary agencies and transfer that threat to the State. The unit would investigate across similar systems under the jurisdiction of a variety of State agencies. That would force the most serious allegations to be defined according to a common standard and ensure that they get the attention they deserve. Further, for NYSARC in particular, by limiting litigation against voluntary providers, this approach narrows the spillover liability chapters share as part of a single corporation.

#### IV. **Prevention**

The most effective way to deal with developmental disabilities is to prevent them in the first place. Prevention has always therefore been a top priority for NYSARC.

1. ***NYSARC Objective:*** promote legislation imposing a tax on alcoholic beverages.

***Background:*** Fetal Alcohol Spectrum Disorder (FASD) is the leading preventable cause of intellectual disabilities and birth defects. We are just beginning to understand the massive costs that prenatal alcohol exposure exacts on our society - economically and in human terms. Furthermore, recent research suggests that alcohol exposure may have multi-generational "epigenetic" effects.

Research has also shown that a modest increase in alcohol taxes is a "win-win" which both reduces alcohol problems (especially underage and heavy adult drinking) and raises revenue for addiction, health, and human services organizations. For example, according to information provided by The New York Alcohol Policy Alliance (NYAPA), a dime-a-drink increase in alcohol taxes in NYS could be expected to generate about \$540 million in revenue.

While securing a tax increase of any kind will be very challenging in this political climate, a similar effort in Maryland recently accomplished this feat through a careful, well-designed advocacy strategy. Key partners in the Maryland campaign included the developmental disabilities community - including the Maryland Development Disabilities Coalition and the Arc of Maryland.

## V. Special Education

1. **NYSARC Objective:** Advocate and promote legislation as necessary to continue to protect State funded Early Intervention Services and federally funded Part C state grants which support state early intervention services.

**Background:** Early Intervention Services have been shown to improve the skills of children with disabilities and obviate the need for additional services later in life. Preserving these services is very important in the development of young children with disabilities. This year Early Intervention Services suffered a 5% across the board cut which will result in a diminution of services to very young children and families. Further, federal Part C grant funds are primarily used for administration which is crucial to Early Intervention services. The federal Part C program has historically been woefully underfunded which has put great stress on states to maintain this program. These funds are under threat in Washington along with other discretionary funds as a result of current agreements to slash the federal deficit.

## VI. Employment

1. **NYSARC Objective:** Promote legislative or administrative action, as appropriate, to encourage employment opportunities for people with developmental disabilities through, for example, tax incentives and any other means that would facilitate this objective.

**Background:** In the current economic environment it is difficult for individuals with disabilities to find employment. Many individuals with developmental disabilities want to work but cannot find work. This is true of others with disabilities. As an example, veterans are finding difficulty in finding jobs.

Also, people with developmental disabilities may be performing tasks which could qualify as paid employment in, for example, Day Habilitation programs.

Every opportunity to bring people with developmental disabilities must be explored and, when practical, pursued.

2. ***NYSARC Objective:*** Engage in federal advocacy to protect funding for Supported Employment.

***Background:*** New York State along with other states receives federal Supported Work state grants under Title VI of the Rehabilitation Act. The Obama and Bush Administrations both have tried to eliminate this program. As a discretionary program it may be subject to additional cuts or elimination pursuant to deficit reduction legislation recently agreed to by Congress and signed by the President. Supported Employment is critical to our central goal of supporting people to attain full and meaningful lives.