



2009 Disability Priority Agenda

As New York strives to cope with historic budget shortfalls, there is an opportunity to make systemic reforms to ensure that services and supports for people with disabilities are available in the most integrated setting, as required by the US Supreme Court's *Olmstead* decision. Substantial cost savings can result from shifting State funding from institutional and other segregated services to fully integrated services and supports in the community – for example, through Medicaid and long term care reform that expands consumer directed service models, funding for integrated employment services rather than sheltered and other segregated models, and support for Independent Living Centers (ILCs) in their work to ensure individuals are served effectively in the most integrated setting by all service systems.

Increasing funding for Independent Living Centers carries no cost to the State because of the substantial savings generated by these essential services. In fact, not doing so costs the State money in lost savings. ILCs have saved New York taxpayers more than \$9 in deinstitutionalization costs for every State dollar invested in ILCs. ILC services contribute to a net savings to the State of upwards of \$110 million each year as a result of avoided institutionalized care for people with disabilities. A recent national study of ILCs, funded by the federal Centers for Medicare and Medicaid Services supports this, finding that:

Centers for Independent Living continue to demonstrate value in assisting individuals with disabilities of all ages to gain needed skills and obtain needed supports to live independently in integrated community settings. Centers have proven to be effective partners in helping government comply with the Americans with Disabilities Act and save money by supporting individuals with disabilities to live in less-costly community settings. (Rutgers Center for State Health Policy, June 2008)

In 2008, NYAIL sponsored a statewide needs assessment, conducted by the Center for Governmental Research, which showed significant gaps in services and underserved geographic areas statewide. The report provides ample evidence of the

need for additional ILC services in communities across the state, to lessen current inequities in the availability of ILC services and provide critical safety net services during the economic downturn.

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. Independent Living Centers (ILCs) are controlled and primarily staffed by people with disabilities and provide a variety of community-based 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 independent, fully integrated lives in their communities.

For further information and copies of NYAIL's statewide needs assessment final report, please contact:

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2009 BUDGET PRIORITIES

INDEPENDENT LIVING CENTER (ILC) FUNDING

- Restore \$1.2 million in 2008-09 SFY budget cuts. Increase ILC funding to generate additional savings to the State and provide critical services to people with disabilities.

In SFY 2008-09, ILC funding was cut twice, in April and during the August special session, for a total cut of \$1.2 million from the previous level of \$13.2 million. These cuts should be fully restored and an additional investment made in ILCs to generate even further savings to the State. ILCs have conservatively saved New York taxpayers more than \$9 in deinstitutionalization costs for every state dollar invested in ILCs for a net savings of upwards of \$110 million each year as a result of avoided institutionalized care for people with disabilities. (VESID, 2007) NYAIL's 2008 statewide needs assessment report outlines significant gaps in services and underserved areas of the state, resulting in substantial funding inequities and lost State savings. (Center for Government Research, 2008) Strengthening ILCs also furthers the State's goal of serving people with disabilities in the most integrated setting possible, in compliance with the US Supreme Court's *Olmstead* decision. ILCs play a key role in enhancing individual independence and economic self-sufficiency, and provide critical safety net services in the current economic downturn.

HEALTH CARE

- The State should increase access to and use of consumer-directed models of service for community-based long term care to generate structural Medicaid savings and ensure people with disabilities of all ages are served in the most integrated setting.

People with disabilities want to choose and manage their own services, delivered in their homes. The Consumer Directed Personal Assistance Program (CDPAP) saves State Medicaid dollars because the reimbursement rate for services is nearly 1/3 less than traditional, agency-directed services. Broadening use of the CDPAP program will generate structural Medicaid savings and increase access to services in the most integrated setting. To accomplish this, the State should:

- 1) Invest savings generated by the CDPAP program in outreach, training and transitional services for individuals who wish to participate in CDPAP. ILCs have demonstrated expertise in providing these services;
- 2) Set saving targets for counties to enroll or transition individuals to CDPAP;
- 3) Amend regulations regarding payment to family members for attendant services to be consistent with federal regulations.

- Response to 2009-10 SFY Executive Budget proposals:
 - The proposal for Regional Long Term Care Assessment Centers seems to address disparities in the availability of services from county to county, particularly in upstate regions; if these centers are solely focused on cost savings, however, continued under-authorization of services may result.
 - The resources proposed for the Cash & Counseling demonstration would be better invested in transitioning people who wish to participate in the Consumer Directed Personal Assistance Program (CDPAP) from costlier agency directed services.
 - Cuts to home care services, particularly personal care, should be rejected. Making cuts to home care rates, particularly personal care, is a counterproductive strategy. Cuts in personal care rates will lead to lower compensation for personal care attendants, just as the State is trying to improve the compensation of home health aides who provide costlier agency-directed services.
 - Housing subsidies are essential to the success of the Nursing Facility Transition and Diversion (NFTD) Medicaid waiver program. We applaud Governor Paterson for again including \$2.5 million for housing subsidies. In implementing the NFTD program, the State will assist 5000 seniors and people with disabilities to live in the most integrated setting and avoid or end unwanted and costly nursing home placement. Access to affordable, accessible, and integrated housing is critical to the success of this program.

SSI BENEFITS / POVERTY

- Restore the 2009-10 SFY Executive Budget proposed cuts to State benefits for SSI to individuals and couples living in the community.

Although there has been no increase in the state supplement for 20 years, the 2009-10 Executive Budget proposes to cut the SSI state supplement to individuals and couples

living in the community by between \$16 and \$28, effective June 1, 2009, as a means to save the State \$84 million in 2009-10 and \$79 million in 2010-11. Despite the expected cost of living increase to the federal benefit, individuals who depend on their SSI income in order to pay their rent or buy their groceries cannot afford the proposed cuts to state benefits. Now more than ever we need to preserve the safety net for SSI beneficiaries.

MOST INTEGRATED SETTING

- Ensure that all individuals with disabilities have the right to choose and receive services in the most integrated setting. Establish a presumption that community-based services are more appropriate than institutional or segregated settings. Require all State agencies to promote such integration through a plan and annual report. *A.7277 of 2007-08*

Under the 1999 US Supreme Court *Olmstead* decision, people with disabilities are entitled to receive the services and supports they need to live in the community and avoid unwanted placement in nursing homes and other institutions. The impact of the *Olmstead* decision has not been fully realized in New York, in terms of facilitating the transition to fully integrated community-based services, in spite of some recent progress made by the State's Most Integrated Setting Coordinating Council (MISCC). The long-standing financial and policy bias toward institutional and segregated placements by New York's disability service systems, including Medicaid, continues to exist, leading to unnecessary and costly institutionalization and segregation of people with disabilities. This bill would require State-operated and funded service providers to demonstrate why placement of an individual in an institutional or segregated setting is necessary, creating a presumption that community-based services are the most appropriate, and leading to substantial cost savings to the State in Medicaid and other state-funded services.

EMPLOYMENT

- 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.

There are currently 52,229 individuals enrolled in segregated programs, including sheltered workshops, through OMRDD alone, with a total cost to the state of more than \$1 billion. The cost per person in a segregated program, according to OMRDD's figures, is \$21,309 compared to \$5,291 per person in supported employment. Everyone, regardless of disability, can work in a real job for real wages. All people with disabilities should have the opportunity to make informed choices about where to work and a continuum of employment services, leading to fully integrated employment, should be available. Supported and other integrated employment programs save substantial costs to the State and ensure people with disabilities are served in the most integrated setting possible.

2009 PUBLIC POLICY PRIORITIES

HOUSING

- Incorporate the housing provisions of Section 504 of the Rehabilitation Act into state law. *A.6033, A.7138 and S.3956a of 2007-08*

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.6837a of 2007-08*

"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 mobility impairments 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.

CIVIL RIGHTS

- Incorporate Title II of ADA into NYS Human Rights Law. *A.2571 and A.6303 of 2007-08*
- Waive the State's sovereign immunity to claims under the ADA and Section 504. *A.7653 and S.6698 of 2007-08*

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. It is essential that New Yorkers with disabilities are assured that the provisions of Title II of the ADA are 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 gain critical 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.

EDUCATION

- 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. *A.1862 of 2008*

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 alternatives to their use.

MENTAL HEALTH

- 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.

Parents with psychiatric and intellectual disabilities are vulnerable to the loss of custody and termination of their parental rights because of a long-standing bias in State law. Since 1976, NYS Social Services Law has included as grounds for the termination of parental rights, the inability "by reason of mental illness or mental retardation, to provide proper and adequate care..." of a child. The use of these disability-related grounds for termination promotes the discriminatory belief that parents with such disabilities are unable to care for their children and creates a presumption that these parents are unfit. The safety of children is adequately protected, however, by other provisions of SSL 384-b allowing termination based on a parent's behavior rather than their disability.

ELECTION REFORM

- 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. Require election workers to receive mandatory training in disability etiquette and use of Ballot Marking Devices (BMD). *S.6311 of 2007-08*

People with disabilities must be afforded the 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.

TRANSPORTATION

- Require transportation service providers, such as taxis, limousines and shuttle services, to purchase accessible vehicles or otherwise ensure that they have the capacity to serve people with disabilities. *A.8520 of 2007-08*

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.