Disability Policy
CONSORTIUM

THE OLMSTEAD INITIATIVES

Independence and Quality of Life for Elders and People with Disabilities

February 2010

Disability Policy Consortium

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Introduction

For nine years I have been living in nursing homes…and that's enough. My goals are to get out into the community, get a job, have a home of my own…
Roberto Aponte

I recently got out of prison -- Red Stone Nursing Home. Were it not for Stavros (CIL)…I would probably still be there... Pedro Ramos

Many of us when in crisis, we don't need a locked door. We don't need a locked door. We need a friendly ear and a safe place to be. Ruthie Poole

We know that home care is less expensive than nursing home care, and yet, seniors are forced into nursing homes because they cannot get care at home or in their communities. John Bennett

No matter what the doctor writes on the prescription…consumers get what the prior authorization people think is needed… Martina Carroll

A nursing home operator said the other day, there are only two populations left in institutions, prisoners and the elderly. That's a pretty sad commentary, coming from a nursing home operator, who was speaking the truth. Al Norman

These statements are drawn from the testimony of more than two hundred persons with disabilities, elders, family members, advocates and service providers. They indicate the breadth and depth of the challenges still to be addressed as matters of law and of ethics by the State of Massachusetts.

THE OLMSTEAD INITIATIVES

What is Olmstead?

In 1999, in a landmark decision, the Supreme Court of the United States found that unjustified institutional confinement of a person with a disability is a form of discrimination. The Court also described the effects of discrimination that *severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment*.

Based on the statutory provisions of Title II of the Americans with Disabilities Act (ADA), the Court held that all states, including Massachusetts, have an affirmative obligation to provide services in the least restrictive environment appropriate to the needs of each individual – and that to accomplish this restructuring of service systems, it is necessary to strengthen community-based services and supports, and to reduce institutional placements.

Eleven years since the decision, Olmstead has served as a catalyst for reform. Many states have undertaken restructuring of service systems to comply with the integration mandate of the ADA enabling persons with disabilities to live, learn, work and contribute to the home communities of their choice.

In Massachusetts, three years after the Supreme Court issued the Olmstead decision, advocates formulated the People's Olmstead Plan -- identifying major areas in need of reform in Massachusetts both in the states disability related service systems and in other state functions related to housing, education, transportation, employment and medical care.

In September 2008, Governor Deval Patrick issued the Administration's Community First Plan. It should be noted that Governor Patrick in his role as Assistant Attorney General for Civil Rights in the Clinton Administration was the senior federal official responsible for enforcement of the ADA.

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The Origins of the Olmstead Initiatives

It is now over 10 years since the Supreme Court issued the Olmstead decision in 1999 and nearly twenty years since the ADA was enacted, in 1990, with sweeping bi-partisan support in both houses of Congress. Section 504, the legislative precursor to the ADA was passed in 1973, linking disability policy to Civil Rights law grounded in 14th Amendment and extending Constitutional guarantees of equal opportunity and equal protection to people with disabilities.

And it has been fully 49 years since John Fitzgerald Kennedy, drawing on his own family experience, challenged the people of the United States to end the national disgrace of lives diminished and lost in the wastelands of custodial care.

Much has been accomplished over the past half century. But, as the vision of the Community First Plan makes clear, much more remains to be done. The Commonwealth's own documentary record and the extensive testimony at community forums support the following conclusion:

> Progress towards creation of an effective, empowering and efficient system of "person centered" long-term supports has been compromised by inconsistent political leadership and failure to fully and effectively integrate progressive, non-discriminatory disability policies into the operations of Massachusetts state government.

A striking example of the contradictions that continue to undercut progress was presented when the Office of Administration and Finance proposed in January 2009, that a blanket time-waiver be granted by the Architectural Access Board for construction projects funded with federal stimulus funds. Although the proposal was withdrawn, it still raises concerns that fundamental principles of disability rights, inclusion and community first services and supports have not been effectively integrated into the principles and practices of public administration – from the highest levels of planning and decision making to day to day operations of state programs.

The Olmstead Initiatives -- process and outcomes

It is in the context of the ongoing movement for rights, inclusion and empowerment of persons with disabilities and elders that the Olmstead Initiatives was undertaken. The initiative began with three community forums designed to give stakeholders, advocates and those most directly affected – persons with disabilities, Deaf persons, elders and their family members opportunity to:

- To review and comment on the proposals and actions by the Commonwealth to advance the goals of the Community First Plan,

- To identify gaps, inequities, problem areas and operational deficiencies in service systems, and

- To make recommendations to strengthen and advance the goals of the ADA's Civil Rights protections in relation to the Community First Plan.

The kind of community involvement represented in the forums is consistent with the democratic values and specific statutory requirements of the ADA, the Fair Housing Act Amendments of 1988, Section 504 of the Rehabilitation Act and the whole body of state and federal disability rights law.

The Olmstead Initiatives was undertaken by the Disability Policy Consortium (DPC) in partnership with 47 disability advocacy and service agencies. The idea grew out of a meeting between representatives of the DPC and the Commissioners for the Massachusetts Rehabilitation Commission, Massachusetts Commission for the Deaf and Hard of Hearing, and the Massachusetts Commission for the Blind.

This report presents a summary of testimony provided by 250 persons with disabilities, family, members and advocates at three Community Forums. The forums were organized and convened by the DPC in October 2009, in Holyoke, Worcester and Boston in partnership with 47 community advocacy and provider agencies, 10 departments and agencies of the Commonwealth and 7 state legislators.

Holyoke Community College, October 23 --70 participants
Worcester Public Library, October 28 -- 65 participants
Gardner Auditorium, the State House, Boston, October 30 -- 120 participants.

Additional information including CART transcriptions of testimony, YouTube video links and links to the DHHS Community First Plan with supporting documents can be found at the DPC web site www.dpcma.org under Issues/The Olmstead Initiative.

A panel of senior state officials attended each forum and is to be commended for staying to hear the testimony of 250 persons with disabilities, family members, caregivers, advocates and service providers.

Those officials included the Assistant Secretary of the Department of Health and Human Services (EOHHS), The Secretary and Assistant Secretary of Elder Affairs (DEA), and the Commissioners of the Massachusetts Commission for the Deaf and Hard of Hearing (MCDHH), The Mass Rehabilitation Commission (MRC) and the Mass Commission for the Blind (MCB).

At the beginning of each forum, Dr. Jean McGuire, Assistant Secretary of the Executive Office of Health and Human Services, summarized the vision and goals of the Community First Plan. Dr McGuire also gave an overview of the demographics of the disability population in Massachusetts, briefly described programs of long terms support and their cost, and identified areas where the Commonwealth believes that progress has been made. She also identified those where more work – often a great deal more work – needs to be done to realize the goals of the Community First Plan.

Dr. McGuire and other state officials presented a somber assessment of the impact of the state budget crisis on the implementation of Community First reforms and the states ability to maintain current levels of service in some areas.

Organization of the Report: the report is organized as a dialogue between government and community policy makers and advocates, gatekeepers and current and potential recipients of services.

Dr. McGuire's presentation* of the Community First Vision and goals is summarized along with statements by her and other state officials regarding the current status of the Commonwealth's reform efforts.

Comments and recommendations by advocates and others who attended forums and follow-up testimony and comments have been summarized, clarified and illustrated with excerpts from testimony. These are grouped under seven headings. The first six correspond to the Community First Goals. The seventh heading presents additional issues not directly subsumed under the Community First goals but contributing to the overarching 'vision' of the Plan.

The Community First Vision statement is restated in the concluding Section with summary statements of the community's understanding and assessment of the status of Community First Plan; general recommendations are also presented for short and long term solutions and actions

Community First Vision and Goals

Vision: *Empower and support, people with disabilities and elders, strengthening and integrating systems of community based long-term supports that are person centered, high in quality and provide optimal choice.*

Six Goals:

1. Help individuals transition from institutional care
2. Expand access to community based long-term supports
3. Improve capacity and quality of community based long-term supports
4. Expand access to affordable and accessible housing and supports

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* See the PowerPoint slides presented by Assistant Secretary McGuire at www.dpcma.org under Issues/The Olmstead Initiatives "The Olmstead Plan Update 2009" in the left column

5. Promote employment of people with disabilities and elders

6. Promote awareness of long-term supports

Demographics of Disability & Need for Long-Term Supports

15% of the total population of the Commonwealth is persons with disabilities. Two out of three, or approximately 630,000 state residents need long-term supports to maintain independence and live active, fulfilling lives. Most live in the community and more than half are under the age of 65.

The population needing long-term supports is expected to increase 15% by 2020. Growth will be driven both by the general aging of the population and by advances in medical practices across the life span including neonatology, developmental medicine, trauma care, rehabilitation medicine chronic disease management, and gerontology.

The Commonwealth currently spends approximately $5 billion on long-term supports provided through programs administered by the Departments of Mental Health, Developmental Services, Public Health and Veteran’s Services, the Executive Office of Elder Affairs, the Commission for the Blind, the Rehabilitation Commission, the Commission for the Deaf and Hard of Hearing and also through MassHealth in large part through the Office of Long-Term Care.

Fifty-seven percent (57%) of total expenditures by the Commonwealth across all programs are for community programs and 43% for institutional programs. More than half of Medicaid dollars (63%) are still spent on institutional services. but the balance is shifting towards community-based services. Spending for community programs includes funding through ‘waivers’- these include a frail elder waiver, a traumatic brain injury waiver and a mental retardation waiver.

Goal 1: Help individuals transition from institutional care

Most individuals who need long-term support live in the community today, but others are still housed in institutions operated directly by state agencies or by providers operating nursing homes or other residential facilities with state funding.

The state is in the process of moving persons from institutions operated by the Department of Developmental Services (DDS) and the Department of Mental Health (DMH) into community settings. The plan to close four of six remaining DDS facilities over the next four years was supported by a recent federal court ruling blocking an attempt by pro-institution groups to keep the Fernald State School open.

Attorney Matthew Engle of the Disability Law Center spoke in favor of accelerated action by DDS to close institutions and asked that the Department also take steps to open lines of communications and address the fears of family members.

> *We urge DDS to proceed as quickly as possible to effectuate the closing while ensuring placements for remaining residents, and in light of the court's decision, and the Department's excellent record, in closing state schools, we believe a realistic should be to close all such facilities within the next five years.*

Housing, education, coordinated health care, employment and transportation are essential for many, but state programs do not facilitate appropriate access for persons in recovery from mental illness. Cost-neutrality has become the overriding rule. This way of thinking engenders a minimal response instead of a search for excellence.

The Department of Mental Health is moving to reduce the number of persons in state run psychiatric facilities. A report was issued in July 2009, by a commission convened to address closing institutional settings. Dr. McGuire stated that the DMH patient study commission will result in 200 institutional beds closing during this fiscal year, also. She also announced that the long-term care financing plan would have a series of public sessions in early November and December. Further, she stated, [p]*art of the challenge is that we don't have some of the resources we need and they're not in the right places.*

A number of advocates in recovery from mental illness responded, pointing out the inconsistency between rhetorical commitments to community-based services and the state's decision to spend $350 million to build a new mental hospital in Worcester, especially at the same time that community services are being slashed.

Ruthie Poole called for strengthening peer supports as an alternative to hospitalization: *Many of us when in crisis, we don't need a locked door. We don't need a locked door. We need a friendly ear and a safe place to be.*

Clubhouses were heralded as a mainstay of peer supports and community-based services by representatives of the mental health recovery communities. Their value was summed up by James McCarthy in Boston.

> *The Clubhouse is the first place I call from the hospital after I'm admitted and the first place I call when released. They help me get back on track after each hospitalization. They are always there and meet my needs immediately. I walk through the door and see friend to see support me. It's a place of well being and survival. I get overall support.*

Advocate Jonathan Dosick strongly endorsed expansion of peer supports in emergency rooms and residential settings. He spoke on behalf of peer services as a cost effective and personally empowering alternative to the medical model of intervention.

> *I believe there is a potential revolution…with the movement (for) peer based services…The idea of a peer run home which would prevent expensive hospitalizations, prevent crises and would provide perhaps the best therapy of all…the understanding of one's own peers!*

Commenting on the status of people in mental hospitals, Karen Tally, a lawyer with the Disability Law Center said:

> *There are still far too many people in State institutions that don't need to be there. And just in the last few weeks alone, the DLC attorneys have encountered people in state hospitals who have been there 31 years, 15 years, 14 years . . . one client who's been there 15 years is a client of mine. He said 'I've been here 15 years I want to get the hell out of the hospital.' I had to double check because I couldn't believe he was there 15 years…. everyone when they enter the hospital, they have their picture taken. And he had a full head of jet-black hair when he entered the hospital and it all turned gray….I've been doing this for a long time, and I don't feel like I want to cry often but that made me want to cry.*
>
> *There is also a steady irregular influx of people who are in state hospitals incompetent to stand trial, especially if they have a could current injury that's not amenable to psychiatric treatment, they may stay there for years and this is due to a lack of collaboration from the state agency, and cross disability training and supports that would allow these people to be discharged to the community. And the time that they spend in the psychiatric institutions are most often getting low care only.*

Even as state-run institutional populations are reduced, the Commonwealth relies excessively on nursing homes to warehouse persons with disabilities of all ages.

Some are placed in nursing homes ostensibly for short-term medical stabilization and rehabilitation, only to find themselves incarcerated for years - while others are forced to seek admission by gaps and failures in the system of long term supports.

> *I recently (got) out of prison, Red Stone Nursing home,* said Pedro Ramos. *Were it not for Stavros (Center for Independent Living) I would probably still be there. After having fought as hard as I could with the limited knowledge I had to get out of that place for over a year, Miss Buckley came in, and in three weeks did what the staff hadn't done in a year. I think possibly the only good thing that I could ever say about a nursing home is that they do let you see the sun shine once in a while.*

Efforts to provide the kind of assistance Mr. Ramos received are hampered by poor communication, lack of coordination between community service advocate/providers and state agencies, and by misallocation of funds that limit community supports. Susan Amann of the Center for Living and Working testified to the difficulty for people in nursing facilities with very limited incomes to pay for the steps necessary to get housing and move:

> *...requires a birth certificate, which cost $10, a Mass I. D. Card for $25 which she will need for the preliminary housing meeting. I can tell you first hand I am working with a consumer who still is in a nursing facility and receives a monthly stipend of only $72 a month. Her expenses just for the I. D., the birth certificate and a ride are $115. Well over her monthly stipend. She would need to continue to save for her trip to the social security office for her duplicate card.*

Clearly, there is a need to establish funding mechanisms for people returning to the community from institutional settings.

> *We're trying to get people out of nursing homes… give us the names; we'll help bring them out. A nursing home operator said the other day, there are only two populations left in institutions, prisoners and the elderly. That's a pretty sad commentary, coming from a nursing home operator, who was speaking the truth.*
>
> Al Norman, Mass Home Care

Chapter 211, the Equal Choice Act was signed into law in 2006. It promised that elders and persons with disabilities would receive counseling and assessment before admission to nursing homes so they knew their options before admission. Counseling is mandatory pursuant to the Choice Act for MassHealth recipients and must be offered to people with private insurance.

Written testimony submitted by Mass Home Care emphasized the importance of such counseling and shortfall in preadmission counseling now provided:

> *It is absolutely vital that people know their options. The General Court mandated that Options counseling be done by Aging & Disability Resource Consortium. These groups can independently help determine what services a person needs to stay at home---because they do not own the services they recommend.*
>
> *As of today (October 2009), there are only 3 sites in the state where consumers can get this help. In most parts of the state, there is no Options*

> *Counseling project. Given the fact that this law was adopted in the summer of 2006, there really is no credible excuse for why this program has not been implemented statewide.*
>
> *If a consumer goes into a nursing home without knowing their community options, they could end up spending a small fortune on a level of care they do not need. They also are being unjustifiably segregated in a restrictive setting that separates them from the rest of their community.*

Priscilla Chalmers described how a short-term nursing home admission turns into a long-term confinement:

> *Mrs. P. had been hospitalized because she had fallen in her home and fractured her ankle. . . She had other health concerns. Upon release from the hospital, she was sent for rehab to a local nursing home. The recuperation went slower than expected, and she was without informal supports. She was recently widowed, she had no children, and she had an older brother. So she went to the nursing home, and eventually she had to give up her apartment, and its contents. She depleted her savings and ended up being covered by Medicaid in the institution. She desperately wanted to come home. . . . she did come home four and a half years later, after she had spent her savings… an apartment, furnishings were found for her… staff did work with Stavros very well on behalf of that consumer. When she came home, she was not eligible for Medicaid . . . She was eligible for Medicaid in the institution, but coming back home, she wasn't eligible for Medicaid in the community, without being converted 300% SSI. So she does live at home now….and she is where she wanted to be, but it was four and a half years later.*

Recommendations on transitioning individuals from institutional care:

- Accelerate closing institutions serving people with developmental and intellectual disabilities
- Assess the need to continue facilities after the current residents no longer need care
- Expand peer support resources including peer counselors and group homes

run by person in recovery form mental illness as alternatives to institutional care for people with mental health disabilities

- Expand resources for clubhouses as a first line of support for preventing and responding to period of hospitalization

- Provide funding streams for fees and other household expenses necessary to re-establish community life after institutionalized care

- Implement Options Counseling statewide through Aging and Disability Resource Consortiums

Goal 2: Expand access to community based long-term supports,

Dr. McGuire stated that most of the individuals who qualify for long-term community-based support services are poor. But, she acknowledged, others are driven into poverty because access to long-term support services is limited by rigid eligibility thresholds and distribution mechanisms. Advocates emphasized that the lack of flexibility and inability to act preventively both undercuts the 'person centered approach' called for in the Community First Plan and increases long term costs.

An important step in expanding access to the system of supports for elders would be to implement the Section 6086 State Plan amendment removing the restriction that a person must need a level of care equal to that provided in a nursing facility before receiving home care. Adoption of the amendment would have the additional benefit of enabling the Commonwealth to receive federal matching funds with no need to secure additional federal waivers.

Persons with adult-onset disabilities, including neurological conditions such as Multiple Sclerosis, Amyotrophic Lateral Sclerosis and Parkinson's Disease, as well as chronic diseases such as Lupus, Cancer and HIV / AIDS -- are often not eligible for MassHealth and other long-term support programs because their assets exceed eligibility thresholds.

Virginia Morse of the Adult Onset Disability Alliance testified,

> *It's been over six years since people with adult onset disabilities came to light in the context of the Olmstead -- they have worked in good faith with the administration to address these issues and we're left with no entry point into the health services issue. Adults with onset conditions are not allowed access to the same support that's available to others throughout the state including those in other waivers. There needs to be a solution to an ongoing situation.*

Long-term supports are not structured to enable individuals and families to effectively manage chronic and progressive health conditions while maintaining personal and financial independence. Roseanne diStefano, of Merrimack Valley

Elder Services, commented on chronic care while recommending expansion of a chronic disease self-management program:

> *But what's so good about the chronic disease self-management programs that are blossoming across the state is they are instructing people how to self-manage with a chronic condition. It's about learning how to, what do you do when, what do you do if, and the other piece of good news is that it can be done with lay leaders, and it should be done with lay leaders.*

Kathy Hackett of the Adult Onset Disability Alliance described the destructive effect of eligibility thresholds set at levels that delay support until health conditions worsen and families are impoverished and too often broken apart.

> *How can someone expect to fight for their financial future when their whole world is in turmoil? We have to fight this disease. I'm here today asking for the help. It's been almost a year since my husband was diagnosed. We have been seen significant changes in the fiscal and emotional needs…Right now the focus is on money and not care and it is unfair to the family circle. The stress of the financial worries has made it difficult to enjoy the remaining time with my husband. I recently retired to take care of my husband full-time. We've been spending the last six months waiting approval of SSDI.*

Destabilizing individuals and families increases long term human and financial costs. But Homelinks, a successful model of adult onset services created as a partnership between the state and the MS Society, has been severely cut back due to state revenue losses. This action also calls into question a commitment to Community First.

Family Supports, a successful program of the Department of Developmental Services, enables families to care for severely disabled children at home. But it is not available to other families with similar needs -- an example of the kind of categorical funding that disadvantages the families of individuals with certain types of disabilities.

Joe Johnson and his wife are caring for a son at home who is deaf and blind, but with program equivalent to DDS's Family Supports in the Commission for the Blind. Creating a new program would be costly and probably inefficient but defining eligibility and proving access based on need rather than diagnosis would affirmatively answer the questions Mr. Johnson presented in his testimony:

> *We do need to get out now and then. We do need to have some assistance from the daily grind of providing, for activities of daily living. I just don't understand how you can both empty the institutions and cut the support for those of us who have decided that what we want is to provide care for our own in our own homes, with as much of our resources as possible.*

Other factors that destabilize families where one spouse has a disability and is covered by MassHealth's CommonHealth program are the disincentive imposed on spouses serving as caregivers and restrictions on spousal income waivers.

The Commonwealth has failed to take advantage of progressive changes in federal regulations that now allow spouses to be paid as caregivers – under conditions described by Rochelle Sugarman

> *Analysis would include evaluation and appropriateness of a spouse as caregivers in the system. A number of other states have already moved beyond Massachusetts in this regard. . Studies have found the consumers are more satisfied with the care from relatives and use of spouses as caregivers…(and this) will also help alleviate the anticipated worker shortage that's predicted in the long-term health care field.*

Jim Began, spoke as a person with an adult onset disability about the impact of financial disincentives on family and household stability:

> *Exemption of spousal income -- you have to realize that spousal income keeps families together. It keeps children educated…(and) provided for. It keeps homes, mortgages being paid.*

Spousal income restriction are waived when a husband or wife is in a nursing facility and the Commonwealth has the ability to change its regulation for home and community based services but has not chosen to do so.

One of the most devastating ways in which the inclusion of spousal income hurts people with disabilities is so called "marriage tax" built into the CommonHealth program. CommonHealth was initiated over 20 years ago as a way of removing economic disincentives and enabling people with severe disabilities to go to work while buying into the same menu of services provided to Medicaid recipients, including personal care assistance (PCA) services.

Ken MacDonald, a subscriber to CommonHealth services, testified about the kind of decisions the 'marriage tax' imposes:

> *I started my employment at an independent living center and…I have been part of CommonHealth for many years and have seen the premiums steadily increase. Several years ago, I met a woman and we decided that we would get married. Friends of mine in the disability community said that was not the coolest idea… if we got married, my CommonHealth premiums would most likely double. But I thought out of principle, that that just didn't seem right and so I did get married in 2005, and as a result, my CommonHealth premiums doubled from somewhere around $400 to $800… Would I be better off getting a divorce?*

Some individuals and families report that they have lost eligibility for MassHealth when they cross eligibility thresholds by very small amounts. To regain eligibility they are subjected to the financial burden of meeting 'spend down' obligations – paying out of pocket at levels that often exceed the ability to pay without destabilizing their households and families.

Spend down requirements subject elders and people with severe disabilities to long delays of essential medical and support services. This puts individuals at great risk and subjects families to overwhelming stress. John Bennett, Mass Senior Action, testified on behalf of a friend:

> *It's just an absolute disaster that families have to spend all that they have in order to care for poor people who are sick or disabled towards the end of their life to have to give up everything they have in order to keep them at home or in fact, to even provide lower expensive institutional care.*

Proposing and alternative that would be to allow a buy-in by or on behalf of the those needing services, Independent Living advocate Paul Spooner asked pointedly: *Why do we have programs that find people ineligible when they're $10* *over a fiscal limit? Why don't we have a buy-in program for them? Why don't we make a buy-in program for all people with disabilities?*

Among the recommendations with broad and enthusiastic support at all forums was the idea that state funds should be allocated based on individual need following the widely discussed approach known Money Follow the Person..

> *We need to rebalance our spending and let the money follow the person. It would help to set a three-year goal for shifting funds into the community. And the guiding principle of our long term care spending should be give consumers their choice of setting and have the dollars follow the choice. If we did that today, we would not have a waiting list for home care because consumers*
>
> Tom Barbera, 509SEIU

Implementing Money Follows the Person policies was seconded by representatives of both the elder and disability communities who describe the state's failure to apply for federal funding during a critical window as a lost opportunity. Opportunities to implement Money Follows the Person should be promoted under the commitment to 'person centered' services offering consumer empowerment and choice.

> *Why don't we have money follows the person in Mass? Why don't we have it? Why isn't the dollars for my care available to me to choose where I want to be, instead of having people tell me, well, we have open beds in a nursing home but you can't get into home care. Money follows the person is long overdue. We passed up an opportunity to get federal money to do that but we didn't pass up the opportunity to restructure of our state funding globally, so that people can make the choice to stay at home.*
>
> Al Norman, Mass Home Care

Recommendations to expand access to community based long-term supports

- Adopt a Section 6086 State Plan amendment to cover home care services
- Consider ways to expand Family Supports to all families providing care and support to severely disabled children at home and out of institutional settings

- Aggressively plan for and implement reforms based on Money Follows the Person

- Eliminate the “marriage tax” on CommonHealth members

- Expand the spousal waiver to people in the community as well as institutions

- Tie income and asset limits directly to federal payment schedules

- Expand buy-in options that enable individuals and families whose incomes are over asset thresholds to pay on a sliding scale.

Goal 3: Improve capacity and quality of community based long-term supports

Dr. Jean McGuire observed that “Advances in trauma and acute medical care have not been matched by progress in rehabilitation and reconstructive medical services.”

However, testimony at the forums emphasized that the major problems in the operation of the MassHealth system are not caused by the lack of effective practices in rehabilitation and reconstructive medicine, but by the failure of the MassHealth system to approve funding for medically necessary services, equipment and supplies. This not only contradicts the Community First “person centered” vision, but is medically and ethically irresponsible.

Martina Carroll, Stavros Center for Independent Living, described repeated and persistent problems with the prior authorization process related to PCA hours and the provision of durable medical equipment and supplies.

> *No matter what the doctor writes on the prescription… consumers get what the prior authorization people think is needed… Doesn't matter if a doctor says you need ten boxes of gloves a month, they give you four. Latex gloves, catheters, adult diapers, you name it, it doesn't matter what your doctor thinks you need. And I…have to mention the enormous struggle people have trying to get their wheelchairs or scooters repaired or replaced…it can take months and months and months.*

Some individuals and families are put at serious risk because the level of services – such as hours for Personal Care Assistance - is inadequate to their needs. Others are thrown into crisis when services are delayed or arbitrarily cut by the MassHealth prior authorization units. Devastating decisions at odds with reasonable professional standards of treatment and support are often made with bureaucratic indifference to the consequences and without appropriate deference to the “person centered” recommendations of professional evaluators and health care providers.

Mary Day testified to the potential consequences of rigid and arbitrary decisions by the prior approval unit on her families dedicated effort to prevent the institutionalization of her son whose severe disability was caused by a traumatic brain injury.

> *I have people in Boston who have never seen Nicholas who don't know anything about Nicholas, deciding what is best for him, hours…cut his hours, although Stavros advocated for an increase of hours. Nicholas…. cannot feed himself. He cannot dress himself. He cannot toilet himself. He does nothing for himself. I have an attorney in Boston and nurses in Boston telling me that he doesn't need the hours. It's okay, Mrs. Day, if he sits in his own urine, if he doesn't eat or drink…They don't look at individual cases. They look at a box that says, if you have a TBI, you get A, B and C, no one knows how to look outside that box. We don't want him in an institution. We promised him that we would never do that to him. I will not put him in an institution as long as I live…but without the hours, what do I do? What do we do?*

When appeals are undertaken, the individual or family takes on an additional risk of incurring unsustainable debt if the appeal is denied. The recommended solution that MassHealth should provide services at the level recommended by evaluators and medical professionals during appeal processes.

Another way to expand capacity is to make it to provide support to elders and individuals with disabilities who need assistance administering medication in their homes. Improved data collection might illustrate the number of people in nursing facilities because of their inability to self-administer insulin injections.

According to Mass Home Care's written testimony, allowing appropriate non-professional assistance under the supervision of a skilled nurse would:

- *Help improve patient care and safety.*
- *Increase the role of nurse oversight for many patients whose medication needs may otherwise not be properly addressed.*
- *Respond to the public policy goal of developing state level solutions that support long-term care in the least restrictive setting.*

- *Acknowledge the need to bring more nurses into home care with a plan to utilize their skills most effectively.*

- *Advance more cost-efficient care by reducing nursing home admissions and increasing seniors' independence through quality home health services.*

Recommendations to improve capacity and quality of community-based long-term supports:

- Immediately establish a problem solving mechanism within Mass Health to expedite decision making when credible information is provided that an individual may be at risk of exacerbations, injuries or other adverse consequences resulting from denials or delays

- Revise Prior Authorization policies and procedures to ensure that services are provided in a timely manner based on individualized "person centered" evaluations by staff of PCA fiscal conduit agencies and the medical professionals most knowledgeable of each individuals needs

- Provide services during appeal processes at levels recommended by evaluator-consultants and the primary-care physician or medical specialists most knowledgeable of the individual's needs

- Revise eligibility and monthly payment standards to eliminate the CommonHealth Marriage Tax

- Revise eligibility and monthly payment standards to bring income calculations into alignment of state and federal definitions of taxable income

- Revise eligibility and monthly payment standards to ensure that eligibility thresholds are automatically adjusted when SSI / SSDI payments are increased

THE OLMSTEAD INITIATIVES

Goal 4: Expand access to affordable and accessible housing and supports:

II you can't afford a subsidized unit, where are you going to go? We…know one place they go to, and that is a nursing home. Joe Tringali, Stavros

Safe, accessible and affordable housing is an essential resource for many elders and persons with disabilities; for some it is the cornerstone of the supports they need to live active lives in their communities and to avoid displacement to an institutional setting.

Joe Tringali summed up the concerns of many housing advocates when he described the housing picture in the state as nothing less than “dismal”.

He explained that Stavros, the Center for Independent Living where he works received 769 calls last year from individuals with disabilities looking for housing. Callers were usually referred to the Housing Registry - a database of accessible units, while Stavros made inquiries of local housing managers and monitored regional rental listings.

With an estimated 84,000 individuals awaiting subsidies and 9000 nursing home residents expressing a desire to return to community living, Tringali concluded *the calls come in much faster than the units become available.*

The Housing Committee of the Systems Transformation Grant submitted a number of recommendations to the Department of Housing and Community Development (DHCD) three of which he summarized briefly:

- Increase availability of "deep subsidies" that enable persons with limited financial resources such as SSI recipients to access units whose cost even with a standard subsidy would exceed their ability to pay.

- Provide incentives for developers to build “visitable” units, with an accessible entrance on the entry level, and a bathroom, a kitchen, and if possible, a bedroom on the entry level.

- Discourage grouping of accessible and subsidized units in ways that create

> “little ghettos”.

The lack of accessible housing remains one of the most vexing issues. The lack of units is compounded by the unmet need for supportive services by many residents.

Group Adult Foster Care, funded by the Division of Medical Assistance, provides housing and services for people with disabilities over 22 if they need personal care seven days a week. Established within public housing, this program needs additional funding.

The economics of the private housing market limit the contributions of the private sector to meeting the need of people with disabilities for accessible and affordable housing. Designers, developers and owners are often confused by inconsistencies between federal and state access codes and standards such as federal Fair Housing standards in relation to the requirements of the Massachusetts Architectural Access Board. Incentives are inadequate to promote the design of homes for “visitability” much less the preferred goal of “universal design”.

Joe Tringali pointed out that not only in the current crisis environment but even in the relatively good times that preceded it, the private housing development market has come up short in producing the accessible housing needed by people with disabilities.

> *I think that the response that we got in general was, it's the economy. We can't develop new properties because the investors aren't there, despite the low income housing tax credits, the tax credits don't mean a lot in this environment, in this economic environment, but what happened, this economic downturn wasn't here five years ago, it wasn't here ten years ago, where what was happening then.*

Paul Remy described the consequences of inflexibility in the administration of Section 8 vouchers that prevent him from transferring his site-based voucher to a housing unit closer to members of his family.

> *It's crucial for me to live near my brother and sister-in-law to help in emergency situations and I would be able to visit them and my two nieces more often. Unfortunately, it's difficult for me to get an apartment. My present apartment has a site-based section 8 voucher and it's not*

> *transported to another base. Because my income is slightly over, I must wait two years for a transfer from Section 8.*

Elder advocates emphasize the importance of expanding the **Going Home** program, and describe it as an effective way of preventing premature nursing home placements. The Going Home model, similar in some ways to group homes provided for some younger people with disabilities, utilizes existing housing to provide services in a home-like environment.

Surprisingly, home modification programs did not receive significant comment during the forums commensurate with their importance. Home modifications are nevertheless one of the key supports enabling persons to remain at home after the onset of disability, and for elders to age in place. Many individuals returning home from hospital or rehab facility stays are unaware of the loan program available through the Massachusetts Rehabilitation Commission.

Eileen Feldman submitted written testimony that added perspective on the impact of code confusion and lack of oversight on the shortage of accessible housing.

> *Poverty plus disability plus invisibility of people with disabilities as a civil rights class has resulted in a hidden housing crisis, with People With Disabilities having a much higher incidence of worst case housing needs than has been recorded and reported on.*

Feldman explained that hundreds of State-bonded "affordable" housing developments have been constructed or renovated since 1988 when the Fair Housing Amendments Act was enacted and HUD issued 504 regulations. Her conclusion is that:

- Lack of oversight and confusion over housing accessibility code has resulted in loss of a large number of accessible and adaptable units.

- Many units rehabbed at 75% of replacement cost and some new construction appears not to have even an accessible front entrance!

- 5% of units required to be wheelchair accessible units, plus 2% required to be sensory-accessible represent a large stock of (accessible) housing units not available to persons needing those features, as well as (the shortage of) adaptable units, due to lack of compliance policies and oversight.

The operation of Pubic Housing Authorities is an area where Eileen Feldman and Joe Tringali both raised important issues. Tringali described lack of coordination between state and local housing authorities: *The state prepares a five-year plan to reduce barriers to fair housing, and housing authorities prepare one-year plans to do the same. The question is, who's watching these plans?*

Feldman explained that Pubic Housing Authorities as recipients of HUD funds have an obligation under Section 504 to address access and operational issues systematically, but many have failed to meet their legal obligation to conduct Self-Evaluations and carry out Transition Plans. Feldman listed the following as evidence on non-compliance by some PHAs:

- Public housing practices and policies are often not in compliance with Section 504 requirements. Effective communication procedures and resources are not in place. Housing Authorities rarely have staff with the knowledge and skills to respond appropriately to requests for procedural accommodations or reasonable modifications to units.

- Sites operated by PHAs often do not have access routes on sidewalks and many lack accessible interior common-use and program areas.

- Access improvements are typically not undertaken unless initiated by a tenant complaint.

Tringali reported that calls have been received from public housing tenants having “problems” getting the modifications they need to stay in a unit. These individuals are often at risk of being displaced to a nursing home or other institutions. Some housing authorities refuse to meet their legal obligation to provide modifications despite a memo outlining PHA’s responsibilities distributed by the Department of Housing and Community Development. Tringali emphasized that a memo is not enough and that DHCD has failed to provide the kind of active enforcement, oversight, technical assistance and training needed.

Recommendations to expand access to affordable and accessible housing and supports:

- Investigate, document and evaluate the impact of systemic weaknesses and discriminatory practices on the short-fall of accessible and affordable housing. Review findings with DHCD and HUD for corrective action.

- Strengthen DHCD in-house and contract resources to:

    - Coordinate policy development with Public Housing Authorities

    - Provide training to PHA staff and Board members

    - Provide technical assistance to PHAs in preparing and implementing Self-Evaluation and Transition Plans

    - Provide information, oversight and technical assistance to all state supported affordable housing developments

- Publicize the home modification loan program through discharge planners and Options Counselors

Goal 5: Promote employment of people with disabilities and elders,

The elimination to disincentives to employment has been a central issue in the reform of federal and state rehabilitation policy since the early 1970s. Historically, severity of disability had been associated with inability to engage in gainful work. In Massachusetts prioritizing vocational services to persons with severe disabilities, the establishment of Centers for Independent Living, the development of personal care assistance and supportive employment programs are all benchmarks in the reform of disability employment policy.

In 1988, the Commonwealth assumed national leadership in disability employment reform with the creation of the CommonHealth program. CommonHealth addressed disincentives to employment by making it possible for employed persons with disabilities to buy-in to MassHealth coverage for pre-existing conditions and uninsurable medical and rehabilitation expenses.

Advocates and health professionals provided testimony that the performance of CommonHealth and MassHealth system as a whole has deteriorated significantly since the early 1990s. Today, long delays and outright denials of essential services, equipment and supplies undercut the ability of job ready individuals to become employed and keep their jobs.

One of the common complaints about the MassHealth system is that maintenance and repair of power wheelchairs -- for many the single most important piece of equipment enabling them to work -- often takes months.

Chris Palames testified in Holyoke that approval of a simple replacement of a battery charger for a power rim wheelchair was delayed for months at a time when both of his wrists were injured in a way that made use of his manual chair painful and risky.

Dr. McGuire in her introductory comments had emphasized that the Commonwealth is committed to becoming a Model Employer of elders and people with disabilities and that the Model Employer initiative is an important dimension of the Community First Plan, which the governor is taking steps to extend to the private sector:

> *(The Commonwealth now has) a Strategic Plan that the Governor announced to make Massachusetts a model employer of people with disabilities, including those that are aging with a disability and he announced that in November 2009 he is going to large sector private employers saying 'I want to be this and I want you to be it, too, to really get an affirmative hiring approach, even in a bad economic time'.*

Phil Zukas praised the Commonwealth's Model Employer program and recommended expansion of the successful summer internship program on a year round basis. But he cautioned that a critical review of the state's transition and vocational rehabilitation programs are needed because *young people don't arrive with appropriate sense of workplace culture and job environment*. In other words, young persons with disabilities are not job-ready when they enter the employment market.

Concern was expressed that the Executive Office of Health and Human Services and other state department enter into contracts with provider agencies that do not meet their non-discrimination obligations under Title I of the ADA to ensure equal employment opportunity for people with disabilities.

Robyn Powell described a long and frustrating job search: *I went on over 30 interviews, all with service providers. Some outwardly expressed their reluctance to hire me while others never returned a phone call.*

Powell also pointed out that what she and other job seekers with disabilities have experienced are clear violations of disability rights law:

> *Human service agencies violate the ADA by not hiring people with disabilities. The Commonwealth spends billions of dollars on residential care, employment, counseling, medical care, support services, et cetera, without any expectation that employing people with disabilities should be a goal.*

Robyn Powell is now gainfully employed but many other well qualified persons with disabilities are not. In December 2009, the Bureau of Labor Statistics of the US Department of labor estimated the unemployment rate of non-institutionalized persons with a disabilities age 16 and older at 13.8 percent, compared with 9.5 percent for persons with no disability).

Jenna Knight recommended that the Executive Office of Health and Human Services work with the Department of Workforce Development to provide information and training for employer on reasonable accommodations.

The EOHHS and all state departments are obligated under Title II of the ADA to ensure that contractors providing services for the state are in compliance with all requirements of the ADA including but not limited to providing reasonable job accommodations and taking all steps required to ensure that people with disabilities enjoy equal opportunity to seek and maintain employment.

Recommendation to promote employment of people with disabilities and elders

- Implement programs within the Secretariats to ensure that all state contractors adopt and implement equal employment opportunity policies including provision of reasonable job accommodations as required under Title I of the ADA

- Continue to refine and expand the Model Employer program and develop a reporting capability

- Extend the Model Employer concept to private sector employers

- Expand internship programs to provide year-round job skill development and exposure to the world of work for young persons with disabilities

Goal 6: Promote awareness of long-term supports.

In 2007, the Massachusetts Department of Public Health published *Study of Unmet Needs of Adults with Disabilities in Massachusetts, which* reported that 34% of survey respondents stated that they did not know where to get information on essential health and social services.

Navigating Massachusetts service systems can be a daunting process even for experienced consumers and advocates. Information networks now rely on computerized phone systems like the one to which the EOHHS web site directs individuals with “questions.” The system then requires choices among multi-level prompts that are confusing to many users. And have the fundamental flaws that a) the prompts do not provide a clear choice for speaking directly to a service professional and b) when voice communication is established the information provided is often inaccurate and unreliable;

Equal Choice legislation passed unanimously by the Legislature in 2006 authorized development of Options Counseling programs for elders. But three years later, funding remains inadequate and the program is only in operation in three locations.

> *People don't know about Equal Choice… We are now surveying our members and friends to find out how many people are in nursing homes, who are not told that they have the opportunity to be cared for at home. that's the question . . . because if you don't know that you have the choice, then it isn't a choice.*
>
> John Bennett, Mass Senior Action

Awareness of basic resources like the Home Modification Loan Program is limited. This is also true for other programs providing equipment exchanges, hearing aid distribution, etc.

The Massachusetts Aging and Disability Locator web site, with links to major information sources,, remains a hidden gem. Otherwise knowledgeable consumers, advocates and professionals are often unaware of this asset.

Misinformation is a common criticism.

> *...you try to get information-- from MassHealth. How did you calculate my monthly payment, which went up 500% from one year to the next? , There's a complete lack of transparency in how the monthly payment is derived. But when I gave them the information that I was now receiving unemployment . . .- I was told, 'Oh, yes your payment will come down $200, but your eligibility will be gone.'*
>
> Chris Palames

Palames, an experienced advocate who has a disability, submitted written testimony about problems he experienced trying to reach a MassHealth representative.

> *"At the pharmacy my wife had to pay out of pocked for an antibiotic - so I knew right away I'd been dropped even though I'd talked with someone at MassHealth who said everything was OK with my documentation. So I called MassHealth again and followed the prompts but this time I could not get a real human being to talk too. The next day I called the Office on Disability and got another number, but I got lost again in the maze. So finally I called Secretary Bigby's office and they connected me with someone, who connected me with someone who finally connected me someone who knew what she was doing. She fixed the problem easily enough, but she also said "A lot of people have trouble getting to us and the person you spoke too before might have been a temporary worker who didn't know the computer system."*

Recommendations to promote awareness of long-term supports

- Expand awareness of the Massachusetts Aging and Disability Locater website throughout the general human service and health delivery systems

- Publicize home modification load programs more widely through discharge planners and target clinical practices

- Upgrade and simplify the MassHealth voice system to facilitate direct access to well trained and experienced staff

Part 7: Other issues affecting the Community First Plan

This section presents issues raised in testimony at the forums and subsequent written comments that do neatly fit any of the six Community First goals but which will effect the realization of the Community First vision.

John Bennett of Mass Senior Action addressed the connections between reform efforts in Massachusetts and federal legislation. He called for support for the Class Act initiated by Senator Kennedy the Empowered At Home Act sponsored by Senator Kerry and the Independence At Home Act sponsored by Representative Markey. He summarized the importance of this progressive federal reform agenda stating that “all find new ways of funding health care, funding long-term care and new ways of increasing Medicaid funds so that they could be directly given for home care.”

John Morris of Stavros described another critical limitation that can only be addressed through updated federal standards. “Back in 1972, when SSI first came out, the asset limits were $1,800 for an individual and $2,700 for couple. Since then, there's only been two increases in that asset limit legislation, the last . . . in 1989, which raised it to the current rate of $2,000 per individual and $3,000 for a couple.” “The inflation rate” he pointed out “has gone up74.2% since 1989”.

Issues of civil rights are the foundation of the Olmstead Initiatives as they are of the Community First Plan. Much of the testimony summarized in the previous sections can be interpreted from the perspective that our society does not yet adequately protected the rights of people with disability to equal opportunity and equal protection.

Additional testimony was presented on civil rights issues:

Ruth Moore testified that some doctors do not provide interpreters for deaf patients.

This disregard for the ADA effective communication obligations also applies to clinics and hospitals. Some also fail to recognize that sensibilities regarding the gender of interpreters may be an issue for some deaf persons in medical settings.

The incidents in which deaf persons are denied the interpreter services to which they are entitled may become more common because the Massachusetts Commission for the Deaf and Hard of Hearing no longer provides after-hours ASL interpreter referral.

MassHealth is one of many agencies of the Commonwealth that advocates assert are not yet meeting their obligations under Title II of the ADA to provide written information in alternative formats including Braille, large print and audio recordings. Electronic forms on web sites are not always accessible. And the effective communication obligation also requires that new technologies be incorporated when they are necessary to eliminate barriers to the flow of information. As an example, Vlogs (American Sign Language video presentations) have not yet been incorporated in the public education programs of the Department of Public Health or other state entities.

Advocates believe that the Commonwealth has taken some initial steps but could use its licensing and registration authority more extensively to ensure that health and medical institutions and social service agencies are both physically and programmatically accessible.

Some also argue that inequities in asset limits, benefits, co-pays, etc. violate Constitutional principles of equal opportunity and equal protection.

Domestic violence and sexual assault were not addressed directly during forums, but additional testimony was submitted on a number of critical issues. . Abuse, violence and sexual assault must be addressed within the context of both institutional and community based services.

The Disabled Persons Protection Commission (DPPC) serves non-elderly person with disabilities; similar protective services are provided for elders by the Department of Elder Affairs through Aging Service Access Points (ASAP). The scope of both services is broadly the same but differs significantly in details.

The DPPC has been significantly under-funded for years and progressive proposals to expand the agency‘s mandate to include financial abuse have been stalled in the legislature for years.

Advocates are concerned that state funded domestic violence services are not fully accessible to women with disabilities and their children, especially those with severe disabilities and those who are Deaf. The services of the DPPC are provided to women and men with disabilities who are victims of caretaker abuse,

Women with disabilities who experience domestic violence and sexual assault are served through a provider network of underfunded domestic violence and rape crisis centers. The state has not taken appropriate steps or provided adequate funding to ensure that these programs are brought into compliance with their obligations under ADA title II.

According to Laura Raucher in written testimony submitted after the forums:

> *Both sexual assault and domestic violence cases involving women with disabilities or those who are deaf are poorly handled from start to finish due to: 1) lack of police training in communication and handling this population as first responders, 2) inadequacy of services to get women CONNECTED, not just referred, to services that are accessible and disability sensitive, and 3) limited availability of knowledgeable legal support to handle complex court cases. Deaf women in particular are at high risk of losing their children due to Social Services agencies, police, and courts that cannot communicate effectively and do not understand their culture.*
>
> An essential step i addressing these concerns are to develop an accessible and coordinated way to link women in need with shelters and services that are accessible to their disability needs. Safelink – a key resource in the domestic violence / sexual assault network -- is underfunded and does not have up to date information on availability of accessible shelters across the state – the resulted is that accessible shelter spaces are underutilized. Also, Safelink staff need to be trained and to assess the needs of disabled and deaf callers and to make appropriate referrals

Access to the system of justice is a fundamental right of citizenship as well as key resource for those experiencing abuse. But an assessment of ADA compliance in court houses conducted for the Administrative Office of the Trial Courts (AOTC) documented substantial areas of non-compliance with ADA Title II requirements.

A compliance plan addressing procedural and architectural issues has been only partially implemented and the allocation of resources has been inadequate.

Addressing the extensive physical, communications and programmatic issues in 127 courthouses dispersed across the Commonwealth illustrates the importance of a sustained long-term systemic commitment to carrying out well defined compliance and transition plans as required under title II.

AOTC and MCDHH are working on a system to improve communication access for deaf and hard of hearing defendants who are on trial and witnesses. But neither entity has adequately addressed the complex legal and programmatic issues involved in providing communication access for potential jurors.

Widespread systemic deficiencies in ADA compliance have also been documented in the Commonwealths system of higher education in ADA compliance and accessibility studies of a number of state and community colleges and the University of Massachusetts in Amherst. Yet the Higher Education bond Bill made no allocation of resources to implement or update existing ADA Transition Plans

The Massachusetts Attorney General's office has historically not been proactive on these and other civil rights issues regarding people with disabilities.

Recommendation on other issues affecting the Community First vision and goals

- ADA compliance must be elevated to a priority within the highest levels of state government.

- All documentation regarding previous and current ADA compliance efforts should be critically reviewed and updated to:

  a) Produce Self-Evaluations and Transition Plans that are thorough, complete and legally sufficient,
  b) Provide effective ongoing coordination of compliance efforts across all branches, Secretariats and Departments of the Commonwealth.

Conclusion: continuing the movement towards full human and civil rights

The Commonwealth's adoption of the Community First Olmstead Plan is an important step forward in a long struggle for human and civil rights. The vision and goals of the Community First Plan are a general guide, not a blueprint for reform. The following was stated early in this report:

> Progress towards creation of an effective, empowering and efficient system of "person centered" long-term supports has been compromised by inconsistent political leadership and failure to fully and effectively integrate progressive, non-discriminatory disability policies into the operations of Massachusetts state government.

Attention to the urgent need for progressive policy development, realistic budget priorities and program restructuring will continue for the months and years to come.

Planning and decision making is now supported by better data tracking and analytical tools enabling monitoring of progress towards achieving the goals and objectives of the Community First Olmstead Plan. Unfortunately, what the data reveals is unnecessarily slow movement towards overdue reforms - at immense and continuing human cost.

Significant progress has been made in closing state run hospitals and 'schools', but far too many individuals are still isolated from their communities and subjected to the dehumanization that is inherent in institutionalization. But even as the number of residents remaining in large custodial institutions declines nursing homes continue to be over-utilized.

The purpose of the Olmstead Initiatives and the community forums is to breathe new life into a stalled process of reform. To state clearly and uncompromisingly that the Commonwealth of Massachusetts must move forward by every available means – despite the state budget crisis and competing priorities – to realize the values and principles articulated in the vision statement of the Community First Plan:

Empower and support, people with disabilities and elders, strengthening and integrating systems of community based long-term supports that are person centered, high in quality and provide optimal choice.

The forums, gave consumers, advocates and those still denied essential services and opportunity to express ideas for improvements in systems proving long term supports to elders and persons with disabilities. Many of the ideas advanced are not new.

- To develop policies that provide access to support services to those with adult onset disabilities before individuals and families are impoverished.

- The need to prevent institutionalization by implementing the Choice act by providing effective Options Counseling through ADRCs.

- The need to develop better and more comprehensive approaches identifying people who are ready, willing, and able to leave institutional settings for community living – and to act on their behalf.

The impact of the budget crisis cannot be dismissed. But lack of progress on many of the fundamental systemic issues described in this report cannot be explained or excused by the current state of the economy.

Paul Spooner summarized the case for overdue reforms from his perspective as a provider of Independent Living services and as an advocate/consumer.

Clearly, our current system, even if it was not in an economic crisis, isn't serving the people it needs to serve.

This troubling assessment was seconded my many who testified including AL Norman of Mass Home Care who reported.

"A nursing home operator said the other day, there are only two populations left in institutions, prisoners and the elderly. That's a pretty sad commentary, coming from a nursing home operator, who was speaking the truth."

Dr. Jean McGuire acknowledged that the system is still institutionally slanted with Medicaid dollars going disproportionately to fund institutional rather than community based services and supports.

Even though the process of shifting resources to community based services is constrained to some extent by federal requirements of cost neutrality, this does not explain why existing waivers are not fully utilized, and the Choice Act has not been aggressively implemented

Approximately 9000 Massachusetts residents now in nursing homes say that they want to go home. Yet, the Commonwealth has dragged its feet in establishing ADRCs and failed to build the capacity of Independent Living Centers and Home Care Agencies to facilitate and support nursing home residents return to home and family.

So advocates must ask: *How can those charged with carrying out a Plan promising "choice" fail to implement the Choice Act?*

Instead of enabling those in nursing homes to return to their homes and communities, many elders and people with disabilities continue to receive sub-standard care because they do not know about or are not eligible for community based services. And while there, many are paying out of pocket for sub-standard care until their assets are exhausted - qualifying them for community based Medicaid services.

The long-term support system is still seriously out of balance with more Medicaid dollars going to institutional than community based services and supports.

While the allocation of resources is gradually shifting towards community options, progress has been unnecessarily slowed by federal requirements that cost neutrality be demonstrated for additional 'waivers'.

There is no disputing that many barriers to reform need to be addressed administratively and legislatively at the federal level, but advocates still want to know why existing waivers are not being fully utilized, and the Choice Act is not being implemented aggressively.

It is urgent that Section 6086 of the Medicaid State Plan be amended equalizing the footing (meaning not clear) for community based services as called for in the Olmstead Plan (give a specific cite) with December 31, 2009 as the target date for implementation.

The system that has been put in place over the last 40 years is not only flawed but in many ways broken. Programs have been layered on top of programs without thinking through the structural, programmatic and administrative logic.

Paul Spooner of Metrowest Center for Independent Living summarized the case for fundamental structural reforms from his perspective as a provider of Independent Living services and as an advocate/consumer. *Clearly, our current system, even if it was not in an economic crisis, isn't serving the people it needs to serve.*

The system is both rigid and inequitable:

- Many who fulfill general eligibility criteria are denied access to the specific service they need because they do not fit the right diagnostic category.

- Eligibility thresholds delay access to essential services or interrupt services until individuals and families are in crisis or impoverished.

- Service systems have become too complicated even for people working in them everyday to understand and navigate effectively.

- Provider networks have grown with some vendors becoming multi-faceted agencies with large staffs and budgets while smaller agencies struggle to survive.

- The workforce of hands-on direct service staff - from personal care assistants to those working in community residences - is universally underpaid and often works with no benefits or inadequate benefits.

- There is a serious lack of transparency and accountably in the Mass Health system. Decision making by the prior authorization units is not based on established medical/rehabilitation best practices, the process is too slow to respond in a timely way to changes in medical needs and appeals processes are biased towards denial of services .

Paul Spooner is one among a growing alliance of advocates calling for fundamental structural reform based on a *'money follows the person'* approach.

> *I think it's now time to take a good hard look at our system and take the opportunity (presented by the fiscal crisis)…Do we need all the agencies we have? Do we need all the providers we have? Or do we need a model of services that are attached to the individual and what… he or she needs to live in the community?*
>
> *Why don't we have a simple, equitable, fair system that treats people based on need, not disability, not income, not spousal relationships . . . ?*