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Center for Disability Rights, Inc.

January 25, 2016

Re: Written Testimony to the Joint Budget Committee on the 2016-2017 Executive Budget

Thank you, Chairwoman Young, Chairman Farrell, Senator Hannon, Assembly Member Gottfried, and the Joint Committee for this opportunity to comment on the 2015-2016 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.

From a Disability Rights perspective, the most notable thing about Governor Cuomo's 2016 Built to Lead agenda is that issues important to the Disability Community are virtually nonexistent. The Governor has chosen to emphasize transportation infrastructure, environmental protection, homelessness, and raising the minimum wage, but all of these priorities, as presented, fail to include people with disabilities, even though housing and transportation are vital supports for the Disability Community, and New Yorkers with disabilities are among the lowest-paid workers in the state.

It is disappointing that Governor Cuomo has failed to advance any of last year's agenda in this year's budget, but is it insulting to the Disability Community that he has also excluded us from this year's agenda altogether. Although he has called for increasing the minimum wage, he did not include funding to increase the wages for our Medicaid-funded personal assistants and has not addressed the problem that New Yorkers with disabilities can be excluded from even receiving minimum wage in New York.

Accordingly, I wish to bring to your attention the following issues:

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OLMSTEAD & LONG TERM SERVICES AND SUPPORTS

The Governor's plan to shift people with disabilities who are not eligible for institutional services out of Managed Long Term Care must be handled with great care, and must not lead to the loss of services.

The Governor's Budget proposes to limit Medicaid Managed Long Term Care (MLTC), going forward, only to individuals with disabilities who are at the institutional level of need.[1] CDR has learned that this change will require people who are eligible for both Medicare and Medicaid (dual-eligible), but not at the institutional level of need, to receive long-term services through the fee-for-service system which the MRT has been disbanding across the last four years. People who are not dual-eligible and are not at the institutional level of need must receive services through Medicaid Managed Care.

CDR understands that this change was precipitated by the State's concerns that it was over-paying for individuals with less significant assistance needs, which confirms problems in MLTC which CDR, the Disability Community, and other consumer advocates have been pointing out for years, including the fact that MCOs are not prevented from gaming the system by selecting only those enrollees at the low end of the cost curve. MCOs have done this by driving enrollees out of their plans through the use of poor and unresponsive customer service, repeated assessments, and repeated and ongoing campaigns to reduce service hours or other benefits.

By placing long term services and supports in managed care, the State has turned control of the Governor's Olmstead Plan over to insurance companies, but has not implemented any controls which can require those insurance companies to effect the goals of his plan. In addition, by restricting MLTC to only people at the institutional level of need, the State is limiting the size of the pool of service recipients whose costs must balance each other, making it even more difficult to meet the needs of people with the most significant disabilities.

In light of these problems, CDR calls for sensible reforms to the delivery of long term services and supports in Medicaid through managed care.

- Create a High Needs Community Rate Cell (HNRCR) sufficient to reverse the existing incentives within the capitation for MCOs to push enrollees with significant disabilities into institutions or out of their plans;

- Include all providers of Medicaid home and community based services and supports in the prompt payer law on an equal basis to the provisions proposed in the Governor's Budget for Early Intervention providers;

- Implement Person-centered Planning as a billable service in managed care, independent of assessment and of service authorization, which ensures that the social, environmental, and physical needs of people with disabilities are met;

- Increase funding to the Independent Consumer Advocacy Network (ICAN) (also known as the "Ombuds" program) in order to ensure that all Medicaid recipients are aware that ICAN exists and how it can help them, and to ensure that ICAN is sufficiently resourced

[1] 2016 Built to Lead Health and Mental Health (HMH) Budget, pp 13-14.

to respond to all demand and to take strategic action to improve service delivery to Medicaid recipients;

- Require detailed reporting data from MCOs to the Department of Health (DOH), ICAN and the public, through Open Health or another public data source, to assure that Managed Care does not undercut the community integration of people with disabilities. MCOs must be required to report all reductions in home care hours and new permanent placement in nursing facilities including data on the number of hours of homecare previously received by the new nursing home resident, if any, the reason for permanent placement, and an explanation of why services are not being provided to the individual in a community setting;

- Create and make available to ICAN, and the public, through Open Health or another public data source, the "dashboard" which the Governor committed to creating in his 2013 Olmstead Plan, including detailed reporting on the number of individuals currently in long-stay nursing facility population, as well as the efforts of the State and of MCOs to transition to community settings individuals in that population who wish to live in the community. The Disability Community has been waiting for this data for many years.

- Implement a consumer protection process comparable to the investigative process in the 1915(c) waivers, in order to address exploitation, abuse, and neglect of all persons with disabilities; and

- Amend the flawed UAS-NY assessment tool to include a cognitive component that has been peer-reviewed and is based on scientific evidence.

In addition, the State must clarify how people at the hospital level of need are able to receive services in the community, as required under the New York Medicaid State Plan Amendment that implements Community First Choice. These changes are necessary to ensure that New York's Managed Care system ensures the civil right of people with disabilities to live in the community and lead an independent life.

CDR calls for the creation of a new State Office on Community Living in order to give people with disabilities a place within State Government.

Last year's budget called for a stakeholder process, under the leadership of the Commissioner of the Office for the Aging, to discuss the creation of a new Office on Community Living (OCL), with a focus on furthering the Governor's Olmstead Plan and strengthening the No Wrong Door approach to service delivery.[2] That stakeholder process resulted in a report which identified a number of gaps in existing services and areas for improvement in coordination of service delivery.

During the stakeholder process, the State did not present any model of what the OCL could look like or how it could operate. Consequently, the lack of specifics – combined with misinformation on the proposal – caused some stakeholders to fear that the OCL was merely an attempt to eliminate NYSOFA. Stakeholders from the Disability Community presented models to both the aging community and the State in which NYSOFA would be preserved. Ultimately the Disability Community – which has no state agency dedicated to its unique needs – urged that the

[2] 2015 Opportunity Agenda, Health and Mental Health Budget, p. 70.

Administration create OCL as an independent office dedicated to the needs of the Disability Community, leaving NYSOFA as a freestanding State Office.

The Governor has not pursued the creation of OCL – even independent of NYSOFA. The decision not to create OCL validates the perception and confirms the fears of the aging community that the OCL process was indeed an attempt to eliminate NYSOFA. The creation of the OCL can be a powerful force to ensure that people with disabilities receive needed supports and services without being forced into institutions, and CDR calls for Governor Cuomo to propose the creation of OCL in the Budget Amendments.

CDR calls for the Governor to support amending the Nurse Practice Act in order to realize the promise of community integration for all New Yorkers with disabilities.

On October 23, 2015, the Center for Medicare and Medicaid Services (CMS) approved New York's State Plan Amendment implementing Community First Choice (CFC). CDR has estimated that implementation of CFC can generate $299 million in net revenue when existing services are implemented through CFC. As the State proceeds to implement the Governor's Olmstead plan and transitions people from nursing facilities and other institutions into the community, that amount increases to $439 million annually.

To realize the promise of community integration for people with disabilities in New York, home health aides in the community must be able to perform health related tasks like administration of medication and assistance with feeding tubes or ventilators. These tasks can currently only be performed by nurses which has limited the community integration of people with disabilities. Last year, a workgroup of stakeholders, including CDR, produced a thoughtful proposal for the creation of Advanced Home Health Aides, trained, certified workers who could perform these tasks under the supervision of a nurse. That proposal is being examined by the New York State Senate. The Governor should support legislation amending the Nurse Practice Act to allow nurses to assign those tasks to AHHAs. This is a vital and important step to secure the right of individuals with disabilities to receive services and supports in the community.

FUNDING COMMUNITY BASED SERVICES

The budget process must create a rate and mechanism sufficient to pay CDPAS personal assistants for overtime as required by new federal regulations.

Federal Labor Regulations took effect in 2015 which require the payment of time-and-a-half of base wage to personal assistants for hours worked over 40 in a given work week, and payment for time that personal assistants spend traveling between consumers.[3] This regulation was not accompanied by federal funding to ensure that attendants would actually be paid more for their work. Without funding, fiscal intermediaries would be required to cap attendant hours at 40. Such a cap puts consumers at risk of institutionalization. During last year's budget, Governor Cuomo promised to provide at least $20 million in funding in the Medicaid Base to pay for overtime and travel for Consumer Directed Personal Assistant Services (CDPAS) attendants in New York.

Despite the Governor's support, DOH has not implemented a rate or payment mechanism to ensure this funding is paid to CDPAS attendants. Instead, DOH implemented an across-the-board increase of $0.34 per hour to both the CDPAS and home care rates, along with a statement that

[3] 29 C.F.R § 213.

this increase was sufficient to pay for overtime not exceeding 10%. This amounted to approximately a 50% cut in the funding that was promised to CDPAS attendants. The administration has acknowledged that this approach is insufficient for CDPAS as an across-the-board rate increase does not address the degree of overtime variance that FIs experience. Nor does this policy ensure that FIs will receive any additional funding from MCOs. The current approach punishes those FIs which offer disabled people the highest degree of control over their lives.

Despite the Governor's commitment to fully fund overtime for CDPAS attendants, the 2016 Budget simply maintains the current mechanism which is insufficient to pay for overtime and travel time for CDPAS attendants. CDR calls on the administration to move forward with the creation of overtime and travel billing codes or code modifiers in order to ensure that people with disabilities who rely on CDPAS attendants are not forced into institutions.

The State must fund the minimum wage increases for CDPAS attendants.

A showpiece in Governor Cuomo's 2016 agenda has been the proposal to increase minimum wage to $15 per hour.[4] The Governor has not, however, put his funding where his rhetoric is with respect to workers who provide State-funded Medicaid services for people with disabilities. To the contrary, the Governor's position on Medicaid-funded services is that the two minimum wage increases this year are "nominal" and that Medicaid providers can absorb these wage costs. The Governor has no problem calling out fast food companies for failing to pay workers, but when it comes to paying for workers that provide life-sustaining services, he seems unwilling to follow his own rhetoric.

On their own, these costs may have been nominal, but they come after years repeated cuts and cost increases which have driven down reimbursement. In this context, these cost increases are not nominal. In fact, reimbursement rates for CDPAS FIs in 2015 were lower than they were in 2006. The CDPAS program is stretched too thin to accept this latest cost increase without allocated funding. The State must fund its minimum wage increase.

The State must propose and fund a wage premium for CDPAS attendants.

The work of personal attendants ensures that people with disabilities are able to live in the community and lead lives of our own choosing. This work is vital, not only to the lives of disabled people, but also the State of New York, which has a legal and moral obligation to secure the fundamental civil rights of its citizens and residents. CDR does not accept the Governor's position that he should raise the wages of people who flip burgers, while failing to support the people whom provide vital supports to seniors and people with disabilities, including assistance with medications, ventilators and other skilled tasks.

The Governor must propose and fund a state-wide wage premium for CDPAS attendants, over and above the minimum wage. Prior to repeated cuts and cost increases unaccompanied by funding, CDPAS attendants were paid well-above minimum wage. State policy has eroded their pay to the point that without a wage premium, attendants will leave the industry in favor of easier jobs which pay the same wage. Consequently, the Governor's minimum wage proposal will exacerbate the widespread attendant shortage which already keeps people with disabilities trapped in institutions.

[4] 2016 Built to Lead Education, Labor, and Family Assistance (ELFA) Budget, pp. 163-164.

Additional funding is also necessary to comply with the CMS conditions associated with Community First Choice (CFC). When the CMS approved CFC, it directed the State to equalize the payments of developmental disability (DD) providers and other home and community based services providers. DD providers receive reimbursement rates over $40 per hour, while CDPAS providers receive less than $20. Failure to address this is discriminatory and could put CFC funding at risk.

Accordingly, we call on DOH and the State Department of Labor to conduct a study of wages and workers in CDPAS in order to determine the cause of the shortage of personal attendants and to recommend necessary changes, including the creation of a wage premium, in order to ensure the sufficiency of this workforce.

Include CDPAS and other vital services and supports in amendments to the prompt payment law.

The Budget includes a provision which would amend the prompt payment law for Early Intervention (EI) providers.[5] Under the proposed law, MCOs must identify defective claims within 15 days of receipt; unless a defect is identified in that time, the claim is deemed approved.

Late payments and rejected claims threaten not only EI providers but many providers whose services and supports are vital to the community integration of people with disabilities. Of particular note are CDPAS FIs which have struggled under reduced rates, loss of trend factors, and increased overtime costs for years. FIs are obligated to pay attendants for hours worked and should be assured of prompt payment for all qualified claims. Accordingly, CDR proposes that all community-based service providers be included in the prompt payment law amendment the Governor proposes.

CDR urges the Cuomo administration to increase funding for Independent Living Centers.

In order to realize the goals of the Olmstead Plan and the promise of independent living, the State must invest in the State's network of Independent Living Centers (ILCs). ILCs are at the forefront of ensuring that people with disabilities have the assistance we need to live integrated, independent lives in our communities. ILCs are absolutely necessary to ensuring that people with disabilities live independently and in our own homes and communities rather than institutions. In addition, each ILC provides additional services that address the particular challenges and needs of the community or region where it is located.

Last year, the State provided a long-overdue funding increase of $1 million dollars. This year, the budget proposes level funding. ILC services should be funded at a level that ensures centers are able to effectively serve the anticipated increase in people with disabilities living in the community thanks to CFC. The state is drawing down significant funds under CFC that should be dedicated to implementing the Olmstead Plan. A portion of this funding should be used to increase ILC funding.

Data from ACCES-VR indicates that the work of ILCs has saved the State more than $1.4 billion since 2001, as ILCs have helped people who would otherwise be forced into institutions to remain in their homes and their communities. In light of the value that ILCs deliver, and the

[5] HMH Budget, pp. 59-71.

funding available through CFC, the State should invest in the health of all ILCs by raising the base funding level to at least $545,000 for each center.

ACCESS TO HEALTHCARE

The State must require CDPAS Fiscal intermediaries to be certified

The CDPAS program is critical to thousands of New Yorkers with disabilities who rely on CDPAS to remain independent in their communities with the support of personal assistants that the disabled individual trains, supervises and terminates. CDPAS is also the only completely unregulated industry in healthcare. In the past two years, CDPAS has experienced a 50% growth rate with a variety agencies seeking to provide fiscal intermediary services, despite their lack of knowledge of CDPAS regulations and history. Many of these new agencies are not operating as an FI; but as a scofflaw home care agency by sending in their own workers, on their schedule, eliminating the consumers' control over hiring and scheduling. Still worse, many agencies enroll people who are not good candidates for CDPAS, endangering their lives.

The State must implement a certification process for all CDPAS fiscal intermediaries to ensure and set standards of quality for the fiscal intermediaries providing critical services to seniors and people with disabilities in the CDPAS, while still safeguarding the integrity of consumer control and independence. The Legislature unanimously passed legislation to create such a process last year, which the Governor vetoed. In his veto statement, the Governor said that this process should be created in the budget, and we call on him to introduce the process in the budget if that is where he believes it should be.

The State must not eliminate the Prescriber Prevails provisions in Medicaid.

CDR opposes the Governor's proposal to eliminate the "prescriber prevails" provisions in the fee-for-service and managed care programs.[6] Although A-rated generic equivalents are considered to be therapeutically equivalent by the FDA, using generic instead of brand-name medication can have negative consequences for some disabled individuals. Evidence suggests that variations in bioavailability and clinical effectiveness between different drug formulations may in fact be significant. Cases have been documented where switching a disabled individual from a brand name medication to its generic equivalent resulted in negative outcomes. One report has documented the case of a 14-year-old boy with bipolar affective disorder, autism and an intellectual disability who had been switched from a brand-name to generic medication. The change resulted in a rapid deterioration of his mental state which was not related to any physical illness or other medication adjustment. It resolved as rapidly when the generic medication was switched back to the brand-name. Such complications may happen with a variety of patients but are far more likely for individuals with disabilities.

In addition, some individuals with sensory, intellectual, and cognitive disabilities rely on the unique size, shape, and color of a pill to distinguish it from others they take. It is imperative that individuals with disabilities continue to have access to the brand name medication.

Don't undercut marriage by narrowing the spousal refusal provisions in Medicaid.

The 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

[6] HMH Budget, pp. 18-19.

disabled spouse's household.[7] 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.

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 of them 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. Disabled people should not be forced to decide between their families and the services they need to live.

The Community Spouse Resource Allowance must be maintained at the current amount.

The Governor's budget proposes to reduce the resource allowance for community spouses to the minimum allowed by Federal law, $23,844.00.[8] This proposal will prevent many people from living in the community with their spouses. In other cases, spouses will impoverish themselves in order to meet the reduced allowance, and in so doing will put themselves at risk of having to go on public assistance themselves.

As with the proposed change to spousal refusal, CDR opposes this policy, and any policy, which will have the effect of forcing a person with a disability to choose between their fundamental human right to marry and the equally fundamental human right to live in the community. It is especially disturbing that New York has proposed to reduce this resource limit after it was extended to apply to the spouses of disabled individuals living in the community. The current Community Spouse Resource Allowance must be kept at the current amount.

Thank you for your time,

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[7] HMH Budget, pp. 14-15.
[8] HMH Budget, p. 15.