

# **New York Statewide Systems Advocacy Network**

## **2006 Annual Report**

October 1, 2005 – September 30, 2006

### **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 and Support Sites**

As defined in the 2005-2007 SPIL, the network has a two-tiered structure: the SSAN Centers, with a higher funding level, were to take a primary leadership role; the SSAN Support Sites, with less funding, were to provide support to the Centers by increasing the volume of responses to Action Alerts. Through a competitive RFP process, 15 Centers and 18 Support Sites were awarded SSAN contracts with the implementation of the 2005-2007 SPIL. One SSAN Support Site's contract was not renewed in the 2005-2006 contract year. There are currently 15 Centers and 17 Support Sites.

The current SSAN Centers are located in: Binghamton, Buffalo (Western New York Independent Living Project), Cortland, Kingston, Manhattan, Newburgh, Plattsburgh, Rochester (Center for Disability Rights), Rochester (Regional Center for Independent Living), Syracuse, Troy, Utica, Watertown, White Plains, and Yonkers. The current SSAN Support Sites are located in: Albany (*please note: no data was received from the Albany site for this contract period*), Amsterdam, Auburn, Bronx, Brooklyn, Buffalo (Native American Independent Living Services), Corning, Herkimer, Ithaca, Jamestown, Massena, Niagara Falls, Olean, Oneonta, Oswego, Poughkeepsie, and Putnam.

#### **B. Recent Changes**

With the implementation of the 2005-2007 SPIL, NYSILC subcontracted with the New York Association on Independent Living (NYAIL) to oversee coordination of

the SSAN. In October 2005, NYAIL hired a fulltime network coordinator, based in the NYAIL offices in Albany, NY, to oversee the activities of the statewide network. This individual replaced two independent contractors based in Buffalo and Oriskany Falls, NY. Having one SSAN coordinator located in the NYAIL office has created a centralized source of information and eased communication between NYAIL and the network.

With the transfer of responsibility for coordination of the SSAN to NYAIL came the opportunity to redesign the SSAN monthly reporting system. The reporting system used to collect data from the network Centers and Support Sites each month for the first 6-months of this reporting period (October 2005-March 2006) had proven an inadequate tool for accurate data collection and challenging from the users' perspective as well. After a great deal of planning to ensure the system was easy to use and an effective data collection tool, the new monthly reporting system, housed on the NYAIL website, was launched in April 2006. The feedback has been overwhelmingly positive. Data collected starting in April 2006 shows significant improvement with respect to performance at each of the SSAN Centers and Support Sites. This may indicate that the lower numbers reported in previous months were a result, in part, of the inadequacy of the earlier data collection system.

### **C. Technical Assistance**

During the 2005-2006 contract period, NYAIL provided ongoing technical assistance to SSAN Centers and Support Sites as needed, often having daily contact with Systems Advocates. This included technical assistance around use of the SSAN listservs, monthly reporting, performance requirements, the voter pledge database, and substantive issues related to specific SSAN Action Alerts and the legislative process. In addition to providing orientations for new Systems Advocates via conference call as needed, NYAIL provided two Internet and telephone-based trainings (on June 13 and June 15, 2006) to address issues that were identified as training needs in the SSAN 2004-2005 year-end report.

## **II. Collective Impact**

The following is a summary of the progress made by the SSAN during the October 1, 2005 - September 30, 2006 contract period. The data collected is based on performance measures defined by the annual contracts each site 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 attachments I and II.

**A. Volunteer recruitment:** The collective SSAN recruitment goal for 2006 was 744 new volunteers. From October 1, 2005 to September 30, 2006, the SSAN Centers and Support Sites recruited 840 new volunteers, exceeding the goal by 96 volunteers. Five hundred sixty-five of the total volunteers were recruited by Centers, while 275 were recruited by Support Sites.

- B. Volunteer training:** The collective SSAN volunteer training goal was 109 training opportunities. In the past year, SSAN Advocates provided 262 training opportunities to volunteers. This is more than twice the targeted number of trainings. SSAN Centers conducted 165 trainings and 97 were conducted by Support Sites.
- C. Media contacts:** The collective goal for new media contacts made by Systems Advocates was 188. During the past year, SSAN Centers and Support Sites made 264 new media contacts. This number exceeds the goal by 76. One hundred sixty-three new media contacts were made by Centers and 101 were made by Support Sites.
- D. Media hits:** The collective goal for media hits was 342. The SSAN Centers and Support Sites generated 2,121 in the past year! This is more than six times the goal! Out of this total number, 1,441 were generated by Centers and 680 by Support Sites.
- E. Voter registrations:** The collective voter registration goal for 2006 was 804. Centers and Support Sites reported 811 voter registrations for the year, again exceeding the goal. Four hundred fifty-five voter registrations were reported by Centers and 356 by Support Sites.
- F. Voter pledges:** The collective goal for voter pledges in 2006 was 526. SSAN Centers and Support Sites reported obtaining 1,088 pledges from voters; this is more than two times the target number. Six hundred thirty-five pledges were obtained by Centers and 453 by Support Sites.
- G. Public testimony:** Systems Advocates at each of the 15 SSAN Centers are required to deliver oral and written testimony at one public hearing during the contract year. Fourteen of the 15 Centers have met this requirement. While one Center did not meet this requirement, several others far exceeded it. This is not a required activity of SSAN Support Sites; however, 11 reported having provided oral and written testimony at a public hearing. A total of 81 public testimonies were given by Centers and Support Sites in the 2005-2006 contract period.
- H. Public policy subcommittee participation:** Systems Advocates at each of the 15 SSAN Centers are required to actively participate in at least one NYAIL public policy subcommittee. All 15 Centers have reported participation in at least one NYAIL public policy subcommittee. While not a requirement of SSAN Support Sites, seven reported participation in at least one NYAIL public policy subcommittee.
- I. Action Alerts:** The collective goal of the SSAN with respect to Action Alerts was 1,152 responses to SSAN Action Alerts. Collectively, the network reported 1,104 Action Alert responses—this is a 45% improvement over last year's performance. With one less SSAN Center, the network reported 367 more Action Alert

responses in the 2005-2006 contract period. The network fell short of meeting the collective goal by only 48 Action Alerts. SSAN Centers reported 586 responses and 518 were reported by SSAN Support Sites.

The Action Alerts issued between October 1, 2005 and September 30, 2006 addressed the following issues:

### **State Issues:**

*Note: number in parentheses indicates number of SSAN Action Alerts issued on the issue*

- Community mental health recovery and rehabilitation services (1)
- HAVA implementation (9)
- Increasing prescription drug coverage for dual eligibles (6)
- Commission on Health Care in the 21<sup>st</sup> Century public hearings (1)
- EPIC for people with disabilities (2)
- Disaster preparedness public hearing (1)
- Increasing state funding for Independent Living (1)
- Adult home initiatives (1)
- Medicaid Preferred Drug Program (1)
- Housing: Section 504 implementation/Accessible Housing Registry (2)
- Banning use of special housing units (SHUs) for prisoners with psychiatric disabilities (9)
- Blocking state funding cuts/eligibility restrictions for Medicaid (2)
- Access to Home Program (1)
- Housing Waiting List (1)
- Blocking use of seclusion/restraint in mental health facilities (1)
- Incorporating ADA Title III into state law (1)
- Pollster opinion survey – including disability question (1)
- DHCR 2007 Action Plan (1)
- Development of 2008-2010 State Plan for Independent Living (1)

### **Federal Issues**

*Note: number in parentheses indicates number of SSAN Action Alerts issued on the issue*

- Blocking federal budget cuts: Medicaid, housing, education, food stamps, TANF (8)
- Home and community-based services expansion (1)
- Exempting dual eligibles from Medicaid Preferred Drug list (1)
- Money Follows the Person rebalancing demonstration – New York application (1)
- Federal funding for Independent Living (2)
- Blocking federal legislation to undermine state health insurance anti-discrimination policies (1)
- Nursing Facility Transition and Diversion Waiver approval by CMS (1)
- Medicare coverage for Power Mobility Devices (1)

### III. Major Systems Advocacy Accomplishments

Many significant system change outcomes were realized during the 2005-2006 contract period around issues on which the network worked tirelessly. 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. Statewide advocacy organizations, including the New York Association for Psychiatric Rehabilitation Services (NYAPRS) and the Urban Justice Center, and grassroots advocacy leaders such as Tom O'Clair of the Timothy's Law campaign, have publicly recognized the efforts of the SSAN.

#### A. Major Accomplishments—legislative goal achieved in full

- Increase in State Funding for Independent Living Centers (ILCs)  
SFY 2006-07 Final Budget contained a \$1 million increase in funding for ILCs, to bring the Total State funding up to \$11,730,600.
- Extension of Medicaid Coverage to Individuals Dually Eligible for Medicaid and Medicare
  - A.9462 (Gottfried) – Passed Assembly
  - S.6410 (Hannon) – Passed Senate
  - VETO OVERRIDEN BY BOTH HOUSES

Provided temporary emergency prescription drug benefits under Medicaid during the implementation of the federal Medicare Part D Prescription Drug program (through December 31, 2006) for elderly and disabled individuals who are dually eligible for Medicaid and Medicare and who are wrongfully being denied access through Medicare Part D.

- Enactment of Legislation Establishing the ACCESS TO HOME Program
  - A.11687-A (Alessi) – Passed Assembly
  - S.7847 (Bonacic) – Passed Senate
  - CH. 159 of the Laws of 2006

The Access to Home program provides financial assistance to property owners and renters to make existing dwelling units accessible for low- and moderate-income persons with disabilities. Grants are provided to municipalities and eligible not-for-profit entities that have substantial experience in adapting or retrofitting homes for persons with disabilities. Homeowners and renters qualify for a loan or grant from an Access to Home awardee under the following criteria: an occupant has a physical disability or has substantial difficulty with an activity of daily living; the dwelling unit is the primary residence of a person with a physical disability; and the total household income does not exceed 80% of median income.

- Blocked Enactment of Legislation to Expand Use of Physical Restraint for Psychiatric Patients

- A.9986-A (Rivera) – Passed Assembly
- S.6706-A (Morahan) – Passed Senate
- VETO Message #340

Bill would authorize a physician assistant under the supervision of a physician to order the restraint of a patient in a behavioral health setting following a personal examination of the patient.

**B. Major Impacts**—legislation around which progress was made

- Passed Legislation to Restrict the Use of Solitary Confinement in Special Housing Units (SHUs) for Prisoners with Psychiatric Disabilities
  - A.3926-A (Aubry) – Passed Assembly
  - S.2207-C (Nozzolio) – Passed Senate
  - Veto Message #324

Bill would establish correctional facilities that provide for the confinement and medically appropriate care and treatment of inmates with serious mental illness and would exclude inmates with serious mental illness from isolated confinement related to inmate discipline or maintenance of order.

- Advancement of Legislation to Expand Elderly Pharmaceutical Insurance Coverage (EPIC) to People with Disabilities
  - A.3074-A (Koon) – Advanced to Ways & Means Committee
  - S.1357-B (Seward) – Advanced to Finance Committee

Bill would add certain low-income persons with disabilities who are under age 65 to the list of persons eligible to receive benefits from New York's EPIC program, which currently provides prescription drug coverage to certain elderly individuals.

- Advancement of Legislation to Incorporate Provisions of Section 504 of the Federal Rehabilitation Act into State Law
  - A.7867 (Paulin) – Passed Assembly
  - S.4933-A (Morahan) – Advanced to Rules Committee

Bill would require any program or activity relating to housing which receives federal financial assistance to comply with Section 504, ensuring that housing protections offered to people with disabilities under Section 504 are also offered and enforced on the state level.

- Advancement of Legislation to Establish a Statewide Accessible Housing Registry
  - A.7868 (Paulin) – Passed Assembly
  - S.4875-A (Morahan) – Advanced to Finance Committee

Bill would establish a centralized statewide registry of accessible or adaptable housing for people with disabilities to be known as “Access New York,” which would contain up-to-date information regarding the existence and availability of such housing.

- Advancement of Legislation to Create a Housing Waiting List
  - A.2895-A (Rivera) – Passed Assembly
  - S.3653-A (Morahan) – Passed Senate
  - Veto Message #323

Bill would enable the State to track the wait time for persons with psychiatric disabilities seeking supportive, supervised or congregate housing in the Office of Mental Health (OMH) system through the establishment of community housing waiting lists.

- Advancement of Legislation to Incorporate Title III of the Americans with Disabilities Act (ADA) into State Law
  - A.7294 (Paulin) – Passed Assembly
  - S.5074 (Spano) – Passed Senate
  - Veto Message #329

Bill would clarify the scope of protections against discrimination on the basis of disability in the area of public accommodations to be consistent with the ADA to improve enforcement on the state level.

### **Attachments**

- Attachment I: October 1, 2005 - September 30, 2006 Activity Chart
- Attachment II: October 1, 2005 - September 30, 2006 Point Score Chart