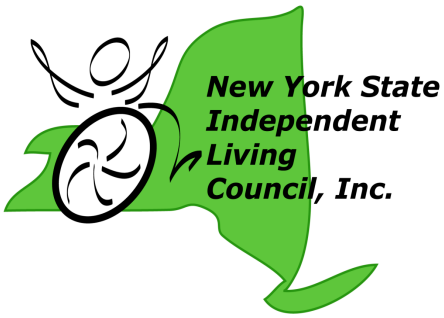


# 2012 Annual Report

**Brad Williams, Executive Director**

**Prepared May 2013**

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## **Section 1.** NYSILC Background

The New York State Independent Living Council, Inc. (NYSILC) is an independent, not-for-profit, Federally-mandated state council with the primary responsibility to jointly develop, monitor and evaluate the three-year Statewide Plan for Independent Living (SPIL). NYSILC operates separately from any New York State agency and meets the requirements of Section 705 of the Federal Rehabilitation Act, authorized to perform the functions outlined in section 705 (c) of the Act.

NYSILC is a champion of systemic change promoting opportunities and full participation in all aspects of society for people with disabilities. Our mission is to advocate the independent living philosophy through the network of Centers for Independent Living (CILs) and statewide partnerships by engaging in or supporting research, education, employment, community organization, advocacy, and systems reform.

## **Section 2.** Composition of Council

In 2012, NYSILC had 20 voting Council members and 2 non-voting ex-officio members along with three vacancies. We are proud to highlight that 64% of our Council members are individuals with various disabilities. The most current list of Council members can be found at www.nysilc.org/council.htm.

## **Section 3.** 2012 NYSILC Council Membership

| NAME | POSITION | APPOINTMENT CATEGORY | VOTING STATUS |
|---|---|---|---|
| Denise A. Figueroa | Chair | CIL | Voting |
| Susan Gray | Vice Chair | Organization Serving | Voting |
| Shelley M. Klein, Ph.D. | Acting Secretary | Advocate | Voting |
| Chad Underwood | Treasurer | CIL | Voting |
| Wendy Strobel, MS, CRC, ATP | Member-At-Large | Organization Serving | Voting |
| Robert Gumson | Ex-Officio | ACCES VR | Non-Voting |
| Julie Cardone, CRC | Ex-Officio | CBVH | Non-Voting |
| Clinton H. Brown, III | Member | Organization Serving | Voting |
| Kari Cooke, M.A., CRC | Member | Organization Serving | Voting |
| Lynn Drucker | Member | Parent/Guardian | Voting |
| Brett Eisenberg | Member | CIL | Voting |
| Helen Fang | Member | Advocate | Voting |
| Ralph Giordano | Member | Other | Voting |
| Luis Gutierrez | Member | Organization Serving | Voting |
| Susan J. Hoger | Member | CIL | Voting |
| Maura Kelley, CPRP | Member | Advocate | Voting |
| Carla Lewis-Irizarry, M.P.A., M.A. | Member | Advocate | Voting |
| Marc Rosen | Member | Youth Representative | Voting |
| Sue Ruff | Member | CIL | Voting |
| Melanie Shaw | Member | Other | Voting |
| Kenneth L. Stewart | Member | Advocate | Voting |
| David Whalen | Member | Parent/Guardian | Voting |

## **Section 4.** SPIL Objective Highlights

The SPIL outlines 14 objectives to be achieved through the joint efforts of NYSILC, New York State Education Department/Office of Adult Career and Continuing Education Services – Vocational Rehabilitation and the Office of Children and Family Services/Commission for the Blind and Visually Handicapped (CBVH). The full narrative of these objectives can be found at www.nysilc.org on the bottom of the homepage at the link for the Amended SPIL 2011 – 2013.

Four of those objectives stand out to be highlighted:

- Objective 3: Statewide Systems Advocacy Network (SSAN)
- Objective 5: Youth Leadership
- Objective 8: Statewide Strategic Media Services
- Objective 11: Capacity Building Grant Opportunities

### OBJECTIVE 3

Support a Statewide Systems Advocacy Network (SSAN) by developing local partnerships and coalitions and engaging in community education initiatives centered on issues impacting people with disabilities. These efforts will result in increased visibility of Independent Living and at least one significant statewide system change each year through September 30, 2013.

### OUTCOMES

The SSAN established 145 new partnerships and coalitions, exceeding the goal of 75.

Progress was realized on not one but seven significant statewide systems change priorities including rejection of the Governor's proposal to eliminate spousal refusal; the state budget providing for the expansion of Facilitated Enrollment (FE) services; the Supportive Housing Development Program to increase housing opportunities for people with disabilities; DOH reporting requirements on mandatory managed long term care; the SafeRx/pharmacy language to assist individuals with limited English proficiency; increased access to enteral formula to include all people with disabilities; and Consumer Directed Personal Assistance affirmed as a mandatory service under both Medicaid Managed Care and Managed Long Term Care.

The SSAN participated in 504 public education activities, surpassing the combined goal of 300. They included public relations efforts; teaching classes, workshops and trainings; appearing on public access cable; participating in social activities; and more.

1,069 "action alerts" were disseminated and responded to by the SSAN volunteers and advocates.

Facilitation of 200 local grassroots community organizing activities by the SSAN including recruitment of dozens of new systems advocate volunteers; demonstrating at a protest against the new inaccessible NYC taxis; organizing volunteer attendance at the accessible voting conference in Syracuse; holding a public forum for OPWDD Commissioner, Broome DDSO staff, Medicaid Service Coordinators, advocates and ILC staff to tell first hand stories about de-institutionalization and local IL challenges; organizing volunteers to attend a NYAIL rally to support the Community First Choice option and an Olmstead plan in NY.

134 oral and written public testimonies were provided, as requested by the SSAN, submitted to address priority issues affecting people living with disabilities.

## OBJECTIVE 5

Support youth leadership through sponsorships for attendance and participation in IL conferences and national disability and youth leadership trainings each year.

### OUTCOMES

Eleven young adults applied for sponsorship from across the state (Albany-1; Cortland-7; Rochester-3). The goal of 8 applicants was exceeded.

All 11 applicants were approved for the $250 sponsorship and attended IL conferences such as the National Conference of Law Students with Disabilities in Washington DC; NCIL Annual Conference in Washington DC (including one day march, rally and Hill visits); National Spinal Cord Injury Association Roll on Capitol Hill in Washington DC. The goal of four attendees was exceeded.

The goal to appoint one young adult to the NYSILC was not met. Although two indicated interest in the NYSILC Youth Subcommittee and future appointment to NYSILC. Mitigating circumstances prevented an appointment, mostly due to the availability of an appropriate vacancy on the council and the importance of maintaining Federal appointment ratios.

## OBJECTIVE 8

Support statewide strategic media services to promote public awareness of Independent Living in multiple media markets each year.

### OUTCOMES

With a goal of securing 12 statewide media hits through distribution lists and social network posts, 27 state and national articles were distributed, exceeding the goal by 15. Articles included: Roll In Protest Against Taxi of Tomorrow; In State Care 1,200 Deaths and Few Answers; Class Action Lawsuit Seeks End to Segregated Sheltered Workshops; Women, Culture, and Disability, 80% of Wounded Veterans Cite Mental Health Woes; Disability Activists Storm U.S. Supreme Court Demanding Support for the Affordable Care Act; and White House Sends U.N. Treaty to Senate for Ratification.

Aiming to achieve 80 media hits in statewide media markets (television, radio, newsprint, online media) either purchased or PSA, the goal was not only met, it was far surpassed, with interested Centers working with Tim Cronin of Communication Concepts to determine each community's unique outlets and opportunities, 505 media hits were leveraged statewide.

Looking to reach local media markets, 35 media hits supporting Center's for Independent Living were secured, exceeding the goal by 17. These local markets include promotion of Troy's ILCHV Banner Campaign in the Troy Record (print and web), Latham Life and Greenbush Life; The Bronx Center's Consumer Banking and Credit ad plan resulting in promotion in the Bronx Times, a News 12 story and ads in the ABLE News; The Brooklyn Center's services and ADA event promotions through ads in a Brooklyn newspaper, the Canarsie Courier and ABLE News; The Kingston Center monthly radio talk show, "Ask the Expert" on WKNY1490 AM resulting in 8 media hits with shows focused on disability issues.

Progress was made on two proposals whose outcomes cannot yet be measured. With the assistance of radio personality Ted Williams, The Rockland Center will be using their SAMHSA grant to film clips of the Center's events and activities for an upcoming documentary. Rochester (CDR), Troy (ILCHV) and Queens (CIDNY) will participate in WNYIL's Points of View disability issue discussion show. Taping occurred in September 2012 and conversation was focused on managed care and the ADA 22 Years Later.

## OBJECTIVE 11

Through a competitive RFP process, provide four $30,000 capacity building grant opportunities to CILs and SCILs each year for three years.

## OUTCOMES

Grants were awarded to four Centers for programs that serve people from the identified target populations.

The awardees were ARISE in Syracuse, CDCI in Albany, NCCI in Plattsburgh and CIDNY in Queens who collectively provided services to 317 individuals in various target populations in year-one preliminary numbers. The programs will receive continued funding for two more years (2013 and 2014).

By the Numbers:
ARISE directly served 40 veterans with disabilities and 4 more individuals through focus group participation.
CDCI served 86 individuals through various health and wellness programs for people with disabilities.
NCCI provided services to 67 veterans with disabilities.
CIDNY served 120 young adults (students) with disabilities.

First quarter highlights:

ARISE connected with fifteen other groups within their community and nine additional veterans or legislative offices. Their main thrust has been on establishing focus group and delivering individualized services for veterans with disabilities.

CDCI worked with independent farmers in Montgomery County to obtained fresh fruits and vegetables at a reduced cost, launched the *Wii Have Fun* Be Fit Program and provided Tai Chi instruction for consumers.

NCCI created a staff manual related to providing services to veterans with disabilities, made community connections to veterans groups, connected with AmeriCorps to improve volunteer relationships with the program, and delivering individualized services for veterans with disabilities.

CIDNY youth coordinator attended Citywide Special Education, DDSO and Literacy Zone meetings to keep informed of changes. They established programs in seven city high schools promoting youth program such as Strides Curriculum (Job Club), Step Up Program (Transition and Benefits Advisement), and CIDNY Youth Consumer Action Network (CAN).

**Stride Success**

An 18-year-old African American female with physical and intellectual disabilities reported that she learned about being more self-confident through Job Club because it inspired her to take Access A Ride on her own. During the last session of Job Club curriculum, she was also informed about the CIDNY services including Consumer Action Network (CAN). CAN is an advocacy group comprised of consumers who advocate for policy changes that affect the disability community. This student reported that she was interested in joining.

**Step Up Success**

An 18-year-old Hispanic female with Muscular Dystrophy attended a one-day workshop focused on preparing for the new school year. She will begin her senior year this fall and is interested in going to college next year. During the workshop, the student signed up for Step UP to seek assistance with obtaining information about college, applying for ACCES-VR and a half-fare Metrocard. She also signed up to become a member of CIDNY's Youth Consumer Action Network (CAN). She reported that the Step Up program will assist her in having an easier transition into adulthood.

**Section 5.** SPIL Objectives Evaluation Plan & Assessment

Background

The 2011 – 2013 State Plan for Independent Living (SPIL) was NYSILC's first plan to be outcome-based. Because of the outcomes focus, a new evaluation process was necessary to involve Council members and staff in valuing measurable and specific terms of each objective in the plan. An evaluation process was established, implemented and then reviewed after year one. This review gleaned additional training for Council members as well as "value-added" recommendations to some of the objectives to improve knowledge about the process and to obtain better impact data.

Objectives

Of the 14 objectives in the 2011 – 2013 SPIL, 2 were not intended to have work done on them in 2012 (Objectives 9 – year one only; Objective 13-year three only). Nine objectives had measurable performance targets for 2012 (Objectives 1, 2, 3, 5, 8, 10, 11, 12, 14) and 3 objectives had content and activities not addressed this year (Objectives 4, 6, and 7).

| OBJECTIVE | | ASSESMENT |
|---|---|---|
| Objective 1: | Support the basic operations of the Council | Fully Met<br><br>Measures core responsibilities of the Council including meetings with a quorum, timely 704 reporting and achieving an "unqualified" financial audit |
| Objective 2 | Provide IL services on a fee-for-service basis to legally blind eligible individuals through CBVH | Partial Progress<br><br>Of four targets - one was exceeded, one fully met, one partially met at 88% and the fourth is being analyzed |
| Objective 3: | Support a Statewide Systems Advocacy Network (SSAN) through local partnerships and coalitions, community education, grassroots activities, testimonials and collective support of significant statewide systems change | Fully Met<br><br>Six of six targets were exceeded. Also met additional value-added target. Year three will further refine definitions, measurements and outcomes |
| Objective 4: | Support direct consulting services and coaching for the statewide network of centers | Content and activities not addressed this year<br><br>Performance outcomes set to "0" to account for RFP schedule |
| Objective 5: | Provide sponsorship for young adults with disabilities to attend and participate in IL conferences and trainings in support of leadership development | Partially met<br><br>Of the three targets, two were exceeded. Progress was made on the third. |
| Objective 6: | Support annual training opportunity to promote the Nursing Facility Transition and Diversion waiver consistent with the IL philosophy, best practices and technical support | Content and activities not addressed this year<br><br>Not Met – Performance outcomes set to "0" to account for RFP schedule. Recommended to discontinue objective due to lack of response to the RFP and only one year left to re-engage interest. |
| Objective 7: | Support a statewide consumer-controlled, non-partisan Disability Voting Rights Network (DVRN) to promote voter registration, education and use of new accessible voting systems | Content and activities not addressed this year<br><br>Fully Met<br><br>Due to issuance of RFP and award notice date, no activity for 2012 |

| OBJECTIVE | | ASSESMENT |
|---|---|---|
| Objective 8: | Support statewide strategic media services and promote public awareness about IL in statewide media markets | Fully Met<br><br>Three of three targets exceeded. Gleaned additional media projects and value added improvements |
| Objective 9: | Support statewide consumer satisfaction survey | Year one only |
| Objective 10: | Support a consultant to establish outcome-based evaluation criteria for SPIL review and development | Partially Met<br><br>60% overall completion rate for 2012. Objectives amended to reflect true work of the consultant |
| Objective 11: | Provide four $30,000 capacity building grant opportunities for Centers for Independent Living and Service Centers through competitive RFPs | Fully Met<br><br>One target exceeded – two met. All four projects are operational and have contributed data |
| Objective 12: | Develop technical specification for and create a database to compile, analyze and interpret data collected from the statewide network | Not Met<br><br>No activity in 2012 |
| Objective 13: | Statewide IL conference | Year three only |
| Objective 14: | Support a youth-led organization annual cross-disability statewide conference for young adults with disabilities to increase conference attendance, member connection to the statewide CIL network and cross-disability and cultural membership | Partially Met<br><br>Of the five outcomes- two were fully met, two made progress toward adjusted attendance rates. The fifth has a flawed measurement tool making assessment difficult |

Analysis

There were 12 objectives active in year two of the SPIL with a total of 41 performance targets. The year two goal was a 90% completion rate. Of the 41 performance targets, 30, or 73%, were successfully completed. Despite coming up 17% short of the 2012 completion goal for performance targets, the Council saw strong improvement over year-one results, which was just 44% for completion of performance targets.

The increase in successfully meeting outcomes from year one to year two was the result of two primary factors: 1- most projects had a full year to implement yielding stronger project outcomes, and 2- as a result of year one's evaluation process, objectives were amended to more accurately reflect the work being done and the timing needed to successfully implement it.

## **Section 6.** NYSILC 2012 Needs Assessment Findings

The NYSILC Needs Assessment Committee (NAC), facilitated by consultant Alan Krieger of Krieger Solutions, spent six months constructing the 2012 NYSILC Needs Assessment. Through research of data, reports, surveys and outside assessments, they determined which questions would identify the critical needs in New York for Independent Living (IL).

An assessment was created, administered, analyzed and compiled into the Needs Assessment Report that identifies needs important to New Yorkers with disabilities and the Statewide Independent Living network. It will be used to guide the development of the 2014-2016 Statewide Plan for Independent Living (SPIL). The full 2012 NYSILC Needs Assessment Report can be found at www.nysilc.org.

The assessment was focused around four research questions:

- What geographic areas are most in need of IL services?
- What unserved/underserved ethnic, minority and disability communities are most in need of IL services?
- What are the most important unmet service needs for New Yorkers with disabilities that live, or wish to live, independently?
- What are the most important needs that the SILC should address to strengthen New York's independent living network?

GEOGRAPHY

Utilizing a methodology that reconciles upstate and downstate factors, the Counties in New York with the greatest need for Independent Living services are Bronx, Kings, Livingston, New York, Ontario, Orleans, Queens, Suffolk, Wyoming and Yates.

**How New Yorkers with Disabilities Rate**

| | |
|---|---|
| General Population Living with Disabilities (Based on ACS sample data) | 11% |
| Veterans with Disabilities (Among Civilian Population) | 25.1% |
| Poverty Rate of New Yorkers with Disabilities (18-64) | 28.6% |
| Employment Rate (New Yorkers With Disabilities (18-64) | 32.2% |
| Employment Rate Gap (New Yorkers With/Without Disabilities; 18-64) | 40.8% |
| Income Gap (New Yorkers With Disabilities (16 and Older) | $10,903 |

UNSERVED/UNDERSERVED

In addition to a recognized need to improve outreach and service access to the Hispanic/Latino and Asian populations, the top underserved groups were male veterans with disabilities, female veterans with disabilities, rural residents with disabilities, homeless individuals with disabilities, young adults with disabilities, and immigrants with disabilities.

UNMET NEEDS

With almost 600 survey respondents, consumers' most challenging issues are finances and paying bills, transportation, and employment. They identified the services needed most to live independently as being transportation, advocacy and medical/health issues.

IL NETWORK NEEDS

Center Directors indicated that the greatest barriers to expanding or starting new services are lack of finances, scarcity of consumer transportation, need for additional space/infrastructure, and marginal awareness of Independent Living Centers. The consumers surveyed echoed the Centers' by emphasizing their own need for transportation, home visit options, advertising of center services, closer proximity to facilities, and increased online resources.

STATE INSTUTIONALIZED POPULATION

NYSILC had to FOIA most State Agencies to obtain data related to the State's institutionalized population. The data was tabulated for the settings defined by county and led to an estimated Statewide institutionalized figure of 220,277. Utilized for the upstate/downstate needs assessment, this vital information was shared with stakeholders and submitted as testimony during Olmstead hearings (See Appendix II: Table 1.5A for a detailed chart in the statewide report).

**Section 7.** 2012 Presidential Post-Election Poll Results

NYSILC recently conducted an online post-election poll of New Yorkers with disabilities that voted in the 2012 Presidential Election. The online poll was conducted on Survey Monkey during the weeks after Election Day through the month of November 2012. The report covers typical post-election results, as well as voting trends for issues like volunteering for campaigns, running for office, and contributing to campaigns.

## Survey Sample

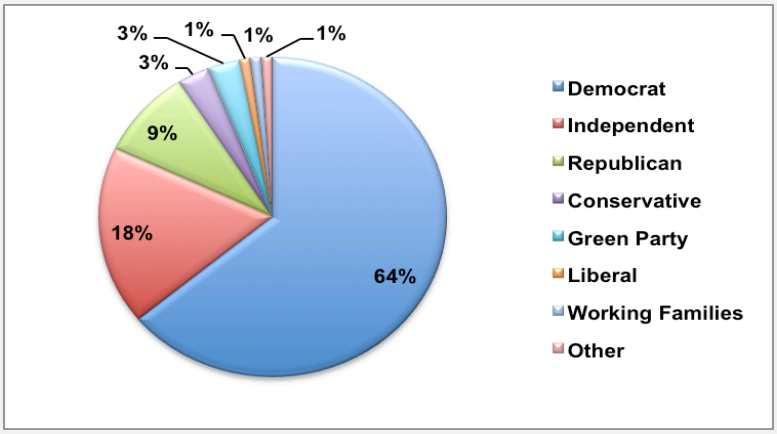
**112 Voters** **Various Disabilities** (self-identified) **Across NY State**

**Are you registered to vote?**

| | |
|---|---|
| Yes | 99% |
| No | 1% |

**Did you vote on Election Day?**

| | |
|---|---|
| Yes | 99% |
| No | 1% |




**What factors help you to vote for a candidate?**

**Greatest Impact**

| | |
|---|---|
| Position on key issues that impact the country | 83% |
| Position on disability issues | 71% |
| Position on issues that impact me personally | 62% |

**Least Impact**

| | |
|---|---|
| Party affiliation | 28% |
| Image | 11% |
| Political campaign ads | 8% |
| How friends and family are going to vote | 4% |

**In the Presidential Election, who did you vote for?**

Barack Obama 76% Mitt Romney 14% Jill Stein 6% Other 4%

## Disability Voting Trends

**How did you vote?**

71% Scanners
23% Ballot Marking Devices
3% Absentee Ballot
3% Other

**Did you encounter any problems or access issues with the voting technology?**

Yes 22%
No 69%
Other 9%

"The person who had me sign the voting book didn't know what a BMD

"I was told there was a machine for disabled voters but it was broken"

"Tried to use BMD and the polling site didn't know how to use the machine..."

**Did you encounter a physical barrier or any issues at the polling place?**

Yes 19%
No 80%
Other 1%

"Numerous stairs, but I was told once inside, there was an elevator

"I have a hearing disability...after I asked her the third time to speak up, she laughed."

"No automatic door and polling place poorly marked."

**Do you feel the poll workers were adequately trained and knowledgeable about the voting technology and your needs?**

Yes 61%
No 31%
Other 9%

**Were you able to vote privately without someone seeing your voting choic**

Yes 81%
No 16%
Other 4%

**Have you ever been trained or served as a poll worker?**

Yes 12%
No 88%

**Have you ever volunteered for an election campaign?**

Yes 27%
No 72%
Other 1%

**Have you ever run for office?**

Yes 8%
No 92%
If yes, were you successfully elected? 23% Yes 62% No 15% Other

**$ Contributions $**

38% Have contributed to a campaign
62% Have not contributed to a campaign
47% Would contribute to a disability PAC
35% Would not contribute to a disability PAC
18% Other- with comments

**Section 8.** 2012 NYSILC Financial Information

NYSILC filed all appropriate federal and state financial documents and reports last year. In December 2012, Lubbe & Hosey, PC, Certified Public Accountants, performed an audit of the NYSILC finances for the year ending September 20, 2012.

NEW YORK STATE INDEPENDENT LIVING COUNCIL, INC.
STATEMENT of ACTIVITIES
Year Ended September 30, 2012

| | 2012 | 2011 |
|---|---|---|
| **Unrestricted Net Assets** | | |
| Revenues | | |
| Governmental Contracts | $408,540 | $393,699 |
| Contributions/Grants | $1,800 | $2,731 |
| Interest income | $268 | $94 |
| Total Revenues | **$410,608** | **$396,524** |
| | | |
| Expenses | | |
| Program Services | $357,258 | $354,949 |
| Management and General | $54,967 | $43,298 |
| Total Expenses | **$412,225** | **$398,247** |
| | | |
| Increase (Decrease) in Net Assets | ($1,617) | ($1,723) |
| | | |
| Net Assets Beginning | $53,091 | $54,814 |
| Net Assets Ending | **$51,474** | **$53,091** |