

January 2003

Dear Interested Party:

On behalf of the Massachusetts Statewide Independent Living Council (SILC), we are pleased to present for your review, The People's Olmstead Plan, a comprehensive document that assists the Commonwealth with meeting the community-based service demands for people with disabilities.

In 1999, the US Supreme Court held in *Olmstead v. L.C.* that the unnecessary segregation of individuals with disabilities in institutions might constitute discrimination based on disability. The court ruled that the Americans with Disabilities Act may require states to provide community-based services rather than institutional placements for individuals with disabilities. As a result, each state is now creating a plan that describes how activities and resources will be allocated to increase the community-based services for people with disabilities. This comprehensive plan will become one of the most useful tools in ensuring that people have a choice in determining their living situation, thus combining high moral principles and fiscal responsibility.

Unfortunately, due to the budget crisis, the previous administration has taken steps that have drastically affected our state's ability to draft a comprehensive plan. The SILC, along with other disability organizations, the new administration, legislators, and others is working to ensure that a fair and equitable option be made available to all citizens of the Commonwealth. As a result, the SILC has spearheaded the publication of the People's Olmstead Plan, a tool and resource to be used by all parties in construction of Massachusetts Olmstead Plan.

Statewide Independent Living Councils across the country were created by The Rehabilitation Act Amendments of 1992. Our council is composed of people with disabilities, Independent Living Centers (ILCs) and related agencies in order to create and establish policy, planning and coordination for independent living services. As a result of this law, the Massachusetts Statewide Independent Living Council was established by Executive Order No. 373 in 1994. The Massachusetts SILC represents the eleven centers for independent living (CILs), state agencies, organizations serving individuals with disabilities, parents, businesses, and individuals with disabilities statewide.

It is important to note that recent census data indicates that there are over **one million** residents of Massachusetts who have disabilities and that this number is on the rise. The SILC, working with the eleven Independent Living Centers across the state, is providing the Commonwealth with vital

information concerning Independent Living Programs and Services. In addition, the SILC is currently working on developing a cost analysis/business plan to show that community-based services will save the Commonwealth money over institutional services. This and other information will be forthcoming in the next few months.

Please contact us via the SILC Coordinator, Joe Bellil, if you have any questions. He can be reached at 508-620-7452 or jbellil@masilc.org.

We thank you in advance for your time and immediate attention to this matter.

Sincerely,

Joseph Tringali
SILC Chair

Paul W. Spooner
Advocacy Committee Chair

The People's Olmstead Plan

**The plan to provide comprehensive community
based services**

January 2003

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Executive Summary

The People's Olmstead Plan The voice of the Massachusetts Disability Community

INTRODUCTION

On June 18, 2001, President George W. Bush signed Executive Order No. 13217, Community-Based Alternatives for Individuals with Disabilities. The Order calls upon the federal government to assist states and localities to implement swiftly the decision of the United States Supreme Court in *Olmstead v. L.C.*, stating: The United States is committed to community-based alternatives for individuals with disabilities and recognizes that such services advance the best interests of the United States.

“By the authority vested in me as President by the Constitution and the laws of the United States of America, and in order to place qualified individuals with disabilities in community settings whenever appropriate, it is hereby ordered as follows: The Federal Government must assist States and localities to implement swiftly the Olmstead decision, so as to help ensure that all Americans have the opportunity to live close to their families and friends, to live more independently, to engage in productive employment, and to participate in community life.”

President George W. Bush, Executive Order 13217

The Supreme Court's *Olmstead* decision, which is based on the requirements of the Americans with Disabilities Act, suggested that states take the following actions:

- Demonstrate that the state has a comprehensive, effectively working plan for placing qualified people with disabilities in the least restrictive setting appropriate to their needs; and
- Maintain a waiting list that moves at a reasonable pace which is not controlled by state endeavors to keep its institutions fully populated.

The Massachusetts grass roots People's Olmstead Plan

The Supreme Court's landmark decision in *Olmstead* gave people with disabilities of all ages the right to live in the community, outside of an institution, in the least restrictive setting possible. Collectively, people with disabilities, elders, and others rise up to claim our rightful independence.

The People's Olmstead Plan is not a bureaucratic response to the independence yearnings of the disability community. It is a passionate declaration from the front lines. It is a statement from people who have lived or still live in the nursing homes, our state hospitals, chronic care facilities, and a multitude of other spirit-killing institutions where society has placed, and continues to place, thousands of its citizens' with disabilities.

In July 2002 three state agencies (EOHHS, EOEA, A&F) released *Enhancing Community Based Services, Phase One of Massachusetts' Plan*, which is the state's plan to comply with the Olmstead mandate to provide services to people with disabilities of all ages in the most-integrated, least-restrictive setting. The foundation of this plan was five public "listening sessions" held across the state between October 2001 and January 2002. Over 1,000 people with disabilities attended sessions held in Westfield, Fairhaven, Worcester, Boston, and Lynn, with more than 250 people testifying-- usually with an intense passion evolved from personal experience-- on the need to end state-supported institutionalization and instead direct resources into true community-based supports and services.

Subsequent to these listening sessions members of the disability and elderly communities, in conjunction with state officials, produced four reports on how Massachusetts can move forward to comply with the Olmstead ruling. These reports form the basis of the People's Plan. It is the contention of the Statewide Independent Living Council that these reports, and not the lengthy processes that form the basis of *Enhancing Community Based Services*, are what must serve as the basis for public policy on people with disabilities in Massachusetts.

We are in a time of unprecedented budget cuts to Human Service programs. Aggressive implementation of cost-effective, community-based services and supports, as recommended in the People's Olmstead Plan, is **fiscally prudent**—and it soundly promotes the preferred way of living for the vast majority of people with disabilities.

Summary of critical mandates in the Plan

The Massachusetts People's Olmstead Plan consists of four committees' extensive findings, recommendations, and action steps. The four reports cover:

- **Individuals Who Are Institutionalized**
- **Individuals At Risk of Institutionalization**
- **Community Services and Supports**
- **Housing**

The following key points have been extrapolated from the extensive reports and represent the most urgent need in each subject area. This summary is not meant to supersede the additional important areas of change recommended in the Committee reports, which are part of this plan.

Individuals Who Are Institutionalized

Institutional bias in long term care funding must be eliminated in Massachusetts.

Resources will be shifted to minimize institutional capacity while creating maximum community capacity.

Vigilance must be exercised to ensure that people are diverted from institutions by providing a range of viable choices in the community.

A rigorous, independent process is needed for assessing individuals who are seeking long-term care, or who are referred for placement in an institution.

Individuals At Risk of Institutionalization

Massachusetts faces the challenge of how to remove the bias towards institutionalized care from the present system of long-term care, and to promote the use of home and community based alternatives.

The primary goal is that, Massachusetts' long-term care system will be one where a waiver is required for a person to enter institutionalized care, instead of one where waivers are needed in order to provide Medicaid-funded community options, as is true in the current system.

Community Services and Supports

It is the goal of the Commonwealth to reduce its reliance on institutional long-term care services, and expand the range of options for community care. The Commonwealth shall shift the proportion of state resources devoted to community care versus institutional care, and enhance the provision of community services and programs that avoid or delay institutional admissions, and **make institutional care a last resort**.

Housing

Housing programs and property development by the state should be consistent with the following principles:

Integration: Housing for people with disabilities should be designed to integrate people with disabilities into the community as fully as possible. In the most integrated, least restrictive housing environment, support services should be available when necessary to help ensure a successful tenancy and lease compliance.

Housing and Services Relationship: Before a housing model is funded or endorsed, the relationship between housing and services must be reviewed and determined appropriate for the targeted population.

Maximum Control: People with disabilities should have the maximum control possible in their housing choices and management.

Informed Choice: People with disabilities must be able to choose their housing. In order to do this, they must be informed fully, in a manner understandable to the individual about the choices available and the responsibilities that accompany these choices.

A Variety of Choices: In developing a system of housing for people with disabilities, the overall state system

should promote a variety of choices.

Accessibility: All housing for people with disabilities must be accessible.

Reading the committee reports is essential. But they were framed by the words of those who testified during the Olmstead listening sessions, and these statements may best tell about the mission on which we must embark.

“I’ll do without an operation I need before I go to another nursing home.”

“I lived in Belchertown...Institutions should be closed! It is much, much, much better to live out in the community than it is where you’re told where to go, what to do, what to do with your life.”

“For too long we have been jailed in institutions and hospitals.”

“I was homeless and had to go in a nursing home... I got in the nursing home in just two hours...It took eight and a half months to get out.”

“I worked with DMH as a psychologist for 34...The cost of deinstitutionalization is much less, we could save a lot of money. There’s no place like home.”

“I don’t want to give up my independence. Going in a nursing home at my age would kill me. I’d rather be dead, I’d rather be dead.”

“I would become a number in a nursing home. I have my own home. I use PCAs. I don’t want to become a number.”

“I lived in an institution half my life...I do not want to go back.”

“The institutional bias of Medicaid and the lack of family supports and housing forced me to institutionalize my daughter.”

“We think of freedom as an American right...unless you have a disability.”

“People in institutions are incarcerated.”

“I worked twenty years in a nursing home and never heard someone say ‘this is where I want to live.’ “

“It’s hard to imagine a state institution if you haven’t walked the ward... Hundreds sit, day after day, year after year, in some cases, even when staff says they’re ready to leave.”

“Close the institutions.”

Massachusetts Independent Living Centers

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The following information is from:

**Enhancing Community
Based Services**

***Phase One of
Massachusetts' Plan***

July 31, 2002

**Submitted by:
Executive Office of Health and Human Services
Executive Office of Administration and Finance
Executive Office of Elder Affairs**

APPENDIX A

COMMITTEE MEMBERSHIP LISTS:

Steering Committee
Interagency Leadership Team
Olmstead Advisory Group

Enhancing Community Based Services

Steering Committee

Robert Gittens	Secretary, Executive Office of Health and Human Services
Lillian Glickman	Secretary, Executive Office of Elder Affairs
Elmer Bartels	Commissioner, Massachusetts Rehabilitation Commission
Michael Bolden	Commissioner, Department of Youth Services
Kimberly Egan	Acting Commissioner, Massachusetts Commission for the Deaf and Hard of Hearing
David Govostes	Commissioner, Massachusetts Commission for the Blind
Howard Koh	Commissioner, Department of Public Health
Gerry Morrissey	Commissioner, Department of Mental Retardation
Michael Resca	Commandant, Soldier's Home, Chelsea
Linda Ruthhardt	Commissioner, Division of Health Care Finance and Policy
Lewis Harry Spence	Commissioner, Department of Social Services
Marylou Sudders	Commissioner, Department of Mental Health
John Wagner	Commissioner, Division of Transitional Assistance
Jane Wallis Gumble	Director, Department of Housing and Community Development
Wendy Warring	Commissioner, Division of Medical Assistance
Ardith Weiworka	Commissioner, Office of Child Care Services

Enhancing Community Based Services

Interagency Leadership Team

Cheryl Bushnell	Acting Director, Division of Special Health Needs Department of Public Health
Mark Fridovich	Deputy Commissioner Department of Mental Retardation
Debra Kamen	Director, Statewide Head Injury Program Massachusetts Rehabilitation Commission
Eliza Lake	Director, Community Support Services Executive Office of Elder Affairs
Michael O'Neill	Acting Assistant Commissioner Department of Mental Health
Betty Anne Ritcey	Assistant Secretary for Disability Policy Executive Office of Health and Human Services
Eleanor Shea-Delaney	Director of Plans for the Elderly and Disabled Division of Medical Assistance
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Mardia Coleman	Research Associate
Debra Hurwitz	Consultant

Olmstead Advisory Group

Charlie Carr	Executive Director, Northeast Independent Living Program
Deni Cohodas	National Empowerment Center
Christine Griffin	Executive Director, Disability Law Center in Boston
Ben Haynes	Board Member, Massachusetts Senior Action Council and Disability Policy Consortium
Bill Henning	Director, Cape Organization for Rights of the Disabled (CORD)
Sandra Houghton	Self-Advocacy Leadership Institute
Arlene Korab	Executive Director, Massachusetts Brain Injury Association
Linda Long	Deputy Executive Director, Governor's Advisory Commission on Disability
John O'Neill	Executive Director, Somerville/Cambridge Elder Services
Angelina Ramirez	Program Coordinator, Stavros Independent Living Center of Amherst and Springfield
<u>Ex Officio State Advisors</u>	
Robert Gittens	Secretary, Executive Office of Health and Human Services
Lillian Glickman	Secretary, Executive Office of Elder Affairs
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APPENDIX B

Olmstead Advisory Group:

**Report of the Subcommittee on Individuals
who are Institutionalized**

Olmstead Advisory Group

Subcommittee on Individuals Who Are Institutionalized

Sub-committee Chairs:

Linda Long, NSARC
Betty Anne Ritcey, EOHHS

Sub-committee Members

Sarah Bachrach, DPH
Ed Bielecki, MASS
Deni Cohedas, M-POWER
Ellie Shea Delaney, DMA
Chris Griffin, DLC
Jack Riley, DMR

Sandy Houghton, MASS
Eliza Lake, ELDER AFFAIRS
Louann Larson, NSARC
John O'Neill, Mass Home Care
Walter Polesky, DMH

Overview of Subcommittee Work:

The Olmstead sub-committee on Individuals in Institutions met on 5 occasions. Much discussion evolved around defining the term “institution” and also around reasons why people are admitted to or not discharged from institutions. Sub-committee members weighed in at various points along the philosophical continuum of the Commonwealth’s need to have institutions. Although these meetings have been filled with differing opinions we have forged ahead and found much common ground via healthy discussions that are reflected in the following document, which is being presented as the consensus of this sub-committee.

Definition:

An institution is a publicly or privately funded congregate setting where the individuals who are served do not have autonomy over their daily routines and activities, and are not living in the least restrictive setting. A facility is not considered an institution for our purposes if it provides time-limited rehabilitation, or other kinds of short-term, medically necessary treatment, and if each person receiving services has an active discharge plan in place. As soon as that facility accepts long-term “residents” or allows people to remain in the facility without actively working on discharging them to a less restrictive setting, that facility would become an “institution” by our definition.

Guiding Principles

Individuals must be able to choose where they would like to live

Historically, the decision to institutionalize people has been due to lack of resources in the community, rather than a real choice made by people with disabilities and their families. It is to be expected that some people who have been institutionalized for decades, and who have formed deep and lasting relationships with those with whom they live, may choose to remain where they are, no matter what alternative is offered to

them. Similarly, guardians may be uncomfortable with the idea of agreeing to move their loved ones from settings they have come to trust, to new and unfamiliar settings. Institutions should be allowed to downsize through attrition and consolidation, and eventually, when no longer sustainable, to close their doors.

For more than two decades, researchers, as well as community service providers, have recognized that **with proper funding and the appropriate kinds of supports**, all individuals with disabilities can be served in small, community-based settings:

“By every measure, living in the community shows clear increases in quality of life compared to living in larger, congregate settings. And, the supports, supervision and care go with the person to their new home. And, people with disabilities and their families choose where to live, who to live with and decide about the programs that will support their loved one in their new home.” (Deinstitutionalization in America, David Mank, Indiana Institute on Disability and Community.)

This is reinforced by David Braddock and his co-writers of the federal sourcebook (funded by Administration on Developmental Disabilities in HHS), State of the States in Developmental Disabilities (Feb. 2002, p. 26, Coleman Institute at the University of Colorado), when they cite trends nationwide in the delivery of services: “Another mechanism for gauging trends in the states is the rate of decline in state financing of institutional care. Across the nation during 1977-1991, the public and private institutional care sector grew every year in inflation-adjusted terms. After the peak in spending in 1991, institutional spending declined each year from 1991 to 2000. During 1996-2000, inflation-adjusted institutional spending in the U.S. declined 10%. Among the states that have not completely closed their public institutions, Indiana, Kansas, Maine, Massachusetts, Oregon and South Dakota reduced their inflation-adjusted institutional spending by more than 39% during 1996-2000.” In addition, Judge Ruth Bader-Ginsburg, writing for the 6-3 Court majority, described the essence of the Court’s ruling: “We confront the question of whether the proscription of discrimination may require placement of persons with mental disabilities in community settings rather than in institutions. The answer, we hold, is a qualified yes” (*Olmstead v. L.C.*, 1999).

Institutional bias in long term care funding must be eliminated in Massachusetts:

Resources will be shifted to minimize institutional capacity while creating maximum community capacity

Vigilance must be exercised to ensure that people are diverted from institutions by providing a range of viable choices in the community

A rigorous, independent process is needed for assessing individuals who are seeking long-term care, or who are referred for placement in an institution. (Refer to Goal 4 of Community Services and Supports Subcommittee report)

The Commonwealth's Report on Long-Term Care, dated August 2001, states that long-term care spending in Massachusetts "is heavily weighted to institutional care, which consumed nearly \$1.2 billion or 83% of total spending." This report also points out that "Massachusetts has a 65% greater rate of Medicaid nursing facility utilization than the national average." These figures reflect the extent to which the state has committed its resources to the institutional side of the long-term care equation.

When an individual is leaving an institution, funding should be provided that is adequate to support the individual in the community, to be used flexibly as his or her needs change. Experience has shown that many individuals can be supported for less money in the community, while others may require more costly supports. The important concept here is that the current roadblocks to funding of community based supports that lead people inevitably to "choose" institutional placement, or to remain in an institution, must be removed. New and creative funding mechanisms must be designed, or exploited more effectively, to channel resources to less restrictive environments.

Long-term care plans must be Person-Centered.

Service must be designed and coordinated to meet the specific needs and preferences of the individual. The current rigid system primarily operates by funding "slots" and fitting people into them. It must be replaced by a dynamic system that configures an array of flexible supports, enabling the individual to realize their dream of where and how and with whom they will live.

Recommendations:

The Massachusetts Olmstead Plan will provide for community-based supports and services necessary for individuals living in an institutional setting to transition successfully to a living situation in the community of their choice.

- A. The State agencies currently funding institutional placements (DMR, DMH, DPH, DMA, DOE and DYS) will **produce a report which identifies how many people are currently residing in institutions**, their ages, the level of care required by these individuals, and the current cost of providing this care. (U. Mass group is preparing some information about numbers and current costs)
- B. The State (EOHHS and EOEA) will **identify all existing community supports and services**, their current capacities and funding mechanisms.
- C. The State will **identify potential service gaps in the community system**. Some of the gaps that must be addressed are:

a. Direct care staff salaries

Currently, salaries and benefits at state institutions are, for the most part, superior to those offered in community-based programs. For instance, within the DMR system, starting salaries for comparable direct care workers run \$3,000-4,000 higher in the state-run system than in the private sector. Also, state employees receive periodic increases, while salary adjustments in the private sector are completely dependent on the whim of the legislature and administration, and when granted, are minute (under 3%) and retroactive rather than prospective.

The state must provide adequate funding to community-based service providers to ensure a capable and reliable workforce.

b. Housing options (See Housing Subcommittee Report)

c. Institutional bias in the financial and clinical eligibility criteria for state-funded programs (including Medicaid)

d. Underfunded and underdeveloped community support system (See Community Services and Supports Subcommittee Report) Funding for flexible, individualized, community supports should be made available to individuals, even where formal supports do not yet exist to be purchased. These resources will serve as an engine, generating the demand for community-based supports, and propelling service providers to organize themselves to meet the demand.

The following recommendations are not meant to be prescriptive, or exhaustive, but rather, are meant to provide a sample framework for the systematic identification, matching, and tracking of needs and resources:

D. The State will **identify independent entities to protect the interest of individuals with disabilities who reside in institutions**. These entities will:

Educate each individual and/or their guardians about the array of community options, semi annually

Such education might include (not an exhaustive list):

- Development of an informational booklet explaining the right to integrated community-based services, and the various options and remedies available.
- Review of the contents of booklet with individual (and/or guardian)
- Asking each individual to sign a Freedom of Choice form which will be included in their file, indicating that they have been informed of each option and documenting their choice(s) of long term care services.

Perform assessments

Individual assessments may include:

- Identification of the assessment team and their qualifications.

- Identification of such factors as the existing array of supports enjoyed by the individual, the services an individual needs, the types of services that *could be* provided in the community but which do not yet exist, and any reasonable accommodations that might be required to enable the individuals to benefit from particular services.
- Identification of the specific interests, goals, likes and dislikes of the individual
- An evaluation of the individual's functional limitations, living arrangements, support systems, medical issues, financial resources, and the risk of abuse, neglect, or exploitation.
- Any family, friends or advocates chosen by the individual (or guardian) to be present.

Provide case management

Case management may include:

- Identification of the array of services and supports required enabling the individual to be served in the community. (See Community Supports Subcommittee Report)
- Coordination of the transition process, including peer support or mentoring (if appropriate).
- Development of appropriate timelines for transition to community supports and services

E. State funding should support the following **supplemental options**:

- pre-placement home visits and overnights.
- pre-service training for community support staff – prior to actual placement – on individual service needs.
- start-up money, including moving expenses, first month's payment, cost of home and/or vehicle modification and other kinds of temporary, one-time payments.
- alternative placements if the initial placement is discovered not to be appropriate during the first 6 months and at any time thereafter based on evidence of inadequate services or harm. Concept of "bed-hold" should be examined.
- provide support to informal caregivers

F. State agencies will **implement a tracking system to monitor the progress of each individual's program plan** and identify where progress is lagging. Data will include, but not be limited to:

- Numbers of individuals moved to the community, type of placement, location of placement, and services and supports.
- Numbers of individuals returning to institutions and reasons.
- Data on consumer satisfaction with services semi-annually, and yearly thereafter.
- Tracking of the length of time it took to get assessed for community placement.
- Tracking of the length of time from assessment to placement

G. **Determination of baseline of total resources, in dollars, devoted to institutional vs. community care** (measure to include such things as dollars spent on salaries, training, facilities, supplies, etc.). Annual targets will be set for

subsequent years to change the ratio to one that increasingly favors community based care.

- H. The State will establish a **method of evaluating and monitoring** the living situations of those who have moved out of state-run institutions to ensure they are effective and that human rights are protected.

APPENDIX C

Olmstead Advisory Group:

**Report of the Subcommittee on Individuals
at Risk of Institutionalization**

Olmstead Advisory Group

Subcommittee on Individuals at Risk of Institutionalization

Subcommittee Chairs:

Lillian Glickman, Elder Affairs
Christine Griffin, Disability Law Center

Subcommittee Members:

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John O'Neill, Mass Home Care
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Angelina Ramirez, Stavros
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Introduction

Massachusetts faces the challenge of how to remove the bias towards institutionalized care from the present system of long-term care, and to promote the use of home and community based alternatives. While there are community supports in place for most populations, this support is either too little to maintain individuals in the community, or the supports are only offered to certain persons with disabilities after institutionalization occurs. It is much more difficult to transition individuals into the community than to prevent their institutionalization.

The Commonwealth needs to focus on diverting as many individuals from institutionalization as possible. Effective state policy and legislation must be passed that enables those services that keep people in the community to occur in a transparent, coordinated fashion that benefits every Commonwealth citizen with a disability who needs such services. The goal should be that, eventually, Massachusetts' long term care system is one where a waiver is required to enter institutionalized care, instead of one where waivers are needed to provide Medicaid community options, as is true in the current federal system.

The Individuals At Risk of Institutionalization Subcommittee of the Governor's Olmstead Advisory Group presents the following recommendations as a way to achieve a truly diversionary long-term care system. The Subcommittee met five times between January and April of 2002. Starting with the themes that were raised in the Olmstead hearing that were held around the state in November, December and January, the Subcommittee members crafted the recommendations to best address the needs of those individuals in the Commonwealth who are at risk of institutionalization.

Definition of Population

People who are at risk of institutionalization are individuals of all ages with physical or psychiatric disabilities, cognitive impairment, or behavioral issues who also have unmet needs and whose lack of skills and supports jeopardize their ability to remain in the community.

Goals and Objectives

I. Goal: Identify who is at risk of institutionalization

A. *Objective: Identify individuals currently at risk of institutionalization.*

1. Recommendation: Examine lists of those individuals currently waiting for long-term care services from state agencies to determine their ability to remain living in the community.
2. Recommendation: Analyze state agencies' current client populations for individuals at risk of institutionalization.
3. Recommendation: Identify individuals who are not covered by any state agency's eligibility criteria, including those ineligible as a result of their diagnosis. These individuals may have significant unmet needs, including the need for case management, and are therefore at risk of institutionalization.

B. *Objective: Coordinate case management or service planning*

1. Recommendation: Develop a single assessment tool with specialized modules to be used with all people with disabilities seeking state funded long-term care services.
2. Recommendation: Develop single entry point into long-term care system through contracts with community-based agencies. These agencies would serve as a sole referral and triage point with a goal of diversion. Individuals with disabilities would be referred to the most appropriate service providers, except in those cases where there is a previous legislative mandate dictating the admitting body.
3. Recommendation: Develop clear communication and collaboration mechanisms between the organizations serving as the point of entry and all state and community agencies, both public and private, that provide long-term care services.
4. Recommendation: Develop an interagency dispute resolution process to resolve questions of responsibility arising between state agencies providing long-term care, including the Department of Education.

C. *Objective: Enlist all sources of referral for identification of individuals at risk*

1. Recommendation: Work with all entities that make referrals to the long-term care system to assist in the identification of individuals at risk of institutionalization.

II. Goal: Identify the unmet needs of this population

A. *Objective: Identify the unmet needs of individuals currently at risk of institutionalization.*

1. Recommendation: Examine data of those individuals currently waiting for long-term care services from state agencies to determine unmet needs, and those services needed in order for them to remain in the community.
2. Recommendation: Analyze state agencies' current client populations to determine unmet needs.

B. Objective: Coordination of information

1. Recommendation: Develop a single assessment tool to be used with all people with disabilities seeking state funded long-term care services.
2. Recommendation: Develop a common list of definitions, including service definitions, for all state agencies in order to facilitate communication about clients and their cases.
3. Recommendation: Survey residents of institutions and review relevant data to determine what needs are met by the institutionalization, and which could be met by existing services in the community.
4. Recommendation: Analyze data from Nursing Facility Transition Grant and other relevant data sources to determine what community services are needed to successfully transfer a resident back into the community, what needs may not be filled, and what the characteristics are of successful transfers (including frailty level, length of stay, etc.).
5. Recommendation: Develop a web based data center whereby a client's service could be tracked across all providers of both acute and long-term care services in order to collect data regarding needs, both met and unmet.

III. Goal: Link individuals with services in order to divert them from institutional placement

A. Objective: Coordination of case management or service planning

1. Recommendation: Work to develop a web based data center whereby a client's service could be tracked across all providers of both acute and long-term care services, and those to whom the client agrees to allow access could share this information
2. Recommendation: Streamline, unify, and expand the services coordinated by existing case management systems across state agencies, advocacy agencies and associations, and private non-profit agencies.
3. Recommendation: Develop on-going process to educate all state agencies that provide long-term care services about the systems and services of other state agencies.
4. Recommendation: Use the single assessment tool with specialized modules to assess all people with disabilities seeking state funded long-term care services in order to facilitate comprehensive service plan design and communication between different providers.
5. Recommendation: Establish a mechanism for unified case management for individuals who require the services of more than one agency.

B. Objective: Education for all sources of referral

1. Recommendation: Create education/training program for all entities that refer individuals to institutions. The goals would be to create relationships between the gatekeepers and providers, including state agencies, and to ensure that they know all the resources that are available in the community.
2. Recommendation: Establish mechanisms used by all sources of referral to refer individuals to the most appropriate providers.

C. Objective: Transition planning for youth (moving from children's services to the adult long-term care system)

1. Recommendation: Establish a mechanism for unified case management for children who require the services of more than one agency.
2. Recommendation: Establish a mechanism to facilitate service delivery to individuals who, by reason of age, are no longer eligible for services needed

to support them in the community, e.g. those aging out of DSS, DYS or DOE, or not meeting adult DMH or DMR eligibility criteria.

3. Recommendation: Ensure that transition planning for youth would include planning and support for the following elements of community living: health care, housing, relationships to family and other community members, safety issues, skill development, employment readiness, and civic involvement.

IV. Goal: Promote self-advocacy and consumer empowerment

A. *Objective: Education about range of options in order to promote informed choice*

1. Recommendation: Establish a network of independent advocates; coordinators that can help consumers and their caregivers navigate through the array of service options and care settings.
2. Recommendation: Provide, without regard to source of referral or potential funding stream, every person (and his/her caregivers) who is seeking admission to or placement in a long-term care facility with an in-person consultation with an independent advocate care/coordinator.

V. Goal: Analyze/expand system infrastructure

A. *Objective: Equitability of access*

1. Recommendation: Make Medicaid services and eligibility between institutional and community settings comparable. Income eligibility and spousal impoverishment rules that apply to institutions should also apply to community services.
2. Recommendation: Create equitability of access to community-based long-term care services across the age spectrum, which could include the spousal waiver for people with disabilities under the age of 65.
3. Recommendation: Examine the role of the state in providing the necessary case management to all populations that are currently unserved, including those that are ineligible due to diagnosis.

B. *Objective: Expansion of access*

1. Recommendation: Establish a commission to develop a plan for a publicly managed long-term care insurance product, based on the Prescription Advantage model. This long term care insurance product would be premium driven, open to people of all ages, with the premiums for the low-income elders and MassHealth individuals being subsidized with public monies. This would provide the Commonwealth with the ability to stabilize the funding of long-term care.
2. Recommendation: Expand Medicaid income and asset eligibility requirements in order to provide necessary community supports to individuals who are not currently eligible yet who are too poor to pay privately for care.
3. Recommendation: Give people with disabilities who meet the eligibility criteria for MassHealth nursing facility or other institutional services a choice of care either in the community or in an institution. Adequate funding will be provided for either choice.

C. *Objective: Expansion of services*

1. Recommendation: Expand the provision of community services and supports, including Personal Care Attendant services (See the Services and Supports Subcommittee Report).

2. Recommendation: Expand the availability of accessible and affordable housing in the community (See the Housing Subcommittee Report).
 3. Recommendation: Develop and implement a flexible, effective and safe system of medication management across the long-term care system.
 4. Recommendation: Expand the availability of mental health services for individuals of all ages (See the Services and Supports Subcommittee Report).
- D. Objective: Prevention of unnecessary hospitalizations*
1. Recommendation: Develop and support community programs providing preventive health care services.
 2. Recommendation: Develop and support community programs providing diversionary health and mental health care services.
 3. Recommendation: Develop and support peer advocacy, peer education, and peer-run support groups as a part of the service infrastructure.
- E. Objective: Alter providers' philosophy of care where needed*
1. Recommendation: Develop trainings for providers to promote consumer involvement and independence. The training teams shall include consumers.
- F. Objective: Transfer positive aspects of institutions into community, e.g. accountability, responsiveness, and financial security of providers*
1. Recommendation: Examine those institutions and community care models, including those in other states, that have developed best practices in providing consistent accountability, responsiveness and financial security in order to identify positive elements that could be transferred to existing community care.
 2. Recommendation: Offer incentives and grants to nursing facilities to develop and promote new models of care and accommodation that change the focus of care from long-term to short-term care.
 3. Recommendation: Promote such models to transform facilities into a viable and desirable community option.

VI. Goal: Support caregivers

A. Objective: Support and empowerment of caregivers

1. Recommendation: Expand programs that allow non-professionals to serve as paid caregivers, including family members exclusive of the spouse (e.g. PCA program, Elder Affairs' Consumer Direction)
2. Recommendation: Provide trainings for providers on working collaboratively with families, including families of minors
3. Recommendation: Provide incentives of improved wage & benefits packages, as well as retraining, for institution workers who wish to transition to community care

B. Objective: Education

1. Recommendation: Publish an information booklet, in multiple languages and audiotape, which give consumers and caregivers an outline of service options, provide instructions on how to access same, and stress their rights to self-direct their care if they so choose.
2. Recommendation: Develop a 1-800 consumer information line and an interactive web site to handle long term care inquiries, perhaps building upon the information and referral system the Executive Office of Elder Affairs already has in place.

C. *Objective: Examination of the roles and responsibilities of the family*

1. Recommendation: For minors, recognize the role of parents as the 24/7 caregivers and provide skill training to professionals and to parents to promote the practice of family collaboration and the partnering with parents as equals.
2. Recommendation: For adults, expand existing state-funded caregiver programs that provide training and support to families, as well as provide training for providers on working collaboratively with clients and families.
3. Recommendation: Hold diverse focus groups to elicit feedback on the role of the family versus the role of the state in the provision of care to the elderly and individuals with disabilities.

APPENDIX D

Olmstead Advisory Group:

**Report of the Subcommittee on Community
Services and Supports**

Olmstead Advisory Group

Subcommittee on Community Services and Supports

Subcommittee Chairs:

Charles Carr, NILP

Betty Ann Ritcey, EOHHS

Subcommittee Members:

Ed Bielecki, MASS

Cheryl Bushnell, DPH

Bill Henning, CORD

Sandra Houghton, DD Council

Eliza Lake, Elder Affairs

Karen Langley, MRC

Linda Long, North Shore ARC

Al Norman, Mass. Home Care

John O'Neill

Ted Taranto, DMH

Larry Tummino, DMR

INTRODUCTION

The Olmstead Community Services and Supports subcommittee met a total of five (5) times. A comprehensive listing of Common Themes taken from the five (5) statewide public hearings was used to facilitate the development of this report. Detailed notes were taken at each meeting, and distributed in advance of the next. Corrections, deletions, and additional topic areas were discussed and agreed upon based, in part, on these notes. Agreement was reached through healthy group debate, and negotiations. This report represents the consensus of the subcommittee.

GOALS AND OBJECTIVES

Goal 1: IDENTIFY THE NUMBER OF INDIVIDUALS WITH DISABILITIES THAT ARE INSTITUTIONALIZED, AND THOSE APPROPRIATE FOR TRANSITION.

Objective: The Commonwealth shall identify the number of individuals with disabilities in the Commonwealth that are institutionalized, and define the type, duration and funder/agency of the placements.

Action Step: Agency staff need to determine how to more precisely measure these placement activities. There is a wealth of data on state operated facilities, but incomplete or conflicting information on publicly funded placements in private facilities. State agencies must act aggressively to review this population and the programs that serve them.

Goal 2: EQUAL CHOICE OF SETTING

All individuals with disabilities in the Commonwealth who meet the criteria, or are eligible, for long term care as defined in state regulation, shall be permitted to choose between home and community based care, or, institutional care, to ensure their care is provided in the most integrated setting appropriate to their needs. The decision about where a person with a disability will receive long-term care services must be the choice of that individual. The setting of that care should not determine the entitlement. A person's level of disability should create an entitlement to care, irrespective of the setting chosen. Medicaid, the largest payer of long-term care services in the Commonwealth, must give people with disabilities the choice of setting, and the dollar's to pay for such care. Nursing home care is a Medicaid entitlement. Over time, as the decision of care settings change, adequate money should continue to follow that decision. The financial value of these services shall "belong" to the individual, not to the setting, and may be used flexibly by the individual as his or her need for setting changes.

Objective: All state agencies that offer long term care to people with disabilities shall develop a financial value to their community care and institutional care benefit. The only difference between said benefits shall be that the institutional benefit shall include a room and board component.

Action Step: State agencies shall assign staff to reengineer long term care in accordance with the goal of providing a uniform institutional and community based service package, with an add on for room and board in the case of residential services.

Goal 3: ENHANCEMENT OF COMMUNITY CARE, NURSING HOMES, INSTITUTIONAL CARE, AS A LAST RESORT

It is the goal of the Commonwealth to reduce its reliance on institutional long-term care services, and expand the range of options for community care. The Commonwealth shall shift the proportion of state resources devoted to community care versus institutional care, and enhance the provision of community services and programs that avoid or delay institutional admissions, and make institutional care a last resort.

Objective: All state agencies that offer long term care shall establish a baseline of resources now committed to community based care, and develop a three-year plan to shift more resources into community care and use institutional care as a last resort.

Action Step: The Commonwealth shall produce a plan to maintain or reduce its number of institutional admissions, and generate a list of specific expansions to the "least restrictive" community based services that could serve as alternatives to nursing home care, such as foster homes, evening and overnight care, expansion of the personal care attendant program, etc.

Goal 4: CREATE A SINGLE ENTRY POINT FOR LONG TERM CARE ASSESSMENT AND MANDATORY ASSESSMENT OF COMMUNITY ALTERNATIVES

To ensure that all individuals with disabilities are presented with their options for community care, the Commonwealth shall develop a uniform intake process for assessing individuals with

disabilities of any age, for long term care services, using an independent entity(ies) to perform the assessment that are not providers of long term care services.

Furthermore, a lead entity will be designated to arrange for a single source document that outlines all the community based services that currently are available for people with disabilities to be made available in alternative, accessible formats and be kept current. A clearly defined appeal procedure will be available to all people with disabilities in state programs.

Objective: All state agencies that offer long term care shall pre-screen all individuals seeking long term care services for appropriateness of community care. Private paying individuals also shall be offered such a screening assessment. A rule out of community services shall be a mandatory feature of such assessments. In addition, any individual referred to an institution shall be assessed again no later than 14 days after admission, unless statutorily prohibited, to conduct a subsequent “community rule out” assessment. No hospital or nursing home shall conduct institutional screenings or community rule out.

Action Step: Each state agency offering a long-term care plan shall redesign the current intake features of their long term care to incorporate a community alternatives rule out, and 14-day reassessment in institutional placements. Each state agency shall develop a verification process to ensure that informed choices were provided.

Action Step: Each state agency shall provide resources, and assist, the Massachusetts Office on Disability (MOD) to plan, and implement a series of statewide trainings to assure that all providers and agency staff are aware of Olmstead and its implications. This statewide training program should encourage networking across agencies.

Objective: Develop a vehicle to provide those in institutional care with extensive information on community-based services two weeks after their placement in a nursing home— and when awaiting discharge.

Action Step: Independent Living Centers, ASAPs, and other entities, may be uniquely qualified to engage in these tasks.

Goal 5: CONDUCT A STUDY, WITH SPECIFIC RECOMMENDATIONS, THAT IDENTIFIES THE SERVICE NEEDS, AND APPROPRIATE AGENCY TO DELIVER THEM, TO PEOPLE WITH SIGNIFICANT DISABILITIES, WHO ARE AT RISK OF INSTITUTIONALIZATION, AND DO NOT PRESENTLY MEET THE ELIGIBILITY CRITERIA FOR LONG TERM CARE SERVICES.

Objective: Address the rapidly growing problem that people with significant disabilities that do not meet the eligibility criteria of the current state agencies and, are not being served in an institutional setting, are going unserved. People with autism, acquired brain injury, agoraphobia, etc., have fallen between the cracks, as a result of tightening eligibility criteria, and, although they qualify for SSI and SSDI, they don't have an agency to go to for services.

Action Step: Create (or designate) an agency, with adequate funding, to provide needed services for these populations pending a comprehensive study conducted by the

Commonwealth that includes, in all phases, active participation of members of these populations.

Goal 6: SIGNIFICANTLY REFORM SPECIFIC MEDICAID FUNDED PROGRAMS, PRACTICES, PROCEDURES, AND REGULATIONS, TO PROVIDE, AND STRENGTHEN, COMMUNITY BASED ALTERNATIVES TO INSTITUTIONAL CARE.

Objective: To eliminate the institutionally biased hardship created by the practice of the "lifetime" spend-down under 65, which becomes a 6-month spend-down once you turn 65. Individuals just can't "afford" to be in the community because the spend-down bankrupts them financially.

Action Step: Eliminate the Medicaid Spend-down.

Objective: Address the major, and well-founded, fear of people with disabilities, especially those who are aging, is the loss of benefits once eligibility terminates for CommonHealth for working adults. Loss of coverage for durable medical equipment, medications, and personal care attendants—benefits often of acute importance to people with disabilities— occurs when someone stops working. This puts people at extremely serious risk of being institutionalized. The spend-down to get MassHealth benefits is prohibitive for most.

Action Step: Eliminate Medicaid Spend-down for those transitioning from CommonHealth to MassHealth

Objective: To eliminate the institutionally biased inequity evidenced when a nursing home resident has financial eligibility for MassHealth determined without regard to spousal income, while spousal income is deemed to individuals with disabilities choosing to remain at home. The result is that individuals with severe disabilities may be forced into long-term care facilities as the only way to meet the expenses of their medically necessary care needs.

Action Step: Apply for, secure, and implement a Home and Community-Based (HCB) waiver that prevents the deeming of spousal income that is not available to people under age 60. A younger individual with a disability who is married to someone who works is likely to be ineligible for MassHealth/CommonHealth unless a substantial deductible is met and thus is unable to access community care. Waivers of spousal deeming should be made available to married individuals under age 60 with disabilities.

Objective: Many individuals with significant disabilities require some form of personal assistance to live in the community whether provided by family, personal care assistants, home health aides or others. In order to ensure that people with disabilities have the opportunity to live in the community access to Personal Care Assistance (PCA) services that meet a broad range of physical and cognitive needs must be assured. In addition, timely Prior Approvals, adequate reimbursement rates, and benefits and benefits for PCA's must be considered in making the service viable. The PCA program is a bedrock independent living program that must always maintain consumer control.

Action Step: Eligibility for PCA services must be broadened to include people over age 65 who would have otherwise been eligible based on Medicaid's income eligibility criteria for people under 65; and eligibility must include people with disabilities who need

prompting and cuing in order to complete activities of daily living, or personal safety supervision for those with a surrogate.

Action Step: The Division of Medical Assistance (DMA) must continually act to streamline the approval process, which can take over six months, without compromising the vital role of independent living in the process. You can get in a nursing home in a day or less; why does it take up to nine months to get a comparable community-based service? Presumptive eligibility for three-months PCA services after provider evaluations would be a big first step.

Action Step: Inadequate compensation limits the workforce and thus PCA utilization; regular review of wages and implementation of a health insurance program for full-time PCA's is needed in order to maintain and increase the labor pool. It is notable that those working in state institutions have, in comparison to the high majority of community-based workers, an enhanced plan of wages and benefits.

Objective: Individuals with disabilities of any age qualifying for long term care services in the Commonwealth shall be able to use family members and relatives--with the exception of spouses--to serve as paid personal care attendants. Individuals, who are unable to identify any surrogate to assist them in the PCA service, shall have a surrogate supplied to them by the Commonwealth.

Surrogates necessary to assist a person in managing the PCA program can be either paid or volunteer. When a non-family member volunteers to be a surrogate that individual shall be required to have had CORI checks and meet with the PCA coordinating agency and the individual using the service quarterly to assure the individual is satisfied with the support and necessary services are being delivered.

Additionally, if an individual with a disability cannot identify a family member or volunteer, paid surrogates through a supported living provider will be allowed and encouraged. Provision of the service through a provider agency will ensure screening, supervision and back up when needed for this vital service.

Action Step: Amend the Medicaid State Plan to include the provision and payment for case management including "surrogacy" case management.

Objective: Each state agency offering a personal care attendant program shall adopt regulations that allow family members and relatives, with the exception of spouses, to be retained by the disabled person as a personal care attendant. These agencies shall also develop a program of surrogacy to guarantee that no disabled person is unnecessarily segregated because of lack of a surrogate to help direct their own care.

Action Step: Agencies shall begin the redesign work to format their PCA services to comply with this objective.

Assistive Technology(AT) provides individuals with disabilities the ability to access and control their environment as their non-disabled peers do. Funding for medically necessary durable medical equipment and devices is provided by DMA. Funding for non- medically necessary equipment and devices is limited in each agency.

Assistive technology reduces the individual with a disability's reliance on others to provide many tasks, such as the use of an adapted computer to pay bills, make medical appointments, order groceries, correspond with others, control lights and other electrical devices.

Objective: To expedite the approval of medical equipment, assistive technology, and home modifications needed in order to get people out of institutions or otherwise remain independent in their own homes.

Action Step: Encourage agencies to allocate funds to develop AT programs to provide funding for the evaluation of need, purchase of equipment and training for those individuals seeking to improve independent functioning where they live, and to either prevent institutionalization or to leave an institution.

Action Step: Assess the AT needs of all individuals with significant disabilities moving into the community.

Action Step: Establish an AT Working Group to explore the creation on an Assistive Technology Loan fund similar to the Home Modifications Loan Fund (HMLF) to enable families with members with disabilities to take low interest loans to purchase equipment.

Goal 7: SUPPORTED LIVING

Although the provision of affordable, accessible housing and personal assistance may afford the ability for many people with disabilities to move into or remain in the community it is often not sufficient enough to maintain them there. Individuals with cognitive or emotional limitations sometimes find the demands of coordinating their daily activities overwhelming or beyond their capacities. To enable individuals with these limitations to function as independently as possible in the community Supported Living (SL) programs were established by several state human service agencies.

Extensive supported living services are provided by DMR to assist their consumers with tasks such as reading mail, paying bills, and dealing with other daily life activities. Such services are distinct from personal care. Like programs are needed for non-DMR consumers transitioning from institutions or for people who are at risk of institutionalization, especially because of a combination of physical and cognitive or mental health disabilities. Supported living can provide the assistance needed to achieve maximum independence.

Objective: Supported living models are called different things in different agencies; SL case management, SL service coordination, individual supports etc. Whatever it is called, supported living should provide case management or service coordination supports in those areas that the individual cannot manage independently. It is recommended that a SL service delivery model NOT "bundle" all services together such as, housing, personal assistance, case management to be provided by a single provider agency as that situation tends to set up conflicts which inherently limits consumer choice and independence. For example, if a consumer of service disagrees with a provider recommendation for and is therefore terminated from SL services they may also lose their provider sponsored housing or if the consumer wants to have another provider of service they may also lose housing if services are "bundled" in a package of all or none.

Action Step: It is recommended that the SL program model be expanded, and its philosophical tenets be adopted by other EOHHS agencies. These include:

- Incorporate consumer choice either by a self directed model, or through the initial selection of an approved SL provider and an annual opportunity to change to another approved provider, if they so choose, during an “open enrollment period”,
- Consumers of service involved in the selection of case managers/service coordinators on interview committees for the SL program and in the selection of their own case manager.
- Funding of SL case management/service coordination follows the consumer, it is not the program’s “slot”. If consumers of service choose another provider or move the funding follows them, they do not wait for a slot with another provider,
- Supported living service/service coordination are generally not in a “bundled” package with housing and PCA by a provider agency.
- People with disabilities have the right to make choices even if those around them feel they are the wrong ones and to experience the results of their choice

Goal 8: TRANSPORTATION

The availability of accessible transportation is a fundamental component of the integration picture for people with disabilities. It is an undisputable link to employment, education, recreation, and numerous other elements of leading a normal life. Vehicle ownership is often limited among people with disabilities because of the nature of their disability or the poverty so closely associated with having a disability. This fosters a tremendous dependence in the disability community on public systems and human service systems.

Objective: Public transit, though, is limited in suburban and rural areas in Massachusetts; much fixed-route service, including that run by the MBTA, is not fully accessible; and paratransit service is often unreliable and not in compliance with ADA mandates. The human service system is often uncoordinated and duplicated and run by agencies that provide other services such as housing, case management, and personal care. The individual’s life becomes totally dependent on one or two providers, an unhealthy infringement on independence, notably so when there are problems with a service provider.

Action Step: Develop and implement a plan to bring all state-funded fixed-route service, including bus, subway, and ferry service, into compliance with ADA access requirements.

Action Step: Comprehensive review of paratransit services run by the MBTA and the RTA’s to ensure that they are operated in compliance with ADA eligibility requirements.

Action Step: Review of human service transportation programs by the state, including elderly services, to eliminate duplication, increase coordination, create interregional

transit comparability and reciprocity, and otherwise increase use of mainstream public transportation by people with disabilities.

Goal 9: MENTAL HEALTH COMMUNITY SERVICES

The need for more and better services so that individuals with mental illness can choose to live independently in the community rather than having to be institutionalized.

Objective: DMH will fully support the concept that all individuals are entitled to have opportunities to live, receive treatment and achieve rehabilitation in the communities of their choice. In keeping with these values, DMH will continue to develop mental health services in normative community settings that offer greater choices to persons with the mental illness. In particular, these services have been, and will continue, to be targeted to persons who have been served in institutions for time periods that exceed their need for such intensive care.

Action Step: Residential Services - DMH will devote existing and new resources to the development of a wide spectrum of residential services in the community. These services will be provided through models ranging from 24 hour on-site staff supervision to supported housing, with clients living on their own and receiving in-home assistance, as needed. DMH has identified over 200 individuals who are currently living in our state hospitals and who could be discharged, given the availability of appropriate community services. Provided there are sufficient increases in the DMH base budget over the coming years, DMH planning calls for the creation of new residential opportunities.

Action Step: Programs of Assertive Community Treatment - DMH supports the statewide expansion of a new and exciting model of community services management, the Program of Assertive Community Treatment or PACT. A team of multi-disciplinary staff provides comprehensive treatment, support and rehabilitation to an identified group of 50-80 clients at risk of inpatient admission. Clients receive all needed services in the communities in which they live. This approach assures community treatment, constancy of providers, and integration of clients into the life of their communities. Because of the emphasis on blending mental health and rehabilitation services, PACT has consistently demonstrated success in helping clients gain both mental health stability and achievement of personal goals (e.g. job, housing).

Action Step: Continued, and increased, state funding for DMH-funded clubhouses, and peer support models.

Objective: Expand the availability of community based mental health services to disabled elders seeking to live in the least restrictive settings.

Action Step: The Executive Office of Elder Affairs should promulgate new regulations at 651 CMR to make Mental Health services on an outreach basis a home care service to extend the period of time an elder can remain living in the most integrated setting appropriate to their needs.

Goal 10: PROMOTE THE HEALTH OF PEOPLE WITH DISABILITIES AS AN ASPECT TO ENSURE COMMUNITY LIVING, PREVENT SECONDARY CONDITIONS, AND ELIMINATE DISPARITIES BETWEEN PEOPLE WITH AND PEOPLE WITHOUT DISABILITIES IN MASSACHUSETTS

Access to quality health care as a part of community services and supports is critical. Without access to basic health care, people with disabilities often develop secondary, and tertiary health complications that result in frequent, and costly, hospitalizations, and subsequent nursing home/chronic care hospital placements.

Objective: To ensure equal access to community-based health care that promotes healthy living and full community inclusion across the lifespan for people with disabilities

Action Step: Train health care professionals to understand disability rights/independent living

Action Step: Establish a mechanism for consumer/family input regarding barriers and facilitators to accessing health care in the community.

Objective: To ensure availability of high quality health care services in the community, including primary care, dental care, specialty care, and mental health services.

Action Step: Train health care professionals on how to provide accessible care, including physical, communication and equipment access.

Objective: To ensure that community-based health care services are available in a manner consistent with civil and human rights

Action Step: Establish a mechanism for monitoring health care entities receiving public funds to assure adherence to disability access laws and regulations.

Goal 11: MAXIMIZING RETAINED REVENUE FOR SERVICES

In order to maximize revenues for services for people with disabilities, all programs for people with disabilities that generate Federal Financial Participation (FFP), shall credit such FFP back into the least restrictive, community based, program services.

Objective: FFP that is generated by the work of staff in programs serving people with disabilities, shall be "credited" back to the program, and not deposited to the General Fund. The Executive Office of Administration and Finance shall prepare an accounting of all such revenues, by line item and amount.

Action Step: Administration and Finance, working with the House and Senate Ways & Means committees, shall identify all line items in the state budget which generate federal match, and shall direct such FFP revenues to the line item accounts from which they are derived, to further maximize the revenue capacity of said programs, and require at least maintenance of effort in their base funding.

Goal 12: ADEQUATE COMPENSATION FOR STAFF OF COMMUNITY-BASED SERVICES

Without adequate, competent staff, community-based services fail, and cannot expand. Unless compensation is adequate, there is less staff, and those who are hired may not have the skills required to perform their jobs.

Currently, salaries and benefits at State institutions are, for the most part, superior to those offered in community-based programs. For instance, within the DMR system, starting salaries for comparable direct care workers run \$4,000-\$5,000 higher in the state-run system than in the private sector. Also, state employees receive periodic increases, while salary adjustments in the private sector are completely dependent on a periodic decision by the legislature and administration, and when granted, are minute (under 3%) and retroactive rather than prospective.

Objective: The Commonwealth must provide adequate funding to community-based service providers to ensure a capable and reliable workforce. The principle of equal pay for equal work should be adopted. Salaries in state operated services and in the state contracted service system should be the same for the same work.

Action Step: The Commonwealth should appropriate the funds necessary to equalize salaries in state operated and state Contracted Services.

Action Step: The Funding to provide annual salary adjustments should be built into the budgeting process of each state Contracting Agency for both state employees and the employees of the private agencies contracting with the Commonwealth.

Objective: Training for Direct Care and supervisory staff must be improved in order to insure that staff have the skills to perform the work of providing direct care to individuals with disabilities.

Action Step: Expand and increase the availability of training programs through the Community Colleges, which has recently begun, and provide salary incentives to staff that successfully complete training curriculums based on approved standards for Direct Care Workers.

Goal 13: EMPLOYMENT

The multiple barriers to employment and economic empowerment of adults with disabilities include the fragmentation of existing employment services; the isolation and segregation of people with disabilities from mainstream programs and services; the lack of access to health insurance; the complexity of existing work incentives; the lack of control and choice in selection of providers and other agents; inadequate work opportunities resulting from attitudinal barriers based on historical and erroneous stereotypes; and the lack of accurate data on employment of people with disabilities needed to measure progress in eliminating barriers to their employment.

Objective: The following actions are planned to help address these barriers and to increase employment opportunities for people with disabilities.

Action Step: Increase and promote the choice of regional One-Stop center employment services for people with disabilities, including those transitioning to the community from institutions or those at risk of placement in residential facilities. Efforts must be made to ensure full, equal access to all services, including those of the Massachusetts Rehabilitation Commission (MRC), at One-Stop centers.

Action Step: Direct MRC, and the state Department of Education to evaluate and improve transition services provided to youth with disabilities that are making the transition from school to work or postsecondary education.

Action Step: Continue swift implementation of the Ticket to Work Program to develop a viable infrastructure of SSA certified Employment Network (EN) providers, both public and private.

Action Step: Continue to actively enforce the new VR regulation that eliminates extended employment as a final employment outcome under the State Vocational Rehabilitation Services Program, so that an employment outcome may only be counted if an individual with a disability is working in an integrated setting in the community

APPENDIX E

Olmstead Advisory Group: Report of the Subcommittee on Housing

Olmstead Advisory Group

Subcommittee on Housing

Subcommittee Chairs:

Bill Henning, CORD
Linn Torto, EOAF

Subcommittee Members:

Arlene Korab, Mass Brain Injury Assoc,
Bill Henning, CORD
Joe Bellil, Advocate
Carole Collins, DHCD
David Eng, DHCD
Sarah Young, DHCD
Edward Chase, MassHousing
Maggie Dionne, Elder Affairs
Michael O'Neill, DMH

Joseph Tringali, Stavros I.L.
Ben Haynes, MA Sr. Action
Linn Torto, EOAF
Maura Hamilton, DHCD
Marc Slotnick, DHCD
Anne Marie Gaertner, DHCD
Richard Dahill, MassHousing
Margaret Chow-Menzer, DMR
Joseph Valley, DMH

Introduction

The Commonwealth of Massachusetts has been a leader in developing affordable housing for low-income persons including persons with disabilities. These programs provide opportunities for people with disabilities to live in the community, including many integrated settings.

- Massachusetts is one of only two states that have a state-funded public housing program; the program includes over 33,000 housing units for the elderly and people with disabilities.
- The Commonwealth has applied for and been awarded Section 8 funds targeted towards people with disabilities since the inception of these programs.
- The Department of Housing and Community Development supports the production of housing for persons with disabilities through the Housing Innovations Fund Program and the Facilities Consolidation Fund Program, both of which have funded the development of thousands of units of supported housing.
- For over 24 years, MassHousing has required developers to set-aside units for people with psychiatric disabilities and mental retardation, creating hundreds of integrated housing units.
- With the innovative “Mixed Populations” legislation, the Commonwealth developed a new rental voucher program to allow people with disabilities to rent apartments in the community rather than in what is largely elderly housing.
- Massachusetts was the first state in the Country to develop a database of accessible units in order to better match people requiring access with owners who have units available.
- The Commonwealth has been aggressively assisting people with disabilities to live successfully in the community with projects such as DHCD and Elder Affairs’ Service Coordinators and MassHousing’s Tenancy Preservation Project.
- The Commonwealth’s public housing and Section 8 programs recognize persons in institutions as “homeless” providing the prioritization for housing that comes with this designation.

These are only some of the state's accomplishments in this area. Despite these efforts, the Commonwealth recognizes that additional work needs to be done to ensure people with disabilities have the right and the availability of opportunities to live in the community. The work of the Housing Subcommittee of the Olmstead Task Force seeks to address these issues.

Overview of Committee Work

The Housing Subcommittee met 5 times. Presentations to the subcommittee were made regarding the housing needs and preferences of the following specific populations: persons with psychiatric disabilities, persons with mental retardation, persons with head injuries and elders. In addition, the Department of Housing and Community Development and MassHousing provided information regarding current and potential housing programs for the targeted populations, including people with physical disabilities.

The following provides a set of principles agreed to by subcommittee members and recommendations developed from these presentations.

Principles

The Olmstead Housing Committee believes that housing programs and property development should be consistent with the following principles:

Integration: Housing for people with disabilities should be designed to integrate people with disabilities into the community as fully as possible. For example, a unit for a person with a disability within a housing development with units not exclusively targeted to people with disabilities is more integrated than an isolated three or four-person group home standing by itself in a wooded area. In the most integrated, least restrictive housing environment, support services should be available when necessary to help ensure a successful tenancy and lease compliance.

Housing and Services Relationship: Before a housing model is funded or endorsed, the relationship between housing and services must be reviewed and determined appropriate for the targeted population. Many people with disabilities, disability advocates and service providers believe that the historic "bundling" of services and housing has been detrimental for people with disabilities. For example, when services and housing are bundled together, the consumer's choice of services is limited and conflicts of interest may arise. Further, such arrangements restrict the options of the state in finding appropriate services and housing. Many elders and elder service organizations, however, believe that bundling services and housing is necessary to provide adequate supports to many frail elders. The assisted living model, for example, links housing and services specifically to ensure frail elders can remain in the community rather than be institutionalized. In all models, adequate and appropriate services should be available as needed and chosen by the resident to ensure their successful tenancy in the community

Maximum Control: People with disabilities should have the maximum control possible in their housing choices and management. Having and meeting the obligations of a lease or a mortgage in their own name, with or without assistance, is the goal for most people with disabilities.

Informed Choice: People with disabilities must be able to choose their housing. In order to do this, they must be informed fully, in a manner understandable to the individual about the choices available and the responsibilities that accompany these choices. Different housing options and any necessary tenant support services must be made available.

A Variety of Choices: In developing a system of housing for people with disabilities, the overall state system should promote a variety of choices. Currently some systems and/or geographic locations within a system have too much of one housing option or another; a variety of housing types and geographic locations should be considered in developing the system further.

Accessibility: All housing for people with disabilities must be accessible. The Commonwealth will seek to promote maximum visitability in all publicly funded housing. This will better ensure people with disabilities have access to integrated housing in all communities.

Overview of Recommendations

Additional housing and supportive services including tenant supports are needed in order to ensure people with disabilities are not unjustly or unnecessarily institutionalized. The needs of some individuals can and will be met by better using existing resources and breaking down the programmatic and community barriers to housing for people with disabilities. Ensuring that housing and programs are made accessible will guarantee that resources will become routinely available to people with physical disabilities, including elders, in the future.

I. Recommendations to Break Down Barriers to the Development and Maintenance of Housing for Persons with Disabilities

- Commit to **an aggressive public education effort** in coordination with housing and disability services providers to combat the Not In My Back Yard” (**NIMBY**) syndrome. In addition, enlist the support and resources of the **HUD Fair Housing Division and the Attorney General’s Offices** of Public Protection and Disability Rights in enforcing C.151B where communities continue to discriminate against people with disabilities
- Support the recommendations of the **Governor’s Special Commission on the Barriers to Housing Development** to engage state and local public building and fire officials in training sessions and educational sessions through the Architectural Access Board and others on the rights of persons with disabilities to live in the community in the least restrictive settings appropriate to the individual. The Executive Office of Administration and Finance is working with state building code and fire officials around the promulgation of the new state building and fire codes to insure that housing development is consistent with the principles of independent living and pose no unnecessary barriers to the development of housing for persons with disabilities.
- Insure that persons with disabilities can live independently wherever they choose. Therefore, housing and service providers must consider accommodations around **transportation**, for example, which will enable residents to live in many different community settings. Work with communities to develop a mutual understanding of the housing needs of persons with disabilities within their community and create a plan to identify housing opportunities for residents in all neighborhoods of the community.

Insure that planning efforts in this regard include the input of persons with disabilities in these processes. See City of **Boston/EOHHS siting agreement**

II. Recommendations to Maximize Existing Resources

In this period of limited funding availability, maximization of existing housing resources is key to expanding community-based housing options for people with disabilities.

- Support community housing resources through the **reprogramming of capital and operating funding** currently being used to support institutional living arrangements.
- Revisit housing and service programs to identify places **where innovative and creative funding opportunities** can be implemented within the context of existing laws and regulations. Consider modifications to laws and regulations as appropriate to allow for greater flexibility and targeted resources for this development initiative. State agencies should conduct this review. In particular Elder Affairs' Supportive Housing model should be reviewed.
- The discharge service plan model which emerged from the committee's many discussions is **community based housing that includes:**
 - Rent subsidies;
 - Housing search assistance (where the subsidy is a tenant-based voucher) including access to security deposit and move in funds;
 - Tenant stabilization; and
 - Adequate and appropriate support services.
 - Accommodation plans for tenants who may need temporary hospitalization or nursing home placements to insure no loss of housingPlacing a person with a disability – especially someone who has been institutionalized – in the community without access to this menu of supports will not result in a successful tenancy. State agencies, institutions and service providers must incorporate all of these components into individual service plans. Programs such as HOP's housing search and the Tenancy Preservation Program should continue to be funded.
- Direct state agencies to coordinate housing resources, and to possible "trade" where appropriate. For example, DMH has a significant stock of nonvendor-owned C.689 and C.167 developments. If some DMH consumers are able to move from these properties/programs towards supported housing (with provision of subsidies), resources may be freed up for use by DMR. DMH would expect alternative replacement housing for that given to DMR. This may be a quick and cost-effective way to "create units". State human services and housing agencies should review resources to identify any current "surplus" and establish a system for on-going review of resource utilization and exchange of this information to maximize use of resources for all EOHHS consumers.
- In light of the changing needs of persons with disabilities and the growth of the not for profit housing delivery system, the C689/67 program should be reviewed and evaluated. DHCD will convene a working group consisting of all relevant parties to undertake this review and make necessary recommendations for amending the program in response to current client needs.
- Develop a **database** so that agencies can share information about "surplus" properties or units and needs. State agencies should review whether Mass Access could play this role.
- Devise a coordinated plan to match people with particular housing needs in a particular geographic with available housing resources in that area in a timely manner, such as

Mass Access. State housing and human services agencies should explore development of a system to accomplish this.

- Develop a single point of entry for consumers and advocates into the housing system. Explore whether the Housing Consumer Education Centers or other entities are an appropriate point of entry. Ensure that HCECs have the ability to provide information about reasonable accommodations for people with disabilities in housing including adjustments in programs that offer options to amend the payment and utility standards for persons with disabilities.
- Ensure that limited **resources within developments**, such as the 13.5% in state-funded public housing and designated percentages in private housing, are **fully used**. **DHCD and MassHousing and other public entities to conduct utilization review and generate recommendations for increasing utilization of resources.**
- Ensure **targeted resources** such as AHVP and targeted Section 8 programs are **fully used**. DHCD should continue to apply for various Section 8 programs and maximize the vouchers available to people with disabilities.
- Promote the availability of **local tax abatements and deferrals** to help keep elders and people with disabilities in their homes.
- Use “**excess capacity** “ in C.667 congregate, DHCD/Elder Affairs’ Supportive Housing programs and group homes to **help transition people** into the community. Unless consumers choose such settings for permanent housing, use them only for transition purposes. DHCD should continue to share information about excess capacity with state human services agencies.
- Research whether underutilized housing developments for the elderly and persons with disabilities can be **reconfigured or reconstructed** to provide larger, more usable and desirable housing units. Pursue sources of funding including working with HUD and federal legislators to authorize use of federal Section 202 funds by local housing authorities for reconfiguration.
- Develop ways to help **service and housing providers work better together**, including ASAPs and LHAs, working creatively with existing local resources. Housing and service agencies should continue aggressive efforts to develop partnerships of qualified providers and engage in initiatives to promote the creation of different kinds of housing models for persons with disabilities and elders, most especially units integrated in new or existing developments available to the general public
- DHCD has defined persons within nursing facilities as homeless. Revisit the notification and public education effort with local housing authorities and other housing providers receiving state funds to ensure that other individuals within institutional settings may receive this preference, including persons in rest homes, rehabilitation facilities and institutions operated by DMR, DMH and DPH.
- Increase availability of accessible transportation to maximize use of existing accessible units.
- Streamline process for development of affordable housing. A successful example of agency collaboration and efficient review process is the Affordable Housing Trust model, which agencies should seek to replicate wherever possible.
- Work with HUD and federal legislators to change federal statutes and regulations for project-based Housing Choice Vouchers. Current tenant selection requirements make it very difficult for housing authorities and service providers to effectively serve persons with disabilities in project-based units with supportive services. Changing federal statute to allow owners/service providers to identify eligible applicants and maintain the

waiting list for project-based units would allow housing with services to be appropriately matched to persons with disabilities.

- Develop a system for ensuring state funds are not being used to develop new housing that will negatively impact other affordable housing already in place. For example, ensure state funds are not being used to develop elderly housing in an area where there is a surplus of C.667 housing.
- Support MassHousing's efforts to have HUD refinance 202 developments in order to both refinance mortgages and obtain additional support services funds for the developments.
- DHCD and service agencies will work together to insure Project Based Section 8 resources are utilized and allocated to best serve the needs and preferences of persons with disabilities, including developing integrated models of housing as an option.

III. Recommendations to Develop Additional Resources

Additional housing resources are needed for *all* populations. Some of the agency needs include:

- **Department of Mental Health:** DMH has enough group residential housing at this point, though DMH is always in search of higher quality housing stock with project-based subsidies. DMH prefers any expansion be with Supported Housing model, specifically with individual subsidies and individualized supports. Certain types of new programs such as consumer-directed households could rely on development of housing that has the appearance of more traditional group homes.
- **Department of Mental Retardation:** DMR has a significant issue with an aging population. Accessibility becomes a significant issue at many group homes. DMR prefers all new development to have a maximum of 4 persons in one living situation.
- **Statewide Head Injury Program:** Service funding is really the issue, not the bricks and mortar. This population is underserved. A range of programs is needed, as there is very little available for this population.
- **Executive Office of Elder Affairs:** Agency would like to see an expansion of the following programs: Supported Housing model, Service Coordinators and affordable assisted living. The congregate model has worked on a limited basis; no expansion desired.

Support services, however, are also necessary to enable consumers to access these housing resources:

- Use housing funds targeted towards people with disabilities, e.g. HIF or FCF, (and/or the RFR point system) to **provide an incentive for developers to include set-asides for people with disabilities** in new construction or rehabilitation projects. DHCD and MassHousing could include such targeting in their RFRs. Once in place, the agencies should assess whether such incentives were successful in creating integrated housing.
- **Improve the housing development system** for people with disabilities. This may mean improving relationships between housing and service providers and providing incentives for housing providers to deliver units for these groups.
- Ensure adequate and appropriate services are available as needed and chosen by the tenant to ensure their successful tenancy in the community. If preferable to the funding agency in support of the clients being served in the community, seek to insure that the

housing and service contracts are separate and divisible, most preferably with different providers (including those owned by a related party).

- Ensure new housing is developed using flexible model. Ensure the **model is a long lasting one**. Working together, the state housing and human services agencies should look at some successful programs as models and develop “Best Practices” models
- Continue discussions and arrangements with Division of Medical Assistance on using Medicaid (most likely waivers) to **support services** that keep elders out of institutional settings (such as 24-hour care model). Research how MassHousing’s Elder Choice program uses GAFC to increase affordability.
- Provide access to **MassHousing’s assisted living** model or for other low-income assisted living models to the small **number** of Olmstead consumers who may prefer and be appropriate for this model.

IV. Recommendations to Ensure Resources are Accessible

Housing resources will be unusable by elders and people with physical disabilities if they are not accessible.

- Ensure all existing publicly financed housing has completed 504/ADA self-evaluations and implemented transition plans up to the point of undue financial burden, alteration of the program or structural infeasibility. DHCD, MassHousing and other entities shall continue to verify that this standard is met.
- Ensure **assisted living developments** for elders and/or people with disabilities are accessible.
- Ensure **that new construction and substantial rehabilitation projects** are made accessible by enforcing access requirements. DHCD, MassHousing and other entities shall continue to ensure this occurs. Ensure **leased/owned properties are accessible** before recontracting services with vendors. This is a model DPH/SA use successfully to ensure access throughout the substance abuse treatment system. DMR, DMH and other agencies should meet with DPH to review how their substance abuse treatment system made itself accessible and implement similar procedures.
- Develop a funding source to make housing serving people with disabilities accessible where such funds are not already available, e.g. for smaller private landlords.
- Ensure continued funding of the Home Modification for the Disabled Loan Program. By providing loans for access modifications such as ramps, elders, and people with disabilities and children with disabilities are able to remain in their own homes.
- Ensure accessible units are occupied by persons who need the design features by requiring use-of lease addendums in publicly funded housing that allows the manager to move households as needed to accommodate persons with disabilities. DHCD’s access project can serve as a model.