

# NYSILC 3-Year Public Policy Agenda (2016-2018)

The New York State Independent Living Council, Inc. (NYSILC) is an independent, federally mandated, non-profit state council that advances Independent Living (IL) philosophy through the network of Centers for Independent Living (CILs) and statewide partnerships. Its primary duty is to jointly develop, monitor and evaluate the three-year Statewide Plan for Independent Living (SPIL) as described in Section 705 of the Federal Rehabilitation Act, as amended. The council has developed this public policy agenda to articulate and support issues that are important to New Yorkers with disabilities and the statewide network, for the intention of public education and systemic change. Statewide systems change is supported in the current SPIL and the Purpose of Title VII of the Act, as amended.

NYSILC conducts a Statewide Needs Assessment the year before each 3-year SPIL's formulation and development. The 2015 NYSILC Statewide Needs Assessment Report is available online at: <http://nysilc.org/images/NeedsAssesFinalRep.docx>. Three overall themes emerged from the findings: Gaps and barriers, state institutionalized population and priority underserved populations. In addition, the report highlighted priority issues. Affordable and accessible housing and transportation emerged as top concerns, especially when coupled with statewide forums. Other key issues included finances (paying bills) and employment. Last, based on survey and public comment results, priority unserved and underserved target populations included: Lesbian, Gay, Bisexual, Transgender, Queer/Questioning, Intersex, or Asexual (LGBTQIA) community with disabilities; veterans with disabilities; Hispanic/Latino, Asian, or Russian communities with disabilities; seniors with disabilities; youth and young adults with disabilities; deaf/blind community; and rural residents with disabilities.

## I. Housing

*Guiding principle: NYSILC supports the development of affordable, accessible, and integrated housing options for New Yorkers with disabilities. The council will oppose efforts that have a negative impact and/or impose harmful cuts that may create barriers to life in the community for New Yorkers with disabilities.*

Based on "Priced Out in 2014: The Housing Crisis for People with Disabilities,"<sup>1</sup> the average income of a single individual receiving SSI was \$8,995, which is 23% below the 2014 national poverty level of \$11,670. In 2014, the national average rent for a studio apartment was \$674, equal to 90% of monthly SSI payments. In New York, the 2014 SSI average monthly payment was \$808. The most affordable area in New York State was Utica/Rome, which averaged 69%/SSI for a 1-bedroom and 68%/SSI for an efficiency apartment. However, seven locations were near or exceeded 100%/SSI and effectively priced peers out of affordable housing. Those areas were: Albany/Schenectady/Troy, Ithaca, Kingston, Nassau/Suffolk, New York, Poughkeepsie/Newburgh/Middletown, and Westchester County. The three most unaffordable locations in the state were: Nassau/Suffolk 173%, Westchester County 160%, and the New York City metro area at 155%.

---

<sup>1</sup> Priced Out in 2014: The Housing Crisis for People with Disabilities, <http://www.tacinc.org/media/52012/Priced%20Out%20in%202014.pdf>

## Agenda items supported:

- **Rental discrimination based on source of income** (A.05431, Weprin, S.01898, Comrie) - A bill to prevent housing discrimination based upon an individual's source of income, making it discrimination if a landlord rejects a potential tenant who has rental subsidies (such as Section 8, Public Assistance, Waiver Programs) as their source of income. It will be illegal under New York State Human Rights Law.
- **New home construction visitability** (A.1023 Simon, S.3315 Kruger) - A bill to amend the real property law related to the visitability of new home construction for persons with disabilities. It establishes minimum regulations for the design and construction of new single family homes, townhouses or the ground floor unit of a building with three or fewer dwelling units by builders who receive state or federal funds and subsidies to provide for the occupancy by and the visitability for persons with disabilities. It establishes minimum standards for the accessibility by the mobility impaired 1) from the public street or driveway to the exterior door of a dwelling, 2) interior doors, 3) environmental controls, 4) habitable space and 5) interior bathroom requirements. There is also an enforcement/civil penalty clause of not less than fifty and not more than five hundred dollars for each offense and for each day the violation continues to occur.
- **The Housing Fairness Act of 2017** (H.R. 149 Green) - The Veterans, Women, Families with Children, Race, and Persons with Disabilities Housing Fairness Act of 2017 or the Housing Fairness Act of 2017. This bill directs the Department of Housing and Urban Development (HUD) to conduct a nationwide testing program to detect discriminatory practices against persons seeking to rent or purchase housing or obtain a mortgage. It will also seek to measure the patterns and prevalence of discrimination due to race, color, religion, sex, familial status, disability status, or national origin of a renter, home buyer, or borrower. It also seeks to implement pilot projects that test solutions to help prevent or alleviate housing discrimination and segregation.

## II. Transportation

*Guiding principle: NYSILC recognizes and supports the right of New Yorkers with disabilities to have public and private sector transportation options that are affordable, accessible, timely and reliable. The council will oppose efforts that have a negative impact and/or impose harmful cuts to the freedom and independence of people with disabilities.*

Based on a U.S. Department of Transportation survey,<sup>2</sup> about 1% of our peers rarely leave their homes. Compared to the non-disabled population, fewer people with disabilities drive a car, report being a passenger, and fewer travel longer distances (100-mile radius or more). For local travel, 62% of people with disabilities drove motor vehicles, 47% walked (or rolled), 18% rode bicycles, 11% carpooled, 5% rode school buses, 6% rode subway/rail, and 15% other (6% motorized person transportation, 6% public paratransit/bus, and 3% specialized transportation service). According to the results of NYSILC's 2016 Presidential Post-Election Poll, 62% of New Yorkers with disabilities use a motor vehicle, 24% use a fixed route bus, 20% use paratransit, 15% subway, 13% taxicab, 13% train, 12% use an accessible/modified motor vehicle, 4% accessible taxicab, 3% bicycle, 3% use a private car service, 1% ferry, and 7% other.

---

<sup>2</sup> U.S. Department of Transportation survey, Bureau of Transportation Statistics, [https://www.rita.dot.gov/bts/sites/rita.dot.gov/bts/files/publications/freedom\\_to\\_travel/html/data\\_analysis.html](https://www.rita.dot.gov/bts/sites/rita.dot.gov/bts/files/publications/freedom_to_travel/html/data_analysis.html).

## Agenda items supported:

- **Energy efficient, accessible transportation services** (A.5537 Weprin, no same as) - A bill that looks to amend vehicle and traffic law in relation to pre-arranged for-hire vehicle transportation services and the maximization of energy efficiency, universal design and accessibility for persons with disabilities. Provisions have been established for replacement of vehicles based on the size of the company's fleet. At five years post-passage of this law, a fleet of less than ten vehicles must replace at least one with an energy efficient and accessible vehicle. Those businesses with 10 to 100 vehicles must replace 20% of their fleet with energy efficient and accessible vehicles. Those with a fleet over 100 must replace 25% with energy efficient and accessible vehicles.
- **Cap on fares for paratransit transportation** (A.3980 Sepulveda, S.2382 Alcantara) - An act to amend the transportation law and the public authorities law, in relation to capping fares for paratransit transportation. This is to ensure that fares for paratransit transportation are set no higher than fares for transportation of non-disabled adults.
- **Statewide accessible livery vehicle service** (A.4900 Titus, no same as) - A bill that requires the vehicle and traffic law to provide people with disabilities with access to prearranged for-hired vehicles and shuttle services. The owners of these prearranged for-hire and shuttle services with no more than ten vehicles must advertise and provide accessible transportation upon request and purchase at least one wheelchair accessible vehicle the next time one is purchased. Companies with more than 10 but less than 100 vehicles must advertise and provide accessible transportation upon request and replace 10% of their fleet within three years of the effective date. Companies with more than 100 vehicles must advertise and provide accessible transportation upon request and replace 20% of their fleet within five years of the effective date. Failure to comply will result in a fine between \$50-150 per day from the date the violation occurred until it is remedied.

## Agenda items monitored:

- **Upstate transportation network companies providing private driver services**. The 2017-2018 state budget included Transportation Network Company (TNC) services in upstate New York. This agreement did not directly address the accessibility or accommodation needs of people with disabilities. Instead, it created an Accessibility Task Force to examine the impact of the issue. NYSILC insists that members of the disability community be invited to join the Accessibility Task Force to ensure that the concerns and needs of the disability community are adequately met.

## III. Employment

Guiding principle: *NYSILC endorses the Employment First philosophy, which includes rising above the poverty level through gainful and integrated, community-based employment. The council will oppose efforts that have a negative impact and/or impose harmful cuts to this essential life goal.*

Based on the 2016 Disability Compendium Annual Report, the **employment rate** for New Yorkers with disabilities (ages 18-64) was a mere 33.0%, resulting in a gap of 41.9% compared to individuals without a disability in the State. This has slightly improved since the previous year. The **poverty rate** for New Yorkers with disabilities (ages 18-64) was an astounding 30.1% - almost three times that of

persons in the State without a disability. This represented close to no change since the last report. The **median earnings** for New Yorkers with disabilities (16 or older) was \$13,308 less compared to a person without a disability - a gap that continues to widen each year.

### Agenda items supported:

- **Full Implementation of Governor Cuomo's Employment First Commission's Report** The Commission's March 2015 report recommends a 5% increase to the employment rate, a 5% decrease to the poverty rate, a NYS Business Leadership Network of at least 100 businesses, the inclusion of disability into the Minority Women Business Enterprise (MWBE) state procurement system, creation of a small business employment tax credit (based on the developmental disability model), development of a policy to connect regional economic planning councils to people with disabilities, and other directives.
- **Disability inclusion in MWBE program** (S.3785 Marcellino) - A bill to include people with disabilities as "minorities" in the Minority and Women Business Enterprise (MWBE) state procurement program defining disability under NYS Human Rights Law. This will help to encourage self-employment by allowing peers to operate certified businesses under this new classification. This measure also helps to promote the marketing of services by certified vendors who are diversified from dual to triple classifications.
- **Cross-disability small business tax credit** (A.1369 Cusick/S.3688 Addabbo) - A bill to establish a small business tax credit for hiring people with disabilities. A small business is defined as 100 employees or less. A person with a disability must be employed for 35 hours a week or more and remain in employment for a year for the business to earn a \$5,000 tax credit. The small business cannot exceed \$25,000 in tax credits in a year.

## IV. Health Care/Community Living

Guiding principle: *NYSILC supports affordable and accessible health care that maintains protections crucial for people with disabilities and their ability to exercise consumer control concerning their lives in the community. The council will oppose efforts that have a negative impact and/or impose harmful cuts in funding. This includes anything that could negatively impact "quality of life", or create barriers for people with disabilities living independently in the community.*

Based on a "fact sheet" issued by the World Health Organization on Disability and Health,<sup>3</sup> there are several barriers to health care for people with disabilities. The cost and/or value of health care and plans is prohibitive, coupled with a lack of transportation, which are the two major reasons why peers do not receive the health care they need. Another barrier is the lack of available services in any given area, combined with the lack of physical, communication, and print access related to services and treatment. Last, education and awareness exists to train inadequate health care workers and professionals. Compared to people without disabilities, disabled individuals were two times more likely to find health care workers' skills inadequate to meet their needs, four times more likely to report being treated badly, and three times more likely to report being denied care.

---

<sup>3</sup> Disability and Health, <http://www.who.int/mediacentre/factsheets/fs352/en/>.

## Agenda items supported:

- **Fund a living wage for CDPAS attendants** The State must propose and fund a living wage for attendants providing Consumer Directed Personal Attendant Services (CDPAS) to ensure that people with disabilities can live independently in the community. New York has approved a calibrated, regional plan to increase the minimum wage across the state to a maximum of \$15 an hour over the next few years. This will deplete the availability of attendants as people seek opportunities in higher paying sectors. The Governor must respond by proposing and providing a wage premium for CDPAS attendants that is over and above the increased minimum wage to stabilize the workforce. Otherwise, the State will be putting the CFC funding and numerous peers at risk.<sup>4</sup>
- **\$5 million increase to the State Appropriation for Independent Living Centers (ILCs)** - The Governor and Legislature need to increase the State Appropriation for Independent Living Centers (ILCs) to increase the base amount to \$18 million. The much-needed increase is long overdue and essential to sustaining IL services statewide. ILCs are essential community-based advocacy and service organizations that serve as the safety net to ensure people with disabilities have access to services and supports to live independently in their communities. After receiving level funding for eleven years, ILCs finally received a much needed \$1 million increase in the 2015-16 SFY. This \$1 million increase was intended to provide each of the existing 39 state funded ILCs with a \$25,641 increase. However, a significant portion of the increase was utilized to create two new centers. Thus, existing centers did not receive the fiscal relief this modest increase was intended to provide. In addition, adequate funding of ILCs is essential to ensuring successful *Olmstead* implementation in New York and would result in additional Medicaid savings to the State. Data from the New York State Education Department, ACCES-VR, shows that the work of ILCs to transition and divert people with disabilities from costly institutional placements saved the State more than \$1.8 billion since 2001 because of avoided institutional care. ILC transition and diversion activities save the state more than \$9 in institutionalization costs for every state dollar invested in ILCs.<sup>5</sup>
- **Support passage of the Federal Disability Integration Act** (S.910/Schumer, HR 2472/Sensenbrenner) - The Disability Integration Act creates a comprehensive solution to assuring the full integration of people with disabilities and disabled seniors in the community. Instead of focusing on changing Medicaid, the legislation: 1) clarifies and strengthens the ADA's integration mandate and clarifies that every individual who is eligible for LTSS has a federally protected right to a real choice in how they receive services and supports; 2) assures that states provide LTSS in a manner that allows individuals with disabilities to live in the most integrated setting, including their own home, have maximum control over their services and supports and assure that LTSS are provided in a manner that allows people with disabilities to lead an independent life; 3) establishes a comprehensive state planning requirement comparable to the transition planning process required under the ADA that includes enforceable benchmarks; and 4) establishes a requirement for clear and uniform annual public reporting by states.

---

<sup>4</sup> Center for Disability Rights Analysis of the 2016-2017 Executive Budget: Proposals that Impact People with Disabilities.

<sup>5</sup> NYAIL 2016 Disability priority Agenda Executive Budget Response.

## V. Civil Rights

Guiding principle: *NYSILC supports all human and civil rights efforts to remove legal, physical and attitudinal barriers that prevent full inclusion into the mainstream of American society for New Yorkers with disabilities. The council will oppose efforts that have a negative impact and/or rollback the human or civil rights of our peers.*

In a 2014 article published in the American Bar Association's *Human Rights Magazine*, Alexander Wohl summarizes a "long and often horrific chronology of exploitation, neglect, discrimination, and segregation" of disabled people in the United States. Even with the passage of the ADA, "persons with disabilities experience the highest rates of poverty of any subcategory of Americans" along with a disproportionately high rate of unemployment.

Wohl points to the Olmstead Act of 1999 as a key tool to fighting segregation and unfair employment practices. He notes that "advocates have used Olmstead to mount successful attacks on unjustified confinement in several of state institutions," as well as expanding the law's interpretation to include preventing the exploitation of disabled people in sheltered workshops and sponsored day-programs.

The disability rights movement must continue to gain acknowledgment as one of the most important civil rights movement in our country's history. "Ultimately, the ability of the disability rights movement to transform Olmstead into its *Brown v. Board of Education* and to ensure that people with disabilities have the civil and economic protections that every other American has will depend on several factors: additional legal victories, increased political power, and greater focus by those who have supported other civil rights movements. Only with this combination will the ability to inform and educate the public change the paradigm of how society views and treats people with disabilities."<sup>6</sup>

### Agenda items supported:

- **Waive the State's sovereign immunity to claims under the ADA and Section 504** (Lifton/ A.2546, Avella S.1522) Waives the state's sovereign immunity to liability for violations of the Americans with Disabilities Act of 1990, the Fair Labor Standards Act, the Age Discrimination in Employment Act, and the Family and Medical Leave Act; also waives the immunity of all instrumentalities and political subdivisions of the state.
- **Change local, village, county, and City of New York elections to coincide with the dates of state and federal elections** (S.382/Carlucci) Provides that all local, village, town, county and city of New York elections shall be in an even-numbered year.

### Agenda items opposed:

- **ADA Education and Reform Act** (H.R. 620/Poe). While the education aspect of this bill is supported, the reform segment is not. "H.R. 620 would create significant obstacles for people

---

<sup>6</sup> Wohl, Alexander. "Poverty, Employment, and Disability: The Next Great Civil Rights Battle." *Human Rights Magazine*. Vol. 40, No. 3, 2014.

[http://www.americanbar.org/publications/human\\_rights\\_magazine\\_home/2014\\_vol\\_40/vol\\_40\\_no\\_3\\_poverty/poverty\\_employment\\_disability.html](http://www.americanbar.org/publications/human_rights_magazine_home/2014_vol_40/vol_40_no_3_poverty/poverty_employment_disability.html). Accessed 15 May 2017.

with disabilities to enforce their rights under Title III of the Americans with Disabilities Act (ADA) to access public accommodations, and would impede their ability to engage in daily activities and participate in the mainstream of society. Rather, the burden of protecting the right to access a public place is shifted to the person with the disability, who first must be denied access; then must determine that violations of the law have occurred; then must provide the business with specific notice of which provisions of the law were violated and when; and finally, the aggrieved person with the disability must afford the business a lengthy period to correct the problem.”<sup>7</sup>

## VI. Other

***Guiding principle: NYSILC supports other initiatives that are consistent with IL philosophy, the SPIL, statewide needs assessment, public policy agenda, and issues supported by this committee and the council. The council will oppose efforts that are inconsistent with key documents and positions and have a negative impact and/or impose harmful cuts to our network or our peers.***

Based on the statewide needs assessment and public comment results, priority unserved and underserved target populations were identified. They include: Lesbian, Gay, Bisexual, Transgender, Queer/Questioning, Intersex, or Asexual (LGBTQIA) community with disabilities; veterans with disabilities; Hispanic/Latino, Asian, or Russian communities with disabilities; seniors with disabilities; youth and young adults with disabilities; deaf/blind community; or rural residents with disabilities. The State Plan identifies ten capacity building projects to address outreach to various communities (concluding in 2017) along with a best practice demonstration project (starting in 2018) to address one or more of the target groups for the priority issues of affordable, accessible housing and transportation. In the second year of the plan (2018), the Statewide Systems Advocacy Network (SSAN) will direct a public education campaign fund to address a priority issue.

### Agenda items supported:

#### **Youth with disabilities:**

- **Expand the availability of transition age youth and young adult peer support and advocacy services** - Since there are only a few young adult peer support providers in the state, young adults have access to very few programs designed for their age group. Every state service system must increase funds for peer advocacy programs. The programs should not be limited to Medicaid billing services. They should be community-based programs open to the public and focus on empowerment, suicide prevention, substance abuse prevention, health and wellness, self-determination, independent living skills, post-secondary education, and employment for transition age youth and young adults.<sup>8</sup>
- **Strengthen the housing subsidy program for foster youth** - Approximately 1,300 New York youth age out of foster care each year. About one-third experience homelessness and many others face unstable housing arrangements during this crucial time period. The state should increase (double)

---

<sup>7</sup> ACLU Coalition Letter of Opposition for ADA Education and Reform Act of 2017 (H.R. 620), <https://www.aclu.org/letter/coalition-letter-opposition-ada-education-and-reform-act-2017-hr-620>.

<sup>8</sup> Youth Power! 2016 Priority Agenda.

the monthly housing subsidy to \$600, increase the age limit eligibility to 24 (from 21), and allow youth receiving the subsidy to live with unrelated roommates.<sup>9</sup>

**Lesbian, Gay, Bisexual, Transgender, Queer/Questioning, Intersex, or Asexual (LGBTQIA) community with disabilities:**

- **Strengthen LGBTQIA rights and public education** - All community-based programs must be knowledgeable and ready to support and serve the LGBTQIA community. This includes respect for name and gender identification as well as peer support and participation in public education opportunities.<sup>10</sup>

**Veterans with disabilities:**

- **Support Veterans Home and Community Based Care** (A.3415 DenDekker, no same as) - An act to amend the state finance law, in relation to establishing the Veterans Home and Community Based Care Services pilot program.

**Agenda items opposed:**

**Physician Assisted Suicide:**

- **Patient Self-Determination Act** (S.2045 Bonacic, no same as) - A bill to amend the public health law, in relation to patient self-determination at end of life. Assisted suicide legislation reinforces the idea that people with disabilities are burdensome and our lives are not worth living. Fears of becoming disabled and facing functional loss are often reported by doctors as reasons patients request assisted suicide. Proponents of assisted suicide often cite a loss of dignity as a reason to terminate one's life. The disability community strongly opposes the belief that requiring the assistance of another individual for activities of daily living, such as dressing, bathing and toileting is undignified or a legitimate reason to legalize physician assisted suicide. Proponents of physician assisted suicide often argue that this option is necessary to prevent suffering at the end of life. This is not the case as there are alternative options to prevent suffering. It is already legal in New York for individuals to create an advance directive to cease treatment under any circumstance they choose and to refuse treatment at any time. Palliative care is available and can provide pain relief to ensure a person is not in pain. Many assisted suicide bills contain no reporting requirements aside from a few entries in the medical record and the request form, which are subject to the strict confidentiality requirements of HIPAA. Such bills are typically immunity statutes, protecting everyone involved in the death except for the patient, no questions asked.<sup>11</sup>

---

<sup>9</sup> Youth Power! 2016 Priority Agenda.

<sup>10</sup> Youth Power! 2016 Priority Agenda.

<sup>11</sup> NYAIL 2016 Memorandum of Opposition.