

Center for Disability Rights, Inc.

Analysis of the 2014 -2015 NYS Executive Budget:
Proposals that Impact People with Disabilities

January 29, 2014

The Center for Disability Rights (CDR) is a disability led, not-for-profit that 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

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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 in 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.

Each year, CDR closely reviews and responds to the New York State Executive's proposed budget. CDR's response focuses on the proposed Executive Budget's impact on people with disabilities and, more specifically, how the budget affects the ability of people with disabilities to live independently in the community.

Last year, in our budget analysis, CDR applauded Governor Cuomo's vision for a streamlined system that emphasized community-based services. Later in the year, CDR praised the Governor and his Olmstead Cabinet for producing a strong Olmstead Plan that made significant reforms and committed to reducing the long term stay nursing facility population by 10 percent across five years. As 2013 ended, the state took another major step forward and submitted an application to the Centers for Medicare and Medicaid Services to implement the Community First Choice

(CFC) Option. Although there were some concerns about specifics in the application, CDR and the Disability Community again applauded the administration for moving forward to implement CFC.

The 2014-15 Executive Budget is the first budget Governor Cuomo has developed since releasing his Olmstead Plan and moving ahead with the state's application for CFC. CDR and other advocates expected to see the Governor's vision operationalized in policy and budget initiatives. Disappointingly, that was not the case.

The Executive Budget does not leverage millions of dollars in on-going federal funding that incentivize community based long term services and supports. Instead, it invests state funds in an antiquated institutional, medical model with congregate settings. It fails to make necessary investments in disability-led organizations, consumer-directed services, and the community-based attendants who provide the assistance people with disabilities need to be independent. Some budget initiatives actually undercut the goals established in the Governor's Olmstead Plan.

Still, there are opportunities embedded in the Governor's budget. Because the enhanced federal funding associated with implementing the Community First Choice Option has not yet been allocated in the state budget, it can be targeted to make the investments in pro-Olmstead initiatives. The Governor has also opened the door for changes in state policy that can improve the lives and independence of people with disabilities - including initiatives that address the unique disaster preparedness and response needs of people with disabilities, respond to bullying and harassment in our schools, prevent unintended consequences from well-intended legislation - like Lauren's Law, and expand the M/WBE program to include people with disabilities.

CDR applauds the vision that Governor Cuomo established over the past year. CDR stands ready to work with his administration to develop the state policy and budget changes that are needed to make that vision a reality for New Yorkers with disabilities as part of the 21 Day Amendments.

LONG TERM SERVICES AND SUPPORTS/OLMSTEAD IMPLEMENTATION

CDR urges the Cuomo administration to leverage more than \$100 million of annual, on-going federal Medicaid funding by working in partnership with the Disability Community to finalize statutory language amending the Nurse Practice Act and as part of the Governor's 21 Day Amendments.

In December 2013, the Cuomo administration submitted a proposed State Plan Amendment to the Centers for Medicare and Medicaid Services to implement the Community First Choice (CFC) Option, but has not included critical statutory changes needed for full implementation of this initiative in its 2014-15 budget. Additionally, it is our understanding that the Governor has left more than \$100 million of additional, on

going revenue on the table that should be leveraged to rebalance New York's Medicaid system for providing long term services and supports.

For the past three years, CDR and other disability rights advocates have urged the Governor to implement the Community First Choice Option, providing financial analysis that the state would receive approximately \$150 million in federal Medicaid matching funds through an additional 6% in Federal matching funds transforming how the state provides long term services and supports. Although the state would need to expand the availability of these services, we projected that after paying for this expansion New York State would still net about \$90 million in federal funds. This enhanced federal match does not sunset, so the state would continue to receive these funds on an on-going basis.

The revenue lost by not fully implementing CFC extends well beyond the \$150 million of federal funds associated with CFC, identified three years ago. Governor Cuomo's Olmstead Plan promises to reduce the long-term Medicaid nursing facility population by 10% over the next five years. Shifting two percent of the approximately \$7.5 billion that New York's Medicaid program spends on nursing facilities to home and community-based services, would result in about \$7.5 million in cost avoidance and an additional \$8.5 million of additional federal FMAP through CFC. In one year, the state would save an additional \$16 million.

As the state continued to make progress on its Olmstead Plan, that amount would increase by \$16 million each year. By year five of the plan, New York State would achieve an additional \$80 million in cost avoidance and additional federal funds. Adding the annual \$90 million in projected net savings from initial implementation of CFC with the savings and additional federal funds associated with the state's Olmstead Plan, in year five (and every year thereafter) the state would see a combined savings and increased funding of \$170 million.

The administration understood that it needed to address the provision of assistance with health-related tasks, such as medication administration, ventilator assistance and assistance with feeding tubes in order to secure these funds. Last year, CDR and other advocates – the New York Association on Independent Living and the Consumer Directed Personal Assistance Association of New York State – provided recommended language to the state so that it could amend the Nurse Practice Act in the 2014-15 Executive Budget and draw down these federal funds.

CDR and many others in the Disability Community were deeply disturbed that the administration chose not to make these necessary changes. Consequently, the administration was only able to include an extremely limited amount of federal revenue associated with CFC (less than \$20 million a year). Not only does this break the promise that the administration made to the Disability Community to fully implement of the Community First Choice Option, it leaves \$170 million of federal funding untapped.

The administration did propose a blanket exemption to the Nurse Practice Act for staff working in non-certified settings funded, authorized or approved by the Office for People with Developmental Disabilities (OPWDD). Although this proposal, alone, would reduce state costs by \$3.5 million in fiscal year 2015 and beyond, it would not allow the state to fully leverage the additional funding available through CFC. In fact, this exemption would increase the State's use of a program similar one offered by CFC but, one that does not qualify for the additional 6% in increased FMAP. That makes no sense.

In its CFC application, the state indicated that if it did not secure an amendment to the Nurse Practice Act, "aides/attendants will perform any health-related tasks allowed under current law under the supervision of a nurse and CFCO participants will have continued access to other health-related services through the State plan, waivers or demonstrations, for which the enhanced FMAP available under CFCO will not accrue." The rules are clear that individuals enrolled in CFC need to be provided assistance with health-related tasks under CFC. CMS would not waive this key requirement and allow the state to secure the additional federal funds.

The ability of the state to leverage significant federal resources depends on an amendment to the Nurse Practice Act to allow non-licensed professionals to perform assistance with and maintenance of skills necessary for the individual to accomplish health-related tasks, as required by the CFC statute. It is critical that this change be done in a manner that gives individuals with disabilities maximum independence while including appropriate levels of oversight. Without amending the Nurse Practice Act, CFC will not be able to reach the scope and vision intended for the program, and New York will leave significant federal funds on the table.

CDR supports the restoration of the two percent Medicaid provider payment reduction.

Over the past few years, home care services have faced repeated cuts. Home care agencies and consumer directed fiscal intermediaries have been unable to increase attendant wages and in some cases actually were forced to cut wages and/or benefits. Although this is simply a restoration of funds that these organizations previously had, it is a first step in assuring that they have the funds needed to attract good workers and provide quality community-based services.

CDR urges the Cuomo administration to improve the wages of attendants providing Consumer Directed Personal Assistance services across the state and fund changes required by the Obama Administration's changes to the Fair Labor Standards Act.

CDR supports Governor Cuomo's efforts to address the shortfall facing Certified Home Health Agencies, Long Term Home Health Care Programs and Licensed Home Care

Service Agencies in New York City through the investment of \$300 million. To address a growing wage gap, problems with continuity of care and many of the same cost increases faced by the traditional providers, the Cuomo administration needs to increase the wages of attendants providing Consumer Directed Personal Assistance Services, which it maintains will be the priority home and community based service under managed care.

CDR supports the recommendation of the Consumer Directed Personal Assistance Association of New York State (CDPAANYS) which is asking for a \$1.35 per hour increase to cover the costs associated with increased workers compensation costs, unemployment, taxes and other direct service costs. This increase - \$22 million in state share - is less than the increased federal funds the state will draw down by converting the program to the Community First Choice Option (\$27 million). These increased funds are being brought into the state because of the Consumer Directed Personal Assistance Program and should be reinvested in that program.

Increasingly, workers in Consumer Directed Personal Assistance, who can perform all tasks from Level I personal care to skilled nursing, are making two or three dollars less per hour than someone who is only performing Level I nursing tasks. This has led to consumers' inability to attract or retain high quality workers.

The state also needs to pay for the increased costs associated with changes in the federal Fair Labor Standards Act which require that attendants be paid travel time between individuals and time-and-a-half of their base wage for hours over 40. Despite repeated pleas from the Disability Community, the state has not yet even assessed the impact of these changes, which go into effect in January 2015.

It is imperative that the state adjust the rates for fiscal intermediaries to account for these changes. CDR and other advocates are deeply concerned that if the state does not fund these changes, there will be a crisis-level shortage of attendants created when attendants are no longer permitted to work more than 40 hours a week because the current reimbursement rates simply don't support time-and-a-half wages.

This problem particularly affects people with the most significant disabilities, many of whom have attendants already working more than 40 hours a week. Without additional funding, those in consumer directed programs will be forced to cut the hours of long-term attendants and significantly increase their workforce, dramatically increasing costs to managed care and, indirectly, the State, due to the increased fringe costs of these workers. Consumers are already experiencing difficulty in finding attendants who are unwilling to accept jobs knowing their hours will be cut. One consumer, experienced in hiring, had to resort to the sixth choice of preferred candidates before someone accepted a position.

The state must also address the increased costs associated with traditional home care organizations. Advocates are concerned that these organizations - fearing the risk of

unreimbursed overtime – will be less likely to agree to serve individuals with the most significant disabilities who are likely to generate such costs.

Given the Olmstead implications, it is imperative that the state fund the Federal government’s mandate for the provision of overtime and travel costs. CDR is working with the Consumer Directed Personal Assistance Association of New York State to estimate the 2014-15 fiscal year impact of these changes. These costs – and the ongoing costs in succeeding years – can be funded from the increased federal funding associated with the Community First Choice Option.

CDR supports the proposals in the Governor’s Executive Budget which invest in systems that promote community living and calls on the Governor to make similar investments in the state’s disability-led organizations which have spear-headed community transition efforts.

CDR supports the Cuomo administration’s commitment to reinvest the savings associated with the closure of inpatient psychiatric services or other reductions in bed capacity to fund investments in community-based programs. CDR acknowledges and supports efforts at OPWDD to increase community integration of individuals with developmental disabilities. Likewise, CDR supports the investment of \$250,000 to train local Area Agencies on Aging staff so they can provide up-to-date information and services to older adults. However, it is notable that the Governor’s budget does not invest additional resources in the state’s extensive network of Independent Living Centers (ILCs) or other disability-led organizations.

The ILCs, Self Advocacy Association and peer-run organizations serving people with psychiatric disabilities have spear-headed efforts to transition individuals with disabilities into the community from segregated institutional settings, provided peer support needed for successful community integration and increased opportunities for consumer control over services and supports.

These organizations are critical to the success of the Governor’s Olmstead Plan. For example, according to data released by the New York State Education Department, the state’s Independent Living Centers have saved the State more than \$1 billion since 2001 as a result of helping individuals with disabilities avoid or transition out of institutional placement.

Not only have the disability-led organizations advocated for these changes, developed successful models for consumer direction and transition, they have secured the very federal funding opportunities that the state is using to rebalance its system for providing long term services and supports. Additionally, these organizations meet the needs of the disability community in a culturally-competent manner that organizations not comprised of and run by people with disabilities simply do not.

Federal funding from the Balancing Incentive Payment Program could provide immediate, but time-limited, funding for such initiatives, while the increased federal funding available from the Community First Choice Option could be used to provide on-going funding.

An additional \$1.5 million should be allocated to the Independent Living Network, providing \$300,000 in base state IL funding to the two autonomous, federally-funded centers that currently receive no state IL funding and increasing the state funding to the remaining 30 autonomous non-profit organizations that receive independent living funding by \$30,000. The state should make similar investments in other disability-led organizations.

CDR opposes the Cuomo administration's statutory change to guarantee that nursing facilities indefinitely receive the fee-for-service rate in the absence of a negotiated rate of payment between a residential health care facility and a managed care plan because there is no matching protection for home and community based services.

The Center for Disability Rights and other disability rights groups supported the Medicaid Redesign Team process and the shift to managed care because these changes had the potential to rebalance New York's system for providing long term services and supports, end the institutional bias in Medicaid and "Free Our People!" Other states have, in fact, used the shift to managed care to promote community integration.

Advocates have expressed concerns that instead of using the transition to managed care to support people with disabilities living in the most integrated setting, that the state has actually used managed care to undercut home and community-based services. Advocates have repeatedly expressed concern that – even though nursing facilities account for nearly two-thirds of the Medicaid spending for long term services and supports for seniors and people with disabilities – they were initially excluded from managed care. When nursing facilities became part of the managed care system, the state then excluded existing Medicaid enrollees who were considered "permanently placed" in nursing facilities from managed care enrollment.

The Governor's budget continues unequal treatment between nursing facilities and home and community based services by creating a statutory requirement that guarantees nursing facilities indefinitely receive their fee-for-service rate in the absence of a negotiated rate of payment with a managed care plan.

The state has written transition guidance that required the managed care plans to pay the fee-for-service rate to home and community-based providers, but these policies were time-limited. Unlike the transition proposals for home and community-based services, the Governor's proposed policy for nursing facilities is statutory and does not sunset. This policy has undercuts Olmstead compliance as it provides preferential

treatment of institutional placement in nursing facilities over home and community based services.

CDR opposes the Cuomo administration's proposed statutory requirement that managed care contracts with nursing facilities support standardized compensation for nursing facility workers because there is no similar matching protection for home and community based attendants.

The second proposal about managed care payments to nursing facilities moves beyond establishing a baseline for rates to creating a mechanism for the state to require managed care plans to pay rates to nursing facilities that support a new standardized compensation package for facility workers.

This proposal isn't simply about worker wages in nursing facilities. If the Governor intended to assure that nursing facility workers receive a standardized wage, he could have simply established a requirement that nursing facilities pay the standardized rate. Instead, he established an additional requirement on managed care payments to nursing facilities. This policy is fundamentally flawed and will create significant *Olmstead* issues.

First, this requirement only applies to nursing facilities. Managed care organizations are not required to pay rates for home and community based services that would support the same rate of pay. Improving worker rates and benefits in nursing facilities so that they are better than community-based rates creates a financial incentive that will shift workers from home and community-based settings into the institutions. By eroding the community-based workforce, the state will degrade the ability of providers and consumers in Consumer Directed Personal Assistance from recruiting and retaining a high quality workforce, making community living a less viable option.

Second, because the managed care organizations are paid through a standardized capitation model based on individuals - not setting, there is a fixed amount of money that they are receiving for all long-term services and supports. They will be forced to pay for these higher contract costs for nursing facilities from that single pool of funds. They have options for managing their costs, but will only be able to do so through changes to home and community-based services. The managed care organizations will have only two options: cut the hours of home and community-based services they authorize, or reduce the rates paid to home and community-based providers.

This proposed requirement will shift funding from home and community-based services and providers to the institutions. It will either erode the wages and benefits of community-based workers or result in reductions in the availability of home and community-based services. Either way, this policy significantly reinforces the state's institutional bias is contrary to the stated goals of Governor Cuomo's *Olmstead* plan.

CDR opposes elimination of spousal refusal and urges the Cuomo administration to comply with federal law that extends spousal impoverishment protections to home and community-based services, instead of continuing to support and implement policies which force individuals with disabilities to give up their freedom to assure the financial well-being of their spouse and family.

Although there are federal protections that prevent the impoverishment of someone when his or her spouse is placed in a nursing facility, there have been no similar protections when the couple would prefer to remain together in the community with Medicaid long term services and supports. Consequently, someone whose spouse has a disability and is placed in a nursing facility would actually have more income and resources – for him or herself alone – than a couple would have – together – when receiving services and supports at home. Spousal refusal has served as the safety net for those receiving home and community based services.

This year, the Governor is once again proposing to eliminate spousal refusal. The budget anticipates saving only \$10 million this year, a significant reduction from last year. This reduction is due to the fact that the state extended spousal impoverishment protections to all Managed Long Term Care (MLTC) enrollees because they qualified under the institutional exemption. However, the Affordable Care Act extended spousal impoverishment protections to all recipients of home and community based services as of January 1, 2014 for a period of five years. It is our understanding that the administration did not account for the expansion of spousal impoverishment protections in federal law when it developed this 2014-15 budget proposal.

CDR urges the administration to extend spousal impoverishment protections to home and community based services as part of its 21 Day Amendments; however, the extension of spousal impoverishment protections to home and community-based services sunsets in five years. CDR also urges the state to maintain spousal and parental refusal to address the population whose needs are not addressed by the expansion of the spousal impoverishment protections.

CDR opposes the proposal to allow the Commissioner of the Office of Temporary Disability Assistance (OTDA) to privatize fair hearing proceedings and urges the Governor to retract this proposal and restore the due process rights of people with disabilities in managed long term care as part of his 21 Day Amendments.

Throughout the Medicaid Redesign Team (MRT) process, advocates for people with disabilities and the disability community have been concerned that, instead of rationalizing Medicaid, the shift to managed care was designed to reduce access to home and community-based services, without addressing the underlying problem of the state's over-reliance on expensive institutionalization. One of the most concerning policy changes has been the administration's policies that undercut the due process rights of individuals with disabilities enrolled in managed care.

Under current policy, managed care organizations are permitted to significantly cut home and community based services at the end of an authorization period, potentially forcing individuals into institutional placement without allowing the disabled individual to continue to remain at home and receive the same level of home and community based services during an appeal. Advocates have become increasingly concerned that the current managed care rate structure actually creates a financial incentive for managed care organizations to institutionalize individuals with significant disabilities. Consequently, CDR and other advocates have repeatedly urged the administration to ensure that individuals with disabilities – including those with the most significant disabilities – have adequate due process rights in managed care, and the Assembly Health Committee Chair Richard Gottfried developed legislation that would address these issues.

While working with the Disability Community and other advocates to resolve these concerns as they relate to the Fully Integrated Dual Advantage (FIDA) program, the Cuomo administration has proposed to further undercut the due process rights of people with disabilities by privatizing the process in managed care by eroding both the Medicaid and Olmstead rights of people with disabilities who want to receive home and community based services. This furthers the belief in the Disability Community that the state's plan for implementing managed care is designed to limit access to home and community based services.

CDR opposes investments the Executive Budget makes in settings that are neither truly integrated and won't qualify for enhanced federal funding.

The Disability Community has been gravely concerned that, rather than provide long term services and supports in a truly integrated model, some states simply change the funding mechanisms of the institutional settings and claim that the individuals have been integrated into the community. In fact, a previous administration has done this in New York. The state shifted the funding for its Intermediate Care Facilities to Medicaid Home and Community Based Services Waiver funding, and renamed these institutions "Individualized Residential Alternatives." Overnight, the people with developmental disabilities living in these facilities were "integrated" into the community – even though virtually nothing noticeable changed in their lives.

The Governor's 2014-15 budget extends the phase in of 6,000 Assisted Living Program beds, simplifies the application process for Adult Care Facilities and Assisted Living Residences, and includes nursing facilities in the Capital Restructuring Financing and Health Facility Restructuring programs. In the context of an Executive Budget that includes proposals that reinforce the institutional bias and fails to fully implement the Community First Choice Option, these proposals which support congregate living models are cause for concern that a similar approach is being planned to "integrate" seniors and people with disabilities. CDR opposes any plans which would simply

restructure, rebrand and reframe institutional settings into congregate settings that don't provide real integration and independence.

More importantly, overreliance on congregate models of supporting individuals with disabilities may also have serious implications impacting the state's ability to draw down the enhanced federal funding associated with the Community First Choice Option. To address the concerns of the Disability Community, the Centers for Medicare and Medicaid Services recently release rules clarifying the permissible settings for utilizing CFC. Settings eligible for the enhanced federal funding must be integrated in and support full access of individuals receiving Medicaid HCBS to the greater community, including opportunities to seek employment and work in competitive integrated settings, engage in community life, control personal resources, and receive services in the community, to the same degree of access as individuals not receiving Medicaid HCBS. CDR is concerned that – as currently structured and operated – these congregate settings in New York do not qualify for the enhanced federal funding.

Although CMS permitted states to utilize CFC in provider-owned or controlled residential settings, a number of conditions must be met for states to receive the enhanced federal funds when CFC services are provided in such settings. Importantly, the unit or dwelling is a specific physical place that can be owned, rented or occupied under a legally enforceable agreement by the individual receiving services, and the individual has, at a minimum, the same responsibilities and protections from eviction that tenants have under the landlord tenant law of the state, county, city or other designated entity. For settings in which landlord tenant laws do not apply, the state must ensure that a lease, residency agreement or other form of written agreement will be in place for each participant and that the document provides protections that address eviction processes and appeals comparable to those provided under the jurisdiction's landlord tenant law.

The state's proposed CFC State Plan Amendment indicated that individuals living in licensed settings have rights substantially similar to individuals renting their own apartment or house. CDR disagrees. The Cuomo administration acknowledges that an individual may be asked to leave a provider-owned/controlled setting involuntarily for medical or other reasons. Under current state policy, residents may be given less than 30 days of notice about losing their housing when they are hospitalized or temporarily out of home and the provider determines that they will not be able to meet the needs of the individual when they return. Such policies are inconsistent with tenant-landlord law in New York which does not permit eviction based on such "medical reasons."

Additionally, the CMS rules require that the setting is selected by the individual from among setting options, including non-disability specific settings and an option for a private unit in a residential setting. CDR believes that to qualify the state must provide a viable alternative in a private unit residential setting, rather than just indicate that individuals "chose" a congregate model. Barriers to accessing services and the lack of

affordable accessible integrated housing often preclude individuals from being able to choose home and community based services to live on one's own in a private unit residential setting.

The administration needs to reconsider investing in settings that won't qualify for the enhanced funding available through the Community First Choice Option and work with the Disability Community to develop a plan to transform the current system for providing long term services and supports to one that promotes true the independence and integration of people with disabilities.

CDR urges Governor Cuomo to include a 21 Day Amendment that expands the scope of the Justice Center to include nursing facilities.

Last year, CDR supported efforts to increase oversight of abuse in institutions through the creation of the Justice Center. We supported having oversight done by a state agency that, as a law enforcement agency, has primary responsibility for tracking, investigating and prosecuting serious abuse and neglect complaints, but expressed serious concerns that that nursing facilities did not fall under the scope of the Justice Center.

The state omitted Article 28 facilities, claiming there would be a conflict between the federal regulations that govern Article 28 facilities and the state's authority. In fact, the state can impose additional oversight and enforcement and they do it now with nursing facilities, which have dual oversight from CMS and the Department of Health. Further, the state could avoid the challenge of capturing Article 28 hospitals by inserting language that explicitly references residential health care, which shall mean nursing facilities, because these facilities are regulated under 10 NYCRR 415 and exclude hospitals, which are part 405.

During the past year, it became clear why nursing facilities belong under the jurisdiction of the Justice Center. It was reported that the administrator of Monroe Community Hospital, the county-run nursing facility in Rochester, took away a 77-year-old resident's motorized wheelchair and confined him to his bed for four days as a punishment for not following facility policies - even though the man's behavior was not a safety issue.

If an able-bodied adult in any other circumstance were confined to a bed - or even a room - for four days, the person responsible for this would have been charged with unlawful imprisonment in the second degree (class A misdemeanor) for restraining another person. Given the length of time, the individual might even be charged with unlawful imprisonment in the first degree (a class E felony) because their actions would have put the confined individual at risk of serious injury. But law enforcement refused to take action on this issue.

CDR confirmed that this was not an isolated incident and urged law enforcement including the Monroe County Sheriff's office and NYS Attorney General to take action on this case, but despite clear documentation and witnesses, no criminal charges were filed.

Governor Cuomo created the Justice Center to establish a mechanism to prosecute abuse like this in the state's developmental disability system. It's time to extend these same protections to residents in nursing facilities.

HOUSING

The availability of affordable, accessible and integrated housing is critical to allow people with disabilities to live in the community with long term services and supports. CDR applauds Governor Cuomo for making a historic, multi-year investment in housing. CDR is concerned, however, that the state isn't leveraging this investment to address the housing needs of people with disabilities to allow them to transition out of nursing facilities and other institutions and prevent unwanted institutionalization in the future. Although CDR is calling for increased investments in affordable, accessible and integrated housing for people with disabilities, there are also several initiatives the administration could undertake as part of House NY which would be budget neutral.

CDR urges the administration to allocate \$10 million of its 2014-15 Medicaid Redesign Team (MRT) Supportive Housing funding to housing subsidies for individuals transitioning out of nursing facilities and other institutions.

The Medicaid Redesign Team has been focused almost entirely on "supportive housing" that combines service delivery with housing, some of which will not qualify for the enhanced federal funding available under the Community First Choice Option. Prior to last year, although there had been a number of initiatives to transition individuals with disabilities from nursing facilities into the community, there was no specific statewide benchmark. To support a small number of individuals transitioning each year, the state had provided a housing subsidy associated with the Nursing Facility Transition and Diversion Waiver.

In his Olmstead Plan, Governor Cuomo committed to reducing the long term stay nursing facility population by 10 percent across the next five years. CDR applauds the Governor for establishing this aggressive benchmark, but it is imperative that the state immediately begin to transition individuals with disabilities out of nursing facilities and into the community in order to achieve this. To do that, it must address the lack of affordable, accessible and integrated housing options.

The proposed 2014-15 budget includes \$260 million over 2 years (\$100 million in 2014-15 and \$160 million in 2015-16) to fund MRT Supportive Housing projects. The MRT

Supportive Housing Workgroup is scheduled to meet in February. It is imperative that the workgroup allocate \$10 million of their funding to support housing subsidies for individuals transitioning out of nursing facilities and other institutions.

CDR urges the administration to establish requirements for at least 10 percent of the housing units built under the Governor's initiatives be accessible to individuals with mobility disabilities, 4 percent be accessible to people with sensory disabilities and assure that these units are affordable to people with disabilities.

The state cannot afford to build all of the accessible housing needed to support the transition of individuals from institutional to the community. It must leverage the other housing development being done in the state. At a minimum, it must assure that the housing funded by the state includes accessible, affordable, integrated units.

Homes and Community Renewal has historically failed to require the minimum level of accessibility in its projects, assuming that units which could be adapted to provide accessibility should be considered accessible. Consequently, the state agency – under previous administrations – did not build the appropriate number of accessible units.

To address this long-term compliance issue and increase the availability of accessible housing, the state should immediately double the percentage of accessible units it builds with federal funds. The state should also expand these requirements to all housing which is built using funding from the state, rather than fund housing which is unusable by people with disabilities.

CDR urges Governor Cuomo to fully restore the "Access to Home" program.

In the 2012 budget, allocation to the Access to Home program was cut by 80 percent. Despite the Governor's investment in housing, this remains level-funded at \$1 million. Even at pre-2012 levels, the program could not meet the needs of New York's seniors and people with disabilities who need home modifications to be able to remain independent in their own homes. This program needs to be restored.

CDR urges the administration to better leverage the housing resources available through the Public Housing Authorities (PHAs) across the state to support the transition of individuals with disabilities out of nursing facilities and other institutions.

CDR understands that the state's resources are not unlimited. At the national level, CDR has worked with ADAPT to secure guidance from HUD that describes how states can work with their Public Housing Authorities to address the need for affordable, accessible and integrated housing. HUD simplified the process that PHAs need to use

in order to establish preferences in their programs for people with disabilities leaving nursing facilities and other institutions. CDR urges Governor Cuomo, a previous HUD Secretary, to convene a statewide meeting of the PHAs and develop a statewide plan for them to meet their obligations under Olmstead and support the state's efforts to transition people into the community. Not only would such an approach be important for Olmstead compliance in the state and leverage additional resources to address the housing needs of people with disabilities, the Governor would immediately be recognized as a national leader in addressing this critical issue.

CDR calls on the Cuomo administration to restore and fully-fund (\$2 million in 2014-15) the Housing Education and Advocacy initiative which originally received funded through the Money Follows the Person Demonstration.

In order to create the number of accessible, affordable, and integrated housing units needed by the state to implement the Olmstead Plan, the state needs the local government and local non-profits to support this effort. As part of its Money Follows the Person Demonstration Program, the state had agreed to fund a statewide housing education and advocacy effort through the Independent Living Center network. Unfortunately that project was not fully funded and was restructured in a way that virtually eliminated any local advocacy efforts. The project ended last year.

Because the decisions on the allocation of housing funds are made at the local level, we need local disability advocates to be at the table and advocate the inclusion of Olmstead priorities in local housing initiatives. Without this voice, local housing policy continues to overlook the needs of people with disabilities and fails to allocate adequate resources for accessible, affordable and integrated housing, which hampers the state's efforts to promote true community integration for people with disabilities. To do this, the state needs to allocate \$2 million to fully-fund the original MFP Housing Project operated through the New York Association on Independent Living.

HEALTHCARE

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 published last year 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.

Additionally, 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 so CDR opposes eliminating the “prescriber prevails” provisions.

CDR is concerned about unintended consequences of Lauren’s Law and recommends that the Cuomo administration allocate \$250,000 to fund Disability Rights New York to study the issues, assess the impact of Lauren’s Law, determine if adequate protections are in place, and recommend any needed policy changes to protect the rights and lives of people with disabilities and to ensure the informed consent of potential organ donors who fill out the driver’s license application form.

The Governor proposes amending section 6 of Chapter 465 of the Laws of 2012, to make permanent certain aspects of Lauren’s Law which rule requires “anyone over the age of 18 obtaining a new driver’s license to check off a box declaring whether or not they would be an organ donor.”

Although few people think of organ donation as controversial, there are some serious concerns about this program within the disability community. Those who are newly-disabled and may be potential candidates for organ donation are vulnerable to being exploited through aggressive procurement tactics. A prominent and respected brain injury specialist in New York resigned from the board of an organ procurement organization because families complained that staff were overly aggressive in urging them to "pull the plug" and donate organs, yet when they refused, the patients recovered and went home.

In November of 2013, Not Dead Yet, a national disability rights organization that opposes legalization of assisted suicide and euthanasia as deadly forms of discrimination, issued a message to the Organ Procurement and Transplantation Network (OPTN) expressing concern over proposed organ procurement protocols. These proposals would have allowed organ donation to be discussed with individuals who depend on life sustaining treatment and their families before a decision to withdraw life-sustaining treatment has been made, affecting people with upper spinal cord injuries, neuromuscular disabilities and severe brain injuries.

Additionally, the procedures for determining "brain death" are in part determined by hospital policy. The differences are significant enough that a person can be legally

declared dead in one hospital while another hospital would find them to be alive and in need of treatment. Health care providers are also not able to predict outcomes with total reliability, and they are sometimes far from accurate. For example, last year it was reported that a woman in a Syracuse hospital had woken up just as doctors were preparing to harvest her organs.

The driver's license application question does not include anything about these issues and potential conflicts. In general, people don't have enough information about organ procurement policies to make an informed decision. Expecting people to make a choice about future health care without informed consent is problematic. Faced with such a forced choice, some people will simply check "yes" because to do otherwise would make them feel selfish.

Perhaps the biggest risk is that hospitals will use a "yes" on the form to overrule one's health care decision maker under the Family Health Care Decisions Act. But it's also possible that a person's trusted doctor could try to save a person's life while the family uses the form to argue against life saving measures in order to avoid the person having a future with significant disability.

These are complex issues that need further study before making Lauren's Law permanent. CDR recommends that the state allocate \$250,000 to fund Disability Rights New York to study these issues, assess the impact of Lauren's Law, determine if adequate protections are in place, recommend any needed policy changes to protect the rights and lives of people with disabilities, and develop additional disclosure materials and related training to help ensure the informed consent of potential organ donors who fill out the driver's license application form.

In addition, CDR recommends that the following language be added to the driver's license application question about being an organ donor: "My consent to organ donation is not intended to supersede the authorized decisions of my health care power of attorney or surrogate decision maker under the New York Family Health Care Decisions Act."

EMPLOYMENT AND ECONOMIC DEVELOPMENT

CDR supports Governor Cuomo's proposed disparity study to assess the state's contracting with businesses owned by Veterans with service-connected disabilities, but urges the Governor to allocate an additional \$250,000 for a disparity study to examine the equity in contracting for business owners who have disabilities.

The Executive Budget allocates \$250,000 for the Division of Veterans Affairs to conduct a study to undertake a disparity study to examine the equity in contracting for service-disabled veteran small business owners. This will be the first action intended to establish up to a five percent goal in awarding State contracts to service-connected

disabled veterans. For a number of years, CDR and other disability rights advocates have urged the state to expand the Minority and Women Owned Business Enterprises (M/WBE) program to include businesses run by people with disabilities, but we have been told the administration was unwilling to open up this statute.

Now that Governor Cuomo has proposed New York move towards establishing up to a five percent goal in the awarding of state contracts to service-disabled veteran-owned small businesses, we urge Governor Cuomo to also fund a similar study for businesses owned by people with disabilities.

There is a strong, established rationale for doing this. Although post-9/11 veterans have an unemployment rate of 10 percent, non-veterans with disabilities have an even higher unemployment rate – over 13 percent. That figure only includes people with disabilities who have been actively seeking employment during the four weeks prior to being surveyed. In reality, the number should be much higher, as many people with disabilities – who have faced repeated rejection by potential employers – simply have stopped trying to find work. In fact, only 17.8 percent of people with disabilities were employed according to a report released by the U.S. Bureau of Labor Statistics. In contrast, 63.9 percent of non-disabled individuals were part of the workforce.

Because of the difficulty they have securing employment, people with disabilities are nearly twice as likely to be self-employed than their non-disabled peers. Expanding the M/WBE program to include people with disabilities would have a significant impact on the lives and fiscal independence of people with disabilities, reducing the poverty rate for this population, thereby lowering costs associated with participation in numerous government programs.

CDR urges the State to cease contracting with and funding entities that utilize the 14c exemption that allows them to pay less than minimum wage to people with disabilities.

Last year, Governor Cuomo demonstrated that he supports workers by raising the state's minimum wage. However, his policies excluded a significant group of workers: people with disabilities.

Employment is a critical component to the independence and integration of people with disabilities, but employment may not mean economic independence for people with disabilities. Businesses exempt from section 14c of the Fair Labor Standards Act can legally pay people with disabilities far below minimum wage. This primarily occurs in the manufacturing or production industry. Because these entities can pay less, they do.

Further, they perpetuate this unconscionable act by putting people with disabilities in work environments that preclude them from advancing. For example, charging someone with one arm to complete a task that requires intricate dexterity and then

claiming that they are eligible for sub-minimum wage because they do not meet arbitrary standards of production is ridiculous.

While it is permissible under federal law to pay individuals with disabilities less than minimum wage, it is wrong. Governor Cuomo and New York State should be leaders in addressing this issue. CDR has consistently called for the elimination of this exemption, but the state has been unwilling to do this. As a first step, the Cuomo administration could begin to address this issue by establishing a policy that the state will no longer contract with or fund entities that have a 14c exemption.

DISASTER PREPAREDNESS AND RESPONSE

CDR supports the Governor's proposed usage of Federal funds to improve New York's disaster preparedness.

During his State of the State, Governor Cuomo highlighted the work he has done to support the communities affected by Superstorm Sandy, Tropical Storm Irene, and Tropical Storm Lee. He also highlighted the preventative measures the state will take in preparation for future storms. Unfortunately, he didn't acknowledge the impact that these storms had on people with disabilities and the importance of inclusion of people with disabilities in emergency preparedness and disaster response planning.

A recent federal court decision, *BCID v. Bloomberg*, found that New York City violated federal civil rights law by failing to plan and respond to the needs of people with disabilities. (<http://www.cidny.org/testimony.php>)

These federal civil rights law violations resulted in conditions that endangered the lives of people with disabilities. There were consistent and serious problems with accessibility of information and resources and the content of emergency messages. People with disabilities who lived in the community were not only displaced from their homes, but lost their freedom and independence when their only alternative was placement in a nursing facility or other institutional setting. People with disabilities were stranded in their homes, some of them high rises, with no means of obtaining assistance or evacuating. Transportation for evacuation was not accessible. Recovery efforts, including restoration of benefits, were not accessible for people with disabilities. Shelters were not accessible and people were turned away during the storm in New York City. To this day, people with disabilities are still struggling to get back to where they were before the storms.

The Disability Community has repeatedly raised concerns about inclusion of people with disabilities with State emergency planners, but the New York State Office of Emergency Management has ignored the community's concerns. The administration has simply stonewalled advocates.

Given the significant investment the Governor is making in disaster preparedness and response, CDR urges him to address the needs of people with disabilities by providing \$500,000 in funding to the New York State Independent Living Council each year for the next three years to coordinate and establish statewide efforts to improve civil rights compliance in the area of emergency preparedness and disaster response. This

initiative should include statewide community forums on addressing the emergency preparedness needs of people with disabilities, as well as support regional or local disability community engagement in the planning process, surveillance of ADA compliance, review of materials related to emergency preparation, disability literacy training for responders, and development of collaborations that would increase the efficiency and civil rights compliance of disaster preparedness and emergency response and recovery. This project should coordinate efforts to connect the regional and local emergency management response teams to the disability community through the ILC network, and targeted efforts to increase the number of individuals with disabilities who successfully complete Community Emergency Response Team (CERT) training and serve during emergencies at Disaster Recovery Centers (DRCs).

SCHOOL BULLYING

CDR supports Governor Cuomo's proposal to address bullying and harassment in schools because students with disabilities are more likely to be bullied than their non-disabled peers.

Studies show that children with disabilities are two to three times more likely to be bullied than their nondisabled peers. One study documented that 60 percent of students with disabilities report being regularly bullied compared with 25 percent of all students.

Addressing bullying and harassment is critical to assuring that students with disabilities have equal access to education. Bullying and harassment creates a hostile environment that interferes with, or prevents a student's participation in or receipt of benefits, services, or opportunities in school. It isolates and stigmatizes students with disabilities, undercutting the positive impact that integrating students with disabilities in schools can have on society. It also undercuts the ability of students with disabilities to excel in school so we lift the next generation of people with disabilities out of poverty. A hostile environment may exist even if there are no tangible effects on the student where the harassment is serious enough to adversely affect the student's ability to participate in, or benefit from the educational program.

CDR applauds Governor Cuomo's proposed requirement that all public schools notify the State Education Department (SED), the Division of Human Rights and the State Police if there is a pattern of discrimination or harassment. We are willing to work with

the Governor's administration, the Commissioner of Education and the Board of Regents to assure that these efforts improve the education and lives of students with disabilities.

PUBLIC BENEFITS

CDR supports the pass-through of the federal COLA for Supplemental Security Income.

The Executive Budget authorizes the pass-through of the Federal Supplemental Security Income (SSI) Cost of Living Adjustment, which becomes effective on or after January 1, 2015. This is a necessary action because without this mechanism in statute, there will be no means for the state to draw down the additional federal funds. People who receive SSI will see a modest – but important – increase in their monthly checks.

About the Center for Disability Rights

The Center for Disability Rights (CDR) is a disability led, not-for-profit organization headquartered in Rochester, New York, with satellite offices in Geneva, Corning, and Albany. 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.