

## **2017 DISABILITY PRIORITY AGENDA**

The New York Association on Independent Living (NYAIL) represents Independent Living Centers (ILCs) and the people with disabilities they serve. NYAIL is dedicated to removing barriers to full community integration and safeguarding the civil rights of people with disabilities of all ages. More than 25 years after the passage of the Americans with Disabilities Act, New Yorkers with disabilities continue to experience lower educational attainment, lower levels of employment and wages, greater social isolation, worse health outcomes and greater levels of poverty than their nondisabled counterparts. Despite these gross inequalities and further threats to people with disabilities' rights and services at the federal level, the 2017-18 Executive Budget fails to advance the State's community integration efforts. We urge the Legislature to take legislative and administrative action as outlined below toward the full integration of New Yorkers with disabilities.

### **INDEPENDENT LIVING PRIORITIES**

#### **NYAIL Strongly Supports/Recommends:**

- increasing base funding for Independent Living Centers (ILCs) to \$18 million as recommended by the State Education Department and Board of Regents.
- providing a voice for people with disabilities in state government by reactivating the duties of the State Office for the Advocate for Persons with Disabilities.
- requiring wheelchair-accessibility as part of any transportation network proposal.
- prioritizing employment for people with disabilities by implementing policies in the Employment First report, including establishing a small business tax credit for New Yorkers with disabilities.

### **HEALTH/MEDICAID**

#### **NYAIL Strongly Supports/Recommends:**

- addressing the home care crisis by providing a living wage to home care workers.
- establishing a high-needs community rate cell to allow MLTC plans to serve those with the greatest needs.
- fully funding the Community Health Advocates (CHA) program at \$4.75 million.
- removing the 20-visit cap on physical therapy, occupational therapy and speech therapy.

#### **NYAIL Strongly Opposes:**

- prohibiting a spouse or parent from refusing to financially support their child or spouse in order for that individual to obtain Medicaid.
- eliminating Provider Prevails.
- eliminating Medicaid payments for bed holds for nursing facilities.
- the proposed \$4 million reduction to New York's No Wrong Door system.
- the proposed \$20 million reduction to the State's investments in the Medicaid Redesign Team Supportive Housing workgroup initiatives.
- granting the Governor broad authority to make budget changes mid fiscal year.

### **ACCESS TO HOUSING**

#### **NYAIL Strongly Supports/Recommends:**

- restoring Access to Home funding to \$4 million.
- a Visitability tax credit to help homeowners retrofit their homes to make them more accessible, or to incentivize including visitable features at the time of construction.
- preventing homelessness for people with disabilities and other vulnerable populations by enacting the Home Stability Support (HSS) program.

## **INDEPENDENT LIVING PRIORITIES**

- **Increase base funding for Independent Living Centers (ILCs) to \$18 million as recommended by the State Education Department and Board of Regents.**

ILCs provide critical services to people with disabilities all designed to assist them in navigating the ever-changing service system in order to live independent, fully integrated lives in the community. As the State continues to redesign health care in ways that are intended to increase quality and decrease costs, ILCs play a crucial role. ILCs provide a wide range of services based on the local needs, all of which are aimed at addressing the social determinants of health: education, employment, housing, social skills.

ILCs have been woefully underfunded for the past twelve years while the cost of doing business has increased dramatically, creating a crisis for centers and the people with disabilities they serve. In 2015/2016, the state's network of ILCs served 103,573 people with disabilities, family members and others; an increase of more than 20,000 in just five years. This demonstrates the pressing need for IL services in communities, and the number served would likely be higher had the IL funding kept up with the capacity needs of centers.

Furthermore, investing in ILCs saves the State money. Data from the New York State Education Department, ACCES-VR, show that the work of ILCs to transition and divert people with disabilities from costly institutional placements saved the State more than \$2.3 billion since 2001 as a result 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.

- **Provide a voice for people with disabilities in state government by reactivating the duties of the State Office for the Advocate for Persons with Disabilities as established by former Governor Mario Cuomo in 1983 through Executive Order No. 26.**

The Office, then located within the Commission on Quality Care (CQC), was intended to serve as the State advocate on behalf of people with disabilities, tasked with advising and assisting the Governor in developing policies designed to help meet the needs of people with disabilities and serving as the State's coordinator for the implementation of Section 504 of the Federal Rehabilitation Act of 1973 (this would now include the Americans with Disabilities Act and *Olmstead*). Though this office was maintained by Governor Andrew Cuomo through the continuation of the establishing Executive Order, the office has since dissolved with the Commission on Quality Care. The Justice Center, which succeeded the CQC, has reorganized itself without any advocacy functions for people with disabilities. A new home for advocacy and independent living must be established. At a minimum, and immediately, the responsibilities of the Office for the Advocate must exist in State government and the Governor should reaffirm his commitment to this Executive Order as soon as possible. NYAIL also supports the statutory creation of a state agency which focuses on the community integration needs of people with disabilities.

- **Require wheelchair-accessibility as part of any transportation network proposal.**

The absence of accessible and affordable transportation is a major barrier for New Yorkers with disabilities, impacting their ability to work and participate in the community. This is particularly true upstate, where there are limited public transportation options and people with disabilities rely more on private transportation to get to and from work, as seen in data from the American Community Survey of the U.S. Census. Allowing ridesharing services to operate throughout the State has the potential to dramatically increase transportation opportunities for people with disabilities.

However, any new transportation option must serve all people with disabilities. Proposals from Governor Cuomo and the Senate would provide transportation network companies (TNCs) such as Uber and Lyft with state-wide authority without ensuring wheelchair access and would prevent localities from imposing any accessibility requirements. The current proposals include a provision to form a task force to evaluate the need for accessible vehicles; however, there is no deadline for the needs assessment or any requirement that operating TNCs implement the recommendations.

We do not need a task force to look into the need. The disability community has been advocating for more accessible transportation options throughout the State for years. However, without accessibility requirements, this proposal has the potential to make the situation worse by putting what accessible transit options there are upstate out of business, as we have already witnessed in NYC. The State should not and cannot allow a new business to operate throughout New York that refuses to serve a segment of the population. The State must include wheelchair-accessibility as part of any rideshare proposal.

- **Prioritize employment for people with disabilities by implementing policies in the Employment First report, including establishing a small business tax credit for New Yorkers with Disabilities.**

Despite a commitment to enacting all of the recommendations in the report, very little progress has been made in the two years since first issued. Despite assurances that the Commission's recommendation to establish a small business tax credit would be included in the Executive budget, the budget does not include such a proposal. We urge the State to make the employment of people with disabilities a priority in this year's budget by creating a cross-disability tax credit geared toward small businesses, as laid out in A1369/S3688.

### **HEALTH/MEDICAID**

- **Address the home care crisis by providing a living wage to home care workers.** While the State did allocate \$225 million to support the direct cost of the FY 2018 minimum wage increases for health care workers that provide services reimbursed by Medicaid, this is not sufficient. This funding only brings home care workers up to minimum wage – the same pay rate as fast food workers – however these are not minimum wage jobs. Home care workers help many of our most vulnerable citizens

by giving them the care they need to live at home. These are vital, not to mention physically and emotionally taxing jobs. Simply providing enough funding to meet minimum wage is insufficient to address the home care crisis we are facing in New York. In many parts of upstate, people are unable to get care at home because not enough people want these jobs due to the low pay. The State has also failed to provide sufficient funding to cover the additional costs associated with new labor laws, putting home care, particularly the Consumer Directed Personal Assistance Services (CDPAS) program at risk.

- **Establish a high-needs community rate cell to allow MLTC plans to serve those with the greatest needs.** The creation of a high-needs community rate cell will provide managed care organizations (MCOs) with sufficient funding to serve those with the greatest needs. The current capitation rates do not provide for this, and as a result, those with the most significant disabilities may not be able to get the supports and services they need to live in the community. In order to ensure that those with the most significant needs are able to get the supports and services they need to live in the community, NYAIL calls on the State to create a high needs community rate cell.
- **Fully fund the Community Health Advocates (CHA) program at \$4.75 million.** The CHA program assists New Yorkers, including many people with disabilities, to navigate the complex and ever changing health care system. Governor Cuomo proposed funding the CHA program at \$2.5 million, however increasing that funding to \$4.75 million would allow CHA to provide services to more communities across the State and handle the additional influx of cases from constituents who are fearful and confused about the potential repeal of the Affordable Care Act (ACA).
- **Remove the 20-visit cap on physical therapy, occupational therapy and speech therapy.** The 20-visit limit on Medicaid Physical Therapy, Occupational Therapy, and Speech Therapy should be subject to an override. Arbitrary visit limits don't make sense and discriminate against people with disabilities. Medicare provides for an override, and Medicaid Utilization Thresholds which have been used in New York have provided a procedure for a physician override. Such a procedure should be implemented with these limits.
- **NYAIL strongly opposes prohibiting a spouse or parent from refusing to financially support their child or spouse in order for that individual to obtain Medicaid.** This proposal will eliminate the longstanding right of "spousal/parental refusal" for vulnerable populations such as severely ill children and low-income seniors. As proposed in the budget, the refusal will only be honored and Medicaid be granted if a parent lives apart from their child or if a spouse lives apart or divorces the potential Medicaid recipient. NYAIL opposes denying Medicaid to these vulnerable populations. If this proposal is enacted it will force low income individuals to institutionalize their loved ones purely for financial reasons, creating a discriminatory institutional bias.
- **NYAIL strongly opposes eliminating provider prevails.** This proposal would repeal an important patient protection in the Medicaid program which restored "prescriber prevails" for several classes of drugs in the fee for service and managed care

programs. A prescriber, with clinical expertise and knowledge of his or her individual patient, should be able to override a preferred drug. Different individuals may have very different responses to different drugs in the same class. Sometimes only a particular drug is effective or alternative drugs may have unacceptable side effects. Prescribers are in the best position to make decisions about what drug therapies are best for their patients. NYAIL urges the State to recognize the importance of specific prescription drug combinations and protect provider prevails.

- **NYAIL opposes eliminating Medicaid payments for bed holds for nursing facilities.** The Governor proposes to eliminate Medicaid payments to nursing facilities to reserve a bed after a resident leaves the nursing facility. Bed hold payment plays a crucial role in ensuring continuity of care for some of New York's most vulnerable people. People in nursing facilities routinely need to be temporarily hospitalized and then return back to the nursing facility. NYAIL is gravely concerned that eliminating this payment will have a detrimental impact on the stability and continuity of care for nursing facility residents.
- **NYAIL opposes the proposed \$4 million reduction to New York's No Wrong Door system.** As part of the Balancing Incentive Program, the State has expanded its No Wrong Door system to bring together the federally funded Area Agencies on Aging and Independent Living Center networks to create a true single point of entry system for accessing long term services and supports. Ensuring access to comprehensive, accurate and unbiased information about long term service and support options and linkages to services is essential as New York continues to implement major systemic reforms to the State's Medicaid system that drastically change the way long term care is delivered.
- **NYAIL opposes the proposed \$20 million reduction to the state's investments in the Medicaid Redesign Team Supportive Housing workgroup initiatives.** The lack of affordable and accessible housing is the biggest barrier to transition for people with disabilities and older adults. The MRT Supportive Housing workgroup has funded important programs that assist people with disabilities to return to or stay in their community, including Access to Home for Medicaid eligible individuals, the Nursing Home to Independent Living pilot program and the Olmstead Housing Subsidy program. The 2017-18 Executive Budget proposes reducing its future investments in these initiatives by \$20 million. New York must continue to invest in these programs, including making the Olmstead Housing Subsidy a permanent funding stream, to ensure people with disabilities and older adults have access to affordable, accessible, integrated housing.
- **NYAIL opposes granting the Governor broad authority to make budget changes mid fiscal year.** The looming changes at the federal level create uncertainties for all programs and the people impacted by them. However, any sudden changes to federal support that require action by the State must be addressed jointly by the Executive and Legislature and should include a process for stakeholder input.

## **ACCESS TO HOUSING**

- **Restore Access to Home funding to \$4 million.** Access to Home is an important program administered by NYS Homes and Community Renewal (HCR) that provides funding for home modifications to allow individuals with disabilities and older New Yorkers to stay in their homes and out of costly institutions. For the past several years, the program has been severely underfunded at only \$1 million statewide, leaving many parts of the state without the program and resulting in years long waiting lists. The State did allocate \$19.6 million to the program in the 2015-16 SFY from the J.P. Morgan settlement funds, however those funds were limited to veterans with disabilities. Much of this funding has gone underspent. Despite recommendations to broaden eligibility to the appropriation language in the 2016-17 budget, eligibility is still limited. New York should use funds from the JP Morgan Chase settlement to adequately fund Access to Home for all people with disabilities.
- **Create a Visitability tax credit to help homeowners retrofit their homes to make them more accessible, or to incentivize including visitable features at the time of construction.** Despite strong support from the legislature, Governor Cuomo has vetoed legislation to create a visitability tax credit for the past two years. In both veto messages, the Governor indicated support for the program, but stated that such a proposal would need to be handled during budget negotiations. Despite his stated support for the program, Governor Cuomo has failed to include this tax credit in his proposed executive budget. This is a priority for the disability community as a tax credit would help keep people in their homes and out of institutions by assisting people with the costs associated with making their homes more accessible. NYAIL urges the legislature to include the \$1 million pilot program as proposed in A.9303B/S.6943A of 2016.
- **Prevent homelessness for people with disabilities and other vulnerable populations by enacting the Home Stability Support (HSS) program.** HSS provides a statewide rental subsidy for those facing eviction, homelessness, or loss of housing due to domestic violence or hazardous living conditions. When people become disabled and unable to work, they are at great risk of eviction. Shelters are inappropriate for people with illness or disability due to unsafe and unsanitary living conditions. Further, they are often inaccessible, fail to provide reasonable accommodations, and people are often unable to receive services, such as home care in shelters. Current shelter supplements are inadequate to help people afford rent, and other rental programs, such as Section 8, typically take years to obtain. This rental subsidy would stabilize many of our most vulnerable citizens.

### **For further information, please contact:**

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