

Center for Disability Rights, Inc.

The "Beacon for Social Progress" must light the way for the Disability Community as well! Analysis of Governor Cuomo's 2018 State of the State January 5, 2018

Governor Andrew Cuomo's 2018 State of the State speech had an optimistic tone for what even he acknowledged was going to be a "tough year." The Center for Disability Rights (CDR) finds the Governor's focus on social and economic progress to be heartening, but we fear that he will fall short on involving the Disability Community in his agenda. It is positive to hear a sitting Governor declare that "inclusion is our operating principle, and forging community is our ultimate goal" and that "the most important element of New York's social progress agenda is equality." However, our optimism is tempered by years of working with the administration of a governor who has often ignored our community.

Each year, CDR closely reviews and responds to the State of the State and the Governor's proposed Executive Budget. CDR's response focuses on how the Governor's proposals would impact people with disabilities, and more specifically, how the proposals affect the ability of people with disabilities to live independently in the community. The following is our analysis of Governor Cuomo's 2018 State of the State. We will release an indepth analysis of the Executive Budget after it is released.

COMMUNITY LIVING

The Disability Community unequivocally values community living. All people, regardless of age or disability, should be able to live independently and participate fully in their communities. When a person needs supports or services, those can and should be provided in such a way to allow that person to continue living in the community consistent with the Supreme Court's *Olmstead* decision and with our constitutional right to liberty.

HEALTHCARE IS A RIGHT, NOT A LUXURY

In his speech, Governor Cuomo recognized that the federal government is working to roll back healthcare, and he aptly stated "In New York, we believe healthcare is a right, not a luxury." We could not agree more. In fact, disabled New Yorkers were on the front lines of the fight against the attacks on Medicaid and Obamacare. We put our bodies and criminal records on the line to fight to preserve Medicaid funding because we know that the right to freedom is a Constitutional right. Without Medicaid funding, many disabled people would be locked away in nursing facilities and other institutions.

Unfortunately, despite the Governor's belief that healthcare is a right, not a luxury, far too many disabled and elderly New Yorkers are stuck in institutional settings against their will, and even more are being pushed into these restrictive and segregated settings by the Cuomo Administration's implementation of managed care. The current model incentivizes Managed Care Organizations (MCOs) to cap service hours and push people with significant disabilities into institutions. To address this, the Governor should direct his administration to create a High Needs Community Rate Cell which is an increased reimbursement rate dedicated to supporting individuals in the community whose service needs significantly exceed the reimbursement rate that MCOs receive to serve them. Creating a High Needs Community Rate Cell would ensure that disabled New Yorkers freedom is not sacrificed to support the MCOs bottom line.

LONG TERM SERVICES AND SUPPORTS SERVICES MUST INCLUDE THE DISABILITY COMMUNITY

CDR commends the Governor's efforts to support the state's aging population. The launch of the Long Term Care Planning Council will benefit many aging and disabled New Yorkers. However, the absence of any

mention of the Disability Community in its leadership and composition is concerning. The Disability Community cannot be left out of a council focused on addressing gaps in the provision of long term services and supports. The link between aging and disability is too obvious to ignore. This situation begs for the leadership of the Office of the Advocate for People with Disabilities. Sadly, the Governor has not maintained the Office of the Advocate for People with Disabilities which was established by his father. We call on the Governor to reestablish the Office of the Advocate and charge the Advocate with serving on the Long Term Care Planning Council alongside the Commissioner for Health and the Director of the Office of the Aging.

RURAL NEW YORK NEEDS IMPROVED HEALTHCARE

Disabled and elderly people living in rural areas of New York have long experienced disparities in the healthcare and long term services and supports they receive. We are excited about Governor Cuomo's proposal to improve access to healthcare in rural areas by expanding telehealth services and strengthening the emergency medical services system but recognize that these efforts are not enough, and – if not thoughtfully implemented – may have unintended negative consequences. Disabled and elderly individuals in rural areas struggle to receive adequate healthcare due to unreliable access to transportation. We have seen disabled people lose their doctors because Medicaid transportation has cancelled too many times with little or no notice. No disabled person should miss their appointment or lose their doctors' services because of systemic inadequacies in their area. Telehealth can assist disabled and elderly individuals with basic needs, but it is not a replacement for a reliable Medicaid transport system. Telehealth is also only helpful for individuals with access to the internet, and because disabled people often live on fixed incomes, internet may not be available to many in rural areas. Additionally, Governor Cuomo's administration must work hard to ensure that the introduction of telehealth does not drive out the few in-person providers in rural areas.

While these initiatives may help with some healthcare needs, they do not address the critical shortage of attendants in rural areas. Governor Cuomo should include an initiative to attract and retain more attendants in rural areas so that disabled and elderly New Yorkers can continue to live in their communities and receive they help they need in their own homes, lest they be forced into nursing facilities without such attendants.

WOMEN WITH DISABILITIES MUST BE A PART OF THE WOMEN'S AGENDA

The Governor promised to continue his work on the Women's Equality Agenda, which in part addresses domestic violence. These efforts are laudable; however this work must include greater consideration for the violence experienced by disabled women. Women with disabilities are at least twice as likely to face abuse and violence as non-disabled women. The situations in which disabled women experience violence often differ from non-disabled women; while many women with and without disabilities experience abuse in the community, many disabled women are also subjected to the very distinct violence of institutional life. It's difficult to highlight the statistics on this because it is believed most incidents are not reported. The Governor must include disabled women both in facilities and in the community in his promise to keep New Yorker's safe.

Women living in the community are likely to face violence from family, friends, attendants/workers that come into their home. Many women are afraid to speak up about violence because they may lack the supports and services needed to continue to live in the community when their partner or family member is their sole support. It is also a factor that people stay with their abusers because of the lack of accessible shelters in their area, lack of accessible transportation and severe lack of accessible housing for them to move in to.

CDR recommends that the New York State Council on Women and Girls to research and disseminate up to date information on the frequency of people with disabilities facing violence in nursing facilities and in the community in New York State. The Council must also make addressing this violence a higher priority.

ACCESS TO HOUSING

Community living is not possible without housing. If New York is truly to be "the nation's beacon for social progress" it must begin to address the critical shortage of affordable, accessible, integrated housing. The shortage is a significant obstacle to realizing Governor Cuomo's own Olmstead plan. The housing shortage is keeping many disabled New Yorkers stranded in nursing facilities, which are not the most integrated settings possible. Confinement to a nursing facility severely limits person's involvement in the surrounding community and restricts one's ability to make basic choices about one's daily activities. No disabled person should have to live or die in a nursing facility because the State failed to supply adequate accessible housing.

By failing to address the shortage of accessible housing, the State is actually costing itself millions of dollars that it could otherwise claim under the Community First Choice Option. In a year when the Governor is bemoaning a \$4 billion dollar budget shortfall,¹ an investment in accessible housing would reap long-term financial benefits and serve the needs of disabled New Yorkers at the same time.

THE GOVERNOR MUST PROPOSE THE VISITABILITY TAX CREDIT IN THE BUDGET

Notably absent from the Governor's initiatives was a proposal for a Visitability Tax Credit. For the past three years, the Disability Community has successfully advocated for the passage of this legislation which would create a credit for homeowners to make certain accessibility modifications which render their homes "visitable" to a person with a disability. Governor Cuomo has vetoed this legislation three times because it was not included in the budget, but year after year he does not include it in his own budget. CDR calls on the Governor to include the Visitability Tax Credit in his budget this year and sign this important legislation.

HOUSING & SERVICES PROVIDED UNDER THE GOVERNOR'S HOMELESSNESS PLAN MUST BE ACCESSIBLE

Since 2016, Governor Cuomo has been focused on combatting homelessness, and we commend him for proposing an initiative this year to increase mental health and substance use disorder services to those experiencing homelessness. However, the Governor's initiatives do not go far enough because Governor Cuomo's initiatives and programs do not recognize people with long term service and support needs as part of the homeless population. The Governor's initiatives must be provided in a way that addresses the needs of New Yorkers who are currently stuck in nursing facilities and other institutions, and in a manner that does not discriminate against the many disabled people who are homeless.

Homeless shelters are often inaccessible and disabled individuals are often placed in nursing facilities when they become homeless. Many New Yorkers with disabilities in institutions do not have homes to return to, yet because they are being housed in an institution, they are not considered homeless and are therefore not eligible for supports provided under initiatives combatting homelessness. Although disabled people who are in institutions may have a bed and a roof, they are no less homeless. CDR calls upon the Cuomo administration to include New Yorkers with disabilities in institutions that do not have homes to which they can return in the definition of "homeless" in order to qualify for additional support.

STATE-FUNDED HOUSING MUST MEET ESTABLISHED ACCESSIBILITY REQUIREMENTS

The fact that people living in institutions cannot secure other housing to transition into further emphasizes the need to expand access to affordable, accessible, integrated housing, discussed above. In addition to supporting a Visitability Tax Credit, CDR urges Governor Cuomo to require all housing units created with state funds to meet the accessibility requirements listed in the Fair Housing Amendments Act (FHAA).

¹ <u>http://buffalonews.com/2018/01/03/as-4-billion-deficit-awaits-cuomo-offers-less-expensive-policies-for-2018/</u>

LABOR AND EMPLOYMENT

We are pleased to hear in the State of the State that unemployment and underemployment are down in every region with the help of 6,300 Regional Economic Development Councils projects in the works. We are also encouraged by the Governor's projection that there will be 362,000 job openings per year over the next ten years. Our optimism is limited, though, by our knowledge of the true breakdown of employment statistics by subpopulation. According to the federal Office for Disability Employment Policy, the national unemployment rate in November 2017 for people with disabilities was 8.5%; compared to 3.7% for those without disabilities. And New York ranks a dismal 36th, at 33%, in the ranking of states by employment rate of people with disabilities in the 2016 Annual Disability Statistics Compendium.² The findings of the Compendium are a good reason to address the fact that New York itself does not gather and report data on the employment of people with disabilities. Collecting this data would better enable the state to develop employment opportunities for disabled workers. CDR calls on the Governor to direct the State Department of Labor to collect and publish this data, because doing so would enable the State to develop employment strategies for disabled workers and, more importantly, ensure that job creation actually creates employment opportunities for all New Yorkers.

NY WORKS MUST INCLUDE EMPLOYEES WITH DISABILITIES AND DISABILITY-LED ORGANIZATIONS

In the "NY Works" section of the State of the State, the Governor lays out multiple plans to invest in and develop the workforce in various sectors. For instance, he highlights the importance of investing in nonprofits. Many non-profit human services organizations, such as the Center for Disability Rights, rely on state funding. Investing in nonprofits like independent living centers would help us attract qualified candidates and decrease turnover, so we strongly support the Governor's intentions to invest in nonprofit jobs. Increasing base funding for ILCs in SFY 2018-19 to \$18 million with the long term goal of increasing the State appropriation to \$25 million would show that the Governor is serious about developing the workforce and would have the added benefit of helping get more people with disabilities back into the community.

The breadth of the NY Works plan is encouraging; however, there is no mention of any investment in disabled workers. The funding of vocational programs like those offered by ACCESS-VR and the Commission for the Blind is ignored, and no training programs for people with disabilities are mentioned. New York State must work to ensure that people with disabilities are part of competitive hiring and incentivize private employers to hire and pay fair wages to New Yorkers with disabilities.

NEW YORK MUST END SUB-MINIMUM WAGES

Regarding the protection of workers' rights, we welcome the New Year along with the increase in the statemandated minimum wage, as well as the proposal to explore ending the minimum wage tip credit in New York State to protect the livelihood of workers in certain workplaces. However, it is terrible that the livelihood of workers in sheltered workplaces was ignored in the State of the State. In a state that boasts equality, it is still legal to pay workers with disabilities pennies per hour³. CDR calls upon the governor to end this exploitation.

HIGHER ATTENDANT WAGES MUST BE A PRIORITY

The Governor spoke of the need to protect workers' rights and of his commitment to fair wages. Governor Cuomo must extend this support to our attendants who do some of the most important tasks and allow us to live our lives in the community, but who are among the lowest paid workers in the state. Not paying our attendants enough affects both their livelihood and our well-being. Low wages is one of the primary reasons attendants leave our employ and it is the reason we struggle to replace attendants when they leave. Furthermore, there are

² <u>http://fortune.com/2017/02/28/disability-employment-rank/</u>

³ <u>http://webapps.dol.gov/elaws/whd/flsa/14c/</u>

stronger protections for fast food workers who make more money than our attendants. Without adequate wages, attendants doing this important but difficult work will be attracted to easier jobs with higher pay in the retail and the fast food industries. The Governor must create adequate payment structures that will maintain a sufficient workforce to provide services in home and community based settings. It is also important that whatever measures the State takes, it must ensure any funds pass directly through the MCOs and to the workers. State funds do us no good in the pockets of Managed Care Organizations.

INFRASTRUCTURE AND DEVELOPMENT

The Governor put forward numerous, broad-reaching infrastructure and development plans for fueling economic growth in our state. Not only will he support local business and agriculture, he will update our transportation systems, exhibition centers, and parks to make travel and tourism more attractive. Furthermore, he will continue to invest money in localities to help revitalize their downtown centers. Whether it is updating subway systems or building a new hall at the state fairgrounds, the extent to which the State incorporates accessibility for disabled New Yorkers and visiting tourists alike will determine whether or not these additions help turn New York into the 'beacon for social progress' the Governor claims that the state already is.

NEW YORK NEEDS ACCESSIBLE TRANSPORTATION INFRASTRUCTURES

A number of the State of the State proposals offers evidence for the Governor's ambitions for New York's transportation systems. Improvements for Stewart Airport, the Long Island Railroad, the MTA, the AirTrain to LaGuardia and the Governor's proposed investment in improving New York State Thruway Service Areas all speak to the governor's goal of a world class transportation system. The Disability Community would like to see a world class transportation system in New York State, but we know something that the Governor has yet to understand, that a world class transportation system requires world class accessibility. Our state has a long history of developing transportation options with no consideration for the needs of disabled New Yorkers. We have seen this with the MTA and a subway system that is the least accessible of any major American city, and saw it just last year when the state rushed in ridesharing with no plan to make it accessible. Disabled New Yorkers are tired of being an afterthought. The Governor must make accessibility central to any and all transportation infrastructure development.

THE DOWNTOWN REVITALIZATION INITIATIVE SHOULD DEVELOP INCLUSIVE COMMUNITIES

CDR is pleased that the Governor wants to extend the Downtown Revitalization Initiative (DRI) into a third round. This Initiative invests millions into communities in each of the State's ten regions in order to turn them into "livable, walkable, dynamic neighborhoods." In choosing recipient communities, the Regional Economic Development Councils are charged with considering nominees whose downtown areas are "attractive and livable" communities for "diverse populations of all ages."⁴ We urge the Governor and the Regional Councils to remember that livable communities must be accessible to people with disabilities, and that diverse populations include individuals with and without disabilities. Any and all projects coming from DRI must be accessible to people with disabilities. Proper implementation of the DRI would mean a significant improvement in the lives of New Yorkers with disabilities and much needed progress in implementing the State Olmstead plan.

AUTONOMOUS VEHICLES SHOULD DRIVE THE DISABILITY COMMUNITY FORWARD, NOT LEAVE IT BEHIND

Given the shortage of accessible transportation option across the state, we are intrigued by the Governor's plan to promote the development of autonomous vehicles in the State. While these cars and buses have the potential to be transformative, it will be just another in a long line of disappointments if the State does not push

⁴ <u>https://www.governor.ny.gov/news/governor-cuomo-unveils-third-proposal-2018-state-state-round-three-downtown-revitalization</u>

developers to build in accessibility as they develop the technology. Done right these vehicles could offer many in the Disability Community greater independence, but as we have seen with ridesharing, taxis, and trains retrofitting access is rarely effective. The Governor's efforts to develop this industry must include comprehensive accessibility as a requirement.

GROWING ACCESSIBLE TOURISM ACROSS NEW YORK

The Governor could easily achieve his aim of growing tourism across the State by tapping into the multi-billion dollar accessible tourism market. He could do this by ensuring accessibility in all tourist attractions the state will be investing in this year. Disabled travelers, especially elderly people and their families, place a high premium on accessibility and the State could easily become a destination of choice if an effort was made to improve access. These improvements in transportation and infrastructure would have the added benefit of meeting the needs of disabled New Yorkers as well. Right now the MTA's appalling inaccessibility and other gaps in accessible infrastructure and transportation prevent the State from achieving the Governor's lofty vision for state tourism. Making the state accessible to disabled tourists would make the Governor's rhetoric that "all are welcome" in New York⁵ meaningful to people with disabilities.

EXPANDING EDUCATION OPPORTUNITIES FOR ALL

LEAD-K IS NEEDED IN EARLY CHILDHOOD EDUCATION

CDR is pleased to see the Governor making early childhood education a priority and we propose that he add Lead-K legislation to his initiatives. Deaf children in early childhood education have been so thoroughly underserved that they are coming into Kindergarten with communication skills significantly behind their hearing peers. A greater understanding of the processes of language acquisition and the effects of language deprivation are vital to the success of Deaf kids entering the education system. Lead-K would provide this understanding and point the State in the right direction to correct it. The Governor has said in the past that a college degree is the new equivalent of a high school diploma. Deaf and hard of hearing children cannot expect to attain that degree when they are entering the school system behind and leaving it with on average a third or fourth grade reading level. By including LEAD K in his early childhood education proposals, the Governor would ensure Kindergarten readiness for Deaf and hard of hearing children. It is time to invest in the Deaf Community.

EFFORTS TO SUPPORT AT-RISK YOUTH MUST INCLUDE DISABLED YOUTH

We applaud Governor Cuomo's efforts to better support at risk youth both after school and in employment. The Governor may be focused on fighting gang involvement, but young people with disabilities are disproportionately a part of these at risk populations and it is our hope that these initiatives can contribute to circumventing the school to prison pipeline that has claimed the lives and freedom of so many disabled people of color in our state. We need to expand supports available to beyond the narrow group of students we currently identify as 'at-risk'. They need to be available to all disabled students and students of color, who have been consistently served poorly by an education system that has segregated them, written off their education, and set them up for either prison or poverty. The State must work to repair the harm it has done these students and change the systems that do this harm.

IMPROVING MENTAL HEALTH SERVICES IN SCHOOLS

It is good to see the Governor address community schools support for students mental health needs. Student trauma and mental health have gone without consideration for far too long. Without supports and accommodations, navigating the school system with a psychological disability can make getting an education

⁵ <u>https://www.governor.ny.gov/news/statement-governor-andrew-m-cuomo-thanksgiving-1</u>

more difficult. New York needs to do everything it can to support these students. Not doing so will have a terrible long term impact on the lives of many students, affecting not only their immediate schooling but their future educational and professional opportunities.

CONTINUING THE SUCCESSFUL NEW YORK STATE MENTORING PROGRAM

Like the Governor, CDR is also concerned with the disproportionately high drop-out rate of disabled students. We believe the state mentoring program is useful tool in fighting this. We also believe it would be more useful if the State made a concerted effort to provide disabled students with successful disabled mentors. Exposure to mentors who are themselves disabled would counter the negative messages many disabled students receive about themselves. It would put them in contact with people who may share their experiences and have advice that simply cannot be provided by a nondisabled person and offer them a model for their own success.

ADVANCING THE DEMOCRACY AGENDA

The Governor rightly calls voting "the cornerstone of our democracy." His State of the State proposal to offer early voting, as well as same-day and automatic voter registration are moves that will safeguard our democracy by opening up voting to more of our citizens. The Disability Community has long supported these changes. Given the limited transportation options available to disabled New Yorkers, early voting in particular will make the voting process much more accessible.

We were also glad to see the Governor note that all these proposals must work within accessibility requirements. Polling place and ballot accessibility are rights protected under the Americans with Disabilities Act (ADA) and the Help American Vote Act (HAVA). Despite being protected in theory by federal law, in practice disabled people are forced to use absentee ballots because their local election site remains inaccessible. Whether it is a temporary situation or a permanent site, no inaccessible location should be used for any election activities. The use of absentee ballots is not a substitute for access. CDR calls on the Governor to advance his Democracy agenda to ensure that all New York state polling places are accessible to all voters.

ACCESSIBILITY OF THE SPEECH

In the past we have often had to use space in this response to take this and other Governors to task for the lack of accessibility in their State of the State speeches and broadcasts. It is only right that we now make the same effort to commend Governor Cuomo on the accessibility of this year's address. Not only did he have a Certified Deaf Interpreter on screen for the entire speech offering the speech to American Sign Language users, but there was Digital Live Captioning for other Deaf and Hard of Hearing observers. The captioning itself was far more accurate than in the past as well. This meant that the Deaf Community as whole could access the State of the State for possibly the first time ever. We are hopeful that this will be a precedent setting case and that all Governor's future broadcast will follow suit.

About the Center for Disability Rights

The Center for Disability Rights (CDR) is a disability led, not-for-profit organization headquartered in Rochester, New York, with satellite offices in Geneva, Corning, and Albany. CDR advocates for the full integration, independence, and civil rights of people with disabilities. CDR provides services to people with disabilities and seniors within the framework of an Independent Living Model, which promotes independence of people with all types of disabilities, enabling choice in living setting, full access to the community, and control of their life. CDR works for national, state, and local systemic change to advance the rights of people with disabilities by supporting direct action, coalition building, community organizing, policy analysis, litigation, training for advocates, and community education.