

Submitted Testimony

Center for Disability Rights, Inc.

February 2, 2015

Re: Written Testimony to the Joint Budget Committee on the 2015-2016 Executive Budget

Thank you to 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.

This year, the State has the opportunity to make real and meaningful progress improving integration and community living for people with disabilities in New York. The 2015-2016 Budget contains a number of initiatives which will make this opportunity a reality, including the commitment to Community First Choice (CFC) and the allocation of CFC funding to further the goals of the Governor's Olmstead Plan, the proposed amendments to the Nurse Practice Act, and the process of consulting with stakeholders around the creation of an Office on Community Living. We are very excited about and strongly supportive of the ambitious direction that is laid out in the Budget for future years.

At the same time, these initiatives are an ambitious plan for the future of New York, and the Budget has offered little support for the existing programs and services which are helping our community to live in integrated home and community settings today, including the Independent Living Centers and wages for workers in Consumer Directed Personal Attendant Services. Many of these programs have been in a state of ongoing funding crisis, and we urge the Committee to address these gaps in the budget that will ensure that our community survives to see this ambitious agenda become a reality in future years.

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Accordingly, CDR is advocating on two broad areas of policy that are relevant to the Joint Budget Committee on Health: first, ensuring implementation of CFC and the full integration of people with disabilities into the life of New York, upstate and downstate; second, securing access to health care for all New Yorkers.

I. IMPLEMENTATION OF COMMUNITY FIRST CHOICE & INTEGRATION OF PEOPLE WITH DISABILITIES

CDR applauds commitment to Community First Choice in this Budget, and the designation of CFC funding for implementation of the Governor's Olmstead Plan, but urges the Administration to speed implementation of CFC and to involve the Disability Community in the allocation of CFC funding.

The Community First Choice (CFC) Option is an optional Medicaid funding mechanism that assures individuals who are eligible for institutional placement can receive services and supports in home and community based settings. States that select CFC are eligible to receive an increased federal match of six percent. This additional funding is compounded by the fact that it is cheaper, on average, for the State to provide services and supports in home and community settings than in institutional settings.

In 2011, Governor Cuomo announced that New York would be selecting CFC although implementation was delayed because the State would have been unable to meet the maintenance of effort requirement. In 2013, Governor Cuomo reaffirmed his commitment to CFC, and in December of that year, the Administration submitted the proposed State Plan Amendment to the Centers for Medicare and Medicaid Services.

CDR estimates that implementation of CFC will initially generate \$299 million in net revenue. As the State implements the Governor's Olmstead plan and transitions people from nursing facilities and other institutions into the community, that amount increases to \$439 million annually.¹ It has been more than a year since New York submitted its proposed State Plan Amendment to CMS. Further delay – which prevents the State from leveraging these additional funds – is unacceptable.

This year's Budget designates the additional CFC funding for investment in initiatives that operationalize his Olmstead Plan. CDR applauds this proposal, however, we recognize that the funds – even with this restriction – could be used in a variety of ways. To ensure that people with disabilities and Olmstead advocates are able to play a role in this decision-making process, CDR urges that the allocation plan for utilizing the CFC funding be approved by the Disability Community. CDR also believes that there are specific initiatives and programs which must have their funding increased, and CFC is a natural source of funding. In particular, CFC funding should be used to ensure that attendants providing Consumer Directed Personal Attendant Services (CDPAS) receive a living wage and that funding is available to cover the cost of overtime and travel time under the Fair Labor Standards Act (FLSA). Additionally, CFC funding

¹ Fiscal Analysis of CFC and the New York State Medicaid Budget. (2014, November 18). Retrieved January 27, 2015, from <http://ilny.org/programs/cfc-tap/fiscal-analysis>.

should be used to increase the State base funding level to \$545,000 for each of the 41 Independent Living Centers in New York State.²

CDR supports amending the Nurse Practice Act to support broad implementation of CFC.

In order to secure the federal funds available to New York through CFC, attendants in the community must be able to perform health related tasks like administration of medication and assistance with feeding tubes or ventilators. The Budget includes legislation amending the Nurse Practice Act to allow nurses to assign certain health related tasks to “Advanced Home Health Aides (AHHAs).”³ These are tasks that, until now, only a nurse could perform. When legislation accomplishing this failed to pass last year, the Department of Health convened a workgroup of stakeholders to identify the tasks that could be assigned to attendants as well as make recommendations for training and supervision requirements. CDR participated in this process.

As it is presently written, the amendment to the Nurse Practice Act will require people to work as Certified Home Health Aides for at least a year prior to becoming AHHAs. The stakeholder group felt this requirement would unnecessarily prevent attendants who are certified as Home Health Aides but working as Personal Care Attendants, from becoming AHHAs. This requirement was rejected by the AHHA Stakeholder Committee, and should be removed from the final legislation. With this minor change, CDR calls for the passage of this important legislation.

We urge the State Education Department and the Department of Health to work together to create the training program contemplated in the amendments and develop the necessary regulations in a timely manner. This is a vital and important step to secure the right of individuals with disabilities to receive services and supports in the community.

CDR applauds the creation of a new Office on Community Living, and the commitment of the State to consult with stakeholders in the creation of that office.

The Budget calls for the Director of the State Office For Aging to gather information from stakeholders for the creation of a new Office on Community Living “with the goal of providing improvements in service delivery and improved program outcomes that would result from the expansion of community living integration services for older adults and persons of all ages with disabilities.”⁴ This information gathering process is to focus on furthering the goals of the Governor’s Olmstead Plan, strengthening the No Wrong Door approach to delivering information and services, and improving delivery of services, among other areas. The purpose of this information gathering is to create, by December 15, 2015, a report and recommendations for the creation of an Office on Community Living.

CDR strongly endorses this proposal. There is great potential in New York for such an Office to coordinate resources, policies, and initiatives that are currently spread among multiple agencies; to marshal resources in support of independent living; and to maximize the State’s share of CFC funding. CDR believes that the creation of this Office can be a powerful force for the advancement of the shared goals of people with disabilities and seniors to remain in our homes

² Invest in Community Living. (2014, December 5). Retrieved January 27, 2015, from <http://ilny.org/downloads/category/31-cfc?download=331:investing-in-community-living>.

³ Health and Mental Hygiene (HMH) Budget, p. 117.

⁴ HMH Budget, p. 140.

and our communities, and to receive needed supports and services without being forced into institutions.

Consumer Directed Personal Assistance Services must not be interrupted because of changes in federal labor law.

Despite the efforts of disability rights advocates to delay changes to the Fair Labor Standards Act Companionship Exemption, the US Department of Labor (US DOL) planned to implement a rule on January 1, 2015 that would have required the payment to attendants of travel time and time-and-a-half of base wages for hours worked over 40 per week. This rule did not come with additional federal funding to ensure that attendants would actually be paid more for their overtime hours. Without funding to pay the additional wages and benefits, fiscal intermediaries planned to cap attendant hours at 40. This left consumers at risk of institutionalization unless they could find additional attendants to work the hours above the cap, and disrupted the lives of consumers who were lucky enough to find someone to do that work. Governor Cuomo used Balancing Incentives Payment funds as a temporary fix to pay for some of the new overtime obligation.

The Governor's temporary funding was not needed because at the last minute, two court orders – issued on December 31, 2014 and January 14, 2015 – prevented the rule from coming into effect. Both court orders have been appealed by the US DOL, and it is possible the rule will be put back into effect as soon as six months from now. There is no mechanism, and no ongoing funding, to pay for the additional overtime costs if the appeal is successful. It is estimated that overtime for CDPAS attendants in New York State alone would have cost more than \$20 million in 2013. The State must commit to ensuring that these vital services are not interrupted by changes to the labor law, and that commitment must take the form of an allocation of funding which can be used to pay attendants for overtime if the labor regulation requiring that payment is upheld in the courts.

The State must establish and fund a living wage for consumer directed personal attendants.

The Budget calls for New York to raise the minimum wage to \$10.50 statewide, and \$11.50 in New York City in 2016.⁵ The creation of a living wage is a laudable goal, and raising the minimum wage is a good step in this direction, but – even in this Budget – the State has not provided the funds needed to do this.

The State has established and funded a living wage for some attendants working in traditional home care. Unfortunately, other attendants – including those who work in the consumer directed model – have had their wages held flat for years because of cuts in Medicaid rates and implementation of managed care. Some managed care organizations have pointed to the fact that there are no living wage requirements as a reason that they are free to cut the rates for this program.

The Consumer Directed Personal Assistance Association of New York State has recommended that legislation be passed requiring managed care organizations and Medicaid to reimburse fiscal intermediaries an amount sufficient to pay attendants at a living wage, at 150 percent of the minimum wage, while still meeting all of their other financial obligations. Without adequate wages, individuals with disabilities will be unable to attract and retain workers, and in some cases will be forced into institutions, which are more costly than home and community settings,

⁵ Education, Labor, and Family Assistance (ELFA) Budget, p. 310.

but which are guaranteed to be funded. For the sake of the State's own sound fiscal health, as well as the rights of people to live in home and community settings, the 2016 budget must establish and fund a living wage for CDPAS attendants.

NY Connects must meaningfully engage with the disability community in order to create a true "No Wrong Door" service model.

The Budget includes funding for the State's No Wrong Door service model, NY Connects. CDR has worked on creating this service model for a long time and applauds the Governor's commitment to its ongoing health. NY Connects is a program with a great deal of potential for the goals of the Office on Community Living, and CDR is pleased to see it receive additional funding.

There is room for improvement, however, in terms of NY Connects meaningfully engaging with the disability community in order to ensure that it is a true "no wrong door" service model for people with disabilities as well as the aging community. The Budget briefing book calls for an allocation of \$8.2 million for the 2015-2016 budget year, and an increase to \$18.1 million for the following year. With the allocation of these funds, the State Office for the Aging must mandate that local projects involve the Independent Living Centers. In doing so, NY Connects should be able to take great strides toward including people with disabilities in this important program.

CDR urges the State 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. The core ILC services of skills training; individual advocacy; peer counseling; information and referral; and transition and diversion are absolutely necessary to ensure that we have the right to 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.

The State has left ILC funding at the same level for the past decade, despite the fact that demand for ILC services has increased nearly 28% over that same period. In addition, the costs of operating a center, employing staff, purchasing insurance, and providing services have increased as well. Many ILCs have had to lay off essential staff in order to make ends meet and, without additional funding, will not be able to ensure that people receive the services they need to live in the community.

In addition to the millions of dollars which ILCs can help the State to receive through CFC, ILCs also save the State a great deal of money that would otherwise be spent on costly institutional placements. 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 funding available through CFC, the State should invest in the health of all ILCs by raising the base funding level to \$545,000 for each center.

II. ACCESS TO HEALTH CARE FOR ALL NEW YORKERS

The State must not eliminate the Prescriber Prevails provisions of Medicaid prescription drug coverage.

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 or other cognitive disabilities may rely on the unique size, shape and color of a medication to distinguish it from other medications they take. It is imperative that individuals with disabilities and other chronic healthcare conditions continue to have access to the brand name medication. CDR opposes eliminating the "prescriber prevails" provisions.

The spousal refusal provisions of Medicaid must not be narrowed.

The Budget calls for a change to spousal refusal for receiving supports and services.⁷ CDR opposes this change, because it will narrow the possibility of spousal refusal by requiring a spouse to both 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.

Federal law allows a Medicaid applicant to choose to use spousal refusal budgeting when it is more advantageous to the applicant.⁸ In its current form, the law on spousal refusal has allowed a disabled spouse to receive 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 current 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 separates families or prevents people from getting married. People should not be forced to decide between their families and the services they need to survive.

⁶ HMM Budget, p.13

⁷ HMM Budget, p. 44.

⁸ Spousal Impoverishment Budgeting with Post-Eligibility Rules Under the Affordable Care Act, GIS 14/MA 25, November 3, 2014, retrieved January 28, 2015 from http://www.health.ny.gov/health_care/medicaid/publications/docs/gis/14ma025.pdf

The State must not remove the emergency medical needs funding requirement.

The Budget changes the law to no longer require the local department of social service from funding emergency medical needs for individuals in immediate need of personal care services, including consumer directed attendant services, outside of their period of presumptive eligibility for Medicaid services.⁹ This change in the law is in response to a court decision last year that found that the statute as written did require such funding from the local department of social service.

CDR opposes this change: a person in immediate need of personal care services is, by law, always able to get those services at an institution. It is CDR's position that services should be made available to a person in the most integrated setting by default.

In conclusion, this year's Budget contains an ambitious social agenda that will, if successful, improve the lives of many disabled New Yorkers in the years to come. It is necessary, however, to address as well the gaps in funding which have constrained the growth of community living and integration, and which in some cases have threatened to undo the advances that our community has fought for. I urge the Joint Committee in particular to ensure living wage funding, and overtime funding, for workers in Consumer Directed Personal Attendant Services, and to increase funding for the Independent Living Centers to \$545,000. I thank the Committee for its attention to these important issues.

Thank you for your time,



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⁹ HMM Budget, pp. 45-46.