



**Center for Disability Rights, Inc.**

# **Governor Cuomo Gambles with Disabled Lives & Liberty**

Response to Governor Andrew Cuomo's FY 2019 Budget

January 25, 2018

## **INTRODUCTION**

Following a year in which the Disability Community led the fight to save Medicaid, saving New York billions in federal funding, the Governor has introduced a budget that threatens our lives and liberty as much as any attempt to repeal the Affordable Care Act (ACA) or cut Medicaid. Our right to live in the community is neither aspirational nor negotiable; yet Governor Cuomo's budget that community integration for people with disabilities can be sacrificed in the name of trimming the budget.

Proposals to limit eligibility for Managed Long Term Care (MLTC) and to carve our nursing facilities from MLTC both incentivize institutionalization. Additionally, proposals to increase segregated housing combined with the absence of proposals to address the shortages in the attendant workforce and in affordable accessible, integrated housing call into question the Governor's commitment to his own Olmstead plan. Meanwhile, for two years now, the State has been accepting federal money under the Community First Choice Option, a part of the ACA designed to supplement State efforts to support disabled people's right to live in the community. Initiatives in this budget force us to question whether or not the State has taken this money under false pretenses or if it is planning to abandon this program aimed at ensuring the lives and liberty of Disabled New Yorkers.<sup>1</sup>

As we do each year, the Center for Disability Rights (CDR) sent the Governor a list of priorities to include in the Executive Budget. Our budget priorities offered practical recommendations for the Governor to not only further his Olmstead agenda, but also save the State money by reducing its reliance on nursing facilities and other institutions. However, the Governor's recently released Executive Budget demonstrates that he has chosen a different path – one which will not serve the Disability Community, and may in fact do us great harm.

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<sup>1</sup> In this document we use identity first (disabled people) and person first (people with disabilities) language interchangeably. We respect that there are differing views on how individuals identify themselves and respect each person's choice in how they choose to identify.

## COMMUNITY LIVING

In our 2018-19 Olmstead Budget priorities,<sup>2</sup> CDR highlighted the need for a High Needs Community Rate Cell to promote the community integration of people with significant service needs and to counter the institutional bias in managed care. Under the current system, managed care organizations (MCOs) get a set amount of funding to serve each of their consumers. Generally this is not a problem, but some individuals with more significant disabilities cost more to serve in the community than in a nursing facility, and in those cases it is cheaper to force those individuals into an institution. A High Need Community Rate Cell would pay the MCOs a higher rate for individuals with the most significant disabilities who live in the community as a mechanism to eliminate this incentive for institutionalization, helping ensure our right to live in the community.<sup>3</sup> Without a High Needs Community Rate Cell, MCOs will continue to avoid serving anyone they deem “high cost,” or otherwise push these “high cost” people into institutions. Unfortunately, instead of creating a High Needs Community Rate Cell to honor the rights of disabled New Yorkers to live in the community, the Governor has introduced two proposals that will take the State in the opposite direction and encourage institutionalization.

### **Changing the Eligibility for MLTC Gambles with Disabled Lives**

The first of these two proposals is to change the eligibility criteria for Managed Long Term Care (MLTC) from the current Universal Assessment System (UAS) score of 5 to the significantly higher threshold of 9.<sup>4</sup> While the Governor’s proposal would grandfather in all individuals currently in MLTC with a score of 5 or higher, we have a number of concerns about how this would reshape service provision for future enrollees.

Our first and most obvious concern is that all of the people who would traditionally have been served in MLTC will now be in mainstream managed care or fee for service. Mainstream managed care has no experience serving people with these higher levels of support needs. Also, the influx of higher needs individuals into mainstream managed care could destabilize capitation limits and lead to MCOs authorizing inadequate levels of service for people who are already above the threshold for the institutional level of care. This shift will exacerbate unresolved issues caused by inadequacies of the UAS - namely, its lack of appropriateness as an assessment tool for individuals with cognitive disabilities, such as individuals with traumatic brain injuries. Advocates have been urging the Department of Health (DoH) to address this failing for some time. The reliance on this inaccurate assessment is particularly concerning as the State plans to bring many people from the TBI/NHTD waiver into managed care. The Governor is literally gambling with disabled people’s lives as changes in service provision can cause a person to decompensate to the point where they are forced into an institution, become ill, or die.

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<sup>2</sup> Ensuring Equality & Fairness for All, including New Yorkers with Disabilities: Proposed Olmstead Budget Priorities for New York State SFY 2018-19. <http://cdrnys.org/blog/press-releases/ensuring-equality-fairness-for-all-including-new-yorkers-with-disabilities-proposed-olmstead-budget-priorities-for-new-york-state-sfy-2018-19/>

<sup>3</sup> Olmstead v. L.C., 527 U.S. 581 (1999).

<sup>4</sup> HMM Article VII Part B. Sec.3

Our second concern about the proposal is how it will interact with the Community First Choice Option (CFC). Under CFC the state is required to ensure that eligible individuals have access to the same level and type of services regardless of where or how they enter the system. Changing the UAS qualification for MLTC will further complicate the state's supposed system for delivering CFC services. Because a UAS score of 5 is needed for eligibility for nursing facility placement or CFC services, individuals scoring between 5 and 8 will receive services through either fee for service or mainstream managed care. Others who score 9 or above will receive services through MLTC. We are gravely concerned that utilizing multiple authorization models for services will mean individuals will not receive consistent service authorizations as required under CFC. Failure to comply with these federal rules could put a significant amount of federal funding at risk in future federal audits.

Our final concern with this proposal is that, by taking the lower needs – and presumably lower cost – individuals out of MLTC, the plans will be left with only the highest cost individuals with disabilities potentially destabilizing that capitation model. While DoH and the Governor insist that the capitation is actuarially sound across the plans, these changes make providing services to people with significant service needs even less attractive to the plans. All of this will have MCOs looking for ways to get rid of their higher needs consumers. Sadly, the Governor has also offered them the perfect opportunity to do this through the nursing home carve out.

### **The Nursing Facility Carve Out Incentivizes Institutionalization**

The Governor's budget calls for migrating anyone placed in a nursing facility for more than six months from MLTC to fee for service.<sup>5</sup> The significance of this is that, after six months in an institution, an individual's services go back to being the responsibility of the State through fee for service rather than the MCO under its capitation. In "carving out" individuals who have been in nursing facilities for six months, and placing those individuals into fee for service, the Governor has offered MCOs an incentive to institutionalize anyone with high service needs. Not only would institutional placement be less expensive for some individuals, the MCOs would not even be required to pay it. On its own, this initiative has the potential to undermine all of the hard work that disability advocates and Independent Living Centers have done to realize the Governor's own Olmstead plan. What makes this proposal harder to understand is that as a cost saving initiative, the State's math does not add up. The current MLTC capitation is less than the full fee for service nursing home rate. The state won't save money by paying significantly more, so this proposal will actually increase costs to the State.

The Nursing Home Carve out, in combination with the change to MLTC eligibility, is a prescription for a return to significant institutionalization. In a year when Governor Cuomo is desperately looking to save money and cut costs, he needs to embrace the less costly home and community based services rather than the far more expensive costs of institutional services. When the fiscally sound thing to do is also the right thing to do, there is no excuse for not doing

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<sup>5</sup> HMH Article VII Part B Sec.5

it. CDR calls on the Governor to abandon the nursing facility carve out as well as the changes in eligibility for MLTC.

### **Locking People into Plans Puts Lives and Freedom at Risk**

Governor Cuomo's plan to require continuous enrollment in MLTC plans for 12 months<sup>6</sup> demonstrates that the Governor is willing to put the health of the plans ahead of the health and freedom of Disabled New Yorkers. Locking people into plans exposes them to numerous risks. Once people are trapped in their plans with nowhere to go, there is nothing to prevent plans from cutting hours or services. An individual's ability to go to another plan is one of the few protections they have. Additionally, if a person's provider leaves the plan, the person then loses their ability to receive services from the provider that they know and trust.

The State would not expect a person to stay in a problematic marriage for a year, but the State will require a disabled person to be trapped in a problematic relationship with an MLTC plan for a year. Providing inadequate services and supports is abusive to a disabled person with real world consequences to the disabled individual. This could lead to decompensation, withdrawal from the community, and institutionalization. An action as simple as a plan lowering a person's attendant services by a few hours can have a major impact on their ability to function in their environment. The Governor must allow freedom of movement between plans for the health and wellbeing of Disabled New Yorkers.

### **Inaction on Attendant Wages Puts Disabled Lives at Risk**

Our attendants are vital to our ability to live and thrive in the community. Our ability to pay our attendants adequate wages correlates directly to our ability to recruit and retain quality attendants. The reimbursements we currently receive from the State are wholly inadequate to maintain a quality attendant workforce. We are competing for our attendants with fast food and retail jobs that are far less demanding than attendant services. The Governor fought for higher wages for people working in these other low-wage industries, and we need our attendants to be given the same respect and support from the Governor. The difficulty in recruiting and retaining attendants is a serious issue upstate and has been for some time. The Governor's budget does call for a study to assess this issue in rural areas with the possibility of a potential future Medicaid rate enhancement. However, the rate enhancement amount proposed is misleading: it may be an aggregate of \$3 million, but this amount would be reduced by the cost of the study itself. By structuring the study and rate enhancement this way, it is as if the study would be funded by service providers. And the reality is that the time for studies has passed. The Governor already has enough evidence of lack of service provision upstate and has put off acting on this problem for too long.

It is worth noting that our attendants are paid far less than their counterparts in direct care serving people with developmental disabilities. This inequality and injustice must be remedied.

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<sup>6</sup> HMH Article VII part B Sec 4

Our attendants deserve raises. The State may also be in violation of federal law because when New York accepted money under the Community First Choice option, the State agreed not to discriminate in the provision of services on the basis of disability. Paying significantly different rates based on disability violates that rule and is putting the State at risk. We call on the Governor to ensure that consumer directed attendants receive commensurate wages to their direct-care counterparts.

Inadequate wages has been a long term problem that is turning into a crisis for people with disabilities. Disabled people are already struggling with finding and keeping quality attendants. These problems threaten our ability to stay in the community, keep our jobs, raise our kids, and live our lives. The Governor must create adequate payment structures that will maintain a sufficient workforce to provide services in home and community based settings for all individuals that require such services. It is also important that whatever measures the State takes, it must ensure that the funds it provides actually get to our attendants. State funds do us no good in the bank accounts of the MCOs and the wallets of MCO executives.

### **Criminal History Checks Will Exacerbate the Workforce Shortage**

The Governor proposes requiring background checks for all employees of organizations providing home and community based services.<sup>7</sup> Although we understand the Governor to keep Disabled New Yorkers safe, this ignores both the reality of the current workforce shortage and the need disabled people have for control over who touches our bodies. At a time when we are already struggling to compete with the retail and fast food sectors for our attendants, a policy that will further restrict the pool we can draw from is ill-advised and harmful. Our attendants are people we have to trust with the most intimate tasks. Often, we prefer to hire friends and family – people we know. For people who use Long Term Services and Supports, a conviction history may be insignificant when compared to the established trust and confidence we have in our relationships. Given the choice, many of us prefer to hire a trusted relative with a criminal record over having a complete stranger putting their hands on our bodies. We call on the Governor to withdraw this proposal and ensure the body integrity of disabled New Yorkers.

### **Increase Base Funding for Independent Living Centers**

Independent living centers (ILCs), which are disability-led organizations, have done more to achieve the aims of the Governor's Olmstead plan than any other group inside or outside the government. ILCs have never served more people than they do right now, yet ILC funding levels have been stagnant. The Governor's proposed budget leaves funding at last year's level. The State's neglect of ILCs will mean more people stuck in institutions and more people being forced into them. The Governor must increase base funding for ILCs in SFY 2018-19 to \$18 million with the long term goal of increasing the State appropriation to \$25 million. It is time the State recognize the value these organizations bring to the State and fund them accordingly.

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<sup>7</sup> HMH Article VII Part C Sec. 3

Increasing ILC funding would save the State billions over the long term by transitioning people from institutional settings to cheaper, more desirable community based settings. Not only could the State save money through this deinstitutionalization, but the State could also leverage more federal dollars through the Community First Choice Option. At present, there are enormous disparities in State funding for its ILCs hampering the efforts of many to expand their work. CDR recommends that all funding increases be applied evenly across ILCs.

## HOUSING

Access to affordable, accessible, and integrated housing is critical for the inclusion of disabled New Yorkers in the community and there is a crises level shortage of such housing throughout the state. This shortage is a significant obstacle to realizing Governor Cuomo's own Olmstead plan. In our budget priorities and our response to the State of the State, we called on the Governor to create a tax credit for homeowners who make their homes more accessible, restore funding to Access to Home, prioritize public housing for people transitioning out of institutions and nursing facilities who are otherwise homeless, and increase the amount of accessible units in publicly funded housing projects. The Governor refused to take action on any of these priorities.

### **Creating a Visitability Tax Credit & Restoring Access to Home**

In 2017, the Legislature passed a bill creating a tax credit for visitability in housing for the third year in a row, and for the third year in a row the Governor vetoed that tax credit because it was not in the budget. Additionally, when vetoing Visitability last year, the Governor also cited the Access to Home program as evidence of his support for increasing the accessible housing stock.

This year, although Governor Cuomo boasts a \$20 billion plan for affordable and homeless housing, and spending another \$59 million to create segregated housing for disabled New Yorkers, he refused to prioritize \$1 million to allocate to the Visitability Tax Credit. Governor Cuomo also refused to restore the Access to Home program which has been cut by 75% during his time in office. This is unacceptable.

Both the Visitability Tax Credit and Access to Home could help aging grandmothers build ramps to stay in their homes and help newly-injured paraplegics make their bathrooms accessible – all with a minimal fiscal impact to the State. Yet the Governor has ignored the needs of the Disability Community again by refusing to include Visitability in his budget and refusing to restore Access to Home. CDR now calls on the Governor to include the Visitability Tax Credit in his amendments to the budget, as well as \$10 million in funding for Access to Home. Currently, the State funds of a separate Access to Home for Veterans program for veterans with disabilities, but those funds have been underused because veterans are taking advantage of federal programs. We call on the State to establish a system so that when Access to Home for Veterans veteran funding goes unused, the unclaimed funding be opened up to the entire Disability Community.

### **Prioritizing Housing for Homeless Disabled People with LTSS Needs**

Governor Cuomo's initiatives do not address the needs of New Yorkers who are currently stuck in nursing facilities and other institutions who do not have a home in the community to return to. Homeless shelters are often inaccessible and, as a result, disabled people are regularly forced into nursing facilities when they become homeless. Many Disabled New Yorkers in institutions do not have homes to return to, yet, because they are in an institution, they are, perversely, not considered homeless. They are therefore not eligible for supports provided under initiatives combating homelessness. Although disabled people who are in institutions may have a bed and a roof, they do not have a home. We have pointed this out to the Governor year after year, yet he continues to do nothing to ensure that New Yorkers with disabilities have priority in public housing when transitioning out of an institutional setting. Furthermore, disabled people being distinguished from the homeless population in shelters cannot justify the State failing to address their homelessness too. Warehousing people in institutions is not a solution to homelessness.

### **Ensuring Accessibility in All Housing Projects**

The Governor's Budget plans to continue the five-year investment in affordable housing. While focusing on the affordability of units preserved and created, the Budget does not mention the accessibility of such units. Any housing units created by the State should be accessible to address the housing crisis in New York State for people with disabilities. It is time that the Governor address the State's longstanding history of inadequate enforcement of accessibility requirements. Too often the State has accepted adaptability as accessibility. They are not the same. Additionally, there are far too many loopholes for developers to avoid making units accessible. Lack of accessible housing is a primary reason that disabled and elderly people are unable to transition from institutional settings into the community, and it is also often a reason people are forced into institutions.

CDR calls upon the Governor to ensure that all new publicly funded housing stock includes adequate levels of accessible units to ensure that no disabled person is unable to transition back into the community, or is forced into an institution due to a lack of housing. As part of this we call on the Governor to double the number of accessible units required in all new housing and to remove the loopholes that allow developers to avoid making units accessible.

## **TRANSPORTATION**

Governor Cuomo asked for changes to ensure a world-class transportation system, and we responded by reminding him that world-class transportation incorporates world-class accessibility. As long as the Governor ignores the transportation needs of disabled New Yorkers, New York will have a second-rate transportation system at best.

### **Improving the Metropolitan Transit Authority**

The Metropolitan Transit Authority (MTA) operates the most inaccessible subway system of any major American city. New York can never be the bastion of hope and progress that the Governor

wants it to be while one of the State's most significant pieces of transportation infrastructure, the New York City subway, continues to be unavailable to disabled people. Twenty-seven years after the passage of the Americans with Disabilities Act (ADA), there is no excuse for the State to discriminate against Disabled New Yorkers. For many, lack of transportation is a significant barrier to employment, and it isolates us by cutting us off from friends and family. A significant portion of the Governor's \$836 million Subway Action Plan must be reserved to make the subway accessible to all. These funds must be used to open up inaccessible stations to disabled passengers and maintain access to the stations that are already accessible.

### **Autonomous Vehicle Innovation Must Focus on Creating Accessible Options**

In the Budget, the Governor proposes to remove barriers to the operation of autonomous vehicle manufacturers in New York State. The Disability Community welcomes innovation and the development of this exciting technology as long as the introduction process incorporates accessibility norms and standards so that the Disability Community can equally benefit from autonomous vehicles. We recommend that the "manner and form" of the demonstration of autonomous vehicles as prescribed by the commissioner include a requirement that manufacturers install and demonstrate accessibility features in their vehicles. It could help address the lack of any real accessibility solutions in State's rush last year to introduce inaccessible ridesharing.

### **Improving State Infrastructure Starts by Making it Accessible**

The State is in the midst of investing over \$100 billion in infrastructure improvements. Unfortunately, the State's track record at living up to its responsibility to include accessibility when adding or replacing infrastructure is mixed at best. The State's airports are a nightmare for disabled travelers to reach, navigate, and utilize. This must be fixed by policy changes from the Port Authority, airlines and the federal government. As the Governor moves forward with significant changes to Stewart and LaGuardia Airports, improving disabled access needs to be a priority. Similar considerations need to be a part of changes to the New York Thruway, Penn Station and the Long Island Railroad. As part of improving access, the State must also recognize that accessibility is often about having multiple options available. While cashless tolling on the Thruway and bridges makes life easier for many, they make life difficult for many disabled people who don't have the credit card required to get EZ-Pass. Cash options must remain.

## **EDUCATION**

### **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 entering Kindergarten with communication skills lagging 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. A college degree has become a minimum requirement for jobs. Deaf and hard-of-hearing children cannot expect to attain that degree when they are entering the school system at a disadvantage and leaving it with a third or fourth grade reading level, on average. 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.

### **The Excelsior Scholarships Must Accommodate Disabled Students & DREAMers**

Last year, the Governor proposed a Budget which included a free tuition program for students from certain income levels to attend SUNY and CUNY schools. With this program now in effect, we remain concerned that the program does not address the fees, room, and board costs that may still prevent many students from attending college. In the case of students with disabilities, the value of the tuition scholarship is diminished when the school they want to attend is inaccessible; SUNY and CUNY schools have had ongoing problems with lack of accessibility.

This year, the Governor seeks to expand the program to DREAMers, with conditions. These conditions do not offer enough flexibility for some students with disabilities. For instance, the program requires that the student live continuously in New York while attending high school or an equivalent program. This requirement closes the program to DREAMers with disabilities who have attended out-of-state schools to meet their educational needs.<sup>8</sup> Furthermore, the requirement that the student DREAMer apply to attend to college within five years of receiving a high school or high school equivalency diploma creates a barrier for students who may experience accessibility issues with the new high school equivalency exam in New York or its prep materials. The TASC has been known to not provide meaningful access to some test-takers with disabilities.<sup>9</sup> To require passage of an exam within a given time frame when the test is lacking in accessibility is unfair.

### **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 should know that young people with disabilities are disproportionately included in this at-risk population. 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." Supports need to be available to all disabled students and students of color, who have been poorly served 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.

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<sup>8</sup> <http://www.p12.nysed.gov/specialed/privateschools/os.htm>

<sup>9</sup> <http://nfbny.org/governance/2015-resolutions>

### **Improving mental health services in schools**

CDR commends the Governor for addressing 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 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.

### **Improving 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 a useful tool in addressing 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, whose advice would be that much more valuable, and provide a model for the student's own success. The state should also ensure that these services are provided through Independent Living Centers – the only statewide network of cross-disability, disability-led organizations.

### **Including Public Education Institutions in DHR is a Good Move**

CDR supports the Governor's initiative to include public education institutions in the New York State Human Rights Law. It is a much needed change and a logical role for the Division of Human Rights (DHR) to fill. Students with disabilities who experience discrimination in public education institutions should be able to have their complaints accepted, investigated, and adjudicated by DHR, just as disabled students who experience discrimination at private, tax-exempt, non-sectarian schools.

## **CIVIL RIGHTS**

### **Marriage Equality Should Not Be Threatened by Extortion from the State**

The Executive Budget proposes, once again, to change the law regarding the circumstances under which a married Medicaid applicant may be eligible for services. Under federal law, an option called spousal refusal is available to spouses of Medicaid applicants. Spousal refusal means a person agrees to not use their own resources to support their spouse with the understanding this allows the spouse to receive services and supports through Medicaid. Practically, spousal refusal means that the spouse does not have to spend down their assets or get a divorce in order to reduce their assets enough to qualify the applicant spouse for Medicaid. With this option available, a person receiving services through Medicaid has the freedom to marry without fear of losing their services and supports. Alternatively, the person may choose to live apart from their spouse in order to receive Medicaid services and supports.

The Governor has proposed to eliminate spousal refusal, and thus make it a requirement that a person both refuse to support their spouse *and* live apart from their spouse. The Governor proposes to eliminate spousal refusal every year simply to hold it over the Assembly's head and require them to find the money to restore it. This game that the Governor continues to play threatens to break up families and keep disabled people from marrying.

The Governor's proposal to eliminate spousal refusal is even more insidious this year when combined with his plan to increase the UAS score for MLTC eligibility, as this would reduce eligibility for spousal impoverishment protections. Spousal impoverishment protections are available to couples that have one spouse who is eligible for MLTC or a waiver, and it allows the spouse who is not on Medicaid to maintain a certain income while still allowing Medicaid to pay for their spouse's services and supports. Because the Governor is proposing to increase the MLTC eligibility score from a 5 to a 9, he is reducing the amount of people who will be eligible for MLTC, and in turn, spousal impoverishment. As a result, any individual scoring a 5-8 on the UAS would not be eligible for spousal impoverishment, and when combined with the elimination of spousal refusal, these couples will be left with only two options: go into poverty or institutionalize the spouse using Medicaid to maintain their income.

CDR is vehemently opposed to these changes, as we believe the Governor should not use a family's desire to stay together as a means to extort them in exchange for supports and services. These policy changes would deny disabled people the same marriage equality that the Governor is so proud of demanding for other groups.

### **We Cannot Deal with the Opioid Crisis without Dealing with the Pain Crisis**

Many in the Disability Community experience significant issues with pain. In their attempts to deal with their pain, many have been caught up in efforts to address the opioid crisis. Some have been accused of drug seeking; others have been denied access to effective pain solutions. Though the Governor's desire to address the opioid crisis is commendable, we are concerned that an overly broad plan to reduce opioid prescriptions could catch many disabled people in its wake. It is important to remember that regardless of the occurrence of abuse, the majority of opioid use begins with a focus on treating pain and many in the Disability Community rely on safe opioid usage to do that.

The Governor's proposal does acknowledge that careful treatment planning for those in pain is required but it cannot be DoH and medical professionals alone shaping how treatment planning will work. While we are in the midst of an opioid crisis we are also in the midst of a pain crisis and the people at its center, the people experiencing real pain, need to be consulted as the State develops its approach. Not doing so will lead to solutions that may work for the State, and may work for doctors, but will not work for the people who need it most. An example of this can be found in the state capping physical therapy. The proposed budget doubles the cap, but it is a cap nonetheless. Physical therapy is a non-narcotic option that can provide pain relief. By continuing

to limit access to pain relief options, the Governor is only exacerbating the problem. We call on the Governor to work collaboratively with pain advocates and other disabled people caught in this crisis to help develop a plan that will work. We need innovative solutions shaped by the people experiencing pain, not more bureaucracy.

### **Opening Democracy up to All New Yorkers**

The Governor's proposals to offer early voting as well as same-day and automatic voter registration are moves that will open up our democracy and make it more accessible to the Disability Community. CDR has long supported these changes. Given the limited transportation options available to disabled New Yorkers, early voting in particular will make the voting process accessible to many who would otherwise struggle to vote in a more limited time frame.

We are also glad to see the Governor note that all these proposals must work within accessibility requirements, but his commitment has fallen short; despite being protected in theory by federal law, in practice disabled people are forced to use absentee ballots because their local election site is inaccessible. Whether it is a temporary or 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.

### **End the Exploitation of Disabled Workers**

The Governor has said that "Inclusion is our operating principle, and forging community is our ultimate goal." Yet, the State fails to adhere to its own operating principle and will never achieve its goals as long as it allows disabled workers to be exploited in sheltered workshops and be paid less than the established minimum wage. Even though other states have done away with these modern-day American sweatshops, Governor Cuomo has been reluctant to address this injustice. If New York really is the national leader that the Governor claims it to be, then the Governor must end the use of subminimum wages in New York State immediately!

### **The Women's Agenda Must be Inclusive of the Experience of Disabled Women**

CDR applauds Governor Cuomo's efforts to advance the Women's Agenda as many of the inequities that women experience are magnified in the experiences of disabled women. Governor Cuomo's Women's Agenda illustrates his commitment to women's safety and bodily autonomy. We urge the Governor to further his commitment by working to transition more women out of nursing facilities – where strangers frequently touch women's bodies and where abuse is underreported – and into their own homes in the community. Women are disproportionately impacted by institutionalization as 64% of nursing facility residents in New York are women.<sup>10</sup> Deinstitutionalization is very clearly a women's issue and should be a priority on the Women's Agenda.

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<sup>10</sup> <https://www.kff.org/other/state-indicator/distribution-of-nursing-facility-residents-by-gender/>

Additionally, the Governor's proposal to create a Maternal Mortality Review Board and include experts in women's health on the State Board of Medicine create opportunities to develop strategies to address the disparities that women with disabilities experience in healthcare. We will also have opportunities to ensure that mothers with disabilities not only survive the births of their children but also receive the services and supports they need to successfully raise their children instead of having the State remove their children based on outdated stereotypes that disabled people cannot safely raise children.

### **Accessibility of the Budget Presentation**

The accessibility at this year's State of the State address was so much of an improvement over previous years that we could not help but be disappointed that the Budget address was so lacking. American Sign Language interpretation, so ably handled at the State of the State just two weeks earlier by Certified Deaf interpreters was completely absent at the Budget address. The live captioning was passable, but insufficient to meet the needs of many in the Deaf community for whom English is a second language to ASL. The Governor must do better. Access is not optional – it must be a part of all State presentations.

### **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.