Thank you to the Joint Committee for this opportunity to comment on the 2017-2018 Executive Budget. My name is Adam Prizio and I am the Manager of Government Affairs at the Center for Disability Rights. The Center for Disability Rights (CDR) is a disability led, not-for-profit organization headquartered in Rochester, New York. 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.

The Legislature Must Do for Disabled New Yorkers what the Governor Has Failed to Do
In the Fall of 2016, the Center for Disability Rights and other disability advocacy organizations communicated to the Governor the “2017 Disability Integration Agenda,” a document of outstanding policy priorities, in advance of the budget making process. The priorities we communicated are longstanding recommendations of the Disability Community. The Disability Community, in the form of the Independent Living movement and National ADAPT, as well as other organizations, has secured a significant Federal revenue source for community integration in the form of Community First Choice, which is estimated to bring in between $299 million and $439 million per year, when community-based services are maximized for disabled New Yorkers. The Assembly estimates that CFC will bring in $265 million per year, with no growth, but CFC is designed to grow by providing transition services for institutionalized New Yorkers.

The priorities of the Disability Integration Agenda are intended to spend some of the CFC funding currently coming into the State to secure the Olmstead rights of disabled New Yorkers and to maximize the CFC funding on an ongoing basis. The Governor has chosen not to act on any of our proposals. Because of this, the State will receive less total CFC funding than it otherwise would, and will fail to

1 This document, the 2017 Disability Integration Agenda, is available online at http://cdrny.org/wp-content/uploads/2017/01/2017-Disability-Integration-Agenda.pdf (last accessed February 16, 2017).
secure the civil rights of many disabled New Yorkers who want to live and receive services in the Community. The Department of Health has failed to engage with the Disability Community in implementing CFC, despite the fact that Federal regulations require DOH to consult and collaborate with our community in that implementation.

At the same time, DOH continues to press forward with transitioning the 1915(c) NHTD and TBI waiver populations into managed care, with the promise that CFC will ensure that waiver participants will continue to receive needed services. The Center for Disability Rights has not objected, in principle, to the transition of these waiver participants into managed care, but we, along with many in the Disability Community, have significant and un-addressed concerns about the implementation of CFC. The transition from the waivers into a managed care environment with a robust implementation of CFC has a great potential upside both for the State and for Disabled New Yorkers; the manner in which DOH is implementing CFC virtually ensures that this transition will realize significant downsides instead.

Chapter 57, Part B, Section 37 of the 2015 Laws of New York states as follows:

Notwithstanding any provision of law to the contrary, monies equal to the amount of enhanced federal medical assistance percentage monies available as a result of the state’s participation in the community first choice state plan option under section 1915 of title XIX of the federal social security act, in each state fiscal year shall be made available as additional funds to be used to implement the state’s comprehensive plan for serving New Yorkers with disabilities in the most integrated setting, also know as the state’s Olmstead plan. Such monies shall be expended for the purposes consistent with the Olmstead plan, including, additional funding for services provided pursuant to section three hundred sixty-five-f of the social services law, supportive housing, wage supports for home and personal care workers, transportation supports, and the transition of behavioral health services to managed care. The department of health shall, after consultation with the senate finance committee and assembly ways and means committee, stakeholders, relevant state agencies, the division of budget and the Olmstead cabinet, submit a report to the temporary president of the senate, and the speaker of the assembly, the chair of the senate finance committee, the chair of the assembly ways and means committee, and the chairs of the senate and assembly health committees, setting forth the plan to allocate such investments, and shall notify the senate finance committee and the assembly ways and means committee at least forty-five days prior to implementation of such allocation. The commissioner of health shall report annually to the chairs of the assembly and senate committees on health, aging, and mental health, the chair of the senate committee on finance, the chair of the assembly ways and means committee, and the chair of the assembly task force on people with disabilities on the amount of funding received and disbursed pursuant to this section, the projects or proposals supported by these funds, and compliance with this section.
The State is receiving significant Federal funding through CFC, although less than it could receive if it implemented CFC in a manner that would maximize community-based services for disabled New Yorkers. Nevertheless, the State is receiving approximately $265 million per year through CFC. To our knowledge, however, the State is not applying this money to wage supports for home and personal care workers. Wages for attendants are so low that the Consumer Directed Personal Assistance Association has declared a workforce crisis. To our knowledge, the State has not applied this money to ensure that there is affordable, accessible, integrated housing for disabled New Yorkers to live in when we transition out of institutions. To our knowledge, the Commissioner has not even consulted with stakeholders before submitting his report to the Senate President and Speaker of the Assembly as to how the CFC monies are being sent.

The State’s 2013 Olmstead plan states “the total number of nursing home residents in New York was 119,987, of which 92,539 have stayed 90 days or more. DOH has set a goal of reducing the long-stay population by 10 percent over the next five years.” This is a goal of transitioning approximately 9,254 people from nursing facilities into the community. It is more than three years since the publication of the Olmstead plan: by now DOH should have transitioned approximately 5,500 people into the community, slightly more people than are participating in the 1915(c) NHTD and TBI waivers. If the population of nursing-facility eligible people living and receiving services in the community has doubled, we have seen no evidence of it. While there is rightly a great deal of concern about what will happen to the NHTD and TBI waiver participants, little is being done for thousands of New Yorkers in nursing facilities whose right to live in the community is already violated.

In summary, the relationship of the Department of Health and the Disability Community has been marked by neglect, broken promises, missed goals, and a failure to engage even when that engagement is required by Federal or State law. Accordingly, we call on the Legislature to act where the Governor has failed our community, and to secure our right to live in the community by addressing the following issues in the 2017-18 Health Budget.

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

A crisis has been developing around the wage, reimbursement, and workforce adequacy in Consumer Directed Personal Attendant Services (CDPAS) and home health services. Consumers report that it is impossible to recruit and retain workers at the wages possible under existing reimbursements. Reimbursements were cut by several MLTCs in September, causing workers who have not seen a raise in a decade or more to face a two or three dollar per hour pay cut — up to one-third of their pay. By contrast, the State has protected the reimbursement rates for hospitals in Managed Care, and protects the wages of some home care workers through wage parity. This leaves CDPAS as one of the only places where Managed Care Organizations (MCOs) can cut costs. Due to capitation models that undercut the ability of plans to serve high needs consumers, MCOs have had to cut costs to such a dramatic extent that the integrity of CDPAS in New York is threatened.

This has significant *Olmstead* implications because CDPAS is the service which enables people with the most significant disabilities to live in the community. Home care agencies have typically refused to serve people with significant service needs. Regional staffing shortages have left CDPAS the only

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option. Finally, many people who have required health-related tasks have been unable to receive assistance with those tasks in the community outside of CDPAS due to a lack of nursing services.

In addition to these issues, the State has failed to ensure that CDPAS reimbursement is sufficient to address costs imposed last year under new FLSA Overtime and Travel rules. The State added $0.34 per hour as an intended “pass-through” for personal care services. This approach has not worked. Without set guidelines from DOH on how the funds were to be allocated by the plans, reimbursements were wildly inconsistent and did not bear any resemblance to actual need. In addition, even were every MCO to pass the funding on to providers, the uniform addition creates an incentive for MCOs and providers to cap overtime, restricting the rights of people with disabilities to direct their own services, as well as reducing the take-home pay of CDPAS attendants. The State should revisit its approach and fully fund FLSA travel and overtime requirements and minimum wage increases in a manner that protects the rights of consumers and the wages of attendants.

By allowing these reimbursement cuts and inadequate funding to the program that enables people with significant disabilities to live in the community, the State may well be violating the civil, human, and Olmstead rights of its citizens with disabilities. In order to address this issue, the State should:

- Establish wage protections in a manner consistent with recommendations of the Consumer Directed Personally Assistance Association of New York State;
- Ensure continuity of consumer directed services and the body-integrity of people with disabilities by fully funding the actual costs associated with the FLSA travel and overtime requirements, and increases to the state minimum wage. (estimated $30 M).
- Create a High Needs Community Rate Cell and, through changes in the capitation model, require MCOs to promote the community integration of people with disabilities – including those with significant disabilities.

**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. 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 ease our concerns about the potential to lose our Medicaid funded community based services and supports. CDR urges the Legislature 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 receive the community based supports and services that allow us to live in freedom.

**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. Eliminating the 120 day use of home care services eligibility condition for MLTC is dangerous. People who have few physical home care needs, but may 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 the regular Medicaid Managed Care system. Without adequate supports, people will decompensate and be institutionalized, 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. Again this year, the Governor wishes to use 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, 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 in statute the right to services on the basis of presumptive eligibility. We oppose any attempt to eliminate this right.

Utilize Managed Care to Promote Community Integration
The State’s use of Managed Care should incentivize community based services for all people with disabilities. To date, this has not been the case. Instead the capitation model has created an incentive for MCOs to reduce community based services to dangerous levels, to effectively refuse to enroll high needs individuals, and in some cases to institutionalize people whose service requirements cost more than the capitation pays the MCO.

A recent report shows that some MCOs have engaged in a pattern of unwarranted reductions of people with high service hours. As that report was driven by fair hearing reports, the problem is likely to be much bigger than the report indicates. Many consumers do not make it to fair hearing. Even when consumers win at fair hearing, capricious reductions that are not supported by a change in status but motivated by an MCO’s desire to control costs visit stress and disruption upon people with disabilities. Even more concerning, there is no data on new enrollees being offered services which are inadequate for their needs.

The State must ensure that MCOs provide community based services to all people with disabilities who choose that option. If the State is to continue drawing down the funding it receives through CFC, it must ensure that people with disabilities are able, in practical terms, to receive all of the services they need to live in the community, without fear of the spontaneous reductions and inadequate service authorizations that have characterized community based services in Managed Care for the past few years.

The State has received significant Federal funding through CFC, but has not made available all of the services which CFC requires. The CFC funding is therefore at risk should the Federal Government determine that New York is failing to meet the legal requirements of CFC, such as conflict free person-centered planning, the provision of social transportation, and other services specified in the State Plan Amendment.

Accordingly, the State should:
Ensure that independent person centered planning, required by Federal rules, is provided by organizations independent of the MCOs which are incentivized to restrict access to necessary services. The lack of independent person-centered planning is a significant obstacle to ensuring that people with disabilities can live and receive services in the community. MCOs should be required to contract for this service with independent service coordinators, ILCs, CDPAS FIs, and other qualified organizations;

- Modify the Managed Care model contract to require that MCOs pay for home and vehicle modifications, assistive technology, and other non-medical services identified in the individual’s person centered plan to support them living independently and fully participating in community life, as is required by the approved CFC State Plan Amendment;

- Preserve access to quality complex rehabilitation equipment in order to ensure that people with complex medical needs are able to live in the community, by establishing specific reimbursement and billing procedures for such equipment within the state Medicaid program, such as those seen in S. 3651/A. 5074-C (2015).

- Issue specific guidance to Managed Care plans about their obligations to comply with the Olmstead decision in their policies, procedures and practices, including specific case examples and model policies. This proposal, which is cost-neutral to the State, addresses problems of institutional bias that persist in Managed Care, and without guidance to address this bias, the State is undercutting the integration opportunities of people with disabilities, in violation of its obligations under the ADA, Olmsted, and CFC. The State should articulate, in such guidance, a “Community First” policy by which all individuals with disabilities are first offered services in a community setting, rather than an institution;

- Require MCOs to implement an expedited community-based enrollment process so individuals with disabilities in hospitals and nursing facilities can quickly be approved for community-based services;

- Require MCOs to contract with ILCs and other disability-led organizations, whenever possible, to provide culturally-competent services relevant to the Disability Community;

- Create a certification to operate as a FI in CDPAS, previously passed unanimously by both houses of the Legislature, and should work with the Consumer Directed Personal Assistance Association of NYS to identify a systematic solution to address the danger presented by scofflaw home care provided by organizations under the auspices of consumer directed personal assistance services;

- Address known issues with the New York Uniform Assessment System, including issues establishing the level of care for people with traumatic brain injuries and other cognitive disabilities. The State should address these issues before any individuals currently receiving services through a waiver are required to transition into managed care, and should establish a simple process by which individuals who have a history of receiving waiver services or services in an institution should be determined to be institutionally eligible on the basis of that history.

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

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. 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 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, hospitalization, or even death. This proposal must not force disabled people into institutions or risk disabled lives.

Drug Utilization Review Board
The Prescription Drug 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. 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 condition for which it is prescribed. 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 significantly improve the life of 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 State to consult with the disabled people who rely on rare medications in crafting any replacement proposal.

The “High-Cost” Surcharge
The Prescription Drug 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. 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 Prescription Drug proposal eliminates the “prescriber prevails” provision currently in New York law. 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 individual requires. CDR does not support the elimination of prescriber prevails.
In place of the existing “prescriber prevails” language, the Governor’s proposal includes significantly narrowed language which applies prescriber prevails only to antipsychotic and antidepressant medication, and which requires the prescriber to consult with the preferred drug program in order to justify the use of the particular antipsychotic or antidepressant medication. In fact, even minor differences between different versions of the same medication can have significant impact on their effectiveness and side effects. While CDR does not support this change overall, the restriction to only antipsychotic and antidepressant medication is particularly egregious. Allowing a prescriber prevails process solely for a small category of medication for people with psychiatric disabilities plays on the stigma against these individuals and ultimately is a form of discrimination based on disability.

**Prescription Opioid Control**
The Prescription Drug 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, and by requiring prior authorization for refills of opioid prescriptions while more than seven days of the prescription remain. 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.

**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. 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.

**Stop Paying to Torture Disabled New Yorkers in Out of State Facilities**
New York Currently exiles at least 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.

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. 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.

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. 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 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.

Improve Olmstead Reporting
The Medicaid redesign has removed transparency from certain aspects of health and long term services and supports which are paid for by the State. Reforms are necessary to ensure that the State is receiving value for its Medicaid expenditures, and that the rights of people with disabilities are not being violated by MCOs. The State should:

- Establish and implement a “dashboard” for public reporting on the progress made on the long-range and annual targets for reducing the institutional population, while increasing the number of
individuals receiving community-based services and the associated funding, as described in the Governor's Olmstead Plan;

- Make public the MMCOR data reported by plans on amount and type of services provided. For personal care or CDPAP, public data should include the percentage of members authorized to receive different amounts of services, e.g. percentage receiving 24-hour live-in care, 24-hour continuous "split shift" care, under 20 hours/week, etc., along with the percentage of members in nursing homes. This data is critical for consumers to make informed decisions when selecting a plan.

- Identify and track individuals who are institutionalized they cannot obtain adequate services in the community, and identify the reasons, such as being unable to recruit and hire attendants, or being denied enrollment or adequate services by a managed care plan. The State has, at present, no way to identify that these Olmstead violations are occurring and therefore is unlikely to be able to address the violations. DOH should close this loophole by requiring MCOs to report such institutionalizations, as well as the reason for the institutionalization, in order to enable the State to address the integration obstacles created by a lack of adequate workers;

- Require MCOs to track and report measures that assess the level of community integration and consumer control in their service authorizations;

- Incorporate into Managed Care abuse and neglect protections equivalent to those currently available to 1915(c) waiver participants. There are at present no equivalent protections for enrollees in Managed Care: for instance, when an individual receiving services goes into the hospital, is abused, or is neglected, that event is not reported or tracked. The State should create such protections before the waiver participants are transitioned into Managed Care, in order to ensure that the thousands of New Yorkers currently enrolled in Managed Care are not put at risk of abuse and neglect;

- Publish data showing the number of New Yorkers in institutional settings and on waiting lists for services who would prefer community living;

- Publish repatriation data showing the number of New Yorkers on Medicaid who have been forced into institutions out of state and away from their families and communities, and create a plan for bringing those New Yorkers back home and providing them services in the community.

CDR thanks the Chairs, the Joint Budget Committee, and the Legislature for your attention to these matters. We look forward to working with you this year to secure the rights of all people with disabilities.

Thank you for your time,

[Signature]

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