



2008 Disability Priority Agenda

As a membership organization representing 34 Independent Living Centers (ILCs) across New York, the New York Association on Independent Living (NYAIL) is dedicated to improving the quality of life and safeguarding the civil rights of people with disabilities of all ages. NYAIL opposes all forms of systemic segregation bias in government policies, practices, procedures and funding mechanisms. In all areas of public policy, including the development of new proposals and the enforcement of existing laws and regulations, NYAIL seeks to promote full community integration to enable all people with disabilities to live active, independent lives in their communities. To accomplish this, NYAIL promotes policies and strategies that are aimed at removing barriers, both in the community and within institutional settings, which prevent full integration.

NYAIL's statewide membership is also dedicated to opposing all forms of segregation and discrimination against people with disabilities. The ILCs, which are controlled and primarily staffed by people with disabilities, provide a variety of services, such as peer counseling, independent living skills training, and assistance with medical needs, housing, education, employment and other necessary services that empower people with disabilities to live independently in their communities.

NYAIL's 2008 Disability Priority Agenda is a reflection of these overriding principles and seeks to further these goals. We call on all lawmakers, executive officials, and their staff to work together with us to make these proposals a reality for all New Yorkers with disabilities. It is time to end all forms of bias and discrimination in our State and ensure all citizens full integration and equal participation in every aspect of society.

1. INDEPENDENT LIVING CENTER (ILC) FUNDING

Top Priority:

- **Increase funding for ILCs by an additional \$5 million this year, including full, permanent funding for new Independent Living Centers in Ontario, Putnam, Herkimer and Sullivan counties.**

Background:

NYAIL is pleased that ILCs received an increase of \$1.5 million in state funding last year. This increase provided some additional ability for centers to address existing shortfalls, but funding has not kept pace with the dramatic increase in demand for services over several years. This year, ILCs need a \$5 million increase to continue and expand their work providing people of all ages and disabilities with services that allow them to:

- Develop skills to live independently
- Earn degrees, find jobs, and become self-sufficient
- Reduce their reliance on state and federal benefit programs
- Stay out of institutions and participate fully in community life

2. HEALTH CARE

Top Priorities:

- **Maintain and enhance Medicaid benefits, eligibility, coverage, and access to services. Eliminate the systemic bias that leads to unwanted placement in nursing homes and other institutions.**

Additional cuts or reductions in eligibility for Medicaid beneficiaries put people with disabilities at increased risk of unwanted placement in a nursing home and/or poor medical outcomes. As the Legislature considers Medicaid and other health care reforms, it must make community integration through the provision of vital and accessible services to people with disabilities of all ages its top priority.

- **Expand the facilitated enrollment network to include organizations familiar with public health insurance programs that serve people with disabilities. Expand the facilitated enrollment program into areas/communities where it doesn't currently exist.**

People with disabilities in New York State are uninsured at approximately the same rate as those without disabilities. For those without disabilities, the facilitated enrollment program is an invaluable resource for low-income individuals and families attempting to navigate the public health insurance maze. Unfortunately, the network does not include organizations with expertise regarding disability-related public health insurance options.

The facilitated enrollment network should be expanded to include organizations that focus on the needs of people with disabilities. As Medicaid managed care expands to new counties or becomes part of counties' expansion to include the SSI population, the facilitated enrollment program should be expanded in a variety of additional ways including geographic, population, and assistance with renewal, navigation and access to care.

➤ **Increase rental/housing subsidies to participants in the Nursing Facility Transition and Diversion (NFTD) Medicaid waiver program.**

New York will implement a new Nursing Facility Transition and Diversion Medicaid waiver this year, which will help 5000 seniors and people with disabilities live in their communities and avoid or end unwanted nursing home placement. In order to make this a reality, finding affordable, accessible, and integrated housing is critical. NYAIL thanks the Legislature for the appropriation of \$2.5 million in the 2007 budget for this purpose. Savings to the State from avoiding high-cost nursing home placements should continue to be used to offset the cost of making housing subsidies available and further appropriations should be made in 2008.

➤ **Expand coverage under New York's Elderly Pharmaceutical Insurance Coverage (EPIC) program to people with disabilities under age 65.**

- *A.5178a/S.2644a of 2007*

Many people with disabilities live on marginal incomes which do not qualify them for Medicaid. Some are faced with the choice of either buying medication, or paying the rent or buying food. Those who worked long enough to qualify for Social Security Disability Insurance (SSDI) are eligible for the Medicare Part D prescription drug program, but the significant cost sharing associated with this program will still make it unaffordable for many. EPIC expansion will help people with disabilities stay healthy and avoid costly hospitalization and/or institutionalization.

➤ **Increase access to comprehensive health care coverage for all people with disabilities, with the ultimate goal of providing universal health care for all New Yorkers.**

People with significant disabilities will face unprecedented erosion of their health services, through provider "right sizing efforts," recent federal Medicaid cuts, and more. Many may be forced to pay more for their care, have greater difficulty accessing their care, and forego care altogether. Publicly funded programs should further the community integration of people with disabilities. People with disabilities cannot remain stable and participate in community life if they are unable to access appropriate publicly funded health services.

NYAIL is encouraged by Governor Spitzer's efforts to move the state toward universal health care. All proposals to that end made by the governor or the legislature must take into account the needs of people with disabilities and the growing disparities in access to health care services affecting them. Medicaid benefits for people with disabilities,

including community-based long term care services, must be maintained as the state plans how best to ensure all citizens have appropriate health care.

Background:

Under the 1999 U.S. Supreme Court Olmstead decision, people with disabilities are entitled to receive the services and supports they need to live freely in the community and avoid unwanted placement in nursing homes and other institutions. However, the impact of the Olmstead decision has not been fully realized in New York in terms of facilitating the transition to community-based health care alternatives. Problems with obtaining necessary health care services and supports remain a major barrier to full independence and integration for people with disabilities in New York.

NYAIL applauds Governor Spitzer's efforts to make the healthcare system more "patient centered." While the State is focused on overcoming systemic barriers to access, increasing service coordination, and reducing the costs of Medicaid and other programs, it is crucial that people with disabilities have access to the health care services and supports they need and choose.

3. EMPLOYMENT

Top Priorities:

- **Shift state funding away from sheltered employment programs to more integrated options, with the goal of eventually phasing out state support for sheltered programs completely.**

Background:

Since the establishment of New York's first sheltered workshop in 1954, people with disabilities have been placed in work settings which pay miniscule wages and rarely result in a move to integrated employment in the community. Today, people continue to be segregated in sheltered workshops, making wages as low as 25-30 cents an hour. It is time to transition people with disabilities into supportive and other integrated employment programs. Everyone, regardless of disability, can work in a real job for real wages. Everyone has talents and skills that can develop if properly supported. All people with disabilities should be given the opportunity to make informed choices about where to work and a continuum of employment services, leading to fully integrated employment, should be available.

- **Expand the Medicaid Buy-in program for working people with disabilities by increasing the resource limit, exempting spousal income, and raising the upper age limit for eligibility to include people 65 and over.**
 - *A.9200 of 2007*

Effective in 2003, the Medicaid Buy-in program extends Medicaid coverage to working people with disabilities who have net incomes at or below 250 percent of the federal

poverty level and non-exempt resources at or below \$10,000. Despite its goal to encourage people with disabilities to work while keeping their Medicaid benefits, participation in the program has been low. Increasing the income and resource limits and expanding eligibility to include people 65 and over will allow more people with disabilities to work, or increase their levels of work, and pay taxes. Moreover, a recent study by Mathematica found that participants in the Medicaid Buy-in program cost Medicaid almost 40% less than other Medicaid enrollees with disabilities. Greater participation of people with disabilities in the Medicaid Buy-in program can save Medicaid dollars.

Background:

Despite research findings that decisively affirm the desire and capacity of people with disabilities to work, thousands of people with disabilities remain unemployed and in poverty. In 2006, the employment rate of working-age people with disabilities in NY was 33.5%, while the employment rate of working age people without disabilities was 77.9%. The poverty rate of working-age people with disabilities in NY was 28.8% and for those without disabilities, the poverty rate was 9.6%. These disparities are unconscionable and point to the pressing need for employment of people with disabilities to be a primary goal of disability and health care policy.

4. HOUSING

Top Priorities:

- **Incorporate the housing provisions of Section 504 of the Rehabilitation Act into state law.**
 - *A.6033 and A.7138 of 2007*
 - *S.3956a of 2007*

Housing developers often fail to comply with Section 504's requirement to set aside a certain percentage of accessible units for people with disabilities when federal dollars are used for construction. By including these requirements in state law, the Department of Housing and Community Renewal (DHCR) will be fully empowered to enforce these requirements and ensure that the State is in compliance with federal standards.

- **Establish standards for "Visitability" in state law to require all newly constructed single-family houses, townhouses and ground-floor units of duplexes and triplexes built with public funds to be made accessible.**
 - *A.6837 of 2007*

"Visitability" is a movement to change home construction practices so that new homes offer a few specific features that make the home easier for people with a mobility impairment to live in and visit. The spirit of "Visitability" is the belief that it is unacceptable that new homes continue to be built with gross barriers, given the ease of building basic access into the majority of new homes and the harsh effects major

barriers have on people's lives, including physically unsafe conditions, social isolation, and unwanted institutionalization.

- **Create a housing trust fund that addresses the needs of people with disabilities, including people with very low incomes.**

A housing trust fund should provide people with disabilities with very low to moderate incomes with grants, loans, rental subsidies and other housing supports and services, including home modifications.

Background:

The availability of accessible, affordable and integrated housing opportunities for people with disabilities is critical to sustaining fully independent lives in their communities. The Access to Home program has provided some assistance for home modifications, but more is needed now for New York to fully address the housing crisis facing people with disabilities.

According to a recent study, "Priced Out in 2006, The Housing Crisis for People with Disabilities," by the Technical Assistance Collaborative and the Consortium for Citizens with Disabilities, no person receiving Supplemental Security Income (SSI) in New York State can afford an efficiency or one bedroom apartment. Recipients would have to pay over 127% of their SSI benefits for an efficiency apartment and 138% of their SSI benefits for a one bedroom apartment. The monthly SSI payment to a person living alone with a disability in New York State is currently \$690. Because of the cyclical nature of public and private funding, communities are falling farther and farther behind in addressing the growing need for affordable, accessible, and integrated housing. Yet, decent affordable housing for people with disabilities should not be dependent upon yearly state budget decisions. Instead, the State should ensure that people with disabilities have more opportunities to obtain affordable, accessible, and integrated housing.

5. EDUCATION

Top Priority:

- **Establish a definition and standard for physical restraint in public schools. Require documentation by the school and written notification to the parent when restraint is used.**

Legislation is urgently needed to address the use of physical restraint on students. Students with disabilities are especially vulnerable to inappropriate use of restraints. Physical restraints should be used only in those situations when a child poses an imminent risk of harm to self or others. A single, uniform standard for restraint of students in public schools should be established, including identifying the most effective, least restrictive and safest techniques for modification of a child's behavior, emphasizing de-escalation techniques to avoid the use of physical force. The use of

restraint must be fully documented by the school and parents must be notified in writing. School personnel should receive training on the proper use of physical restraint and, in particular, alternatives to the use of restraints.

6. CIVIL RIGHTS

Top Priorities:

- **Incorporate Title II of ADA into NYS Human Rights Law.**
 - *A.2571 of 2007*
 - *A.6303 of 2007*

- **Waive the State's sovereign immunity to claims under the ADA and Section 504.**
 - *A.7653 of 2007*

Background:

The Americans with Disabilities Act (ADA) of 1990 and Section 504 of the Rehabilitation Act of 1973 each provide comprehensive protection for the civil rights of people with disabilities under federal law. Efforts to weaken the scope of the ADA in particular, and inconsistencies with the provisions of NYS Human Rights Law, have left people with disabilities facing confusion and uncertainty about the scope and enforcement of their civil rights protections in New York.

We are grateful for the passage last year of a bill incorporating Title III of the ADA into state law. Title III provides protection against discrimination in public accommodations and requires that reasonable accommodations be provided to individuals with disabilities. In incorporating this provision into state law, people with disabilities gained access to state administrative enforcement mechanisms through the Division of Human Rights.

It is now essential that New Yorkers with disabilities are assured that the provisions of Title II of the ADA are also incorporated into state law. Title II provides protections against discrimination on the basis of disability in services provided by public entities, including state and local governments. This bill would clarify the scope of protections against discrimination on the basis of disability by these entities, including in the provision of services, programs and activities. Public entities would be required to make reasonable accommodations and individuals with disabilities would have access to the administrative enforcement mechanisms through the state Division of Human Rights.

It is essential that New York State also ensure that the State's immunity to suit under the ADA and Section 504 is waived.

5. ELECTION REFORM

Top Priority:

- **Eliminate provisions in Section 4-104 (1-a) of the NYS Election Law allowing waiver of polling place accessibility requirements. Require polling places to comply with ADA accessibility guidelines and ensure access surveys are conducted at all polling places.**
 - *S.6311 of 2007*

Background:

With the passage of the federal Help America Vote Act (HAVA) in 2002, voters with disabilities in New York State believed that they would finally be afforded full and equal access to the electoral process. Unfortunately, despite concerted efforts by disability rights advocates, New York has been the last state to implement HAVA's requirements and ensure that persons with disabilities can vote independently, privately and securely, and the State is currently being sued by the federal government as a result. People with disabilities must be afforded this basic right as citizens to vote along with their families, friends, and neighbors, and barriers to this right that remain in New York State Election Law must be removed.

6. TRANSPORTATION

Top Priority:

- **Require transportation service providers, such as taxis, limousines and hotel shuttles to purchase accessible vehicles or otherwise ensure that they have the capacity to serve people with disabilities.**
 - *A.8520 of 2007*

Background:

The limited availability of accessible transportation services is a major barrier faced by individuals with disabilities throughout the state, often leading to unemployment, the inability to access medical care, and isolation from friends, family, and full community participation.