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ANALYSIS OF GOVERNOR PATERSON'S 2009-2010 EXECUTIVE BUDGET

The Center for Disability Rights, Inc. is a non-profit Independent Living Center providing services and advocacy to people of all ages and with all types of disabilities. The Center for Disability Rights, Inc. (CDR) is headquartered in Rochester, NY, with a satellite office in Geneva, NY and a policy office in Albany, NY. Each year, CDR closely reviews and responds to the Executive's proposed budget. CDR's response focuses on the proposed 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.

Governor Paterson released the 2009-2010 Executive Budget six weeks early on December 16, 2008. This act was in recognition of the dire financial state of the state. There are two components to the budget: cost-containment and reform. The Center for Disability Rights recognizes the staggering fiscal challenges this administration faces and commends the state's agencies for collaborating with stakeholders to address these issues. Agency staff has been increasingly accessible and transparent. However, despite collaborative efforts, the disability community was particularly harmed through the "shared burden" approach to budget cuts and policy reforms.

CDR vehemently opposes the imbalanced approach to the budget that favors programs for one vulnerable population at the expense of another population. For example, the state proposes streamlining reforms to general Medicaid, including the elimination of the resource test, however long term care users, which include people with disabilities, are excluded from the benefits of these reforms. Another example of this imbalance is the state is increasing social services programs and the public assistance grant, while simultaneously cutting the state's already diminutive supplement to Supplemental Security Income (SSI). CDR supports the proposed increases to social services programs and the public assistance grant, but not at the expense of the SSI population. This approach does not support the state's efforts to impose shared burdens in the budget.

Regarding the reforms to healthcare, in the State of the State address, the Governor stated, "Expanding coverage is not enough. It does not make sense to enroll more people in a broken system. While we have made some progress, we still incentivize the wrong care in the wrong setting at the wrong price. Where we are overpaying for inpatient or institutional care, we must shift funding to primary, preventive and community-based care." The Governor recognizes that the state needs to stop investing in an outmoded system and should be shifting to community-based care, yet several significant items in the Executive Budget are contrary to this objective.

New York State would realize long term structural savings by reducing its investments in outmoded institutions and shifting supports to community-based initiatives, particularly consumer directed programs. Several of the budget's reforms do not account for the consumer—they are either efforts to reduce administrative burdens or offer provider-driven incentives. The state continues to make sweeping reforms to long term care without consideration to the types of services needed or the setting consumers prefer.

Below is an outline of the Center for Disability Rights' position on the Executive Budget's items that impact people with disabilities. There are several items that do not illicit a clear position because although the reform may be beneficial, the approach is flawed. A further explanation of CDR's position follows in the narrative analysis.

GUIDE TO CENTER FOR DISABILITY RIGHTS' POSITION ON 2009-2010 EXECUTIVE BUDGET ITEMS THAT IMPACT PEOPLE WITH DISABILITIES

Ітем	POSITION	PAGE
I. Cuts to State Supplement for Supplemental Security Income (SSI)	Oppose	5
II. Long Term Care		
A. Cuts to Home Care		
Personal Care	Oppose	6
• LTHHCP	Oppose	7
• CHHA	Oppose	7
• Elimination of trend factors for 2008 and 2009	Oppose	7
TBI and NFTD protected from cuts	Support	7
B. Revised Reimbursement Methodology	•	
• 0.7% Assessment of gross receipts for CHHAs, providers of LTHHCP, and LHCSAs	N/A	7
Implement a new regional pricing system for nursing homes	Support	8
• New CHHA reimbursement methodology based on patient conditions and episodes of care	Support	8
Modify CHHA bad debt and charity care (BDCC) program	Support	8
C. CHHAs and LTHHCP providers will not be able to subcontract care providers	Oppose	8
D. Long Term Care Assessment Process	11	
Long Term Care Assessment Center	N/A	9
• The development of a uniform assessment tool for home care (\$5M cost)	N/A	9
• Cut to NY Connects	N/A	10
E. Closing of beds and wards (OMH)		
OMH will close 450 inpatient beds	Support	10
• Closure or restructuring of 18 wards in selected adult facilities.	Support	10
Shift "Continuity Day Treatment" toward community-based.	Support	11
Modify and/or eliminate a variety of duplicative or redundant reporting requirements	Support	11
F. Phase-out of 6,000 nursing facility beds to shift toward 6,000 Assisted Living Program beds	N/A	11
G. Home Care Quality Incentive Pool and Nursing Home Care Quality Incentive Pool	Oppose	11
H. Cash and Counseling Demonstration	N/A	11
I. Capping the amount to beneficiaries of participants in the trust at 10%	Oppose	12
J. Elimination of the Geriatric In-Home Medical Care Pilot Program	Oppose	12
K. Cuts to Long Term Care Ombudsman	Oppose	12
L. Delay implementation of Bridges to Health (B2H)	Oppose	13
III. Eliminate 2009-2010 Human Services COLA	Oppose	13
IV. Pharmaceutical Reforms		
A. Changes to EPIC		
• Eliminate the wrap-around coverage in EPIC for drugs not covered by Medicare Part D	Oppose	13
Assist with utilization of Medicare Part D	Support	13
End the limited Medicaid wrap-around coverage for Part D	Oppose	14
B. Remove NYS from pharmaceutical state pool	N/A	14
C. Limit quantity, frequency, and duration of certain medications	Oppose	14
D. Expand Medicaid Preferred Drug List	Oppose	14
V. Medicaid Managed Care	1	
A. Include personal care in the Medicaid managed care	Oppose	15
B. Aggressively pursue the enrollment of dual-eligibles into managed care	Oppose	15

VI. Streamline and Address Management of Medicaid Services		
A Elimination of asset test, finger printing, and face-to-face requirements	N/A	15
B. Limit participation in case management to one service per enrollee	N/A	16
C. Establish Transportation Managers	N/A	16
VII. Housing		
A. Reduce Rural Rental Assistance Program	Oppose	16
B. Increase funds for the Housing Trust Fund and the Affordable Housing Corporation Program	Support	17
C. NFTD housing subsidy	Support	17
D. Expand the Low Income Housing Tax Credit Program	Support	17
E. Repairs and renovations to existing public housing	N/A	18
F. Development of nearly 3,000 new residential opportunities and housing units	N/A	18
G. Continue to fund Access to Home	Support	18
VIII. Recommendations		18

I. CUT TO STATE SUPPLEMENT FOR SUPPLEMENTAL SECURITY INCOME (SSI)

In the 2009-2010 Executive Budget, Governor Paterson proposes to cut the state supplement to Supplemental Security Income (SSI) by over 25% for individuals and couples living alone in the community and by 45-70% for those living with others. New York State has not increased its share of SSI in over 20 years—relying solely on federal increases that have not kept pace with the rising cost of living. This approach to SSI has left New Yorkers with disabilities struggling to scrape by. Now the state is proposing to cut its already diminutive supplement. The Executive's Budget is structured so that SSI recipients will experience the help of a federal increase in January followed by a monthly income reduction in June 2009, which will require mid-year re-budgeting by New York's poorest residents.

A number of factors make this proposal unacceptable.

People living on SSI are already well below the Federal Poverty Level (FPL). For individuals living alone in the community, the total benefit, including the January 2009 federal increase, measured as a percent of FPL will fall from the current 83.5% to 80.4% of the FPL in June 2009 when the Governor's cut is implemented. This is the largest one year decline since 1981. This is harmful because SSI is already insufficient at meeting people's basic needs for shelter, clothing, basic utilities and food.

Many facets of life are already too expensive for people with disabilities relying on SSI to afford. For example, in Monroe County, the average rent for a studio apartment is 77.5% of a consumer's SSI and it will increase to 80% with the proposed cuts in the middle of the calendar year. That means that 80% of their income has to go to housing which leaves only 20%, or approximately \$170, for food, bills, uncovered medical needs, transportation, and other expenses for an entire month.

Furthermore, the reduction in the state SSI supplement only pertains to people living in the community, not in nursing homes and other congregate settings. It is important to note that if the cut to the state supplement applied to people in facilities, it would actually impact the facilities' payments, not the individuals' small spending allowance. By excluding people living in congregate care and institutions from the proposed cut, the state is in a sense gifting \$10.5M¹ to facilities while slashing \$84 million from individuals with disabilities. The implementation of this cut on people living in the community and not in institutions flies in the face of the most integrated setting mandate of the *Olmstead* decision.

Lastly, the state needs to recognize that SSI is a re-investment into the economy. People on SSI do not save or invest. They are living day to day and check to check. These individuals put all of their SSI income directly into the economy through the purchase of goods and services. According to a report by the Center on Budget and Policy Priorities, tax cuts are not as beneficial to the economy as are measures that provide funds to the poor who put the money right back into the economy (*Capital Gains Tax Cuts Would be Poor Stimulus*, Huang and Greenstein, January 15, 2009). Thus, a cut to SSI is a cut to the economy, not a cost-savings measure.

¹ This figure is based on a comparison to the cut to individuals living with others (June – December 2009, \$16 reduction and January – May 2010, \$11 reduction) as applied to the number of people on SSI in congregate care settings, 62,757.

The concern with this proposed cut to the state's SSI supplement is that the state is asking the poorest of the poor to share the burden by carrying it on their backs. This is a time when the state needs to be expanding its safety net, not cutting resources to its most vulnerable population.

In 2004, Governor Pataki proposed similar SSI cuts when the Federal government was increasing its payment. These cuts were strongly opposed and ultimately blocked. CDR is very disappointed that aged, blind and disabled individuals have been singled out for cuts in their SSI checks by Governor Paterson. This cut must be stopped.

II. LONG TERM CARE

New York State's long term care system needs reform. The current system is complicated, inefficient and biased toward institutional placement for seniors and people with disabilities who need long term care services. As the population ages, the need for long term care services in the community will continue to grow. While the Governor and his administration have spoken of a commitment to reshaping long term care services to support more community-based services, several of the proposals in the budget do significant damage to such services.

A. Cuts to Home Care

Personal Care

According to the Deficit Reduction Act, effective January 1, 2009 there will be a 1% cut and a permanent rate reduction of 1.5% effective March 1, 2009; resulting in a permanent reduction of 2.5%. A modified reimbursement rate system is intended to, according to the Executive, "encourage administrative efficiencies."

In addition, the Governor's budget proposes the elimination of the personal care trend factors for 2008 and 2009. The budget will eliminate the share of the home care and personal care trend factor for the remaining 2008 calendar year, resulting in \$31.5M savings in 2009-2010. The 2009 calendar year trend factor will also be eliminated, producing \$42.7M in savings in 2009-2010. Operating costs increase every year as things become more expensive. By eliminating the trend factors it becomes even more of a challenge to operate. This approach further reduces the reimbursement. CDR opposes this approach to cost-containment.

Because the elimination of the trend factor and the further reduction of the reimbursement rate will ultimately mean wage freezes or decreases and reductions in benefits, these cuts will negatively impact the ability of people with disabilities to receive good services from qualified personal care staff. CDR opposes this cut.

RECOMMENDATION: The Department of Health and Governor's office continues to express concern about what they view as an overutilization of personal care services in New York City. The solution to the observed regional disparities should not be to simply reduce all personal care consumers to the lowest common denominator, but rather to evaluate the reasons for the disparities and formulate solutions on the basis of the facts. For example, one factor that leads to an exaggerated need for personal care hours of service is the lack of adaptive and durable medical equipment that enhances people's independence. For consumers who have access to appropriate equipment, their need for personal attendant services decreases because

they are able to accomplish certain tasks alone. Instead of cutting hours approved to consumers or reducing rate reimbursements to agencies, the state could see long term savings to the system by investing in adaptive and durable medical equipment.

Long Term Home Health Care Program (LTHHCP)

Similar to the rate reductions to personal care, the LTHHCP will experience a 1% cut and a permanent rate reduction of 1.5% effective March 1, 2009; resulting in a permanent reduction of 2.5%.

Certified Home Health Agencies (CHHA)

CHHAs will be impacted differently than personal care or LTHHCP providers. There will be a rate reduction of 1%, effective January 1, 2009, and a *temporary* rate reduction of 3.5% effective March 1, 2009; reverting back to 1% on January 1, 2010.

Although personal care, which is more cost effective and in tune with consumers' needs and preferences, will actually be cut a higher rate than CHHAs in the long run, according to DOH's Office of Long Term Care the CHHAs will be equally impacted due to the revised reimbursement methodology. This approach must prove to be equitable to both consumer directed and agency directed models because the rate cuts do not impact both systems in the same manner. These rate reductions appear to favor agency directed programs by reducing the rates to consumer directed programs, (i.e. CDPAP through personal care) at a higher percentage than agency directed programs, (i.e. CHHAs). Consumer directed programs are more cost-effective to the state and are proven to be preferred by consumers so the state must avoid reforms that favor agency directed programs.

TBI and NFTD waivers protected from cuts.

Despite the significant cuts to home care in State plan programs, CDR commends the Department of Health for shielding the Traumatic Brain Injury (TBI) and Nursing Facility Transition and Diversion (NFTD) Medicaid waivers from cuts. Home and community-based waivers are more cost effective to the state than institutional placements and thus should be protected in times of broad budgetary cuts.

B. Revised Reimbursement Methodology

The new methodology was developed to address the Department of Health's concern that the amount the state spends has increased significantly but the number of people receiving services has not increased at the same rate. While CDR recognizes that the revised reimbursement methodology will increase transparency and could improve the system, the Department of Health's justification is a strictly medical model approach to fixing a system that is both social and medical. More research is warranted to determine *why* there is a significant regional disparity in the number of hours approved per person served.

For CHHAs, providers of LTHHCP, and LHCSAs, an assessment shall be collected of 0.7% of each agency's or provider's gross receipts received from all home health care services, personal care services, and other operating income on a cash basis effective March 1, 2009. Although this act will draw down federal money in order to recoup the difference in assessment, it is still a cut in state investment in home care and a tax on providers already facing rate

reductions. There is a façade that the state supports the shift of people to community-based care, but this assessment is just another example of the state avoiding investment in homecare.

Implement a new regional pricing system for nursing facilities.

CDR generally supports this proposal. The current reimbursement methodology allows nursing facilities great, and undue, latitude in setting their own rate. A regionalized reimbursement cap will result in cost-savings to the state and will not impact consumers. The institutions may bare a financial impact, but this will occur to those facilities that are, in a sense, overcharging. If there is another facility in the same region serving the same population at the same level of care at a more cost-effective rate for the state, then the more costly facility should be able to do the same for less.

CDR is, however, very concerned that this proposal includes \$225 million in "additional transitional adjustments" over four years to ease the facilities' transition to the new rate structure. Yet, there are no such supports for home care providers. This is a flagrant example of institutional bias and putting institutions ahead of community-based, cost-effective, consumer preferred programs. This funding would be much better spent elsewhere, for example, restoring the SSI cuts to individuals.

Replace the current CHHA reimbursement methodology with a pricing methodology based on patient conditions and episodes of care.

CDR supports this proposal. This proposal reflects a rate methodology based on an individual's needs, which is how the system should work. For example, an increased reimbursement rate for high-needs individuals could lead to ensuring that high-needs individuals get the services they need, in the community, instead of being forced into a facility. CDR urges the state to regulate any increases in rates to agencies so the direct care workers (not the agency) receive the maximum portion of the rate possible.

Modify CHHA bad debt and charity care (BDCC) program to require community service plans and annual performance reviews to improve access to underserved populations.

CDR supports this proposal. CHHAs will be required to submit community service plans every three years that demonstrate their commitment to underserved populations. One underserved population is people transitioning out of facilities. This initiative should offer BDCC payments to those CHHAs that specifically target assistance to people with disabilities who transition out of nursing facilities.

C. CHHAs will not be able to subcontract care providers.

Effective January 1, 2010, the Executive Budget would require Medicaid home health services to be provided directly by the CHHA, LTHHCP providers or AIDS home care program, and not via subcontract with a licensed home care services agency (LHCSA). This is an attempt by the state to eliminate excessive reimbursement rates that are due to additional bureaucracy created by CHHAs funneling reimbursements through LHCSAs created under the same agency.

Although this is a positive reform, the state is in a sense punishing all LHCSAs for the inappropriate actions of those few agencies that are circumventing the system. This proposal could have a devastating impact on LHCSAs who rely on contractual relationships with the

CHHAs for referrals to consumers. CDR is concerned that this reform opens the doors for CHHAs to deny long term care Medicaid consumers under the claim that they are inadequately staffed.

In addition, there is a concern that there is an insufficient amount of time and resources provided to the CHHAs to make this transition and some of the county operated CHHAs will subsequently close. Either of these scenarios could lead to devastating interruptions in service and further reduce the options for people with disabilities who require home care.

D. Long Term Care Assessment Process

Establish a Long Term Care Assessment Center for the purpose of assessing recipients accessing home care services.

The Governor has proposed a transfer of responsibility and authority for long term care assessments away from local social service districts to regional assessment centers. The centers will be responsible for authorizing Medicaid eligibility for personal care services, CDPAP, the assisted living program, the new Cash and Counseling Demonstration, and LTHHCP. The centers will determine nursing home level of care. In accordance with the individual's physician and the CHHA, the centers will determine if the individual is eligible for CHHA services beyond 60 days. The long term care assessment center pilot will be in NYC from January 2010 – January 2012 and then expand to the rest of the state.

CDR supports this model because it removes the authority from the counties and places it into regional centers. The concern over counties limiting or capping hours as a cost savings mechanism will be eliminated because the counties will no longer be responsible for assessments.

While supportive of the concept, CDR has significant concerns regarding the development and implementation of these assessment centers.

- The proposal does not indicate how the assessment centers will interface with home and community-based waivers and non-Medicaid recipients.
- The Regional Resource Development Centers (RRDC) in the TBI and NFTD Waivers already provide similar assessment functions in their respective waivers and are regionally based. Consideration should be given to enhancing the capacity of the RRDCs to provide all long term care assessments, instead of building a duplicative structure.
- The assessment centers must prioritize ensuring that people are offered and receive the services needed, not cost-containment by restricting access or hours.

The development of a uniform assessment tool for home care.

The proposal for a uniform assessment tool raises concerns. Previous attempts at a uniform assessment tool, e.g. 1993's Home Assessment Resource Review Instrument (HARRI), were criticized by advocates and consumers for being too task-oriented, without adequate consideration of the individual, the environment or technology-related factors. People with disabilities, even with similar diagnoses, do not have the same needs and cannot be reduced down to rigidly timed tasks.

While this proposal contains promise for standardizing an often disparate system, care must be taken in development and implementation. CDR urges the Department of Health to seek consumer input on the development of the tool. In addition, the consumer advisory committee should have input into the final version, including the option to veto the implementation of DOH's proposal until it satisfies consumer needs. CDR recommends that the assessment tool be implemented by peers, instead of medical model professionals who often only see weakness in people with disabilities.

\$3.5 Million cut to NY Connects

This program, administered by the New York State Office for the Aging, is a point of entry program for people seeking information on long term care services. According to NYSOFA, commitment to the counties remains intact and the local implementation grants, which were increased for the 2008-2009 contract year, will remain unchanged. While this proposed cut will not have a significant impact on the program, it is important to highlight these cuts because both seniors and people with disabilities of all ages rely on these services for their long term care information and referral needs.

RECOMMENDATION: The proposals of the Long Term Care Assessment Center, the uniform assessment tool, and the cuts to NY Connects are indicative of a need to reassess the access and entry into the long term care system. As currently proposed, these proposals will increase fragmentation when a more coordinated, centralized system could be developed. NYS should combine the point of entry system with the assessment center so that people who seek access to long term care services will be able to be served in a cohesive, single point system. The benefit to this is that the workers on the NY Connects phone line would be better trained and more aware of long term care service options if the assessments were administered through the same center. As previously mentioned, the state should explore expanding the roles of Regional Resource Development Centers (RRDC), which already have similar functions and significant experience, to operate as assessment centers.

E. Closing of beds and wards (OMH)

The Office of Mental Health (OMH) will close 450 inpatient beds (11% capacity) and shift 150 toward community-based programs.

CDR applauds this proposal. The disability community has been advocating for structural reform to shift costly institutional beds toward more cost-effective (and preferred) community-based settings for decades. Although, a better proposal would be to shift the entire 450 inpatient bed capacity to community-based initiatives.

Closure or restructuring of 18 wards in selected adult facilities.

According to the Executive, "implementation of these ward efficiencies would reduce staffing needs and allow OMH to redirect a portion of these staff resources into state-operated community-based programs." This action is consistent with the *Olmstead* (1999) decision to redirect funds from facilities to the community. CDR supports this action but is concerned by the vague language regarding "a portion of these staff resources" requirement. A "portion" could be very small. The state should invest the total funds transferred from the facility toward community-based programs.

Shift "Continuity Day Treatment" toward community-based (\$6M).

Community-based programs are always a preferred solution. CDR supports the restructuring of Continuity Day Treatment toward community-based services that focus on recovery, such as peer service programs.

Modify and/or eliminate a variety of duplicative or redundant reporting requirements related largely to the provision of community mental health services.

CDR supports streamlining efforts by OMH and DOH that assist providers in community-based programs to efficiently and more effectively provide the services consumers need. Regulations that reduce documentation burdens and facilitate person-centered processes are a positive reform for the state.

F. Five year phase-out of 6,000 nursing facility beds to shift toward 6,000 Assisted Living Program (ALP) beds.

Although the policy of reducing nursing facility beds is encouraging, it is very troubling that the funds are being shifted toward an increase in assisted living beds, which is just another facility. These facilities are still a form of segregated institutional placement. In fact, some ALPs operate in the same building as a nursing facility.

The state did not consider consumer choice in this reform. People with disabilities in facilities should have been consulted as to their preference for ALPs over community-based care in order to avoid a supply-side proposal which does not advance NYS long term care system. A better solution would be for NYS to reduce nursing facility beds and conversely increase home and community-based funding.

G. Establish a Home Care Quality Incentive Pool and a Nursing Home Care Quality Incentive Pool to reward providers for quality and efficiency improvements.

CDR is concerned by the Home Care Quality Incentive Pool and the Nursing Home Quality Incentive Pool. The CHHA Incentive Pool will be \$20M in 2009-2010 and another \$20M in 2010-2011, while the Nursing Home Incentive Pool will be \$50M in 2009-2010 and \$125M in 2010-2011. This is proposal is biased toward institutions. This is not a person-first reform. Similarly, the failure to provide a quality incentive pool for Personal Care providers reinforces a bias toward expensive, agency-based, home care.

This appears to be another state investment in dysfunctional programs as a solution; rather than investing in better alternatives: consumer directed, community-based programs. With logic like this, New York State would be continuing to invest in building a better black and white television, instead of a plasma screen HDTV. CDR opposes the gifting of \$175 million to facilities.

H. Cash and Counseling Demonstration

In the Executive Budget, the Department of Health Commissioner is authorized to create a Cash and Counseling demonstration for up to 1000 people, in up to ten counties as chosen by the Commissioner based on demographic and geographic features, provided that the counties are willing to participate. The disability community certainly supports consumer directed programs

like Cash and Counseling, but DOH must include advocates and consumers in the development and implementation of this pilot.

Although this is a demonstration, the language in the legislation must be clear to provide guidance to the Department of Health. Because Cash and Counseling fundamentally includes budgeting for direct care workers, the language for the pilot must also be consistent with Department of Labor regulations. Cash and Counseling gives people with disabilities choice in managing their care through flexible budgeting—they can decide what mix of goods and services will best meet their needs. People can use their budget to hire attendants, purchase items, or make home modifications. Under the Cash and Counseling model, people are able to determine their own wage rates for attendants, which results in less turnover and more dependable, capable service. CDPAP agencies should be considered as a vehicle for the pilot because the agencies already serve as fiscal intermediaries for consumers in CDPAP and have the infrastructure to administer payroll and respite for direct care workers. CDR looks forward to collaborating with the Department of Health on this pilot.

I. The amount of money that can be retained in a supplemental trust – sheltered from recovery by Medicaid – upon the death of a disabled Medicaid beneficiary will be capped at 10 percent.

The primary intent of the pooled trust is to allow people who would otherwise have to meet the spend-down requirement for Medicaid to be able to use the funds that would have been "spent down" on essentials like rent and utilities. People cannot make direct withdrawals from the trust, but rather the trust pays third parties directly. The SSDI population, even with the benefit that the trust affords them, is still typically living month-to-month and is not accumulating significant funds that would be directed toward a family member/beneficiary upon death. However, although this may not impact most participants in the trust, this regulation appears to be inconsistent with CMS federal law. There is concern as to the legality of appropriating these funds back to the state, which are the property of the participants. CDR opposes this proposal.

J. Elimination of the Geriatric In-Home Medical Care Pilot Program (\$0.7M cut).

This demonstration program, administered through the NYSOFA, was developed to provide home visits by doctors to seniors to help them remain healthy and in their homes. CDR opposes this cut because the pilot program proved to reduce both hospital admissions and nursing facility admissions.

K. Cuts to Long Term Care Ombudsman (\$0.1M cut).

The Long Term Care Ombudsman provides quality control to nursing facilities to help ensure that consumers are receiving high quality care and do not suffer abuse and neglect. The Ombudsman is on the ground and in the field, directly interacting with people in nursing facilities. This function, largely carried out by volunteers, should not be cut. In fact, if NYS wants to realize long term structural savings then the state must increase its efforts with the Nursing Facility Transition and Diversion (NFTD) Waiver. The Ombudsman could be an avenue to promote the NFTD Waiver to people in nursing facilities who could be served in the community; thus, increasing savings to the state.

L. Delay implementation of Bridges to Health.

There will be \$1M in savings for the remainder of this fiscal year by delaying implementation of slots for the foster care Bridges to Health (B2H) waiver program until 2011-2012. The B2H waiver is intended to help children in the foster system who are assessed to have serious emotional disturbances, developmental disabilities, and medical fragility, to remain in the community and avoid institutional level of care. The NYS Office of Children and Family Services (OCFS) has applauded themselves for this waiver and the disability community supported such accolades. CDR opposes the delay of implementation. This waiver is by definition cost-neutral, so the state's reported savings seem questionable.

III. ELIMINATE 2009-10 HUMAN SERVICES COST-OF-LIVING ADJUSTMENT (COLA)

The Governor's budget calls for reducing the 2008-2009 Human Services Cost of Living Adjustment from 3.2 percent to 2.2 percent effective January 1, 2009 and entirely eliminates the COLA for 2009-2010. This would impact providers under designated Human Services programs, including the Office of Mental Retardation and Developmental Disabilities, Office of Mental Health, Office of Alcoholism and Substance Abuse Services, the Department of Health, the State Office for the Aging and the Office of Children and Family Services.

CDR opposes this cut. Direct care workers, who are employed through human services programs, are already significantly underpaid for their work. Recruitment and retention of quality direct care workers is essential to supporting community-based care. By not supporting direct care workers who provide services to people with disabilities in the community, the state is once again establishing policies that are inconsistent with their claim that they support reducing institutional placements in favor of community-based care. Appropriate wages and benefits for these workers is a critical component of reforming long term care services toward community-based initiatives.

IV. PHARMACEUTICAL REFORMS

People with disabilities frequently have multiple chronic conditions and are directly impacted by the state's pharmaceutical reforms. The state's proposed cost savings initiatives will result in a reduction in coverage and an increase in greater burdens to a population that relies on medication assistance.

A. Changes to EPIC

Eliminate the wrap-around coverage in EPIC for drugs not covered by Medicare Part D.

CDR strongly opposes this proposal. The wrap-around coverage in EPIC for drugs is intended to provide assistance for pharmaceuticals to individuals whose prescriptions are not covered in Medicare Part D. People in the Part D "doughnut hole" will feel the impact. This is not the time for the state to realize savings by removing necessary prescription protections to its most vulnerable populations.

Assist with utilization of Medicare Part D.

The state proposes an increase in funding for local Area Agencies on Aging (AAAs) and community-based organizations to assist EPIC seniors in selecting, accessing, and maximizing appropriate Medicare Part D prescription drug coverage. This type of assistance with prescription coverage is needed, but this proposal is unfortunately part of the state's effort to

eliminate the safety net for individuals victimized by the failures and gaps in the Medicare Part D. Although it is acceptable to encourage seniors to "maximize" prescriptions in Medicare Part D, by eliminating the EPIC wrap-around coverage the state is reducing its short term costs to the long term detriment of seniors.

End the limited Medicaid wrap-around coverage for Part D.

To address the inefficiencies of the federal Medicare benefit, NYS offered wrap-around Medicaid coverage to dual-eligibles with Part D. The program has been eroded to its current limited list including anti-psychotics, anti-depressants, anti-retrovirals, and anti-rejections drugs. Now, the state is proposing the complete elimination of the Medicaid wrap-around, thus ending pharmaceutical protections for dual-eligibles. For many seniors and people with disabilities, these drugs are essential to managing their care and it is unacceptable to eliminate this coverage. CDR opposes this proposal.

B. Remove NYS from pharmaceutical negotiating state pool.

NYS will no longer participate in the National Medicaid Pooling Initiative (NMPI) and the state will now be able to negotiate directly with pharmaceutical companies for rebates. Although it is still premature to determine the impacts of this proposal, CDR supports the Governor's proposal to increase DOH's authority to negotiate for rates directly.

However, CDR strongly opposes the proposal that grants DOH broad authority to impose prior authorization on Medicaid beneficiaries. The proposal eliminates physician over-ride in the Clinical Drug Review Program (CDRP) and would provide sweeping new authority to impose prior authorization on Medicaid drugs, outside of either the CDRP or the Preferred Drug Program (PDP). CDR recognizes the benefit to changing the Supplemental Rebate Program to negotiate better prices; however, we do not support reforms that derive savings by producing obstacles to services and eliminating established consumer protections from the CDRP and the PDP.

C. Limit quantity, frequency, and duration of certain medications.

This regulation will be used to limit the number of units of some medications that have a high incidence of fraud or misuse which, similar to the aforementioned pharmaceutical regulation, may contribute to an increase the stigmatization of people who take certain types of prescriptions. CDR opposes this proposal. People with disabilities often have chronic conditions that require a complex combination of medications. By limiting the quantity, frequency, and duration of certain medications, individuals will be left with lapses between monthly prescriptions. This is unacceptable.

D. Expand Medicaid Preferred Drug List.

The budget proposes an expansion of the Medicaid Preferred Drug List to include antidepressants. The Preferred Drug List is a tool to keep the state's costs down, but the concern is that individuals are often forced to switch their medications to ones on the List, often disrupting their care. This proposal should include a provision for physicians prevail that would allow a doctor to override the restrictions if a patient's care is inadequately met through the List.

V. MEDICAID MANAGED CARE

CDR recognizes that there is a trend toward managed care in both acute and long term care services. However, managed care does not suit the needs of people with significant disabilities and intensive needs for services. There is an inherent conflict of interest in a managed long term care system that has a built-in financial benefit to providers for withholding services and limiting access. People with disabilities who have long term care needs should have access to the services they require, the providers they want, and in the setting they desire without profit-driven capitation and other dysfunctional restrictions.

A. Include personal care services in the Medicaid managed care plan benefit package to improve the coordination of community long term care services.

This proposal will have a direct impact on individuals receiving personal care services. Fundamentally, there is a conflict of interest under a capitated rate system that requires the managed care organization to complete the assessment that determines the amount of services to provide, when their assessment for low service levels will certainly produce the highest return to the managed care organization. Thus, this proposal threatens consumers' access to care and requires them to navigate a confusing process that has yet to produce concrete savings and high quality care.

B. The enrollment of dual-eligibles in managed care plans that participate in both Medicaid and Medicare programs will be aggressively pursued.

The language "aggressively pursue" is troubling. Managed care has not been proven effective at cutting costs or improving health outcomes. Dually-eligible individuals who are pressured to enroll could face significant hurdles, particularly attributed to the complexities of the system, which may result in forgoing necessary care. Consumers should be wary of a system that pressures them to enroll into a Medicaid managed care program that could result in disrupting their plan of care or prove inadequate at providing the services they need.

VI. STREAMLINE AND ADDRESS MANAGEMENT OF MEDICAID SERVICES

CDR commends the state for its proposals to improve people's access to and management of Medicaid services. There were also several budget initiatives that provided for expanded coverage. However the concern is that the disability community, perceived as high-cost to the state, often does not benefit from these initiatives.

A. Elimination of asset test, finger printing, and face-to-face requirements.

In an effort to reduce administrative burdens and outmoded regulations, individuals will no longer be required to complete face-to-face interviews or submit to fingerprinting for Medicaid. In addition, participants will no longer be required to submit detailed resource information to prove eligibility. CDR supports these reforms.

However, these regulations have not been eliminated for the SSI population. This is completely unacceptable. While these reforms will streamline general Medicaid, CDR strongly opposes this blatant discriminatory regulation that will not apply to people with disabilities. The state continues to make reforms for general Medicaid users and at the same time avoid similar proposals in long term care services. This approach highlights the state's bias against SSI-eligible Medicaid users. People with disabilities with chronic conditions who require long term

care do not benefit from such streamlining efforts and are left to continue to navigate an archaic, confusing and often dysfunctional system.

B. Limit participation in case management to one service per enrollee.

There is a potential for consumers to benefit from this proposal because they would no longer have to deal with six different case managers for six different needs. The concern is that there is very high turnover among case managers and in order for this proposal to be effective, the case manager must be highly qualified in multiple chronic conditions and long term care needs. While streamlining and elimination of duplicative services is a positive action, CDR is concerned that people with disabilities, who often have varying medical and social needs, will suffer from this policy and their needs will not be sufficiently met.

C. Establish Transportation Managers.

The state is clearly concerned about the rising costs of non-emergency Medicaid transportation. In order to reign in the program, the Commissioner of Health has the authority to take away the responsibility from localities and contract with an external organization to manage non-emergency transportation services. Non-emergency transportation is essential for people living in the community to be able to get to doctor visits, rehabilitation programs, etc. DOH appears to be concerned that such transportation is somehow being abused or manipulated.

Such concerns and take-over proposals would likely not be necessary if there were adequate paratransit in the state for non-emergency transportation needs. People would be better able to get their social and medical needs met with improved public transit and the state could subsidize an individual who takes public transit at a much lower cost than paying for any medical transportation. People with disabilities cannot live in the community without adequate public transportation.

VII. HOUSING

People with disabilities need accessible, affordable, integrated housing. One of the biggest barriers for individuals who want to transition out of a nursing facility or institution is the lack of adequate housing. NYS needs to bring the issue of housing into the spotlight in the discussion of long term care service reform.

A. Reduce Rural Rental Assistance Program (RRAP).

This is a rental subsidy program for low income people and seniors in upstate New York who live in properties financed through the U.S. Department of Agriculture's "515" program. The state plans to transfer 394 units from RRAP to the Housing Choice Vouchers (formerly known as "Section 8"). Although this will benefit the 394 targeted residents because they will not see a disruption in housing assistance, there is a concern that the plan to shift people from the state program to the federal program will, in a sense, take away the slots that would be available to people eligible and needing Housing Choice Vouchers. There is already immense competition for the limited vouchers, with some localities having waiting lists that are many years long, or not maintaining a list at all because there will be no vouchers. Redirecting Housing Choice Vouchers to cover a cut in the RRAP will only make the competition for vouchers worse. CDR opposes this proposal.

B. Increase funds for the Housing Trust Fund (in DHCR) and the Affordable Housing Corporation Program (in HFA).

There will be \$29M in appropriations and \$148 in reappropriations for the Trust Fund, which provides grants to finance new construction or rehabilitation of low-income apartment buildings. There will also be \$25M in new funds and \$84.5M in appropriations for the Affordable Housing Corporation (AHC) to stimulate local economic growth and stabilize distressed communities.

Accessibility for people with mobility disabilities continues to be a significant barrier to community living. The state gives additional credits to projects with at least 5% of units fully accessible and "move-in ready" for people with physical disabilities, and credits for at least 2% of the units fully accessible for people with visual and hearing impairments. These are federal standards in Section 504 of the Rehabilitation Act, which establishes the minimum of requirements for states. NYS does go beyond the minimum to offer higher scores for projects that are equal to or exceed 10% of total units for people with physical disabilities and 4% for people with hearing or visual impairments.

While the Trust Fund and AHC proposals are a step in the right direction, they are still far from where the state should be in terms of accessibility—even doubling the minimum still results in a project that is 90% inaccessible to people to with disabilities. NYS needs to make regulatory changes to increase the amount of affordable housing that is also accessible. There is no cost to the state to achieve this!

C. Continued support of the Nursing Facility Transition and Diversion (NFTD) waiver housing subsidy.

The Department of Health appropriated another \$2.5M to DHCR for the NFTD waiver housing subsidy. CDR applauds this continued commitment. People with disabilities live on low, fixed incomes and cannot afford the current costs of housing to live in the community and continue to receive the services they need without supports. For those in institutions, Medicaid requires almost all of an individual's monthly SSI payment be transferred to the nursing facility—further reducing the amount that people can save to transition back into the community. NYS must continue to provide affordable housing options because the state would ultimately save money through housing subsidies rather than forcing people with disabilities into costly institutions.

D. Expand the Low Income Housing Tax Credit Program (LIHTC).

There will be an additional \$4 million over 10 years, totaling \$40M, in aggregate credit awards for the development of projects for low-income New Yorkers. The LIHTC follows the federal Low Income Housing Credit Program (LIHC). According to the federal language in the LIHC QAP, "All LIHC-assisted first floor units in new construction projects without an elevator, all LIHC-assisted units in new construction projects with an elevator, and as many LIHC-assisted units as feasible in adaptive reuse or rehabilitation projects shall meet visitability standards, except when such standards are demonstrated to be irreconcilable with federal, state or local statutes, regulations, ordinances or codes." There are too many loopholes to avoid meeting visitability standards. DHCR must mandate that every unit built through the \$40M in funds from the expanded LIHTC program must meet visitability standards. Visitable homes are homes that have enough access to make them usable, comfortable and safe for everyone— residents and visitors, with or without disabilities.

E. Repairs and renovations to existing public housing.

The state plans to invest \$12.8 million in new funding and \$69 million in reappropriations for repairs and renovations to the State's existing public housing. However, the state should not be investing in inaccessible housing. This is an opportunity for the state to expand the availability of accessible housing by ensuring that these funds only be used on units which are already accessible, or to create modifications which make a unit accessible.

F. Development of nearly 3,000 new residential opportunities and housing units.

The breakdown is 1,450 OMH units; 1,100 OMRDD residential opportunities, including 530 associated with the NYS-CARES initiative; 250 OMH units for New York/New York III; and 126 chemical dependence residential treatment units. Several of these units will continue to segregate people with disabilities. There is also concern over the lack of standards for accessibility. Accessible, affordable, independent housing for *all* New Yorkers with disabilities must be the primary focusing for new residential units.

G. Continue to fund Access to Home.

It costs the state more money to renovate and modify units to meet accessibility and visitability standards than it does to build accessible units from the ground up. However, due to decades of bad housing policy, which continues today, home modifications are still necessary for many seniors and people with disabilities. The Access to Home Program is an essential program and CDR commends the state for its continued commitment to modifications to make a home accessible in order for a person to remain living at home, instead of being forced into a facility due to housing problems.

VIII. RECOMMENDATIONS

CDR acknowledges that this administration has made significant strides to reach out to stakeholders. Often, agency staff is very accessible to the disability community. However, a number of the proposals contained in the Executive's Budget were a surprise to very active stakeholders. CDR urges this administration to continue to collaborate on project proposals that significantly impact long term care services for NYS. The approach by the state in the 2009-2010 Executive Budget to propose significant reforms and wait for responses from stakeholders is less productive than it is to work together during the *development* of such reforms to ensure high quality, innovative, and cost-effective long term care services.

The Executive Budget's proposals are intended to address the state's increasing deficit. CDR is concerned that many of the proposed cuts and policy reforms target people with disabilities. There is always more than one approach to reducing the deficit and increasing smart spending. Below are three recommendations for NYS that will have a positive impact on people with disabilities *and* will result in savings to the state.

RECOMMENDATION 1: Shift people to consumer directed programs.

The state could realize long term structural savings by assisting people to participate in consumer directed community-based programs. The state should create enrollment targets for each county through legislation. Although the Consumer Directed Personal Assistance Program (CDPAP) is part of the state plan under personal care services, there is insufficient enforcement and inadequate promotion of CDPAP at the county level.

RECOMMENDATION 2: Increase revenues through the millionaire-tax.

The budget does not implement the "shared sacrifice" that the Governor espouses. New York State's most vulnerable population must not bear the weight of the deficit reduction and proposed restructurings. If the state intends to cut the state supplement to Supplemental Security Income (SSI) for the poorest of the poor, then the state must also implement a progressive income tax plan. The state could raise revenues through a progressive income tax and use the revenues to fund the safety-net and ensure services for low-income populations.

<u>RECOMMENDATION 3</u>: Shift funding toward programs that promote the most integrated setting.

Reforming long term care services must include a comprehensive plan for housing, social services, and transportation. In 1999, the US Supreme Court established in the *Olmstead* decision the civil right that people are to receive all services, including long term care, in the most integrated setting appropriate to their needs. New York State must stop investing in costly, outmoded systems of institutional care and focus on real long term savings through community-based initiatives.