Submitted Testimony

Center for Disability Rights, Inc.

February 27, 2015

Re: Written Testimony to the Joint Budget Committee on Mental Hygiene

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, but 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. These programs include a living wage for consumer directed personal attendants, and supported employment programs to assist people with disabilities, including people developmental and behavioral disabilities, to work and succeed in competitive, integrated workplaces rather than exploitive subminimum wage workshops. 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.

Accordingly, CDR is advocating on two broad areas of policy that are relevant to the Joint Budget Committee on Mental Hygiene: 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. With respect to the Mental Hygiene budget in particular, we advocate for the following policy objectives.

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. 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.

CDR urges the State to end subminimum wages for workers with disabilities.

Section 14(c) of the Federal Fair Labor Standards Act (FLSA) contains an exemption that allows employers to pay people with disabilities a wage that is less than the Federal minimum wage if the worker is working in a "sheltered workshop." Organizations that employ people with disabilities, including non-profit organizations that claim it is their mission to empower disabled people, take advantage of this exemption; some may pay people with disabilities as little as \$0.22 per hour. Not only do these organizations pay workers less than the minimum wage, they are also subsidized by tax credits. This shameful practice must end. People with disabilities must be paid a competitive wage.

Governor Cuomo's ambitious social agenda has initiatives that promise to make wages fair, create sustainable jobs, and to protect the rights of workers. The budget has called for New York State to raise the minimum wage to \$10.50 per hour, statewide, and \$11.50 per hour in New York City because, as the Governor has said, "a reasonable minimum wage is the only way to improve the standard of living for workers, reduce poverty, encourage fair and more efficient business practices, and ensure that the most vulnerable members of the workforce can contribute to the economy."

¹ HMH Budget, p.13

The Governor has also called for the creation of a reform package to protect New York's most vulnerable workers from abusive tactics by employers. The first item that the Governor brings up, in connection with this reform package, is a study showing that one-third of job seekers at certain agencies were offered jobs at less than the existing minimum wage of \$7.25 per hour. The Governor is correct that payment of less than the minimum wage is an abusive tactic that employers use to enrich themselves at the expense of workers, and he is correct to call for an end to this form of abuse. Notably absent from these initiatives, however, is any discussion of ensuring that people with disabilities also receive the minimum wage.

Although the FLSA is a Federal law, New York has the power to override it: states are free to set a higher minimum wage than the FLSA requires, and to close exceptions such as this. Our neighboring state, Vermont, closed its last sheltered workshops in 2003, and in 2012 its integrated employment rate for people with developmental disabilities was twice the national average.² As New York State raises the minimum wage for all New Yorkers, it must include all New Yorkers with Disabilities. The State must repeal the laws that allow sheltered workshops to operate in New York, and that make them eligible for tax credits for employing people with disabilities.

In selecting a relative guardian, New York must not define incapacity in terms of disability.

The Executive Budget creates a definition for a "Successor Guardian" when a relative guardian can no longer care for a child due to death or incapacity.³ The Executive Budget further defines "incapacity" as "a substantial inability to care for a child as a result of: (a) a physically debilitating illness, disease or injury; or (b) a mental impairment that results in a substantial inability to understand the nature and consequences of decisions concerning the care of a child."⁴

This definition of incapacity is at once over-inclusive because is it focused solely on a person's disability and under-inclusive because it is not focused on a person's behavior. Throughout history in the United States, an individual's disability has been used against them to terminate their rights to care for a child.⁵ This definition of incapacity, with its emphasis on disability rather than behavior, furthers existing stereotypes about the ability of disabled individuals to care for children. Deeming an individual unable to care for a child because of "incapacity" which is based solely on the guardian's disability clearly violates the Americans with Disabilities Act as well as the fundamental human rights of the relative and the child.

This definition must be changed to focus on *behavior* that would make a guardian substantially unable to care for a child, instead of relying on disability as determining inability to care for a child.

² Subminimum Wage and Supported Employment, National Council on Disability, August 23, 2012, available at: http://www.ncd.gov/publications/2012/August232012/

³ ELFA Budget, p. 285.

⁴ ELFA Budget, p. 285.

⁵ Rocking the Cradle: Ensuring the Rights of Parents with Disabilities and Their Children. (2012, September 27). Retrieved January 27, 2015, from http://www.ncd.gov/publications/2012/Sep272012/

The Administration must set guidelines for police interaction with people with disabilities, and provide data on police interactions with people with disabilities.

Governor Cuomo's seven-point Justice Agenda includes providing race and ethic data on police interactions statewide. There are countless instances across the State of interactions between people with disabilities and police that have ended in tragedy. Deaf individuals who were unable to hear police commands have been injured and even killed by police. Autistic people have also been hurt when they were unable to respond to directions as quickly as police demanded. People with intellectual disabilities have also suffered at the hands of the police due to the rigidity of police procedures.

It is because of instances such as these that CDR calls on specific guidelines for police interaction with people with disabilities to be incorporated into the statewide "use of force" policy. CDR also calls for the State to provide data on police interactions with people with disabilities.

In conclusion, this year's Budget contains an ambitious social agenda that will, if it is successful, improve the lives of many disabled New Yorkers in the years to come. It is necessary, however, to address as well issues 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. We urge the Joint Committee in particular to ensure that the "prescriber prevails" principle is retained in the Medicaid budget, to end the discriminatory and exploitive practice of paying people with disabilities less than the minimum wage, and to ensure that the needs of people with disabilities are considered in any reform or guidance on police interactions with civilians. I thank the Committee for its attention to these important issues.

Thank you for your time,

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