

# New York Statewide Systems Advocacy Network

## 2009 Annual Report

October 1, 2008 – September 30, 2009

### I. Background

The New York Statewide Systems Advocacy Network (SSAN) is a project that was originally prioritized in the New York Statewide Plan for Independent Living (SPIL) for 2002-2004. Please see text from the Federal Rehabilitation Act of 1973, as amended, below in italics. It is highlighted to emphasize systems advocacy themes consistent with the SSAN.

#### **Chapter 1, Title VII, Section 701: Purpose**

*The purpose of this chapter is to promote a philosophy of Independent living, including a philosophy of consumer control, peer support, self-help, self-determination, equal access, and individual and systems advocacy, in order to maximize the leadership, empowerment, independence, and productivity of individuals with disabilities into the mainstream of American society, by:*

- 1) providing financial assistance to States for providing, expanding, and improving the provision of independent living services; and*
- 2) providing financial assistance to develop and support statewide networks of centers for independent living.*

#### **A. Current SSAN Centers**

The 2007-2010 SSAN contractors are: Southern Tier Independent Living Center, Binghamton; Western New York Independent Living Project, Buffalo; Access to Independence, Cortland; Resource Center for Accessible Living, Kingston; Brooklyn Center for Independence for the Disabled, Brooklyn; Finger Lakes Independence Center, Ithaca; AIM CIL, Corning; Directions in Independent Living, Olean; Catskill Center for Independence, Oneonta; Center for Independence of the Disabled in New York, Manhattan; Independent Living, Inc., Newburgh; North Country Center for Independence, Plattsburgh; Regional Center for Independent Living, Rochester; Center for Disability Rights, Rochester; ARISE, Inc., Syracuse; Resource Center for Independent Living, Utica; Northern Regional Center for Independent Living, Watertown; Westchester Independent Living Center, White Plains; and Westchester Disabled on the Move, Yonkers.

#### **B. Reporting and Data Collection**

All data regarding the activity of SSAN contractors was collected and entered into the online database housed on the NYAIL website by ILC staff. The data collected is based on performance measures defined by the annual contracts each center has with VESID. In the current contract year, which is the second year, SSAN centers are required to obtain a performance measure of 90 points or higher, of a total 100 points, to continue funding into the third year. NYAIL compiled the data and wrote the 2009 Annual Report.

### **C. Technical Assistance**

During the 2008-2009 contract period, NYAIL provided ongoing technical assistance to SSAN Centers as needed, often having daily contact with the 19 systems advocates. Technical assistance was provided regarding use of the SSAN listservs, monthly reporting, performance requirements, and substantive issues related to specific SSAN Action Alerts, policy development and the legislative process.

In addition, NYAIL facilitates monthly SSAN conference calls as a means to foster communication and collaboration among advocates. Through the calls, NYAIL provides additional training in all areas as needed, answers questions regarding SSAN performance measures and reporting requirements, provides updates on budget and legislative priorities and related activities, and provides advocates with an opportunity to share issues of concern and ways to improve performance.

During the 2008-2009 contract period, NYAIL planned and facilitated three SSAN training events:

- On December 17, 2008, Richard Male presented a 1½ hour training via conference call, entitled “Community Organizing & Engagement.” Richard discussed the importance of community organizing, organizing techniques, and tips on recruiting and retaining volunteers. Following the training, 80% of participants that completed an evaluation form rated the training and its usefulness to their role as SSAN Advocate as “excellent” or “good”. Several participants also commented that they would have liked the training to be longer and/or suggested a follow-up presentation.
- On January 27, 2009, following NYAIL’s Legislative Day, NYAIL held a full-day in person training in Albany. The event included interactive presentations by NYAIL staff and systems advocates, as well as an opportunity to practice skills. Training topics included how to conduct a legislative advocacy de-briefing session, cultivating media hits and contacts, and tips for local advocacy efforts, including providing persuasive public testimony and letters. All participants who completed forms evaluated the training as ‘excellent’ or ‘good’. Participants expressed overwhelming support for the opportunity to interact and exchange ideas with other advocates face-to-face. In addition, NYAIL facilitated a supplemental conference call to provide highlights of the NYAIL Needs Assessment Report, including how it can be used by advocates to support their work on priority issues.
- During the third quarter, NYAIL facilitated three regional small group meetings that were held on May 21<sup>st</sup> at the Resource Center on Independent Living in Utica, May 27<sup>th</sup> at the Center for Disability Rights in Rochester, and June 1<sup>st</sup> at the Westchester Independent Living Center in White Plains. Advocates were invited to attend the meeting nearest to their center. In addition, invitations were extended to ILCs that do not have SSAN contracts with the goal of increasing collaboration among advocates on a regional basis.

The regional meetings were primarily an opportunity to further enhance peer-based mentoring within the network and encourage ongoing direct contact and learning among advocates. Participants were asked to discuss their center in more detail, such as size, counties served, and services provided. Advocates also discussed regional housing and transportation issues at great length, including ways in which their center is involved in related activities and advocacy efforts, and local organizations with which they collaborate on these issues. It is NYAIL's hope that these regional meetings have helped to lay the groundwork for increased communication and collaboration among centers on advocacy issues.

## II. Collective Impact

The following is a summary of the progress made by the SSAN contractors as a whole during the October 1, 2008 - September 30, 2009 contract period. The data collected is based on performance measures defined by the annual contracts each center has with the New York State Education Department, Vocational and Education Services for Individuals with Disabilities (VESID). Data collection and scoring charts can be found in attachment I.

- A. Volunteer recruitment:** The collective SSAN recruitment goal for 2009 was 684 new volunteers. From October 1, 2008 to September 30, 2009, the SSAN Centers recruited 953 new volunteers, exceeding the goal by 269 volunteers.
- B. Volunteer training:** The collective SSAN volunteer training goal was 95 training opportunities. In the past year, SSAN Advocates provided 179 training opportunities to volunteers, exceeding the goal by 85 trainings.
- C. Media hits:** The collective goal for media hits was 304. The SSAN Centers exceeded this goal by 148, generating 452 media hits in the past year.
- D. Voter registrations:** The collective voter registration goal for 2009 was 1140. Centers reported 1117 voter registrations for the year collectively, falling short of the overall goal by 23.
- E. Public testimony:** The collective goal for public testimonies was 38. In the past year, 69 public testimonies were presented by the SSAN exceeding the overall goal by 31.
- F. Action Alerts:** The collective goal of the SSAN with respect to Action Alerts was 836 responses to SSAN Action Alerts. Collectively, the network reported 1099 Action Alert responses, exceeding the overall goal with 263 additional action alert responses.

The total number of Action Alerts issued between October 1, 2008 and September 30, 2009 was 62. Issues addressed in alerts included:

**State Issues:**

- Making Timothy's Law permanent (S.5672/ A.8611)
- Amend state Social Services Law in relation to the termination of parental rights (A.6668/S.2835)
- Incorporate Title II of ADA into NYS Human Rights Law (A.781-B/S.5396)
- Waive the State's sovereign immunity to claims under the ADA and Section 504 (A.3651/S.2833)
- Poll Site Access Bill (A.584/S.1058)
- Disability History Week Legislation (A.2242/S.3159)
- Keep Antidepressants OFF the Preferred Drug List
- Change OMRDD's Name to remove the R-word (S.4383/A.7566)
- Assembly resolution K743, urging the US Congress to endorse and support the passage of H.R. 1670, the Community Choice Act of 2009
- Urging Governor Paterson not to appeal the September 7<sup>th</sup> Adult Home decision by Nicolas Garaufis of federal district court in Brooklyn

**Federal Issues:**

- Community Choice Act (H.R. 1670/S683)
- Community First Choice option in health reform
- Ensuring the CLASS Act is included in healthcare reform
- Support Medicaid Matters NY effort to deliver the message about keeping Medicaid strong in healthcare reform
- National Call-in Day for Long Term Support and Services to be included in Health Care Reform
- Participation in NCIL's Virtual Rally in Support of Disability Health Reforms
- Ending the Medicare Disability Waiting Period Act of 2009
- 21st Century Communications & Video Accessibility Act of 2009

**III. Major Systems Advocacy Accomplishments**

Throughout the 2008-2009 contact period, NYAIL has witnessed the increasing strength and visibility of the SSAN in New York State. The advocacy experience, substantive knowledge and organizing capability within the SSAN has resulted in substantial systemic impact for individuals with disabilities and the ILC network. While it is impossible to quantify the precise impact of the network's efforts on the achievements listed below, it is appropriate to say that the SSAN played no small part in affecting change.

**A. Budget Accomplishments**

- Consumer Directed Personal Assistance Program (CDPAP)

The 2009-10 enacted state budget includes \$500,000 for expanding participation in the Consumer Directed Personal Assistance Program, through contracts with peer based programs to provide education and outreach to eligible individuals and training for

discharge planners, LDSS' and others. In addition, the CDPAP statute is amended to require county enrollment targets and annual implementation plans, to promote consistency regarding approved service levels across the state.

- Home Care Funding Cuts

The SSAN was instrumental in helping to stop proposed cuts to funding for home care providers and personal care rates in the November special session and in the enacted 2009-10 State budget.

- State supplement to Social Security Income (SSI)

Although there has been no increase in the state supplement for 20 years, this year, the Executive Budget proposed cutting the state supplement to SSI payments for New Yorkers who are aged, blind or have a disability by over 25% for individuals and couples living alone in the community and 45-70% for those living with others. The SSAN was instrumental in restoring these proposed cuts to the state supplement of SSI in the 2009-10 State enacted budget.

- Enactment of the Special Housing Units Bill "SHU Bill" A.9342 and S. 6422

The 2009-10 Executive Budget proposed to diminish and delay, for an additional three years, the protections afforded by the SHU law, putting off implementation of the law until 2014. In addition, the Governor proposed amending the law to eliminate about half of the correctional beds from the requirements of the SHU law and reduce the training requirements for correctional officers. The SSAN was instrumental in assuring the legislature overturned this proposal in the enacted 2009-10 State budget.

- Prescription drug coverage

Efforts to preserve Medicaid pharmacy benefits for people with psychiatric disabilities were successful in that the proposal to expand the Preferred Drug List to include antidepressants was rejected. Proposals to eliminate EPIC Part D wrap and Medicaid wrap around coverage for dual eligible with Part D were also rejected.

## **B. Major Impacts**—legislation on which substantial progress was made

- Advancement of Title II Bill
  - A.781-B (Paulin): Passed Assembly
  - S.5396 (Huntley): Passed Senate
  - Veto Message No. 61

The New York State Human Rights Law includes some, but not all, of the ADA's protections for people with disabilities. This causes needless confusion for government officials in attempting to comply with both laws. This bill would add ADA Title II language to state statute, clarifying the obligations of government officials and

strengthening the civil rights protections for people with disabilities. This bill imposes no new or additional requirements upon local governments or businesses.

- Advancement of the Polling Site Access Bill
  - A. 584 (Cahill): Passed Assembly
  - S. 1058 (Addabbo): Passed Senate
  - Veto Message No. 60

This bill would require all poll sites to comply with the accessibility guidelines of the ADA. It would also eliminate the practice of granting waivers for inaccessible sites. Waivers have made it possible for counties to avoid having to make inaccessible sites accessible.

- Waiver of Sovereign Immunity Bill
  - A.3651 (Lifton): Passed Assembly
  - S. 2833 (Krueger): sits in Senate Codes Committee

A February 2001 US Supreme Court decision stated that states are immune to claims brought under Title I of the ADA by state employees with disabilities who have been subjected to discrimination. Businesses, schools, cities, counties, towns and villages cannot violate the ADA without the prospect of being held responsible in a court of law. State government must be held to the same standards of conduct. To do otherwise is unfair and unjust. This bill would waive the State's immunity to suit under the ADA and Section 504.

- Making Timothy's Law permanent
  - S.5672 (Huntley): Passed Assembly
  - A.8611 (Morelle): Passed Senate
  - Signed into law – chap 181

Timothy's Law, New York State's mental health parity statute, has delivered greater access to mental health treatment for millions of New Yorkers; however this law was set to expire at the end of 2009. S.5672/A.8611, which would make Timothy's Law permanent, gained strong legislative support by being introduced by Governor Paterson on May 5<sup>th</sup>. The bill subsequently passed both houses and was signed into law by Governor Paterson on July 11<sup>th</sup>.

- Termination of Parental Rights
  - S.2835 (Huntley): Referred to Senate Committee on Children and Families
  - A.6668 (Rivera): Referred to Assembly Mental Health Committee

This bill would amend state Social Services Law Section 384-b to eliminate subdivisions (4)(c) and (6)(a-e), which permit termination of parental rights on the basis of mental illness or mental retardation. The bill roused a great deal of attention this legislative session among legislators, agencies, and advocates. NYAIL is one of over 40 organizations that have signed on to the Coalition Against Termination Discrimination, in

support of this bill. The sponsors of the bill, Senator Huntley and Assemblyman Rivera, have asked state agencies to work with advocates and other stakeholders to come up with a series of recommendations and report to the Legislature by January 15, 2010.

### **C. Federal Issues –**

- IL funding increased in the Omnibus budget bill

On March 10<sup>th</sup>, by a vote of 62-35, the US Senate passed the 2009 Omnibus Appropriation Bill (HR 1105), increasing funding for Centers for Independent Living (CILs) and Statewide Independent Living Council's (SILCs) by 5% from regular appropriations.

- IL funding included in the American Recovery and Reinvestment Act (ARRA)

The American Recovery and Reinvestment Act included \$140M for Independent Living, including \$87,500,000 in Part C and \$18,200,000 in Part B, for a total of \$105,700,000.

- Community Choice Act (CCA) / Community First Choice (CFC) option

The Community Choice Act (CCA), H.R. 1670/S.683, gives people real choice in long term care options. This legislation ends the institutional bias in the Medicaid program by giving individuals who are eligible for nursing facility services or other institutional "care" equal access to community-based services and supports, like attendant services. The SSAN worked tirelessly to garner support for the CCA in New York and to have it included in any healthcare reform bill moving forward. There are currently 19 New York house members signed on as cosponsors, along with New York Senators Kristen Gillibrand and Charles Schumer.

Despite increased support in the House and Senate, the CCA was not being discussed in healthcare reform. Disability advocates worked with Senator Tom Harkin, the bill's sponsor, to develop the Community First Choice (CFC) option as a way to get the key provisions in the CCA in the healthcare reform bill. The CFC proposal for a state option would give states an enhanced federal Medicaid match for providing attendant services and supports as an alternative to institutional placement. New York Senator Schumer introduced the CFC option to the Senate Finance Committee's health reform bill, where it still remains. The SSAN is now working to ensure the CFC option remains in the final health reform bill.

### **D. Public Comment Provided**

Throughout the contract year, SSAN advocates provided testimony to a number of legislative and administrative hearings. Opportunities for testimony highlighted in NYAIL Work Alerts included:

- Most Integrated Setting Coordinating Council (MISCC) Draft Annual Report 2008

- 2010 State Plan for Vocational Rehabilitation and Supported Employment Services (VESID)
- Senate Hearings on Budget Priorities, including Health, Education, Higher Education, and Social Services, including proposed cuts to 2008-09 budget and 2009-10 budget priorities
- Individualized Education Program (IED) diploma
- New York State Board of Elections (NYSBOE) HAVA Implementation Plan
- Senate Standing Committee on Elections
- OMRDD Five Year Plan Feedback Survey
- OMRDD Statewide Comprehensive Plan: 2009 – 2013
- Emerging Trends and People with Disabilities, National Council on Disability (NCD)
- NYS DHCR Draft 2010 Annual Action Plan

**Attached:**

- SSAN Activity Report: October 1, 2008 - September 30, 2009 Point Score Chart