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Proposals to reduce New York State spending and promote the independence and integration of seniors and people with disabilities

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"*We have the highest [Medicaid] rate in the nation, and that's just not sustainable…I want to bring in the people who are actually doing business with the State and say, 'Guys, we can't afford it anymore. We have to reduce the amount we spend on Medicaid. Let's redesign the program together, otherwise, I'm just going to have to cut off the top, and that's not the best way to do it.'*"

- Governor-elect Andrew Cuomo speaking at the Roswell Park Cancer Institute, October 25, 2010

The disability rights community could not agree more. To this end, the New York Association on Independent Living (NYAIL) and the Center for Disability Rights (CDR) offer the following action plan for both immediate and long term savings in New York's Medicaid program. NYAIL is a membership organization of Independent Living Centers (ILCs) across New York State which works to improve the quality of life and safeguard the civil rights of people with disabilities. ILCs are community-based not-for-profit organizations which are controlled by and largely staffed by people with disabilities. ILCs are cross-disability providers of services and advocacy to people of all ages. CDR is a statewide organization providing services and advocacy devoted to the integration, independence and civil rights of all people with all disabilities. CDR is a member of NYAIL, as well as a leader in the disability rights movement through its support of ADAPT, a national, grassroots, disability rights network devoted to eliminating Medicaid's institutional bias.

The Independent Living Center network has served as the voice of the disability rights movement in New York since its inception more than two decades ago. ILCs help the state advance policies of community integration and move people with disabilities from institutions and other segregated settings to the community, as required by the Americans with Disabilities Act and the *Olmstead*[1] decision. Major successes of the ILC network's advocacy include the creation of the Most Integrated Setting Coordinating Council (MISCC), the state Medicaid Buy-In for Working People with Disabilities program, the Nursing Home Transition and Diversion (NHTD) Medicaid waiver program, and the NHTD waiver housing subsidy.

ILCs have been transitioning and diverting people from institutions for more than 20 years and have played a critical role in implementing the Nursing Home Transition and Diversion waiver program, with five ILCs serving as the Regional Resource Development Centers (RRDC) for the waiver, and many others providing waiver services. Data collected by VESID has shown that ILC transition and diversion efforts have saved the state more than $110 million per year in institutionalization costs, including Medicaid and other state funds.[2] In addition, NYAIL and ILCs are helping the state rebalance the long term care system through the federal Money Follows the Person Rebalancing Demonstration (MFP). NYAIL is working to increase accessible, affordable, integrated housing for seniors and people with disabilities, while ILCs are identifying and assisting individuals in nursing facilities who wish to live in the community.

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[1] *Olmstead v. L.C.* [527 U.S. 581 (1999)]

[2] *NYS Independent Living Centers Deinstitutionalization Cost Savings*, October 2001-September 2009 Statewide Report, VESID

A significant reason that New York's long term care system is so expensive is that it remains unnecessarily biased towards institutional care, at a time when other states have reduced Medicaid costs by "rebalancing" their Medicaid programs. Statistics to support this are provided in the recommendations.

Ample opportunity for reform exists. There is a large population of New Yorkers, both current users and those at risk of needing long term care, who want to live in the community. Consider the following statistics:

- According to the state's 2010 3rd quarter report on the Center for Medicare and Medicaid Services (CMS) Minimum Data Set (Q1A), there are currently 22,248 New Yorkers living in nursing facilities that indicated they wish to return to the community.
- According to the AARP Policy Institute, 89% of Americans over age 50 want to remain in their own homes as long as they can.[3]
- Through an analysis of federal data from the Department of Health and Human Services, National Public Radio's Investigative Unit found that young people ages 31 to 64 now make up 14 percent of the nursing home population, an increase of 10 percent in 10 years.[4]

As importantly, rebalancing the long term care system will help meet the state's legal obligation to provide its citizens with assistance in the most integrated setting under both the federal Americans with Disabilities Act and the 1999 *Olmstead* ruling by the U.S. Supreme Court. In 2010, the state has already been found to be non-compliant with *Olmstead* by the *Disability Advocates Inc. v. Paterson*[5] ruling. Clearly, the state should be designing its system into compliance, rather than having federal judges order changes in the long term care system. Importantly, these efforts will also result in more than $1 Billion structural savings in the state's Medicaid program over five years.

Proposed Policy Change	**Associated FY 2011-2012 MA Non-Federal Share Savings**
Shift people from institutions to community-based settings:	
1. Increase transitions on the NHTD waiver	$6.31 M
2. Divert people from nursing facility placement using the NHTD waiver	$6.21 M
Take advantage of the Federal health reform initiatives that support community-based programs:	
3. Implement the Community First Choice option	$7.85 M
4. Authorize the State Balancing Incentive Program	$4.02 M
Transition from a medical-model to a consumer directed model of care:	
5. Shift people from CHHAs to Consumer Directed Personal Assistance Program.	$4.46 M
6. Shift people from personal care assistance to CDPAP	$1.93 M
7. Expand pool of direct care workers	$11.48 M
8. Increase use of assistive technology to increase independence	$1.74 M
Total Medicaid Non-Federal Share Savings	**$44.00 M**
Total Medicaid Non- Federal Share Savings Over 5 Years	**$1.009 Billion**

[3] *Providing More Long-Term Support and Services at Home: Why it's critical for health reform.* AARP Public Policy Institute, Fact Sheet, 2009.

[4] *A New Nursing Home Population: The Young. National Public Radio,* http://www.npr.org/2010/12/09/131912529/a-new-nursing-home-population-the-young, December 9, 2010

[5] 653 F. Supp. 2d 184 (EDNY 2009)

SHIFT PEOPLE FROM INSTITUTIONS TO COMMUNITY-BASED SETTINGS

National research has demonstrated that states which shift from using institutional care, including nursing facilities, to community-based models of care are leveling out their long term care costs, while states that are not making this transition are continuing to see their long term care costs escalate. According to a recent study in *Health Affairs*, "It seems apparent that states offering noninstitutional LTC services as an alternative to institutionalization are not only complying with the *Olmstead* decision and meeting the demands of their citizens with disabilities, but are also potentially saving money."[6]

Unfortunately, state policy makers in New York have not recognized this potential. Instead of supporting the shift toward community-based services, over the past several years these services, particularly the state's Personal Care program, have been criticized in New York State as exorbitant "Cadillac care". In budget presentations, Department of Health staff repeatedly point out that New York State spends more on personal care than any other state. However, when comparing state Medicaid spending, one cannot analyze New York's personal care program in a vacuum. In New York, the personal care program serves people who are nursing facility eligible. In other states, these people would receive long term services and supports through a Medicaid waiver program. Consequently, when analyzing the spending for the Personal Care program, we must evaluate it in the context of combined spending for both personal care and Aged and Disabled (A/D) waivers.

The most current 2009 data from Thomson-Reuters (formerly Medstat) paints a picture of New York State's long term care system that is drastically different than the view espoused by DOH. New York State does not spend the most for these services, and is a distant fourth in spending for this population. In fact, New York spends $123 *less* per capita than the top-ranked Washington, D.C. Alaska and Minnesota also significantly surpass New York. Additionally, DOH has often noted that the spending in the personal care program has gone up as the number of people in the program has declined. In New York City, advocates have recognized that Managed Long Term Care programs have cherry-picked those individuals with low care needs, leaving people with the highest care needs in the State Plan personal care program.

Not only are these attacks on personal care unsubstantiated and misleading, they have distracted state policy makers from the real problem in New York State's system for providing long term services and supports: the institutional bias and an overreliance on nursing facilities. Moreover, by not addressing the institutional bias and making across the board cuts to home and community based services, New York State will just further lock itself into an expensive and unsustainable system.

While NYS has made some efforts to rebalance the long term care system since the 1999 U.S. Supreme Court *Olmstead* decision, when comparing the progress other states have made, New York has notably slow rebalancing outcomes and has continued to increase institutional spending. Based on data from Thomson-Reuters, New York ranks 35th in long term care rebalancing efforts to increase community-based services (including personal care, home health, and A/D waivers); the state only raised its percentage of community-based spending by 7.43 percentage points since 2000. Conversely, New Mexico gained 55.6 percentage points, rising to number one in balancing efforts and transforming its long term care system to serve people in the community. Since 2000, New Mexico reduced its institutional per capita spending to a mere $29.72 per person, the lowest in the nation.

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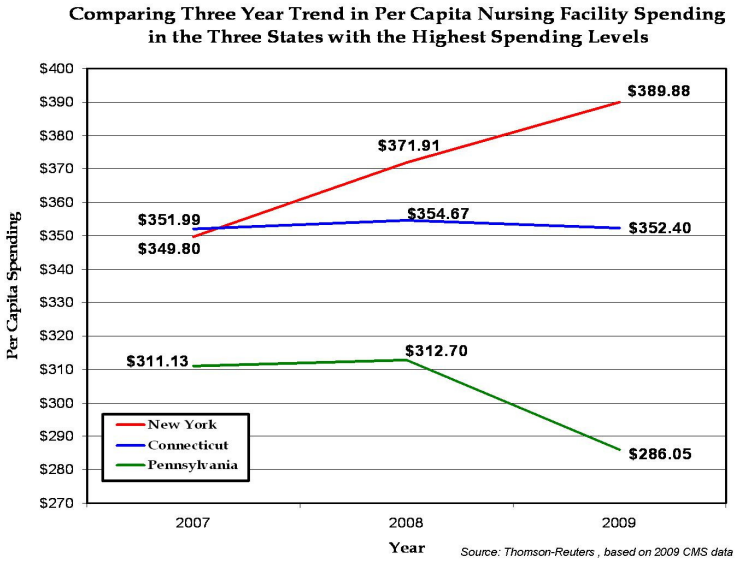
[6] *Do Noninstitutional Long-Term Care Services Reduce Medicaid Spending? Home and community-based services help people with disabilities stay in their homes while reducing long-term care spending*. H. Stephen Kaye, Mitchell P. LaPlante, and Charlene Harrington. *Health Affairs* 28, No. 1, Jan/Feb 2009.

The failure to address the institutional bias in New York is most clear when comparing per capita spending on nursing facilities. In 2007, only three states had per capita spending of more than $300, and New York ranked second at $349.80 per capita, just after Connecticut. Over the last three years, the spending in these three states has moved in very different trajectories. New York State has increased per capita spending on nursing facilities by about $20 each year, exceeding Connecticut's spending in 2008 to now have the highest per capita spending on nursing facilities. Since 2007, Connecticut has leveled its spending on nursing facilities, while Pennsylvania (ranked third) has undertaken substantial rebalancing efforts and significantly decreased per capita nursing facility spending. Based on these data, it is clear that New York State has not committed to reducing institutionalization, complying with the *Olmstead* decision, and rebalancing its system of long term services and supports.



We propose that New York State implement specific policy changes that will contain Medicaid spending for long term services and supports. While the largest savings will develop over years, even with an analysis that uses conservative projections, New York State can achieve significant savings in FY 2011.

The following two recommendations would entail a **policy change** within the Department of Health, which has historically been over reliant on facility placement, to shift people toward more cost-effective community-based services using the Nursing Home Transition and Diversion (NHTD) Waiver. Because of previous advocacy efforts by the disability community and Independent Living Centers, these recommendations do not require additional budgetary or legislative action and the new administration has the authority to implement them immediately.

1. **Increase utilization of the Nursing Home Transition and Diversion (NHTD) Medicaid Waiver to transition people from nursing facility placement to community living, for a potential first year savings of $6.3 million in the non-federal share.**

   According to the state's 2010 3rd quarter report on the Center for Medicare and Medicaid Services (CMS) Minimum Data Set (Q1A), there are currently 22,248 New Yorkers living in nursing facilities that have indicated they wish to return to the community. Only California has more nursing facility residents who have indicated they wish to return to the community. That amounts to $406 million the state could be saving annually by de-institutionalizing this population. In fact, the savings could be more substantial. Studies indicate that this percentage is significantly understated and that a large percentage of people who would like to return to the community is undercounted in the report. In fact, under the state's Money Follows the Person Outreach Program, about 8% of people with limited assistance needs who are listed in the MDS data as not wanting to return to the community, have expressed a desire to return to community living after being contacted by the program. Even this modest percentage has the potential to additionally save more than $123 million each year, raising the potential annual savings to $529 million.

Unfortunately, despite the potential for significant savings, the state's original estimates for Nursing Home Transition and Diversion Waiver enrollment have not been met. The Department of Health estimated there would be 5,000 enrollees by the end of the third year of waiver implementation, in August 2010, but as of December 2010, waiver enrollment was just 674 individuals. While DOH has worked to implement the waiver, overly bureaucratic processes have slowed progress. Department staff – at times – has micro-managed the program resulting in an overly regulated and overly bureaucratic process that simply does not need to exist. DOH has contracted with nine Regional Resource Development Centers to administer the NHTD waiver. An effective strategy to increase waiver enrollment would include utilizing the RRDCs more effectively and allowing them to exercise the level of discretion intended when the program was created. By streamlining state government and reducing the unnecessary bureaucracy, the NHTD waiver has the clear potential to help the state achieve significant cost savings.

The NHTD waiver is too small and too new to have good data to effectively demonstrate its own cost savings, but the cost saving potential is very similar to the state's experience with the Traumatic Brain Injury (TBI) waiver. The TBI waiver's track record is a strong indicator of NHTD's potential for significant savings. The TBI waiver is becoming even more comparable, as the population of younger people in nursing facilities continues to rise. Reversing this trend has the potential to generate significant long-term savings, as over time these individuals have a greater opportunity to develop improved independent living skills and more extensive informal supports.

We use the TBI waiver's savings as a model and conservatively assume only 85% of these savings. If only 10% of the Medicaid-eligible individuals who have expressed a desire to return to community-based living were transitioned to the waiver (112 participants per month), New York State would save $6.3 million in the first year, even factoring in a 1% disenrollment rate. This proposal would save $127.15 million over five years. (*Additional detail on this calculation and the calculations below will be available upon request.*)

2. Establish an expedited enrollment process for the NHTD and TBI waivers to divert people from nursing facility placement, for a potential annual savings of $6.2 million in the non-federal share.

Too often, people are placed in a nursing facility immediately following a hospital stay, and are unable to leave this costly setting later to return to the community. The lengthy and difficult enrollment process for waiver services contributes to nursing facility placement at hospital discharge. This has also slowed enrollments and limited the savings potential of the waiver. The Health Department should create an expedited enrollment process that allows seniors and people with disabilities to immediately return home from a hospital stay.

This approach would promote the goal of individual independence and help people return home with more cost-effective community-based services by reinforcing an attitude of self-reliance rather than promoting dependence on services. (*Specific details on the expedited enrollment proposal are available in a separate paper.*) Although the Department of Health recently created an interim service coordination option as well as a revised initial service plan to hopefully address some of the barriers that have resulted in slowed enrollment, this approach still has the potential to easily bottleneck enrollment. Our proposal would more effectively address barriers to enrollment.

By implementing our recommendations for an expedited enrollment process and diverting just 10% of 13,187 Medicaid-funded nursing facility admissions (only 110 admissions per month), New York State would save $6.2 million in the non-federal share during the first year while promoting the

independence and integration of these individuals by avoiding long-term institutionalization. Over five years, this proposal would save $125.25 million.

TAKE ADVANTAGE OF FEDERAL HEALTH REFORM INITIATIVES PROMOTING REBALANCING

There are significant long term care reform initiatives in the *Patient Protection and Affordable Care Act* that would help New York State rebalance its long term care system and pay for community-based services: The Community First Choice Option (CFC), the State Balancing Incentive Payments Program (BIPP), and the extension of the Money Follows the Person Rebalancing Demonstration (MFP) (Pub. L. No. 111-148). Each offers an incentive for additional federal matching funds to the state's efforts to increase independence, save state Medicaid dollars, and serve people where they choose to live – in their own homes in the community.

3. **Implement the Community First Choice Option (CFC) and shift people from the traditional personal care program into the CFC state plan program, to realize $4.5 million of savings in the non-federal share during the first year, with the potential to save New York more than $391 million over five years.**

The ***Community First Choice Option*** allows states to create a community-based state plan service for people who are at an institutional level of care. There is a substantial financial incentive for creating a program that closely parallels New York's existing Personal Care option. Expenditures under the CFC option receive an additional six percentage points of the federal medical assistance percentage (FMAP). New York State could realize significant savings by drawing down these additional federal dollars through seamlessly shifting nursing facility eligible people in the existing personal care program to the CFC Option.

According to United Hospital Fund, 65 percent of the people enrolled in the state's Personal Care Program are at the nursing facility level of care.[7] We conservatively estimate that because these individuals have the most significant assistance needs, they would account for 85% of the expenditures in the program. Based on 2009 spending data from Thomson-Reuters, New York spent $2.7 billion on personal care services. The additional 6 percent FMAP available through implementing the Community First Choice Option on the $2.3 billion spent for nursing facility eligible individuals would result in nearly $139 million of additional FMAP to New York State on an annual basis. The savings potential to New York is significant, but the CFC option would require the state to make an incremental increase in the eligibility and services of the program, which would partially offset our savings projections, as described below.

As determined in the *Rodriguez*[8] decision, the Personal Care program does not provide safety monitoring as a discrete service. The CFC option would require the state to provide services to people who require this type of support, but don't need hands-on assistance. This small population is already served in New York State nursing facilities. They can be identified using the Minimum Data Set (MDS) Active Resident Information Report from the CMS website. Report G2b indicates that 1.5% of nursing facility residents require no setup or physical help from staff with bathing, the activity of daily living that is most likely to require hands on assistance. The percentage of people who meet this criteria in the community would not likely be different that that in the resident report.

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[7] *An Overview of Medicaid Long-Term Care Programs in New York*. Prepared by Alene Hokenstad, Meghan Shineman, and Roger Auerback. Medicaid Institute at United Hospital Fund. April 2009.

[8] *Rodriguez v. City of New York*, 197 F.3d 611 (2nd Cir., Oct. 6, 1999)

We assume in our calculations that the cost of serving this population under the CFC Option would reduce the potential state savings. Because factors such as the range of care needs, cost, and the potential impact of the "woodwork effect" are already factored into New York's spending on the Personal Care Program, our projections anticipate increased Medicaid spending on Personal Care Services for nursing facility eligible individuals by this same percentage (1.5%). This small percentage increase seems reasonable. Although implementing the CFC expands the available services, the expanded population is already served by Home and Community Support Services (HCSS) in three of the state's waiver programs (NHTD, Traumatic Brain Injury [TBI], and Long Term Home Health Care Program [LTHHCP]). We estimate that adding services for this population would increase state spending by $15 million annually.

The CFC Option would also expand services to individuals who are Intermediate Care Facility (ICF) eligible as well. According to the Commission on Quality Care/Office of the Advocate for Persons with Disabilities, there are 4,000 people on the waiting list for services through the Office for Persons with Developmental Disabilities (OPWDD). All of these individuals are not ICF eligible or currently in need of services as families often add their names to waiting lists long before services are needed. Assuming that 85% of the individuals are ICF eligible and 90% of those actually need services, there would be 3,060 people who would need to be served.

Because this population generally lives with family and is at school or another program during the day, they would not require as many hours of assistance as is typically provided in the personal care program. Assuming that an average individual would need a couple of hours in the evening and some additional hours on the weekend, we anticipate that people would be authorized for 25 hours per week. Using the PCA rate, that would increase state spending by $37 million annually.

New York would eliminate HCSS as a waiver service because that assistance would now be available under the State Plan, and the state would receive additional funding from the enhanced FMAP under the CFC Option. In-home assistance accounts for the bulk of the cost in serving waiver enrolled individuals, and New York would be able to draw down the enhanced 6 percent FMAP on all of these services, further increasing the savings associated with our earlier recommendations to facilitate expedited enrollment in these waivers. Transitioning all people receiving HCSS services under the waivers to the CFC option would generate an additional $4.8 million in the enhanced FMAP funding annually.

The implementation of the CFC Option would also allow New York to move toward a more cost-effective model for providing assistance in the community. Because the CFC Option serves people with all types of disabilities, it could be the first step in developing a consolidated service system and allow the state to eliminate costly, redundant and confusing state bureaucracies. The addition of this level of service has the potential to provide a more cost-effective option for serving individuals with developmental and intellectual disabilities.

Implementation of the CFC Option should also address a critical need in community living: medication administration. According to the recent proposal by PHI,[9] the state should create "medication aides" to address the issue of medication administration – a service not currently covered in traditional personal care. Rather than modify the existing Personal Care or Certified Home Health Aide programs, however, the state should incorporate this health-related task in the

[9] *A Home and Community-Based Service System Reform Blueprint*. Rick Surpin. PHI and Independence Care System, November 2010.

CFC option, which would further promote the use of this service and increase the state's ability to draw down the additional federal funds.

Although many of the recommendations above could be implemented administratively, the CFC Option will also require legislative action, including it in the state budget and amending the Nurse Practices Act to allow for the incorporation of consumer direction in the new service option.

Ultimately, the state's long term care system would evolve into a three-tiered system. Personal Care Aide services would provide in-home assistance with activities of daily living (ADLs) to people who are not at the nursing facility level of care. Consumers who are nursing facility eligible and need basic in-home supports would receive assistance through the CFC program. Finally, those with additional needs (such as home modifications and structured day program services) would be able to get these auxiliary services through the HCBS waivers. (*See chart to the right.*)

How New York's Long Term Care System Could Incorporate the Community First Choice Option

Program	People Served
HCBS Waiver Services	Individuals at or above the nursing facility level of care who need assistance with the activities of daily living and instrumental activities of daily living as well as more intensive supports like home modifications and independent living skills training
Community First Choice Option	Individuals at or above the nursing facility level of care who need assistance with the activities of daily living and instrumental activities of daily living
Personal Care Program	Individuals below the nursing facility level of care who need assistance with the activities of daily living

Finally, it is well-understood that New York's current long term care system is dominated by diagnostic "silos". The CFC Option, because it is based on functional need and not diagnosis, has the potential to be the first step in rationalizing the state's service delivery system across disability categories and state agencies. This would not only eliminate gaps in the service systems and simplify navigating the long term care system, it could generate millions of dollars in savings through the elimination of duplicative state bureaucracies. CMS is expected to release the rules shortly and the state can implement the CFC option as of October 2011. The base proposal would save the state $4.5 million during the first year. Over five years, it would generate over $332 million is savings.

4. Take advantage of the State Balancing Incentive Payments Program to access $12 million in additional Medicaid funds; use Money Follows the Person incentives to continue these rebalancing efforts.

New York State is eligible to participate in the ***State Balancing Incentive Payments Program***. This program offers an additional two percentage points of the federal medical assistance percentage (FMAP) to states with less than 50% of total Medicaid long term care expenditures on community-based services. In order to receive the additional funds, the state must make a proposed budget that details the State's plan to expand and diversify medical assistance for non-institutionally-based long-term services and supports, and exceed 50% spending on community-based services by October 1, 2015. The state will receive an additional 2% FMAP for the community-based expenditures used for the rebalancing, for expanding programs like personal care, the Consumer Directed Personal Assistance Program (CDPAP), and waiver programs.

To participate in this program, states must propose budget plans for three initiatives: (1) "establishment of a 'no wrong door—single point of entry system,'" (2) conflict free case management, and (3) uniform assessment instruments to determine eligibility for community-based

services. New York is already on the path to implementing these programs and would not have to invest significant resources to participate in the rebalancing program to draw down the additional FMAP.

DOH recently de-funded the NY Connects program, which had been implemented by the New York State Office for the Aging through the Area Agencies on Aging. Some have proposed this program serve as New York's single point of entry. Rather than fund an entire new system, we propose that the state use a "no wrong door" approach, for the purpose of participation in the balancing incentive payments program, by utilizing its extensive network of Independent Living Centers along with local Area Agencies on Aging, to provide information on long term care services to seniors and people with disabilities. New York State can capitalize on the service planning component of the Medicaid waivers and CFC Option to meet the requirement for conflict free case management. Finally, the state has contracted with InterRAI to develop a comprehensive uniform assessment tool to assess functional need which would meet the requirement for uniform assessment instruments. Not only is the state eligible to participate in the State Balancing Incentive Program, but to do so would require no significant additional resources because the state has the ability to or has already begun implementing these initiatives.

LTC In NYS	Expenditure	Percentage	Community v. Institution
Personal Care	$2.721 B	14%	47%
All HCBS Waivers	$4.854 B	24%	
Certified Home Health	$1.775 B	9%	
Nursing Facilities	$7.618 B	38%	53%
ICF-MR	$3.112 B	15%	
Total	$20.080 B	100%	100%
Based on 2009 CMS data analyzed by Steve Gold, presented at the New York Association on Independent Living Olmstead Conference, October 2010			

New York State is eligible for this enhanced FMAP until its long term care spending shifts by three percent toward the community. Factoring in a reduced growth rate in total long term care spending – to account for needed budgetary reductions – New York State can expect to achieve a savings of $12M in total long term care spending over three years by rebalancing the system toward community-based options. 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 2% match.

Under the *Patient Protection and Affordable Care Act*, the Money Follows the Person Rebalancing Demonstration Program (MFP), scheduled to end in 2011, was extended for five years, with an additional annual appropriation of $450 million for each FY 2012-2016. Although states are required to spend the additional FMAP available through this program on rebalancing initiatives, and thus there are no cost savings generated directly by this program, MFP was specifically designed to support these rebalancing initiatives.

DOH's MFP workgroup, which advises the state on the program's implementation, has strongly recommended continuing and expanding two critical elements of the project:

1) activities intended to increase affordable, accessible and integrated housing for seniors and people with disabilities, and 2) outreach to individuals in nursing facilities who may wish to live and receive services in the community. Both of these initiatives are critical to the state's rebalancing efforts.

In 2005, the Independent Living Centers and disability rights community worked closely with DOH on the state's initial MFP application to CMS, identifying the lack of affordable, accessible and integrated housing as the primary barrier to successful Nursing Home Transition and Diversion. The

advocate group also identified providing residents who might choose to leave a nursing facility with information about transitioning to community living, on a peer to peer basis, as a promising way to identify transitions that could generate the most significant savings through enrollment in the NHTD waiver.

Independent Living Centers play a major role in both of these initiatives. In fact, New York's MFP program has become a national model of collaboration by a state with the Independent Living Center community. According to a report produced by CMS in association with Ascellon that examines the relationship between Centers for Independent Living (CILs) and MFP,

> *"CILs are key partners in the MFP Demonstration in the five states included in this report [including New York]. Keys to a successful relationship between project staff and CILs are learning about each other's philosophy and developing a process that supports choice and independence while recognizing and preparing for the risks that might accompany the consumer's choices."*[10]

More generally, another recent study funded by CMS supports the critical role of ILCs in helping states comply with federal law and save costs:

> "*Centers for Independent Living continue to demonstrate value in assisting individuals with disabilities of all ages to gain needed skills and obtain needed supports to live independently in integrated community settings. Centers have proven to be effective partners in helping government comply with the Americans with Disabilities Act and save money by supporting individuals with disabilities to live in less-costly community settings.*"[11]

The state should direct additional resources from the increased FMAP available through MFP for rebalancing activities to ILCs during the five year MFP extension. These funds should be used to continue and expand the existing initiatives, which have been implemented in partnership with ILCs, to increase affordable, accessible and integrated housing for seniors and people with disabilities and to provide outreach to individuals in nursing facilities who may wish to live in the community

TRANSITION FROM A MEDICAL-MODEL TO A CONSUMER DIRECTED MODEL OF CARE

Not all home and community-based services are alike or equally cost-effective. A person may receive long-term services and supports in the community from a medical model agency or through a consumer directed program. Medical model services were developed during a time when disability was seen as a medical condition requiring medical intervention. In contrast, consumer directed programs evolved because seniors, people with disabilities, and their families wanted to assert more direct control over the services they received.

In a consumer directed program, *consumers* (or family members), as opposed to an agency, manage the services and are empowered to hire, direct, and dismiss their attendants in accordance with their plan of care. This results in lower costs to the state through reduced reimbursements, because consumers take on the administrative roles (i.e., scheduling) that an agency nurse or case manager is typically responsible for. In addition, aides can perform skilled tasks that under an agency model are performed by expensive medical personnel.

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[10] *Exploring the Relationship between the Money Follows the Person (MFP) Program and the Centers for Independent Living (CILs), Final Report.* Robert Mollica, Rhonda Simms, and Sheila Scott. Prepared by the Centers for Medicare and Medicaid and Ascellon. Contract No. GS 10F 00244S, Task No. HHSM-500-2007-00262G. April 30, 2010.

[11] *Independent Living Centers: Experienced Local Partners for Medicaid Home and Community Based-Services.* Center for State Health Policy, Auerbach and Claypool, June 2008.

Studies have proven that consumer directed services result in higher satisfaction among consumers. According to a report by the National Council on Disability, "Studies of consumer direction indicate positive outcomes in terms of consumer satisfaction, quality of life, and perceived empowerment. There is no evidence that consumer direction compromises safety—in fact, the opposite appears to be true. Individuals who have participated in consumer directed systems express strong preference for consumer direction and satisfaction with their care."[12] The state should offer consumers real choice in long term care and promote programs, like consumer direction, that produce higher levels of satisfaction and reduce costs.

5. Implement a plan to shift some people currently receiving long term services through the Certified Home Health Agency (CHHA) program to the less costly Consumer Directed Personal Assistance Program, for a potential first-year savings of $4.5 million in the non-federal share.

The Consumer Directed Personal Assistance Program (CDPAP) is the most cost-effective model for assistance in the home because the per-hour rate for CDPAP is less costly than other home care services. As previously mentioned, cost savings results from reducing or eliminating the nurse/case manager role in scheduling, training and supervising the direct care worker. Additional dramatic savings accrue under CDPAP by allowing direct care workers to perform skilled tasks which otherwise would be performed by expensive medical personnel.

New York State relies significantly on agency-controlled home care, ranking number one in Certified Home Health Agency (CHHA) care per capita spending at $90.85 in 2009. Certified Home Health care accounts for 14.75% of the state's Medicaid long term care spending for aged and physically disabled individuals. In other states, CHHA services account for a far smaller percentage of long term care spending. For example, Certified Home Health care in Washington State is just 2.04% of spending. Compared to Certified Home Health Agency care, CDPAP reduces Medicaid spending by $9.52 for every hour of service. The state can realize significant savings by better utilizing CDPAP instead of CHHA services.

We recommend the state initiate efforts targeting the CHHA population receiving long term services. Because CHHA services are not authorized through the Local Departments of Social Services (LDSS), the Department of Health can identify usage for each county, including consumers who are the long term, high cost users of CHHA services. The LDSS could meet with these consumers and assess whether they would be appropriate for CDPAP, paying particular attention to whether the consumer has a "self-directing other" (such as a family member) who could manage the services if the consumer cannot do this for him or herself. The State should direct counties to meet specific transition targets based on these usage reports.

Using a conservative assumption of 5 hours of service per day and shifting approximately 1,000 people over one year from Certified Home Health care to CDPAP, the state would reduce Medicaid spending by approximately $8.9 million (a savings in the non-federal share of $4.5 million) during the first year of implementation.

Assuming that the state pursues the CFC Option as a way to secure the enhanced FMAP, this proposal would generate additional savings. In addition to saving money because people are being served in a more cost-effective model, were CDPAP incorporated into the CFC Option, the state would receive an additional $1.11 million in the first year. This amount would increase in each year

[12] *Consumer directed health care: how well does it work?* National Council on Disability, October 2004.

as more people transition into the program, resulting in an additional $22.36 million is savings over five years.

The Independent Living Center and disability rights community successfully advocated in the 2009-2010 state budget for a change in state law to expand participation in CDPAP .[13] The amended statute requires counties to set CDPAP enrollment targets and develop annual implementation plans, with the goal of increased consistency in approved service levels across the state. It also provided funding to implement a peer based program of education and outreach to eligible individuals, and training for discharge planners, local Departments of Social Services, and others. As a result, DOH issued an RFP and is currently negotiating a contract with the Consumer Directed Personal Assistance Association of New York State to implement the program in 2011. As counties identify consumers in CHHAs who could be effectively served at a lower cost in CDPAP, the counties could refer these consumers to the new program to assist with the transition. This proposal requires no additional funding and can be implemented administratively through the Department of Health.

6. **Implement a plan to shift some people currently receiving Personal Care Services to the less costly Consumer Directed Personal Assistance Program, for a potential annual savings of $1.9 million in the non-federal share.**

   CDPAP is less costly than traditional Personal Care services because the state reduced the allowable direct care and training costs as well as the allowable percentage for administrative costs. Although these savings are not as dramatic as transitioning individuals from CHHAs, they are still significant. More importantly, the process necessary to realize these savings requires no additional staff or infrastructure and dovetails into existing work done by the LDSSs. People who receive personal care – in both traditional personal care and the consumer directed program – are required to be reassessed every six months for the service. During this already routine assessment, the local Departments of Social Services could assess for CDPAP eligibility and refer consumers to CDPAP.

   Because many staff in the local Departments of Social Services are more comfortable with the traditional medical model programs, implementing this proposal would require a strong policy commitment from Albany. To assure local implementation of this initiative, the Department of Health should set aggressive targets for each county. On average, CDPAP is 6.89% cheaper than traditional personal care with a per hour Medicaid savings of $1.46. By shifting about 2,000 people from Personal Care to CDPAP, at an average of 7 hours of service per day, in the first year the state would reduce Medicaid spending by about $3.9 million (a savings in the non-federal share of $1.9 million). Over five years, this proposal saves $38.85 million in non-federal share spending.

7. **Expand the pool of direct care workers in the Consumer Directed Personal Assistance Program to match the federal rules for paid family caregivers, which would promote the use of this cost-effective service, for a potential annual savings of $11.48 million in the non-federal share.**

   The relationship between an attendant and the consumer is essential to the success of the any home care service, but the ability to select who comes into your home is a critical component to the success of the Consumer Directed Personal Assistance Program. To increase the savings generated by using CDPAP, the state should implement policies which would promote its use. Because of the type of assistance that is being provided, individuals with disabilities, particularly seniors, often prefer having a family member serve in this role. In addition, family members often choose to

[13] Social Services Law § 365-f

institutionalize a senior who would otherwise live with them, because they do not want to have strangers providing services in their homes.

Federal regulations state that personal attendants cannot be a family member who is "legally responsible" for the care of an individual (42 C.F.R. § 440.167). This has been interpreted to include spouses and legal guardians (parents) of minors. However, New York State is currently much more restrictive than the federal regulations and prohibits additional members of the consumer's family from working as an attendant, including a daughter, son, daughter-in-law or son-in-law (18 NYCRR § 504.14(h)(2)). Based on vigorous advocacy last year, proposed regulations for CDPAP were recently issued, and include this expansion of eligible workers (18 NYCRR § 504.28). Final regulations are expected to be adopted by the end of CY 2010. We strongly support the inclusion of the expanded definition of eligible workers in the final regulations.

Changing this regulation would allow a large nursing facility population to transition to the community. For example, a daughter or daughter-in-law of an elderly woman in a nursing home could leave her current job and be paid to provide her relative with care at home. Concerns have previously been raised about paying people who might otherwise provide informal support, however Departments of Social Services still control authorizations and balance the availability of informal supports with paid care. Departments of Social Services are gatekeepers for authorization of hours and are the front line defense against fraud or abuse. By amending the state regulations to expand the definition of personal attendant, we estimate that 1% of the Medicaid-funded nursing facility population over 65 years could transition into the community and the state would save $22.9 million annually in institutionalization costs during the first year ($11.48 million in the non-federal share).

This proposal, combined with implementation of the CFC Option, would generate additional savings from the enhanced FMAP. The state would receive an additional $2.23 million in the first year. This amount would increase in each year as more people transition into the program, resulting in an additional $36.20 million is savings over five years.

This change would also address a critical shortage of home care workers that has stalled efforts to shift toward a community-based model of long term services and supports. Previous efforts in New York State to address the shortage of direct care workers have focused primarily on making the job more desirable to workers by providing improved benefits or a career ladder. While these efforts have had some impact, the efforts target the same pool of workers and have a limited effect in bringing in additional workforce. Our proposal significantly expands the pool of workers available and encourages additional workers who would not otherwise be attendants to provide these critical services, addressing a significant barrier to increasing cost-effective community-based services and reducing the state's Medicaid spending.

8. Better utilize assistive technology to reduce personal care spending, for a potential first year savings of $1.74 million in the non-federal share.

While there are options for obtaining assistive technologies (AT) under the NHTD and TBI waivers and through vocational rehabilitation services, the Department of Health has generally overlooked assistive technology as a potential method of cost savings. Increasing use of tele-health has been proposed in policy discussions about the use of technology, but meeting more basic needs of individuals who want to live independently has been ignored. Technology, however, has the possibility of significantly reducing long term care costs. According to a study in the *American Journal of Public Health*, "The multivariate models show a strong and consistent relation between equipment

use and hours of help—the use of equipment was associated with fewer hours of help, after control for other factors."[14]

For example, people who require 24-hour or overnight home care because they are unable to get out of bed independently to open the door for the morning attendant, could potentially receive reduced hours if they were provided with assistive technology to allow them to open the door. We recommend that the Department of Health instruct local Departments of Social Services to assess consumers who receive a high number of service hours as to whether assistive technology could reduce the hours of service necessary. The Departments of Social Services would refer these consumers to the NHTD waiver for service coordination and assistive technology. Assuming that the state provides such assistive technology to only 12 people a month from across the state, reducing their need for personal care by 8 hours a day (an overnight shift), and factoring in a 1% disenrollment projection, the state would reduce Medicaid spending by $1.74 million in the non-federal share in the first year.

PROJECTED SAVINGS OVER FIVE YEARS

While immediate one-year reductions in Medicaid spending are the first priority, the new administration must consider ways to contain costs over the longer term as well. By implementing our proposals, the state can fundamentally restructure its long term care system, comply with the *Olmstead* decision which requires the state to serve individuals in the most integrated settings, take advantage of additional federal funding, and change the trajectory of New York's long term care spending.

Projected Savings in State-Share Medicaid Over Five Years

	Year 1	Year 2	Year 3	Year 4	Year 5	Total
Recommendation 1	$6.31 M	$17.01 M	$26.51 M	$34.93 M	$42.39 M	$127.15 M
Recommendation 2	$6.21 M	$16.77 M	$26.12 M	$34.40 M	$41.75 M	$125.25 M
Recommendation 3	$7.85 M	$66.09 M	$102.85 M	$106.03 M	$108.57 M	$391.39 M
Recommendation 4	$4.02 M	$4.10 M	$4.19 M	$0 M	$0 M	$12.31 M
Recommendation 5	$4.46 M	$12.04 M	$18.75 M	$24.71 M	$29.98 M	$89.94 M
Recommendation 6	$1.93 M	$5.20 M	$8.10 M	$10.67 M	$12.95 M	$38.85 M
Recommendation 7	$11.48 M	$28.56 M	$40.78 M	$49.52 M	$55.77 M	$186.11 M
Recommendation 8	$1.74 M	$5.02 M	$7.96 M	$10.58 M	$12.93 M	$38.23 M
Total	$44.00 M	$154.79 M	$235.26 M	$270.84 M	$304.34 M	**1,009.23 M**

If the proposed pace of enrollment in the NHTD waiver is maintained over the next five years, the state will reduce Medicaid spending by $254.3 million through transitions from nursing facilities ($127.15 million non-federal share) and by $250.5 million through diversions ($125.25 million non-federal share).

Implementing the Community First Choice Option would address a number of critical issues in the state's system for providing long term services and supports, including the need for assistance with medication administration, while saving New York more than $391 million over five years, with FMAP savings continuing into the future.

Calculating CFC Savings

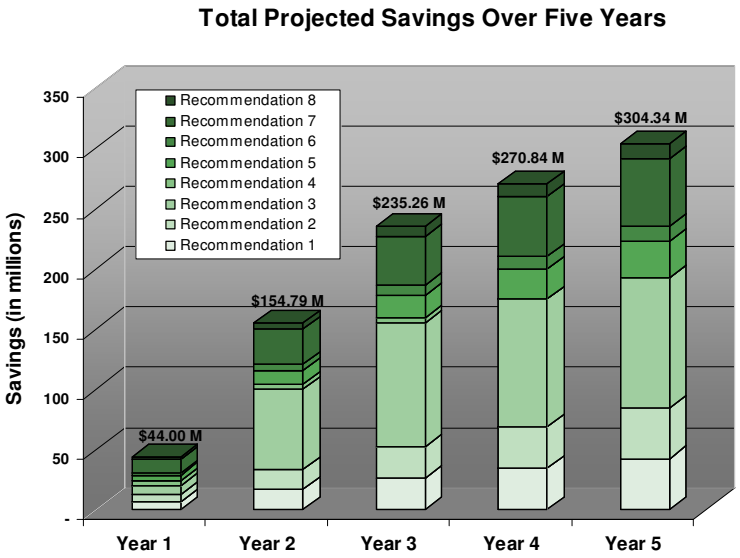
	Year 1	Year 2	Year 3	Year 4	Year 5	Total
PCA/HCSS to CFC	$4.51 M	$57.54 M	$90.26 M	$90.26 M	$90.26 M	**$332.83 M**
Impact of CFC on Rec 5	$1.11 M	$2.99 M	$4.66 M	$6.14 M	$7.46 M	**$22.36 M**
Impact of CFC on Rec 7	$2.23 M	$5.56 M	$7.93 M	$9.63 M	$10.85 M	**$36.20 M**
Total	**$7.85 M**	**$66.09 M**	**$102.85 M**	**$106.03 M**	**$108.57 M**	**$391.39 M**

As New York rebalances the long term care system, we should shift away from a medical model of service provision that is over-reliant on expensive medical professionals to perform tasks that family

[14] "Does Assistive Technology Substitute for Personal Assistance Among the Disabled Elderly?" *American Journal of Public Health*. Helen Hoenig, MD, Donald H. Taylor, Jr, PhD, and Frank A. Sloan, PhD. 2003 February; 93(2): 330–337.

members have always performed and that paid attendants should be able to perform as well. This will help the state comply with the ADA and the *Olmstead* decision and reduce Medicaid costs. If the state encouraged the transition of 1,000 people annually from Certified Home Health programs to the Consumer Directed Personal Assistance Program, by the end of the fifth year Medicaid spending would be reduced by $179.8 million ($89.94 million non-federal share). Similarly, by shifting 2,000 people annually from traditional personal care to consumer directed services, the state could realize a reduction in Medicaid spending of $77.7 million ($38.85 million non-federal share).

As proposed above, a regulatory change in the consumer directed program could also yield significant savings. If the state expands the pool of direct care workers to be aligned with federal regulations, over the next five years the State would reduce Medicaid spending by $372.2 million ($186.11 million non-federal share). Finally, by providing assistive technology options to consumers who would benefit and who currently receive high hours of personal care, New York State could realize a reduction in Medicaid spending of $76.5 million ($38.23 million non-federal share).



If these policy recommendations are implemented today, by the end of the fifth year, **New York State would reduce its Medicaid spending by more than $1.009 Billion.**

CONCLUSION

In New York today, a "perfect storm" of economic, policy and legal issues threaten its ship of state:

- Annual budget deficits approaching $10B;
- A long term care system out of balance both with what New Yorkers want, and what New York taxpayers can afford;
- Increased federal efforts by both the Department of Justice (DOJ) and the courts demanding that States comply with the Americans with Disabilities Act and the U.S. Supreme Court's *Olmstead* decision (now 10 years old), which further threaten state solvency without preemptive action.

In the face of this storm, with these recommendations, the disability community is prepared to stand shoulder to shoulder with Governor Andrew Cuomo to pursue aggressive efforts to balance the state budget, while advancing our established legal rights.

Detailed plans for each proposal that outline specific steps necessary for the State to achieve projected savings, as well as copies of supportive research identified in this paper, are available upon request. For additional information, please contact Bruce Darling, President/CEO, Center for Disability Rights (BDarling@cdrnys.org; ph. 585-546-7510) or Melanie Shaw, Executive Director, New York Association on Independent Living (MShaw@ilny.org; ph. 518-465-4650).