DEVELOPING A COMPREHENSIVE, EFFECTIVELY WORKING OLMSTEAD PLAN IN NEW YORK STATE

Prepared by The Coalition to Implement Olmstead in New York (CTIONY)

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I. INTRODUCTION

The Coalition to Implement Olmstead in New York (CTIONY) was formed to advocate for the implementation of this historic decision in our state and has coordinated advocacy activities to promote seniors and people with disabilities living in the Most Integrated Setting. Currently, eligibility criteria for community based services available in New York State for people with disabilities and seniors exclude some groups based on their age or diagnosis. It is important to stress that the *Olmstead* Decision applies to people of ALL ages and with ALL types of disabilities, including Alzheimer's disease, other dementias, multiple sclerosis, developmental disabilities, stroke, psychiatric diagnoses, and spinal cord injuries. Although the systems divide us by diagnosis, age, and our location within the state, our Coalition is united in the belief that ALL seniors and ALL people with disabilities have the right to live in the Most Integrated Setting.

During the last year we have advocated for New York State legislation (A.9913-B/S.7342-A) designed to begin the Olmstead Planning process in New York State. On September 17, 2002, Governor George E. Pataki signed the Most Integrated Setting bill into law. This law calls for the creation of a Most Integrated Setting (MIS) Coordinating Council which is charged with the development and implementation of a comprehensive, effectively working plan to ensure that individuals with disabilities of all ages are able to live and receive services in the Most Integrated Setting as required by the Supreme Court's *Olmstead* Decision.

Now that New York State is beginning its Olmstead Planning Process, CTIONY has developed this policy paper to provide input to New York's Olmstead Planning Process to ensure that the plan that is developed is both comprehensive and effective. We have based this policy paper on our combined years of experience navigating through New York State's long-term care system, consumer input, and research on Olmstead related policies, including the requirements of HCFA – the predecessor of the Center for Medicare and Medicaid Services (CMS), a review of Olmstead Plans from other states, and recommendations from the National Association of Protection and Advocacy Systems.

Our recommendations for New York State's comprehensive, effectively working Olmstead Plan can be divided into three major areas: (1) process for creating the plan, (2) components of the plan, and (3) issues that the plan must address.

II. PROCESS FOR CREATING A COMPREHENSIVE, EFFECTIVELY WORKING OLMSTEAD PLAN

Advocates throughout the country have found that certain components of the planning process are critical to the development of an Olmstead Plan which is both comprehensive and works effectively to promote people living in the Most Integrated Setting.

Primary stakeholders must be fully involved in the development, implementation and evaluation of the state's Olmstead Plan.
A comprehensive, effectively working Olmstead Plan must be developed with advocates, seniors, and individuals who have disabilities. Not only should advocates, seniors, and individuals who have disabilities be represented on the MIS Coordinating Council as required by the statute, they must be meaningfully included in all facets of plan development, including any committees formed by the Council and any individual agency workgroups. Seniors and individuals who have disabilities are the people who have first hand experience with the issues that the plan will address and understand the implications of the Council's decisions on the lives of real people who need community-based services. The inclusion of these groups and their advocates must entail more than just inviting representatives to participate, it means involving these primary stakeholders and the people who represent them in a meaningful way. There are a number of activities the MIS Council should undertake to assure adequate consumer and advocate involvement.

The MIS Coordinating Council should work with Independent Living Centers, Area Agencies on the Aging and their multiple subcontractors to coordinate true statewide consumer participation in the Olmstead Planning Process. These organizations are directly connected to seniors and people with disabilities who will be affected by the Plan; they can easily identify participants and provide real consumer input in a cost-effective manner. We recommend that the MIS Coordinating Council work with these organizations to hold two public hearings downstate at accessible locations and six public hearings at accessible locations around upstate to speak directly with the seniors and people with disabilities who are at risk of institutionalization. These organizations should also coordinate at least 16 focus groups around the state and interview 128 people in nursing homes and institutions who want to get out. By understanding the reasons people were placed in these facilities, the Council will be better able to determine the changes needed to prevent institutionalization. Local Departments of Social Services must also be actively engaged in the Olmstead Planning Process. Finally, seniors, people with disabilities and their advocates must be involved in the implementation of the Plan and the ongoing evaluation of the Plan as it is implemented.

The process for developing the state's Olmstead Plan must be a public process open to public review and monitoring.
All Olmstead planning meetings should be open to consumers, advocates and members of the public, even if they are not on the Council or its committees. This applies to the meetings of the MIS Coordinating Council and any committees the Council forms. All of the individual state agencies that are working on Olmstead-related issues must hold public meetings as well. In an effort to optimize attendance at Council Meetings by interested consumers, meetings should be held in varying locations around the state. In addition to advocates for seniors and people with disabilities, representatives from the United States Department of Health and Human Services, Office for Civil Rights should also be represented in these meetings.

Recognizing that many people interested in this process will not have the resources to attend meetings, New York State must follow the lead of other states and publish detailed meeting minutes, planning materials and related documents on the internet. Of course these materials

should be available in a format that is useable by people with all types of disabilities, including visual impairments. The Olmstead website should also provide an opportunity for people to provide their own input and feedback on the plan.

The Olmstead Plan must be based on empirical and quantitative data.
The state's Olmstead Plan must be based on empirical and quantitative data regarding the utilization of current community based services and institutional settings. This data should include the number of individuals currently receiving various community based services such as home health care, Medicaid waiver services, DSS-administered services including personal care and consumer directed personal assistance, and NYSOFA-funded programs such as home-delivered meals, social adult day services, and EISEP services. The data must also include the number of individuals (both institutionalized and non-institutionalized individuals) on waiting lists for various community-based services, and the number of individuals currently residing in institutional settings. The data should also include current funding levels for each of the above-mentioned areas. The data collected should serve as a starting point in the development of the comprehensive, effectively working Olmstead Plan and could be used to develop target goals and, in later years, to assess the progress which has been made in addressing the institutional bias in New York State's current long term care system.

The Olmstead Plan must include the collection of qualitative data about consumer satisfaction and quality assurance.
Data must also be collected regarding consumer satisfaction with existing services and supports. Consumers and advocates must be surveyed to obtain information on what strengths and weaknesses exist in New York State's Long Term Care System. This data will be used to improve existing community-based services and assist in the development of new services that are needed so that individuals with disabilities and seniors can live in the Most Integrated Setting.

III. COMPONENTS OF A COMPREHENSIVE, EFFECTIVELY WORKING OLMSTEAD PLAN

New York State's Olmstead Plan should be designed so that it promotes full community integration for individuals with ALL types of disabilities and seniors through real systems changes and provides real choice for people who want to live in the Most Integrated Setting. The following components have been identified as critical to a comprehensive, effectively working Olmstead Plan.

The Olmstead Plan must be comprehensive enough to assure that people with disabilities and seniors receive services in the Most Integrated Setting.
Effective Olmstead planning must take into account all areas that affect the lives of individuals with disabilities and seniors, including housing, attendant services, transportation, employment, education, and assistive technology. It is critical that the plan address infrastructure issues such as staffing, capacity, and equipment. Other areas that the plan must address will be determined via input from consumers and advocates for individuals with disabilities and seniors.

The Olmstead Plan must include measurable goals with target dates.
The plan must be substantive in that there must be measurable goals. Goals should be specific and include target numbers of people to be moved out of institutions and nursing homes and target dates by which this deinstitutionalization will happen. The plan must also include target numbers of people diverted from such placements.

Furthermore, timeframes for deinsititutionalization should be the same regardless of disability or type of institution. No one group of individuals should be given preference over another group based on the type of disability or age. Every individual, regardless of age, diagnosis or type of disability, has the right to receive services in the Most Integrated Setting and – if placed on a waiting list for community-based services – to know that the list will move at a reasonable pace[1].

The Olmstead Plan must include recommendations for funding.
Goals without resources are empty promises. The Plan must include recommendations for the funding and resources needed to achieve the Plan's goals. These recommendations must be included in the budgets proposed by the Governor and passed by the Legislature.

The Olmstead Plan must coordinate the state's Olmstead efforts, and drastically restructure community-based services for people with disabilities and seniors.
Because *Olmstead* issues cut across many traditional lines, a number of states have used restructuring as a means of addressing their compliance with the decision. New York's plan, must create the Office of Integrated Community Services. This approach will allow the state to effectively coordinate the various policies that will promote people living in the Most Integrated Setting. The Office of Integrated Community Services will consolidate services and supports from various state agencies that currently oversee both institutional settings and community-based alternatives.

It is clear that the current structure of state departments, offices, and agencies is detrimental to individuals with disabilities and seniors that want to live in the Most Integrated Setting. The maze of services is complicated by the multiple types and levels of bureaucracy. There is also an inherent conflict of interest because state agencies that coordinate community-based services which would allow people to live in the Most Integrated Setting are also responsible for maintaining the institutions these people want to leave.

The New York State Department of Health (NYS DOH) is a good example of this inherent conflict. NYS DOH is responsible for the oversight of nursing homes. This department also manages Medicaid waiver programs and other community-based services such as home health care. In meetings with the NYS DOH, it has become clear that while many of the Department's staff supports the concept of serving people in the Most Integrated Setting, the Department is tied to the nursing home industry. Perhaps the most striking example of this institutional bias is the Department's submission to Project 2015: State Agencies Prepare for the Impact of an Aging New York. The report includes briefs by 36 State agencies describing the impact of New York's changing demographic profile and suggesting strategies to meet these impacts and assure the continuing well being of the state's citizens. NYS DOH's submission to Project 2015 emphasized the need for increased nursing home beds. It mentions "nursing homes" 15 times

[1] According to ADAPT "reasonable pace" is determined to be 90 days.

and community-based services once. The *Olmstead* Decision and its implications were not mentioned even once in the DOH paper.

By reorganizing community-based services under the newly created Office of Integrated Community Services, the state will eliminate this conflict and be able to streamline some of the bureaucracy to cut administrative costs. For example, Medicaid waivers are currently managed by multiple state agencies, each with their own eligibility criteria and bureaucracy. Although these waivers have been demonstrated to be cost effective and provide greater consumer satisfaction, they are seen as afterthoughts. By consolidating the management of community-based services and the various Medicaid waiver Programs, not only will the state reduce the administrative burden on tax payers, it will create an environment where these programs can flourish.

The Office of Integrated Community Services will be headed by a person who is appointed to coordinate the state's efforts to comply with the *Olmstead* decision. This cabinet-level position will serve as the state's point person on *Olmstead* Compliance, coordinate staff support to the Council and its committees, assure that consistent and coordinated policies are developed and implemented, work with Health and Human Service Office of Civil Rights to resolve Olmstead complaints, assure that requests by individuals for reasonable accommodations to allow them to live in the Most Integrated Setting are handled appropriately, and assist individuals and advocates with Olmstead issues in navigating the state's complex system.

The Olmstead Plan must include a comprehensive system for the identification and assessment of individuals for community living.

The Olmstead Plan must include a process for identifying institutionalized individuals who want to live in the Most Integrated Setting as well as those now living in the community who are at risk of institutionalization. The plan must develop assessment tools, which will be used to determine the level and types of services to be provided to reintegrate these individuals, or to prevent their institutionalization. As required by the Health Care Finance Administration (HCFA), the predecessor of the Centers for Medicare and Medicaid Services (CMS), the plan must ensure that:

> "…Individuals with disabilities benefit from assessments to determine how community living might be possible (without limiting consideration to what is currently available in the community)… The plan evaluates the adequacy with which the State is conducting thorough, objective and periodic reviews of all individuals with disabilities in institutional settings… to determine the extent to which they can and should receive services in a more integrated setting." [2]

[2] Letter from Timothy Westmoreland, Director, HCFA Center for Medicaid and State Operations and Thomas Perez, Director, Office of Civil Rights of the United States Department of Health and Human Services, to State Medicaid Directors, dated January 14, 2000 *http://www.hhs.gov/ocr/olms0114.htm*.

HCFA/CMS requires states to evaluate whether their "existing assessment procedures are adequate to identify both individuals in the community who are at risk of placement in an unnecessarily restrictive setting, and institutionalized individuals with disabilities who could benefit from services in a more integrated setting."

The Council will need to develop a new assessment system. HCFA specifically requires that the assessments not be limited to "consideration to what is currently available in the community." The current practice of hospital and nursing home discharge planners is to assess discharge potential by what services are presently available. See 10 N.Y.C.R.R. § 405.9(f)(3)(i).[3] HCFA/CMS specifically forbids this. Instead, the assessment tool must consider whether the person could live in the community with services that may not actually be available, such as accessible and affordable housing, environmental modifications, 24-hour home care (which should be but is not necessarily actually available to Medicaid recipients), case management, etc. The assessment should assume that all individuals can live in the most integrated setting if reasonable accommodations can be made.

To accomplish its purpose as a data-gathering tool, a proper assessment must be standardized and designed with the input of seniors, people with disabilities and their advocates using HCFA's guidelines. The assessment must specifically capture which services would be necessary in order for the individual to be served in the community. Staff conducting or giving input used in these assessments must be specially trained. CTIONY proposes delegating the assessment task to community living specialists who have knowledge of community-based resources and who would solicit information from individuals with personal knowledge of the consumer, a qualified treating professional, family members, friends, and advocates identified by the consumer.

Other states have recognized that the institutional staff are not familiar with community-based services and these states have funded Independent Living Centers, consumer groups, Area Agencies on the Aging and their subcontractors to design assessment tools and implement identification activities. These organizations have many years of experience with community based services. At a minimum the state's plan should identify and assist at least 1% of the nursing home population in New York State move into the community each year. Based on the experience of other states, this would cost about $7.5 million annually. However, this cost could be cut in half by leveraging the federal share if this program were funded as a Medicaid service.

There is currently no method in New York State to identify persons living in the community who are at risk of institutionalization. The Council will need to identify different contact points in the community where people at risk of institutionalization can be assessed. In addition to people admitted to hospitals or rehabilitation programs, anyone who applies for any of the various home care services – both Medicaid as well as EISEP and Medicare – must be assessed.

[3] Current assessments are wholly inadequate. The mere requirement that nursing homes annually assess "discharge potential" in their annual assessments, with no further guidance, does not ensure compliance with *Olmstead.* 10 N.Y.C.R.R. § 415.11(a)(2)(vii).

The Olmstead Plan must create the services and supports which are needed so that placement in the Most Integrated Setting becomes the norm.
New York does currently have the infrastructure or the services to keep people in the community. New York's Olmstead plan must emphasize systemic changes such as restructuring the long-term care system to create and encourage efficiencies, cooperation and collaboration. It must change the way New York does business to best utilize existing resources as well as any new resources.

After reviewing comments from stakeholders, analyzing empirical data about current services and supports, and reviewing consumer satisfaction surveys, necessary community based services and supports should be created so that all individuals with disabilities and seniors can live in the Most Integrated Setting. These services and supports should include a Medicaid waiver for individuals with physical disabilities, cognitive disabilities, such as Alzheimer's disease and other dementias, and seniors. These services must also include the expansion of existing Medicaid waivers, a "money follows the individual policy" that allows individuals who are institutionalized to receive services in the most integrated setting, training of health care providers about independent living philosophy, increases in wages and benefits to community support workers and attendants, development of accessible, affordable, and integrated housing, and availability of adequate transportation for individuals with disabilities.

The Olmstead Plan must include a tracking system to assess the effectiveness of Olmstead-related activities and a data collection system to assess and identify gaps/problems and issues preventing people from living in the Most Integrated Setting.
The Olmstead Plan must include a tracking system to collect data on the number of individuals transitioned to the community, the number of people diverted from institutions, the number of individuals who are re-institutionalized, and the reasons for the return. Data collection should also include the numbers of individuals who are newly institutionalized and the community resources which were unavailable or needed to prevent the institutionalization. Finally data collection efforts should include tracking of any grievances or complaints which were filed.

This tracking system could also use existing MMIS (Medicaid Management Information Systems) and MDS (Minimum Data Set) data to review the length of time it takes to be assessed for community placement and the length of time between assessment and transition. The Olmstead Plan must include a data collection system that identifies gaps in community services and other issues that prevent or delay community integration.

The MIS Coordinating Council should create a review team consisting of various stakeholders, including government agencies, consumers, consumer advocacy groups, and Independent Living Centers, to review data obtained via the tracking system and identify trends and issues and make suggestions for improvements. This review team should meet, at a minimum, on a quarterly basis.

The Olmstead Plan must include quality assurance activities.
The plan must not only track hard data, it must also create a mechanism to evaluate the quality of services and monitor providers and vendors. This monitoring should include face-to-face interviews with consumers, service providers, and other advocates. In its annual report, the MIS

Coordinating Council must report back to stakeholders, including consumers and advocates, not only on the status of target dates and measurable goals, but also on the quality of services and supports being provided.

IV. ISSUES THE PLAN MUST ADDRESS

Consumers and advocates from across New York State have begun the process of identifying issues that New York State's comprehensive, effectively working Olmstead Plan must address. This summary of issues identified is meant to be a starting point for the development of a comprehensive, effectively working Olmstead Plan in New York. CTIONY recognizes that many other issues will be identified through the planning process.

New York State has not taken advantage of the flexibility which has been created at the Federal level.

The Federal government has worked with advocates to identify barriers in Federal policy which have prevented people from living in the Most Integrated Setting. A number of the policies have been changed and the state has been informed of these changes in letters to its Medicaid Director. However, New York State has not changed its policies to reflect the greater flexibility it has been given in at least four areas.

First, neither the Traumatic Brain Injury waiver nor the OMRDD waiver take advantage of the change that allows for individuals to receive case management services for up to 180 consecutive days prior to discharge. Increasing the payment for people transitioning out of institutions and nursing homes would increase the provider base willing to work with individuals who require significant assistance to live in the Most Integrated Setting. The state could use this as a fee-for-service funding stream for identifying and transitioning people back into the community.

Second, the federal government will also approve the inclusion of start-up and transition costs as a reimbursable Medicaid waiver service. To date, New York has not taken advantage of this new flexibility within Medicaid waiver programs.

Third, the Federal government recognizes that hospitalization often results in people losing attendants, so the HCFA/CMS initiated a policy change that allows waiver providers to be given a "personal assistance retainer" payment and allow the individual to "hold" the attendant for up to 30 days. The Consumer Directed Personal Assistance Programs are not authorized to bill for services when a CDPAP consumer is hospitalized or otherwise absent. Attendants cannot typically afford to lose the wages associated with the lost work. The state should ask CMS if it will allow CDPAP providers to receive a "personal assistance retainer" payment.

Fourth, the Federal government would also allow any relative, except spouse or parent of a minor child, to be paid as a personal assistant or attendant. The New York State regulations are far more restrictive than necessary and exclude other relatives who often would be willing to assist but cannot afford to quit their jobs to be a caregiver.

The Coalition to Implement Olmstead in New York would welcome to opportunity to discuss these and other ideas for taking advantage of these flexibilities.

Funding in New York State is securely tied to institutional settings while community resources are unavailable to support people in the Most Integrated Setting.
One significant policy change recommended at the federal level is the development of state policies which allow the money to follow the individual. Even in tough financial times, the state could develop policies which would allow individuals to use the funds which support them in segregated settings for life in the Most Integrated Setting. Rather than look at Olmstead compliance solely as an expansion of community-based services, the state could approach this as a shift of institutional funding to the community. Funding which is currently used in institutions, nursing homes, Intermediate Care Facilities, group homes and adult homes could be shifted on the aggregate to community services and supports.

For example, if it costs $78,110 to serve Mary in a nursing home and she chooses to leave the nursing home, the state would move $78,110 from the line item for nursing homes to cover the cost of serving Mary in her own home. This is basically budget neutral. This policy was implemented as a budget rider in Texas and has been successfully used to transition people back into the community. New York State should implement such a policy.

An easy change would address the issue of Adult Homes. Adult Homes are funded by increasing the state share of Supplemental Security Income (SSI). In 2003, the state will provide an extra $348 per month for individuals living in NYC Adult Homes; people in Adult Homes in other parts of the state receive an extra $318 per month. Many people in these facilities complain that they simply can not find housing at the "Living Alone" SSI rate of $639 per month. The state could allow these individuals to use the extra state-share funds which segregate them in adult homes for a housing subsidy while maintaining their Medicaid eligibility which would allow them to move to a more integrated setting.

The fact that New York State finances the development of nursing homes is a significant barrier to a "money follows the individual" policy for many seniors and people with disabilities. Despite the *Olmstead* decision, the New York State Dormitory Authority continues to issue bonds to support the development of nursing facilities. Rather than continuing to use taxpayer dollars to support the nursing home industry and develop additional nursing home beds, the state's *Olmstead* Plan should put a moratorium on creating additional nursing home beds, stop the issuance of future bonds to nursing homes, and create a rate-setting methodology for allowing nursing facilities to shut down beds and repay any outstanding bonds.

Fragmentation of services which are managed regionally or by county creates confusion, variation in available services, and unnecessarily forces people into institutions.
Coordination, authorization and management of community-based services in New York State is decentralized. Consequently, the availability of community-based alternatives varies widely from county to county. Although the original intent of this system was to provide greater flexibility to address local needs, in fact it has created an inconsistent patchwork of services which frustrates consumers and their families who are trying to navigate the system to avoid institutionalization or secure needed services. The current inconsistency can actually serve as a catalyst for change, spurring us to pull together the various stakeholders, including Area Agencies on Aging and their subcontractors, Independent Living Centers, Local Departments of

Social Services, hospitals, payers and others to look at systemic changes that would make the long-term care system more consumer friendly.

Inconsistency is most notable in the home care/personal care arena. Even though these are statewide programs, it is clear from reviewing county-based statistics that these programs are not implemented uniformly. Some counties favor the personal care option while others tend to use the home health care program. In addition to variation in the type of program, there is significant variation in the level of service which is authorized. Some counties limit authorization on home care services to very low amounts and tell people who need more than a few hours per day that they must go into a nursing facility. Other counties tell people that if they need more than a few hours per week that they must go into a nursing facility. In other counties it is possible to be approved for more hours, including 24-hour personal care or home health services, which enable persons with higher levels of disability, including people with Alzheimer's disease and dementias, to remain at home.

This issue affects virtually all community support services. Even where these services are administered regionally, as through the Office of Mental Retardation and Developmental Disabilities (OMRDD), we have identified significant variations in the availability of community-based services between districts. New York State's Olmstead planning process must address the inequities caused by this fragmentation and inconsistency.

The county share of Medicaid has created a disincentive to authorizing long term care services.

Counties both authorize home care services and are fiscally responsible for a percentage of Medicaid payments. This can create a conflict of interest that can force individuals into institutions and prevents them from living in the Most Integrated Setting. Often counties base authorizations for home care on the financial circumstances of the county rather than the assistance needs of the individual as required by state law. County employees, who are acutely aware of the cost issues and the impact of Medicaid on their local budgets, often arbitrarily limit authorizations for services based on cost.

In some cases, counties pay a lower share of some institutional services furthering the institutional bias. For example, counties pay about 10% of the cost of a Medicaid nursing facility placement, but pay 25% for the services provided under the Traumatic Brain Injury waiver. There is a clear county disincentive to referring people to that program.

New York State's Olmstead planning process must correct the inherent conflict of interest of the county-share system. To address the institutional bias, the state should explore ways to eliminate the county share on community-based services. This would create an incentive for the counties to authorize community-based services. The state could fund this initiative (and other Olmstead-related activities) through a NYS tax on sales by pharmaceutical companies or a tax on their advertising in the state.

New York State has focused virtually all of its Medicaid waiver resources on people with developmental disabilities and significantly limited access to community-based services under its Medicaid waiver programs to other populations.
The system of community-based services in New York State is, in many respects, based on political issues rather than actual needs. In 2001, of the $2.011 billion New York State spent on its Medicaid waiver programs, $1.981 billion was used for the Office of Mental Retardation and Developmental Disabilities Medicaid waiver. Almost 99 percent of all Medicaid waiver dollars serve people with developmental disabilities. Even more disturbing is that most of those funds are used to support people with disabilities in congregate settings. It is clear from these numbers that Medicaid waiver funding for individuals with other types of disabilities and seniors who want to live in the Most Integrated Setting is inadequate.

Even where an effective Medicaid waiver program has been created, eligibility criteria have excluded many people who want community-based alternatives. For example, New York State has a Medicaid waiver program to serve people with Traumatic Brain Injuries (TBI), including stroke. This program excludes people who have their stroke after they turn 65 and those who had their stroke before they turned 65 years old but did not apply for the program until after turning 65. This waiver also excludes people who may have functional needs similar to people with TBI, but whose diagnosis is different, including people with multiple sclerosis, Alzheimer's disease and dementia, or spinal cord injuries. In October 2002, the eligibility criteria for the TBI waiver program was expanded to include people younger than 18 years old who are also covered by the OMRDD waiver. This change creates a group of people who are eligible for both waivers while other groups cannot access funding for community-based alternatives to institutionalization.

New York State has saved considerable dollars through existing Medicaid waiver programs. In fact, the Traumatic Brain Injury (TBI) waiver program saves Medicaid over sixteen hundred dollars per person per month. Even in tough fiscal times, the state could develop a waiver which is limited to transitioning people to the community who have been in nursing homes at least 60 days. The state is already paying for more expensive institutional care rather than allowing people to receive less expensive community-based services. Creating such a waiver would not represent any real increase in expenditures. If the state transitioned just 1% (1,300 people) of the current nursing home population back into the community through a such waiver program. This plan would reduce Medicaid expenditures by over $25 million in the first year alone. This savings continues to accumulate as new savings are added each year when more people are successfully transitioned into the community. The total Medicaid savings over a five-year period would exceed $380 million dollars, with a $152 million reduction in the state share for 6,500 people.[4]

[4]

Average savings /mo.	Number of People	Months	Medicaid Savings
$1624	1300	60	$126,672,000
$1624	1300	48	$101,337,600
$1624	1300	36	$76,003,200
$1624	1300	24	$50,668,800
$1624	1300	12	$25,334,400
		Total Medicaid Savings	$380,016,000
		State Share Savings (40%)	$152,006,400

Additionally, the President's FFY 2004 Budget proposes $350 million ($1.75 billion over five years) for a "Money Follows the Individual" initiative. The Federal grant would pay the full cost of home and community-based waiver services for one year for individuals who transition out of institutions. After one year, the state would agree to continue care at the regular Medicaid matching rate. If funded, the program would vastly increase the Medicaid savings associated with such a waiver. Over five years the state would save the state an additional $152 million.[5] By implementing a waiver program and transitioning one percent of the population back into the community each year for five years, the state would save over $304 million. The lack of waiver programs serving people with disabilities and seniors results in the unnecessary institutionalization of these populations. New York State's Olmstead planning process must address this issue.

The lack of affordable, accessible, and integrated housing forces people into less integrated settings.

Consumers and advocates have identified that the lack of affordable, accessible, and integrated housing for individuals with disabilities and seniors is a major reason people end up in institutional settings. This issue affects every Olmstead-related group. People with mental health disabilities have been forced into adult homes because they cannot find adequate housing. People with physical disabilities end up in nursing homes because they cannot find housing that is accessible and affordable. People with developmental disabilities end up in congregate settings when they could live on their own if appropriate housing were available. Seniors are also forced into institutional settings because of inadequate or inaccessible housing.

Solutions exist. Even in a state facing major budget shortfalls, proposals have been developed which would create the additional revenue needed to address this issue. The state has considered the development of a Housing Trust Fund which would create a revenue stream for developing housing, providing rental subsidies, and paying for home modifications. The proposal would place a $30 surcharge on fines for DWI, DUI, Non-Use of Seatbelts, and Speeding. These illegal activities potentially lead to people acquiring disabilities, and it is estimated that this additional surcharge could generate $20-30 million each year. At one time, representatives from at least seven different state agencies, offices and departments were in discussions about this initiative. Under the MIS Coordinating Council, these discussions should resume and the Housing Trust Fund should be created as part of New York States Olmstead Implementation Plan.

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[5] Average daily waiver cost calculation:

Annual nursing facility cost	$78,110
Subtract annual savings ($1624 * 12)	- $19,448
Annual average waiver cost	$58, 622
Average waiver daily cost (Annual cost divided by 365)	$160.61

HHS Enhanced Match calculation:

Total five year waiver Medicaid cost ($160.61 * 1300 * 365 * 5)	$381,047,225
Total state share of waiver costs reimbursed under HHS program (40%)	$152,418,890

The state could also develop Medicaid waiver programs with home modification components. This would leverage federal funds (50% of the cost) for home accessibility modifications which might be necessary for people to take advantage of community-based housing options.

The state could improve communication with local Housing Authorities. The NYS Division of Housing and Community Renewal (DHCR) must encourage local Housing Authorities to apply for Section 8 vouchers and as a "local preference" target them for people who want to move out of nursing homes and other institutions to live in the Most Integrated Setting. DHCR must do the same with its own Section 8 program. The NYS Department of Health could also improve communication with local Housing Authorities. NYS DOH manages a rental subsidy program which requires people receiving the subsidy to apply for Section 8. The program, however, has no oversight method to assure that people maintain their application and status on the waiting list. One local Housing Authority exhausted its waiting list while the DOH program was under the impression that there was a still a three-year wait. By requiring third-party notification from the Housing Authorities with a simple policy change, the state will be able to leverage more federal housing funds which are currently lost because of inadequate communication.

The New York State Department of Housing and Community Renewal (DHCR) has not adequately addressed the needs of people with disabilities, particularly those in institutions or at risk of institutionalization, in its Consolidated Plan. Housing to meet the needs of this population must be considered a priority for all of DHCR's programs, including Low Income Housing Tax Credits, the Housing Development Fund, and the HOME Program. An initiative similar to the Senior Housing Initiative must be established for people with disabilities to reflect this priority.

DHCR must document that all developments funded and administered with federal funds conform to HUD's Section 504 regulations that require every development to set aside 5% of its units for people with mobility impairments and 2% for people with visual and/or hearing impairments. This documentation and information regarding accessibility should be maintained in DHCR's online Affordable Housing Directory. This Directory currently has no information relevant to accessibility. The absence of this information in the Directory is a glaring omission and suggests that DHCR does not have this information available. DHCR should collect this data and make it available to the Coordinating Council.

The MIS Coordinating Council should recommend that NYS adopt legislation mandating that ALL owners/managers of accessible/adaptable units report vacancies to a central registry. This would include owners/managers of any state or federally assisted units, public housing, and private market developments in New York State. This legislation should be modeled after the Massachusetts Housing Bill of Rights for People with Disabilities (1989). The housing registry could be made available on a website and through independent living centers. All housing would have to remain on the registry for a minimum length of time such as two weeks before rental. This will increase the chances that these units will be rented to a person in need of such a unit. The advantages to this legislation are that vacancy rates for owners/managers would decrease, awareness of accessibility/adaptability standards would increase, and it would greatly assist individuals with disabilities in locating accessible housing. The MIS Coordinating Council should encourage DHCR to continue their discussions with the Citizen's Housing and Planning

Association in Massachusetts and advocate the NYS legislature to create a mandated Housing Registry.

Finally, New York State should enact statewide Visitability legislation that would ensure that all newly constructed single-family homes funded by federal or state tax dollars and speculative housing are accessible to individuals with disabilities. This law would mandate that all such housing at a minimum have doorways at least 32 inches wide, at least one no-step entrance, and an accessible bathroom on the first floor. A statewide Visitability law would increase housing choices for persons with disabilities and seniors. The states of Texas, Kansas, and Georgia have already enacted statewide Visitability laws. New York State must follow suit.

The current home care system was designed in the 1960s and has not changed to meet the needs of people in Post Olmstead era.

The original home care system was designed to support family caregivers providing for their relatives with an acute illness or disability. This system is ill equipped to address the needs of people with disabilities and seniors who want to live independently and be productive members of society. Consequently people are forced into nursing homes because they can not get the home care services they have a right to under New York State regulations and the *Olmstead* decision.

Major issues within the home care system include:

- State regulations have loop-holes that allow home care agencies to refuse to serve individuals who are uninformed about their *Olmstead* or *Catanzano* rights. For example, a request to "assess for home care" or "informal referral" does not result in notification to or by the Department of Social Services that an individual has been "denied" services because a specific "order" for home care was not generated. Individuals who have been informally denied services are never placed on a waiting list and live out their lives in nursing homes unaware that they have the right to home care.

- Hospitals are unaware of the *Catanzano* regulations and do not make the required notifications or referrals. Where formal referrals have been made, some Social Service Districts do not enforce the *Catanzano* regulations. People who depend on home care know that they are likely to lose their services if they go into the hospital, so they avoid medical care for health issues that could be addressed easily (and less expensively). They wait until a situation becomes an emergency and then are taken to a hospital and forced into a nursing facility, when they could have been served at home (at significantly less cost) if they received appropriate medical care.

- Traditional home care agencies often refuse to serve people because they feel the person is not "safe". Many home care agencies require that an individual have a "back up" and deny services to individuals who do not have this support. Even though this is illegal under New York State home care regulations, providers say they are more fearful of being cited by the Department of Health for failing to meet the needs of the person if they accept the case. They explain that they fear NYS DOH will hold them responsible for "safety issues" which may occur at any time, even if the agency is not contracted to

provide service during those hours. Agencies state that they require relief from this over-regulation and that NYS DOH must recognize the dignity of risk.

- The shortage of attendants is a huge problem in the home care system. HCRA 2000 provided increased funding to specific personal care and consumer directed personal assistance, programs, but many community based attendants were not included in the program. Without enough workers, home care agencies cannot cover assigned shifts, forcing individuals into nursing homes.

- As stated above, many local districts fail to authorize sufficient amounts of home care to allow individuals to live in the community, in violation of state law and regulations and federal Medicaid "statewideness" requirements.

New York State must use this opportunity, as part of the Olmstead planning process, to address the critical issues of the home care system.

The NYSOFA administered senior services network lacks adequate community supports which forces people into less integrated settings.
New York's current network of Area Agencies on Aging and their multiple subcontractors lacks sufficient community supports to maintain older New Yorkers including those with Alzheimer's disease and other dementias, in their homes. Non-medical community supports are integral to helping individuals and families live in the most integrated setting. Older adults and their families are forced to spend-down and apply for Medicaid covered services when community supports are inaccessible, unaffordable and when there are no other options to support the individual at home. This can often lead to premature and inappropriate institutionalization. Home and community services, both medical and non-medical, are essential to keeping seniors with chronic conditions, including Alzheimer's disease and other dementias, maintained in their homes and out of costly nursing homes. The availability of affordable and accessible community services as well as state-funded less intensive services such as respite, social adult day care, EISEP, etc. would help maintain persons with lower levels of need.

Furthermore, the assessment process must take into consideration prevention measures that will delay hospitalizations and nursing home placement and prolong independent living. For example, instituting fall and injury prevention assessments, mental health assessments and medication management programs at the time an initial assessment is done will save the state significant dollars. Currently, falls cost the health care system $20 billion per year and thirty percent of all hospitalizations of people over the age of 60 are due to adverse drug interactions.

New York State must use this opportunity, as part of the Olmstead planning process, to address critical issues of medical and non-medical community support services for seniors and their families, including Alzheimer's disease and other dementias and for persons of all ages with disabilities.

The Mental Health system lacks adequate community supports which forces people into less integrated settings.
The existing mental health system focuses on "treatment of the illness" and tends to overlook basic assistance with Activities of Daily Living (ADLs). Although case management services can assist with these tasks on a very limited basis, it is more likely that people who need such supports are pressed into less integrated settings like group homes, family care or adult homes. Although services for adults with mental health disabilities are not covered by the federal Medicaid program (so the state can not create a Medicaid waiver for this population), the state could create flexible waiver-like services. There is precedent for creating such services in New York. The state created such state-funded individualized supports with the OMRDD system. New York State's Olmstead planning process must provide people with mental health disabilities with the opportunity and supports to live in the Most Integrated Setting.

The Developmental Disability system is biased toward congregate living.
The majority of people in the OMRDD Medicaid waiver live in congregate settings. OMRDD maintains that the provider agencies have been reluctant to provide services in individualized settings where people with developmental disabilities live on their own. It is interesting to note that many of these providers also are funded under the TBI waiver which has relatively few people who live in group settings. OMRDD must identify the underlying reasons its system remains biased toward congregate models and eliminate those biases.

The system for approving funds does not easily allow people to move from a less-integrated to a more-integrated setting. One principle reason inhibiting this is that funding for services is allocated to agencies which are allowed to back-fill these slots so that individuals who want to move into the community are not able to transition this funding to community-based alternatives. People who want to move their services into the most integrated setting must meet either "emergency" criteria or "New York Cares" criteria. If a person is living in a safe setting, they do not meet the emergency criteria for funding. If they live in a certified setting, they are not eligible for New York Cares funding. Once funds are approved, providers must get individual rates approved. This process was based on the system to support congregate rate-setting for group homes. Consequently it is just as difficult to set a rate for an individual home as it is for a group home. Billing can become very complicated and cumbersome. These are just two examples of the institutional biases within the OMRDD system which must be addressed as part of the Olmstead planning process.

VESID has largely ignored individuals in nursing homes.
VESID has been lax in providing vocational rehabilitation services for individuals desiring to get out of nursing homes. VESID should give priority for vocational rehabilitation and independent living services to those individuals currently in nursing homes or at risk of being placed in a nursing home. Individuals in nursing homes, or those at risk of being institutionalized, are the "most severely disabled." Providing vocational rehabilitation services such as career planning, training, adaptive technology, and home modifications is not only necessary to assist individuals with disabilities in obtaining employment, these same services will help individuals with disabilities remain in or return to the community. VESID must provide training to their

counselors on community reintegration and direct their counselors to work with community-based advocates in transitioning individuals from nursing homes back into the community.

VESID should allocate funds to Centers for Independent Living Centers or other community-based organizations to identify individuals in nursing homes who want to receive services in the most integrated setting, and then work with these individuals to get them out and provide follow up services. In addition, VESID should provide funding for training and technical assistance for Centers for Independent Living to obtain diversion and relocation skills. This must be a priority.

Finally, VESID should also develop and fund a program to recruit and teach individuals with disabilities to become attendant care workers. This would serve the dual purpose of increasing the attendant workforce pool and give disabled people entry-level employment.

Work force issues are critical to addressing the *Olmstead* decision.
Workforce issues are, and will continue to be a major problem in New York State. While we have heard a great deal about the workforce crisis in the medical facilities and nursing homes, there is an equally serious crisis in the human service system as a whole, and the media has ignored this crisis. Low wages, poor benefits, the lack of career ladders and poor public perception about these types of jobs all contribute to this problem. Wage increases for some personal care and consumer directed personal assistance workers were provided under HCRA 2000, but this targeted effort failed to address the wage issues in a variety of community-based services.

As the population of people who need assistance increases, so too will be the demand on workers in both the health and social service field to meet their needs. Furthermore, the ratio of caregivers to the older population and the disability population will decrease over the next 50 years. This unsubsidized care, if not addressed, will mean more stress on an already overburdened health care system and increase the states costs by billions of dollars.

New York needs to develop a comprehensive strategy to hire and retain workers in both the medical and non-medical service systems, create opportunities for growth, increase the pay and benefits and send a strong and clear message that these are jobs that we value as a society.

New York State Medicaid regulations reinforce the institutional bias.
Existing Medicaid regulations force individuals into nursing homes by terminating their Medicaid coverage in the hospital if they are evaluated to be eligible for nursing home services and do not accept the first available nursing home bed within a 50 mile radius. 10 NYCRR Parts 85-86. Current regulations may require hospitals to consider community placement, but not to give it a priority over institutional care. § 405.9(f)(3)(vii). This regulation is used by hospitals to force people into nursing home placements. The Department of Health has sent letters to hospitals informing them of the responsibility to assist people in moving into the Most Integrated Setting as required by the *Olmstead* decision. However, that letter contradicts the regulation.

Other regulations may also limit community-based options. The Consumer Directed Personal Assistance Program has promoted people living in the Most Integrated Setting by allowing attendants to do work typically assigned to nurses and other licensed professionals. Peer-based

models have demonstrated to be cost-effective, community-based alternatives in the Mental Health System as well. These programs provide people with greater flexibility which allows them to live in the community. New York State's Olmstead planning process must address state regulations, including licensure issues, which promote the institutional bias.

V. CONCLUSION

A comprehensive and effectively working Olmstead Plan must be inclusive of consumers and advocates. It must contain real numbers, real goals, real timelines, and real fiscal allocations. It must take into account the needs and desires of people with disabilities and seniors, and address the underlying institutional bias that forces seniors and people of all ages with disabilities into nursing homes and institutions. But perhaps the most important measure of our plan's effectiveness will be the real people who move out of institutions back into the community or remain in their own homes.

That is the promise of the *Olmstead* Decision and it is a promise New York must fulfill.