Center for Disability Rights, Inc.

Testimony of Center for Disability Rights before the Joint Budget Hearing Health/Medicaid

My name is Gregg Beratan and I am Manager for Government Affairs at the Center for Disability Rights. I would like to thank you for the opportunity to testify today concerning the 2018-2019 Health and Medicaid Budget. 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.

My Testimony today will center primarily on areas that will affect the Community Integration of disabled people. The Center for Disability Rights urges this committee and both of the houses that it draws from to give more consideration to disabled people's right to live in the community, than the Governor's Budget has. The Proposed budget fails to create a High Needs Community Rate Cell, a solution that has been advanced by both advocates and the plans as a way to keep High needs individuals in the community. Instead the Budget proposes to limit eligibility for Managed Long Term Care (MLTC) and to carve our nursing facilities from MLTC, both of which would incentivize institutionalization. Locking people into plans will put people's lives and freedom at risk. The budget does little to address the workforce shortage and treats federal monies received under the Community First Choice Option (CFCO) as a replacement for state funding rather than the supplement it was intended as. Proposals to change spousal refusal amount to denying disabled people the marriage equality the state has proudly fought for, for others. Finally I will touch upon the need for solutions to both the Opioid and pain crises that are not so overly broad and bureaucratic that disabled people are trampled by them rather that aided by them.

Create a High Needs Community Rate Cell

In our 2018-19 Olmstead Budget priorities[1], CDR highlighted the need for a High Needs Community Rate Cell to promote the community integration of people with significant service

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

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

Changing the Eligibility for MLTC Gambles with Disabled Lives

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

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

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

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

The Nursing Facility Carve Out Incentivizes Institutionalization

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

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

Locking People into Plans Puts Lives and Freedom at Risk

Governor Cuomo's plan to require continuous enrollment in MLTC plans for 12 months[2] demonstrates that the Governor is willing to put the health of the plans ahead of the health and freedom of Disabled New Yorkers. Locking people into plans exposes them to numerous risks. Once people are trapped in their plans with nowhere to go, there is nothing to prevent plans from cutting hours or services. An individual's ability to go to another plan is one of the few protections they have. Additionally, if a person's provider leaves the plan, the person then loses their ability to receive services from the provider that they know and trust.

The State would not expect a person to stay in a problematic marriage for a year, but the State will require a disabled person to be trapped in a problematic relationship with an MLTC plan for a year. Providing inadequate services and supports is abusive to a disabled person with real world consequences to the disabled individual. This could lead to decompensation, withdrawal

[2] HMH Article VII part B Sec 4

from the community, and institutionalization. An action as simple as a plan lowering a person's attendant services by a few hours can have a major impact on their ability to function in their environment. The State must allow freedom of movement between plans for the health and wellbeing of Disabled New Yorkers.

Inaction on Attendant Wages Puts Disabled Lives at Risk

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

It is worth noting that our attendants are paid far less than their counterparts in direct care serving people with developmental disabilities. This inequality and injustice must be remedied. Our attendants deserve raises. The State may also be in violation of federal law because when New York accepted money under the Community First Choice option, the State agreed not to discriminate in the provision of services on the basis of disability. Paying significantly different rates based on disability violates that rule and is putting the State at risk. We call on the State to ensure that consumer directed attendants receive commensurate wages to their direct-care counterparts.

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

Ensure that Community First Choice Option Funding is Not Subject to the Global Cap!

When the State signed on to CFCO the enhanced Federal Medical Assistance Percentage (FMAP) that comes with the program was intended to supplement the New York's provision of Home and Community Based Services. The State has tried to place this funding inside the global cap which means that the State is using these funds in place of the State's funding and not as the addition to State funding it was intended to be. The State must ensure that these federal monies are outside of the global cap and are available to do the work promoting Community Integration that they were meant for, in order to comply with CFCO. The funds this would free up could be used to equalize wages across the attendant workforce.

Criminal History Checks Will Exacerbate the Workforce Shortage

The Governor proposes requiring background checks for all employees of organizations providing home and community based services.[3] Although we understand the Governor to keep Disabled New Yorkers safe, this ignores both the reality of the current workforce shortage and the need disabled people have for control over who touches our bodies. At a time when we are already struggling to compete with the retail and fast food sectors for our attendants, a policy that will further restrict the pool we can draw from is ill-advised and harmful. Our attendants are people we have to trust with the most intimate tasks. Often, we prefer to hire friends and family – people we know. For people who use Long Term Services and Supports, a conviction history may be insignificant when compared to the established trust and confidence we have in our relationships. Given the choice, many of us prefer to hire a trusted relative with a criminal record over having a complete stranger putting their hands on our bodies. We call on the legislature to oppose this proposal and ensure the body integrity of disabled New Yorkers.

Marriage Equality Should Not Be Threatened by Extortion from the State

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

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

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[3] HMH Article VII Part C Sec. 3

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

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

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

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

The Governor's proposal does acknowledge that careful treatment planning for those in pain is required but it cannot be DoH and medical professionals alone shaping how treatment planning will work. While we are in the midst of an opioid crisis we are also in the midst of a pain crisis and the people at its center, the people experiencing real pain, need to be consulted as the State develops its approach. Not doing so will lead to solutions that may work for the State, and may work for doctors, but will not work for the people who need it most. An example of this can be found in the state capping physical therapy. The proposed budget doubles the cap, but it is a cap nonetheless. Physical therapy is a non-narcotic option that can provide pain relief. By continuing to limit access to pain relief options, the Governor is only exacerbating the problem. We call on the State to work collaboratively with pain advocates and other disabled people caught in this crisis to help develop a plan that will work. We need innovative solutions shaped by the people experiencing pain, not more bureaucracy.

Make Community Integration and disabled people's lives a priority

As it does every year the budget process has the potential to do immense good or great harm to disabled New Yorkers ability to live our lives in the community. I urge you to make community integration a priority as you consider, fight for and oppose sections of this budget. Thank you for the opportunity to offer this testimony. Please feel free to reach out with any questions you might have at any time during the budget process.

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