

**Marketing & Outreach Subcommittee
Consumer Forum Series Report
September, 2007**



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**Submitted To: MASS C-PASS Coordinating Council & Grant Manager
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Executive Summary

OVERVIEW

The MASS C-PASS Marketing & Outreach Subcommittee (M&O) created a Consumer Forum Series to gather information on barriers to self-direction and community integration from a community perspective. Emphasis was placed on targeting traditionally underserved and un-served racial, ethnic, and linguistic minority groups. The Subcommittee also identified consumers living in rural areas of Western Massachusetts as an underserved population. All elders were also a key population targeted to secure their input; since it is a widely held industry belief that elders do not self-identify as people with disabilities irrespective of their physical health or loss of dexterity and mobility.

The M&O formed partnerships with various racial/ethnic/linguistic and geographical communities to compliment the mission of the MASS C-PASS Demonstration Project. Specifically, the Subcommittee moved to achieve particular activities as spelled out under Goal No. 2 of the Project contract with the Centers for Medicare and Medicaid Services (CMS) as highlighted in the following figure.

Goal No. 2

Explore maximum opportunity for self-direction and flexible use and allocation of supports across age and disability category

Activities

- Identify critical areas of need related to consumer's ability to remain in community.
- Identify populations that may be underserved.
- Document barriers to implementation.

The M&O also successfully engaged in the Series clergy, local service providers, appointed and elected officials, and State agency staff from area offices. Activities toward realizing the Consumer Forum Series were initiated on February 4th, 2005 and were completed on December 8th, 2006. During this year and ten months, the M&O held nine consumer forums throughout various areas of the Commonwealth of Massachusetts.

PROCESS

The M&O formulated and implemented the following design to ensure transparency in the coordination of the Consumer Forum Series:

- Identified, educated, and engaged respected and influential individuals and organizations from communities hosting forums.
- Identified, educated, and engaged consumers to form part of the organizing and planning, as well as to function as co-hosts with consumer stipends.

- Formed planning and organizing committees (POCs) consisting of individuals and organizations from within the host communities.
- Relegated authority to each host community to design the forums in the fashion most comfortable to the people of the community.

OUTCOME

During 2005 and 2006 calendar years, the M&O was engaged both formally and informally in marketing and outreach activities that paved the way for a richly diverse grassroots network of partners and supporters from across the State. This State-wide Grassroots Network grew out of following two venues:

- 1) The initial facilitation and ongoing support provided by the MASS C-PASS Grant Manager & DMR Assistant Commissioner, MRC Deputy Commissioner, DMR Director of Citizen Leadership and MRC Director of Consumer Involvement.
- 2) The formation of consumer forum planning and organizing committees or POCs.

The Network partners are not only from certain local areas, but also from defined racial, ethnic, and linguistic communities as well as from mixed disability subcultures and age groups. As these partnerships build momentum during the 2006 calendar year, nine (9) consumer forums were coordinated and held throughout the State:

- Worcester Consumer Forum, March 3rd, 2006
- Lyn Consumer Forum, June 6th, 2006

- Urban Pride/Martha’s Vineyard Consumer Forum, July 31st, 2006
- Chinatown Consumer Forum, September 16th, 2006
- HAPHI Consumer Forum, September 24th, 2006
- Greater Lawrence Consumer Forum, October 14th, 2006
- NAACP Consumer Forum, October 28th, 2006
- Montachusett Home Care Corporation Consumer Forum, December 7th, 2006
- Western Mass Consumer Forum, December 8th, 2006

The community partnerships also led to the evolution of 10 local, grassroots cross disability, cross age coalitions in Greater Lawrence, Lynn, Mattapan, Greater Boston, Chinatown, Worcester, Greater Fitchburg/Leominster, Springfield, Berkshires and Cape Cod/Martha’s Vineyard. These coalitions expressed the desire - and requested support - to continue to exist beyond the life of the MASS C-PASS Project to negotiate and renegotiate local barriers to self-directed community living.

LESSONS LEARNED

The inspiration for the Consumer Forum Series came to the M&O during a meeting to develop the marketing and outreach plan for the wide distribution of the RFR (Request-for-Response) soliciting proposals for mini-grant projects. As the Subcommittee formulated a distribution list, the members made the observation that there was a limited number of local, grassroots organizations providing culturally and linguistically competent services and supports; and, there were close to none formally funded to address the needs of elders, individuals with disabilities, and

their families. Given this observation, the Subcommittee believed the concept of the Series would be easily embraced; but, instead, the idea was met with apprehensiveness and skepticism by people and organizations outside and inside the targeted communities. By way of practicing transparency the Committee counteracted the uneasiness; but, this point was the onset of the four key lessons learned.

Lesson No. 1

Every individual is affected by membership in several social groups such as race, ethnicity, language, creed, gender, income and community. People with disabilities and elders are not just members of the aging and disability support network. The human services support culture operates through other systems of opportunities and barriers. This gives rise to vastly different support experiences among elders and among individuals with disabilities.

Lesson No. 2

Elders and individuals with disabilities who are also members of diverse minority communities are whole people whose needs are affected by their personal life condition and social location. Their need to access culturally competent services is beyond the scope of the traditional aging and disability services network.

Lesson No. 3

Elders and individuals with disabilities living in the community gain strength from working within coalitions to negotiate and

renegotiate services and supports at a local level.

Lesson No. 4

The limitations elders, people with disabilities, and their families face do not stem from the physical environment but rather from the social and psychological responses of local communities and society in general.

FINDINGS/BARRIERS:

Across community forums there were seven barriers that consistently surfaced:

1. Lack of affordable, accessible, and safe housing.
2. High cost of living.
3. Limited employment opportunities; and, no support to pursuit or retain the limited employment opportunities.
4. Inadequacy of public school special education programs, such as the non-connection of the individual educational plans with the service plans developed in disability services programs.
5. Insufficient amount of personal assistance or attendant care hours, as well as insufficient hours for respite.
6. Community cruelty and intolerance toward elders and people with disabilities.
7. Lack of culturally and linguistically competent services.

Other barriers and service improvement recommendations were equally important and were integrated with the preceding

seven most common to draw the five more general assumptions or findings that follow.

- A. Local communities are ill prepared to support consumers' capacity to succeed at self-directed community living.
- B. Inadequacies of current services and supports hinder capacity to address the wide range of consumer needs.
- C. Consumers would like training and continuing education for themselves, families, service providers and community:
 - Personal assistance, service providers, and school personnel should be trained and certified across disabilities, emergency response, and in cross cultural competence.
 - Elders, individuals with disabilities, and their families are calling for training on personal growth and development, leadership, advocacy, disabilities and in emergency response (First Aid, CPR, and the like).
 - Community education programs so that they can feel safe in the community in which they live.
- D. Consumer service and support needs extend beyond the traditional aging and disability services networks.

- E. Lack of cultural and linguistic competence presents access and quality problems for traditionally underserved racial, ethnic, and linguistic minorities.

RECOMMENDATIONS

- 1) The State should address service gaps in traditionally underserved and underserved racial, ethnic, and linguistic minority communities through support and funding of culturally and linguistically competent grassroots organizations.
- 2) Promote self advocacy and self-determination through support and funding of the Statewide Grassroots Network that emerged as a result of consumer planning and organizing committees (POCs) to address local, community barriers to successful self-directed community living.
- 3) Expand the collaboration of agencies under the Executive Office of Health & Human Services to other state agencies to provide comprehensive solutions for meeting the wide range of services and supports needed by elders, individuals with disabilities, and their families.
- 4) Establish self-directed, flexible support model options from which all elders and individuals with disabilities can choose.

Preface

This Consumer Forum Series Report is a narrative account and an interpretive analysis written on behalf of the Marketing & Outreach Subcommittee (M&O) of the Coordinating Council – the management collaborative for the Massachusetts Community Integration Personal Assistance Services and Supports (MASS C-PASS) federal demonstration project funded by the Centers for Medicare and Medicaid Services (CMS). It forms part of five reports describing the various strategies employed to realize the mission of the MASS C-PASS project. The mission specifically was to enhance the Commonwealth of Massachusetts’ capacity to deliver flexible, consumer directed PASS for elders, individuals with disabilities, and their families. Movement toward said end was achieved through an interagency, cross disability collaboration that joined consumers and private sector service providers with State agencies to design consumer driven personal supports. The process entailed gathering data, drawing assumptions, and developing recommendations toward systems change by way of a five tier strategy: Project Evaluation, Policy Analysis, Two Mini-Grant Projects, Annual Symposiums and M&O Consumer Forum Series. This Report is focused on the implementation of the Consumer Forum Series by the M&O and their efforts to incorporate traditionally underserved populations in dialogue and actions toward systems change. Throughout this Report the term “*consumer-directed*” was used interchangeably with the term “*self-directed*,” as was the title *Marketing & Outreach Subcommittee* and the abbreviation *M&O*. Another aspect to keep in mind while engaged in the reading is that the Series explored barriers to self-directed, flexible PASS along with barriers that can impair consumer’s capacity to live in the community of their choice or

succeed at self-directed community living. Whenever possible language was simplified to allow consumer access; however, the main preoccupation was to qualify the information for - and to excite systems change by - State agencies, legislators, service providers and veteran advocates. Toward this end, the Report was divided into the following parts.

Executive Summary: Brief of the entire Report.

Nature of the Consumer Forum Series: Description on the origin and core elements in the coordination and organization of the consumer forums.

The Consumer Forums: Actual descriptions of what transpired at each of the forums and the outcomes.

Interpretive Analysis: Qualification of all of the findings, lessons learned, and recommendations for change.

Appendixes: Seven appendixes with materials developed by the M&O and by the various Planning & Organizing Committees (POCs).

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Marketing & Outreach Subcommittee Consumer forum Series Report

The Consumer Forum Series of the MASS C-PASS Marketing & Outreach Subcommittee (M&O), ended December 8, 2006, with nine (9) consumer forums coordinated and held from January of 2006 through December of 2006. While the primary emphasis of the forums was on “Consumer Driven” processes, many of the forums included as part of the organizing and planning process other partners such as service providers, clergy, appointed and elected officials, and state agency staff at a local and community level. Secondary emphasis was placed on targeting un-served and under-served racial, ethnic, and linguistic (including the deaf and hard-of-hearing) minority groups. Yet a third emphasis was placed on ensuring participation from the elder community regardless of race, ethnicity, or language. The general purpose of the Series was to compliment the work performed under the various MASS C-PASS Demonstration Project components by way of collecting additional information to answer the questions: What needs to happen to build the State’s capacity to deliver self-directed, personal assistance services and support; and, in so doing, can the State advance community integration and increase opportunities for consumers to succeed at self-directed living in their community of choice? This Report, then, is designed to describe how the notion for the Series evolved, what happened, discoveries, and emerging findings and recommendations.

A: The Consumer Forum Series Evolves

The Marketing & Outreach Subcommittee was formed at the First Annual MASS C-PASS Symposium: *Ordinary People, Extraordinary Scientists* – held January 14, 2005. These symposiums are primarily tailored to the working needs of the MASS C-PASS Coordinating Council – the Demonstration’s Management Collaborative. The purpose of this Symposium was to organize the implementation of the Demonstration. As a result of the Symposium working subcommittees were formed that included the M&O. This Subcommittee was initially charged with developing a marketing plan for wide distribution of the RFR (request-for-response) for Mini-Grant Projects or Pilots that would be issued to solicit proposals to produce and test models of quality assurance, flexible supports and consumer direction. However, at the very first meeting, held February 4, 2005, the members decided to expand their role to undertake outreach and gather information on the current state of service provisions, cultural views on self determination, and the service climate in the state.

The Subcommittee members were comprised mostly of consumers of diverse racial, ethnic, and cultural background. In the course of developing the marketing plan for the RFR, they realized that they shared a certain perspective that was also for them a source of enormous frustration. They believed grassroots organizations operating in communities of color were often excluded from opportunities to obtain grant funding and resources. Whether this situation was by design or default, they shared the experience of not having services needed or having to travel out of their communities for services from organizations understanding little about their life condition, social location, and culture. While they completed the marketing plan for the distribution of the RFR, the Subcommittee extended the meeting time to address their frustration: *How many more people like us exist? What about those poor people who can’t even speak the language? If MASS C-PASS is supposed to be different, what could this Demonstration do to change things?*

Consensus was reached by the Subcommittee members to add to the MASS C-PASS Demonstration a series of consumer forums targeting the un-served and under-served racial, ethnic, and linguistic (including deaf-and-hard of hearing) minorities. Quickly after

the meeting, the M&O Chairperson moved to get buy-in from other members of the Coordinating Council for support on organizing consumer forums across the State. Achieving buy-in was instrumental to convincing the Council to set aside funds from their activities budget to underwrite the cost of the forums. The Chairperson introduced the idea for the consumer forum series first to the Policy Development Subcommittee, who after deliberating for several weeks agreed to support a set aside of funds for the consumer forums. At the March 24th, 2005 meeting of the Coordinating Council, the M&O reported on the RFR Marketing Plan and presented their proposal for the Consumer Forum Series.

The M&O Chairperson introduced the Consumer Forum Series as part of a discussion that the State's "Community First" slogan should be adopted by the Marketing & Outreach Subcommittee. He shared the observation that the slogan reflected the desire of the Subcommittee to include local community participation in systems change through grassroots and community based organizations. The Council considered the lack of information and involvement at the local level; and, they affirmed the importance of the M&O's work to facilitate the participation of racial, ethnic, and linguistic minorities to include un-served and under-served communities in systems change. Said work was initiated by establishing contact with Department of Mental (DMR) Consumer Advisory Boards (CABs) and other established networks to coordinate the Consumer Forum Series and move to achieve the following objectives:

- Introduce local and grassroots communities to the concept of systems change and to the associated jargon and efforts.
- Ensure consumer-forum participants are able to weigh-in on what needs to change by contributing intimate knowledge to evaluate existing systems.
- Encourage consumer-participants to share information and systems change findings and recommendations with their local community stakeholders.

B: Skepticism & Apprehensiveness

The Marketing & Outreach Subcommittee's Consumer Forum Series idea was met with skepticism by some and apprehensively by others during the presentations to introduce the Series concept and during the community outreach to recruit consumer hosts. Skepticism

was expressed by some consumers and advocates who shared this was not the first instance in which the State called for their input then did nothing with the information; and, that, demonstrations are about “professionals” making money off people with disabilities. Some service providers and State agency staff express disbelief consumers could ever self-direct; and, expressed even greater disbelief minorities would participate in forums qualifying the assumption by saying “they never want to participate.” Yet another part of the skepticism entailed that the Series process would be soliciting information too broadly and out of the scope of the agencies under the Executive Office of Health & Human Services (EOHHS). The apprehensiveness was revealed in statements some consumers shared about the practicality in opening up the service system to “out of service” minority groups. These individuals were convinced existing public funds and resources were not enough to go around so an increase in consumers served could constitute a cut to their own services. Service providers and State agency staff express fear of losing their jobs as a result of systems change. But the most challenging expression of apprehensiveness was the allegation that the MASS C-PASS demonstration practiced reverse discrimination.

C: Qualitative Study & Transparency: Trust

The MASS C-PASS Demonstration Project goals were not written to test any predetermined model on self-directed, flexible personal assistance services and supports. In fact, many of the goals and activities were centered on consumers identifying what works, while the remaining encouraged exploration or field works from which processes or models for services, supports, safeguards and quality assurances would emerge. Such a method for implementing the Demonstration conformed to what in the behavioral sciences is referenced as qualitative study and, at times, “grounded research.” It then followed that the experiences of the consumers and other stakeholders involved were central to generating information upon which the emerging models or processes would be grounded. In order for this method of data collection and inductive analysis to work, however, trust had to be established. So the purpose, goals, and objectives of the Demonstration had to be easily understood and made familiar to those sought to be engaged in providing or sharing information. The just described is called transparency and it is practiced frequently by businesses looking to enhance the quality of customer service and to heighten levels of

customer satisfaction; and, given the initial skepticism and apprehensiveness, transparency became a critical part in implementing the Marketing & Outreach Subcommittee's Consumer Forum Series. As such the coordination design entailed operating in the manner highlighted below.

- Identifying, educating, and engaging respected and influential individuals and organizations from communities hosting forums.
- Identifying, educating, and engaging consumers to form part of the organizing and planning, as well as to function as co-hosts with consumer stipends.
- Forming planning and organizing committees (POCs) consisting of individuals and organizations from within the host communities.
- Relegating authority to each host community to design the forums in the fashion most comfortable to the people of the community.

D: Marketing & Presentations

The M&O initiated the process toward getting the Series off the ground with assistance from DMR and MRC (Massachusetts Rehabilitation Commission). DMR Assistant Commissioner – who is also the MASS C-PASS Grant Manager - established contact with DMR Regional Management Teams; and, the DMR Director of Citizen Leadership and the MRC Director of Consumer Involvement facilitated connection with consumer advisory boards (CABs). From the month of May, 2005 through to the month of December, 2005 the Subcommittee marketed the Series idea and made presentations in the order of the following list:

- DMR CAB Chairs, 5/10/05
- MRC Greater Boston Council, 6/24/05
- MRC Taunton Advisory Council, 7/11/05
- DMR Northeast Regional Management Team, 9/1/05
- DMR Northeast Regional CAB, 9/7/05
- DMR Southeast Regional Management Team, 9/22/05
- DMR Central West Regional Management Team, 9/29/05

- Worcester Consumer Advocates, 12/12/05

E: A State-wide Grassroots Network

During the bulk of the 2005 and the 2006 calendar years, formal and informal marketing and outreach activities paved the way for a richly diverse grassroots network of partners and supporters from across the State. This State-wide Grassroots Network grew from the initial facilitation and ongoing support provided by the MASS C-PASS Grant Manager & DMR Assistant Commissioner, MRC Deputy Commissioner, DMR Director of Citizen Leadership and MRC Director of Consumer Involvement. The Network was not a neatly braided composite of partners from various geographical localities. That is, the partnerships were not only from certain local areas but also from defined racial, ethnic, and linguistic communities as well as from mixed disabilities and intergenerational subcultures. These partnerships were solidified during the 2006 calendar year and nine (9) consumer forums were coordinated and held throughout the State:

- Worcester Consumer Forum, March 3rd, 2006
- Lynn Consumer Forum, June 6th, 2006
- Urban Pride Consumer Forum, July 31st, 2006
- Chinatown Consumer Forum, September 16th, 2006
- HAPHI Consumer Forum, September 24th, 2006
- Greater Lawrence Consumer Forum, October 14th, 2006
- NAACP Consumer Forum, October 28th, 2006
- Montachusett Home Care Corporation Consumer Forum, December 7th, 2006
- Western Mass Consumer Forum, December 8th, 2006

The community partnerships also led to the evolution of 10 local, grassroots cross disability, cross age coalitions in Greater Lawrence, Lynn, Mattapan, Greater Boston, Chinatown, Worcester, Greater Fitchburg/Leominster, Springfield, Berkshires and Cape Cod/Martha’s Vineyard. These coalitions expressed the desire - and requested support - to continue to exist beyond the life of the MASS C-PASS Project to negotiate and renegotiate local barriers to self-directed community living.

The Consumer Forums: *What Happen?*

In January of 2006 the MASS C-PASS Marketing & Outreach Subcommittee got off the ground the Consumer Forum Series. The consumer forums targeted the underserved and un-served racial, ethnic, and linguistic minorities (including the deaf and hard-of-hearing), as well as elders in general. Approaching elders without distinction was a decision based on the widely accepted industry belief that elders do not self-identify as people with disabilities. Therefore extra outreach efforts were made to acquire their input. Overall, the Consumer forums were organized in three ways:

1. Geographical locations

Worcester, Lynn, Urban Pride (Cape and Islands), Boston, Greater Lawrence, Western Mass

2. Race and ethnicity

Haitian American Public Health Initiatives, Inc. (HAPHI), Chinatown National Association for the Advancement of Color People (NAACP) (Note that the geographically conducted forums included Vietnamese, Cambodians, and Latinos.)

3. Elders – Montachusett Home Care Corporation, Greater Lawrence, NAACP

The coordinating strategies resulted in characteristically overlapping audiences at each forum. Geographically coordinated forums included a significant number of racial, ethnic and linguistic minorities such as Latinos (of mixed nationalities), African Americans, Chinese, Vietnamese, Cambodians and Samolians as well as elders. Racially and ethnically coordinated forums also included significant numbers of elders in the participating audiences. There were other descriptors for the members of the Planning and Organizing Committees (POCs) and for participating audiences at the forums. They were consumers, community activists, clergy, advocates, service providers, representatives of the regional offices for State agencies (DMR, MRC, DMH) and local government workers (municipal departments and schools) as well as local and State appointed and elected officials. Consumer participants had yet two additional levels of descriptors: (1) parent advocate, self-advocate, caregiver, and surrogate; and, (2) types of disabilities physical, cognitive, and developmental.

The Worcester Consumer Forum

Out of the talks with the DMR Statewide Consumer Advisory Board (CAB) – which is a collective of all the local area CAB chairs – Celia Brown, Director SHDA, learned about the Consumer Forum Series initiative and contacted the M&O. Immediately following a conference call on November 23rd, 2005. Ms. Brown organized consumers to participate in a second conference call on December 12th, 2005. The purpose of the conferencing was to address the consumers' questions and determine whether they would plan, organize, and host a Worcester Consumer Forum. Aside from the fundamental questions surrounding the purpose of the MASS C-PASS Demonstration Project, information was provided about the resources C-PASS would make available to cover the costs of consumers participating in the organizing.

Consensus was reached during the December 12th conference call to move ahead with a Worcester Consumer Forum and Dawn Clark, a self-advocate and Advocacy Specialist at the Independent Living Center for Living and Work, agreed to co-lead the effort with Ms. Brown. Together they created the Worcester Planning and Organizing Committee (WPOC). The WPOC moved quickly. Following the Conference Call, three planning

meetings were held and much took place by means of telephone and electronic correspondence between the meetings. Meetings were held in Worcester, specifically at the Seven Hills Foundation. The entire planning and organizing process took two and a half months as shown in the timeline below.



Several products surfaced from the WPOC meetings and tasks performed between meetings:

1. Outreach Flyer to Service Providers

Consensus was reached that personal contact would be the best outreach strategy for recruiting consumers. Therefore, the decision was made to develop a flyer directed to service providers within the Worcester disability and elder services networks by way of electronic mail. The electronic mail was followed by telephone calls requesting assistance in recruiting consumers for the forum.

2. Consumer Friendly MASS C-PASS Fact Sheet – English and Spanish

The MASS C-PASS’ fact sheet was seen as too technically written by consumer-hosts and it was rewritten by consumer-planner Deborah Orzack, formatted by the MASS C-PASS Director, and translated into Spanish by Tito Santana, Director of the MCS MASS C-PASS Mini-Project in Holyoke.

3. Small Group Discussion Framework

Framework for the small group discussions was developed to solicit information from consumers surrounding two basic questions: What do you need to live independently? What do you need to improve the quality of your life? WPOC wanted to be sure that the small discussion groups would be focused on answering the questions and not on personal issues. As such, it was decided that 11 topic areas would be listed to help cue people and keep discussion flowing. These topic areas included transportation, equipment, housing, food, bilingual services, technology, recreation, safety, work, finances and personal care assistance.

4. Consumer Forum Program

The Consumer Forum Program was designed to make consumer-participants feel comfortable in sharing, by being clear about the purpose of the forum, defining the reasons leading up to systems change movement, and to lend assurance that the information they would provide would be shared with advocates and policy-makers interested in making a difference in the State's service delivery system. The Olmstead Decision, in particular, was discussed to introduce the community integration aspect of the MASS C-PASS federal demonstration.

“At the Consumer Forum”

On Friday, March 3rd of 2006, Worcester's Consumer Forum was held from 2:30-4:35 PM at the Corporate College, the new extension of the Seven Hills Foundation. Thirty-five (35) people were in attendance, which included consumers (people with disabilities and elders), caregivers, and service providers (State and private non-profit). A little over half of the participants were members of the Latino community – most of who did not speak English, as well as people with varying disabilities were present. The remaining numbers were Anglo American elders and individuals with disabilities. Refreshments and networking took place prior to the Program opening.

MRC Deputy Commissioner John Chappell attended and participated along with two Directors from his community services division. During the networking phase of the MRC and the DMR local area staff networked with consumers and their caregivers – the forum

provided an opportunity for further interagency collaboration outside of the MASS C-PASS Coordinating Council.

The Director of the SHDA, Celia Brown, opened the Program, providing a warm welcome. Dawn Clark, CLW Advocacy Specialist, followed with an overview of the forum activities and introduced Keith Jones, Chair of the M&O for MASS C-PASS, Chair of Real Choices CPIG, and Self-Advocate. Keith's presentation revolved around four questions: What is Mass C-PASS? What is the Olmstead Decision? Why are we here? Where is the information we share today going? Upon the conclusion of Keith's presentation, the participants were divided into three small groups, one of which was conducted in Spanish only. At the conclusion of the small discussion groups, the participants reconvened as the larger group and a selected member for each group reported on what they determined as barriers to community living under each of the 11 topic areas.

At the end of the Forum, people continued to talk about what had happened. There was a local reporter, who took the opportunity to speak with people regarding the need for accessible, affordable housing. This aspect of the Forum was of particular interest to local residents since that evening there was a scheduled public hearing on affordable, accessible housing at the Worcester City Council.

Synthesized Small Groups Report

Transportation:

1. Very important - hard to get to appointments, need \$, need person to transport them, emergency, not enough transportation agencies, cars-not enough that are accessible. People don't understand you have to give 2 days notice to schedule ADA transportation.
2. Hard to get to recreation activity i.e. weddings, language of info not available
3. 5-minute window too short.
4. Can't access towns outside of Worcester
5. No spontaneity possible
6. Need \$ to purchase vehicle and maintain it.

7. Inconsistent access to trains, elevators, buses, etc. Sometimes find out when you arrive at your destination that the elevator is not working, etc.
8. No connection between some cities – can't get to final destination
9. Less than sensitive staff – need trainings for all transportation staff

Equipment:

1. Hard to get equipment; process is cumbersome – too many forms
2. Getting equipment fixed once broken – takes too long – months and months
3. Too expensive to purchase initially and to maintain
4. Medicaid does not cover most equipment you need
5. Insurance and Medicaid does not cover assistance technology
6. General knowledge about technology is low

Housing:

1. Need more affordable housing - this includes cost of all utilities as well. - Accessible housing including height of counters, door knobs, etc. is not readily available
2. Location near public transportation
3. Even new buildings do not have turning radius wide enough – can get out of some doors but not others.
4. Safety – being able to exit building is crucial and not consistently OK
5. Dependent on elevators working
6. Fire dept. needs to know that people residing in a house will require assistance to exit the house in the event of an emergency.
7. “All Future state funded housing should have universal design and visitability (a visitor who uses a wheel chair can visit you in your home)”
8. Significant problem with state funded vouchers and Section 8 – wait list is way too long.
9. Educate private developers about universal design and needs of individuals who are disabled.

Food:

1. Nutritional counseling needs to be available
2. Not enough money to afford nutritional food after other necessary expenses.
3. Culturally interesting food not available in all stores that are accessible.
4. Need more choices
5. Cooking abilities of staff need improvement especially for culturally different food.

Bilingual Services:

1. Transportation information needs to be presented in multiple languages
2. Competency of translators needs improvement – especially in crisis situation
3. All state agencies should do better job of training translators
4. Need translation services readily available in emergency rooms and in public telephone services.

Technology:

1. Education/training is needed for all – consumer, providers, schools, vendors, etc.
2. Financial assistance is needed to be able to purchase adaptive equipment i.e. phone
3. Need access to computers
4. TOO expensive – not covered by most health insurances
5. Long waiting list for equipment
6. Need more knowledge of assistive technology, Loan programs and better distribution of this info
7. People with disabilities need access to computers –very low use by people with disabilities and elders
8. Those programs that do exist – Easter Seal, etc. need to be advertised

Recreation:

1. Information in my language
2. Support staff fees – need financial assistance reimbursing staff- can't afford their services
3. People are not clear where to find out about what is going on
4. Respite is flexible but allotment is minimal and not adequate.
5. Access to recreational facilities is minimal i.e. bowling
6. Not enough funding for Rec. activities it is a basic need for all

7. Need better social network

Safety:

1. What happens in the middle of the night when I need help?
2. Access to technology for safety is crucial
3. Lack of safe housing can be used as an excuse to limit people's access to housing

Assistance with Personal Care:

1. Need language friendly support
2. Immigration – limits what supports person can have access to; if arrive after 1992 person is not eligible for supports they could have accessed prior to 1992 ruling
3. Big turnover in staff – learning curve for staff can be too long therefore can't rely on staff being available consistently
4. Low wages and benefits are minimal
5. Not enough services for families raising young children with disabilities.
6. Certain disability populations can not access personal care i.e. cueing/prompts
7. Can't use PCA hours for recreation; need more flexibility scheduling PCA support.

Work:

1. Education/training could be improved.
2. Should not be an assumption of what you are able to achieve.
3. "Retarded" term is negative term –need to education population so people can be treated equally.
4. Lack of paid work
5. Lack of integrated work environments in the community
6. Under employment of people with disabilities
7. Transportation needed at specific times to be able to get to and from your scheduled work time
8. Lack of PCA's at work

Financial:

1. Need public support to manage money
2. Not enough \$ for subsidized housing – rents are higher than allotment.

3. More access to benefits counseling – SYSTEM IS TOO COMPLICATED TO FIGURE OUT BY YOURSELF – KNOWLEDGE OF PASS PLANS is not universally known
 4. Access to applications for public assistance is limited.
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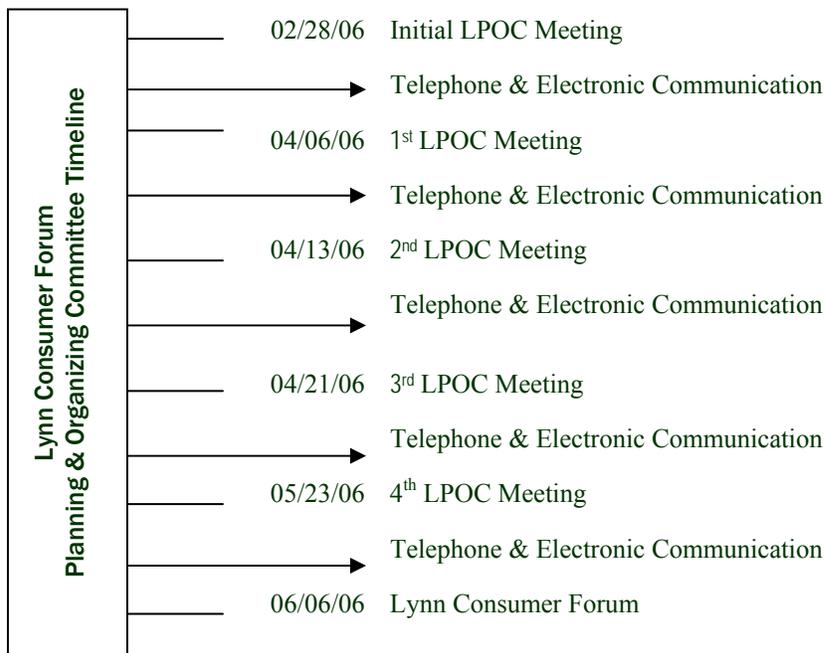
The Lynn Consumer Forum

The Lynn Family Forum initiated discussion with the MASS C-PASS Marketing and Outreach Subcommittee (M&O) to assist in the development of a Lynn Consumer Forum. Out of the initial discussion the Lynn Planning & Organizing Committee (LPOC) was created. Two parents of children with disabilities took the lead role in organizing and planning, with ongoing support from the DMR North Shore Area Office and the Lynn Time Bank. These parents were Rene Williams and Madelyn Soares. Their key strategy was to work with other parents and service providers to recruit consumers for the forum. They designed flyers (English and Spanish), coordinated all of the logistics, and led discussions on the framework for the small focus group discussions during the planning meetings. They decided to adopt the framework developed by the Worcester Organizing and Planning Committee. Such a framework presented three questions:

- 1) What supports do you or your family member need to live independently?
- 2) What supports are needed to be safe and independent in your home and community?
- 3) What barriers hinder getting supports?

The framework also included stimulating discussion by looking at barriers to community living under 11 topic areas: transportation, equipment, housing, food, bilingual services, technology, recreation, safety, work, finances and personal care assistance.

The entire organizing and planning process took approximately 3.5 months. There was an initial meeting with the M&O and LPOC. The M&O meeting was followed by 4 LPOC meetings at the Lynn Time Bank; and tasks were assigned and completed between meetings by way of telephone and electronic communication as highlighted in the timeline that follows.



“At the Consumer Forum”

On Tuesday, June 6 of 2006, Lynn’s Consumer Forum was held from 9:30 a.m. to 12:30 p.m. at the Lynn Housing Authority. Forty-one (41) people participated of which 40.93% were Cambodians, 30% Latinos, 29% Anglo Americans, 0.05% African American and 0.02% Chinese. The diverse group included elders, individuals with disabilities and parents caring for children with varied disabilities: Deaf, Post traumatic Stress Syndrome (PTSD), Autism, Cognitive Delay and ADHD. In many cases, the disability was also compounded by physical challenges. In addition, to the 41 people there were a number of service providers who attended at various times to provide informational materials about their services and upcoming events. Interpreter services were provided in Spanish, Khmer, and in American Sign Language.

Unlike the Worcester Consumer Forum, the Lynn Consumer Forum took place in one large room; that is, the break-up into small group discussions did not require moving participants into other rooms. During breakfast participants were helped to find their designated small discussion/focus group and encouraged to network. The great turn-out from the Cambodian community, required splitting these consumers into two small focus groups.

Altogether there were 5 groups: (1) Deaf Culture, (2) Spanish Speaking, (3) Khmer, (4) Khmer and (5) English Speaking/Diverse (Anglo, African American, and Chinese).

Parent Advocate and LOPC Leader, Rene Williams, opened the Program, providing an exciting welcoming. She was followed by Parent Advocate and LOPC Co-Leader, Madelyn Soares, who presented an overview of the day and introduced Keith Jones, the Chair of the MASS C-PASS Marketing and Outreach Subcommittee (M&O), Chair of Real Choices CPIG, and Self-Advocate. Keith's talk revolved around four questions: What is Mass C-PASS? What is the Olmstead Decision? Why are we here? Where is the information we share today going? Upon the conclusion of Keith's talk, the participants turned to their small discussion/focus groups. After the small discussions groups completed their work, the participants took a lunch break; and, shortly after reconvened as one large audience. Each small group selected a member to report the findings. The closing remarks were delivered by the MASS C-PASS Director, who provided a summary and celebrated the participants and the LPOC for such a successful Forum.

Small Groups Discussion Report

Group 1: People from the Deaf Culture (*Group Living in Residential Home*)

- Need more information on Deaf Culture, accessible equipments for the Deaf ex: TTY, phone flash light, light for doorbells.
- We have diabetes menus. The foods are expensive. We need more money for food.
- Need more staff who know American Sign Language.
- We need a printer and video phone for each house.
- Need more money for recreation activities.
- Need more housework to make the house look better – repairs.
- We need more staff, more money, we need raise. We need more work money for the individual. We need more work support.

Group 2: Spanish-Speaking/Latino (*Notes Interpreted from Spanish to English*)

1. Transportation

- For medical appointments
- Too Expensive
- Medical insurance should pay for taxi
- Lack of information about what is available
- Wheelchair accessible

- Services are different depending on the disability. Services should be more generalized.
 - Transportation is not available to attend activities outside of programs. Not available to go to community activities.
 - Transportation is not always on time.
2. Medical Equipment
- Are limited to limited to the schools or residential homes but not available at the family home.
 - Medical insurance does not approve the necessary equipment or better equipment.
 - Other funds need to be made available to purchase necessary equipment.
3. Services
- People in charge of services and workers need to know more about the needs of the people they serve and their families.
 - Respite care providers should be available for people who work.
 - Agencies are not selecting people who are available to work with different types of disabilities.
 - Workers should be given an orientation or more information about the people they are going to work with.
 - PCAs must have documents to work legally.
 - Families can work with members of the family that have a disability.
 - Too few PCA hours. To use the hours, the hours must be divided.
 - Most PCAs do not want or can't work more than one or two hours in the morning.
 - Services are different during staff vacation and in the summer – no consideration that the families' schedules do not change.
 - Need camp services available on weekends or at night.
4. Independence
- Need more money to not depend on parents.
 - Prepare individuals with disabilities to live a little more independently.
 - Prepare children with disabilities to grow up to be independent adults.
 - Parents single or married have limitations to go out and work outside of the home.
5. Education
- There is no appropriate staff to teach the children.
 - School system needs to improve on special education.
 - There is no bilingual staff.
 - There are no trained translators or interpreters available.
 - Parents want to learn English.
6. Housing
- Assistance for homeowners to make renovation for accessibility.
 - When one is not a homeowner there is a need to obtain permission to renovate for accessibility.
 - Alternatives to exit the building in an emergency.
 - It is difficult to find accessible housing.
 - Long waiting list for housing.

7. Community

- Educate the people in the community and neighbors so that they:
 1. Understand the disability of a family member
 2. Learn to be more tolerant
 3. Accept the differences
- Due to lack of knowledge people discriminate against people with disabilities who are not seen.
- Parents should take the initiative to talk to their children about people with disabilities.
- People with disabilities should accept their disabilities and talk about it.
- People generalize about disabilities in accordance with their religious and cultural beliefs and discriminate.

Group 3: Cambodian Culture

(1 of 2 Groups/ Included PTSD, Autism, Cognitive Delay, ADHD, Elders)

1. Financial Support

- Help pay for rent
- Gas bill too high
- Electric bill too high
- Insurance co-pay too high

2. Transportation

- No license – too afraid to drive – can't pass test
- Going to visit mother in nursing home – no car

3. Language Barrier

- No available interpreters when needed as on emergency purposes without appointment.
- Can't understand when pharmacists explain.

4. Emotional Support

- Need personal and trauma counseling (*linguistic and culturally barrier*)
- Family problem
- Not enough money to pay bills.
- Children not listening, skip school, engage in gang violence, teen pregnancy

5. Medical Coverage

- Co-pays for doctor's visit too high – person with long term disability has to pay \$84.00 per visit.
- Medicine co-pays too high
- Housing
- Waiting list too long
- Too many children need Section 8, but not available program to assist immediately.

6. Racism
 - Family sitting in the porch when is too hot inside the house, but police came to ask without any reason and told them to get inside.
 - Cultural differences – hard to communicate with children because they don't understand my culture.
7. Eye Glasses – can't afford to buy them.

Group 4: Cambodian Culture

(2 of 2 Groups/ Included PTSD)

1. Cost of living too expensive
2. Language Barrier
 - Medical issues
 - Children problems in school or at clinic
3. Housing
 - Reduce rent
 - Provide Public Housing
4. Emotional Support
 - No support from community
 - Isolation/No family
5. Transportation

Needed to go to doctor's appointment/shopping for food and medication/drop and pick up from community meetings or services.
6. Medical Issue

To understand about western medicine or medical
7. Culture

Need understanding of our cultural needs.
8. Education

Access to school – need to know a Cambodian disable need to learn.

Group 5: English/Diverse Group

(African American, Anglo American, and Chinese: Parents and an Individual Consumer)

1. Financial Support – have benefits (SSI + SSDI), need help with math, banking, budgeting, overall financial picture
 - Have benefits (SSI + SSDI), need help with math, banking, budgeting, overall financial picture.

- Help finding other resources (DMR, Arc, flexible funding, MCB, childcare, case management, respite services).
- Money for activities/recreation/social or find free activities (i.e. Bankers), scholarship opportunities

2. Recreation

- Help paying fees associated with activities, can use flex funding but many people need that money for respite services.
- Staff issue – would be helpful to use PCA hours to access recreation opportunities.
- Mobility issues – accessibility issues, not enough handicap seating, need expanded facilities, would increase participation.
- Adaptive equipment needed – i.e. YMCA, especially for transferring.
- Need some one on one time for people to go on recreational outings so they can fully participate.
- Recreation is vital to overall quality of life, mental well-being.

3. Technology/Medical/Dental

- Access to eye glasses (only every 2 years)
- Dental care – need preventive care, routine cleaning
- Need to let State legislators know, make them aware of these issues that impact life.
- Some legislation on the works to allow MASS Health to cover dental.
- Access to services – i.e. speech therapists, OT, PT

4. Safety

- Hard to find good apartments in safe neighborhoods.
- Landlords who won't fix things when they are broken.
- Security of building, people let other people in building.
- Safety in community – some areas not safe especially at night.
 1. Need a ride home (from work or school)
 2. Long waits for public transportation and then have to walk from bus stop home.
 3. Can use Lynn Time Bank
- People can taunt/tease people with disabilities on street, makes them feel unsafe. Need more public awareness to sensitize people.
- Buddy system works but who will accompany person with disability/ (PCA?)

5. Housing

- Low availability
 1. Have special needs can't be on 3rd floor
 2. Finding right home and then being able to stay (landlords sell apartments or houses and people need to find new place to live).
- Would like to have home with yard instead of apartment.

- Maintenance issues – landlords won't fix things when they are broken, tell tenants to fix things themselves.
- Accessibility of apartments – kitchens, bathrooms.
- More universal design.
- It is dangerous when houses are in disrepair or not accessible or have mold or lead paint.

The Urban Pride Consumer Forum

On Monday, July 31st of 2006 the Chairperson of the MASS C-PASS Marketing & Outreach Subcommittee and the MASS C-PASS Director conducted a forum within the Urban Pride Advocates Leadership Conference held at Martha's Vineyard. Invited to participate were 14 Boston mothers and another mother residing in Martha's Vineyard. The resident of Martha's Vineyard requested that MASS C-PASS come back to work with elders and individuals with disabilities from the Cape Cod/Martha's Vineyard area and introduced other residents interested in forging a collaboration to address the issues in those communities. All 15 women were parents of at least one child with a disability. Two of the women were African American and one was Anglo American the remaining 12 were Latinas. Three of the 12 Latinas were Bilingual and the remaining number spoke only Spanish. The 14 women from Boston were all advocates-in-training; and, the one from Martha's Vineyard provides elder services in addition to being a parent of a child with a disability. The M&O Chairperson opened the forum providing an overview of the C-PASS federal demonstration project and the purpose for the forum. He was followed by an exercise led by the MASS C-PASS Director.

"THOU ART AN EAGLE" Exercise

The exercise divided folks into four groups – two were in Spanish and the other two were in English. These groups remain the same throughout the forum. Time was given for the participants to read the fable "Thou Art an Eagle"; and, to draw analogies over what the characters represented in their view: Farmer, Chicken, Eagle and the Naturalist. The fable is provided in the figure that follows.

"THOU ART AN EAGLE"

Once a farmer took his young son on a hike, they tramped through the meadows and woods. They hiked through the pines and up over the hills. They climbed the steep mountains and finally, high above the timber line, scaled the crags and peaks. There they saw a giant eagle soaring overhead. They scanned the cliffs and finally located the nest. The boy climbed precariously up the cliff to where the nest was located. He reached into the nest, which rested on a ledge, and pulled out an egg, which he put inside his shirt. Then he climbed carefully back down the cliff.

He and his father returned home, and the boy put the egg in a nest where a hen was brooding over her eggs. By and by, when the eggs were hatched, each delivered a small chick except the one from which a young eaglet was hatched. Months passed and the eaglet matured. After the eagle was full grown, a naturalist was driving down the highway out in the country. As he drove by the farmer's yard, he saw the giant eagle. He slammed on his brakes, got out of the car, and went over to the fence. He could hardly believe his eyes. He opened the gate, walked into the yard, and found the farmer. "Where did you get that eagle?" he asked. The farmer said, "It's a chicken." The man responded: "I am a naturalist. I know all about these things, and I tell you that is an eagle. Furthermore, I'll prove it." He picked up the eagle, put it on his arm, and said, "Thou art an eagle-fly."

The eagle hopped off his arm and began to scratch in the dirt like the chickens. The farmer said, "I told you it was only a chicken." The naturalist asked for a ladder. He leaned it against the barn. Then he carried the eagle up on top of the barn. He stood at the peak of the roof on the barn, placed the eagle on his arm, and said, "Thou art an eagle-fly."

The eagle swooped down into the yard below and began scratching in the gravel. The farmer hollered up, "I told you it was a chicken."

The man climbed down off the barn. He made an agreement with the farmer. The next morning, long before sunrise, he picked up the eagle. He carried it through the woods and over the meadows. He continued up into the hills and the pines, onward, upward, above the timberline to the peaks and crags and pinnacles of the mountains. He arrived at the mountaintop just before dawn.

As the first rays of the sun began to streak across the sky, he put the eagle on his arm. The fresh, cool winds came through the valleys and trees below and swept up to the cliff where the naturalist stood. The eagle breathed deeply. The first streaks of sunlight caught his eye. He stretched his giant wings, almost six feet across. The naturalist said, "Thou art an eagle-fly." The eagle slowly lifted off the naturalist's arm. It ascended into the sky. It soared higher and higher and further and further. It saw more in an instant than its companions had in an entire lifetime, and from that time forth it was never again content to be a barnyard fowl.

Group 1:

Farmer = Foster Parent or Parents in General, Chicken = Child

Eagle = Ability, Naturalist = Doctor or Government

Story: The Doctor or the Government thought it could help the child. However, if the Eagle had not flown because it was raised as a chicken what would it be? Do not know if the Eagle thinks like the Naturalist; or, if the goals of the Eagle were the same as those of the Naturalist.

Group 2:

Farmer = Father/School Department, Chicken = Students, School, Family

Eagle = Special Education Student, Naturalist = Teacher

Story: The child was misplaced in the school system. The Eagle was accepted as family, student and so were his culture and abilities. The Naturalist taught the child to discover himself.

Group 3:

Farmer = Fathers/Parents/Opressors, Chicken = Stepmother

Eagle = Child, Naturalist = Teacher

Story: The Father was oppressing the child; and, the Stepmother protected the child and raised him as her own. The Teacher taught the child that he was unique in his own way.

The group had an alternate story: The chicken was a child with a disability lost in the school system. The teacher created a fitting learning environment and the child grew to be a productive adult.

Group 4:

Farmer = Father/Son, Chicken = Siblings

Eagle = Son born with many disabilities, Naturalist = Counselor/Mother/Doctor

Story: The Father raised both sons in the same way – “in denial”. The Son was born with many disabilities. The Doctor did all the testing and analysis and educated the father in three ways vision, talking, and actions. The father had to get rid of the notion that everyone is the same. After the process the Eagle-son was interested.

The group also added: The Farmer also represents all the authorities such as teachers, parents, government, institutions, friends, society, community, school systems.

Small Groups Discussion Report

After each group shared their perspectives on the fable with the full body, they took a break for lunch to return to the focus group discussions. They were given a set of questions to work on:

- 1) What Services are you aware of that are available in the community? Who do you go to, when you need help?
- 2) What is the quality of these services?
- 3) What are the barriers, if any, to access these services?
- 4) Are there any services that you need that are not currently being provided to you?
- 5) What would make services better or more appropriate for you?
- 6) What do you believe are your strengths? What are your family strengths?

❖ WHAT ARE THE BARRIERS IF ANY?

- Running Around...People at Entry Level not empowered to do things/
- Bad Communication
- Bureaucracy
- Racism
- No Trust
- No Money
- No Cultural Competency
- Lack of Quality Services
- No Patience
- No Respect/Judgmental Workers
- Agency Politics
- Preference/ Play Favoritism
- Need to talk directly to the workers---not receptionists.
- One Stop Shopping Needed for Getting Services
- Language/ Translation – Documents, Verbally, etc.
- Translation/Language/who understand the language of special education/laws
- Translation of IEP first pages- so the contents are not relevant
- Translation helps but people must understand the concepts-
- Lack of Competency
- Quality of service providers/
- Funding/human services training/consistent requirements
- Location/ transportations/value judgment
- Bad Attitude- why do you want to know...what you looking for-degrade parents- do not understand your accent
- Lack of files- paperwork gets lost
- Childcare to support getting help

-
- Lack of Confidentiality
 - ❖ What are the barriers, if any, to access these services?
 - ❖ Are there any services that you need that are not currently being provided to you?
 - ❖ What would make services better or more appropriate for you?
 - ❖ What do you believe are your strengths? What are your family strengths?
 - New Schools (more buildings), New Services
 - More Programs for High Functioning Autistic/by Abilities
 - Make Clear What Schools Pays and What the State Pays
 - New IEPs
 - Good Social Worker/Welfare and SSI
 - Accountability from DMR and DMH
 - Cross Agency Communication – DMR, DMH, BPS
 - More Economic Resources
 - More Advocates
 - More Lawyers
 - Equipment for Children/Recreational Equipment/Universal Access Playgrounds
 - Mental/Emotional Support
 - Special Team with Knowledge of Disabilities – Train to Respond to Emergencies
 - Training for Parents and Caregivers On How to Respond to Emergencies
 - Certified Monitors on How to Deal with Children with Disabilities
 - Year Long Programs/Recreational & Academic
 - Educational Programs for Parents to Understand and Educate Their Children About People with Disabilities
 - Extended Personal Assistant Hours for Parents that Work
 - Support for Siblings So They Understand the Disabilities.
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The Chinatown Consumer Forum

Originally the intent of the Marketing & Outreach Subcommittee was to coordinate an Asian Consumer Forum, but gaining access to this community was difficult and what eventually came to be was the Chinatown Consumer Forum. The fact that the originally intended Asian forum became the forum for the Chinese community did not undercut the overall desire to reach multiple Asian nationalities. By way of the Lynn and the Greater Lawrence consumer forums, the Subcommittee engaged a large number of individuals from the Cambodian and Vietnamese communities. Nonetheless, the eventual access to the

Chinese community led to learning why they were not so easily engaged; and, the reasons were in effect explanations of what it would take to remove barriers to self-direction for people with disabilities of Chinese origin.

The first opportunity to meet members of the Chinese community came at the 1st Annual MASS C-PASS Symposium held on January 14th, 2005. By way of the DMR Greater Boston Area Director, Chinese consumers were invited to participate in the Symposium and a number of them did. From those who did MASS C-PASS gained a new Coordinating Council Member, who continued to be actively involved in various Project components through the life of the Project. The remaining subgroup joined the Policy Development Subcommittee but quickly tired after the first conference call.

The subgroup of Chinese nationals was monolingual, and the local service provider, Project Able, provided the interpreters who translated what was being discussed on the telephone conference call. This situation made communication awkward at both ends of the call. The experience confirmed for the M&O that the planning and organizing of forums had to take place in the participants' communities and in their preferred language (with interpreter services provided for the M&O members). As it was, the initial response was unfavorable to the M&O overtures to forge discussion for the planning and organizing of an Asian consumer forum.

Eight months went by before the M&O accessed opportunity to present the Consumer Forum Series concept to the members of the Chinese community. Concern about including the Asian community in general was a frequent part of the dialogue during M&O meetings. In answer to said concern the MRC Director of Consumer Involvement introduced a self-advocate of Chinese origin to the M&O. He was engaged as the Community Organizer to coordinate the Asian consumer forum.

The Community Organizer immediately arranged for the Subcommittee to make a presentation before the Parent Association at the Great Wall Center, Inc, in Malden, for the evening of February 15th, 2006. The Association was made up of parents of children with disabilities. At the meeting, the M&O Chairperson and the MASS C-PASS Director were

greeted warmly by the Executive Director and the Association. They were eating dinner when the Chairperson and the MASS C-PASS Director arrived; and, both were invited to dine. When the Association was ready to conduct business, formal introductions were made all around. There were approximately ten Association members in attendance and only three were English proficient. The Chairperson and MASS C-PASS Director made a joint presentation; and, following the presentation, the Association members shared details of the bad experiences they lived in trying to gather resources and support for their children. Still there was apparent hesitation on their part to commit to planning, organizing, and hosting an Asian consumer forum.

When the Chairperson sought clarity over whether they would commit to doing the forum, the Association instead raised issues about the State. Members of the Association expressed feeling used by the State in past occasions. They felt that input solicited in the past on improving delivery and quality of services was ignored. They offered as an example how the State still ignores their expressed need to hire linguistically and culturally competent staff, since the lack of such staff is what has been quoted to them as the reason for failure to provide services or for delay in services. Another clear area of frustration was their belief that the State's policy for allocating funding was discriminatory. The Association members said linguistically and culturally competent, grassroots organizations are excluded through several means from grant awards and resources. Close to three hours later, the meeting concluded with the Executive Director agreeing to explore further whether it would be feasible and, or, prudent for the Association to engage in the Consumer Forum Series.

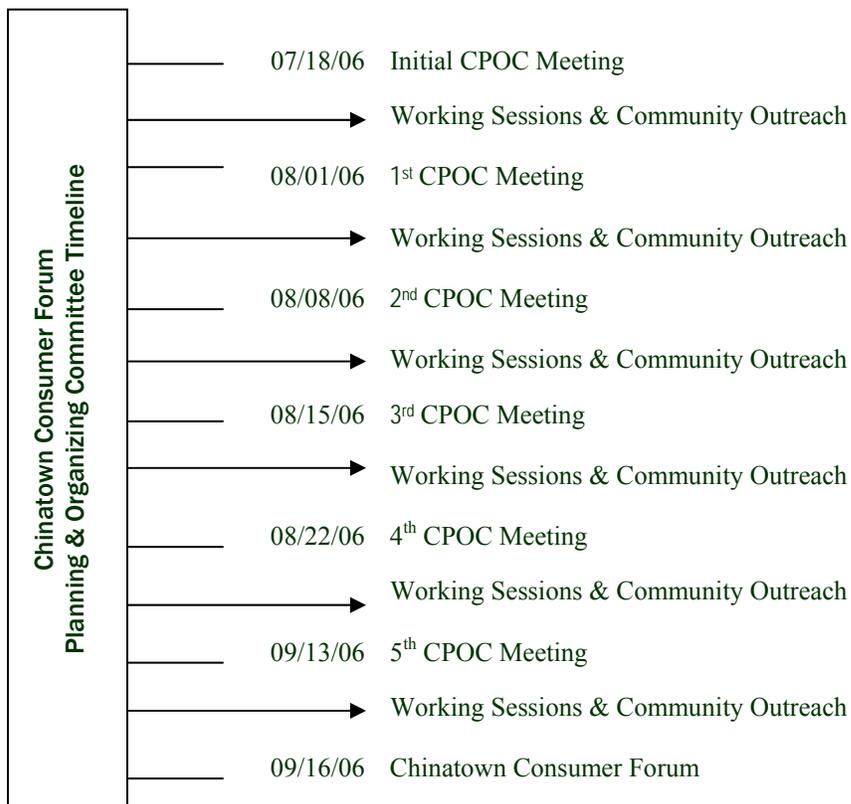
It would be yet another five months of the M&O and the Community Organizer making phone calls and knocking on doors before the Chinatown Planning and Organizing Committee (CPOC) would take form. The Community Organizer worked with the MASS C-PASS Director to cultivate partnership with three key leaders of the Chinese community: The Family Services Coordinator at the Boston Chinatown Neighborhood Center; a parent advocate running Boston Chinese Family Support; and, a UMASS Boston Professor and advocate for children with special needs. On July 17th, 2006, the initial meeting of CPOC took place. In attendance were consumers and several public and

private service providers: MRC, DMR, Boston Chinatown Neighborhood Center and Boston Independent Living Center.

The M&O Chairperson and the MASS C-PASS Director made a formal presentation describing the MASS C-PASS Demonstration Project and the Consumer Forum Series concept. Then there was an extended question and answer period. At the conclusion of that period, brainstorming around the Chinatown Consumer Forum took off. It was then when consensus was reached to conduct the forum entirely in Mandarin and Cantonese – and to provide interpreter services for the English language guests, speakers, and MASS C-PASS members.

The MASS C-PASS gained as a strong and driving ally the Family Services Coordinator at the Boston Chinatown Neighborhood Center. The Coordinator provided meeting space and dedicated significant hours to help guide the planning and organizing. Several attempts by parents were unsuccessful at including the Vietnamese served by Project ABLE. However, Chinese parents served at Project Able responded as individuals to CPOC and pre-registered for the forum.

CPOC continued to move ahead needing nothing more from the M&O than the processing of administrative matters. They created outreach materials, generated interest from the local media, and organized a mailing, as well as modified the consumer forum pre-registration form to include permission for participants to be photographed and video taped. Seen less frequently in the other POCs but to a larger extent with the CPOC was the engagement of their family members in activities; and, most especially, their children with disabilities performing various tasks such as mailings. CPOC members took pictures at some of their working sessions for their own personal record and the M&O asked permission to use these pictures to design a display on the type of grassroots energy generated from the Consumer Forum Series. Overall, the following timeline illustrates the level of activity within the two-month period that led to the Chinatown Consumer Forum.



“At the Consumer Forum”

The Chinatown Consumer Forum took place on Saturday, September 16th, 2006, at the Boston Chinatown Neighborhood Center, from 2:30 pm to 5:00 pm, with the reception scheduled for 1:30 pm. When entering the building there were two greeters at the door directing people to the registration table where they would receive a color coded folder that symbolized their assigned small discussion group for the break out sessions. From there participants requiring English translation were directed to a second table to sign-out the translation equipment; or, they were instructed to move along to the elevators where two hosts would escort participants to the floor where the forum would take place and/or to the floor where rooms were designated for childcare. Additional hosts were at the elevator door on the floor where the forum would take place showing participants to seating, refreshments, bathrooms and answering questions. Chinatown’s World Journal Daily Newspaper and the Boston Globe had reporters moving about and taking photographs. When the Program started there were about 111 people in attendance.

The Family Support Coordinator provided a welcoming and described for the participants what to expect. He introduced the MASS C-PASS Director, who accompanied by M&O Chairperson described the MASS C-PASS Demonstration Project and explained the importance of the Forum. This portion of the Program was followed by a Family Consumer Panel discussion moderated by the Boston Family Chinese Support Parent Advocate. The subsequent paragraphs highlight the very moving life stories shared through the panel discussion.

Panelist No.1: Mr. Hang L.'s Story

An outreaching nurse saw my mom and her two kids and then handed out information. This nurse opened the door of services for me and was the first person to get me admitted to Boston City Hospital and other therapeutic services I needed when I was young. My advice: take advantage of the various information here at this forum

Panelist No.2: Mrs. Jenny C.'s Story

Mrs. C. has a 25 year-old-autistic son graduated from Higashi School in Randolph and moved into a home in Quincy that was suppose to be the first Chinese cultural home with Chinese case workers. The home ends up with three Chinese males, three non-Chinese, and only one Chinese staff who work during the day when the consumers are attending workshops.

People with disabilities are not receiving necessary support for independence and self advocacy. The supports needed are as follows:

- *Provide social interactions that are culturally based.*
- *Continue with functional language therapy.*
- *Pair with buddies & prioritize family gatherings, religious observations, cultural music and food.*
- *Provide appropriate housing within one's neighborhood*

What Prohibits the Disabled in Reaching their Goals

- *Lacking community and state wide support in providing social activities, continuing education, and functional skills trainings that are culturally related as well as language sensitivity.*
- *Lacking trained bilingual staff to work with this population*

The Future: Chinatown will accept and acknowledge the disabled by

- *Providing programs/activities for the disabled such as talent shows, Special Olympics, arts and crafts, bowling, swimming etc...*
- *Building homes for the disabled in the Chinese communities.*

Panelist No.3: Mrs. Linda (L.) W.'s Story

Linda W. has a 13 year-old autistic son and has been looking for after school and weekend recreational activities. She met a lot of resistance based on the reasons below:

- 1. Not enough staff*
- 2. No qualified staff with SPED license*
- 3. An overcrowded program*
- 4. A noise level affecting her son's behavior*

To help her son to live independently, the community and the agency have to

- Provide space and assign time slots for the special needs children and adults, along with DMR (government) support services for staff training.*
- Provide housing for kids turning 22 years old and other adults in the local community by taking advantage of the latest housing development in Chinatown.*

Panelist No.4: Mrs. Zhong (R) Z.'s Story

Mrs. Z. has a 3 year-old boy with autism and an 8 year-old boy with asperger syndrome. Having two young boys with such disorders in one family is tough enough for parents already. What makes it worse for her and her husband is that they are both new immigrants from China, know very little English, and have to support a family. She is working as well as attending school hoping to learn more English.

She wants to learn more about her sons' disorders and how to cope with the problems and the behaviors. She wants to help her boys to live independently in the future. Being a full-time student and a full-time mother with two boys with severe behavior issues wears her down greatly.

She never gives up and has been trying to learn about the two disorders by looking up resources. However, all information handed to her is in English, including websites and brochures. Most trainings, workshops, and support group meetings are also in English.

A simple example, when she was at the first C-PASS meeting in July, she was totally unaware when people asked for the Chinese representative from one of the family support groups she belongs to since she only knew the support group's name in Chinese. She was embarrassed and felt left out all through the meeting. The C-PASS meeting in September gave her a better experience because Mrs. W. made sure the discussion was translated for her and the other Chinese families.

People with disability are not receiving necessary support for independence. *The primary obstacle is language, followed by lack of cultural sensitivity and awareness. People assume we know or we will find*

ways to get the information translated. That's why we, parents, get together to form our Chinese language support group, the BCFS (Boston Chinese Family Support), spearheaded by a group of advocates and educators.

The support necessary for independence and self advocacy is to educate families to help them understand and learn how to deal with the disorders. I think C-PASS will bring a brighter future to the Chinese families with disabilities. Today's forum, conducting it in our own language, is the first of this kind in Chinatown. We certain hope this is not the last. We hope to see many more of this kind of forum and workshops to follow. Only with the support of the community and the government can our dreams come true, and we, parents never stop advocating for our children.

Panelist No.5: Chiu (O) L. Story

Mrs. L. has a 10-year old Cantonese speaking boy with Hunter syndrome that is characterized by dwarfism, developmental delays, and digital contractures that have affected his mobility and requires wheelchair to travel long distance. He has language delays and behavior issues.

People with disability, especially the language minorities, are not receiving necessary support for independence,

New immigrants have enough difficulty accessing resources that are not in their native language. The worse is to seek aid to work with her son's rare disorder. School personnel are supportive but lack experience in dealing with his behavior and health related issues due to the progressiveness of the disorder.

There is a lack of disability awareness in school, in the community, and throughout the whole Massachusetts. Also, the lacking of appropriate social activities and support for the disabled individuals as well as their siblings and families.

Future: *I have faith in our schools and the community. Today's forum is breaking ground in giving a voice to this silent group and their families. Many thanks to BCNC for make it happen. Just in the past year, we have formed our own Chinese family support group, the BCFS organization that is open to the public, organized by devoted advocates and educators. BCNC provides space for our bimonthly meetings and our weekly social gatherings for different age groups in the fall. We started with a zero budget and are relying on public support to expand our outreach to other ethnic groups.*

We are happy to meet the Great Wall Chinese parent support group of Malden. Though my son may not live to see the full blossom of the empowerment of the disabled, I am proud of him for giving me the chance to meet different dedicated mothers and zealous advocates. I treasure every second I have with him. I know the mentally disabled have a very strong will to live but they need functional skills trainings, services and support

from school, community and our government. We, parents, are in need workshop training in Chinese to help us deal with our children's problems and behaviors and to teach us how to help our children to become independent.

Panelist No.6: Wen (Q) P.'s Story

Mrs. P. has an 8-year old mandarin speaking boy with bilateral microtia and atresia resulting in hearing loss. He has no external ears and is in the process of building them. With specially-designed hearing devices, he can attain up to 80% of hearing. However, growing up in a Chinese speaking family along with hearing impairment, he has a hard time understanding others, catching up with his peers of normal hearing, and that result in his learning and behavior problems.

People with disability, especially the language minorities, are not receiving necessary support for independence. We, parents, are not receiving the support we need to help our children to move towards independence due to the Language Barrier and Lack of Resources. With minimal to no support, I have moved my son from all English oriented hearing impaired classroom to all English regular classroom with resource and special support. Now with lots of effort and support, I have transferred my son to a Chinese SEI (Sheltered English Instruction) classroom at Josiah Quincy School.

I feel Boston school system should form a parent support group for Chinese parents with children with special needs and help build a network for language minority parents. As for our community, I think our schools, churches, theaters, museums, and organizations such as BCNC and YMCA should set aside time and space for families of individuals and individuals with specials needs to hold support groups and social events because we are in need of advocacy and support groups that speak our own language. I believe other ethnic /language groups are struggling like us when dealing with children with special needs or disabilities.

All of the panelists shared their life stories in a very moving manner and some cried provoking many in the audience do the same. The Moderator asked the audience to keep these stories and their own in mind as they entered into the next portion of the Program: the small discussion groups.

In preparation for the Consumer Forum, CPOC determined 4 types of small groups and provided color coded folders at registration to indicate the participants preferred discussion: Blue – Independent Adult Customer; Red – Residential Group Homes; Yellow - Teenager's Issues; and, Green – Children's Issues. Each group had a room assigned

away from the general assembling area; and, they were engaged in a 30-minute long dialogue. Immediately following the small group discussions, designated group leaders reported back before the entire assembly of participants (detailed notes of the reported appear under the section labeled Small Discussion Groups Report).

Next in the program was a response to what the groups reported by a panel of State Government Officials: Margaret Chow-Menzer – MASS C-PASS Grant Manager & DMR Assistant Commissioner; John Chappell, Jr. – MRC Deputy Commissioner; and, Kathleen Catano DMR Metro-Boston Area Director. After the panelists provided responses there was a brief question and answer period. Overall, the panelists expressed a commitment to address the problems raised. The MASS C-PASS Director was asked to deliver the closing remarks along with the Family Services Coordinator.

Small Discussion Groups Report

Independent Adult Customer

- Need the Mayor of Boston, Thomas Menino, to listen to us
- People with disabilities to be accepted in our society
- Educational program for people with disabilities that are older than 22 years old
- School always provide fresh food
- Increase budget
- Improve fiscal management
- More resources
- Require all public places (i.e. Hotels, restaurants etc.) to have ramps
- Improve public transportation accessibility issues
- Increase Mass Health eligibility
- Improve translation services in hospital
- Improve DMR services (staff's attitude, trained people)
- Recreation for people with disability (i.e. swimming pool, gym, language learning, and social gathering). Special facilities are provided
- Job training
- Help with job search
- Residential program in Chinatown or close to their neighborhood
- Increase number of Asian workers (Asian language speaking) at residential house
- Workers have to be experienced with cultures

Residential Group Homes

- Not enough support
- Not enough Chinese staff even at cultural home
- No Chinese food
- Staff not trained to promote independence

- Families are not included (language and cultural barriers)
- Workshops (job training, self advocacy etc.)
- Group homes in Chinese communities (i.e. Brighton, Quincy, Chinatown, Malden etc.)
- Asian Staff in DMR

Teenager issues

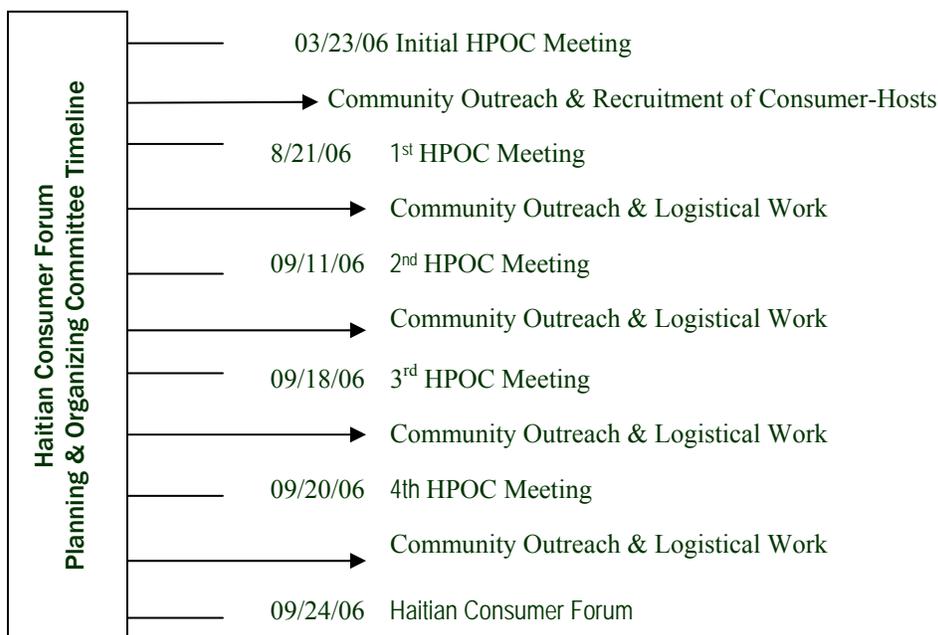
- independent and self-advocacy
- transportation for children to summer schools, weekend programs that are located in different areas in Boston
- enabling parents to work with SVCS in the summer (1/2 month or last month of summer), holidays, or vacations
- programs for teens to be more independent (computer skills, functions)
- understand how MRC, DMR or other government agencies help Chinese
- Are they overlapped?
- Help family with the expenses that spend on baby sitting, child care
- School rules too isolating, difficult for parents to understand
- Increase funding for after school program (help social skills and studies in school)
- Increase normalization for consumer
- Decrease stigma and increase inclusion
- Help with coordinating and access for teenagers
- Time limited for parents or caregiver to have consistent jobs
- Lack of after school programs in the community
- Coordination of state agencies or community organization to fully support parents with low income
- Local support parents
- Community organization provide accessible services
- Beyond 12 in after school program for children with mental retardation

Children issues

- Professional interpreters
- Agencies collaborate (after school or activities)
- IEP meeting (support from other agencies)
- Follow up social worker and home visit
- Training for parents not DMR
- Local community agency
- Placement
- Parental knowledge (APED, IEP)
- Resources (advocacy)
- After school enrichment (funding)
- Qualifications of paraprofessionals
- Language

Haitian Consumer Forum

At the Haitian American Public Health Initiative, Dr. Renald Raphael, Director of the Haitian Family Support Program and his program assistant, Micheline Jean-Baptiste, met with the MASS C-PASS Director as a follow up to a conference call. The meeting focused on determining what it would take to get a Haitian Consumer Forum off the ground; and, what resources would be available to underwrite expenses. Dr. Raphael and Ms. Jean-Baptiste then held a meeting with the Haitian Family Governing Board and recruited three consumer-members to take the lead in realizing the Consumer Forum. The three consumers along with Dr. Raphael and Ms. Jean-Baptiste became the Haitian Consumer Forum Planning and Organizing Committee (HPOC). Administrative responsibilities requiring Dr. Raphael’s immediate attention caused a delay between the time of the Initial Meeting to the steadier planning and organizing taking place later.



HAPHI-C-PASS COMMUNITY FORUM SURVEY

At one of the HPOC meetings, the members designed the dialogue for the Consumer Forum. They were able to arrive at the following outline.

Goal: To study the need for change in the current support services system and to promote self-determination and independence for people living with disability.

I. What services do you need or currently receive and what are the most needed ones for your youth or young adult to become independent?

- 1) Language
- 2) Housing
- 3) Social/Community Skills (After-School Program)
- 4) Recreation
- 5) Transportation
- 6) PCA
- 7) Transition: Travel skills, Job training, Transition to College
- 8) Employment
- 9) Other

II. What kind of problems or barriers do you encounter in receiving or getting these services?

- 1) What kind of barriers have you encountered in receiving PCA services?
- 2) Describe what kind of issues you are experiencing with your PCA service.

III. What barriers are you facing to help your son/daughter to become independent?

For example: Has your young adult child received services like: job training, support to go to College, life skills training, travel training, etc...

IV. Describe the type of changes would you recommend to make the services received more appropriate or to get the services you need for your youth or young adult to become independent

For example: After-School program, Job training, Recreational programs, Employment etc...

V. Describe the support you personally need to contribute to your youth's or young adult's independence? For example: English-as-a second language, training on advocacy, person-centered care, training on transition to adulthood, effective communication, life skills training, training on Disability and Child Development, other...

VI. If you are a person with disability receiving services, please describe the supports you currently receive; and, how they are contributing to or hindering your independence.

“At the Consumer Forum”

On Sunday, September 24th of 2006, from 4:00 P.M. to 8:00 P.M., the Haitian Consumer Forum took place at the HAPHI facility. There were 61 participants all members of the Haitian community, who were people with disabilities, parents of children with disabilities, and elders. The Director of the Haitian Family Support Program, Dr. Renald Raphael, opened the forum providing a welcoming and introduced Keith Jones – the Chair of the MASS C-PASS Marketing & Outreach Subcommittee.

The M& O Chairperson provided an overview on the C-PASS Project and described the purpose of the forum. Following said presentation, Dr. Raphael introduced the MASS C-PASS Director, who focused her remarks on how important the participants’ input would be toward building the State’s capacity to deliver self-directed, flexible personal assistance services and supports. The participants were assured their shared insights into the barriers and any recommendations they offered would be presented to State officials who could put the information to good use.

There was a brief question and answer period surrounding the C-PASS goals; and, some participants talked about their personal experiences and commented on how the C-PASS proposed changes could make life easier. Emphasis was placed on the need to provide HAPHI the resources to obtain facilities that are universally accessible or to renovate the current site. Concluding the opening ceremony, participants were then divided into three smaller groups to identify barriers and generate recommendations.

Small Discussion Groups Report

Group 1

Language

- No information available in my own language
- Need translation services
- Need ESL programs with flexibility
- Have information available in both French and Creole

Housing

- Too expensive
- Not available
- No safe housing

- No parking sometimes that fit people with disability needs
- No apartment available for people with disability to live in
- Need accommodations
- Waiting list too long for people with disabilities
- Need help with utilities

Transportation

- Needed for after school programs
- For outing
- As a result there is a lack of community activities for our children
- Expensive

PCA

- 1) Why you need to be present with the PCA?
- 2) Why can not we use a family member as your PCA?
- 3) Why can not we have more hours?
- 4) They are not paid enough
- 5) Adjustment problems with changing your PCA too often
- 6) Because of little time spent and not enough pay, we have to change our PCA too often kids don't like changes.

Respite

- Too expensive
- Flexible funding always go to respite for 1 to 2 weeks only for the whole year
- Not enough financial support for respite

Group 2

Language

- Interpreters in schools and hospitals

Housing

- Prioritize applications
- More secure place
- More affordable

Social/Community Skills

- Social Activities
- More after school programs
- Day activities for adults (elders)
- Community involvement

Recreation

- Once an a while movies, park, trips

Transportation

- Home
- Day programs
- Monitor needed on bus
- Travel training

PCA

- Love, care
- comfortable

- More time
- More money
- Same culture
- Training program

Employment

- Employment Training

Transition

- Job training
- Travel training
- After school tutoring
- Community/Life Skills
- Transition to Day Programs: Housing: Employment

Other

- Residential, group homes
- Residential support
- More money
- Preparation for vocational school, college
- Schools too far

More important Ones to Solve Now

- Transportation
- After school program (more)
- Recreation program cannot be effective because of lack of transportation
- Revise PCA eligibility – too little time – not enough pay – more money
- More social support/recreation programs
- Accessible space for the Haitian Family Support Program

Group 3

Language

- No enough Haitian providers
- Interpreters

Housing

- Safety issues
- Prioritize needs of people with disabilities

Social/Community Skills

- More social activities in residential

PCA

- Same culture

Employment

- Opportunity
- Training
- Workshops one-on-one

Additional Bullets Notes – Group 3

- 1) Need interpreters: our needs are not met because we can not express our ideas: language barrier is a big issue. The HFSP needs more staff to help use with the meetings (IEP, SSI). If we have at least 4 meetings in one day, HFSP would have to choose to leave one of the parent by herself (himself).
- 2) Housing: It is a must to have an advocate for housing. We have some single parent with 7 children who still can not have housing support (no Section 8; no State or federal housing). With \$1600/a month for rent, we disqualify for housing because in the past we made had problem to pay the rent.
- 3) HAPHI is the only place where the Haitian Community feels comfortable but it is not accessible.
- 4) After school: we need after school for our children. If the school gives you the after-school; they do not provide transportation. We need after school because language barriers to help with homework we desperately need that.
- 5) Recreation: because of financial limitations, our disable children do not have structured activities; they home all the time if it is not for school. We need big sisters/big brothers to go out with the children (mentor).
- 6) We need money for transportation. We need a van to ourselves and children for the program: for social events. HFSP do have a recreation program; but, because of transportation they cannot attend the program.
- 7) PCA
 - More hours compare to needs
 - More money (use allocations money to pay for PCA)
 - Eligibility for PCA had to be revised – culture of family
- 8) Transition
 - Travel skills are needed
 - Our children come out from public school without knowing (sometimes) how to write their name
 - They make you think our disabled children can not learn. We need our children to be educated because they can.
- 9) This is a big challenge. After one week at work, the disabled child can come home with a check of less than \$5. The parents have to provide lunches, clothes and they wake up early. This is discouraging.
- 10) Other:
 - School advocacy
 - Medicaid/Medicare share payment for medication
 - Appropriate placement for job
 - Misusage of children potentialities

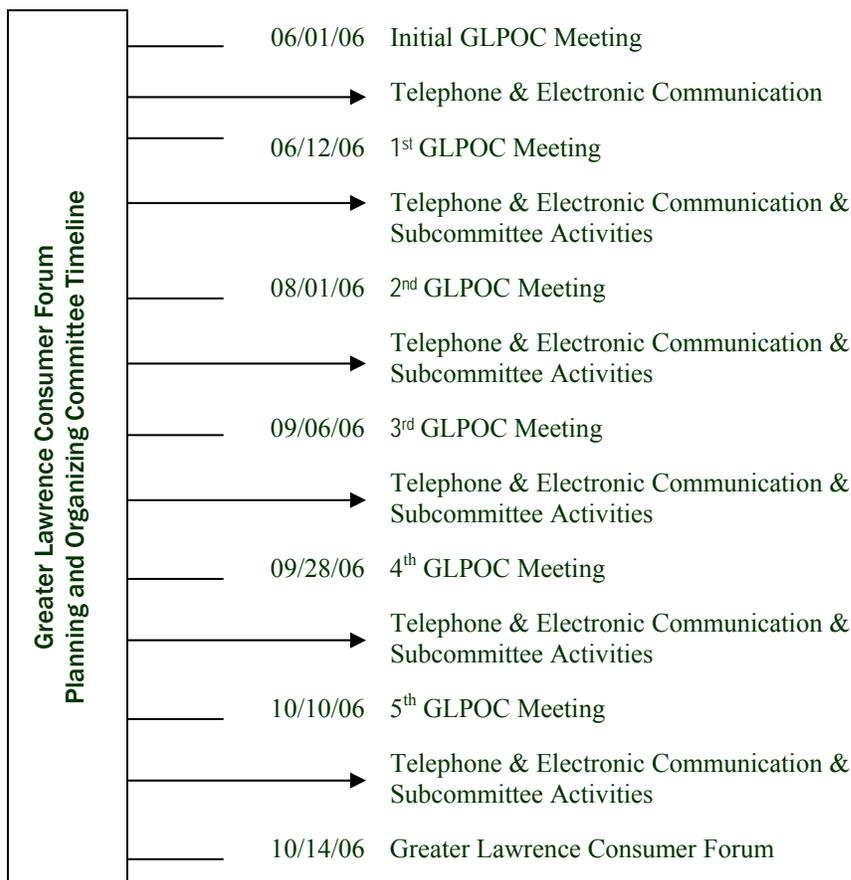
The Greater Lawrence Consumer Forum

Whereas the City of Lawrence is the home of the MASS C-PASS Director - who is also an eight-year, four-term Lawrence City Councilor – a wide range of individuals and organizations were immediately receptive to the idea of realizing a Greater Lawrence Consumer Forum. But her reputation as a local legislative ally to elders and people with disabilities was not the only reason that prompted the warm reception. Additional motives stemmed from her capacity as a mother to a child with a learning disability and her marriage to a person with dual disabilities (speech and hearing impairments). After several formal and informal presentations to stakeholders in the community, the MASS C-PASS Director and the M&O Chairperson arranged for an initial consumer forum planning meeting on May 8th, 2006, with a core group of individuals who brainstormed around who ought to be invited to form the Greater Lawrence Planning and Organizing Committee (GLPOC). Following two additional meetings on May 22nd, 2006 and June 1st, 2006 GLPOC was formed comprised of 28 individuals.

In addition to GLPOC's general planning meetings, members gathered separately as working subcommittees: Outreach - developed flyers and performed targeted distributions in Lawrence, Methuen, North Andover and Andover; Small Discussion Groups - designed questions to stimulate dialogue, conducted a mini workshop for facilitators, created facilitators instruction sheet and coordinated materials necessary to run the small discussion groups; Program - mapped out the forum day, organized the content for distribution packages, secured speakers and panelists and raffle prizes; and, Logistics – reserved space for the forum and planned its use for general assembly and break-out rooms, developed breakfast and lunch menus and saw to the meals preparation, presentation, and serving.

The local organizations contributed resources to supplement the MASS C-PASS Demonstration budget for the Forum. DMH and MRC brought supplies such as news print and pens. Lawrence Public Schools carried the cost of printing 3,000 of the colorful outreach flyer containing photographs as well. Lawrence Council on Aging waived the cost for the use of their facility and associated maintenance fees in addition to covering the

costs for the cooks, servers, and clean-up workers along with half of the price of the meals and snacks. Garden of Options Ministry arranged for at least one raffle prize from each pastor or minister of the evangelic churches in Lawrence. The GLPOC activities took place within the span of five months beginning June 1st, 2006 through to the actual Consumer Forum date – October 14th, 2006. The timeline is shown in the figure that follows.



One additional GLPOC meeting took place on December 14th, 2006 for the purpose of debriefing. At the conclusion of the Consumer Forum, the members expressed interest in continuing to exist as a local coalition dedicated to locally addressing the issue and barriers impairing the capacity of people with disabilities and elders to succeed at self-directed community living. At the December 14th meeting this interest was revisited and it remained strong. State Senator Tucker’s Representative asked: *How is it possible for consumers to self-direct when customer service is so poor in many of the State agencies?* She revealed the frustration shared by the Senator and her staff over constituents needing to turn to them to access services and supports for which they are eligible. They spent a significant amount

of time facilitating services and supports, which cuts into their legislative work. She again posed the question slightly different: *How can consumers self-direct if they have trouble getting through the door in the first place?* The members agreed and qualified the frustration among the core reasons for the continued existence of GLPOC.

The Senator's Representative recommended that the MASS C-PASS work be supported through a state appropriation that would work locally to nurture the appropriate service environment and address local barriers to self-direction. The members brainstorm around what forms this nurturing could take:

- Retrain local State agency staff to work under a model of self-direction.
- Offer training for consumers to enhance their abilities to self-advocate and self-direct.
- Create tools for consumer self-direction, such as consolidating information on services and supports available locally.
- Consolidate information to make it handy for consumers.
- Develop and broker organizational solutions to address barriers to self-direction present in the structure and processes of the public and private service providers. An immediate call for this action was the problems parents and students face with the special education program in the Lawrence Public Schools.

The GLPOC agreed to continue to meet to address the pressing issues parents raised in regards to the schools. It was decided that another meeting would be convened to develop a strategy to meet with the School Superintendent to broker solutions for the parents' immediate concerns. The GLPOC shared the belief, the high number of parents who are frustrated with the school system suggest the problem is systemic in nature.

The Consumer Forum Program was made up of seven parts: Breakfast and Registration, Opening Ceremony, Small Discussion Groups, Buffet Lunch, Small Discussion Groups Report Back, Panel Discussion and Closing Remarks.

Greater Lawrence Consumer Forum Program	
<u>Breakfast & Registration</u>	9:00 am – 9:45 am
<u>Opening Ceremony</u>	9:45 am – 10:45 am
Masters of Ceremony Honorable Michael J. Sullivan, Mayor of the City of Lawrence	
Welcoming Nilka I. Álvarez-Rodríguez, DA, MA MASS C-PASS Director & Lawrence City Councilor	
Introduction to MASS C-PASS Margaret Chow-Menzer, JD MASS C-PASS Grant Manager & DMR Assistant Commissioner	
Keynote Address Charlie Carr, Executive Director of Northeast Independent Living	
The Statewide Consumer Forum Series Keith Jones, Chair MASS C-PASS Marketing & Outreach Subcommittee	
<u>Small Discussion Groups</u>	10:45 am – Noon
<u>Luncheon</u>	Noon – 12:30 pm
<u>Small Discussion Groups Report Back</u>	12:30 pm – 1:00 pm
<u>Panel Discussion</u>	1:00 pm – 2:15 pm
Moderator Honorable Susan Tucker, Massachusetts State Senator	
Panelists Margaret Chow-Menzer - DMR Assistant Commissioner John Chappell, Jr. – MRC Deputy Commissioner Honorable Martin T. Meehan – U.S. Congressman Dorothy Smith – DMH Essex North Site Director Dr. Wilfredo Laboy – Superintendent of Lawrence Public Schools	
<u>Closing Remarks</u>	2:15 pm – 2:30 pm

“At the Consumer Forum”

On Saturday, October 14th, 2006, the Greater Lawrence Consumer Forum took place from 9:00 AM to 2:30 PM at the Lawrence Senior Center and Council on Aging. One hundred forty seven people (147) attended and participated. The estimated racial, ethnic make up was 50% Latino (mostly Caribbean – 1st, 2nd, and 3rd U.S. generations), 27% Anglo American, 11% Cambodian (1st and 2nd U.S. generations), 11% Vietnamese (1st and 2nd U.S. generations) and 1% African American. About 70% were consumers and this number included people with disabilities, elders, caregivers and surrogates. Simultaneous interpreter services took place in Spanish, Khmer, and Vietnamese. Small discussion groups were offered in these languages - eliminating the need for interpreting and translation services during the “break-out” or small discussion grouping. Throughout the day lots of informal networking and information sharing took place.

The Mayor of Lawrence served as Masters of Ceremony for the “Opening Ceremony.” He opened the function describing commitment to enhance the capacity of the City to accommodate and support people with disabilities and elders. His honor described past and current City initiatives in this regard and new public policy developed with the Lawrence City Council Housing Committee that prescribed setting aside 20 percent of the vacant and abandon properties for universally accessible, affordable housing - both rental and homeownership

The Lawrence Mayor moved the activities of the “Opening Ceremony” and provided brief biographies when introducing each speaker. In delivering the welcome, the MASS C-PASS Director also introduced the GLPOC members and expressed appreciation while describing their contributions. The MASS C-PASS Grant Manager also a DMR Assistant Commissioner, introduced MASS C-PASS describing its inception and its part in a larger effort to create systems change in long-term care. Motivation and inspiration for consumers underscored the Northeast Independent Living Executive Director’s delivery of the keynote address – as he shared his life story and described the evolution of his advocacy work and the “Independent Living” philosophy. The M&O Chairperson took center stage to provide an account for the creation of the Consumer Forum Series: Why did it start? Who is involved? What is expected of forum participants? What is done with the

information gathered? At the conclusion of the Ceremony, the Mayor mingled with participants as they moved to break out rooms for the next portion of the Program: Small Discussion Groups.

The assembled were divided into 8 small discussion groups. Special attention to language and culture predetermined 4 of the groups formed: 2 Latino (Spanish proficient with limited English) groups; one Cambodian group; and, one Vietnamese group. These four linguistic and cultural groups included cross disabilities and age categories (youth and elders). The remaining four groups were distinguished as such: One group primarily consists of parents of children deaf or hard of hearing and to a lesser degree children with other physical disabilities; another group gathered Anglo American seniors or elders; one more group was made of consumers and service providers (public and private); and, lastly, another group identified special education as their main preoccupation.

During the luncheon prizes were raffled. The raffles, to an extent, turned out to be a needed distraction while the GLPOC resolved the problem of running out of food. Despite the intensified outreach, the GLPOC did not anticipate 147 people and planned for at most 120. Luckily the food preparation took place in the kitchen of the Senior Center and the cooks creatively remedied the situation; but, it involved making sure Asian type foods (mostly vegetarian menu) were given to the Cambodian and the Vietnamese. This caused a bit of a stir, as two seniors were not sufficiently distracted by the raffles to not protest. Another much needed distraction while the food problem was resolved was the fluid intermingling done by the State Senator, the Lawrence Public Schools Superintendent, the DMR Assistant Commissioner, the MRC Deputy Commissioner and the DMH Essex North Site Director as well as Congressman Meehan's Representative.

After lunch, the program moved on to the "Small Discussion Groups Report Back" segment. Reporting back to the larger assembly entailed each group selecting a recorder (group notes separately appear in the section *Small Discussion Group Report Back*). Reporting back also meant each group selected a person to present the identified issues and/or barriers to self-directed, flexible personal assistance services and supports leading to "Self-Determination," as well as emerging recommendations. One by one, each group

representative came before the assembly to present; and, on two occasions the presenters were accompanied by an interpreter. The tone of the reporting and of the assembled mirrored the fun experienced during the raffles. There were applauds and “ooh” reactions.

The speakers on the panel coming up next listened as it was their purpose to respond to what the groups reported. State Senator Tucker, whose aide had been very active in representing her in GLPOC, was familiar with many of the issues faced by people with disabilities and elders. The Senator delivered a speech describing her commitment and touching on what she had heard at the Forum that day.

Congressman Meehan’s representative served as the moderator of the Panel of State Officials and briefly spoke of the Congressman’s efforts to improve the quality of life for people with disabilities and elders before turning to the panelists: DMR Assistant Commissioner, the MRC Deputy Commissioner, and the DMH North Essex Site Director. Ten minutes were designated to each panelist to talk about their work and respond to the small discussion groups reporting back. A very brief answer and question period followed. Closing remarks concluded the forum. Participants remained to speak individually with members of the panel and to talk amongst themselves. All participants exhibited signs of feeling highly spirited. There was so much excitement it took a while to empty the Senior Center, which made anxious the group next scheduled to use the facilities that day.

Small Discussion Groups Report

Group 1: Parents of Children with Hearing Impairments

- ❖ ASL being taught in schools no programs in City of Lawrence – 52 kids in LPS today.
- ❖ Not enough services for mental, DHH, low achievers (after school) no fire alarms for DHH, no adaptive technology
 - Too much exclusion (lack of training – students, teachers, etc)
 - Parents have to advocate for their kids
 - Schools need to be more accessible
 - Tell school committee too
 - Not enough info distribution, promotion
 - Intervention not early enough
 - Schools ignore recommendations for hospitals

- ❖ Transition plans not in place in all school systems. Lawrence, Methuen needs to improve. Parents must help advocate for youth.
- ❖ Obstacles ... finding social worker to verify disability. When they turn 18 parents have no voice.
- ❖ How to work with school system
- ❖ How to get information to
 - Parents
 - Schools
 - Community
- ❖ Schools don't know info
- ❖ Kids with disabilities all the same
- ❖ IEPs do not look at long range. Don't sign if not happy.

Group 2: Senior Group

- (1) What services are you aware of?
 - Elder Services – AAA Insurance
 - Meals on Wheels
 - Senior Center
 - ½ fare on bus
 - Different ages for senior citizens insurance
 - Food pantry, food stamps
 - Wee Bus
- (2) Quality of Services
 - Wee Bus wait long time
 - Elder services very good
 - Meals on wheels very good
 - Senior Center very good
 - Home care good
- (3) What are the barriers?
 - Word of mouth
 - Home ownership barrier
 - Voice automated systems hinder getting information
 - Internet not that useful for most seniors
- (4) Are there services you need that are not currently provided?
 - Conversation line that you could call if lonely
 - Elder Abuse
 - Snow removal
 - Access for disable and elderly
 - Cleaning the sewers
- (5) How can services be made better?
 - Listen to our complaints
 - E-mail address for complaints
 - Money follow the person
 - Who do you call for wheelchair repair?
- (6) What are the strengths?
 - Wake in the morning – Fear of Dying

- Good friends
 - Neighbors
- Group 3: Cambodian

- (1) What services are you aware of:
 - SSI – SSA, South Union Street
 - Welfare
 - Immigration – Asian Center
 - Counseling – Arbor Counseling, have Cambodian translators
 - Hospital – Lawrence General, Holy Family
 - School counselors
 - Fuel assistance – City of Lawrence
 - Lawrence Senior Center – socializing learning about services
 - Legal services
- (2) Quality of Services
 - SSI mixed – some workers are rude – “act like money is coming out of their own pockets,” no translators in Khmer
 - Welfare – mixed same as SSI
 - Asian Center good quality – Cambodian outreach worker who helps them translate and navigate State, City, and Federal services
 - Counseling – good – Khmer language
 - Hospital mixed – lack of translators, long wait in emergency room, no knowledge of Asian culture tone of voice (loud)
 - Doctors – mixed – some don’t take Mass Health/Medicare
 - School counselors – don’t make clear school policies; don’t communicate with family; don’t follow through; don’t call early if child not in school.
 - Fuel Assistance – hard to get a hold of; yell when you show up without appointment.
 - Elder Services – good at Senior Center, open for Cambodian culture
 - Legal Services – good services; need more legal services – don’t handle immigration, divorce.
- (3) What are the barriers?
 - Lack of translators
 - Lack of transportation
 - Rude, arrogant attitude of providers
- (4) Are there services you need that are not currently provided?
 - Help with plans after leaving high school, graduating, what’s available
 - Independence training for special needs clients, especially when caretakers are no longer around
 - More house to house transportation
 - Enough affordable/accessible housing
 - More translators/Translations in Khmer
 - Easier handicap parking permits for clients and those who transport them
 - Snow plowing – not to block handicap ramps
- (5) What are the strengths?
 - Traditional family strengths
 - Cambodians don’t abandon their family members; take in those in need.

- Settle family problems within the family – not as likely to ask for help.

Group 4: Vietnamese

- ❖ C-PASS - provide workshops for the families about benefits and services – homecare, personal care.
- ❖ Transportation, Language
- ❖ Need full time interpreter
- ❖ Provide education class for caregivers: healthcare
- ❖ Fitness pass to access special physical and exercise program
- ❖ Legal services

Group 5: Parents, Self-Advocates, Service Providers

(1) Abuse - Financially

Speakers and workshops on fraud and money management; home repairs, solicitations, transportation costs, lack of.

(2) Health Insurance – Universal for Everyone

Either don't have it, can't afford it, or doesn't pay for much, prescription cost

(3) Social Support

Isolated, depressed, anxious, worried, frightened – We have energy and wisdom - listen to us.

Group 6: Education

(1) School District, School Meetings, Workshops - Outreach – More Parent Involvement

(2) Poor security

- Need more security
- Supervision

(3) Transportation

(4) After-school programs/extended programs that are adequate for special needs kids

(5) Community Activities

(6) Better outreach

- More education for staff/teachers
- More guidance to services

(7) Family Unity

- Communication among each other
- The desire to make a change

Group 7 & 8: Latino/Spanish Speaking Groups Combined Responses

(1) What services are you aware of; and, how would you rank the quality?

(“+” = Positive; “-” = Negative)

- Arc information services – family support (+)
 - DMR (+)
 - Greater Lawrence Family Health Center (+)
 - Community Action Council (+)
 - Housing (-); Housing not accessible or adequate
 - MRC (+)
 - VNA (+)
 - Elder Services (+)
 - Senior Center (+)
 - PCA (Not Ranked)
 - Financial (Not Ranked)
- (2) What are the barriers?
- Language (ex. Nurses)
 - Waiting list
 - Health Insurance Coverage
 - Family support services
 - Inadequate information
 - Support to obtain accessible housing
 - Snow removal during the winter
 - School services
- (3) Are there services you need that are not currently provided?
- Therapy for children in the schools
 - Counselors for adults
 - Translation of IEP
 - Recreational programs for special education children
 - Transportation
 - Improved quality of services (ex. Clinics, PCA, House Cleaning)
 - Local dentists (specialists) that accept health insurance coverage
 - More orientation surrounding children’s disabilities
 - Contact with the family and school
 - More PCA hours (weekends)
 - Health insurance – medicine
- (4) What are the strengths?
- Love for the children
 - Patience
 - Faith (religious)
 - Assistance in Support Groups
 - Exercising the right to vote
 - Voluntarism
 - Family
 - Friendship (Social Circle)

The NAACP Consumer Forum

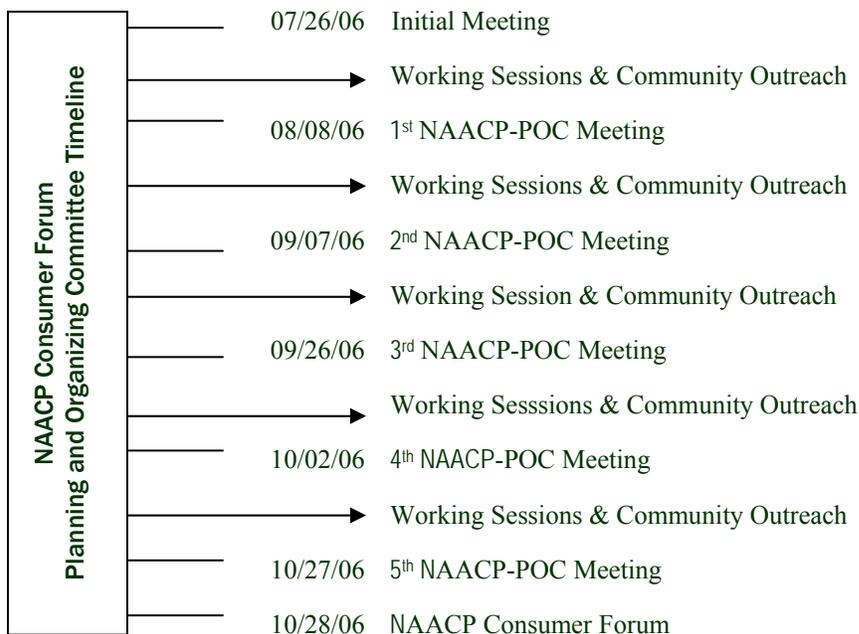
In June of 2006, the Marketing & Outreach Subcommittee Chairperson, during a telephone call with the MASS C-PASS Director, expressed his excitement over the success of an NAACP organized event addressing educational concerns in which a large number of African Americans participated. As a speaker at this event, the Chairperson addressed concerns over the quality of special education in the Greater Boston area. This prompted the Director to explore the possibility for the African American community to hold a consumer forum. At that time only five African Americans participated in the forums already held and there was no indication that more would attend the four forums under development. The decision was made to check into the best fashion for increasing the participation of African Americans. As a result, the MASS C-PASS Director approached the DMR Director of Citizen Leadership, who was a partner to the Subcommittee and a member of the NAACP, to discuss the likelihood the organization could help plan and organize a consumer forum targeting African Americans.

The idea of connecting the NAACP to the consumer forums appealed to the Director of Citizen Leadership and he agreed to introduce it to the Executive Board. Two days later he informed the MASS C-PASS Director that the NAACP was interested and arranged an informational conference call with the First Vice President of the Boston Branch. The informational call took place and the Vice President agreed to introduce the concept of the forum to the Executive Board for discussion and a vote. Over the course of three weeks, several electronic messages and telephone calls were exchanged among the three as well as with members of the Marketing & Outreach Subcommittee. Shortly after, consensus was reached to move forward with a NAACP Consumer Forum.

On July 26th, 2006 the initial meeting took place at the NAACP office in Roxbury. Present at the meeting were consumers and the 1st Vice President, a Boston Public Housing Committee Member, DMR Director of Citizen Leadership as well as representatives from Parent Management and from Support Our Special Children. The M&O Chair and the MASS C-PASS Director were invited to explain MASS C-PASS and the Consumer Forum Series. The Chairperson talked about how great he felt over the NAACP decision to help

plan and organize a consumer forum. He shared that the disability rights movement was also a civil rights movement and, as such it was critical for the NAACP to support people of color with disabilities. His statements encouraged discussion surrounding the number of problems experienced by people with disabilities and elders in the Greater Boston area such as poor transportation, lack of affordable and accessible housing, deficient special education services and poor service by State service providers. The NAACP Planning & Organizing Committee (NAACP-POC) took form.

The NAACP-POC helped to set up meetings and performed community organizing and outreach between meetings. Their planning and organizing timeline is illustrated below.



The NAACP-POC worked arduously and consistently from July 26, 2006 through to October 28, 2006 – the Consumer Forum date. They developed community outreach materials, designed the small discussion groups, pre-registered participants, and planned a full program of activities running from 9:30 am to 2:30 pm.

“At the Consumer Forum”

The NAACP Consumer Forum was held on Saturday, October 28th, 2006 at the Boston Dudley Library in Roxbury, with a program running from 9:30 am to 2:30 pm. There was shared disappointment at first, because they had planned for 100 participants but it was

raining heavily and mercilessly. At about 10:30 participants slowly filled the room and in the end there were 44 participants. Everyone agreed it was not a bad turnout given the inclement weather. Breakfast was served, while the participants registered and became situated. The make up of the participants was approximately 60% African American, 38% Somalian, 1.5% Anglo American and 0.05% Latino. Interpreter services were needed only in Somali. Among the participating audience were also service providers, Boston Public Schools, and State agencies. Margaret Chow-Menzer - the DMR Assistant Commissioner and MASS C-PASS Grant Manager - arrived early and actively interacted with the NAACP-POC and the participants.

The NAACP 1st Vice President, Attorney Julia Cofield, opened the forum. She invited to center stage the DMR Assistant Commissioner to provide the welcoming and deliver introductory remarks surrounding the MASS C-PASS work. Ms. Haffeezah Bell of Parent Management Inc and Ms. Joana Johnson-Smith of Support Our Special Children – both parents and self advocates – jointly provided an overview of the day. The Marketing & Outreach Subcommittee Chairperson, Keith Jones, described the purpose of the Consumer Forum Series. Following the Chairperson’s talk, Ms. Cofield divided the participating audience into four (4) small discussion groups; and, a break was announced for people to have refreshments and move into their corresponding group.

While group discussions took place Kathleen Catano, DMR Metro Boston Regional Director and John Chappell, MRC Deputy Commissioner arrived and intermingled with the members of the NAACP-POC. They were scheduled to take part in an afternoon panel that would respond to the reports made by each group on the issues raised and recommendations generated. During lunch they both sat with members of the participating audience for free flowing talks; and, their panel was expanded to include a representative from the Boston Public Schools and an attorney from the Disability Law Center. At the end of the luncheon, all of the panelists sat to listen to each group report back. Then each sat for the panel discussion moderated by the M&O Chairperson.

Each panelist was given time to describe the nature of their work and respond to the issues raised and the suggested recommendations for systems change. The exchange was fluid but

time constraints resulted in the dialogue concluding with participants wanting more. Many of the participants called for the continued existence of NAACP-POC to address the issues raised on an ongoing basis through workshops, forums, advocacy and the like. Ms. Cofield shaped the closing process and asked the MASS C-PASS Director to share a few words on what would happen with the information collected during the Forum; and, then, Ms. Cofield provided the closing remarks. Despite the official closing, the participants continued to talk about future actions to improve on the quality and effectiveness of services and supports for people with disabilities and elders in their community.

Small Groups Discussion Report

Group 1

IDEA: What does fully independent mean?

Problem: Not able to go to park/playground, benches, water fountains, PCA – can not take child out. How children with disabilities be involved in the community when they do not have accessible swings or playgrounds.

- Park
 - Short pathway to get in park (Elders)
 - More signs
 - More things for young adults to do, so seniors could go out
 - More benches
 - Slide bigger, wider
 - Slide had rail on both sides
 - Men as peer for young men
 - Monkey bar – the bars are too far apart
- Bus
 - Structure in side seat bus – more room
 - Disrespect security on bus
 - More seats available
 - Make people more aware of people with disability on bus
 - No bars behind driver on all buses
 - Attitude of bus driver
 - Special MBTA bus for students
 - Female bus driver told that she should be thankful
 - Retrofit the front of the bus with average height and weight
- Get an appointment – available in community
- Legal representation – support
- Caregiver to live or spend the night

- Educate people that live in the community in regards to people with disability/Sensitivity course/police sensitivity/medical personnel/Fire fighter training – EMT/Healthcare = sensitivity = education.
- Safety issue = What out there services waiting period for services = MBTA training; it's a requirement, car getting tickets park on bus stop = 24 hours NHP-10
- City Hall
 - Call City Hall to link with what services are available in community
 - Public Health Commission
 - City Hall must rethink outreach efforts
- Why not in our community?
 - Group Homes – Public Service announcement
 - Schools – user friendly
 - Health – religious sensitivity (RIDE)
- Harassment of bill collector 24/7
- \$88 for Health Insurance
- Outreach/Lack of education from social security
- Creditor = Why they target seniors?
- Attorney General = Education/Outreach/Visual Education
- Boston Housing Authority (BHA)
 - Food pantry for senior/people with disability
 - Give more of a choice where to live/apartments
 - BHA/Section 8 more information, how it works, need to stay for 1 year in the apartment
 - Statute of limitation, CORI check
 - HUD need to hold BHA more accountable for seniors and people with disabilities
 - Some way of getting money to pay for home owners for repairs or retrofitting existing homes – home owners with children with disabilities and/or seniors
- DMR Waiver
 - Only up to 8 years old; what happens to teens?
 - One-on-one
 - AIDS
 - Puberty
 - \$300 per week
 - How can children be diagnosed without having to pay if can't afford
- Public School – IEP
 - Tutors for special aids – no child left behind, 503 Contract Federal Government. 501 federal people
 - IDEA – Rehabilitation Act. 504 Guide Line

Group 2

Barriers in your community

- Not enough ramps on street/side walk
- Accessibility problems, had trouble accessing polling location. No signs, not wheelchair accessible

- After participating in a special education/learning program, there are no further assistance afterwards
- Polling question are not simplify enough, not easily understandable; a person may bring a helper to help read off polling question if he/she have disabilities still questions not understandable.
- Have trouble accessing help and information for services/programs
- MBTA accessibility – hardship; why should disabled person renew their MBTA T-Pass every five years?

Housing

- Housing listing/ information not available at Roxbury Elderly Services
- Inaccurate information
- Elderly being sent off to many different places to obtain service information/housing

What are the barriers for you to live independently?

- Difficulties in getting a tutor for a general subject for person with special needs
- Not enough assistance, lack of service for people with disabilities and elderly with special needs. Some people only get one meal a day and only get an hour and a half a week from workers/assistance
- Bus driver passes by a person on wheelchair without stopping
- People in special needs education do not get adequate help and trainings. No follow ups from educators.
- Some people need special education/training for the rest of their life
- Limited agency funds resulting in limited services – for elderly disable and people with special needs
- No services for people with low self-esteem resulting in not being able to excel in life.
- CORI – criminal records that stays with a person affects a person's chance to obtain housing assistance
- Housing – affordable housing – sky rocket high prices

What seniors need? Services...

- More housing affordable and easier accessibility
- Need information on what their rights are (know their rights)
- Accessibility to jobs
- Difficulties communicating through the telephone – automated computer talking/responding; languages only English and Spanish
- Educated employers when people with learning disabilities are employed
- Advocacy
- MBTA needs to be improved (The Ride) on time transportation
- Violence – Security
- More outreach/social worker to spread news, information, and services

What is needed to improve quality of life?

- All of the above mentioned
- Accessibility everywhere – navigating (wheelchair/disabled)
- Accessibility in services – more and easier access to information

- Unprofessional, people with attitude working at a Bank, Stores, social work/service providers etc. Elderly disabled and special needs are treated differently – discriminated.
- Identification issues – ID proof.

Group 3

Barriers/ Needs

- Support person/back up for parents/caregivers
- No after school programs
- Transportation to programs
- Respite for parents/caregivers (Facilities and Individuals)
- PCA Hours – 2 + person with disability in one family – family is shortchanged with PCA; evaluation process
- Quality of Medical Care – 2nd Opinions
- Faire distributions of resources
- BHA – access barriers/door slants
- Need for increase communication between agencies
- Special Education Services
 - Parents need to know rights
 - Need advocates
 - DMR training for parents – questions about services for people with Medicare through waiver
- Autism services
- Access to Medicaid transportation depends on doctor’s advocacy/ knowing rights
- MBTA bus
 - won’t lower platform for you
 - won’t let child ride free Sunday nor reduced fare
 - MBTA reduced fare pass – now identifies you as disabled “Access Pass” – seniors have “senior”
 - MBTA driver attitudes
 - The Ride not reliable – long waits for pick up
- Access – sidewalks, curbs, roads
- Respite – should be separate facility for children
- Finding out information on resources, need for centralized information
- Public boards/agencies held at inaccessible locations
- Transition to adult services
 - DMR problems
 - Reality doesn’t match plans – need accurate information
 - Need to make information public and known – written
 - Equal playing field
 - PCA eligibility standards
- Consumer control/choice of services needed
- More sports and recreation for people with disabilities like tennis lessons
- Need centralized information

- Website
- Fully accessible
- Updated
- School/Healthcare providers distribute centralized information – family ties – best buddies
- Addressing isolation – parents and children
- Accessible housing
- Public awareness/attitudes
 - Inclusion
 - Ethnic attitudes to disability
- Access to computers – group homes didn't allow it
- Group homes limiting access to family members
 - Need open door policy
 - Not following medical orders; not communicating with family
- Transportation for adults living at home
- SVS when parent sick

Group 4: Somalian Community

What stops you from getting the help?

- The language barrier
- Lack of resources
- Not having people of same culture knowing the system
- Not having some place to meet for community connections
- Need English class for adults and seniors
- Would like transportation and another experience elder to teach the class
- Assistance with burial services, cultural and religious barriers, and finance for burials

If you would like to stay in your community what service would you need?

- An elders leadership council
- More people to be aware of the culture (higher authority)
- Would like to be more a part of the community to encourage future Somali voters
- Need doorbells in the BP housing building. Miss a lot of services because front door is locked.
- Transportation door to door
 - For medical and shopping
- Assistance on understanding the language
- The elders are the key to success
- The ability to train and hire a family member for disability help
- Social day care for active seniors
- ESL for elderly (including transportation)
- To make sure that today is not the only day where their opinions matter.

The Montachusett Homecare Corporation Consumer Forum

In order to increase the number of elders participating in the Consumer Forum Series, the M&O reached out to Margaret Woovis, Executive Director at Montachusett Home Care Corporation. Ms. Woovis, who is also a member of the MASS C-PASS Coordinating Council was easily engaged and immediately arranged for the Consumer Forum to be held on December 7th, 2006 as part of the Widower Support Group meeting.

“At the Consumer Forum”

Unlike the other consumer forums, this one-hour Forum did not entail breaking participants into small discussion groups. All 25 participants were Anglo American elders who had experienced the loss of their spouse. Despite the somber nature of the Widower Support Group, the elders were warm and receptive to the facilitators of the discussion. There were three facilitators: Nilka Alvarez-Rodriguez, The MASS C-PASS Director; Jacqueline Dunaway, MASS C-PASS Technical Consultant; and, Jeff Keilson the MASS C-PASS Policy Consultant. They shared in describing the purpose of the MASS C-PASS Demonstration Project and of the Consumer Forum Series. The set of questions originally developed to stimulate dialogue were abandoned for free flowing discussion. Questions were posed in response to what the elders were sharing about their life experiences as caregivers and surrounding the support necessary to successfully continue to live in their community of choice. At the end of the hour, the elders continued to interact with the facilitators one-on-one as they enjoyed refreshments.

“Consumer Forum Results”

There were no apparent differences between the women and the men. All shared with the same degree of ease - pieces of their experiences as caregivers and elders. Below are highlights on much of what they shared:

- Not knowing who to approach or where to go to get support around caring for a terminally ill spouse.
- The doctor was the person who they sought information from.

- Their terminally ill spouses when placed in nursing homes were not allowed to continue under the care of their own doctor – with whom they achieved a certain level of trust and intimacy.
- Were never informed there were alternatives to nursing homes; or, were accused of not being able to competently care for their spouse.
- Need support around – and respect for- making their own choices.
- Hospices services are good for the terminally ill spouse but support should be made available for themselves as caregivers during hospices.
- Do not like dealing with computerized telephone services when seeking resources and information – it is difficult to hear and to follow the instructions.
- Do not use computers or the internet to search for information.
- Wished home health aide and/or personal care assistance could help them with household chores.
- Not being able to perform household chores due to either,
 - Being overwhelmed by responsibilities of caring for a terminally ill spouse; or
 - Loss of physical dexterity and mobility
- Believe maintaining house and physical environment clean is a health issue.
- Would like transportation for recreational purposes or to move about in the community.
- Felt their widower support group was the only means to cope with depression and loneliness or isolation.
- Wish there was better snow removal.
- Think maintaining or acquiring home ownership (condos or houses) should be made easy – property taxes and water/sewer fees are too high.
- Want government to change laws to allow the widowers to receive some portion of their late spouses' social security and other benefits to keep up with the cost of living.

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- Want government to allow them to receive a greater portion of their social security to compliment private retirement benefits – cost of living too high but they should not have to depend on public programs.
-

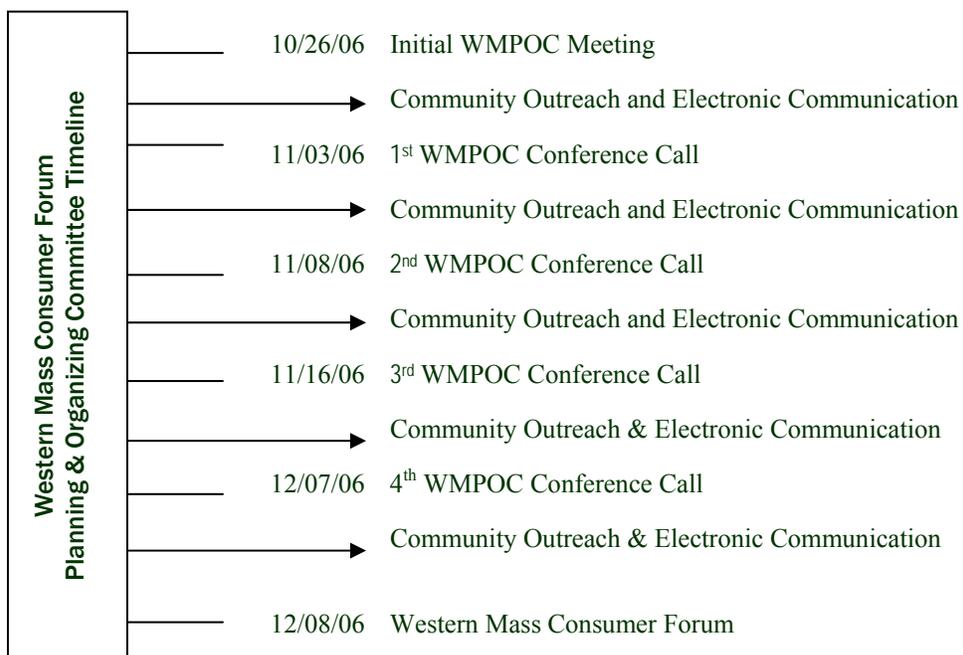
The Western Mass Consumer Forum

The Marketing & Outreach Subcommittee Chairperson and the MASS C-PASS Director pursued the importance of performing special outreach efforts to include Western or rural Massachusetts in the Consumer Forum Series. This was aligned with the Subcommittee's plans at the onset of the Consumer Forum Series to convene a Forum in Springfield that would draw participants from Western Massachusetts – especially the rural communities. MASS C-PASS Coordinating Council Member and Parent Advocate, Alfia Thompson, led the effort but encountered difficulties initially in getting the Western Mass Forum organized. The MASS C-PASS Director then gathered the MASS C-PASS Technical Consultant and the Marketing & Outreach Chairperson to double the efforts.

The Parent Advocate sent out an electronic invitation to a long list of identified stakeholders in Western Mass seeking their participation in an initial meeting to discuss the feasibility and willingness to coordinate a consumer forum. She received limited response; but, nonetheless, the initial meeting was held on October 26th, 2006 at a café in Springfield. There were six people in attendance: The Marketing & Outreach Subcommittee Chair, the Parent Advocate, the MASS C-PASS Technical Consultant, the MASS C-PASS Director and three consumer advocates. It was a loosely held type of meeting, rather informal but rich in dialogue over how to realize a Western Mass Consumer Forum. The discussion concluded with the decision to move ahead and the next steps would be to continue to reach out to stakeholders, identify a place, date, and time for the Forum, and develop a pre-registration, flyer and the like. The WMPOC was formed and others joined later.

The membership of the WMPOC was relatively small in comparison to other planning and organizing committees; but, there were lots of people outside of the WMPOC helping to

move the forum forward. Ms. Thompson had her entire family as well as personal and professional networks helping. Self-Advocates Hoyt Baxter and Michelle Wheels had their family, friends, and professional networks engaged in helping out as well. The Executive Director and MASS C-PASS Mini-Project Director at Multicultural Community Services were key people in securing space and interpreter services. Another important ally was the DMR Senior Service Coordinator for Western Massachusetts. Various others electronically weighed in on planning and organizing issues. The original pressure to make the Forum happen within a month required weekly meetings and constant communication between meetings. Many could not commit to such a process but it was evident they wanted to help – in whatever manner possible. Therefore the original forum date of November 18th of 2006 was changed to December 8th of 2006. As the outreach materials were developed several organizations appeared as sponsors: The Association for Community Living, DMR, MRC, MSPCC, MCS, Springfield College, Springfield Technical College and Starvos Independent Living Center. The entire organizing process took place over a span of 2.5 months:



“At the Consumer Forum”

The Western Mass Consumer Forum took place on December 8th, 2006, from 3:00 PM – 6:00 PM, at the Greek Cultural Center in Springfield and it was freezing weather. Despite

the shivering freeze thirty-seven (37) participants arrived. Approximately 52% were Latinos, 46% were Anglo Americans, and 2% African American; and, they were self-advocates, parent advocates, school representatives, service providers and State agency representatives. Also present were the Marketing & Outreach Subcommittee Chairperson, the DMR Assistant Commissioner/MASS C-PASS Grant Manager, the MRC Deputy Commissioner, the MASS C-PASS Director and the MASS C-PASS Technical Consultant. All of the participants mingled while having an early dinner prior to the program opening.

The Marketing & Outreach Subcommittee Chairperson opened the program encouraging each participant to self-introduce; then, he moved forward to tell the purpose of the Consumer Forum Series. Following his talk he asked the MASS C-PASS Director to address the participants; and, she spoke about the important role of life experience and intimate knowledge in shaping the development of public policy, programs, and services. The MRC Deputy Commissioner spoke of his start as an advocate and how the grassroots organizing in which he took part changed the life of many people for the better and possibly forever. Immediately following, the DMR Assistant Commissioner gave a description on the overall MASS C-PASS project demonstration and told of how she would be working along with others to ensure the issues raised and the recommendations generated get into the hands of those State Officials with the influence to make a difference. The Chairperson with the help of the DMR Assistant Commissioner directed the participants into three small discussion groups; and, at the same time, assigned herself and the MRC Deputy Commissioner and the MASS C-PASS Director to a group. One hour later the groups reassemble as one to listen to each other report back. The Western Mass Consumer Forum was an informal and relaxed process that allowed for a fun fill environment, while significant interaction took place between officials and participants.

Small Groups Discussion Report

Group 1:

- Attitude issues
 - Education of community
 - Relationship building
- Ongoing effort needed to keep new people, with new problems aware of what's out there.

- Lack of accessible, affordable housing pitting elder community against disability community.
- Difficulties transitioning from public schools to adult life, due to lack of
 - Home Aides
 - Jobs
 - Case Workers
- Government agencies not working together
 - Undercut efforts
 - Create disincentive to work
- Social integration
 - Autism – not finding services for youngsters
 - Tailor program to child not V.V.
 - Community awareness
- Berkshires – lack of transportation after 7:00 PM.

Group 2:

- PCA program discriminates against people with cognitive disabilities
- PCA pay is also a barrier
- MASS Health/CMR4224 restricts eligibility
 - If you have a cognitive deficit you can not get the service (program based on a medical model)
 - They should update model to supportive PCA service
 - Help with PCA management for consumers
 - Model it to where people can still remain in their home
- Assessment process makes it difficult to retain service hours or same/familiar staff
 - More need for background checks for PCAs on an agency level
 - Need to be some type of quality standard for PCAs and quality control
- MASS Health – training for PCAs is an issue. Training is available through some agencies on a voluntary basis however incentives need to be in place to have PCAs attend
 - Universal training to include sensitivity training for dealing with people with disability
 - A better trained workforce
- Lack of information (accurate information) to consumers regarding PCA services
- SILE on a school level housed in the hospital which assist in transition to the communities
- Transitional living programs in institutional setting that can be translated in to the community at large. The program should be modified so there is one that provides support (PCA, etc.) for transition in the consumer's home within the community.
- Training as well as support for consumers while he/she is learning new situations and transitioning into the community. Whether you are an elder or child, people need to be trained on how to manage their services (PCA, etc.).
- Supports can be restricted or cut with an increase of self-sufficiency. What a person understands of his or her own care impact services

- The time allotted in services does not meet the need for the consumer for a majority of the time, which leaves the consumer in a continual deficit in relation to services and service quality
- Accessibility issues - regulation on housing accessibility have to be enforced.

Group 3:

Services & Quality & Barriers

- Better communication with the school
- Know about school services
 - IEP
 - List of agencies – what services
- Have school/agencies point parents in the right direction
- Have doctors help direct parents
- Services outside schools – What is available?
- TAP Program, HCC Grant
- Hampden County - resource mapping helping with transition
- Not enough blending and braiding of services
- Abuse, prevention training more supports for persons with mental health problems
- PCA – don't work for TBI, MI
- IEP vision statements (misleading because no services to help child achieve vision)
- Need more self-advocacy groups
- Better employment opportunities
- Better access to transportation
- Not getting MRC/VR services before 18 – work is important – graduating early (before 22) with MCAS
- Transportation – not dependable – people with disability 2nd class citizen
- Transition planning
 - How to find housing, services
 - Need self-esteem – build confidence
 - Need choices

Support or Service Improvements

- Students are tracked; few choices (e.g. sewing, cooking – how to advocate with IEP)
- Misinformation
- Culture/attitude of schools – integration – low expectation of child
- Advocates; don't appear to be representing parent/child – better to advocate on one's own
- More parent advocacy training
- IDEA - under funding by federal government – classroom materials
- SPED students needs trumped by MCAS, etc
- Assistive technology; social and networking after school
- Parent support group
- Help get funding to get graduate degree – need MSW to get job

Hopes, Future

- Affordable respite care; after school programs
- Housing – waiting list – want own apartment
- Kids in high school – financial management training

Interpretive Analysis: What Does It All Mean?

The Marketing & Outreach Subcommittee worked from February 4th, 2005 through to December 8th, 2006, close to two years (1.10 years precisely), at implementing the Consumer Forum Series; and it was not an easy task. The M&O faced several challenges along the way. These challenges made the very coordination, planning, and organizing of the Series – or the process - equally as telling of the barriers as was what surfaced from the actual forums. Therefore this interpretive analysis is not only an integration of what surfaced from the small discussion groups at the various consumer forums, but also includes the lessons learned while the coordination took place and concludes with a review of how the Subcommittee's work advanced certain aspects of the MASS C-PASS Demonstration Project.

Lessons Learned

The inspiration for the Consumer Forum Series came to the Marketing & Outreach Subcommittee (M&O) during a meeting to develop the marketing and outreach plan for the wide distribution of the RFR (Request-for-Response) soliciting proposals for mini-grant projects or pilots. As the Subcommittee formulated a distribution list, the members made

the observation that there was a limited number of local, grassroots organizations providing cultural and linguistically competent services and supports; and, there were close to none formally funded to address the needs of elders, individuals with disabilities, and their families. Given this observation, the Subcommittee believed the concept of the Series would be easily embraced; but, at first, the idea was met with apprehensiveness and skepticism by people and organizations outside and inside the targeted communities.

The M&O openly acknowledged and addressed the uneasiness and the history of barriers that produced it by way of correcting misconceptions, communicating with different constituents, developing common language and a shared vision/goal, gaining trust from disaffected consumers and advocates, operating a community-building effort from the State agency office and maintaining transparency in a politically-charged environment. In a broader sense, the M&O promised to conduct the planning, the forums, and the follow-up activities in a transparent manner – with no hidden agendas and no attempt to steer or edit the outcomes. By practicing transparency the M&O counteracted the uneasiness; but, this point was the onset of the four key lessons learned.

Lesson No. 1

Every individual is affected by membership in several social groups such as race, ethnicity, language, creed, gender, income and community. People with disabilities and elders are not just members of the aging and disability support network. The human services support culture operates through other systems of opportunities and barriers. This gives rise to vastly different support experiences among elders and among individuals with disabilities.

The assumption that racial, ethnic, and linguistic minorities and elders experience the disability services culture differently formed the impetus for the Consumer Forum Series. Said assumption was further substantiated by observations made during the coordination and at the actual forums. These observations revealed the disability culture is complicated by peoples' membership into other social subgroups; and, these memberships can

maximize opportunities or multiply barriers to not only services and supports but to living an optimal quality of life. The following list of observations can shed greater light.

- Consumer advisories and provider management teams had limited to zero minority representation. Without minority input, the policies and practices developed further marginalizing racial, ethnic, and linguistic minorities.
- Minority activists as well as consumers and their families expressed opportunity for services and supports were limited by the lack of cultural and linguistic competence.
- Minorities who are also members of the working poor or poor experience continuous decline in the quality of their lives without access to services and supports. They do not have the option to purchase services and supports needed by virtue that they also lack opportunity for gainful employment (living wage and benefits).
- “Cultural shock” for Cambodian refugees living with a disability is greatly complicated by post traumatic stress and the lack of linguistically and culturally competent mental health services.
- Who benefits from opportunities offered by systems change toward self-determination is affected by religious beliefs. For example, Puerto Ricans who embrace “fatalism” or believe their lives are predestined will have difficulty thriving under a service philosophy of self-determination. Note however that at the consumer forums members of this same group of Puerto Ricans - anxious to improve upon their own lives or that of a loved one – expressed a willingness to try to self-direct if training in personal empowerment were provided.
- The Series also constitute an effort to join the relatively new initiative to integrate elder and disability services. Across race and ethnicity, there were elders who attached debilitating illness and/or lost of

physical dexterity and mobility as an evitable consequence of aging. As such, they self identified as elders but not people with disabilities. What is more, most elders were comfortable depending on the retirement benefits in which they were vested; but, view dependency in public services and supports embarrassing after a lifetime of independence and pride in the fruit of their labor.

The M&O's inescapable duty to tailor the marketing and outreach strategies differently for each of the nine consumer forums presented greater evidence that despite common challenges joining people together as part of a disability culture each person's unique social makeup present opportunities or barriers within the service delivery system. That is, those opportunities or barriers significantly influence the extent to which each elder and person with a disability gains access to personal assistance services and supports; achieves full integration into their community of choice; and, thus, succeeds at self-directed community living.

Evidence or examples can continue to multiple, however, there is one more observation worth sharing. While many veteran consumer advocates expressed the belief that training or certification is not necessary and should not be required in the provision of self-directed personal assistance services and supports, many elders and members of underserved communities call for such training and certification. They identified the need for training at three levels:

1. Personal assistance, service providers, and school personnel should be trained and certified across disabilities, emergency response, and in cross cultural competence.
2. Elders, individuals with disabilities, and their families are calling for training on personal growth and development, leadership, advocacy, disabilities and in emergency response (First Aid, CPR, and the like).
3. Community education program so that they can feel safe in the community in which they live.

Lesson No. 2

Elders and individuals with disabilities who are also members of diverse minority communities are whole people whose needs are affected by their personal life condition and social location. Their need to access culturally competent services is beyond the scope of the traditional aging and disability services network.

Elders and individuals with disabilities from diverse minority communities were discovered as whole people whose needs were affected by their personal life condition and social location; and, as such, their access to culturally competent services were often beyond the scope of the traditional aging and disability services networks.

Skeptics of the Consumer Forum Series also raised the issue that the process allowed participants to identify barriers too broadly and outside the scope of the agencies under the Executive Office of Health and Human Services (EOHHS). While many of the identified barriers to self-directed community living clearly fell under the traditional aging and disability services, there were other necessities that did not. The fact that EOHHS is taking the lead to rebalance long-term care does not mean systems change must be restricted to its authorized boundaries. People can not be compartmentalized. EOHHS with due diligence can open avenues to expand into a seamlessly, comprehensive, and flexibly service delivery system. Below are identified barriers that surpassed EOHHS boundaries. .

1. There were other barriers in the lives of elders and individuals with disabilities that need and should be addressed through other sources: HUD, DOE, DPH, DSS, DET, DOL, DOR, etc.
2. Yet another set of barriers surrounded feelings of isolation, alienation, and depression as disclosed by forum participants of all ages that need to be addressed by community based organizations: social, recreational, job training, educational, sports and fitness, fine arts, community events, religious and the like.
3. Lastly, there was the identified need for the municipalities to include consideration for elders and individuals with disabilities in carrying

activities such as in planning and community development (including housing and universal accessibility), public safety measures, job creation, service fees and taxation.

Lesson No. 3

Elders and individuals with disabilities living in the community gain strength from working within coalitions to negotiate and renegotiate services and supports at a local level.

In all nine of the consumer forums realized, the Planning & Organizing Committees (POCs) and forum participants asked for support to continue to work together as coalitions that will help negotiate and renegotiate services and supports for elders, individuals with disabilities, and their families. Strangers became very close during the organizing and at the forums, since they shared very personal stories about their struggles and ordeals. The resistance and distrust they exhibited initially disappeared as they worked closely together: consumers, service providers, community activists, religious leaders and appointed/elected officials. The collaborative progress also prompted the creation of other coalitions making the MASS C-PASS Statewide Grassroots Network the umbrella: Greater Lawrence, Lynn, Mattapan, Greater Boston, Chinatown, Worcester, Greater Fitchburg /Leominster, Springfield, Berkshires and Cape Cod/Martha's Vineyard.

The coalitions articulated the belief that they can nurture an appropriate community environment for self-direction by way of the following ideas:

- Retrain local State agency staff to work under a model of self-direction.
- Offer training for consumers to enhance their abilities to self-advocate and self-direct.
- Create tools for consumer self-direction, such as consolidating information on services and supports available locally.
- Consolidate information to make it handy for consumers.

- Broker organizational solutions to barriers to self determination that is created by the structure and processes of public and private service delivery system

Lesson No. 4

The limitations elders, people with disabilities, and their families face do not stem from the physical environment but rather from the social and psychological responses of local communities and society in general.

The M&O adopted a Multicultural, Grassroots Approach to engage local community partners and to ensure the inclusion of the traditionally underserved and un-served racial/ethnic and linguistic minorities, rural residents, and elders in systems change. While the process engaged underserved populations, the outcomes have broad base application as qualified in what follows:

1. In service delivery recognition of individuals' unique personal characteristics and social makeup can only improve the quality of services for all consumers regardless of race, ethnicity, creed, gender, age, income or language.
2. Success at self-directed community living necessarily means establishing local connections to overcome historical bias and to facilitate full community integration.

It then follows that the mechanisms to overcome barriers to self-directed community living includes offering opportunity for personal enhancement coupled with reworking the sociology of local communities as articulated below.

- ❖ Consumer growth and development to learn how to be "free" and/or autonomous must be promoted and achieved, in order for consumers to negotiate local community systems, surmount varied levels of discrimination (age, disability, race, ethnicity, creed, income and gender), enjoy equal protection (citizen/human rights: access to all the powers and freedoms afforded to all citizens) and foster healthy interdependencies.

- ❖ Building community receptiveness is instrumental to overcome historical bias/prejudices to reduce feelings of alienation and foster consideration of consumers as "whole people" (ensure access to service organizations, local government agencies, religious institutions, civic organizations, cultural groups, local media and recreational opportunities).
- ❖ Enhancing the capacity of local communities to address the specialized needs of consumers in strategic planning and local initiatives. For example, ensure the specialized needs and talents of consumers are considered in public safety measures (natural disasters, evacuations, fires, crime prevention, terrorists attacks and the like), and in community planning and development (housing, transportation, work-force, education, community revitalization, and neighborhood restoration).

Findings/Barriers

Described within this section are five assumptions or findings based on interpretations drawn from the direct observations of work performed by the various Consumer Planning and Organizing Committees (POCs) and from the reports of the discussion groups at each forum. These assumptions were drawn in a broad framework but across community forums there were seven barriers that consistently surfaced:

8. Lack of affordable, accessible, and safe housing.
9. High cost of living.
10. Limited employment opportunities; and, no support to pursuit or retain the limited employment opportunities.
11. Inadequacy of public school special education programs, such as the non-connection of the individual educational plans with the service plans developed in disability services programs.
12. Insufficient amount of personal assistance or attendant care hours, as well as insufficient hours for respite.
13. Community cruelty and intolerance toward elders and people with disabilities.
14. Lack of culturally and linguistically competent services.

Other barriers and service improvement recommendation were equally important and are hereto integrated with the preceding seven most common to draw the five more general assumptions or findings that follow.

- (A) Local communities are ill prepared to support consumers' capacity to succeed at self-directed community living.
- (B) Inadequacies of current services and supports hinder capacity to address the wide range of consumer needs.
- (C) Consumers would like training and continuing education for themselves, family, service providers, legislators and community.
- (D) Consumer service and support needs extend beyond the traditional aging and disability services networks.
- (E) Lack of cultural and linguistic competence present access and quality problems for traditionally underserved racial, ethnic, and linguistic minorities.

Finding A:

Local communities are ill prepared to support consumers' capacity to succeed at self-directed community living.

1. Affordable and universally accessible housing
2. Improve responsiveness of public housing authorities
3. Assistance for homeowners to renovate, retrofit, or make repairs
4. Opportunities for homeownership – to buy or to maintain (high property taxes, etc.)
5. Physical environment or structure that is accessible (ramps, snow removal, clean sewers, sidewalks, curbs, etc.)
6. Safe housing and safe neighborhoods
7. Public safety – protection against taunting and harassment
8. Suitable transportation
9. Local emergency management plan that addresses the needs of people with disabilities and elders.

10. Access to recreational activities and universally accessible playgrounds
11. Recreational and parks accessible for elders – social days
12. Integrated work environments, job opportunities, and job training
13. Community meetings and events held at accessible hours
14. Summer, camp, and after-school programs for children with disabilities
15. Education for people in the community and neighbors, so they can understand the disability of a family member, learn to be more tolerant, and accept the differences
16. Social network and access to become involved in the community – isolation, depression, alienation
17. Income to afford the high cost of living
18. Community and statewide support in providing social activities, continuing education, and functional skills trainings that are culturally relevant as well as language sensitive
19. Community service agencies that are accessible and available
20. Information on community services and resources

Finding B:

Inadequacies of current services and supports hinder capacity to address the wide range of consumer needs.

1. Medicaid does not cover assistive technology and does not cover most equipment.
2. Financial assistance is needed to purchase adaptive equipment. Medical equipment is limited to schools or residential homes.
3. Insurance co-pays are too high – for doctor’s visit and medicine.
4. Insurance does not cover eyeglasses or preventive dental care.
5. Financial assistance and more economic resources to meet high cost of living.
6. Significant problem with Section 8 – waiting list too long.
7. Respite is flexible but allotment is minimal – not adequate.
8. Need more flexibility in scheduling and in use of personal and home care assistants
9. Eligibility for PCAs needs to be revised to fit culture of family.
10. Too few hours of personal and home care assistants.

11. Not enough services for families with more than one child with a disability.
12. Access to applications for public assistance is limited.
13. More access to benefits counseling – system is too complicated to figure out.
14. Nutritional counseling is not available.
15. Services are generalized – when services are different depending on disability.
16. Services are not based on needs.
17. Respite care providers should be available for people that work.
18. Services are different during staff vacation and in the summer – there is no consideration that the families’ schedules do not change.
19. Parents single or married have limitations to go out and work outside the home.
20. Special education programs need to be improved so children can grow up to be independent adults.
21. Recreation is not considered a vital service.
22. Some service providers are rude, insensitive, and/or judgmental.
23. Services and supports need to be linguistically and culturally appropriate.
24. One Stop Shopping in the community is needed for getting services and supports.
25. State agencies need to work collaboratively to meet consumer needs.
26. Voice automated systems hinders communication. The internet systems are also a problem.

Finding C:

Consumers would like training and continuing education for themselves, family, service providers, legislators and community.

1. All State agencies should do a better job at training translators and/or interpreters.
2. Educate developers and municipal planning departments about universal accessibility.
3. Assistive technology training is needed for consumers, providers, schools, etc.
4. Education and job training programs should be improved for consumers; and, offered in groups and one-on-one.
5. Training should be developed for personal care assistants.

6. Provide community education on disability and elder issues.
7. Develop cultural competency training programs.
8. Offer consumers and their family advocacy training and leadership development – including an elder leadership council.
9. Training for parents and caregivers on how to respond in emergencies.
10. Certify bus monitors who work with children with disabilities.
11. Provide life skills training.
12. Train bilingual staff to work with people with disabilities and elders.
13. Recruit and train multi-lingual and cultural sensitive individuals with diverse backgrounds in the community to work in the state local offices.
14. Provide workshops for consumers and their families to learn about disabilities.
15. Develop training program for school personnel to learn how to help children with disability grow-up to be independent.
16. Transitional living programs should be offered for consumers transitioning into the community.

Finding D:

Consumer service and support needs extend beyond the traditional aging and disability services networks.

1. Housing – universal accessibility, affordable rents, home/condo ownership
2. School Department – special education issues
3. Municipal ordinances and services – snow removal, universal accessibility, sewers, taxes and fees
4. Employment – lack of job opportunities and training
5. Legal - human rights violations, immigration, landlord-tenant, civic, etc.

Finding E:

Lack of cultural and linguistic competence present access and quality problems for traditionally underserved racial, ethnic, and linguistic minorities.

1. Culturally appropriate foods should be allowed as part of the consumer's diet.
2. Transportation information needs to be in multiple languages.

3. Competency of translators/interpreters needs to be improved – especially in crisis.
4. Translation services are not readily available in telephone services or emergency rooms.
5. All information about services and supports are not available in multiple languages.
6. Personal and home care assistants lack cultural and linguistic competence.
7. Lack of culturally and linguistically competent mental health professionals, counselors, medical-personnel, pharmacists, and therapists results in long waits for services or in no services.
8. More staff that knows American Sign Language is needed.
9. There are no language classes available for consumers and their families to learn English.
10. Services and supports do not address cultural differences between parents and children.
11. Consumers face racial discrimination and prejudice from some providers, community people, and public safety personnel.
12. Need for more grassroots, culturally, and linguistically competent service organizations in the community.
13. Need for more culturally competent recreational and social activities.
14. Schools do not provide IEPs in the appropriate language and do not have properly trained translators/interpreters to discuss educational plans and services. Schools have low expectations of children with disability whose needs are compounded by cultural issues.
15. Some cultural social groups lack services due to federal and state immigration laws.

Conclusion: Recommendations

- 1) The State should address service gaps in underserved and un-served racial, ethnic, and linguistic minority communities through support and funding of culturally and linguistically competent grassroots organizations.
- 2) Promote self advocacy and self determination through support and funding of the Statewide Grassroots Network that emerged as a result of the consumer planning and

organizing committees and continue as grassroots coalitions to address local, community barriers to successful self-directed community living.

- 3) Expand the collaboration of agencies under the Executive Office of Health and Human Services to other state agencies to provide comprehensive solutions for meeting the wide range of services and supports needed by elders, individuals with disabilities, and their families.
- 4) Establish self-directed, flexible support model options from which all elders and individuals with disabilities can choose.

Marketing & Outreach Subcommittee Consumer Forum Series

Appendixes

- A: Consumer Forum Findings Chart
- B: Consumer Forum Series Activities & Expenditures
- C: MASS C-PASS Basic
- D: MASS C-PASS Fact Sheets
- E: Consumer Forum Survey Questions
- F: Planning & Organizing Committees (POCs) –

Note: Appendixes C, D, E, and F are in a separate files.

Appendix A: Consumer Forum Findings Chart

CODES: W = Worcester, L = Lynn, U = Urban Pride,
C = Chinatown, H = Haitian,
GL = Greater Lawrence, N = NAACP
M = Montachusett, WM = Western Mass

Finding A	Local communities are ill prepared to support consumers' capacity to succeed at self-directed community living.	W	L	U	C	H	G L	N	M	W M
1	Lack of affordable and universally accessible housing	X	X		X	X	X	X		X
2	Lack of responsiveness from public housing authorities	X	X			X	X	X		
3	Lack of assistance for homeowners to renovate, retrofit, or make repairs.		X					X	X	
4	Lack of opportunities for homeownership – to buy or to maintain (high property taxes, etc.)				X		X	X	X	
5	Lack of physical environment or structure that is accessible (ramps, snow removal, clean sewers, sidewalks, curbs, etc.)				X		X	X	X	
6	Lack of safe housing and safe neighborhoods.		X			X		X		
7	Lack of suitable transportation	X	X	X	X	X	X	X	X	X
8	Lack of local emergency management plan that addresses the needs of people with disabilities and elders.	X								
9	Lack of access to recreational activities and universally accessible playgrounds.	X	X	X	X	X	X	X		X
10	Lack of recreational and parks accessible for elders – social days					X		X	X	
11	Lack of integrated work environments, job opportunities, and job training	X	X	X	X	X	X	X		X
12	Lack of community meetings and events held at accessible hours	X	X			X		X		
13	Lack of summer, camp, and after-school programs for children with disabilities.		X	X	X	X	X	X		X
14	Lack of education for people in the community and neighbors, so they can understand the disability of a family member, learn to be more tolerant, and accept the differences.	X	X		X	X	X	X		X
15	Lack of a social network and access to become involved in the community – isolation, depression, alienation.	X	X		X	X	X	X	X	X
16	Lack of income to afford the high cost of living,	X	X		X	X	X	X	X	
17	Lack of public safety – protection against taunting and harassment	X	X							
18	Lack community and statewide support in providing social activities, continuing education, and functional skills trainings that are culturally related as well as language sensitive.	X	X		X	X	X	X		X
19	Lack of community service agencies with accessibility and availability.	X		X	X	X	X	X		
20	Lack of information on community services and resources	X						X	X	X

Finding B	Inadequacies of current services and supports hinder capacity to address the wide range of consumer needs.	W	L	U	C	H	G	N	M	W
							L			M
1	Medicaid does not cover assistive technology and does not cover most equipment.	X	X				X	X		
2	Financial assistance is needed to purchase adaptive equipment. Medical equipment is limited to schools or residential homes.	X	X			X	X	X		X
3	Insurance co-pays are too high – for doctor’s visit and medicine.	X	X				X			
4	Insurance does not cover eyeglasses or preventive dental care.						X			
4	Financial assistance and more economic resources to meet high cost of living.	X	X	X	X	X	X	X	X	X
5	Significant problem with Section 8 – waiting list too long.	X	X			X	X	X		
6	Respite is flexible but allotment is minimal – not adequate.	X				X	X		X	
7	Need more flexibility in scheduling and in use of personal and home care assistants	X			X	X	X	X	X	X
8	Eligibility for PCAs needs to be revised to fit culture of family.	X	X		X	X				X
9	Too few hours of personal and home care assistants.		X			X	X	X	X	X
10	Not enough services for families with more than one child with a disability.	X			X	X	X			
11	Access to applications for public assistance is limited.	X			X					
12	More access to benefits counseling – system is too complicated to figure out.	X					X	X		X
13	Nutritional counseling is not available.	X	X							
14	Services are generalized – when services are different depending on disability.		X	X	X	X	X	X	X	X
15	Services are not based on needs.	X	X	X	X	X	X	X	X	X
16	Respite care providers should be available for people that work.		X	X	X	X			X	
17	Services are different during staff vacation and in the summer – there is no consideration that the families’ schedules do not change.		X		X	X		X		
18	Parents single or married have limitations to go out and work outside the home.		X	X	X	X	X	X		
20	Special education programs need to be improved so children can grow up to be independent adults.	X	X	X	X	X	X	X		
21	Recreation is not considered a vital service.	X	X		X	X	X	X	X	X
22	Many service providers are rude, insensitive, and/or judgmental.	X	X	X	X	X	X	X	X	X
23	Services and supports need to be linguistically and culturally appropriate.	X	X	X	X	X	X	X		X
24	One Stop Shopping in the community is needed for getting services and supports.	X		X	X	X	X	X		
25	State agencies need to work in coordination to meet consumer needs.	X		X	X		X	X	X	X
26	Voice automated systems hinders communication. The internet systems are also a problem.	X			X		X	X	X	

Finding C	Consumers would like training and continuing education for themselves, families, service providers and community.	W	L	U	C	H	G	N	M	W
							L			M
1	All State agencies should do a better job at training translators and/or interpreters.	X	X	X	X	X	X	X		
2	Educate developers and municipal planning departments about universal accessibility.	X			X		X	X		
3	Assistive technology training is needed for consumers, providers, schools, etc.	X					X			
4	Education and job training programs should be improved for consumers; and, offered in groups and one-on-one.	X			X	X	X	X		X
5	Training should be developed for personal assistants.	X	X		X	X	X	X		
6	Provide community education on disability and elder issues.		X		X	X	X	X		
7	Develop cultural competence training program.		X		X	X	X	X		
8	Offer consumers and their family advocacy training and leadership development – including an elder leadership council.		X		X	X	X	X		X
9	Training for parents and caregivers on how to respond in emergencies.		X	X			X	X		
10	Certify bus monitors to work with children with disabilities.			X						
11	Provide life skills training.			X	X	X	X	X		X
12	Train bilingual staff to work with people with disabilities and elders.			X	X	X	X	X		
13	Recruit and train bilingual and bicultural individuals in the community to work in the State local offices.	X			X	X	X	X		
14	Provide workshops for consumers and their families to learn about disabilities.		X	X	X	X	X	X		X
15	Develop training program for school personnel to learn how to help children with disability grow-up to be independent.		X	X	X	X	X	X		X
16	Transitional living programs should be offered for consumers transitioning into the community.						X			X

Finding D	Consumer service and support needs extend beyond the traditional aging and disability services networks.	W	L	U	C	H	G L	N	M	W M
1	Housing – universal accessibility issues, afford rents, home/condo ownership	X	X		X	X	X	X	X	X
2	School Department – special education issues	X	X	X	X	X	X	X		X
3	Municipal ordinances and services – snow removal, sewers, accessibility, taxes and fees		X		X	X	X	X	X	X
4	Employment – lack of job opportunities and training	X	X		X	X	X	X		X
5	Legal – human rights violations, immigration, civic, etc.	X	X		X	X	X	X		

Finding E	Lack of cultural and linguistic competence present access and quality problems for traditionally underserved racial, ethnic, and linguistic minorities.	W	L	U	C	H	G L	N	M	W M
1	Culturally appropriate foods should be allowed as part of the consumer’s diet.	X			X					
2	Transportation information needs to be in multiple languages.	X								
3	Competency of translators/interpreters needs to be improved – especially in crisis.	X	X		X	X	X	X		
4	Translation services are not readily available in telephone services or emergency rooms.	X								
5	All information about services and supports are not available in multiple languages.	X	X	X	X	X	X	X		
6	Personal and home care assistants lack cultural and linguistic competence.	X	X	X	X	X	X	X		
7	Lack of culturally and linguistically competent mental health professionals, counselors, medical-personnel, pharmacists, and therapists results in long waits for services or in no services.		X	X	X	X	X	X		
8	More staff that knows American sign language is needed.		X				X			
9	There are no language classes available for consumers and their families to learn English.		X		X		X	X		
10	Services and supports do not address cultural differences between parents and children.		X				X			
11	Consumers face racial discrimination and prejudice from some providers, community people, and public safety personnel.		X	X			X			
12	Lack of grassroots, culturally, and linguistically competent service organizations in the community.				X	X	X	X		
13	There are no supports for culturally competent recreational and social activities		X		X	X	X	X		
14	Schools do not provide IEPs in the appropriate language and do not have properly trained translators/interpreters to discuss educational plans and services. Schools have low expectations of children with disability whose needs are compounded by cultural issues.	X	X	X	X	X	X	X		
15	Some cultural social groups lack services do to federal and state immigration laws.	X	X		X	X	X			

Appendix B: Consumer Forum Series Activities & Expenditures

- ▶▶ **Marketing & Outreach Subcommittee Meetings, Presentations, Consumer Forums**
- ▶▶ **Marketing & Outreach Meetings and Presentations**
- ▶▶ **Worcester Consumer Forum**
- ▶▶ **Lynn Consumer Forum**
- ▶▶ **Urban Pride/Martha's Vineyard Consumer Forum**
- ▶▶ **Chinatown Consumer Forum Series**
- ▶▶ **HAPHI/Haitian Consumer Forum Series**
- ▶▶ **Greater Lawrence Consumer Forum Series**
- ▶▶ **NAACP Consumer Forum Series**
- ▶▶ **Western Mass Consumer Forum Series**
- ▶▶ **Montachusett Home Care Corporation**
- ▶▶ **Total Cost of Consumer Forum Series**

Marketing & Outreach Subcommittee Meetings, Presentations, Consumer Forum Series

Date	Activity	Date	Activity	Date	Activity
02/04/05	Subcommittee	04/06/06	LPC	08/29/06	CPC
03/10/05	Subcommittee Conference Call	04/13/06	LPC	09/05/06	GLPC
04/12/05	Subcommittee Conference Call	04/21/06	LPC	09/06/06	GLPC
05/10/05	DMR CAB Chairs Conference Call	05/08/06	GLPC	09/07/06	NAACP Planning Committee
06/24/05	MRC Greater Boston Council	05/22/06	GLPC	09/11/06	HAPHI Planning Committee
07/11/05	MRC Taunton Advisory Council	05/23/06	LPC	09/16/06	Chinatown Consumer Forum
09/01/05	DMR Northeast Reg. Management Team	06/01/06	GLPC	09/20/06	HAPHI Planning Committee
09/07/05	DMR Northeast Regional CAB	06/06/06	Lynn Consumer Forum	09/24/06	HAPHI Consumer Forum
09/12/05	DMR Central Middlesex CAB	06/12/06	GLPC	09/26/06	NAACP Planning Committee
09/15/05	Subcommittee Conference Call	07/18/06	CPC	09/28/06	GLPC
09/22/05	DMR Southeast Regional Management Team	07/26/06	NAACP Planning Committee	10/02/06	NAACP Planning Committee
09/29/05	DMR Central West Regional Management Team	07/30/06	Urban Pride/Martha's Vineyard Consumer Forum	10/10/06	GLPC
11/23/05	Subcommittee Conference Call	07/31/06	Urban Pride/Martha's Vineyard Consumer Forum	10/14/06	Greater Lawrence Consumer Forum
12/12/05	WPC – Conference Call	08/01/06	GLPC	10/26/08	WMPC
01/11/06	WPC	08/01/06	CPC	10/27/06	NAACP Planning Committee
02/01/06	WPC	08/03/06	CPC	10/28/06	NAACP Consumer Forum
02/15/06	Malden Parent Association	08/08/06	CPC	11/03/06	WMPC Conference Call
02/28/06	Lynn Family to Family - LPC	08/08/06	NAACP Planning Committee	11/08/06	WMPC Conference Call
03/03/06	Worcester Consumer Forum	08/15/06	CPC	11/16/06	WMPC Conference Call
03/23/06	HAPHI Planning Committee	08/21/06	HAPHI Planning Committee	12/07/06	Montachusett Home Care Corporation Consumer Forum
03/30/06	LPC	08/22/06	CPC	12/08/06	Western Mass Consumer Forum

Notes: WPC – Worcester Planning Committee, LPC – Lynn Planning Committee, GLPC – Greater Lawrence Planning Committee, CPC – Chinatown Planning Committee, WMPC – Western Mass Planning Committee

MARKETING & OUTREACH SUBCOMMITTEE MEETINGS AND PRESENTATIONS

Meetings & Presentations

Date	Activity	Refreshments	Consumer Allowances				Total
			Transportation /Mileage	Stipend	Childcare	PCA	
02/04/05	Subcommittee Meeting	79.77	354.00	-0-	-0-	-0-	\$433.77
03/10/05	Subcommittee Conference Call		-0-	-0-	-0-	-0-	-0-
04/12/05	Subcommittee Conference Call		-0-	-0-	-0-	-0-	-0-
05/10/05	DMR CAB Chair – Conference Call		-0-	-0-	-0-	-0-	-0-
06/24/05	MRC Greater Boston Council		-0-	-0-	-0-	-0-	-0-
07/11/05	MRC Taunton Advisory Council		-0-	-0-	-0-	-0-	-0-
09/01/05	DMR Northeast Regional Management Team		-0-	-0-	-0-	-0-	-0-
09/07/05	DMR Northeast Regional CAB		0-	35.00	-0-	-0-	\$35.00
09/15/05	Subcommittee Conference Call		-0-	-0-	-0-	-0-	-0-
09/22/05	DMR Southeast Regional Management Team		-0-	-0-	-0-	-0-	-0-
09/29/05	DMR Central West Regional Management Team		-0-	-0-	-0-	-0-	-0-
11/23/05	Subcommittee Conference Call		-0-	35.00	-0-	-0-	\$35.00
Total		79.77	354.00	70.00	-0-	-0-	\$503.77

WORCESTER

Worcester Consumer Forum

Date	Activity	Material Goods & Services			Consumer Allowances			Total
		Supplies	Translation	Refreshments	Transportation /Mileage	Stipend	Childcare	
12/12/05	* Conference Call	-0-	-0-	-0-	-0-	140.00	-0-	\$140.00
01/11/06	Planning Meeting	(Donated)	-0-	-0-	293.37	245.00	-0-	\$538.37
02/01/06	Planning Meeting	(Donated)	-0-	-0-	-0-	85.00	-0-	\$85.00
03/03/06	Consumer Forum	(Donated)	*** 85.00	74.00	671.22	645.00	-0-	\$1,475.22
Total		-0-	85.00	74.00	964.59	1,115.00	-0-	\$2,238.59

NOTES:

- * Conference Call Cost Not Processed Through Seven Hills
- ** Celia Brown’s Consumer Advocacy Program covered refreshments during planning meetings
- *** Translation services were for ASL and planning members donated the Spanish translation.

Lynn Consumer Forum

Date	Activity	Material Goods & Services			Consumer Allowances			Total
		Supplies	Translation	Refreshments	Transportation /Mileage	Stipend	Childcare	
02/28/06	Initial Meeting	-0-	-0-	-0-	-0-	-0-	-0-	-0-
03/30/06	Planning Meeting	-0-	-0-	-0-	183.01	35.00	-0-	\$218.01
04/06/06	Planning Meeting	-0-	-0-	-0-	102.50	120.00	-0-	\$222.50
04/13/06	Planning Meeting	-0-	-0-	-0-	-0-	70.00	-0-	\$70.00
04/21/06	Planning Meeting	-0-	-0-	-0-	-0-	70.00	-0-	\$70.00
05/23/06	Planning Meeting	-0-	-0-	-0-	-0-	35.00	-0-	\$35.00
06/06/06	Consumer Forum	138.61	* 208.50	420.00	342.12	\$1,835.00	-0-	\$2,944.23
Total		138.61	208.50	420.00	627.63	2,165.00	-0-	\$3,559.74

Urban Pride/Martha's Vineyard Consumer Forum

Date	Activity	Material Goods & Services			Consumer Allowances			Total
		Supplies	Translation	Refreshments	Transportation /Mileage	Stipend	Childcare	
07/30/06	Orientation	-0-	-0-	-0-	-0-	-0-	-0-	-0-
07/31/06	Consumer Forum	-0-	150.00	-0-	-0-	50.00	-0-	200.00
Total		-0-	150.00	-0-	-0-	50.00	-0-	\$200.00

Chinatown Consumer Forum

Date	Activity	Material Goods & Services				Consumer Allowances			Total
		Supplies	Space	Translation	Refreshments	Transportation /Mileage	Stipend	Childcare	
02/15/06	Malden Parent Association/ Great Wall	-0-	-0-	-0-	-0-	-0-	50.00	-0-	\$50.00
05/05/06 – 07/17/06	* CO & Outreach	-0-	-0-	-0-	-0-	-0-	475.00	-0-	\$475.00
07/18/06	Initial Meeting	-0-	-0-	-0-	26.50	-0-	225.00	-0-	\$251.50
07/19/06 - 08/02/06	CO & Outreach	-0-	-0-	-0-	-0-	-0-	350.00	-0-	\$350.00
08/03/06	Planning Meeting	-0-	-0-	-0-	41.15	-0-	190.00	-0-	\$231.15
08/07/06	CO & Outreach	-0-	-0-	-0-	-0-	-0-	35.00	-0-	\$35.00
08/08/06	Planning Meeting	-0-	-0-	-0-	-0-	-0-	190.00	-0-	\$190.00
09/09/06 – 08/14/06	CO & Outreach	-0-	-0-	-0-	-0-	-0-	175.00	-0-	\$175.00
08/15/06	Planning Meeting	-0-	-0-	-0-	-0-	-0-	190.00	-0-	\$190.00
08/16/06 – 08/21/06	CO & Outreach	-0-	-0-	-0-	-0-	-0-	225.00	-0-	\$225.00
08/22/06	Planning Meeting	-0-	-0-	-0-	-0-	-0-	190.00	-0-	\$190.00
08/23/06 – 09/12/06	CO & Outreach	-0-	-0-	-0-	-0-	-0-	570.00	-0-	\$570.00
09/13/06	Planning Meeting	-0-	-0-	-0-	-0-	-0-	140.00	-0-	\$140.00
09/14/06 – 09/15/06	CO & Outreach	-0-	-0-	-0-	-0-	-0-	70.00	-0-	\$70.00
09/16/06	Consumer Forum	431.08	250.00	240.00	410.66	-0-	100.00	360.00	\$1,791.74
Total		431.08	250.00	240.00	478.31	-0-	3,175.00	360.00	\$4,934.39

HAPHI/Haitian Consumer Forum

Date	Activity	Material Goods & Services				Consumer Allowances			Total
		Supplies	Consultant /Facilitator	Translation	Refreshments	Transportation /Mileage	Stipend	Childcare	
03/23/06	Initial Meeting	-0-	-0-	-0-	-0-	-0-	-0-	-0-	-0-
08/21/06	Planning Meeting	-0-	-0-	-0-	-0-	-0-	-0-	-0-	-0-
09/11/06	Planning Meeting	-0-	-0-	-0-	-0-	-0-	-0-	-0-	-0-
09/20/06	Planning Meeting	-0-	-0-	-0-	-0-	-0-	-0-	-0-	-0-
09/24/06	Consumer Forum	-0-	700.00	200.00	200.00	-0-	\$550.00	-0-	\$1,650.00
Total		--0-	700.00	200.00	200.00	-0-	\$550.00	-0-	\$1,650.00

Greater Lawrence Consumer Forum

Date	Activity	Material Goods & Services				Consumer Allowances			Total
		Supplies	Consultants /Facilitators	Translation	Refreshments	Transportation /Mileage	Stipend	Childcare	
05/08/06	Initial Meeting	-0-	-0-	-0-	-0-	2.40	35.00	-0-	37.40
05/22/06	Planning Meeting	-0-	-0-	-0-	-0-	185.41	100.00	-0-	285.41
06/01/06	Planning Meeting	-0-	-0-	-0-	50.85	179.29	190.00	-0-	420.14
06/12/06	Planning Meeting	-0-	-0-	-0-	200.00	-0-	210.00	-0-	410.00
07/19/06	Facilitators /Organizers	-0-	-0-	-0-	9.80	-0-	-0-	-0-	9.80
07/21/06	Outreach Committee	Donated	-0-	-0-	-0-	-0-	70.00	-0-	70.00
07/28/06	Outreach Committee	Donated	-0-	-0-	-0-	-0-	70.00	-0-	70.00
08/01/06	Planning Meeting	-0-	-0-	-0-	Donated	-0-	175.00	-0-	175.00
09/05/06	Facilitators Meeting	-0-	-0-	-0-	Donated	-0-	-0-	-0-	-0-
09/06/06	Planning Meeting	-0-	-0-	-0-	Donated	-0-	70.00	-0-	70.00
09/28/06	Planning Meeting	-0-	-0-	-0-	Donated	-0-	50.00	-0-	50.00
10/02/06	Planning Meeting	-0-	-0-	-0-	Donated	--0-	-0-	-0-	-0-
10/10/06	Facilitators /Organizers	-0-	-0-	-0-	Donated	-0-	100.00	-0-	100.00
10/14/06	Consumer Forum	100.86	201.25	201.25	595.00	290.00	**1,650.50	280.00	3,318.86
Total		100.86	201.25	201.25	855.65	657.10	2,720.50	280.00	\$5,016.61

NOTES: * Donations:

- Supplies and flyers donated by the Lawrence Public Schools; at the forum all participating agencies donated supplies.
- Garden of Options – collected donations from the evangelic churches for the raffle prizes.
- Refreshments
 - 5/8, 5/22 Nilka Alvarez-Rodriguez
 - Lawrence Senior Center - 8/1, 9/6, 9/28, 10/2, 10/10 (C-PASS incurred only \$595.00 of the breakfast and luncheon for the actual forum 10/14/06)
 - 9/5, MRC – Lawrence

****** Only consumer-organizers and consumers losing wages for participating received a stipend.

NAACP Consumer Forum

Date	Activity	Material Goods & Services			Consumer Allowances			Total
		Supplies	Facilitator	Refreshments	Transportation /Mileage	Stipend	Childcare	
07/26/06	Planning Meeting	-0-	-0-	18.50	-0-	85.00	-0-	103.50
08/08/06	Planning Meeting	-0-	-0-	Donation	3.00	120.00	-0-	123.00
08/22/06	Planning Meeting	-0-	-0-	-0-	3.00	155.00	-0-	158.00
09/07/06	Planning Meeting	-0-	-0-	-0-	3.00	155.00	-0-	158.00
09/26/06	Planning Meeting	-0-	-0-	-0-	3.00	105.00	-0-	108.00
10/02/06	Planning Meeting	-0-	-0-	-0-	-0-	105.00	-0-	105.00
10/14/06	Community Outreach	-0-	-0-	-0-	-0-	85.00	-0-	85.00
10/19/06	Community Outreach	-0-	-0-	-0-	-0-	35.00	-0-	35.00
10/21/06	Community Outreach	-0-	-0-	-0-	-0-	70.00	-0-	35.00
10/24/06	Community Outreach	-0-	-0-	-0-	-0-	35.00	-0-	35.00
10/25/06	Planning Meeting	-0-	-0-	-0-	3.00	70.00	-0-	73.00
10/28/06	Consumer Forum	300.00	50.00	1,100.00	-0-	50.00	200.00	1,700.00
Total		300.00	50.00	1,118.50	15.00	1,070.00	200.00	\$2,753.50

Western Mass Consumer Forum

Date	Activity	Material Goods & Services				Consumer Allowances			Total
		Facilities	Translator	Technical /Consult	Refreshments	Transportation /Mileage	Stipend	Childcare	
10/26/06	Planning Meeting	-0-	-0-	-0-	Donation	460.39	170.00	-0-	630.39
10/27/06	Community Outreach	-0-	-0-	-0-	-0-	-0-	35.00	-0-	35.00
11/03/06	Conference Call	-0-	-0-	105.00	-0-	-0-	35.00	-0-	140.00
11/04/06	Community Outreach	-0-	-0-	-0-	-0-	52.00	50.00	-0-	102.00
11/08/06	Conference Call	-0-	-0-	105.00	-0-	-0-	35.00	-0-	140.00
11/14/06	Community Outreach	-0-	-0-	-0-	-0-	18.80	35.00	-0-	53.80
11/16/06	Conference Call	-0-	-0-	-0-	-0-	-0-	-0-	-0-	-0-
11/21/06	Community Outreach	-0-	-0-	-0-	-0-	12.40	35.00	-0-	47.40
12/07/06	Forum Coordination	-0-	-0-	-0-	-0-	-0-	50.00	-0-	50.00
12/08/06	Consumer Forum	350.00	Donation	-0-	477.40	-0-	100.00	-0-	927.40
Total		350.00	-0-	210.00	477.40	543.59	545.00	-0-	2,125.99

NOTES: Conference Call Cost Not Processed Through Seven Hills

[B-10]

Montachusett Consumer Forum

Date	Activity	Material Goods & Services			Consumer Allowances			Total
		Supplies	Facilitator	Refreshments	Transportation /Mileage	Stipend	Childcare	
12/07/06	Orientation	-0-	105.00	-0-	-0-	-0-	-0-	105.00
Total		-0-	105.00	-0-	-0-	-0-	-0-	105.00

Total Cost of Consumer Forum Series

Date	Forum	Material Goods & Services					Consumer Allowances			Total
		Supplies	Space	Consultants /Facilitators	Translation	Refreshments	Transportation /Mileage	Stipend	Childcare	
03/03/06	Worcester	-0-	-0-	-0-	85.00	74.00	964.59	1,115.00	-0-	2,238.59
06/06/06	Lynn	138.61	-0-	-0-	208.50	420.00	627.63	2,165.00	-0-	3,559.74
07/31/06	Urban Pride	-0-	-0-	-0-	150.00	-0-	-0-	50.00	-0-	200.00
09/16/06	Chinatown	431.08	250.00	-0-	240.00	478.31	-0-	3,175.00	360.00	4,934.39
09/24/06	HAPHI /Haitian	-0-	-0-	700.00	200.00	200.00	--0-	550.00	-0-	*1,650.00
10/14/06	Greater Lawrence	100.86	-0-	201.25	201.25	*855.65	657.10	2,720.50	280.00	5,016.61
10/28/06	NAACP	300.00	-0-	50.00	-0-	1,118.50	15.00	1,070.00	200.00	2,753.50
12/07/06	Montachusett	-0-	-0-	*105.00	-0-	-0-	-0-	-0-	-0-	105.00
12/08/06	Western Mass	-0-	350.00	210.00	-0-	477.40	543.59	*545.00	-0-	2,123.99
Total		970.55	600.00	1,266.25	1,084.75	3,623.86	2,805.91	11,390.50	840.00	\$22,581.82