

Center for Disability Rights, Inc.

Analysis of the 2013-2014 Executive Budget: Proposals that Impact People with Disabilities

February 1, 2013

The Center for Disability Rights (CDR) is a disability led, not-for-profit corporation headquartered in Rochester, New York, with satellite offices in Geneva and Corning, as well as a policy office in 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

ISSUES ADDRESSED

Health/Medicaid

Managed long term care ombuds
Streamlining Medicaid administration
Nursing facility living wage
2% reduction, COLA, trend factor
Scope of practice for home health aides
Fully Integrated Dual Advantage demo
OPWDD DISCOs
Spousal and parental refusal
Balancing Incentive Program
Protections for Fiscal Intermediaries
Expedited managed care expansion
Managed Long Term Care quality
Justice Center
OMH deinstitutionalization
Mental health incident review panels

Employment

Minimum Wage

Independent Living

Independent living center funding

Public Benefits

SSI federal COLA pass through

Housing

Medicaid reinvestment in housing (MA)
Access to Home
Low Income Housing Trust Fund
Rural and Neighborhood Preservation
Rural Rental Assistance Program
Medicaid waiver housing subsidy
Source of income discrimination

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.

Each year, CDR closely reviews and responds to the 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. CDR is particularly cognizant of changes that may impact the State's design and implementation of the Community First Choice Option.ⁱ The order of the following issues in no way indicates priority of importance.

While the Executive Budget proposes an amalgam of sweeping reforms in Medicaid managed care, affordable housing, and agency administration, there is no single, isolated proposal that would have a detrimental effect on the freedoms of people with disabilities. However, combined, these disparate reforms paint a concerning picture for a new New York for people with disabilities under the umbrella of care management for all.

It is important to note that this fiscal year is particularly challenging because, due to the holiday calendar, the Legislature is expected to depart Albany on March 21, 2013; requiring an even more aggressive on-time budget than previous years under the Cuomo Administration.

According to the Executive Briefing Book:

“The Executive Budget supports the Governor’s ongoing efforts to fundamentally improve the protection and care of vulnerable individuals. Strategic investments are funded by programmatic efficiencies and system-wide solutions to reduce State operations costs in service delivery, purchasing, business services, information technology, and other areas. To ensure that individuals receive appropriate services, the Executive Budget increases funding for certain lower-cost program models, and redirects funding from high-cost institutional services to more effective community-based programs.”

The Center for Disability Rights applauds the Governor’s vision for a streamlined system that emphasizes community-based services. Although not explicitly in the Executive Budget, the following analysis is viewed through the lens of Community First Choice (CFC) Option implementation. No other single initiative will have a greater impact on the independence of people with disabilities than CFC. CDR applauds the Governor for his continued commitment to reforming the State’s Medicaid long term services and supports system in a manner that reflects the unique and individualized functional needs of people with disabilities. The Department of Health has been collaborative with the aging and disability communities, as well as other human services agencies, and we are very pleased with the direction of the CFC Development and Implementation Council.

THEMES OF CDR BUDGET POSITIONS

- Incentivize community-based services in managed care through rate setting, performance measures and contract language.
- Streamline Medicaid administration in a manner that advances the State’s compliance with *Olmstead*.
- Ensure people’s due process rights are preserved in managed care.
- Avoid policies that create barriers to community integration.
- Establish mechanisms to prevent conflict of interests in managed care that focus on reducing costs over providing comprehensive supports and services.
- Use Medicaid reinvestment funds for accessible, affordable, integrated housing.

HEALTH/MEDICAID

CDR supports the \$3 million appropriation for the “managed long term care ombuds program.”

As a member of Medicaid Matters New York (MMNY) and a co-author of the proposal put forth by MMNY to establish a Medicaid Managed Care Ombudsman Program, CDR wishes to thank Governor Cuomo for providing the funds needed to support the establishment of the “managed long term care ombuds program.” This commitment to provide individual and systemic advocacy assistance for seniors and people with disabilities in managed care is consistent with the proposal offered by MMNY. We urge the Legislature to approve the \$3 million provided for the “managed long term care ombuds program” in the Aid to Localities budget. This program will help managed care enrollees resolve disputes with managed care entities; monitor, document, and investigate systemic problems such as inadequate accommodations for people with mobility disabilities; offer information, guidance, and support; and provide direct representation in grievances, Fair Hearings, and appeals. With the roll out of mandatory Managed Long Term Care (MLTC) already underway, CDR supports implementation of this program as soon as possible.

CDR supports the concept of streamlining the administration of Medicaid; but ultimately, the priority must be on the quality of services provided in the most integrated setting.

Perhaps one of the most significant proposed reforms is the streamlining initiative that folds Medicaid administration (e.g. rate setting, negotiation of managed care contracts, claims processing) under the Department of Health (DOH), removing these functions from the Office for People with Developmental Disabilities (OPWDD) and the Office of Mental Health (OMH). According to the Executive Briefing Book, “This will standardize administrative practices, generate efficiencies, and free agencies to focus on Medicaid policy and the implications of Medicaid on their constituencies.” There is a belief that this will essentially gut these health and human services agencies, leaving them with no authority to implement health policies. While the Center for Disability Rights is sensitive to the concern that each sector of the disability community has a strong stake in the system, CDR believes that a truly reformed service delivery system will look past diagnosis to address an individual’s functional needs. To this end, the Community First Choice Option seeks a streamlined service delivery system that breaks down silos and allows people to access the services they need.

The Community First Choice (CFC) Option is a cross-disability, cross-generational home and community-based service and service delivery system that will be available to Medicaid recipients at the institutional level of care. The proposed shift of Medicaid administration under the single state agency of the Department of Health could assist the state in reducing bureaucratic redundancies, consistent with CFC implementation. As previously mentioned, the State is well underway in designing the model for CFC and is expected to submit the required state plan amendment this summer. CDR supports streamlining administration *only* for the purpose of improving services and service administration. CDR urges the State to build in quality of care in the most integrated setting. CDR recognizes the value of agencies that are dedicated toward populations with unique needs and we do not support the elimination of these human services agencies. New York must reform, reorganize, and strengthen its health and human services agencies in a manner that is culturally competent and breaks down barriers to home and community-based services.

CDR is concerned by the potential to reinforce an institutionally-biased system and urges rate structures to support *Olmstead* compliance.

The Governor’s proposal to require managed care contracts with nursing facilities to support wages for nursing facility workers has the potential to impact the State’s ability to comply with the Supreme Court’s *Olmstead* decision.ⁱⁱ CDR is concerned that this budget proposal will become the impetus to adjust the State’s managed care rate setting methodology to drive funds toward the nursing facilities when the State needs to do the exact opposite. Ultimately, this budget proposal lays the groundwork for reinforcing the institutional bias and undercutting people with disabilities’ civil right to live and receive services in the most integrated setting. The Executive Budget adds new subdivision 9 to section 4406-c of the Public Health Law. According to subpart (d) of the bill, “the commissioner shall distribute notice of such rates to all such nursing homes, which shall be deemed to be a term of, and included as part of, all contracts subject to this section. “ This is clearly a step backwards from where the State should be heading.

Notably absent in the Executive Budget language is clear incentives within managed care to provide services for people with disabilities in the most integrated setting. CDR strongly urges

the State to employ rate setting methodologies that incentivize community-based services and assure compliance with *Olmstead*. CDR, in collaboration with other advocates, has already provided specific recommendations to the State.ⁱⁱⁱ These mechanisms could include establishing an outlier rate cell for the small group of highest-need individuals or, at a minimum, establish stop-loss payments for community-based care for high-need individual, as opposed to stop-loss payments for nursing facility care. This stop loss mechanism would only be available to members who remain in the community. In addition, the State should employ performance measures to provide incentives for community-based services, as well as sanctions to health plans for failing to comply with certain benchmarks.

The State should require health plans to comply with performance measures:

- Support nursing facility diversions and transitions
- Ensure that the community is the default
- Require consumer-directed services be the first option for enrollees
- Expand the use of assistive technologies that maintain independence in the community
- Comply with quality of care and quality of life measures, both medical and social

Managed care for all is promoted as providing the right care, in the right place, at the right time, but the provisions of long term services and supports is more than a "health care" issue. It is a civil rights issue. The State should not just use managed care to control costs, it must use managed care as mechanism to move the State forward in its compliance with *Olmstead*. To do this, the State must build in incentives for community-based services into the rate setting methodology, as well as in contract language.

CDR is concerned by the continued fiscal challenges placed on community-based providers who are expected to do more with less.

As the State seeks to close a \$1 billion dollar deficit, with the potential for a budget gap increase as the State negotiates the CMS Medicaid overpayments, we are pleased that no further across the board cuts were proposed. As anticipated, the Executive Budget extends the two-percent reduction through March 31, 2015. However, on top of this continued two-percent reduction, once again, there is a one year deferral of the Human Services Cost-of-Living-Adjustment (COLA). The COLA is particularly critical for the Consumer Directed Personal Assistance Program (CDPAP), which has a very low administrative cost, where the majority of the COLA is passed through to the direct care workers' wages. The Executive Budget also establishes a permanent elimination of the trend factor for all Medicaid reimbursements including home care and personal care. These actions have a direct impact on many community-based service providers who are continuously tasked with doing more with less. CDR is greatly concerned that the providers of these services, which assist the State in its compliance with *Olmstead*, will face financial hardship as the cost of doing business increases, while rates are held flat. As the State shifts toward a managed care system of Medicaid, again, CDR urges the State to pursue incentives to provide community-based services through the rate setting methodology, performance measures, and contract language, which will move the State toward a rebalanced community-based system that supports the independence and integration of people with disabilities.^{iv}

CDR is concerned by the focus on medical model approaches to addressing the needs to long term services.

The Executive Budget proposes significant reforms to the scope of practice of home care aides. These are primarily reflected in amendments to the Nursing Practice Act in Article 139 of education law. First, an amendment to section 6908(1)(a)(iv) would allow home health aides to

administer medication in accordance to physician orders. Second, a new section to Public Health Law would create a new advanced certification for home health aides. And third, education law part 6908(1)(i) would authorize these new certified advanced home health aides to perform some skilled nursing tasks to self-directing consumers, while supervised by a registered nurse. These recommendations emerged from the Medicaid Redesign Team's (MRT) Workforce Flexibility and Scope of Practice Workgroup.^v The MRT proposals are prescriptive in relation to medication administration, the training of advanced aides, and the requirement that the advanced aides are specific to one consumer and the training is not transferable; however the budget proposals do not currently match the recommendations of the MRT.

Perhaps of even greater concern is the lack of connection of these proposals to the Community First Choice (CFC) Option. Although the State is committed to CFC, and CDR wishes to thank the Governor, CFC was not included as part of the Medicaid redesign process and therefore many of these proposals that emerged through the MRT process were not considered in the context of CFC. While these provisions begin to move the tasks from the registered nurse to an advanced aide, this still perpetuates the medical model approach to long term services and support. The State should stop building off old systems of care, and rather focus on how it can truly transform the system to support individual choice and maximum control based on individual's functional needs, consistent with the vision and intent of CFC.

CDR supports the State's pursuit of the Fully Integrated Dual Advantage (FIDA) demonstration, but has concerns with the approach laid out in the Executive Budget.

The Executive Budget authorizes the creation of the FIDA demo and makes provisions for moving the demo forward, particularly for those who receive services through OPWDD. The FIDA demo would create new private insurance plans that would be responsible for all Medicare, Medicaid, and prescription medication services – not just long term services – to nearly 130,000 dually eligible New Yorkers, as well as 10,000 New Yorkers receiving services through OPWDD. These plans hold the promise of coordinating care for beneficiaries rather than expecting them to navigate multiple plans and health systems on their own. While CDR supports the State's pursuit of this demonstration,^{vi} CDR has a number of concerns with how it is laid out in the Executive Budget.

First, the proposal grants the Commissioners of DOH and OPWDD the authority to waive any DOH or OPWDD regulations, respectively, that are necessary to allow OPWDD FIDA plans to provide or arrange health care services. CDR wants the FIDA demo to be afforded the flexibility needed to innovate and improve existing managed care systems, but that flexibility cannot come at the expense of public engagement and stakeholder participation. Second, the establishment language in part (a) rightly identifies the FIDA initiative as a program jointly conceived and developed by DOH and the Center for Medicare and Medicaid Services (CMS), but it fails to note that FIDA is a *demonstration*, not a permanent health program. If New York's demonstration proposal is approved by CMS, there will be ongoing monitoring and oversight to ensure that beneficiaries are provided with coordinated care and that savings are achieved for both the Medicare and Medicaid programs. CDR urges the State to add language to the establishment subsection to indicate that the program, if approved, will act as a demonstration. Third, CDR is concerned that subsection (f) authorizes the Commissioner of DOH to contract with MLTC plans without requiring a competitive bid process. Given the proposal to begin FIDA plan enrollment in January 2014, CDR understands the need for expediency, but due to

the newness of this program, the complex needs of the demo population, and the still developing rules and standards governing these plans, we believe a public plan selection process is needed. Alternatively, if an RFP or competitive bid process is not possible, DOH and OPWDD in collaboration with stakeholders must establish clear and transparent guidelines for plan selection. Fourth, CDR is concerned by the provision for “up to three managed long-term care plans” for OPWDD FIDA. This language suggests that the Commissioner could select only one FIDA plan provider for OPWDD FIDA enrollees. In order to ensure sufficient consumer choice, we urge the State to establish a requirement for a minimum of three plans. Lastly, the State should employ mechanisms that incentivize community-based services and assure compliance with *Olmstead* in demonstrations that coordinate Medicare and Medicaid services to dually eligible individuals.

CDR supports the direction of OPWDD to create a stronger care coordination system, but has several concerns about the proposed DISCOs.

For the past year, CDR has tracked the development of the proposed care management systems emerging from OPWDD including the Developmental Disability Individual Support Care Coordination Organizations (DISCOs); the People First Waiver; and the new entryway to services, Individualized Community Services (ICS). While careful consideration is worthwhile, CDR believes it is time for the OPWDD to move forward with new care management models but only with the intent of improving care, increasing community integration, maximizing consumer control and independence, and balancing the system toward community-based services. Focusing on the DISCOs, which are detailed in the Executive Budget, CDR’s primary concerns are the inherent conflict-of-interest within DISCOs; the lack of oversight; the weak references to due process rights; and the lack of clarification on the future of individual advocates.

Care management mechanisms must:

- Increase community integration
- Maximize consumer control and independence
- Improve care
- Balance the system toward community-based services

First and foremost, CDR firmly contends that DISCOs should not conduct assessments. The State must establish conflict of interest protections to ensure that the entities that have a fiscal incentive to limit services are not bestowed the responsibility of assessing the needs of people with developmental disabilities. It is not enough for a nurse to determine what they think the person’s basic needs are. The person must be in control of the process, and it is not just about basic needs, it is also about what people want. The rhetoric for person-centered planning must ensure that in practice, the process is person-centered and not medically or fiscally driven. Second, the language “may waive rules and regulations of their respective department or office, including but not limited to, those pertaining to duplicative requirements concerning record keeping, boards of directors, staffing and reporting,” raises significant concerns for oversight. The DISCOs should not be a mechanism for dismantling oversight processes, including boards. Third, CDR believes the bill language does not go far enough in ensuring people’s due process rights.

While final decisions have not been made, the elimination of the Medicaid Service Coordinator as a discreet service will have a direct impact on the State’s ability to achieve the previously mentioned goals of conflict free assessment, oversight, and due process rights. If the State is removing oversight functions and eliminating this advocate function, who will have the responsibility of ensuring people with developmental disabilities receive the services they need

and want? This cannot fall on the DISCOs. CDR contends that the State should not reinvent the wheel. The original design of the Medicaid Service Coordinators was based on the premise that people with developmental disabilities would benefit from personalized, individual advocacy assistance. The primary role of the Medicaid Service Coordinator is to work for the individual. They assist the individual to ensure the individual has access to the full menu of services that are unique to them *and* follows them through the process up through fair hearing, if necessary. They spend years building relationships, including family members. CDR is concerned that if these responsibilities fall to a care coordinator, the care coordinator has a perverse incentive to limit an individual's choice. Essentially, the care coordinator will have to serve two masters: the individual and the health plan. It is our concern that the fiscal constraints of the health plan will override the individual's needs and wants. Again, the Community First Choice Option begins to address many of these outstanding issues by explicitly prescribing a person-directed plan and planning process that supports choice.

CDR opposes the elimination of spousal and parental refusal.

The elimination of spousal and parental refusal has a direct impact on people with disabilities' ability to access Medicaid community-based services. It is being framed as "requiring spousal support for the cost of community-based long term care," according to the Health and Mental Hygiene memorandum. This amendment to the Social Services Law simply changes the "or" to an "and" but it has major implications for low income families of people with disabilities. This proposal prohibits a spouse or parent from refusing to contribute any available income or assets towards the costs of health care services being provided to a spouse or family member to reduce unnecessary Medicaid financing of long term care services. This proposal is incorrectly positioned as a fraud prevention mechanism to prevent wealthy couples from taking advantage of the system. The reality is that this proposal actually harms low income families. Low income couples will be forced to divorce in order to qualify for assistance or be forced to institutionalize the spouse who requires long term care services. This proposal actually places more strain on the system as people will lose their natural supports. While CDR opposes the elimination of spousal refusal, the State could consider modifying the proposal to accomplish their goal. This would entail: capping spousal refusal so that it is only available where the refusing spouse's income and assets are within the spousal impoverishment limits for nursing home care; including a hardship exception for those applicants where the spouse truly refuses to contribute or even to document his/her assets, such as in cases of domestic violence; and including a provision so that parents may also exercise refusal up to the same thresholds used by a spouse of a nursing facility resident, even though there is no exact analogous standard for parents of minor children.

Conversely, the Governor proposes extending spousal impoverishment protections to all Managed Long Term Care (MLTC) enrollees, which CDR supports. Spousal impoverishment protections benefit married couples where one spouse receives home care; however, this is a different mechanism than spousal refusal.

CDR supports the State's pursuit of the Balancing Incentive Program (BIP) and urges the State to use the additional federal assistance to support cross-disability initiatives that promote access to community-based services.

CDR has been advocating for the State to pursue this option made available as part of the Affordable Care Act and we applaud the Governor's commitment with the appropriation of \$10

million. New York State is eligible for a two-percent enhanced federal match until its long term care spending shifts by three percent toward the community, or the program sunsets in 2015. It is actually to the State's benefit, where possible, to avoid significant cuts to Medicaid long term care at this time in order to draw down additional federal dollars through the enhanced match. Clearly, New York could benefit from an infusion of federal funds to strengthen its own "no wrong door" program, particularly now with the shift toward care management for all. We urge the Department of Health to partner with the Independent Living Center (ILC) community, a federally-authorized network, to develop an effective "no wrong door" system that is inclusive of people with disabilities as well as the senior community.

Independent Living Centers are unique disability-led, cross-disability, locally administered not-for-profit organizations providing comprehensive, unbiased information and assistance to the population entering the Medicaid managed care system, as described in the State's proposal to expand managed care. ILCs assist people with disabilities of *all* ages and with *all* types of disabilities in navigating multifaceted service systems and advocate to ensure access to their chosen services and supports in the community. ILCs understand the complexity of Medicaid-funded services, as well as all other available community-based services for older New Yorkers and people with disabilities. ILCs are experts in transition and diversion from nursing facilities and other institutions. ILCs are ideally positioned to provide information about long term care options and to provide community outreach and linkage to services using these new resources. However, NY Connects continues to ignore the disability community, only sporadically partnering with ILCs in select parts of the State. Finally, health plans, enrollees and other stakeholders would greatly benefit from an enhanced awareness of New York's commitment to rebalancing care from nursing facilities to the community, through contract and rate incentives for providing community-based services as well as consumer tools for comparing options, all of which could be made possible with the BIP funding.

CDR urges the State to extend the same protections for Fiscal Intermediaries that other entities receive from health insurance plans in regards to timeliness of payment.

Prompt-pay provisions in state insurance law, sections 3224-a and b, assure that health insurance plans pay claims within a prescribed period of time to providers in the insurance system. Currently, Fiscal Intermediaries that provide fiscal management functions, as well as other duties, in the Consumer Directed Personal Assistance Program (CDPAP) are not protected under the State's prompt-pay law. This is due to a historical error that could not envision CDPAP folded into the managed care system when it was created in 1995. However, on November 1, 2012, CDPAP was carved into mainstream managed care and Managed Long Term Care. CDPAP is the most cost-effective and empowering home care program in the State.

In CDPAP, under the supervision of the individual or the individual's designated representative, direct care workers can perform housekeeping tasks, personal care, rehabilitative therapies, and skilled nursing tasks, at a fraction of the cost of other analogous Medicaid services. Presently, 10,000 seniors and people with disabilities statewide use CDPAP to remain independent in their own homes and out of costly nursing facilities. This number is expected to significantly increase as managed care plans recognize the value of this program. We have already witnessed the impacts of the lack of this protection in the brief time period since November 1st and Fiscal Intermediaries cannot sustain prolonged periods with no payments. Further, without this protection, if a health plan ceases operations, a Fiscal

Intermediary would be last on the list of entities that would receive a court ordered recoupment. Fiscal Intermediaries are required by law to issue earned wages to direct care workers who provide personal assistance to individuals in CDPAP. Therefore, the money is going out but it is not coming in. Without this protection, particularly on the precipice of MLTC expansion, Fiscal Intermediaries will not be able to continue to operate CDPAP, thus threatening the independence of thousands of seniors and people with disabilities. CDR urges the State to include CDPAP in insurance law sections 3224-a and b through the budget.

CDR is concerned by the expedited push for care management for all, without concurrently resolving critical consumer concerns.

The Executive Budget proposes to give the Commissioner of Health the authority to phase-in populations into managed care, away from fee-for-service, more expeditiously than originally proposed in the State's care management for all expansion schedule. The proposal expands the list of exempted and excluded populations and gives the authority to mandate enrollment for all special populations when program features and reimbursement rates are approved by the Commissioner of Health, in connection "as appropriate" with the Commissioners of OMH, OPWDD, OCFS, and OASAS. CDR contends that individuals who choose to voluntarily elect managed care should be allowed to do so. CDR understands the nuances of managed care expansion, and the State's purpose for exempting certain populations, but it is a contradiction of choice that many people with disabilities are excluded, not exempt, from managed care.

Most importantly, CDR urges the State to resolve some of the critical outstanding issues with the managed care system before it proposes a full fold-in of all populations.

Conflict-free assessment

The assessment process must remain conflict-free. CDR has always contended that entities that do assessments must not be affiliated with managed care plans in order to avoid inherent conflict-of-interests, which will emerge, that limit access to needed services. In addition, it is not just about basic needs determined through a nursing assessment. The State must mature beyond medical models of assessment and be responsive to the desires and interests of the individual. If the authorization only reflects the basic needs assessment, then the system has failed. The Community First Choice (CFC) Option begins to resolve this. CFC is predicated on supporting an individual's right to lead an independent life in the most integrated setting, and connecting people to the appropriate services to achieve this goal.

Due process rights

The State must resolve issues with due process. Before managed care expansion, when assessments resulted in reductions in hours or services, consumers had the ability to continue to receive services in the manner and at the level they did before their fair hearing was resolved, referred to as "aid continuing." This is particularly important to individuals who receive community-based long term because interruptions in care could result in an unnecessary nursing facility placement. As the State expands mandatory Managed Long Term Care, the State's policy has been that aid continuing will only apply for the health plans' first authorization – that which takes place within 60 days from when the individual in transitioned to MLTC. Further, fair hearing rights will only apply after an individual has exhausted plans' internal and external appeal processes. The combination of these decisions has strong implications for consumers as they seek to navigate the new system. For

consumers in the community-based long term care system, delays in their service will mean hospitalization, institutionalization and a possible life-long loss of independence.

Incentives for community-based services

As previously noted – because it cannot be stressed enough – managed care could be an opportunity for the State to creatively address the imbalanced service system that favors institutional placement over community-based services. The State must employ mechanisms that incentivize community-based services both through the rate setting methodology and contract language.

CDR supports efforts to invest in quality incentives for Managed Long Term Care and puts forth recommendations.

The Executive Budget proposes dedicating \$20 million for health plans that meet high levels of performance, building off of the successes of the Quality Assurance Annual Report (QAAR). There is no programmatic language in the budget and without additional information, CDR cannot weigh in on the value of this proposal. However, CDR has long maintained that the State should invest in mechanisms that result in increased quality in managed care. Performance standards and quality measures for each health plan should be publically available in a readily accessible system. People enrolled in health plans should have access to a tool that summarizes quality data and allows for comparisons across plans. For people with disabilities, it is not enough for plans to provide flu shots and routine care (though, these are important measures); rather, the State must hold plans accountable by using quality measures that are both medical and social. This is particularly important for Managed Long Term Care plans and Fully Integrated Dual Advantage plans that are required to coordinate complex services systems for enrollees with complex needs. CDR joined other consumer advocates in submitting recommendations to the State through its FIDA demonstration workgroup on quality.^{vii} While these are nuanced quality measures, many of these are endorsed by the National Quality Forum (NQF).^{viii}

Sample quality measures that the State should explore:

- The degree of individual participation in person-centered planning process
- Amounts and types of monthly grievances and appeals, including data on the timeframe and manner of resolution
- The degree to which individuals experience an increased or maintained level of functioning
- Various compliance measures with the Americans with Disabilities Act
- The degree to which individuals report that plans are sensitive to their linguistic, cultural, or ethnic backgrounds

CDR supports efforts to increase oversight of abuse in institutions, but urges the State to invest resources in transitioning individuals out of institutions.

On June 30, 2013, the Justice Center for the Protection of People with Special Needs, will be established. Thus, there are several components in the Executive Budget in order to move forward with the Justice Center. These include: transitioning the operation of the Commission on Quality of Care and Advocacy for Persons to Disabilities (“CQC”) to the Justice Center; the creation of new positions necessary to operate the agency; the creation of a statewide hotline to handle allegations of abuse; the creation of a direct care workers registry; the authority to represent the State at employee disciplinary cases; the development of investigation standards; and the consolidation of and elimination of redundant reporting by multiple state agencies. These sweeping reforms will improve the oversight and enforcement capacity of the State’s complex institutional system. CDR, however, remains very concerned that nursing facilities do 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. Further, Governor Cuomo has effectively used his bully pulpit to address abuse in institutions and CDR urges him to promote deinstitutionalization and *Olmstead* compliance with the same vigor.

CDR supports the Office of Mental Health's deinstitutionalization initiatives.

The Governor proposes to further downsize the State's psychiatric hospital system and reinvest savings into community-based services. CDR applauds the efforts of the Office of Mental Health (OMH) to comply with *Olmstead*. The Executive Budget gives the Commissioner of OMH the authority to make determinations for bed closures based on several criteria including what services are provided, proximity to other hospitals that can provide needed services, etc. The State should work with disability rights advocates to maximize the use of the Community First Choice Option to provide home and community-based services for people with mental health disabilities, promoting the closures of psychiatric hospitals.

CDR supports the Mental Health Incident Review Panels, but is concerned about the stigma implications.

The Governor is proposing the establishment of mental health incident review panels in order to improve government response to violent acts involving people with mental health disabilities. According the Executive Briefing Book, "these reviews will result in policy recommendations to help prevent future occurrences and to enhance public safety." We understand that these panels are building off of the successful review panel that emerged from NYC in 2008. CDR supports this process, but cautions the State to be mindful of increasing stigmas for people with mental health disabilities. Studies show that people with significant mental health disabilities are 11 times more likely to be *victims* of violent crime than the general population.^{ix} CDR is most concerned that policies emerging from this panel could actually discourage people from self-identifying as having a mental health disability or seeking treatment, even if otherwise desired. People are already reluctant to self-identify as a person with a mental health disability because of the stigma that exists. We must be vigilant in protecting, not violating, hard fought for rights. Again, we believe the State's intention is to build off of the successes of efforts that focused on real solutions from providers and avoided blaming the person with a disability. This is the only appropriate action for the State.

EMPLOYMENT

CDR supports increases to minimum wage but urges the State to ensure that people with disabilities are not adversely impacted.

While CDR applauds the Governor's vision for supporting workers, this initiative fails to address the current practice in New York that supports segregated and sub-minimum wage for people with disabilities. The poverty rate for people with disabilities is nearly three times the poverty rate of people without disabilities (27.9% compared to 9.8%).^x Further, in NYS, only

36.2% of the non-institutionalized working age population with disabilities are employed compared to 78.9% of the working age population for people without disabilities. Employment is a critical component to the independence and integration of 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 this is a permissible act through federal law, CDR urges the State to cease contracting with and funding entities that are eligible for this exemption.

The State must also address the impact of this proposed change on home and community-based services. If the State does not increase rates to offset the cost of an increase in minimum wage, then community-based providers will not be able to endure this requirement. In addition, time and half is not calculated on base rate pay, but rather on minimum wage so some providers will feel this impact more than others. CDR urges the State to establish an adjustment to the Medicaid rate so that Medicaid providers like CDPAP Fiscal Intermediaries can accommodate the change and support direct care workers.

INDEPENDENT LIVING

CDR applauds the Governor's commitment to independent living centers.

The Executive Budget proposes level funding for Independent Living Centers (ILCs) at \$12.4 million. CDR applauds the Governor for sparing centers, which are already underfunded, from additional cuts. We recognize that closing the deficit is no easy task and we thank the Governor for ensuring that ILCs are off the table for negotiation. ILCs are invaluable nonprofit, community-based resources that provide extensive services to people with disabilities of all ages in New York State in order to support their independence and integration in the community. According to data released by the New York State Education Department, ACCES-VR, ILCs' efforts to transition and divert people with disabilities from costly institutional services saved the State more than \$1 billion since 2001 as a result of avoided institutional placement.

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, 2014. 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 increase in their checks.

HOUSING

In order to comply with *Olmstead* and provide long term services and supports in the most integrated setting, the State must expand its accessible, affordable, integrated housing stock. CDR is pleased to see the Governor take a strong position in support of affordable housing. According to the Executive Briefing Book,

“The Executive Budget proposes a new House NY program that would invest \$1 billion of additional resources over five years to preserve and create 14,300 affordable housing units statewide. This would create significant economic benefits for the State, including long-term stabilization of distressed neighborhoods and the creation of jobs during construction. This multi-year initiative would include the revitalization of 45 Mitchell Lama affordable housing projects that suffer from significant physical deterioration (\$706 million), the creation and preservation of over 5,000 affordable housing units through various housing and community development programs (\$231 million), and other initiatives.”

CDR supports the commitment of \$91.5 million for affordable housing through the Medicaid Redesign Team initiatives.*

Through the Medicaid Redesign Team, the State has committed a three-year reoccurring appropriation of \$75 million for affordable housing. CDR applauds the Governor for committing an additional \$12.5 million in this year’s Executive Budget, as well as directing an additional \$4 million made available from hospital and nursing facility bed closures. The lack of affordable, accessible, integrated housing options can be one of the most significant barriers to people with disabilities living independently in the community. CDR believes that dollars saved from hospitals and nursing facilities closures and downsizing must go towards increasing housing and community-based supports and services that allow individuals with disabilities to live fully integrated in the community and avoid costly institutionalization. There are several ways that the State can use these funds to comply with *Olmstead* without defaulting to traditional models that tie services to housing. Housing should not be conditioned on compliance with treatment or with a service plan. (1) As we transition the State’s long term services system to mandatory managed care, New York must build on the successes of the Medicaid housing rental subsidies (available through the Nursing Facility Transition and Diversion waiver and Traumatic Brain Injury waiver) by creating a broader housing subsidy program to ensure seniors and people with disabilities who need long term services and supports will not end up in nursing facilities solely due to a lack of affordable, accessible housing. The state could use the new uniform assessment tool to identify people who are at an institutional level of care in order to prioritize waiver subsidies. (2) Expand the Access to Home Program, administered by Homes and Community Renewal. See below for more information on Access to Home’s critical role in improving the State’s inaccessible housing stock. (3) Fund the development of housing units affordable to people with disabilities living at extremely low incomes, well below 30% of area median income (AMI).

The State should use these funds to:

- Expand housing rental subsidies for people with disabilities who are institutionalized or at risk of unnecessary institutionalization due to the lack of accessible, affordable, integrated housing
- Increase funding for the Access to Home program
- Develop housing options that target people below 30% AMI

*CDR includes this position under housing, but this funding is tied to the Medicaid budget.

CDR urges the State to save Access to Home!

The Access to Home program, which sustained a devastating 75 percent cut in the 2012-2013 budget, is maintained at the funding level of \$1 million. Due to decades of bad housing policy, which continues today, home modifications are still necessary for many seniors and people with disabilities in order to remain independent in their own homes. The Homes and Community Renewal's program, Access to Home, provides grants for modifications, assisting many individuals to avoid nursing facility placement solely due to housing problems, which is particularly important under the context of managed long term care. CDR commends the Executive for allocating \$1 million to Access to Home, yet the State's Division of Homes and Community Renewal will, once again, not be committing their annual allocation amount of \$4 million, which was already woefully underfunded. Even the usual commitment of \$4 million is far below need and HCR typically receives applications for five times the amount of available funding. In other words, Access to Home always scrapes by, functioning far below the level of need. Yet this year may be the last year for this critical program if the Legislature does not provide for additional funding. CDR urges the Legislature to support Access to Home and increase the funding for this program!

CDR supports the continued capital funding of the Low Income Housing Trust Fund.

The Low Income Housing Trust Fund capital funding is maintained at last year's level of \$32.2 million. Units are for people who are below 90 percent area median income (AMI). (The federal program is for people below 60 percent AMI.) While CDR supports advances in affordable housing for all populations, it is still problematic that the State program does not target people below 30 percent AMI, which is where most low income people with disabilities fall. In a real sense, this proposal will not provide the critical assistance to those people with disabilities who are extremely poor. CDR will continue to advocate for changes with the State's low income housing program to ensure that people below 30 percent AMI are prioritized.

CDR supports the use of the excess reserved from the Mortgage Insurance Fund for affordable housing initiatives.

For the past several years, the Rural and Neighborhood Preservation Programs have been slowly chipped away in the budget, with several budget years proposing a full elimination of funding. Rural Preservation Companies (RPCs) and Neighborhood Preservation Companies (NPCs) serve communities that rely on affordable housing. Not only do RPCs and NPCs provide vital affordable housing assistance to low income individuals, but they are extremely successful at leveraging their limited state funds. According to the New York State Rural Housing Coalition, by the 2008 fiscal year, RPCs achieved a leverage ratio of \$30 for every RPC dollar appropriated. CDR applauds the Governor's proposal to use excess reserves from the Mortgage Insurance Fund (MIF) to support these programs, though the amount of \$12.1 million appears to be woefully low when \$100 million is being diverted to general funds. The Executive Budget also proposes to consolidate the NPP and RPP into a single Community Preservation Program (CPP) under article 27 of the Private Housing Finance Law (PHFL), repealing articles 16 and 17 of the PHFL that established the NPP and RPP. The purpose is to eliminate regional disparities, and shift to a performance based standard for awarding funds, which would be prescribed by the Housing Trust Fund Corporation. Consolidating and streamlining these programs makes sense, but the concern is that reduced staff will further limit their ability to

provide resources to people who need affordable housing, or worse yet, result in forced closure of some of these critical organizations.

CDR supports the proposal to use additional excess reserves of the Mortgage Insurance Fund of \$17.6 million for the purpose of refinancing and capital repairs of 36 Mitchell-Lama affordable housing projects, as well as much needed \$20.4 million for the Rural Rental Assistance Program (RRAP). RRAP is a rental subsidy program for approximately 4,700 low income people with disabilities and seniors in upstate rural New York who live in properties financed through the U.S. Department of Agriculture's 515 program.

CDR opposes the proposal to transfer \$100 million of the MIF to general funds. CDR contends that the state must establish through legislation a dedicated Housing Investment Fund that would be the receptacle of federal housing trust funds (established by the Housing and Economic Recovery Act of 2008) when available, as well as other funds like excess reserves from the MIF, in order to ensure that these dollars go to support affordable housing in New York State. Further, dollars should be targeted at projects that support people below 30 percent Area Median Income (AMI), which would capture people with disabilities who receive Supplemental Security Income (SSI).

CDR supports the continued commitment to the Nursing Home Transition and Diversion Waiver Subsidy.

The Executive Budget includes an appropriation of \$2.3 million for the housing subsidy available to participants in the Nursing Home Transition and Diversion (NHTD) Waiver. CDR applauds the State's continued commitment to this program. It is clear that this Waiver subsidy works – as every dollar is used every year to support people with disabilities in accessible, affordable, integrated housing. As the State seeks additional dollars to support this subsidy, CDR urges the State to concurrently improve the NHTD waiver. CDR has put forth over 60 specific and readily achievable recommendations to the State, including establishing deadlines for assessment and review; reducing unnecessary paperwork to complete a service plan; ending duplicative eligibility determination practices; addressing delays in authorizing personal care; and establishing a process to approve the Initial Service Plans (ISP) for service coordination and HCSS.^{xi}

CDR supports the proposal to include source of income discrimination in the Human Rights Law.

While not in the Executive Budget, in his State of the State address, the Governor proposed “amending the Human Rights Law to prohibit landlords from discriminating against tenants based on lawful sources of income.” Currently, there is a lack of protection for tenants seeking housing. Landlords and realtors are allowed to openly discriminate against tenants with lawful sources of income. This proposal was attributed to women's equality but it will have the added benefit of supporting people with disabilities who rely on housing subsidies to live in their own apartments in the community. In addition to Section 8 Housing Choice vouchers, people with disabilities who participate in the Traumatic Brain Injury (TBI), Nursing Home Transition and Diversion (NHTD), and OPWDD Medicaid waivers are eligible for housing subsidies tied to the waivers. If a person has a lawful source of income that allows them to pay their rent, landlords should have to consider them as a viable candidate to rent the apartment. This protection would not prevent a landlord from running a credit check or from requesting references. The

landlord would be able to vet the individual or family as they would any other potential tenant. We applaud the Governor's proposal to expand discrimination to include source of income and we urge the Governor to include Medicaid waiver rental subsidies in addition to Section 8.

This analysis was prepared by Leah Farrell, Manager of Government Affairs for the Center for Disability Rights (CDR). For additional information, contact Leah Farrell at CDR's Albany office: (518) 320-7100 or lfarrell@cdrnys.org.

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- i The *Community First Choice Option* was made available to states through the *Affordable Care Act*, by adding section 1915(k) to the Social Security Act. It is a community-based Medicaid state plan service and service delivery system, which includes hands on assistance, safety monitoring, and cueing for assistance with activities of daily living, instrumental activities of daily living and health related tasks based on functional need, not age or diagnosis.
 - ii The Supreme Court decision in *Olmstead v. L.C.*, 527 U.S. 581 (1999), applied the integration mandate of Title II of the Americans with Disabilities Act (1990) to long term services and supports. The decision affirms that services must be provided in "the most integrated setting appropriate to the needs of qualified individuals with disabilities."
 - iii *Incentives for Community-Based Services and Supports in Medicaid Managed Long Term Care: Consumer Advocate Recommendations for New York State*, March 23, 2012: <http://wnylc.com/health/download/304/>
 - iv Ibid.
 - v *Medicaid Redesign Team Workforce Flexibility and Scope of Practice Work Group, Final Recommendations*, November 21, 2011. http://www.health.ny.gov/health_care/medicaid/redesign/docs/workforce_flexibility_scope_of_practice_wg_recommend.pdf
 - vi *Consumer advocates' comments to the Department of Health on "New York State Department of Health's Demonstration to Integrate Care for Dual Eligible Individuals,"* May 17, 2012. <http://www.wnyc.com/health/download/310/>
 - vii *Consumer advocate recommendations to the State Department of Health on Performance Standards and Quality Measures for FIDA Program.* http://cdrnys.org/files/performance_st_qa_fida_prog-010913.pdf
 - viii *Appendix H Measuring Healthcare Quality for the Dual Eligible Beneficiary Population, Final Report to HHS*, June 2012. http://www.qualityforum.org/Publications/2012/06/Measuring_Healthcare_Quality_for_the_Dual_Eligible_Beneficiary_Population.aspx
 - ix Teplin et al. Crime victimization in adults with severe mental illness. *Archives of General Psychiatry*. 2005 Aug. 62. 911-921
 - x Ericson, W Lee, C., & von Schrader, S. (2009). 2008 Disability Status Report: New York. Ithaca, NY: Cornell University Rehabilitation research and Training Center on Disability Demographics and Statistics.
 - xi *Recommendations for Improving the Nursing Home Transition and Diversion Waiver*, January 26, 2011. http://cdrnys.org/files/recommendations_improving_NHTD_Waiver-012611.pdf