



## Center for Disability Rights, Inc.

Governor Cuomo Fails  
Disability Community

### Response to Governor Cuomo's 2017 State of the State and Budget

January 25, 2017

#### INTRODUCTION

Each year, the Center for Disability Rights analyzes the Governor's State of the State Agenda and Budget to identify the effect of these proposals on the Disability Community in New York. The *2017: Ever Upward* Agenda and Budget indicate that, again this year, the Governor's priorities are not with the Disability Community. Our

community provided the Governor with a list of outstanding priorities in advance of the budgetmaking process. Governor Cuomo chose to ignore the needs of the Disability Community and focus his attention on ambitious and expensive projects, many of which exclude our community entirely, and a few of

which are unlikely to support the integration of disabled New Yorkers without significant advocacy from our community.

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## **EXECUTIVE SUMMARY:**

Last year, CDR and others in the Disability Community issued a number of proposals with which Governor Cuomo could show his support for the integration of disabled New Yorkers. We submitted budgetary investments and items without a fiscal component. We were counting on a Governor who has claimed before a national audience that New York is a safe haven for those who are discriminated against and marginalized, and we were ready to praise him for his attention to our priorities.

Instead, this year the Governor proposed changes to Managed Long Term Care (MLTC) which restrict the MLTC benefit, rather than working with our community on reforms which expand access to cost-effective community-based services. Governor Cuomo proposed a prescription drug program which will restrict our community's access to some medications, and an opioid program which will interfere with disabled people's access to necessary pain management.

On ridesharing, the Governor seems to believe that access to transportation is an option, not a right, for disabled people: he declined to hold either ridesharing companies or taxis accountable to provide accessible transportation. On education, the Governor proposed making SUNY and CUNY tuition free for middle-class families, but has proposed nothing to address pervasive discrimination in primary and secondary school for disabled students, which will prevent many in our community from being admitted to college in the first place. He proposed expanding charter schools, which are in many cases the worst offenders in discriminating against disabled students. On housing, the Governor proposed incentives for developers but nothing to ensure that developments will be accessible to disabled people, integrated, or affordable to people using public assistance. The

Governor's reforms of the justice system will have a significant effect on the many disabled people who interact with the police, judiciary, or corrections systems on a daily basis, but disability is not central to those reforms.

The Governor spent a great deal of time last year advocating to raise the minimum wage, but he has left behind both the Disability Community, which is still subject in New York to subminimum wages, and the attendants whose work supports our independence. Governor Cuomo pointed out in his Budget presentation that agency budgets were flat this year compared to last year, and that flat really means a reduction in light of inflation. We agree: the reimbursements which support workers' wages have been flat. Attendants, who used to make more than the minimum wage, now make less than fast food workers. Funding for Independent Living Centers has been flat. The funding for Access to Home has been flat. Flat, even according to the Governor, means a cut.

The Governor proposed early voting, which would – if accessible – be a tremendous boon to disabled voters. The text of his early voting proposal suggests that accessibility is optional.

This separate and unequal treatment must end.

We call on the Governor to live up to his soaring, progressive rhetoric. He has said that discrimination does not work in New York, and that New York is a safe haven for oppressed and marginalized people. For this to be true, Governor Cuomo must make New York a place where all disabled New Yorkers are able to live in the community and to lead an independent life.

## **DISABILITY PRIORITIES THE GOVERNOR FAILED TO INCLUDE IN HIS BUDGET**

In the Fall of 2016, the Center for Disability Rights and other disability advocacy organizations created an agenda of outstanding policy priorities, which we communicated to the Governor in advance of the budget making process.<sup>1</sup> The Disability Community has advocated for these priorities over the years, and we urged the Governor to include them in his 2017 Budget agenda. *Notably, the Governor did not include even one of the Disability Community's priorities in his Budget agenda this year.*

We include here the policy proposals which are important to the Disability Community but which the Governor has neglected.

### **Create an Office on Community Living to Coordinate Policies Promoting Community Integration**

Two years ago, in response to years of advocacy from the Disability Community, the Governor convened a stakeholder process around creating an Office on Community Living (OCL) modeled after the Federal Administration on Community Living, which would have included services for both the Disability Community and older adults.<sup>2</sup> Many in the Disability Community, including CDR, supported that proposal, as well as an alternate proposal to create an OCL specific to disability so as not to disturb the relationship between the aging community and the New York State Office for the Aging. CDR and others in the Disability Community called on the Governor to create a

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<sup>1</sup> This document, the 2017 Disability Integration Agenda, is available online at <http://cdmns.org/wp-content/uploads/2017/01/2017-Disability-Integration-Agenda.pdf> (last accessed January 23, 2017)

<sup>2</sup> 2015-16 Health Mental Health Article VII, p. 140 et seq.

disability-specific OCL in last year's budget, and we called on the Governor to do the same again in this year's budget.<sup>3</sup>

There remains no State Office or Agency with the mission of securing the independence and integration of disabled people into the community. The Disability Community supports the creation of an Office on Community Living (OCL), tasked with ensuring that the rights of people with disabilities of all ages to live in the community and lead an independent life are reflected in state policy, and which would oversee the various disability-specific programs siloed in various State agencies.

OCL would ensure that the State is able to maximize the funding available through Federal incentives such as CFC, which provide additional Federal resources for services provided to people with disabilities in the community. CFC can draw down between \$300 and \$430 million per year in additional Federal participation<sup>4</sup>. OCL would be charged, for instance, with assisting the State to maximize that funding by assisting to DD waiver participants to community based settings, in order to draw down an additional \$80 million in Federal funding per year.

Since the deactivation of the Office of the State Advocate for People with Disabilities, there has been no State agency with a mission to secure the integration of the Disability Community. The absence of such an agency limits our ability to live in the community. It is time for the Governor to act by creating the Office of Community Living!

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<sup>3</sup> 2017 Disability Integration Agenda, p. 1-2.

<sup>4</sup> New York Association on Independent Living and CDR, Fiscal Analysis of CFC and the New York State Medicaid Budget, available at <http://ilny.org/downloads/category/31-cfc?download=327:cfc-fiscal-analysis>

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

We called for the Governor to increase the State's base funding for Independent Living Centers (ILCs) to provide additional services and meet increased demand for support with community living.<sup>5</sup> We recommended a \$5M increase this year as an incremental increase toward a base funding level of \$25M, which would allow the ILC network to address deficits created by years of flat funding and increased demand for ILC services. The New York State Board of Regents supported this request in its budget proposal to the Governor. We also called for the Governor to increase funding for the highly successful Open Doors program which conducts outreach and transition services for disabled people who want to live in the community. The Governor chose to ignore the Board of Regents and the Disability Community, and continues to restrict the funds for this unique disability-led network.

## **Address the Attendant Workforce Shortage in Consumer Directed Services**

There is a workforce crisis in Consumer Directed Personal Attendant Services (CDPAS) and community-based long-term supports and services in general.<sup>6</sup> Consumers report that it is impossible to recruit and retain workers at the wages available under the existing reimbursements, which have been flat or even reduced from 2008 levels, and which were cut by some MLTCs in September 2016. With a capitation model that undercuts their ability to serve high needs consumers (see below), Managed Care Organizations (MCOs) have been forced to cut reimbursement to such an extent that the CDPA program is threatened. This has significant Olmstead and community

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<sup>5</sup> 2017 Disability Integration Agenda, p. 2.

<sup>6</sup> Id. p.3.

integration implications because CDPAS enables people with the most significant disabilities to live in the community and have the opportunity to control their lives.

The State has failed, further, to ensure that CDPAS reimbursement is sufficient to address costs imposed last year under the new FLSA Overtime and Travel rules and the new minimum wage requirement. The State added \$0.34 per hour as an intended “pass-through” for personal care services to pay for the overtime and travel requirements. This approach created an incentive for MCOs and providers to cap overtime, restricting the rights of people with disabilities to direct their own services and lead their own lives, as well as reducing the take-home pay of CDPAS attendants. The minimum wage was funded in a similar manner, again with a pass through. After months of failing to clarify whether FIs even were eligible for the additional payment, many FIs received only a small portion – if anything – of what they were due. We called on the Governor to fully fund FLSA travel and overtime requirements and minimum wage increases.

**Establish a High Needs Community Rate Cell To Eliminate the Incentive to Institutionalize People with the Most Significant Disabilities**

We called on the Governor to create a High Needs Community Rate Cell<sup>7</sup> and, through changes in the capitation model, require MCOs to promote the community integration of people with disabilities, including those with significant disabilities. Current incentives created by the capitation do not support MCOs providing services to people with significant disabilities. We asked the Governor to reverse this

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<sup>7</sup> Id. p. 4.

incentive by creating a rate cell for high needs individuals to receive services in the community.

### **Ensure Fair Wages for New Yorkers with Disabilities**

Last year, Governor Cuomo spent many hours traveling the state to promote a living wage for New York's minimum wage workers, but his minimum wage increase left out workers with disabilities. The State continues to allow organizations in New York to use subminimum wage certificates under which employers can pay people with disabilities less than the minimum wage, in some cases as low as \$0.85 per hour.<sup>8</sup> Both the Republican and Democratic Party Platforms in 2016 express support for eliminating the subminimum wage exemption, but New York State continues to allow this outdated and discriminatory practice. We continue to call on New York to ban the payment of subminimum wages, and at a bare minimum, to refuse to contract with organizations which pay people with disabilities less than the minimum wage.

### **Make the Employment of People with Disabilities a Priority**

Working-age people with disabilities in New York have a 31.6% employment rate and a 41.1% employment gap compared to non-disabled people. The poverty rate for disabled New Yorkers is 17% higher than nondisabled New Yorkers. We urged the Governor to address the lack of employment opportunities for disabled people by enacting the recommendations of the Employment First Commission's report; establishing a business tax credit for New Yorkers with disabilities; include disability as a minority in the MWBE program; hire a 55 b/c Statewide Coordinator to assist candidates in participating in the Civil Service's Section 55-b program; and increase utilization of the

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<sup>8</sup> Id. p. 4.

Medicaid Buy-In for Working People with Disabilities.<sup>9</sup> The Governor's Budget fails to address the employment of disabled people in any substantive way!

### **Utilize Managed Care to Promote Community Integration of Disabled New Yorkers**

We called on the State to ensure that MCOs provide community-based services to all people with disabilities who choose them by, among other things: requiring fully independent person-centered planning; providing guidance to require MCOs to pay for home and vehicle mods; establishing a policy of "Community First" for Managed Care; requiring MCOs to contract with ILCs for transition and diversion services; to address known issues with the Uniform Assessment System in New York.<sup>10</sup> Many of these proposed reforms would assist disabled New Yorkers to receive community-based services which support our equality and dignity, rather than expensive institutionalization. Managed Care must ensure that people with disabilities receive the services they require to live in the community.

### **Improve Olmstead Reporting on Integrating Disabled New Yorkers into the Community**

The Governor has even failed to implement his own *Olmstead*<sup>11</sup> Transition Plan, which calls for the creation of a public "dashboard" of data showing progress integrating New Yorkers with Disabilities.<sup>12</sup> The data the State currently collects is not made readily available to the public or to organizations working to repatriate people into the community. If Governor Cuomo is serious about the State honoring its

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<sup>9</sup> Id. p. 4-5.

<sup>10</sup> Id. pp. 5-7.

<sup>11</sup> See *Olmstead v. L. C.* 527 U.S. 581 (1999) (establishing that disabled people have a right to live in the community).

<sup>12</sup> Governor's 2013 Olmstead Plan, page 29. Available at

([https://www.ny.gov/sites/ny.gov/files/atoms/files/Olmstead\\_Final\\_Report\\_2013.pdf](https://www.ny.gov/sites/ny.gov/files/atoms/files/Olmstead_Final_Report_2013.pdf))

responsibility to support disabled people living in the community, this information is necessary. We have repeatedly urged the State to make this data available,<sup>13</sup> but the Cuomo administration has refused to take action on this.

### **Stop Paying to Torture Disabled New Yorkers in Out of State Facilities**

New York Currently exiles 591 Medicaid enrollees to institutions in other states. These New Yorkers are forced to live sometimes hundreds of miles away from their families. In adopting the Community First Choice Option, New York has positioned itself to be a national leader in providing home and community based services, but this position is undermined by the State's continued decision to warehouse its residents in out of state institutions.

In addition, approximately 180 of these people are sent to the Judge Rotenberg Center (JRC) in Massachusetts, an institution engaging in practices that the United Nations has deemed torture. JRC uses electro-shock aversives as punishment to discourage its victims from any behaviors or activities that it considers inappropriate, often using shocks to suppress self-soothing behaviors.

New York cannot be "the social conscience" that Governor Cuomo claims we have always been while sending New Yorkers to be tortured in Massachusetts. New York is not a safe haven for oppressed and marginalized people if it is closed to New Yorkers with disabilities. The State must repatriate all of its residents institutionalized out of state and provide them community based services.

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<sup>13</sup> 2017 Disability Integration Agenda, pp 7-8.

## **Create & Fund a Service System to Meet the Needs of Deaf-Blind individuals**

The Disability Community has repeatedly asked Governor Cuomo to establish and fund a service system to address the unique and unmet needs of Deaf-Blind individuals to support them in living independently and participating fully in community life.<sup>14</sup> Without these Supports, Deaf-Blind New Yorkers ability participate in society is being limited at the most basic level. We call on Governor Cuomo to address this injustice.

## **Ensure Affordable, Accessible, Integrated Housing for Disabled New Yorkers**

Access to affordable, accessible, and integrated housing is a key part of Olmstead implementation and the integration of disabled New Yorkers in mainstream society. We called on the Governor to expand the Olmstead Housing Subsidy to a permanent funding stream, to ensure that Federal funding is also dedicated to Olmstead implementation, to prioritize public housing for people transitioning out of institutions and nursing facilities, and to create more accessible housing targeted to people with extremely low incomes. We also called for the Governor to restore funding for Access to Home to \$5 million.<sup>15</sup> He did neither.

## **Create a Tax Credit for Visitability Modifications**

In 2016, for the second year in a row, the Legislature passed a bill creating a tax credit for visitability of housing. The Governor vetoed that tax credit, again. As he did so, he again said that he supports a visitability tax credit, but that this tax credit should be part of the

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<sup>14</sup> Id., p. 10, see also New York Association on Independent Living and CDR, Investing in Community Living (2014) p. 2, available at <http://ilny.org/programs/cfc-tap/fiscal-analysis> (last accessed January 23, 2017)

<sup>15</sup> 2017 Disability Integration Agenda, pp. 8-10.

budget process, yet, in 2017, the Governor did not include the visitability tax credit in his budget.

CDR is deeply disappointed at the Governor's disregard for visitability. There is a crisis level shortage of accessible housing in New York, which has had a terrible impact on the ability of disabled and older individuals to live in the community. The Governor has vetoed this bill twice while claiming to support its intent, and failed to put the proposal into his own budget, twice. CDR now calls on the Governor to include the Universal Visitability Tax Credit in his amendments to the 2017 Budget.

### **Provide Access to the Governor's Own Presentations**

Finally, we called for the Governor to provide ASL interpretation and CART transcription, and to establish a scent-free policy at all of his public events, in order to ensure access for New Yorkers who are Deaf, hard-of-hearing, or who have multiple chemical sensitivity.<sup>16</sup>

The Governor provided six State of the State speeches and a Budget presentation. Captioning was available for all six State of the State speeches, but it was riddled with errors which, in some cases, destroyed the sense of what was said. In all but the first State of the State speech, the Governor provided ASL interpreting to the live audiences, but that interpreting was not provided to the majority of New Yorkers watching online. Neither captioning nor ASL were available for the Budget presentation. The Governor has also not established a scent-free policy for his public events.

When CDR advocates attempted to contact the Governor's Accessibility Coordinator at the phone number listed on the Governors' web page,

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<sup>16</sup> Id. p. 10.

we were informed that that number had been disconnected. Clearly the governor has disconnected from our community.

## **ANALYSIS OF THE GOVERNOR'S BUDGET**

### **Infrastructure**

The Governor's proposed budget includes plans to invest heavily in infrastructure across the state. Some of the state's existing infrastructure sites demonstrate the danger of not making accessibility central to the infrastructure development. The NYC subways system is one of the least accessible transportation systems in the country with, only 17% of its stations fully accessible to disabled people. As the state develops the Woodbury Transit & Economic Hub,<sup>17</sup> The Long Island Railroad,<sup>18</sup> The Empire State Trail,<sup>19</sup> and its many Airport renovations,<sup>20</sup> accessibility must be a primary focus. Further, Amtrak has consistently shirked their responsibility to make their stations accessible. The Governor must ensure that any current renovations or new Amtrak stations created will live up to ADA standards.<sup>21</sup> In order to avoid having to retrofit accessibility features at great expense, the Governor must include people with disabilities in the planning process for all of these projects from the beginning.

The Governor proposes to transition to cashless tolling by mail and EZ-Pass.<sup>22</sup> Any changes to New York's tolls and EZ-pass system must be accessible to disabled people who do not have a credit card or a bank account, as well as people with disabilities affecting executive function who may incur expensive fines if they fail to mail check payments out

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<sup>17</sup> FY 2018 Executive Budget - Briefing Book p.44

<sup>18</sup> FY 2018 Executive Budget - Briefing Book

<sup>19</sup> FY 2018 Executive Budget - Briefing Book p.58

<sup>20</sup> FY 2018 Executive Budget - Briefing Book p.120

<sup>21</sup> TED Part P

<sup>22</sup> FY 2018 Executive Budget - Briefing Book p.118

in a timely manner. The State should provide a cash alternative for payments.

The Governor also proposes to reduce wait times at the DMV by making more services available online.<sup>23</sup> While shorter wait times at physical DMV locations would benefit all New Yorkers, with multiple inaccessible DMV locations, shortened wait times do nothing to help disabled New Yorkers who cannot even get in the door. The Governor should prioritize DMV accessibility and compliance with federal law over changes for convenience.

### **Modernizing New York's Airports**

The Governor proposes to renovate several of New York's airports both downstate and upstate.<sup>24</sup> There is significant potential to improve accessibility at airports for disabled travelers, and we call on the Governor to include wheelchair users, blind people, Deaf people, autistic people, and other disabled people in the planning and execution of all proposed airport modernizations. In particular, our community experiences problems with baggage handlers and others breaking our wheelchairs, power chairs, and other adaptive or durable medical equipment when loading or unloading them from airplanes. The Modernized New York Airports can be a model of proper, accessible handling of these items, and we call on the Governor to make these things a priority in the modernization of our airports.

### **Affordable Integrated Housing**

The budget attempts to position the governor as a champion of affordable housing, something the Disability Community has needed in a governor for many years. A close reading of the Budget however

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<sup>23</sup> FY 2018 Executive Budget - Briefing Book p. 122

<sup>24</sup> FY 2018 Executive Budget - Briefing Book p.120

reveals he is more the champion of housing developers than disabled people in need of affordable accessible integrated housing. Millions in tax abatements or credits for developers to create housing that is too expensive for anyone trying to get by on public assistance and requires no guarantees that all or even a percentage of it will be accessible is not what Disabled New Yorkers need.

### **"Affordable New York" Housing Program**

The Center for Disability Rights would love to support an "Affordable New York" housing program which included accessible, affordable, integrated housing.<sup>25</sup> The Governors proposed tax abatements and incentives may create affordable housing for some New Yorkers, but nothing in his proposal ensures that the housing is affordable or accessible to disabled New Yorkers. It is precisely this neglect of accessibility that has led to the current crisis-level shortage of affordable, accessible, integrated housing in New York. Unless the State clearly requires accessibility in affordable housing, our community will continue to be ignored and discriminated against.

### ***Mitchell-Lama Portfolio***

This 41 million dollar middle income housing project<sup>26</sup> cannot be a priority while there *is* an ongoing crisis level shortage of affordable housing stock. That crisis becomes even more acute when we focus on the availability of affordable accessible housing. The lack of affordable accessible housing is direct result of state neglect, and this cannot continue. This is not a problem the state is unaware of; New York State and many disability organizations have issued reports detailing the problem. It forces many disabled people to choose between life on the streets or life in an institution.

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<sup>25</sup> ELFA Article VII – Part S pp.331-363.

<sup>26</sup> ELFA Article VII – Part R p. 325.

Governor Cuomo must develop real affordable integrated housing solutions that consider the needs of disabled New Yorkers struggling to get by on limited public assistance incomes.

## **Health and Long Term Services & Supports**

### **Prescription Drug Cost Reforms Deny Disabled People Needed Medications**

The Governor has proposed to create a supplemental rebate on the sale of certain drugs in an effort to lower insurance premiums<sup>27</sup>. The details of this proposal, however, are likely to restrict access to specific drugs for disabled people who require that medication. When people with disabilities are denied access to the specific medications they require and that have been prescribed to them, that denial can cause them to decompensate to the point of forced, expensive, and unnecessary institutionalization or hospitalization or even death. This issue must be addressed in order to ensure that this proposal does not force disabled people into institutions or risk disabled lives.

#### **Drug Utilization Review Board**

The proposal calls for a 23-member drug utilization review board, of which the only mandatory members are an actuary, two health care economists, and a representative from the department of finance.<sup>28</sup> This board is not required to include medical professionals, pharmacists, or the disabled people who rely on access to these medications. The board will identify certain medications as "high-cost." In making this determination, the board will consider, among other things, the extent of the medications' utilization and its effectiveness in treating the

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<sup>27</sup> 2017 Health & Mental Health Article VII Part D, p. 16 et seq.

<sup>28</sup> HMH p. 16-17.

condition for which it is prescribed.<sup>29</sup> These considerations do not take into account the effect that a rare medication can have on the life of a disabled or terminally ill person. A medication that is only 40 percent effective might extend the life of a terminally ill person by days or weeks. A medication that is only 30 percent effective at relieving pain can still be a significant reduction for a person in chronic pain, if there is no alternative that works for that person. CDR opposes the creation of this board as proposed, and urges the Governor to consult with the disabled people who rely on rare medications in crafting any replacement proposal.

### **The “High-Cost” Surcharge**

Once identified, the proposal imposes a surcharge on the first sale of a “high-cost” medication, which the pharmacist must bear and is not allowed to pass on to the consumer or the insurer.<sup>30</sup> This provision may cause pharmacists to fail to stock these medications or fill the prescription. CDR opposes the imposition of this surcharge.

### **The Elimination of “Prescriber Prevails”**

The proposal eliminates the “prescriber prevails” provision currently in New York law.<sup>31</sup> Prescriber prevails ensures that disabled people are able to receive the specific medication which they and their doctor recommend rather than a generic or alternative medication which may interact differently with either the individuals’ own disability or with other medication the

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<sup>29</sup> Id. 19.

<sup>30</sup> HMM Part D, p 20-22.

<sup>31</sup> HMM Part D, p. 36-37.

individual requires. CDR does not support the elimination of prescriber prevails.

### **Prescription Opioid Control**

The proposal also restricts prescription of pain-relieving opioids by making the inappropriate prescribing of opioids an unacceptable provider practice in the Medicaid program, which could result in the provider's exclusion from the program,<sup>32</sup> and by requiring prior authorization for refills of opioid prescriptions while more than seven days of the prescription remain.<sup>33</sup> CDR cautions that these proposals, if passed into law, must be applied with care in order to ensure that people with disabilities and terminal illnesses who require opioids for pain management continue to have ready access to those medications.

Requiring participation in Drug Monitoring Tracking Programs and stopping Medicaid reimbursements to those providers feeding and profiting off of the opioid epidemic are effective tools for preventing overprescribing and monitoring doctor shopping. Many New Yorkers, however, have been prescribed opiates appropriately to treat severe chronic pain. To create barriers to access for those who need ongoing pain relief is cruel and ineffective, and may contribute to the use of illegal methods of pain control. As the State addresses opioid abuse, it must not treat as criminals people who use pain medication as a tool along with other effective pain management techniques.

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<sup>32</sup> HMH Part D Section 8, Page 38

<sup>33</sup> HMH Part D Section 9, Page 38-39

## **Non-Emergency Medicaid Transport Must be Improved**

The Governor has proposed to carve out the Non-emergency Medical Transportation (NEMT) benefit from Managed Long Term Care and administer that benefit through the State's Transportation Manager.<sup>34</sup> While there is significant room for service improvement in NEMT, CDR does not believe that this proposal will realize that improvement. The State should instead exercise greater supervision over the delivery of this service to ensure that disabled people are truly able to access their medical needs. Some NEMT vendors do a great job with particular individuals or with individuals with particular disabilities. Some NEMT vendors do not. An individual known to CDR has been "fired" from every doctor's office in her rural area because her local NEMT provider has failed to take her to appointments in a timely manner. Rather than eliminate choice of vendors by taking this benefit on directly, the State should create and enforce quality standards against NEMT vendors who fail to adequately serve our community.

## **Enrollment Restrictions in Managed Long Term Care Indicate Need for Reforms**

The Governor proposes again this year to restrict enrollment in Medicaid Managed Long Term Care (MLTC) to individuals who require a nursing home level of care, while "grandfathering" in those currently in MLTC.<sup>35</sup> Eliminating the 120 day eligibility condition for MLTC is dangerous. People who have chronic or episodic mental health needs and IDD without co-occurring physical disabilities may be mistakenly assessed at below the nursing facility level of care and placed into Fee-for-Service or the regular Medicaid Managed Care system. Without adequate supports in that system, such people may deteriorate and be

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<sup>34</sup> HMM Part F, Page 48.

<sup>35</sup> HMM Part E, page 45 et seq.

institutionalized, a great and unnecessary cost to the State and a significant disruption of their lives and rights. CDR opposes this proposal.

In response to this proposal last year, CDR identified reforms to Managed Long Term Care, which would have addressed problems with the State overpaying for low-cost users through the MLTC system. We sent those reforms to the Governor again in the fall<sup>36</sup> and have summarized them on pages 4 through 7 of this document. The Governor persists in using the blunt instrument of enrollment restrictions rather than real reforms that will help people with disabilities live in the community and avoid costly institutionalization.

In addition to the above concern, this proposal includes language changing the 120 day requirement to a “continuous” 120 days “from the date of enrollment.” CDR believes that this language is an attempt to eliminate the right to services on the basis of presumptive eligibility, and opposes any attempt to eliminate this right.

### **Narrowing Spousal Refusal Denies Disabled New Yorkers the Right to Marry**

Again this year, the Governor’s Budget calls for a change to spousal refusal for receiving supports and services which will require the spouse both to refuse to support the disabled spouse and to be absent from the disabled spouse’s household<sup>37</sup>. The current law requires either the spouse to refuse or the spouse to be absent. CDR opposes this proposed change because it denies people with disabilities the same marriage equality that nondisabled people in New York enjoy.

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<sup>36</sup> 2017 Disability Integration Agenda, passim.

<sup>37</sup> HMH Part E, page 12

Federal law allows a Medicaid applicant to choose to use spousal refusal budgeting when it is more advantageous to the applicant. In its current form, the law has allowed a disabled spouse to receive Medicaid services and supports without the other spouse first having to reduce his or her resources to the point that the household would qualify for Medicaid. This has meant that a couple has not been forced to get a divorce just so that one could receive benefits. It has also meant that a disabled person could get married without losing their services and supports.

The law should not be changed, because, as a matter of basic human rights, the State should not provide supports and services in a way that break up families or prevents people with disabilities from getting married. Governor Cuomo is rightly proud that New York has been a progressive leader in marriage equality. He should not force disabled people to decide between their families and the services they need to live.

### **Bed Hold Repeal Imprisons Disabled New Yorkers in Institutions**

The Governor proposes to eliminate “reserved bed days” which allow people in nursing facilities to return home to their families for up to 10 nights per year, and to spend up to 14 nights per year in temporary hospitalizations, without losing their placement in the nursing facility.<sup>38</sup> CDR strongly opposes this proposal.

Reserved beds in nursing facilities are critical to providing short term acute care needs for New Yorkers with complex behavioral and mental health needs, including people with traumatic brain injuries. New York

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<sup>38</sup> HMH Article VII – Part E, pp.45-46

does not provide any sort of “half-step” transitional living situations for people with these dually occurring complex needs. Many people with these types of needs are sent to facilities in Massachusetts, far from their families, their community, and the resources they need if they are to transition back to living in the community. If reserved beds are no longer available, the State will be condemning nearly 600 New Yorkers to permanent placement in a hospital or nursing home out of state, with no prospect of access appropriate services and supports in the community.

### **Extending the Medicaid Global Cap Must Ensure That Disabled People are not Institutionalized**

The Governor has proposed to extend the Medicaid Global Cap, if this should become necessary due to changes in Federal Medicaid law or policy.<sup>39</sup> The Disability Community has grave concerns about Federal cuts to Medicaid funding with the new Congressional leadership and the new Administration. Medicaid is the largest payer of long term services and supports, and New Yorkers with disabilities rely on Medicaid to receive the services and supports we need to remain independent in the community, instead of being forced into nursing facilities and other institutions. Disabled New Yorkers must be assured that our community based services and supports – and with them, our constitutional right to live in freedom – will remain intact should the Federal government make cuts or changes to Medicaid.

However, given that Governor Cuomo has largely ignored the Disability Community in his budget, his proposal to allow the Director of Budget to account for any changes in Federal Medicaid expenditures or eligibility criteria does not alleviate our concerns about the potential to

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<sup>39</sup> HMM Part G, page 50 et seq.

lose our Medicaid funded community based services and supports. CDR urges the Governor to add language instructing the Director of the Budget to account for any changes to Federal Medicaid in a manner that will ensure that disabled New Yorkers will continue to receive the community based supports and services that allow us to live in freedom.

### **The Cost Sharing Requirements of the Essential Plan must not Disrupt Coverage**

The Governor proposes to increase cost sharing requirements for the Essential Plan, a low-cost health care plan for individuals who do not qualify for Medicaid or Child Health Plus.<sup>40</sup> This proposal requires monthly premium payments of \$20 for individuals enrolled in the Essential Plan with incomes between 138-200% of the Federal Poverty Level, and this payment would be increased by the annual growth percentage in the Medical Consumer Price Index.

This proposal will disproportionately affect people with chronic conditions and home care workers who are overrepresented in the set of people making below 200% of the Federal Poverty Level. CDR is concerned that adding this \$20 monthly premium, plus increases, will disrupt the coverage of people who, whether because of disability or poverty, may fail to pay or whose payment may be held up for technical reasons. In other states where “nominal” monthly premiums has been required for state-run health insurance plans or Medicaid, individuals have lost vital coverage when a processor failed to timely process a payment, or when the insurance plan changed processors and failed to inform the enrollee. The costs to the individual and to the State of losing vital coverage for administrative reasons can easily

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<sup>40</sup> HMM Part C, pp. 15-16.

exceed any savings or income realized by such a proposal. CDR opposes this cost sharing requirement.

## **Employment**

### **Fair Wages For All**

Governor Cuomo, perhaps more than any governor since his father, has spent time talking about the importance of fair wages. He has campaigned across the state to increase the minimum wage. His budget guarantees construction workers to make at least \$60 per hour in Manhattan and \$45 per hour in Brooklyn & Queens;<sup>41</sup> it protects workers trying to recover stolen wages;<sup>42</sup> and it offers fair wage tax incentives to certain industries.<sup>43</sup>

It is beyond comprehension then, that he has done nothing to end the exploitation of disabled New Yorkers being paid subminimum wages. As noted on page 4 above, Governor Cuomo allows organizations to pay disabled workers as little as 85 cents per hour. Disabled workers receiving less than minimum wage often have no choice but to rely on public assistance benefits to live. The Governor must act now to bring New York into line with other states that have already done away with this discriminatory practice.

As noted on page 5 above, the Disability Community has offered the Governor a number of proposals to increase the integrated employment of disabled New Yorkers at fair wages. The Governor has chosen none of the proposals our community put forward. On employment, we are being left behind.

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<sup>41</sup> ELFA Article VII – Part S

<sup>42</sup> ELFA Article VII – Part I

<sup>43</sup> Revenue Article VII – Part M, pp79-84

## **Education**

### **Address the Disability Community's Education Needs so We Can Benefit from Free Tuition**

The Governor proposed making SUNY and CUNY tuition free for students of families earning less than \$125,000 per year.<sup>44</sup> This proposal will fail to address fees and room and board costs which have prevented many students from working-class families from attending college. In addition, the SUNY and CUNY schools have had ongoing and significant problems with a lack of accessibility for students with disabilities. Free tuition means nothing to someone who cannot get in the door or to someone who cannot get into the dormitories to study and interact with their classmates. SUNY and CUNY schools must be fully accessible to students with disabilities.

Given that disabled unemployment is more than twice that of the nondisabled population, no community is more in need of access to higher education than the Disability Community. Disabled students face numerous systemic barriers in navigating New York's primary and secondary education systems, which prevent many disabled students from achieving academic success. Low expectations, a lack of support for IEPs, and a system that funnels disabled students onto a path that does not qualify them for the universities the governor is offering to pay for. In addition, these scholarships are for four years: many disabled students require more than four years to complete their degree.

College is, as the Governor has said, the key to entering the modern workforce. For our community, the lack of support in primary and secondary school will keep many disabled students from being

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<sup>44</sup> ELFA Article VII – Part D P.121 et seq

admitted to the SUNY and CUNY schools. Without addressing these limitations, our community will never benefit from this proposal.

### **Expand High Quality Pre-Kindergarten for Three and Four-Year Olds**

CDR supports the Governor's plan to expand Pre-K services,<sup>45</sup> particularly his call to ensure that there is opportunity for "a pre-kindergarten program in every high-need community in the state". However, Deaf children in early childhood education have been so thoroughly underserved that they require more explicit measures. We call on the Governor to pass legislation ensuring the Kindergarten readiness of Deaf and Hard of Hearing children. It is time to invest in the Deaf Community.

### **Extending anti-discrimination protections to public schools**

The Governor proposes to extend protections against discrimination, harassment, and bullying that currently apply to private schools, to include public schools.<sup>46</sup> CDR supports this proposal. Disabled students experience higher rates of discrimination, violence, bullying, and harassment. We are also often subject to the legal, discriminatory private school admission practices, so we are more likely than most to need protections in public schools.

### **Expanding Charter Schools**

The Governor's Budget includes a potentially massive expansion of Charter Schools in the state.<sup>47</sup> This might make the Governor more popular with middle class parents convinced they will be able to choose what school they will be able to send their kids to, but it does

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<sup>45</sup> ELFA Article VII – Part A pp 66-69

<sup>46</sup> FY 2018 NEW YORK STATE EXECUTIVE BUDGET PUBLIC PROTECTION AND GENERAL GOVERNMENT (PPGG) ARTICLE VII LEGISLATION – Part V – p.133-134

<sup>47</sup> ELFA Article VII p. 12 et seq.

little for the many disabled students that Charter schools have consistently discriminated against in both their admissions and operational practices. This expansion will exacerbate the problems faced by public education. If the governor is serious about fixing our education system he must know that it cannot begin by further undermining public Education. He should be going after existing charter schools for their discriminatory practices, not opening more of them.

## **Transportation**

### **Ridesharing without Accessibility is Discrimination, not Innovation!**

The Governor has proposed to allow ridesharing in all of New York State.<sup>48</sup> The Governor's proposal includes anti-discrimination protections for disabled passengers in the form of requiring ridesharing drivers to obey all applicable nondiscrimination laws relating to disability, including not charging extra for accessible rides and following the law regarding service animals. Our community's concerns about discrimination in ridesharing are earned by experience. In the cities where ridesharing companies have operated, they have resisted their responsibility to provide accessible rides to disabled people. Both ridesharing companies and taxi operators alike discriminate against our community. From our perspective, ridesharing – even under the existing legal framework – is not the future of transportation upstate: it is the same old discrimination and exclusion that our community has experienced for decades. This means that language which calls for compliance with existing language will not be sufficient to ensure that disabled people have access to ridesharing services.

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<sup>48</sup> TED Article VII p. 33 et seq.

The Governor's call for a task force to review, study and make recommendations regarding accessibility needs in the rideshare industry is inadequate.<sup>49</sup> Providing accessible rides to disabled people does not require further study: it requires enough accessible vehicles to ensure that a disabled person receives equivalent service as a nondisabled person. Rather than a task force, the Governor should require that ridesharing companies include in their fleets enough accessible vehicles to ensure that people who use wheelchairs, power chairs, scooters, and other forms of adaptive equipment have equal access to this service in every part of the state.

Adding accessibility after the fact is not effective, and indeed, rarely happens at all. If ridesharing companies will not provide equal access to people with disabilities on day one, what will make them provide equal access after six months, or a year, or a decade. If the State is not willing to require equal access at the time ridesharing is legalized, there is no reason to believe that it will require equal access in six months, or a year, or a decade. In promoting ridesharing, the Governor said that "innovation matters." It is almost 27 years since the passage of the American's with Disabilities Act, and it is time for the Governor and New York to realize that "Accessibility Matters" upstate and down!

## **Civil Rights**

### **Criminal Justice Reform**

The Governor has proposed several reforms to New York's criminal justice system. People with disabilities are often ill-served by the

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<sup>49</sup> Id. p. 100 et seq.

existing system, and CDR salutes the Governor's intention to make criminal justice fairer to New Yorkers. In this spirit of support, CDR offers the following specific suggestions for reforms that are vital to the Disability Community.

It is clear from the criminal justice reforms in the Governor's budget that New York's current policing, judicial, and correctional systems are inadequate to the task of accommodating disabled people. This is not an objection to the reforms the Governor proposes (many of which we support) but is to note the need to go much further. It is estimated that as much as 50% of the people killed in police shootings are disabled<sup>50</sup>. The barriers disabled people encounter when trying to access justice through the courts are too numerous to list but include the lack of Specialist Certified: Legal ASL Interpreters; the ableist assumptions of prosecutors, judges, and the law itself; and physically inaccessible court rooms.

In the corrections system prisoners are "nearly 3 times more likely and jail inmates were more than 4 times more likely than the general population to report having at least one disability"<sup>51</sup> and access needs are rarely accommodated<sup>52</sup>. We know from the disabled prisoners we have worked with, that ADA compliance in New York State prisons is appalling with disabled prisoners being denied access to their wheelchairs and other mobility aids and Deaf prisoners being refused access to video phones. The Governor must comprehensively address this reality: these problems cannot be dealt with piecemeal. CDR calls on Governor Cuomo to assemble a taskforce to study these complex

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<sup>50</sup> David Perry and Lawrence Carter-Long, "Media Coverage of Police Use of Force and Disability." Ruderman Family Foundation White Paper, March 2016

<sup>51</sup> Bureau of Justice Statistics - <http://www.bjs.gov/content/pub/pdf/dpji1112.pdf>

<sup>52</sup> The Center For American Progress - <https://cdn.americanprogress.org/wp-content/uploads/2016/07/18000151/2CriminalJusticeDisability-report.pdf>

issues as a whole and develop comprehensive strategies to reduce or eliminate many of these problems.

Disabled people are victims of crimes, including violent crimes, at significantly higher rates than the nondisabled population, yet it is the ongoing experience of our community that prosecutors often refuse to bring charges when a victim is disabled. The causes of this refusal are likely to include the prosecutor not believing the victim, and the prosecutor anticipating that the jury is unlikely to believe the victim. Whatever the reason, the Disability Community is severely underserved by the criminal justice system. We know that the Governor, as a former prosecutor, takes the rights of victims seriously, and we urge him to call on prosecutors to find ways to establish the credibility of disabled crime victims before a jury, in order to ensure that our community's rights and bodies are protected by the criminal justice system.

### **Bail Reform**

The Governor's plan to reform the bail system<sup>53</sup> is very much needed. People with disabilities are significantly more likely to live in poverty than nondisabled New Yorkers, and often cannot afford to post bail. The current bail system amounts to little more than a modern version of the old debtors' prison. CDR looks forward to working with the Governor to change this system that unnecessarily incarcerates people for the "crime" of being poor.

### **Ensure Access to a Speedy Trial**

The Governor has proposed legislation to protect the right of defendants to a speedy trial.<sup>54</sup> A lack of Specialist Certified: Legal ASL

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<sup>53</sup> FY 2018 Executive Budget - Briefing Book p.109

<sup>54</sup> FY 2018 Executive Budget - Briefing Book p.109

Interpreters in New York courts has prevented Deaf defendants from receiving a speedy trial. Many Deaf defendants report their hearings and trials delayed multiple times due to a lack of such interpreters. This is an area in need of reform and we urge the Governor to include the need for Specialist Certified: Legal ASL Interpreters in his reforms.

### **Raise the Age of Criminal Responsibility**

CDR strongly supports the Governor's proposal to raise the age of criminal responsibility.<sup>55</sup> This proposal will significantly benefit young disabled people, who are much more likely to interact with the criminal justice system than the nondisabled population. Nationally, as much as 85 percent of youth in juvenile detention facilities have disabilities that make them eligible for special education services. Raising the age of criminal responsibility is an important advance toward ensuring that young disabled people avoid the school-to-prison pipeline.

### **Record Police Interrogations for Serious Offenses**

CDR supports the Governor's proposal to video record the interrogations of defendants accused of serious crimes<sup>56</sup>. The interrogation of a defendant is a critical part of criminal prosecution, but in many cases, police do not have the cultural competence to ensure that the rights of disabled defendants are protected. This includes the lack of access to ASL interpreting for deaf defendants, a lack of reasonable accommodations for people with intellectual and developmental disabilities, as well as for people with traumatic brain injuries or mental health disabilities for whom the stress of interrogation can cause the defendant rapidly to decompensate. The Governor should call for police to receive training and oversight to

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<sup>55</sup> FY 2018 Executive Budget - Briefing Book p.108

<sup>56</sup> FY 2018 Executive Budget - Briefing Book p.109

ensure that the rights of all disabled defendants are protected during interrogation.

### **Extend the *Hurrell-Harring* Settlement Reforms**

The Governor has proposed legislation to extend the agreement in *Hurrell-Harring* to the entire State<sup>57</sup>. That agreement requires courts to provide defense counsel to indigent defendants. CDR supports this proposal, because disabled people are both significantly more likely to live in poverty and to interact with the criminal justice system. We urge the Governor to include a requirement that the courts provide qualified ASL interpreters for Deaf defendants' in every interaction with their court-appointed attorneys.

### **Disabled & Aging in Prison**

CDR supports the Governor's plan to provide supports for people leaving State Prisons<sup>58</sup>. People with Disabilities are disproportionately represented in State Prisons and many struggle to avoid re-incarceration because of a lack of community-based services. This proposal must include supports for people with disabilities including those with mental health disabilities.

The Governor's plans for the incarcerated population are not good enough. Fifty beds for older prisoners in one correctional facility are inadequate in a prison network that systematically denies disabled prisoners' rights guaranteed by the ADA. The Governor must bring State Prisons into ADA compliance. This includes the provision of video phones for Deaf & Hard of Hearing Prisoners, access to wheelchairs and other adaptive devices, and adequate mental health services. He

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<sup>57</sup> PPGG – Part D pp.44-48

<sup>58</sup> PPGG – Part E pp.50-75

must also end the use of solitary confinement, an outdated and solely punitive measure that triggers and causes mental health disability.

### **Sentencing Reform**

CDR applauds the governor's proposal to reform sentencing laws<sup>59</sup> and find alternatives to mandatory sentences for minor offences. Roughly one in five incarcerated people have mental health disabilities. The State must provide community based solutions that serve both society and the individual. The prison system as it is currently constructed is the worst possible place to be the State's largest mental health provider.

### **Include Disability in Interfaith Task Force on Hate Crimes**

The Governor's Interfaith Task Force on Hate Crimes has never been needed more than it is today.<sup>60</sup> The task force cannot do its job if it is not intersectional, because Hate Crimes do not fall neatly across identity lines. The Governor must ensure that disability hate crime is part of the task force's remit and that people with disabilities are a part of its composition. The Disability Community intersects across all racial, religious, gender, socio-economic, and sexual orientation lines and we experience hate crimes and violence at higher rates than nondisabled members of our communities. The Task Force will not be able to "promote open-mindedness and inclusivity, and bolster the state's efforts to protect all New Yorkers" if it does not include disability and the Disability Community.

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<sup>59</sup> PPGG – Part E pp 58-59

<sup>60</sup> PPGG Part F, p. 75.

## **Taking lottery winnings from current and former public assistance recipients**

Currently, New York State takes up to 50% of the lottery winnings over \$600 from any individual who has received public assistance benefits in the past 10 years, to “reimburse” the State for the benefits the individual received. The Governor now proposes changing this law to allow the State to take up to 100% of these lottery winnings.<sup>61</sup> CDR opposes the current law and the proposed change.

Individuals who receive public assistance are already heavily stigmatized and this law, as well as the Governor’s proposed change, only serves to further stigmatize New Yorkers who need help. Taking the lottery winnings from individuals who have received public assistance benefits can further harm the individuals. However, if their lottery winnings are taken from them to “reimburse” the state for the benefits, the individual will likely remain in poverty and continue receiving public assistance.

The Governor has refused to end subminimum wages for disabled workers; refused to add disability to the MWBE program for state contracting; failed to include a tax credit for business that hire disabled workers; failed to hire a Statewide 55/b coordinator; and failed to support the increased utilization of the Medicaid Buy-In for Working People with Disabilities – all policies which will enable people with disabilities to achieve economic stability. Now he wants to take away even the remote potential for a windfall through the lottery. The Governor must end this program and retract the new proposal as well.

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<sup>61</sup> ELFA Article VII Part O, pp. 311-313.

## **Discriminating against Disabled and Aging New Yorkers In the name of Protection**

The Governor proposes to enable financial institutions to place a hold on transactions when it believes that a hold is necessary to protect a vulnerable person.<sup>62</sup> CDR is concerned by this proposal, because the definition of “vulnerable person” requires financial institutions to single out members of a protected class — disabled people and older adults — in order to treat these individuals differently than everybody else. The definition of “vulnerable person” in this proposal is so porous that it invites bias and discrimination.

This proposal fails to describe how will financial institutions are to determine who qualifies as “vulnerable” or which transactions are likely to place “vulnerable” customers at risk of exploitation. Despite these gaps, the proposal shields financial institutions from any liability for placing a hold on a transaction pursuant to this law. CDR opposes this proposal to interfere with the autonomy of disabled people.

## **Same-Day Voting Registration**

CDR Supports the Governor’s Proposal to allow same-day Voter Registration<sup>63</sup>. With that said, we foresee in same-day registration a potential hazard which may result in the disenfranchisement of some voters. Local boards of elections should be required to publish clear instructions as to the requirements for same-day registration, in order to ensure that unregistered voters understand those requirements before they show up at the polls. These instructions should be written in a way that is accessible to people with intellectual and/or developmental disabilities, and published in alternative formats such as large print, braille, and accessible electronic formats in order to ensure

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<sup>62</sup> TED – Part AA, pp. 223-228.

<sup>63</sup> Governor’s SAME DAY VOTER REGISTRATION CONCURRENT RESOLUTION

that disabled voters do not show up unprepared to register, and be denied their opportunity to vote.

### **Early Voting for Some is Discrimination; We Want Early Voting for All.**

The Governor has proposed allowing early voting in all districts.<sup>64</sup> Accessible early voting would benefit people with episodic disabilities who may be unable to get out of the house on a particular day, as well as providing needed opportunities for poll workers to set up and operate accessible voting machines. If accessible to disabled voters, early voting would be a great benefit to our community, and would have CDR's strong support.

Unfortunately, the Governor's proposal indicates that accessibility is optional for local boards of elections to consider when selecting early voting sites. Specifically, the notice which the local board of elections is to send out must indicate "whether the site is accessible to persons with physical disabilities." This language implies that discrimination against disabled voters in early voting is acceptable.

We are at a loss to understand how this language was drafted and published by a Governor who holds out New York State as a safe haven for people who are discriminated against. It is more than a decade after the Help America Vote Act, and more than a quarter-century after the ADA. Voting is a fundamental right of all Americans, including disabled Americans. Voting locations, voting machines, and the entire polling process must be accessible as a matter of fundamental civil rights. This is not a difficult question, and the Governor has gotten it wrong.

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<sup>64</sup> 2017 Good Government and Ethics Reform Article VII, Part N. p. 96 et seq.

## **CONCLUSION**

From the perspective of the Disability Community the Governor's Budget was wholly inadequate! The State must do better by its largest minority. The Governor clearly failed to engage with our community in crafting his budget, and doing so he has failed to support the rights of our community. Having said this, we are ready to work with Governor Cuomo and the Legislature to secure the integration and equality of all disabled people in New York.

## **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.