



NYSARC, Inc.
2017 Proposed
Legislative Platform

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

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2017 PROPOSED LEGISLATIVE PLATFORM

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2017 Proposed Legislative Platform

Introduction

As an organization of families of persons with disabilities, NYSARC's Legislative Platform addresses issues of vital interest to individuals with developmental disabilities. The Platform incorporates issues that we believe must be considered by the Legislature as part of the state budget, follow those issues considered in the state budget and following the passage of the budget. Often, issues are considered both as part of the budget and as individual bills outside the budget.

All of the issues which are being highlighted in NYSARC's "It Matters to Me, Too!" grassroots advocacy campaign are an integral part of NYSARC legislative advocacy activities. The 2016 legislative session effectively set the stage for the current campaign. That campaign, in turn, sets the stage for the 2017 legislative session by reinforcing key advocacy messages around issues such as wages, residential development, employment, and preschool.

For example, the issue of insufficient wages for Direct Support Professionals (DSPs) and other developmental disability support workers was the subject of both 2016 budget and post-budget advocacy. While wages are a perennial issue, this year the discussion was greatly intensified by the enactment of \$15 per hour minimum wage. This issue has a direct impact on the services and supports Not-for-profits can provide for people with developmental disabilities. Not-for-profits serving people with developmental disabilities must rely on the state to fund the minimum wage increase and the preservation of career ladders, as the lowest wage workers are brought up to the new minimum wage in annual increments. However, funding provided by the state is woefully insufficient and salaries to DSPs remain far short of a reasonable living wage, given their significant responsibilities. Furthermore, the state has refused to address the preservation of the career ladder in funding our field.

Residential placement development is non-existent. People with developmental disabilities and their families cannot be told to wait for a crisis before placement becomes available. The resources contained in the budget to provide out of home residential placements for people living at home, especially those with aging caregivers, is also far short of what is needed and that issue is the subject of on-going advocacy in both the state budget and the legislative session.

It is critical to note that given the fluid nature of events, the NYSARC Legislative Platform must evolve with changing circumstances, often by adding initiatives not included in the original platform to adjust for circumstances that evolve in the budget and during the legislative session.

The #bFair2DirectCare campaign brings together all of the major developmental disability organizations in New York State to jointly advocate for higher wages for DSPs and other support workers. NYSARC has been instrumental in the leadership of this coalition and the development of its advocacy agenda. The failure to provide adequate wages puts all of the people we serve at risk.

New Legislative Initiatives:

1. **Addressing Residential Development**

NYSARC is engaged in a multi-faceted grassroots advocacy campaign to increase residential development, especially with regard to aging caregivers living at home. As a result of NYSARC's advocacy, OPWDD must now keep an updated waiting list and \$120 million was included in the current 2016-2017 state budget, with \$10 million reserved for people who are at home and are not yet experiencing an emergent situation.

- ❖ **S.6767-B: FAIR ACT** by Chairman Hannon/A.9483 by Chairwomen Gunther, which was drafted with NYSARC leadership, would enact the FAIR Act (Fair Access to Individualized Residences) to give family caregivers the right to request a "caregiver assessment" from OPWDD and, depending on the outcome, an immediate out of home residential placement. The Acting Commissioner must provide an explanation of his or her decision. If a family caregiver disagrees with the decision, the caregiver has the right to an appeal.

The FAIR Act is in response to the acute shortage of out of home residential placements for people who live at home, which has resulted in a waiting list of crisis proportions. Some individuals have not been given the priority for placement which they deserve based on the age, disability, functional level, and circumstances of their family caregivers. Currently, family caregivers must die before a placement is granted to their family member with developmental disabilities. While the \$10 million is intended to begin addressing this crisis, tens of millions more would be needed to make meaningful progress.

Currently, the faces of those individuals impacted by this crisis are lost in a maze of bureaucratic messaging. This bill lays out a transparent process for holding the state accountable for the impact of its policies on distinct individuals and their families.

Status: The bill was amended on the Senate floor but did not pass. The Assembly bill was not amended. The Governor's Office and OPWDD registered concerns and draft amendments were shared with them, but their response was not forthcoming and the legislative session expired. This bill went through multiple iterations during the legislative session and NYSARC will be working to secure support from parent groups prior to the next legislative session.

Recommendation: Continue in the 2017 legislative platform.

- ❖ **S.6840 Bank Settlement Trust Fund to Provide Residential placements for Individuals with Disabilities** by Chairman Ortt/A. 9309 by Assemblyman Weprin establishes a trust fund to provide people living at home with out of home residential placements. The funding is provided through monies received by New York State through settlements with various banks. Those settlements have thus far totaled more than \$5 billion. The bill is in response to the acute shortage of out of home residential placements for people living at home due to insufficient resources. New York State has experienced a huge windfall of monies from various bank settlements -- a small portion of which could substantially resolve this crisis.

Status: The bill was held in the Senate and Assembly Mental Hygiene Committees. NYSARC will work to get the bill introduced in the next legislative session but progress in the Legislature will struggle against other priorities established by the Governor and Legislature for the expenditure of bank settlement monies.

Recommendation: Continue in the 2017 legislative platform.

2. Addressing Rate Rationalization

During 2016, it became evident that problems with Medicaid payment systems were intensifying and legislative action would be necessary. Rate Rationalization, unless addressed, will significantly adversely affect the delivery of necessary services to people with developmental disabilities. NYSARC has been working with the Acting Commissioner of the Office for People With Developmental Disabilities (OPWDD) to resolve a growing number of problems but also recognized that a legislative route would be necessary.

- ❖ S.7668-A Addresses Rate Rationalization problems by Chairman Ortt/A.10501 by Chairwomen Gunther, which was drafted with NYSARC leadership, requires the Commissioner of the New York State Department of Health (NYSDOH) and OPWDD to prepare recommendations to resolve problems caused by rate rationalization. Rate rationalization is a state/federal attempt to move New York's developmental disabilities system to a cost based reimbursement methodology in the wake of the controversy over the \$5,000 per day institutional rate. However, the approach ignores complex funding realities which have developed over decades. For example, savings from efficient operations are essentially confiscated by the State rather than being reinvested, as they have been for years, in chronically underfunded programs and costs. The placement of a budget neutral cap on the field of developmental disabilities ignores rising costs due to increasing needs of aging program participants, the growing population aging out that need adult services and from an unending stream of costly new mandates.

While the financial stress created by rate rationalization in the developmental disabilities system exacerbates or even creates many issues which receive considerable attention from advocates, it has never been formally brought to the Legislature. This legislation is the first attempt to involve the Legislature formally in the issue. It requires the NYSDOH to correct problems caused by rate rationalization.

Status: While the bill passed the Senate, the Assembly did not have sufficient time to resolve technical issues relating to the bill at the end of session. Both houses expressed strong support for the issue and the bill is well positioned for 2017 when NYSARC expects that it will be reintroduced. However, NYSARC expects to take a multifaceted approach to rate rationalization which utilizes political strategies that go beyond legislation, including work with the Acting Commissioner of OPWDD, working with federal regulatory strategies with the Centers for Medicare & Medicaid Services (CMS), and litigation.

Recommendation: Continue in the 2017 legislative platform.

3. Addressing Implementation of New Regulation

- ❖ S.7619 Regarding implementation of new regulations that adversely affect the delivery of services and access to services by people with developmental disabilities by Chairman Ortt/A.10447 by Chairwomen Gunther provides a 90 day implementation window after a final regulation is issued. OPWDD has established a pattern of finalizing regulations on the date that they also become effective, leaving no time for implementation. For example, final regulations requiring the Supported Employment Programs (SEMP) to bill in 15 minute increments were published the day those regulations took effect. This issue can result in the reduction of programs and services because organizations that serve individuals with disabilities cannot maintain themselves in this environment. This very significant change required changes in billing and accounting systems, which took months. However, providers had to implement changes immediately if they were to continue billing and avoid audit risk by the Office of the Medicaid Inspector General. This unfairly presented providers with an impossible task.

Status: The legislation passed the Senate and was held in the Assembly. The Assembly bill was introduced as Assembly Committees were closing down, leaving insufficient time to resolve certain technical issues. However, substantive support for the bill in both houses was strong and NYSARC expects the measure to be reintroduced in the next legislative session.

Recommendation: Continue in the 2017 legislative platform.

Recommended Continuation of Prior Year Legislative Initiatives

1. State Budget, Managed Care, Employment, Transportation, Preschool and Justice Center

1. State Budget - NYSARC will continue to vigorously advocate to protect and enhance funding levels for OPWDD funded programs, and advocate against any state budget cuts. There are three issues which stand out:

a. Out of home residential placements. Additionally, funds must be provided to support the development of new residential placements to meet the increasing demand for people living at home who require out of home residential settings. This includes advocating to continue the highest priority for placement of students aging out of residential school placements.

Status: Resources are critical to create the additional out of home residential placements essential to resolve this crisis. NYSARC will continue to advocate for a transparent waiting list process as well as for additional new funding in the 2017-2018 budget. The \$10 million in the 2016-2017 budget was wholly inadequate to meet current and anticipated future need.

b. Direct Support Professional and Other Support Workers' Wages. It is absolutely critical to enhance funding to support an adequate living wage for direct support staff and other low paid personnel. This is especially important in view of the enactment of legislation increasing the minimum wage to \$12.50/\$15 an hour by 2021. The increased minimum wage will make alternative employment more attractive for DSPs unless increased funding is made available to pay them a competitive wage. This is essential to reverse increasing employee turnover and vacancy rates. The enacted 2016 budget was insufficient and recognized neither the needs imposed on the system through the new minimum wage nor the tremendous responsibilities of DSPs. Without adequate and qualified staffing, our children's lives are placed at risk.

Status: Advocating for adequate and appropriate wages has become the focus of a major ongoing effort of a coalition of all major developmental disabilities providers in New York State. NYSARC helped to found the coalition and was the driving force behind the "bFair2DirectCare" campaign. The effort will continue until the FY 2017-18 budget is finally passed by April 2017 and beyond. The coalition is proposing a ***Budget Stabilization Fund*** to address the current 9.3 percent vacancy rate and 23 percent one-year turnover rate for DSPs and other support staff. The fund would transition staff to an hourly living wage that exceeds the minimum wage over the next six years.

c. Preschool/Early Intervention. Advocate to protect funding in the State budget for Early Intervention and Preschool programs.

Status: The preschool program serving children ages 3 to 5 has been the object of continuing austerity measures by the state. Specifically, the state reimburses the programs at 94 percent of allowable cost and even less of actual cost. Further, the methodology for

reconciling rates from year to year with actual costs does not allow providers to retain funds essential to make critical investments. As a result, many of NYSARC's 19 preschool programs are at risk of shutting their doors within the next few years, unless relief is forthcoming. Last year, preschools received a 2 percent inflation factor, after being frozen for several years.

For this year's budget (FY 16-17) preschool providers, including NYSARC, advocated for a funding increase of 4.8 percent to help bolster the program. Currently, a 4 percent increase was recommended by the SED and is now before the DOB for approval. It is likely that the DOB will only approve a portion of the 4 percent. However, that increase, even if approved, is too small to significantly decrease the fiscal strain on preschool programs.

- d. DDAQEF - The Development Disability Access and Quality Efficiency Fund (DDAQEF) is NYSARC's proposal to provide monies to support transformation and provide investments to facilitate efficiency, modernization, and transition to managed care. The hospital system, through a series of massive grant programs totaling billions of dollars, has been provided with exactly this kind of funding. Similar treatment should be accorded to the developmental disabilities system, particularly in light of the enormous demands and mandates placed on it.

Status: NYSARC actively discussed this proposal with the Division of the Budget (DOB) prior to the release of the Governor's proposed budget for the current fiscal year. DOB greeted the idea enthusiastically, but the concept has yet to move beyond the discussion phase with budgetary decision makers in the Governor's office. NYSARC will continue pursuing the DDAQEF with the Governor's Office and is also considering other approaches to the needs the DDAQEF addresses.

Recommendation: Continue these budget priorities in the 2017 legislative platform.

2. Managed Care - In the event that managed care becomes the basis for a "reformed" system, it must 1) continue to maintain a habilitative model of care; 2) emphasize the needs of DSPs by providing adequate salaries and benefits; 3) include a growth factor to provide home and community based placements for people with developmental disabilities on the waiting list; and, 4) use regulations to efficiently and cost effectively enhance and protect quality.

Status: OPWDD will release updated managed care guidance -- including an operational roadmap, incremental implementation steps, and a timeline to voluntary implementation -- towards the end of the summer. OPWDD appears interested in the development of care coordination models and would likely look favorably on groups of not-for-profits that would be interested in trying different approaches to care coordination. OPWDD would also like to move gradually to the realm of value based purchasing (VBP).

To ensure successful implementation of VBP and managed care, NYSARC is advocating for investments in information technology; for provider fiscal stability in a rate rationalization environment; increased standardization; and new models of care coordination. In addition, time and investment will be necessary for the development of organizational collaborations capable of supporting VBP and initial VBP initiatives should be upside only, with no fiscal penalties for not attaining goals.

Recommendation: Continue in the 2017 legislative platform.

3. Employment – The goal of encouraging more of our children to work is admirable; however, it can only happen if adequate resources support a meaningful workplace. Advocate for 1) enhanced employer tax credits to encourage the hiring of people with developmental disabilities; 2) additional funding for job coaches; 3) additional funding for other supports to enable people with developmental disabilities to retain jobs, and 4) creation of jobs in the state workforce for people with developmental disabilities. Also, defend the ability to continue to pay a subminimum wage, when appropriate, pursuant to section 14(c) of the Fair Labor Standards Act.

Status: No additional employer tax credits were passed this year and it is unclear how much funding was actually included in the state budget for additional job coaches and other employment supports for people with developmental disabilities. NYSARC continues to take an active role in the development of the rules and regulations for the transformation of workshops into integrated businesses. Regarding the subminimum wage, NYSARC continues to advocate to members of the NYS House Delegation why a bill in Congress to phase out 14(c) of the Fair Labor Standards Act was ill advised. The subminimum wage is critical in order to provide employment opportunities for individuals not capable of earning minimum wage.

Recommendation: Continue in the 2017 legislative platform.

4. Transportation - Advocate for adequate transportation to bring people to work, day settings and recreational opportunities.

Status: A study bill was passed as part of the FY 15-16 budget. The bill made OPWDD the lead agency to conduct a study to create more efficient ways to utilize transportation opportunities and expand transportation for employment, recreation and other program opportunities. A consultant has been hired and retained for this purpose. The State of Massachusetts was being held up as a model for the way it transformed its transportation services for human services including services for people with developmental disabilities.

Recommendation: Continue in the 2017 legislative platform.

5. Justice Center Reform - NYSARC proposes to amend the “Protection of People with Special Needs Act” in order to correct, simplify and streamline required background checks, incident reporting requirements and investigative processes which have served to impede the hiring of qualified personnel and lead to other problems that needlessly tie up resources critical to maintain adequate care.

Status: The Governor’s Office was noncommittal to NYSARC’s draft legislation amending the “Protection of People with Special Needs Act.” Several potential legislative sponsors decided to “take a pass” on introducing the bill during 2016. This underscores the sensitive nature of attempting to make legislative changes in the operation of the Justice Center even if the reasons are to increase its efficiency and effectiveness. NYSARC will continue looking for appropriate legislative sponsors to assist us in moving this legislation forward.

Recommendation: Continue this in the 2017 legislative platform.

Other Individual Bills

- Employment First Choice Act (S3893 by Senator Young/A5959 by Chairwomen Gunther). This legislation, initiated by NYSARC, gives people in workshops the right to choose to remain in those settings. The bill is in response to the State's original plan to close all workshops irrespective of the hardships it would cause individuals who have come to rely on them for a paycheck and a network of longtime friends. This bill is modeled after the consent decree between the State of Rhode Island and the U.S. Department of Justice. The Rhode Island Consent Decree seeks to minimize the use of workshops, but also recognizes the right of individuals, consistent with the US. Supreme Court's Olmstead Decision, to choose to remain in them.

Status: The bill served to focus the Administration's attention on the workshop issue and seems to have helped provide the state with the incentive to decide not to close workshops and instead adopt an administrative approach to making workshop locations more integrated and more a part of the broader community. A plan to accomplish this was jointly developed between providers and OPWDD. The plan is expected to be submitted to CMS for approval this fall.

Recommendation: Continue as part of the 2017 legislative platform until such time as the plan to continue workshops as integrated employment settings is approved by CMS.

- Customized Job Programs (S5805 by Senator Young/A8111 by Assemblyman Santabarbara). This legislation, initiated by NYSARC, would create a pilot program aimed at subdividing State jobs into their simple component parts. Those parts would provide minimum wage, integrated employment for people with developmental disabilities who otherwise could not perform the entire job.

Status: The bill was introduced in the 2015 session and did not pass either house, with legislative staff citing cost as a concern. There also may have been union pressure against the bill.

Recommendation: Continue as part of the 2017 legislative platform.

Legislation and Issues We Are Following:

A. Federal

1. Protecting Medicaid

Protecting Medicaid -The federal/state Medicaid program is the backbone for funding services and supports to people with developmental disabilities across the nation, especially in New York.

NYSARC will advocate to:

- protect Medicaid from federal budget cuts,
- to prevent Medicaid from being converted to a block grant,
- to protect the eligibility of Medicaid recipients, and
- to preserve Medicaid as an entitlement.

Status: There were no imminent threats to the Medicaid program in the past year. For a long period, cutting or constraining the growth of Medicaid was a top priority at the federal level, as one means of controlling federal spending and bringing down the federal deficit. In recent years, the move to do this has subsided, as might be expected with partisan gridlock and a Democratic White House. This could change dramatically, depending on the outcome of the 2016 presidential and congressional elections. The nation's debt continues to be a major issue and Medicaid will continue to be a potential target.

2. Federal Discretionary and Other Key At-Risk Federal Programs

Federal Discretionary and Other Key At-Risk Federal Programs - Advocate to protect key federally funded discretionary programs including

- a. supported employment and
- b. IDEA Part C Early Intervention grants.
- c. protect key at-risk entitlements including SSI, SSDI and Medicaid.

Status: The continuing controversy over federal spending makes all federal programs potential targets for future cuts. This is especially of concern in view of the 2016 Presidential and Congressional elections which, depending on the outcome, could substantially increase the risk to programs that support people with developmental disabilities.

The FY 2017 spending bill for IDEA and Early Intervention has only cleared the Senate Appropriations Committee so far, and includes mostly level funding and minimal increases for a few programs from FY 2016.

While SSI and especially SSDI have long been at risk, efforts to make cuts in those programs were stopped in Congress over the last year, including a proposed 20 percent reduction in SSDI.

B. State

1. Amendments for Article 17A of the Surrogate Court Procedure Act (SCPA)

Last session, OPWDD introduced a departmental bill (S4983 by Senator Ort) overhauling Article 17A of the SCPA in response to concerns that the existing statute authorized guardianship for individuals without sufficient attention to their rights and the due process necessary to protect them. The legislation was the result of the collective work of a group formed by the Governor's Olmstead Counsel and included representatives from NYSARC, Disability Rights New York, NYCLU, and others.

NYSARC, however, still had concerns about the legislation. During the course of the 2015 session NYSARC was contacted by Disability Rights New York (DRNY), which threatened to challenge Article 17A in court unless the bill was passed. NYSARC has since indicated to DRNY that it has drafted amendments to the bill. DRNY seems pleased with that direction.

Status: The bill has not advanced in either the Senate or Assembly. Legislative staff has indicated that they want to fully evaluate any proposed legislation and will rely heavily on NYSARC's advice. NYSARC continues to evaluate the positions of all involved in the 17A debate and will engage in policy discussions to ensure the appropriate legislative direction for the NYSARC guardianship programs and membership.

2. State Education Department (SED) Regulatory Activity

SED Regulatory Activity - Monitor and respond to the SED regulatory initiatives threatening to undermine critical legislative achievements by NYSARC. That includes legislation to give the burden of proof in impartial special education hearings to school districts.

Status: A 2005 US Supreme Court decision, *Schaffer v Weast*, would have placed the burden of proof in special education hearings on parents in a dispute with a school district. In 2007, NYSARC led a large, coordinated legislative effort to successfully nullify that decision as it impacted New York State and maintain the burden of proof on school districts, not parents. Since then the SED has attempted to use regulations to undermine that legislation. However, this year there were no regulatory threats to the burden of proof from the SED.