

Marketing & Outreach Subcommittee Consumer Forum Series

Appendixes

- C: MASS C-PASS Basic
- D: MASS C-PASS Fact Sheets
- E: Consumer Forum Survey Questions
- F: Planning & Organizing Committees (POCs) – Materials Part I
(Part II, placed in separate file)

Appendix C: MASS C-PASS Basic

MASS C-PASS

**An Interagency, Cross Disability Collaboration to
Design Consumer Driven Personal Supports**

BASIC

**Origin and Description of the
Massachusetts Community Integration
Personal Assistance Services and Supports:
*A CMS Systems Change Grant for Community Living
Federal Demonstration Project***

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BASIC 1: What is MASS C-PASS?

- MASS C-PASS stands for the Massachusetts Community Integration Personal Assistance Services and Supports. And, it is an interagency, cross disability collaboration to design consumer driven personal supports that extend beyond the traditionally accepted personal care attending (PCA) for activities of daily living.
- MASS C-PASS is a collaboration or coalition of people from various State agencies, caregivers, consumers, as well as service providers and advocates for people with disabilities and elders dedicated to maximizing opportunity for people of all ages, living with any type of disability to control and guide their own services and destiny in the Massachusetts. They are known as the MASS C-PASS Coordinating Council.
- MASS C-PASS is a three-year project funded by the federal Centers for Medicare and Medicaid Services (CMS) through the Massachusetts Department of Mental Retardation (DMR) to demonstrate in Massachusetts:
 - Consumer-directed and flexible supports service delivery models can enable people of all ages with any type of disability (including long-term illness) to improve the quality of their own lives.
 - Personal assistance services and flexible supports can support people of all ages, living with any type of disability (including long-term illness) to become fully integrated into the community of their choice.

BASIC 2: How did the idea for MASS C-PASS come about?

- The idea underlining MASS C-PASS has roots in the American Disability Act (ADA) and in the struggles to protect the human rights of people with disabilities.
- The famous United States Supreme Court “*Olmstead Decision*” in July of 1999 provided a significant push toward the idea underling MASS C-PASS: *Do away with the isolation and segregation of individuals with disabilities as a serious and pervasive form of discrimination; and, in so doing, afford people with disability the opportunity to make decisions about their own care and destiny.*
- The *Olmstead Decision* involved two women, who were diagnosed with *schizophrenia* and with a personality disorder, whose rights were violated under the Title II or the “Integrated Mandate” of the ADA requiring states to place persons with mental disabilities in community settings rather than in institutions when ...
 - ... Treatment professionals determined community placement is appropriate.
 - ... The transfer from institutional care to a less restrictive setting is not opposed by the affected individual.
 - ... The placement can be reasonably accommodated, taking into account the resources available to the state and the needs of others with mental disabilities.

- President George W. Bush in 2001 issued an Executive Order, the *New Freedom Initiative*, calling for the federal government to assist states and localities to quickly implement the Olmstead Decision throughout the nation.
- The New Freedom Initiative is a plan to make sure that all Americans have the opportunity to learn and develop skills, engage in productive work, make choices about their daily lives and participate fully in community life. The goals entail:
 - Increase access to assistive and universally designed technologies;
 - Expand educational opportunities;
 - Promote homeownership;
 - Integrate Americans with disabilities into the workforce;
 - Expand transportation options; and,
 - Promote full access to community life.
- The Centers for Medicare and Medicaid Services (CMS), known before as the Health Care Financing Administration (HFCA), was among the federal agencies that set aside funds for *Systems Change Grants for Community Living*. These grants are to make certain the delivery of disabilities and aging services are consistent with the requirements of the ADA and the Olmstead Decision.
- CMS developed three grant categories under *Systems Change Grants for Community Living*: Real Choice Systems Change (RC), Community-Integrated Personal Assistance Services and Supports (C-PASS), and the Nursing Facility Transition (NFT).
- The purpose for all three categories of grants is to encourage states to implement lasting change in the home and community long-term-care service systems on behalf of children and adults of any age who have a disability or long-term illness, so that, they can achieve the following goals.
 - Live in the most integrated community setting appropriate to their support requirements and preferences.
 - Exercise meaningful choices about their living environment, the providers of services they receive, the types of supports they use and the manner in which services are provided.
 - Obtain quality services in a manner as consistent as possible with their community living preferences and priorities.
- Human rights form a part of the purpose for the Systems Change Grants for Community Living. Another important part includes the probability that assisting individuals with disabilities to live in the community is cheaper than living in institutions so it can save Medicaid dollars.
- The Commonwealth of Massachusetts has been the recipient of eleven Systems Change Grants from CMS designed to promote systems change and enhance community living opportunities for people with disabilities. By way of DMR, in 2003, CMS awarded Massachusetts the Community-Integration Personal Assistance Services and Supports Grant: MASS C-PASS.

BASIC 3: What does C-PASS look like in Massachusetts?

- The Massachusetts Community-Integration Personal Assistance Services and Supports (MASS C-PASS) is a consumer driven project designed to build the State's capacity to provide consumer driven personal supports. That is, personal assistance services and supports that extend beyond personal care attending (PCA) for the traditionally accepted activities of daily living
- MASS C-PASS is administered through the DMR's Systems Integration Unit headed by Assistant Commissioner of DMR Margaret Chow-Menzer and is consistent with the intent of the State's Community First Initiative.
- The management of MASS C-PASS is done through a collaborative or coalition of State agencies, consumers, self-advocates and caregivers, as well as aging and disability service providers. The collaborative is called the MASS C-PASS Coordinating Council.
- The MASS C-PASS Coordinating Council operates through a series of working committees temporary and standard. These committees included other supporters and volunteers not members of the Council. The standard committees are:
 - Project Evaluation Subcommittee
 - Policy Development Subcommittee
 - Marketing & Outreach Subcommittee
 - Technical Support Team

BASIC 4: What are the MASS C-PASS goals?

- Goal 1: Ensure that the scope and quality of services are consistent with need and are delivered in a coherent and timely manner through quality assurance and safeguard procedures.
- Goal 2: Explore maximum opportunity for self-direction and flexible use and allocation of supports across age and disability categories.
- Goal 3: Prepare, support, and empower consumers and/or surrogates to select from a menu of options allowing differing levels of self-determination and control over type/format of services.
- Goal 4: Evaluate the effectiveness of the pilot projects and the achievement of all grant objectives and develop a long-range plan for systems change to sustain MASS C-PASS successes.

BASIC 5: What are the MASS C-PASS strategies?

I. Mini-Projects

MASS C-PASS has contracted services for the operations of two Mini-Projects or pilots. One subcontractor is the Multicultural Community Services of Pioneer Valley (MCS) to concentrate on the Holyoke and Chicopee areas. Another subcontractor is the Arc of Massachusetts focusing in the areas of Boston and Lawrence. The Mini-Projects are working on developing designs for consumer-directed, flexible personal assistance services and supports, as well as quality assurance and safeguard procedures.

II. Policy Development Subcommittee

The Policy Development Subcommittee of MASS C-PASS is conducting a study to identify public policy, procedures, regulations and practices which pose a barrier to the delivery self-directed, flexible PASS, as well as to develop recommendations for regulatory and budgetary policy in the State. Such a study includes literature reviews, interviews with key stakeholders, and focus groups.

III. Marketing & Outreach Subcommittee

The Marketing & Outreach Subcommittee is actively seeking out the substantive input and participation of the greatest number of consumers in an effort to ensure the success of MASS C-PASS. There is special interest to include in the systems change process traditionally un-served and underserved racial, cultural, and linguistic minorities. The idea is to organize a series of consumer forums geared to consumers and caregivers, in order to:

- Build awareness about the MASS C-PASS work.
- Obtain substantive input on barriers to self-direction and flexible PASS.
- Inform the development of a long range systems change plan.
- Facilitate local involvement in guiding the State's development of regulatory and budgetary policy for Self-Directed, Flexible PASS.

IV. Technical Support Team

The Technical Support Team performs ongoing observations of the demonstration and provides problem solving techniques to prevent interruptions in the MASS C-PASS strategy. The Team also identifies what are the things or situations that keep coming up that can demonstrate or show us what needs to happen so that Massachusetts has the capacity to provide consumer-directed or self-directed, flexible PASS.

BASIC 6: What is unique about MASS C-PASS?

MASS C-PASS is exciting consumers, State agencies, service providers and local communities because of its unique multicultural, grassroots approach. It is expected to make significant contributions to inform the entire systems change effort in the Commonwealth of Massachusetts.

- MASS C-PASS is unique from other Massachusetts' systems change grants in its deliberate outreach to underserved populations such as members of minority communities (traditionally un-served and underserved racial, ethnic, cultural and linguistic minorities), as well as residents of rural Massachusetts.
 - In fact, this multicultural approach is so successful that the majority of the consumers participating in the two mini-projects and a substantial number of consumers on the Coordinating Council and in work-groups and forums are representatives of the traditionally underserved populations.
 - MASS C-PASS special emphasis does not ignore the needs of PASS consumers overall, but rather increases opportunities for effectiveness and efficiency by providing for an inclusion that leads to policy, procedures, and practices responsive to the true makeup of the State's consumer population.
- MASS C-PASS' other unique feature is its grassroots approach to increasing opportunities for the success of Self-Directed Community Living by way of coupling consumer's personal enhancement and providers' service changes with reworking the sociology of local communities to maximize the effectiveness of systems change efforts at the Federal and State levels. This approach includes:
 - (1) Consumer growth and development to learn how to be "free" or autonomous, in order to negotiate local community systems, surmount varied levels of discrimination (age, disability, race, ethnicity, creed, economic class, gender), enjoy equal protection (citizen/human rights: access to all the powers and freedoms afforded to all citizens) and foster healthy interdependencies.
 - (2) Building community receptiveness to overcome historical bias/prejudices and to reduce feelings of alienation for consumers and to ensure consideration of consumers as "whole people" (access to service organizations, local government agencies, religious institutions, civic organizations, cultural groups, local media and recreational opportunities).
 - (3) Enhancing the capacity of local communities to address the specialized needs and talents of consumers in strategic planning and local initiatives. Indeed, to do away with the "crisis-oriented service approach" that endangers the health and safety of elders and people with disabilities. For example, to consider - not as an afterthought – elders and people with disabilities 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 and economic development, education, community revitalization and neighborhood restoration).

Appendix D: MASS C-PASS Fact Sheets

- ▶▶ C-PASS One Pager
- ▶▶ Consumer Friendly Fact Sheet
Created by Deborah S. Orzack, Self-Advocate
Also available in Spanish, Haitian, Khmer,
Chinese and Vietnamese

MASS C-PASS

An Interagency, Cross Disability Collaboration to Design Consumer Driven Personal Supports



MASS C-PASS is the Massachusetts Community Integration Personal Assistance Services and Support - a three-year federal demonstration project funded by the federal Center for Medicare and Medicaid Services (CMS) in 2003. It is a consumer driven project designed to build state capacity to provide self-directed, flexible personal assistance services and supports.



MASS C-PASS goal is to develop sustainable mechanisms to support consumer choice and consumer direction in the PASS system so users can enjoy a higher quality of life and succeed at self-directed community living.



MASS C-PASS operates through the Coordinating Council which is a collaborative partnership of individuals with disabilities, elders, state agencies, and service providers from the Disability and Aging Networks. The work is carried out through subcommittees: Project Evaluation, Policy Development, and Marketing & Outreach.



MASS C-PASS funds two pilot projects. One is run by the Multicultural Community Services of the Pioneer Valley targeting Holyoke and Chicopee. The other is run by the Arc of Massachusetts focusing in the areas of Boston and Lawrence. Each pilot is gathering information and producing models for:

1. **Quality Assurances and Safeguard Procedures:** satisfaction surveys, performance standards and training for personal assistants; screening and emergency back-up options.
2. **Self-Direction and Flexible Supports:** identify underserved population; identify critical areas of need to support community living; PASS allocation based on functional need; models that enhance consumer control and quality of life.
3. **Supporting Different Levels of Self-Determination:** methods to evaluate consumer readiness and preference to direct PASS; continuum of fiscal intermediary services; options to enhance flexibility of PASS.



MASS C-PASS is also gathering substantive information toward a long range systems change plan through two of the subcommittees:

The *Policy Development Subcommittee* is conducting a study to identify public policy, procedures, regulations and practices which pose a barrier to the delivery of self-directed, flexible PASS and to develop strategies to overcome these barriers.

The *Marketing & Outreach Subcommittee* is actively organizing a series of consumer forums throughout the State to include in the systems change process traditionally un- and under- served racial, ethnic, cultural and linguistic (including deaf and hard of hearing) minorities.

MASS C-PASS:

An Interagency, Cross Disability Partnership to Design Consumer Driven Personal Support Systems

EMPHASIS: Consumer-Direction and Control

PURPOSE:

- Blend information provided by consumers about what they need, (consumer direction) with information from programs that respond to these needs in both traditional and non-traditional ways, (flexible supports). In addition, using this information to help update the policies of EOHHS and rewrite state laws determining the types and levels of services available for people with disabilities and elders.
- Work to change the PAS regulations and laws to combine ideas from the people with disabilities who use the system and flexible support systems.
- Demonstrate examples of programs that use the system of consumer-directed PASS to promote and encourage independence in people with disabilities and elders.
- Increase community involvement by running programs that develop effective personal and community support networks.
- Provide a multicultural perspective to increase the availability and qualifications of the helpers and support people in CD-PASS for those minority communities that traditionally receive few if any services due to racial, ethnic, or language barriers.
- Develop multi-culturally sensitive training curriculums for community go-betweens and others, including personal care assistants, in CD-PASS programs.

STRATEGY:

- Shared leadership and management of a Coordinating Council made up of those most affected: consumers, self-advocates, caregivers, state agencies, and service providers from the aging and disability service networks.
- Administer two CD-PASS Mini-Projects: The Arc of Massachusetts and the Multicultural Community Services of Pioneer Valley.
- Carry out activities of the following working committees:
 - Marketing & Outreach Subcommittee
 - Policy Development Subcommittee
 - Project Evaluation Subcommittee
 - Technical Support Team

DEFINITIONS AND ACRONYMS:

- **Arc-** is the organization of and for people with mental retardation and related developmental disabilities and their families.
- **CD-**Consumer Direction
- **Consumers-**elders and people with disabilities, including long-term illness
- **Flexible Supports-**support programs and/or agencies flexible enough to respond to the needs of consumers in both traditional and non-traditional ways.
- **EOHHS-**Executive Office of Health and Human Services
- **PAS-**Personal Assistance Services
- **PASS-**Personal Assistance Services and Support

Appendix E:
Consumer Forum Survey Questions

MASS C-PASS Consumer Forum

Survey Questions/Focus Group Discussion

Goal: To study the current personal assistance services and supports system to promote self-determination and self-direction in Massachusetts.

- I. What services are you aware of that are available in your community? Who do you go to, when you need help? For instance,
 - Housing
 - Financial Assistance
 - Healthcare
 - Mental Health
 - PCA
 - Transportation
 - Assistant Technology
 - Social/Community Skills (After School Programs, Adult Day Care)
 - Recreation
 - Personal Assistance/Support
 - Advocacy
 - Transitional (Travel Skills, Job Training, College)
 - Employment

- II. What is the quality of these services? (Rank each service listed during the above brainstorming using G=Good, A=Average, N=No Good).

- III. What are the barriers, if any, to accessing services? For instance:
 - Language
 - Lack of cultural competence
 - Transportation
 - Workers attitudes
 - Accessibility
 - Affordability

- IV. What support or services do you need to live independently in the community of your choice?

- V. Describe the type of support you need to improve the quality of your life; and, the type of changes you recommend to make the services received more appropriate or to get the services you need for you or your child/young adult to become independent.

Appendix F: Part I **Planning & Organizing Committees** **(POCs)**

- ▶▶ **WPOC Minutes and Materials**
- ▶▶ **LPOC Minutes and Materials**
- ▶▶ **HAPHI-POC Minutes and Materials**
- ▶▶ **CPOC Minutes and Materials**
- ▶▶ **GLPOC Minutes and Materials**

Note: All materials and flyers were not accessible in MS Word format and therefore do not appear in this appendix. In particular materials written in Chinese 1, Vietnamese, and Khmer were not accessible. Those interested in accessing copies of said materials should contact the MASS C-PASS Project. In addition, the minutes and materials were included without alteration or as written and submitted by the POCs to the Project Director.

Worcester Planning & Organizing Committee
(WPOC)

- 1) Consumer Forum Program
- 2) Consumer Forum Questions
- 3) WOPC Meeting Minutes
 - a. January 11th, 2006
 - b. February 16th, 2006
- 4) Consumer Forum Flyer
- 5) Proposed Budget
- 6) Consumer Friendly MASS C-PASS Fact Sheet
 - a. English
 - b. Spanish

MASS C-PASS
Central Massachusetts
Consumer Forum

March 3, 2006

Agenda

- 2:30 pm Welcome *Celia Brown*
- 2:40 pm Overview of the Day *Dawn Clark*
- 2:50 pm What is Mass C-PASS?
What is the Olmstead Decision?
Why are we here?
Where is the information we share today
going? *Keith Jones*
- 3:00 – 3:50 Small Group Discussions
- with Theresa Eckstrom
- with Marlene Zamora
- with Ruth Gonzalez
- 4:00 pm Reconvene and report back
Group Recorders
- 4:35 pm Summary *Nilka Alvarez-Rodriguez*

Sponsored by Center for Living & Working, Centro Las Americas, DMR Worcester Area Office, DMR Citizen Advisory Board, Elder Services of Worcester Area, REDD, Seven Hills Disability Resources & Advocacy and Montachusett Home Care Corporation

Supported by MASS C-PASS, the Massachusetts Community-Integrated Personal Services & Support Project, a three –year Federal Demonstration Project managed by the Department of Mental Retardation

MASS C-PASS Consumer Forum Questions
Developed by Central Mass Planning Committee February 2006

What do you need in order to live your life independently?

***This the primary question.** We then broke this down by topic/need areas to help participants identify specific supports they need in order to live independently.*

We also wish to emphasize that we do not equate independent with “by yourself”. We all need the support of others in our lives.

TOPIC/NEED AREAS – DO YOU NEED support in any of these areas?

- **Transportation** - to work, to meetings, to medical appointments, to family events, to recreation activities
- **Equipment** - (durable medical equipment) Do you need assistant technology, adaptive equipment, oxygen? Does the process for getting equipment work for you?
- **Housing** - Is it affordable, accessible, available?
- **Food** – Can you afford the cost of the food you need? Is the quality OK? Are you able to access nutritional counseling?
- **Bilingual Services**- Are you able to get written material translated or in an adapted form for you to understand? Are you able to secure Translators when you need them? How do you communicate? Do you have the support you need in order to communicate your needs?
- **Technology** –Can you afford the cost of the technology you need? Is it available when you need it? Do you know how to contact the supplier? Can you access the education/training you need in order to use the technology?
- **Recreation** –Do you need help paying the fees for recreation you wish to pursue? Can you access your choice of recreation? Do you need support in order to participate? Do you have this support?
- **Safety** – Do you have support you need to be safe in your home and in the community?
- **Assistance with Personal Care** – Are you able to find Personal Care Assistants? Are they trained according to your needs? Are they available when you need them? Are they able to be flexible with their schedule? Can you coordinate their schedule? Can you assign them tasks that you need help with?
- **Work** – Can you access the training you need in order to work? Are you able to get to the site that you work? Is your work site accessible?
- **Financial** – Can you access financial counseling or guidance? Are you able to secure public funding? Can you get to financial institutions such as a bank?

**Central MASS C-PASS planning meeting
January 11, 2006**

Present: Consumers Karen Cusick (SHDRA Self Advocate & Central Mass Work Team member), Deborah S. Orzack (REDD Self Advocate), Anne Fracht (Former President of MASS & MASS C-PASS Coordinating Council member), Jo-Ann Whelan (SHDRA Self Advocate & Human Rights Committee member)

Others: Jean Cusick (Supporter), Theresa Eckstrom (Elder Services, Worcester), Nilka Alvarez-Rodriguez (MASS C-PASS Coordinator & DMR), Dawn Clark (Center for Living & Working), Keith Jones (Chair Real Choices Independent Plus Team, C-PASS Coordinating Council), Ralph Edwards (Office of Citizen Leadership, DMR), Celia Brown (Director Seven Hills Disability Resources & Advocacy)

Keith gave an overview of MASS C-PASS:

- It is a 3-year demonstration project, ½ million-dollar grant to explore and identify the barriers for people who wish to live in the community but need personal assistance.
- They are trying to get services to not be cookie cutter but tailored to the individual and directed by the individual.
- The information gathered will also to barriers to families caring for an individual who needs person assistances.
- Has a grass routes focus to affect systematic change – to tap into communities of unserved and under served populations.
- C-PASS will be gone once funding is over; we are in third year of the grant.
- What needs to change for people to really have the choices they desire in their life.
- Focus in on empowerment of consumers to decide for themselves and direct their supports
- Massachusetts has received 10 and now 11 System Change grants – they are now being consolidated.
- The new grant is all about implementation (Systems Transition Grant).
- CMS = Center for Medicaid and Medicare Services.
- Initially, it costs more for people to transition to the community, but over the time it will save government money.
- Very few people who have language as a barrier and who are ethically different. are able to access the personal assistance they need. C-PASS Leaders wish to be sure these populations were represented in the Central Mass Forum in March.

General Discussion followed Keith's overview:

- DMR Citizens Advisory Boards can help to campaign for better access for services to individuals.
- There is no budget for C-PASS after September 2006. awarded.
- Need one page description of C-PASS Forum goals. We will need to get this description to enable people to lobby locally with their legislators
- Virtual Gateway is not yet working well – people who are targeted don't have computers or access to it!
- The Forum is for everyone – cross disabilities, cross cultural, elders, support staff, family members.
- The Forum goals include informing the audience about C-PASS, gathering and compiling information from a wide variety of constituents.

- We, the planning committee, will need to debrief the Forum and compile the information and recommendations, which will be forwarded to EOHHS.
- A Cross Disability group lobbying with the legislature would be very powerful.
- We hope the Forum suggestions will include ways to improve how to increase the PCA pool, better training and ways to retain PCA's
- Why come to the Forum? Include on the invitation - Need to voice your thoughts so they can be collectively forwarded to Legislators. It doesn't matter what your disability is, you need to come to the meeting.
- There is a bill proposing to increase PCA pay rates relative to time on the job.
- State employees can't lobby with Legislators, but consumers can. So why not develop a real set of priorities of policies that need to be change.
- Break into small groups with us as leaders and list barriers to living independently.

Proposed format - March 3rd Forum:

- Introductions
- MASS C-PASS overview - Nilka
- Break into smaller groups to address questions posed.
- Reconvene in larger format
- Report answers, issues, recommendations shared in small group format
- *Have lists of Legislative Reps and Senators and contact info available to distribute to attendees (Celia's add-on)*

Budget submitted by Celia and Dawn has been approved. Nilka suggested we need more money for Interpreters

Invitations need to be drafted:

Jo-Ann and Karen volunteered to make the invitations. Celia volunteered to provide support.

Next full meeting scheduled February 1, 2006, 1:00 – 3:00pm at Seven Hills Foundation. Smaller local group may meet prior to February 1 – date to be determined.

Thanks for all the passion and energy shared at the meeting.
Respectfully submitted, Celia E. Brown

February 16 the meeting

Attended by: Marlene Zamora, Dawn Clark, Deborah S Orzack, Theresa Eckstrom, Ruth Gonzalez. Celia Brown and Matilda

Clarified facilitator's questions:

- **What Do You Need to be able to live your life independently?**
For example:
 - Transportation**
Work, meetings, medical appointments, family events, recreation, others
 - Equipment** (durable medical equipment)
Assistant technology, adaptive equipment, oxygen, process
 - Housing** affordable, accessible, available, heat, utilities
 - Food** (cost, quality, nutritional counseling)
 - Bilingual Services** (Translation/communicate/interpreters/adapted)
 - Technology** (price and supplier, training)
 - Recreation** (access, cost, support)
 - Safety** (in the home and community)
 - Assistance with personal care** (finding, training, coordinating, assigning tasks, flexibility i.e. escorting)
 - Financial** (counsel, assistance, access to financial institutions)
 - Work** (training, accessible, adapted equipment at the work site)

Suggestions/Solutions

Need recorders and facilitators for each small group:

- Ruth, Marlene and Theresa agreed to serve as facilitators
- We will solicit recorders the day of the meeting.

Question topics will be mailed to attendees prior to March 3 to facilitate dialogue.

“To Do” List:

Celia email to Marlene the questions
Deb will redo C-PASS blurb after checking with Nilka
Theresa will draft info about Olmstead Decision for hand out
Celia will type up agenda
Celia will order refreshments

Celia will draft sign in sheet

Dawn will secure the Bridges film.

Dawn will continue to track rsvp and secure interpreters

Dawn will contact local press

Dawn will encourage attendees to car pool as parking at Seven Hills is challenging.

We decided not to show a film to the large group; but Bridges film will be available to be viewed before and after the meetings

We will videotape the reporting portion

? Who mails questions to people who have RSVP?

Agenda:

- Welcome and nuts & bolts of meeting site - Celia
- Overview of the day and of the handouts, remind people to sign in – Dawn
- 3 handouts: Olmstead Decision, Description of C-PASS, Agenda
- Why are we here today; What is C-PASS? What is the Olmstead Decision? Where the information is collected today going? – Keith
- Small group discussions – facilitators will follow questions listed above trying to solicit quantitative info to add fuel to the report.
- We will reconvene in large group and report back.
- Nilka will summarize the meeting

Dawn has only heard from two individuals to date. We need to encourage people to attend, though the flyer has been distributed broadly.

PARKING!

Please, you may have to park on the street. People do for Bingo and it works out OK.

Please enter through the new entrance, which is adjacent to the large new two-story glass addition. We will be meeting upstairs in the addition.

Become An Agent of Change

We need your help!

Please come to a Consumer Forum
*** *Tell us how support services can be
changed to improve your life****

March 3, 2006
(Snow date March 10, 2006)

2:30 – 4:30 pm

Seven Hills Foundation, 81 Hope Avenue, Worcester, MA
an accessible site

Light refreshments will be served

Sponsored by

**Center for Living and Working, Centro Las Americas, DMR Worcester Area Office, DMR Citizen
Advisory Board, Elder Services of Worcester Area, REDD, and
Seven Hills Disability Resources & Advocacy**

RSVP

Dawn Clark, CLW, 508 363-1226 or DClark@centerlw.org

*If you need special accommodation such as
Language Interpreter, ASL, CART, other
please respond by February 17, 2006*

*Supported by MASS C-PASS, the Massachusetts Community-Integrated Personal Services & Support Project,
a three-year Federal Demonstration Project managed by the Department of Mental Retardation*

Lynn Planning & Organizing Committee
(LPOC)

- 1) Consumer Forum Program Agenda
- 2) Consumer Forum Questions
- 3) LOPC Meeting Minutes
 - a. April 6, 2006
 - b. April 13, 2006
 - c. April 21, 2006
 - d. May 23, 2006
- 4) Consumer Forum Flyer
 - a. English
 - b. Spanish

Agenda

Lynn C-PASS Forum

June 3, 2006

9:00 a.m. – 12:30 p.m.

9:00 a.m. – 9:30 a.m.

Sign-In
Continental Breakfast
Networking

9:30 a.m. – 10:00 a.m.

Introductions

Welcome

Rene B.

Williams

Overview of the Day

Madelyn Soares

What is C-PASS?

Keith Jones

10:00 a.m. – 11:15 a.m.

Group Discussions

11:15 a.m. – 11:45 a.m.

Lunch Break

11:45 a.m. – 12:15 p.m.

Reconvene and Report Back

12:15 p.m. – 12:30 p.m.

Summary

Nilka Alvarez-Rodriguez

Lynn C-PASS Forum

MASS C-PASS Consumer Forum Questions

Primary 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?

***TOPIC/NEED AREAS – DO YOU NEED support in any of these areas?**

- **Transportation:** to work, meetings, medical appointments, family events, recreational activities
- **Equipment:** Do you need assistive technology, adaptive equipment? Does the process for getting equipment work?
- **Housing:** Is it affordable; accessible; available?
- **Food:** Can you afford the cost of food you need? Is the quality OK? Are you able to access nutritional counseling?
- **Bilingual Services:** Are you able to get written material translated and/or secure translators when you need them? Do you have the support you need in order to communicate your needs?
- **Technology:** Can you afford the technology you need? Is it available when you need it? Do you know how to contact a supplier? Can you access the training to use it?
- **Recreation:** Do you need help with paying recreational fees? Can you access it? Do you need supports in order to participate? Do you have the support?
- **Safety:** Do you have the supports needed to be safe in your home and community?
- **Assistance with Personal Care:** Can you find PCA's? Are they trained according to your needs? Are they available when you need them (flexible schedules)? Can you assign them tasks that you need help with?
- **Work:** Can you access the training you need in order to work? Are you able to get to the site? Is your work site accessible?
- **Financial:** Can you access financial counseling or guidance? Are you able to secure public funding? Can you get to financial institutions (banks)?

* Topic areas developed by the Worcester Consumer Forum Planning Committee

Lynn MASS C-PASS Planning Meeting
April 6, 2006

Purpose: MASS C-PASS Planning Meeting

Attendees: Marcel Charpentier, DMR North Shore
Migdalia Cordero, DMR
Susan Gilroy, Autism Support Center
Steve Hayes, Lynn Community health Center
Madelyn Soares, Parent/Advocate
Renee Williams, Parent/Advocate
Bonnie Smarsh, Bridgewell
Nilka Álvarez-Rodríguez, MASS C-PASS Coordinator
Keith Jones, C-PASS Coordinating Council, Soul Touchin' Experience

Nilka and Keith's overview of MASS C-PASS

In addition to the overview items that were presented to the Worcester Planning Committee and recorded in detail in their January 11, 2006, meeting notes, Nilka and Keith discussed:

- *Just the Facts* and *Client Allowances Policy* handouts were distributed.
- The aim is to keep people out of institutions and into the community.
- What are the issues that people feel are most important? We want people to express what services they would ask for if given the funds to do whatever they wanted.
- The primary target is minority groups that are either not being served or are underserved.
- Personal Assistance extends beyond daily living assistance (family supports, childcare needs, housing, recreational supports, etc.).
- Worcester held their Forum on March 3, 2006. Copies of the Worcester Consumer Forum report were presented as an example, although they want us to “think out of the box” in strategizing and planning the forum around the needs of the Lynn community.
- The forum targeted toward the Haitian community will take place in May. Springfield and Malden will hold their forums in June.
- Outreach should be made to consumers and providers
- EOHHS is mandated to make at least one policy change.

Planning Committee discussions:

The planning committee agreed to meet in order to begin making specific plans for the Lynn C-PASS forum. A short discussion was held regarding some possible forum plans (see below); however, specific details will be discussed by the entire group during our next meeting. We will meet on:

Thursday, April 13, 2006, 9:00 a.m.
Lynn Time Bank

The general agenda for this meeting will include developing a format for the forum including:

- Forum format – prepare an agenda, discuss key note speakers, facilitators and recorders, composition of small group discussions (by areas of similar interest and/or language), structuring discussions
- Forum participants: Different members of the group will have access to the various populations of the community that we are targeting for the make-up of the forum (elderly, minorities, parents of young children, adult consumers, providers, family members). Debbie Stone may be able to help get the word out to parents.
- Outreach: How can we encourage people to attend? Flyers could be distributed throughout the community along with reminder telephone calls to person who RSVP. Barbara Cox may have contacts within the Lynn Daily Items that could assist in doing a small article and/or announcement.
- Date - possibly the middle of June while the children are still in school to make it possible for consumers with young children to attend. A Tuesday or Thursday was suggested a preferred day of the week.
- Location: Lynn Housing Authority, 10 Church Street, was suggested.
- Time: 9:30 – 12:30 give us a full three hours and allows time for parents to drop off and pick up children from school.
- Accommodations - childcare, transportation, translators, parking
- Purchase and setup of refreshments/meals (clean-up after forum)
- A resource table to be set up with flyers and brochures as an outreach for other community events (Time Bank, Family Forum, etc.)
- How can we use the Time Bank to assist with accommodations?
- We will need to prepare a budget to submit to Nilka which will include location, transportation, refreshments, childcare, stipends, and supplies (paper, coping expenses, etc).

“To Do” List:

Madelyn will call Lynn Housing Authority to inquire about securing a site for the forum sometime in the middle of June. She will check to see if small rooms may also be available for the small group discussions and/or childcare settings. Darlene Badson may be able to help with a contact person at LHA if needed.

Renee will call Comcast to inquire about having an announcement placed on the Lynn community channel. She will also send an email to all planning committee members with next meeting date and agenda items.

Group: We should all come to the next meeting prepared with ideas and suggestions to address all of the previously mentions agenda items. If as a group we agree to hold the forum in the middle of June, we will have only two months to pull everything together.

Submitted By: Renee B. Williams

Lynn MASS C-PASS Planning Meeting
April 13, 2006

Purpose: MASS C-PASS Planning Meeting

Attendees: Marcel Charpentier, DMR North Shore
Migdalia Cordero, DMR
Steve Hayes, Lynn Community health Center
Madelyn Soares, Parent/Advocate
Renee Williams, Parent/Advocate
Barbara Cox, Lynn Time Bank

The following items were discussed and/or resolved by the Planning Committee regarding the Lynn MASS C-PASS Forum:

Date: Tuesday, June 6, 2006
Respond By: Tuesday, May 23, 2006
Time: 9:30 – 1:00 (9:00 set up)
Location: Lynn Housing Authority
10 Church Street
Lynn, MA
Includes: Kitchen, Television/VCR, Bathrooms

Accommodations:

Food: Coffee, tea, juice, muffins, juice boxes, fruit, cold cuts and salad
Madelyn and Renee will shop for the food items next week in order to get an estimate of the food charges for the forum budget. Sam's Food Club, Shaw's Supermarket, Peapod.com and the caterer located in the Leo Building were suggested as places that could provide affordable food items in large quantities. Steve will email Renee with information on the caterer at the Leo Building.

Translators: Spanish, Cambodian and hearing impaired translators will be needed for the forum. In addition, the flyers will need to be translated into Spanish and Khmer. Marcel will contact Sophor regarding Cambodian translations.

Childcare: Barbara will look into getting people from the Time Bank to earn time dollars for childcare. Persons listed in the Time Bank Directory as childcare providers have already been through the background check. The time dollars will be supplied by Time Bank contributions.

Transportation: Madelyn will call Murielle Clemente at Greater Lynn Senior Services (781-599-0100) to inquire about the availability of handicap accessible vehicles.

Forum Format:

- We will target four consumer groups: adult services, children services, elderly services, and hearing/vision impaired
- The group has not yet finalized the make-up of the smaller discussion groups. This is an area that we can try to resolve at the next meeting. Suggestions from the group included:
 - four target groups (adult services, children services, elderly services and hearing impaired)
 - having Spanish, Khmer and ASL groups, facilitated by a translator, that will discuss all of the targeted areas of need
 - having linguistic discussion groups divided into targeted areas of need and provide several Spanish, Khmer and ASL translators to facilitate each of these groups
- The size of the forum should be approximately 40 people.
- We will need to discuss the agenda for the forum. We would like Keith Jones to be the keynote speaker.
- Facilitators and recorders will be needed to compile the information and recommendations from each group. Having the recorders use flip charts was recommended.
- Having a greeter at the door to welcome and assist forum participants was suggested. Using Fred, with a support person, as a greeter was proposed as a way to help him earn Time Dollars.

Outreach:

The group will contact the following organizations and let them know that we are targeting the minority population in the Lynn.

PACE program (Steve Hayes), Lynn Schools (Debbie Stone, Debbie Morrison), North Shore Arc/ Lynn Support Group (Susan Gilroy), MA Commission for the Blind (Marcel), Dept. of Public Health (Migdalia), Bridgewell (Bonnie)

Madelyn and Renee will get together next week to design a flyer. The following statements will be included on the flyers:

- *Leading questions:* “Do you or a family member have a disability? Are you getting all of the services you need? Are your services being delivered in a way that maximizes your independence? Do you have the supports you need to be safe in your home and in the community?”
- Let Your Voice Be Heard!
- Date/Time/Location Respond by: May 23rd
Registration required
- For information or to register RSVP: Renee 781-595-7182, Madelyn (Spanish) 781-913-3297 or Sopher (Khmer)
- Translation, transportation and/or childcare will be available upon request

- light refreshments will be served
- Supported/Sponsored by MASS C-PASS, The Massachusetts Community-Integrated personal Services & Support Project, Lynn Community Health, Department of Mental Retardation-North Shore, Bridgewell, New Americans, North Shore ARC, Lynn Time Bank, Lynn Family Forum

The group will post an announcement to display on the Lynn Community bulletin Board. This is a free service provided by Lynn CAM TV. The group will decide what information to include in the announcement at the next meeting, and plan to run it for the 30 days prior to the registration deadline.

Budget:

Marcel will send Madelyn and Renee a copy of the Worcester budget to use as a sample. A budget will need to be prepared. Renee will contact Nilka to get more information on when the budget is due and Stipends requirements.

“To Do” List:

- Renee: Call Nilka regarding budget/stipend, contact Darlene and Debbie Stone regarding distributing information
- Madelyn: Call GLSS regarding handicap accessible vehicles
- Madelyn and Renee: Shop to get estimate on cost of food, prepare flyer
- Marcel: Contact MA Commission for the Blind and Sheila Burke, DMR, provide Madelyn and Renee copies of the Worcester budget
- Steve: Contact Elizabeth Broderick at P.A.C.E., email caterer information to Renee
- Barbara: Locate Time Bank members that may be able to provide childcare, clean-up, transportation and/or translation
- Migdalia: Contact Goldman at DPH

Next Meeting: Friday, April 21, 2006
11:30 a.m.

- Agenda: Identify facilitators, recorders, speakers, greeters, set up person(s)
- Prepare a forum agenda
- Determine make-up and structure of small group discussions
- Discuss information compiled from above “To Do” list
- Finalize flyer and prepare bulletin board announcement

Submitted By: Renee B. Williams

Lynn MASS C-PASS Planning Meeting
April 21, 2006

Purpose: MASS C-PASS Planning Meeting

Attendees: Marcel Charpentier, DMR North Shore
Migdalia Cordero, DMR
Steve Hayes, Lynn Community Health Center
Bonnie Smarch, Bridgewell
Madelyn Soares, Parent/Advocate
Renee Williams, Parent/Advocate
Barbara Cox, Lynn Time Bank

The following items were discussed and/or resolved by the Planning Committee regarding the Lynn MASS C-PASS Forum:

Update from previous meeting's "To Do" list:

- ✓ Renee called Nilka and Darlene and is waiting to hear back from them. Debbie Stone was on school vacation and could not be reached.
- ✓ Madelyn called GLSS regarding transportation and is waiting to hear back from them.
- ✓ Madelyn and Renee did get a chance to get food estimates from Shaw's and BJ's (see accommodations) and make a draft flyer (see outreach).
- ✓ Marcel is waiting for a return call from MCB. Sheila from DMR, would be available to either assist and/or locate people who could translate for the hearing impaired. He will try to locate the copy of the Worcester budget.
- ✓ Steve did get a chance to speak with Elizabeth Broderick at P.A.C.E. They would like to get more literature on the C-PASS program. Caterer information was presented at meeting.
- ✓ Barbara can recruit Time Bank members for services. She will need to know the approximate ages of children needing childcare.

Accommodations:

Food: The group decided to plan a food budget for 60 people (40 possible forum attendees, speakers, translators and helping hands). Steve submitted information about the caterer, Marilyn Perry (phone 781-581-5391). Marilyn can provide a meal for the cost of \$5.00 per person which includes salad, main course, dessert, beverages and paper goods (this would not include the breakfast menu).

Madelyn provided a price list of food items for both the breakfast and lunch meal. She will calculate the totals for both options (caterer or BJ's) and give the group the food cost to add to the budget. The LHA does not have a large coffee urn, and Dunkin Donut's box of coffee is \$12 and serves only 10 cups. Marcel will try to borrow a coffee urn from the DMR office.

Translators, Childcare and Transportation:

The group determined that it would be more practical to wait until we have received all of the requests for services so that we can appropriately plan for them. We did not want to be under or over prepared for providing these accommodations. Barbara will outreach to the Time Bank members for these services and let them know the forum date and time.

Forum Format: An agenda for the forum was prepared. The hall (which can hold 200 people) is available to us from 8:30 – 1:30. This gives us setup and cleanup time. The forum will run from 9:00 – 12:30.

9:00	Sign-in, Breakfast, Network	
9:30	Welcome	Renee B. Williams
9:40	Overview of the Day	Madelyn Soares
9:50	What is MASS C-PASS?	Keith Jones
10:00	Small Group Discussions	
11:30	Break for refreshments (lunch)	
11:45	Reconvene and report back	
12:15	Summary	Nilka Alvarez-Rodriguez

The facilitators and recorders will be finalized at the next meeting. Flip charts will be used to record group notes. We will continue the discussion on how to structure the small groups in order help participants identify specific areas of need. The linguistic make-up of the smaller group discussions will also be finalized at the next meeting when we have a better picture of the number of people needing translators.

Outreach: The group reviewed the flyer that was submitted by Renee and Madelyn. Changes were made to combine two of the leading questions, list the day of the week that the forum is on, and emphasize the need to register. Madelyn will translate a copy into Spanish. Steve will forward the copy to Sophor to translate into Khmer. The flyer will be emailed to all group members who could then distribute copies. Renee will purchase colored paper (500 sheet pack) to give to Marcel so that he can print the flyers. Flyer should be completed by early next week.

As people call to register, Renee, Madelyn and Sopher will collect the following information:

- Name, address and phone number (to register and for a reminder call)
- Disability, Language (to plan for group design)
- Accommodations needed

Budget: Marcel will forward a copy of the Worcester budget to Renee and Madelyn as an example. Madelyn will total the food budget and check with GLSS regarding transportation fees. Renee will call Nilka to get specifics on how to submit the budget to her. Renee and Madelyn will put the budget proposal together.

“To Do” List:

- Renee: Call Susan Gilroy to get approval to list North Shore Arc as a sponsor, call Nilka regarding Budget and forum summary, contact Keith regarding speaking at the forum, contact Darlene and Debbie Stone regarding distribution of flyers, edit and email flyer, purchase colored paper
- Madelyn: Prepare list of food prices, translate flyer, call GLSS, and work on budget
- Marcel: Send Renee and Madelyn budget copy, print flyers, forward C-PASS information to Steve to pass on to Elizabeth at P.A.C.E, check on coffee urn
- Bonnie: Get approval to list Bridgewell as a sponsor on the flyer
- Steve: Forward flyer to Sopher for translation
- Migdalia: Contact Goldman at DPH
- Barbara: Locate Time Bank members available to help on June 6th, contact Fred regarding being a forum greeter
- Group: Distribute as many flyers as possible and get the word out.

Next Meeting: Tuesday, May 23, 2006
9:30 a.m.
Time Bank Office

- Agenda: Finalize:
- forum discuss groups and accommodations based on registration responses
 - facilitators and recorders
 - food items
 - what needs to be done in the next two weeks

Submitted By: Renee B. Williams
Madelyn Soares

Lynn MASS C-PASS Planning Meeting
May 23, 2006

Purpose: MASS C-PASS Planning Meeting

Attendees: Marcel Charpentier, DMR North Shore
Migdalia Cordero, DMR
Madelyn Soares, Parent/Advocate
Renee Williams, Parent/Advocate
Barbara Cox, Lynn Time Bank
Susan Gilroy, Autism Support Center

The following items were discussed and/or resolved by the Planning Committee regarding the Lynn MASS C-PASS Forum:

Update from previous meeting's "To Do" list:

Renee: Spoke with Susan Gilroy. It is OK to list the North Shore Arc as a sponsor. Spoke with Nilka who stated that we should prepare a budget as soon as possible and send it to her with our vouchers. Keith stated that he would be honored to be the key note speaker. The flyers were edited and distributed via email to the group, to Darlene Badson for distribution at the April MASS PAC meeting and to Debbie Stone for distribution to families in the school's special education programs.

Madelyn: Translated the flyer into Spanish and finalized the food list and prices. GLSS would have a price attached to any transportation that they could provided, however, they do not feel they will have any vehicles available.

Marcel: Forwarded flyer to Sheila for the hearing impaired. Located a coffee urn we can use.

Bonnie: Emailed Renee on April 24th and gave the OK to list Bridgewell as a sponsor on the flyer.

Steve: The flyer was forward to Sophor.

Migdalia: Goldman at DPH was contacted regarding distribution of the flyers.

Barbara: One Time Bank member is available to provide childcare. Barbara will try to locate one more member to help. Fred will not be available as a greeter.

Susan: The Family Resource Center sent flyers out.

Consumer Stipends:

Nilka contacted Marcel to inform him that money is available to compensate consumers and non-staff caregivers (parents, family members) that attend the forum. This should be a big help with getting people to register. A Stipend in the amount of \$50 will be provided to consumers/caregivers that complete a Consumer Stipend/Voucher form. This form will be attached to the agenda and distributed as participants sign in. During Madelyn's overview, she will instruct participants to return the forms prior to leaving in order to receive the Stipend. Persons providing childcare during the forum will also be entitled to the \$50 Stipend. In an attempt to prevent registrations from participants that are primarily interested in receiving the stipend, outreach should be made to persons that fit the targeted groups and are legitimately interested in participating in the discussions.

Accommodations:

Food: The group has decided to purchase the food items instead of using a caterer. Madelyn will contact BJ's to find out if they can direct bill Nilka at DMR. Madelyn and Renee will pick up the food items from BJ's on June 5th. The paper goods and plastic utensils will all be purchased at the same time so that they can be included in the voucher total.

Transportation: GLSS stated that they may not have vehicles available for our use. Barbara will call Mary Margaret at the Independent Living Center regarding any transportation that they may be able to provide. She will also continue to recruit Time Bank members that will be able to provide transportation.

Childcare: One Time Bank member is already secured. Barbara is working on finding at least one more. Time Bank members will receive the \$50 Stipend in addition to earning Time Dollars. As parents request childcare as an accommodation, they will be asked if they would like to provide a toy or other form of recreation, that their child would enjoy. Madelyn has also agreed to bring some things from home that the kids may enjoy playing with.

Translators: Spanish, Cambodian and hearing impaired interpreters will be needed. An Interpreter Request Form was faxed to MA Commission for the Deaf and Hard of Hearing requesting two signing interpreters for the forum. Migdalia has volunteered to be the Spanish interpreter. Renee will contact Sophor regarding a Cambodian interpreter.

Outreach:

Although we have only five people registered, Marcel believes that we can count on attendance from the following groups:

Physically Disabled-

Cambodian community- (Sophor will be able to come up with a group)

Spanish community (Migdalia and Madelyn will outreach through the DMR

list)

Hearing / Visually Impaired (outreach through Gail and Sheila)

Adult consumers (Bonnie may be able to come up with a group of

individuals)

The \$50 consumer/caregiver stipend will be a great asset in our attempts to recruit additional forum participants. Please continue to have people call to register so that we can have an idea of how many people to expect.

Forum Format:

- Participants will first be directed to sign-in. This will help with obtaining a count of the number in attendance. At this time agendas with the attached Consumer Stipend/Voucher form will be handed out, and persons needing childcare and/or translators can be identified. Coffee and muffins will be available.
- The room will be set up in preparation for the small groups with signs labeling each area. A resource table will be provided for various organizations and programs to display flyers and brochures.
- After the welcome, Madelyn will do the overview and let everyone know our plans for the day. The planning Committee finalized the makeup of the small groups. The formation of the small discussion groups may be adjusted if needed. For example, if there are only 2-3 people for the elderly group it will be combined with another group. The hearing impaired will have an interpreter provided in the groups of their choice (2) unless the numbers and/or request express a need for a separate group for the hearing impaired.
- A volunteer from within each group will be recruited as a recorder. Flip charts and markers will be used. Below is a list of the breakdown of the groups along with the name of the facilitators.

Children Services - Renee B. Williams
Adult Services - Susan Gilroy
Spanish Group - Madelyn Soares - Migdalia will be the recorder
Elderly Services - (Steve will be contacted for suggestions)
Cambodian Group - (Sophor will be contacted for suggestions)

Group discussions will begin with introductions. The framework will be surrounded by two basic questions. What supports do you or your family member need to live independently? What supports are needed to be safe and independent in your home and community? We will use the topic areas developed by the Worcester group as a guide to help cue people about areas of need only after the group has been afforded the opportunity to come up with their own list.

- After Nilka's summary, we will remind everyone about the resource table and let them know that flexible funding applications will need to be submitted before the end of the week.

“To Do” List

Renee: Type both the forum agenda and topic questions. Call Steve to see if he has any people interested in registering and/or available to be a facilitator. Call Sophor to let her know about the consumer stipend, get her number of registered individuals and see if she has an available interpreter.

Madelyn: Contact BJ's regarding direct billing to Nilka.

Renee/Madelyn: Meet on June 5th to shop for food items.

Marcel: Contact Gail and Sheila to let them know that stipends will be available to participants. Bring the coffee urn to LHA at 8:30 on forum date.

Migdalia: Contact Goldman at Department of Public Health to let her know that stipends will be available to participants. Provide a list of DMR names for Madelyn to call.

Barbara: Recruit Time Bank members for childcare and transportation.

Group: Continue the outreach to recruit forum consumer/caregivers and providers to attend the forum. Have interested parties call to register.

No other planning meeting is scheduled. We will continue to communicate via phone and/or emails.

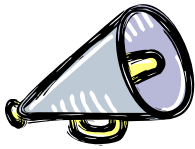
Submitted by: Renee B. Williams & Madelyn Soares

***Do you or a family member have a
disability?***

Are you getting all of the services you need?

***Do you have the supports you need to be safe and
independent in your home and community?***

Let your voice be heard! ?



**Tuesday, June 6, 2006
9:00– 12:30**

***Lynn Housing Authority
10 Church Street
Lynn, MA***

Light refreshments
will be served.



***Registration required!
Respond By May 23rd***

Please call:


Renee Williams (781) 595-7182
Madelyn Soares (781) 913-3297 (Spanish)
Sophor Chhour (781) 595-7747 x332 (Khmer)

***Translation, Transportation and/or Childcare
will be available upon request.***

Sponsored by MASS C-PASS, The Massachusetts Community-Integrated Personal Services & Support Project, Lynn Community Health Center, Department of Mental Retardation-North Shore, Bridgewell, New Americans, North Shore ARC, Lynn Time Bank, Lynn Family Forum

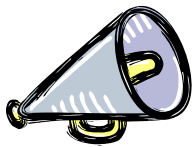
***¿Tienes tu o un miembro de tu familia una
incapacidad?***

***¿Estas recibiendo todos los servicios que
necesitas?***

***¿Tienes el soporte que necesitas para estar
seguro y independiente en tu casa y comunidad?*** 

¡Haz que tu voz sea oída!

**Martes, 6 de junio, 2006
9:00 – 12:30**



***Lynn Housing Authority
10 Church Street
Lynn, MA***

Se servirá café



***→ ¡Registracion es Requerida! ←
Responda no mas tarde del 23
de Mayo***

Para registrarse llame:

Madelyn Soares (781) 913-3297 (Español)

***Traducción, Transporte y/o Cuidado de Niño será
disponible cuando solicitado.***

Patrocinado por: MASS C-PASS, The Massachusetts Community-Integrated Personal Services & Support Project, Lynn Community Health Center, Department of Mental Retardation-North Shore, Bridgewell, New Americans, North Shore ARC, Lynn Time Bank, Lynn Family Forum

HAPHI/Haitian Planning & Organizing Committee
(HPOC)

- 1. Planning Meetings & Framework**
- 2. Consumer Forum Flyer**
 - **English/Creole**

C-PASS/HAPHI Community Forum
August 21, 2006
4:00 PM-7:00 PM
Planning Meeting

- 1) Three Family members of the Haitian Family Governing Board were designated to take the lead in the coordination of the logistics for the community forum.
- 2) Presented the information on C-PASS, discussed the logistics of the forum and set-up a committee with three parents to work on the logistics, which include the forum format , materials, and the development of an outreach flyer. 3 Staff and 3 parents will run the sub-group discussions.
- 3) On August 18, a letter was sent to Haitian families to inform them about the upcoming community forum and the need for participation.

C-PASS / HAPHI COMMUNITY FORUM
September 11, 2006
5:00 PM-8:00 PM
Planning meeting

A) Reframing of issues related to self-determination and independent living (New version)

- 4) What supports do you or your family member need to live independently?
Language, Housing, PCA, Transportation, Recreation, Transition, Safety, travel skills, job training, community skills, Employment
- 5) What existing barriers do you think you or your son/daughter are currently facing in meeting each of these needs?

Language: _____

PCA: _____

Housing: _____

Transportation: _____

Transition: _____

Academics: _____

Job training _____

Travel skills _____

Community/Social Skills _____

Communication _____

Computer _____

Employment _____

- 6) List by order of priority the most important barriers that need to be addressed and supports needed to help families and their son/daughter live independently?

B) September 13, 2006: Letters and Flyers were sent out to the community.

C) MEETING LOGISTICAL PREPARATION:

- 1) Introduction of C-Pass to all members
- 2) Divide in 3 sub-groups, each one with a facilitator
- 3) Designate someone or the facilitator to report
- 4) Report to the whole group

Logistical Support: Wall Sheet to list out goal and topics, Translation in English of answers for each topic discussed, Write answers on the wall sheet, List per order of priority the barriers and supports needed

Beverages while conducting the sub-group discussion

Food at the end

D) To review logistical preparation: Wednesday 20, 2006 from 12:00 through 2:00 PM

HAPHI COMMUNITY FORUM

**Do you or a family member have a disability?
Are you getting all of the services you need?
Do you have the supports you need to be safe and
independent in your home and community?**

Let Your Voice Be Heard!

**At the Haitian Family Support Special Meeting
10 Fairway Street, Room 211
Mattapan, MA 02126**

*Sunday September 24, 2006
4:00-7:00 PM*

Confirmation Required!

Please Call:

**Renald Raphael: (617) 298- 8076
Micheline Jean-Baptiste (617) 298- 8076**

Translation & child care will be available!

Vini pou nou pote chanjman nan sèvis n'ap resevwa e pou ou ede pitit nou vin endepandan

Nan HAPHI- Haitian Family Support
Dimanch 27 Out, 2006, de 4:00 a 7:00 PM

Vini an foul, ap gen moun pou tradwi pou ou an Anglè
e moun ki pou siveye timoun ou.

Pou tout enfomasyon, kontakte Renald Raphael oubyen
Micheline Jean-Baptiste nan (617) 298-8076

Fè rezevasyon bonè!

Ap gen manje ak rafrechisman!

Sponsored by Mass C-Pass, The Massachusetts Community-Integrated Personal Services & Support project.

Chinatown Planning & Organizing Committee
(CPOC)

Minutes

Chinatown C-PASS Committee
Tues., July 18th, 2006/10:00AM-12:00 PM
Boston Chinatown Neighborhood Center, Boston MA

PARTICIPANTS

Keith Jones, Soul Touchin' Experiences
Nilka Álvarez-Rodríguez, MASS C-PASS Coordinator
Hang Lee, Chinatown C-PASS Coordinator
Joseph Wu, Family Director BCNC
Ralph Edwards, DMR
Agnes Wong, Boston Chinatown Family Services
Junie Wong, BCFS
Ben Wong, BCFS
Jenny Chan, Parent
Louise Hogan, BCIL
Stacy Rogers, BCIL
Linda Lawrie-Pfifer, MRC
Kathleen Catano, DMR
Some Asian woman, Project ABLE.
Lily Chin, Great Wall Center.

S C-PASS Coordinator

- **Gave a brief introduction to C-PASS, plus the fact that everything will be pay for by DMR. And tells a personal story about the 1970s when people were laid off in NYC, the government's slow response to these social changes resulted in tragic loss of life in the city where she grew up.**

The Coordinator then pass the conversation to Mr. Keith Jones, who explains the there are changes coming from the federal government. And that these changes will effects the quality of life issues to all people with disabilities and the people who are connected them. This forum is about voicing what people with disabilities in the community needs in order to live a qualitative life, be it working, socializing, eating, etc.. Keith also emphasize that despite the acronym of C-PASS it does not involved the PCA program, but involves the wide community; family members, people with all types of disabilities, and agencies that provide direct and indirect services with people with a disabilities.

Jenny a Chinese parent, whose son is living in a group home, explains how the vendor hires staff that lacks Chinese cultural competency by telling us the staff does not know how to cook for Chinese consumers. Keith Jones immediately interjected that the kind of thing the forum is design for. Louise inquires about culturally competent materials. Agnes Wong of BCFS strongly urged that all materials be translated into Chinese and that the forum, be conducted in Cantonese. Nilka told everyone that in the Haitian forum, it was conducted solely in Creole with non-speakers listening to English translation through headset another story about an agency almost banning her from all activities. Joseph Wu inquired the C-PASS budget. Nilka said she'll email him the Haitian forum flyer with the budgetary items. Nilka then ask can we meet in two weeks to see if this is an opportunity we want. It was unanimous vote to go ahead with the Forum. Thus a second meeting for all who attended this meeting was set for August 1, 2006.

Chinatown C-PASS Committee
Tues., Aug 1st, 2006/3:30PM-4:30 PM
Boston Chinatown Neighborhood Center, Boston MA

PARTICIPANTS

Hang Lee, Chinatown C-PASS Coordinator
Joseph Wu, Family Director BCNC
Agnes Wong, BCFS
Junie Wong, BCFS
Ben Wong, BCFS
Lily Chin, GWC
Jenny Chan, Parent

Background: This meeting was set up to strategize a well-developed plan to present to DMR on the Aug. 3 meeting. It was also see if a C-PASS Forum was really necessary.

Joseph started out by asking Hang to review the C-PASS Basic document. Hang started to explain, but diverted into the system change grants, saying in Mass., there are two grants that are offered from CMS. The C-PASS in Mass is unique in that it is one that focuses on multi-cultural communities that have been underserved. Hang also said he has been to several C-PASS forums: Worcester where there's a large Hispanic community and Lynn, where there's a significant Cambodian community.

Lily and Agnes both raised an interesting question. The C-PASS grant is in its final year why haven't DMR approached anyone in the Chinese community until now? Hang believed Project ABLE was approached last year but they refused. Lily then said if DMR is willing to fund the forum why not have it? It's no cost to us and perhaps the Chinese population will get a chance to be heard, Agnes then want to know if this forum will happened I want to have a Q&A session where DMR and MRC Officials will be present to answer people from the Lily agreed. Joseph then asked everyone if they agreed to work toward a C-pass forum. The decision was unanimously positive. The Committee agreed to present DMR with our answers. Joseph passed out a copy of the Haitian Forum Flyer and said the next time we meet as a Committee we will delegate the responsibilities. Junie and Joseph will work on a rough draft of the flyer and Registration forms. Agnes will continue to inform BCFS about the forum. Hang will reach out to find people who will set up information both, as well as families and people with disabilities to participate. . We also agreed that the material and information handed out must be in Chinese.

Chinatown C-PASS Committee
Thurs., August 3rd, 2006/10:00AM-12:00 PM
Boston Chinatown Neighborhood Center, Boston MA

PARTICIPANTS

Nilka Álvarez-Rodríguez, MASS C-PASS Coordinator
Hang Lee, Chinatown C-PASS Coordinator
Joseph Wu, Family Director BCNC
Ralph Edwards, DMR
Agnes Wong, Boston Chinatown Family Services
Junie Wong, BCFS
Ben Wong, BCFS
Jenny Chan, Parent
Louise Hogan, BCIL
Stacy Rogers, BCIL
Lily Chin, Great Wall Center and her daughter, Katie

Discussion:

Nilka asked Hang to open the meeting, in which he handed the talk over to Joseph.

Joseph spoke about the proposed forum format. It will consist of first opening statements, with vendors offering information in Chinese. Joseph suggested that someone (either DMR or someone in the committee) seek a translator. Lily said she knows someone who was hired by GWC for a Justice Fair done a few years ago and will investigate the translators schedule. After the opening, a family/consumer testimonial panel consisting of a consumer parent of a developmentally delayed adult, and a youth After this, the forum will be split into group discussions, Then we'll CONCLUDE THE FORUM with a Q&A panel discussions with State Officials from DMR, MRC, Agnes wants this forum to be conducted in Cantonese Chinese and reiterated the need to have translated materials so that families will collect them. Joseph stated the Committee has already started developing marketing materials and will begin working on outreaching to various agencies. Joseph wanted to meet with Nilka to discuss about the budget at the end of the meeting. Joseph said the Committee will contact vendors and representatives for the next meeting in a few weeks.

Chinatown C-PASS Committee
Tues., August 8th, 2006/10:00AM-12:00 PM
Boston Chinatown Neighborhood Center, Boston MA

PARTICIPANTS

Hang Lee, Chinatown C-PASS Coordinator
Joseph Wu, Family Director BCNC
Agnes Wong, BCFS
Junie Wong, BCFS
Ben Wong, BCFS
Mei Wong, Parent
Lily Chin, GWC
Frank Chan, parent

Junie and Joseph presented drafts of the English flyer and bilingual registration form respectively for review. Agnes wondered how the flyer will look if one side was printed in English, the other side in Chinese. Lily advocated keeping both flyers separate to keep it simple. Some basic changes were wanted by members, like adding the Great Wall Center to the list of sponsors below, as well as a check spot for parents who needed child care. Joseph said do not send these copies to anyone for usage. He said he will have the finalized copy by next meeting. Members also talked about an estimate amount of people can each person bring to the Forum AGNES SAID she has at least 50 mothers from BCFS WHO POTENTIAL MIGHT COME, and from Project Able, 30. Project Able also serves the Vietnamese community and Agnes added that some Vietnamese speak Cantonese. Agnes also spoke about Project Able's board voting to become autonomous from Bay Cove (Own notes- this could have a bearing on their ability to participate in the Forum). Hang mentioned about 10, but said he bring people who have information on disability services and information useful to consumers and caretakers. Hang will continue working at that end.

Next meeting will be Tues. Aug 15th 10 am at BCNC

Chinatown C-PASS Committee
Tues., August 15th, 2006/10:00AM-12:00 PM
Boston Chinatown Neighborhood Center, Boston MA

PARTICIPANTS

Hang Lee, Chinatown C-PASS Coordinator
Joseph Wu, Family Director BCNC
Agnes Wong, BCFS
Junie Wong, BCFS
Ben Wong, BCFS

Junie and Joseph came up with the next to final versions of the Bilingual registration forms and the English and Chinese versions of the Flyers. Members examine them minor changes were recommended. The members approved the changes and Joseph will emailed everyone the finalize be distributed.

Agnes inquired about Professor Lusa Lo, Cantonese speaking Special Ed. Professor at UMASS/ Boston. Hang tried contacted Prof. Lo but she's been out of town for almost three weeks Agnes responded by say Prof. Lo would want to help when she's back in Boston. Joseph brought up the subject of the first panel and suggests that the speakers submit their testimony. Also, Joseph wants to finalize the 1st panel. There will be 4 speakers each representing one of the following group and given 5 minutes to speak, Independent living, residential, children, and teenager. Joseph will Emailed the 1st panel group plus testimony next week.

Agnes wants to form a mail team next work after the scheduled meeting. She said she wants to send more than 50 flyers and regular forms. Agnes wants to keep the mailings simple, after Junie suggested a different way of mailings. The organizations suggested were Project Able, Golden Age Center, the Federation, and Great Wall Center. She also will hand them to U-CANN during Wednesday afternoon. Hang will distribute them on the internet. Hang also recruited a friend, Lisa Mandelblatt an occupational therapist who has worked with Children with disabilities and has worked with Chinese parents. She'll probably have materials translated in Chinese.

Next week; stuff envelopes and send them off to Project ABLE and BCFS families.

Chinatown C-PASS Committee
Tues., August 22nd, 2006/10:00AM-12:00 PM
Boston Chinatown Neighborhood Center, Boston MA

PARTICIPANTS

Nilka Álvarez-Rodríguez, MASS C-PASS Coordinator
 Hang Lee, Chinatown C-PASS Coordinator
 Agnes Wong, Boston Chinese Family SERVICES
 Joseph Wu, Family Director BCNC
 Ben Wong, BCFS
 Jenny Chan, Parent and her son Francis
 Lily Chin, Great Wall Center & Her daughter - Katie
 Mrs. Leung and her son
 Dr. Lusa Lo U.MASS//Boston

Note: This is Prof. Lo's first meeting.

Discussion:

Everyone helped to finalize the Forum Agenda.
 The schedule is listed below.

Agenda

Time	Event
11:30 - 1:30	Setup
1:30 - 2:00	Refreshment
2:00 - 2:10	Introduction
2:10 - 2:40	Panel
2:40 - 3:00	Q/A
3:00 - 3:30	Groups
3:30 - 3:45	Report
3:45 - 4:45	Panel
4:45 - 5:00	End
5:00 - 5:30	Deadline Close
5:30 - 6:00	Clean-up

*There needs to be a report back from each group

The Consumer Panel was too finalized with testimonies already submitted to the Committee.

Consumer Panel (5 minute each) Facilitator: Agnes

Hang	Independent
Jenny/Kitty	Residential
Linda/Junie	Teenager
Leung/Qiu/Lusa	Children/Disabled

Community Panel Facilitator: Joseph/Lusa

(I) BCIL	(Stacy Rogers)
(I)BCIL	(Luis Logan)
DMR	Nilka (C-Pass)
(I)DMR	Margaret Chow (Asst Commissioner)
(I)Independent Living	John Chapel (Deputy Commissioner IL)
(I)DMR	Kathleen Catano (Metro-Boston Area Dir)
(I)Federation	Richard

(I) = Panelists

(I) = Possibly not on the panel

(I) = Find influential people

Bill Henning from BCIL?

Focus on needs of communities

The finalized version of the Community Panel will be discussed next week.

Booth

Lisa Weber	*MRC	Translation of Material
	*Federation	Translation of Material
Stacy.	*BCIL	Translation of Material
	*Lisa (OT)	Translation of Material
	New England Index	Information Only
Mass Rehab		

Member Representation but send materials

Will need Cantonese interpreters to Set up booth

Create an invoice

Getting the word out:

-E-mail, faxes

-UCAN

- Lusa will email APA educators.

-Churches

-Schools

-Project Able (Core)

- South Cove

Interpreter

Simon Chan

Richard Cheng said Simon agreed (Richard will work behind the scene)

Get volunteers and other people- Lusa will help with this issue.

DMR has translation equipment for 3 languages

Mandarin Language issue (possibly have someone hired?) - Lusa will look into it, but depends on how many Mandarin speakers - more than 10 we might need a Mandarin Interpreter.

Agnes- Can't translate verbatim from Chinese to English

Equipment and translation (Home cultural people selected)

-Our selves

Joseph -Contact media, i.e. Boston Globe,

Some organizations have no diverse support. Give out copies.

Greater Lawrence Planning & Organizing Committee
(GLPOC)

- 1. Minutes**
- 2. Pre-Registration Form**
- 3. Program**

Greater Lawrence Planning Committee Meeting Minutes
Monday, May 8th, 2006/10:00 AM - Noon
Northeast Independent Living Center

Participants: Yajaira Blanco - The Arc of Greater Lawrence & Class Inc.
Adalberto Escoto - Lawrence Public Schools
Zoila Gomez, Esq. - The Arc of Greater Lawrence
Elizabeth Quinn - Northeast Independent Living & ADRC

Chair: Bill Pitochelli - Parent, MASS C-PASS, & Class, Inc.

Staff: Nilka I. Alvarez-Rodriguez, MASS C-PASS Coordinator

All of the participants at this meeting were people familiar with the MASS C-PASS federal demonstration Project. Therefore, the focus of the meeting was to initiate discussion toward realizing the Greater Lawrence Consumer Forum:

- I. Why is it important to organize a Greater Lawrence Consumer Forum?
 - II. What localities constitute the Greater Lawrence area?
 - III. Who should form part of the Greater Lawrence Planning Committee?
-
- I. Why is it important to organize a Greater Lawrence Consumer Forum?

Bill Pitochelli opened the discussion sharing his feeling about the work that MASS C-PASS is performing. Bill spoke about how much easier it would have been for his family to overcoming the challenges of getting quality care for his son, if what MASS C-PASS is looking to achieve would have been in place. He further stated that he could imagine how much more difficult it must be for families who do not speak the English language and who have very limited resources. Yajaira Blanco followed the discussion talking about the many families and individuals with disabilities she works with who have difficult with the public school system and of the inadequacy of translation services when available. Yajaira also talked about how much easier things have been for the consumers participating in the MASS C-PASS pilot under the Arc of Massachusetts Mini-Grant. She stated the flexible support dollars has improved the quality of their lives. Elizabeth Quinn talked about the stigma that she would not be able to take care of herself or earn a living because she suffers from epilepsy.

Everyone agreed that the Greater Lawrence area could benefit greatly from a Consumer Forum. The idea shared was that the Forum would not only bring attention to the concerns and special talents of people with disabilities and elders but the organizing can lead to a network of advocates and providers in the area to maximize results.

II. What localities represent the Greater Lawrence Area?

It was decided that the City of Haverhill will not be included in the Greater Lawrence Consumer Forum. There was interest expressed by people working in Haverhill. However, the Committee shared the belief that including Haverhill will make the Forum too big to be effective. The idea was accepted that a Greater Haverhill Consumer Forum could be pursued after the Greater Lawrence Consumer Forum was well on its way. This meant the localities in the Greater Lawrence Consumer Forum would include Lawrence, Methuen, Andover and North Andover. Quickly after resolving what will constitute the Greater Lawrence Area, people began to think about places the where the forum could be held:

Places to hold the Consumer Forum

- a. Massachusetts School of Law (MSL)
- b. Cambridge College
- c. Lawrence Senior Center

III. Who should form part of the Greater Lawrence Planning Committee?

Brainstorming lead to the following list:

- a. Consumers/Caregivers
- b. Local Office of MRC
- c. Local Office of DMR
- d. Local Office of DMH
- e. Class Inc/ARC of Greater Lawrence
- f. Northeast Independent Living Program
- g. Elder Services of the Merrimack Valley
- h. Lawrence Council on Aging/ Lawrence Senior Center (COA)
- i. Lawrence Housing Authority (LHA)
- j. Mayor of Lawrence
- k. Lawrence Public Schools
- l. Faith Based Programs
- m. Asian Center of Merrimack Valley, Inc.

IV. Next Steps

- Yajaira Blanco, Adalberto Escoto, and Elizabeth Quinn will begin to talk with consumers, elders, and caregivers to participate in the Planning Committee.
- Nilka Alvarez-Rodriguez will reach out to DMR, DMH, MRC, COA, LHS, Faith Based Programs, Mayor of Lawrence, Lawrence Senior Center and Asian Center of Merrimack Valley.
- Zoila Gomez will touch base with MSL about space for the consumer forum and will work with Bill Pitochelli and Yajaira Blanco on generate questions that could be used for the focus groups at the Forum.
- Bill Pitochelli will work with Yajaira Blanco and Zoila Gomez to begin to generate questions that could be used for the focus groups at the Forum.

Next Meeting will be held Monday, May 22nd, 2006, 10:00 AM - Noon
At Northeast Independent Living Program

Greater Lawrence Planning Committee Meeting Minutes
Monday, May 22nd, 2006/10:00 AM - Noon
Northeast Independent Living Center

Participants: Yajaira Blanco - The Arc of Greater Lawrence & Class Inc.
Sara Dubik Unruh, Elder Services of the Merrimack Valley & ADRC
Adalberto Escoto - Lawrence Public Schools
Keith Jones - Self-Advocate, Soul Touchin' Experiences, MASS C-PASS
Jackie Morales – Caregiver & The Arc of Greater Lawrence
Elizabeth Quinn - Northeast Independent Living & ADRC

Chair: Bill Pitochelli - Parent, MASS C-PASS, & Class, Inc.

Staff: Nilka I. Alvarez-Rodriguez, MASS C-PASS Coordinator

Despite the outreach efforts outlined at the previous meeting, the turn out for the meeting was not greater due to the Flood Emergency in Lawrence and people out on vacation. The discussion at the meeting revolved around two main topics. Chair of the MASS C-PASS Marketing & Outreach Subcommittee, Keith Jones, made a presentation about his involvement and the importance of the Forums for consumers. What followed was more logistical discussion around the actual forum.

I. The Importance of the MASS C-PASS Consumer Forums

Keith Jones began his presentation by describing how he was waiting for a cab and someone walked up to him giving him a dollar. Keith joked about thinking maybe he needs to dress better so people do not think he is out begging for money simply because he is in a wheelchair. Then, he spoke about how much of the work we need to do revolves around changing attitudes not only of the average person but also of those providers – including special education teachers – who believe because you are a person with a disability you will not accomplish very much in life. This piece of the presentation inspired others to share experiences as parents with children with disabilities who also have to deal with the ignorance of others.

Keith described the various systems change grants he has been involved in and how difficult it is to find consensus between people with disabilities and elders. Elizabeth Quinn and Sara Dubik Unruh both working with the ADRC (Aging and Disability Resource Collaborative) contribute to the description stating elders do not believe themselves to be disabled but only getting old. Keith also stated young people with disabilities do not see themselves as old and do not fit into a housing environment where elders are seeking peace and quiet. Young people with disabilities want to party just like any other young person. Despite the differences, Keith stated there is the common goal of demonstrating that young or old the system needs to change so that people with disabilities of all ages and even with long term illnesses can enjoy a good quality of life.

Keith continued to talk about the other systems change grants he is involved in chiefly the Real Choice and the Systems Transformation Grant and why MASS C-PASS is different. He said MASS C-PASS is unique from the other 11 systems change grants because of its multicultural, grassroots approach to ensure that the traditionally underserved and unserved racial, ethnic, and linguistic minorities are included in the discussions for systems change. We are reaching out to everyone in the churches, schools, community programs and the like. He further stated that most professionals in the field find this population MASS C-PASS is targeting to be hard to engage so they move on with whoever is at the table; but, we have taken on the challenge to make sure everyone is represented at that table.

Keith warned that during our recruitment for the Greater Lawrence Consumer Forum consumers may act indifferent and will not be as excited as we are. He went on to say that in organizing throughout the State, the question most frequently asked is why should consumers participate in the forum; that is, what makes this forum different from any other. He stated he knows exactly why consumers would ask this question. He expressed empathically how he too participated in forums in the past intended to change the delivery of services and then nothing happened. He described this movement as different because both levels of government and the people in power to create change in the systems are at the table looking for ways to do it. He talked about the involvement of the State's Executive Office of Health and Human Services and of the involvement of the federal government in concert with the State; and, how all of the federally funded systems change grants must lead to real enduring change in order for the State to be in compliance. He also spoke about how the CMS (the Centers for Medicare and Medicaid Services) expects helping people out of institutions and to succeed in self-directed community living will save Medicaid dollars. This is an added incentive for CMS to ensure people with disabilities and elders obtain the freedom to direct their own care and live in their community of choice. He emphasized we can rest assured the consumers' issues will be heard and will be used to guide changes in the delivery of personal assistance services and supports (PASS).

II. Logistics

- The MASS C-PASS Coordinator explained the Project's Consumer Allowance Policy. Consumers and caregivers who participate in the organizing and the planning of the consumer forums are entitled to receive reimbursements for childcare and for mileage or transportation, as well as a small stipend. She then distributed the package with the Consumer Allowance Policy and attached were the forms: Childcare, Mileage and Stipend. The W9 tax form was also included in the package and it was explained that the tax form is only filled out once and when the consumer is requesting a stipend for the very first time.
- Some ideas were discussed for how the Consumer Forum might be designed.
 - Give a history of the Olmstead Decision and MASS C-PASS.
 - Make sure small discussion or focus groups do not turn into gripe sessions.
 - Perhaps discuss what happens when their child gets older.
 - Encourage consumers/caregivers to ask the question: If the system says X, how do I fit?
 - Provide definition of flexible supports – beyond PCA/ADL.
- The Committee will continue to work on the next steps outlined at the 5/8/06 Meeting.

Next Meeting, Thursday, June 1st, 2006, from 10:00 AM – Noon
At Northeast Independent Living Program

Greater Lawrence Planning Committee Meeting Minutes
Thursday, June 1st, 2006/10:00 AM - Noon
Northeast Independent Living Center

Participants: Yajaira Blanco - The Arc of Greater Lawrence & Class Inc.
Joe Bockman, Department of Mental Retardation
Martina Cruz, Lawrence School Committee & Community Family Care
Adalberto Escoto - Lawrence Public Schools
Kevin Farrell – ADRC & Northeast Independent Living Program
Zoila Gomez-Diaz, Esq. – Law Office of Zoila Gomez-Diaz
Keith Jones - Self-Advocate, Soul Touchin’ Experiences, MASS C-PASS
Elana Killilea, Asian Center of Merrimack Valley
Luz Melendez, Parent
Jackie Morales – Parent & The Arc of Greater Lawrence
Elizabeth Marad, Department of Mental Retardation
Lucilia Prates, MORE Program/Elder Services of the Merrimack Valley
Elizabeth Quinn - Northeast Independent Living & ADRC
Flordaliza Rodriguez - Parent
Brunilda Roman – Consumer & Garden of Options
Maribel Serate – Consumer & Parent & Garden of Options

Chair: Bill Pitochelli - Parent, MASS C-PASS, & Class, Inc.

Staff: Nilka I. Alvarez-Rodriguez, MASS C-PASS Coordinator

I. Overview of MASS C-PASS

Bill Pitochelli led the discussion on the scope and purpose of MASS C-PASS for the benefit of those not familiar with this federal demonstration project and to establish the foundation on which the Consumer Forums are based. Bill described this Project from the perspective of a parent of a child with a disability and the challenges he faced. Yajaira Blanco who is running one of the sites in the Arc of Massachusetts’ MASS C-PASS Mini-Project/Pilot and the MASS C-PASS Coordinator contributed to the discussion.

It was established that MASS C-PASS is a federal demonstration project evolving from the Presidential Executive Order entitled the New Freedom Initiative, which stemmed as a measure to facilitate each state the ability to implement the 1998 US Supreme Court Olmstead Decision. Said decision involved two women with psychiatric disabilities who desired to live in the community and not in an institution. The Supreme Court ruled that any person with a disability should have the opportunity to live in the community and support services should be in place to accommodate their community living. In order to accomplish this mandate each state will need to identify and implement changes to the service delivery systems for people with disabilities and elders. One of the federal agencies responding to the Executive Order is the Centers for Medicare and Medicaid Services (CMS), which funds six different types of systems change grants and among these the C-PASS (Community Integration Personal Assistance Services and Supports).

In Massachusetts C-PASS or MASS C-PASS is of eleven systems change demonstration project. The Project reaches out to everyone across the board to design consumer-directed (or self-directed) personal assistance services and flexible supports. MASS C-PASS is unique from others in two aspects: (1) multicultural approach to ensure traditionally underserved and un-served racial, ethnic, and linguistic minorities are engaged in systems change so that the delivery of services is truly responsive to Massachusetts' diverse service population; and, (2) in its grassroots approach to establish local networks of support for individuals to succeed at self-directed community living.

II. Marketing & Outreach Subcommittee & the Consumer Forum Series

Keith Jones, Chairperson for the MASS C-PASS Marketing & Outreach Subcommittee provided a briefing on the work of his Subcommittee and explained the Consumer Forum Series. Keith described that the Subcommittee is gear toward reaching traditionally underserved and un-served racial, ethnic, and linguistic minorities. In so doing, the Subcommittee developed the idea to hold a series of consumer forums across the State to obtain information on what are the barriers to self-directed, flexible personal assistance services and supports (PASS) and generate recommendations to change the State's delivery system. The findings from the Consumer Forums, as well as from the overall C-PASS Project, will be used to inform the self-direction quality management initiatives for the 1115 Medicaid Waiver and the States Systems Transformation Initiative.

V. Barriers, Programs, and Evolution of Services

The overview on MASS C-PASS and of the Marketing & Outreach Subcommittee generated lots of discussion about barriers to flexible supports. All in attendance shared perspectives on surrounding pilot programs like the Coordinated Community Family Care. The local DMR Office and the Asian Center of Merrimack Valley contributed significantly to the discussion on the evolution of services: institution – group homes – independent “ISO”, as well as on Chapter 171 flexible supports. The role of the Lawrence Public Schools was talked about at length with issues surrounding MCAS/testing, need to include teachers, and the effectiveness of translation services. Overall, there was substantial discussion over how to change stigmas within cultural groups.

VI. Conclusion

The meeting did not include any concrete measures toward the actual forum but the discussion helped newly joining members gain perspective on the scope and purpose of the consumer forum. Participants reported feeling motivated to get involve and to engage others in the planning of the consumer forum.

Next Meeting will be held
Wednesday, July 12th, 2006 at Asian Center of Merrimack Valley
12:00 PM - 2:00 PM

Greater Lawrence Planning Committee Meeting Minutes
Wednesday, July 12th, 2006/Noon – 2:00 PM
Asian Center of Merrimack Valley

Participants: Josephina Arroyo – Parent Advocate
Franchesliz Arroyo - Consumer
Yajaira Blanco - The Arc of Greater Lawrence & Class Inc.
Tim Connors - Northeast Independent Living
Martina Cruz, Lawrence School Committee & Community Family Care
Wanda Cruz, Massachusetts Rehabilitation Commission
Jorge A. DeJesus – Office of the Mayor of Lawrence
Adalberto Escoto - Lawrence Public Schools
Anahay Fuchu – Northeast Independent Living Program
Anna Fuchu – Psychological Center
Elana Killilea, Asian Center of Merrimack Valley
Mary Ratkevicius – Lawrence Housing Authority
Julina Mercedes, Parent
Luz Melendez, Parent
Jackie Morales – Parent & The Arc of Greater Lawrence
Jenny Pickett – Northeast Independent Living Program
Elizabeth Quinn - Northeast Independent Living & ADRC
Flordaliza Rodriguez - Parent
Brunilda Roman – Consumer & Garden of Options
Jeanine Sanchez – Massachusetts Rehabilitation Commission
Ban Sat - Parent
Maribel Serate – Consumer & Parent & Garden of Options
David Tagliaferri, Department of Mental Health
Nikki Toeur – Asian Center of Merrimack Valley
Martha Velez – Lawrence Council on Aging & Lawrence Senior Center

Chair: Bill Pitochelli - Parent, MASS C-PASS, & Class, Inc.

Staff: Nilka I. Alvarez-Rodriguez, MASS C-PASS Coordinator

I. Opening Remarks

Bill Pitochelli and the MASS C-PASS Coordinator provided a quick snap shot of the origin of MASS C-PASS and its connection with the New Freedom Initiative federal executive order and the 1998 US Supreme Court Olmstead Decision for the benefit of those attending for the very first time. The involvement of the State's Executive Office of Health & Human Services in systems change initiatives was highlighted. The purpose of the MASS C-PASS Marketing & Outreach Consumer Forum Series was described in detail; and a summary of the recently held Lynn Consumer Forum was given for illustration. The Lynn Consumer Forum had a diverse group of 40 of which approximately 40% were Cambodians, 20% Latino, 20% Deaf Culture and 20% elders (who we are also targeting). Discussion took place on how the issue of language and appropriate translation is an issue critical for the Deaf Culture as it is for racial and ethnic linguistic minorities. This illustration served also to help the Committee identify who is the target population: people with disabilities and caregivers who are members of the traditionally underserved and un-served racial, ethnic,

cultural and linguistic minorities; and, we are targeting all elders since they have been difficult to engage in the systems change because they do not self-identify as people with disability. The transformation of PASS and the overall long-term care system does unavoidably affect the lives of elders.

II. Who else needs to be a part of the Forum?

Discussion about systems change and who is the targeted consumer population led to talks about who else needs to be a part of the forum. The idea moved toward having the consumers make a presentation of barriers to - and recommendations for – successful self-directed community living to key dignitaries.

The MASS C-PASS Coordinator announced that State Senator Susan Tucker, Lawrence Mayor Sullivan, June Black Lawrence Coordinator for Congressman Meehan and DMR Assistant Commissioner Margaret Chow-Menzer is interested in participating. The Mass C-PASS Coordinator further stated she expects to be able to bring officials from the Executive Office of Health and Human Services and from CMS given their focus on systems change. Wanda Cruz and Jeanine Sanchez said they believe they can get the participation of their MRC Commissioner; and, David Tagliaferri shared he will look into getting his DMH Commissioner to attend. Jorge DeJesus representing the Mayor of Lawrence accepted responsibility for having the Mayor invite other mayors, other State legislators, and local officials from within the Greater Lawrence area.

III. Forum and Pre-Focus Groups

It was suggested that the forum had to be at least 3 hours long, provide for breakout groups that would be divided by language. The work was said to culminate in a report back. There was also some discussion on whether the focus group discussions should be driven by categories but not conclusion; but, the decision was made that sessions should be held with facilitators to preparation to run the focus groups at the forum.

Elana Killilea of the Asian Center of Merrimack Valley spoke of the need to have consumer focus groups prior to the actual consumer forum, since most traditionally underserved and un-served racial, ethnic, cultural and linguistic minorities are not accustomed to working in groups and in large forums. The idea was welcomed by the participants and it was also suggested that a type of position paper can be drafted to help articulate the concerns and recommendations of the consumers. It was further suggested that this type of preparation will then allow for the work that needs to be done at the forum to run smoothly. Several people volunteered to help design the Pre-Focus Group Discussion Guide: David, Yajaira, Bill, Elana, Wanda, Jeanine, Nikki and Ban Sat.

IV. Community Outreach

In addition to contacting the local print, radio, and television media, as well as the outreach to service community of the participating organizations there was discussion specifically on outreach to parents and elders. Martina Cruz and Adalberto Escoto agreed to work on recruiting parents. Martha Velez and Mary Ratkevicius volunteered to actively recruit senior citizens. In addition, Adalberto agreed to work with Josephina and Franchesliz Arroyo to create and design a variation of a couple of versions of a flyer to bring to the next Planning Meeting for feedback.

V. Logistics

The Committee agreed to have the consumer forum on Saturday, October 7, 2006 at the Lawrence Senior Center. Logistical issues pertaining to the physical set-up, breakfast, and lunch were discussed. Martha, Mary, and Anna agreed to take responsibility for said logistics. Another logistical matter pertained to use of EZ Transportation. The Mayor's Office was asked to check on their availability. Jorge accepted responsibility for discussing the item with the Mayor and moving on arrangements.

VI. Next Steps

- Martha and Mary will work on logistics.
- David, Yajaira, Bill, Elana, Wanda, Jeanine, Nikki and Ban Sat will work on a design for the Pre-Focus Groups.
- Jorge DeJesus (Mayor's Office) will work on EZ Transportation and at having the Mayor invite other mayors, other State legislators, and local officials from within the Greater Lawrence area.
- Martina and Adalberto will work on the recruitment of parents.
- Martha and Mary will work on the recruitment of senior citizens.
- Adalberto will work with Josephina and Franchesliz to create and design a variation of a couple of versions of a flyer to bring to the next Planning Meeting for feedback.

Next Meeting
Tuesday, August 1, 2006
10:00 AM – Noon
Lawrence Senior Center
(Refreshments will be served courtesy of the Lawrence Senior Center)

Greater Lawrence Planning Committee Meeting Minutes
Tuesday, August 1st, 2006/10:00 am - Noon
Lawrence Senior Center

Participants: Josephina Arroyo – Parent Advocate
Franchesliz Arroyo - Consumer
Yajaira Blanco - The Arc of Greater Lawrence & Class Inc.
Jan Burkholder, Office of Massachusetts State Senator Susan Tucker
Martina Cruz, Lawrence School Committee & Community Family Care
Wanda Cruz, Massachusetts Rehabilitation Commission
Jorge A. DeJesus – Office of the Mayor of Lawrence
Adalberto Escoto - Lawrence Public Schools
Kevin Farrell, Northeast Independent Living Program, Inc.
Noemi Gonzalez, Lawrence Council on Aging and Lawrence Senior Center
Flordaliza Rodriguez - Parent
Brunilda Roman – Consumer & Garden of Options
Jeanine Sanchez – Massachusetts Rehabilitation Commission
Ban Sat - Parent
Maribel Serate – Consumer & Parent & Garden of Options
David Tagliaferri, Department of Mental Health
Nikki Toeur – Asian Center of Merrimack Valley

Chair: Bill Pitochelli - Parent, MASS C-PASS, & Class, Inc.

Staff: Nilka I. Alvarez-Rodriguez, MASS C-PASS Coordinator

I. Updates

The Mass C-PASS Coordinator provided a briefing on the Urban Pride/Martha Vineyards Consumer Forum, as well as on her presentation in Montana to the various states also working on C-PASS Demonstrations and Independent Plus (Waiver development on self- direction). She explained that the Urban Pride/Martha Vineyard Consumer Forum revealed the lack of services going out to the Island and the Boston Parents serious issues with the State Agencies and the Boston Public Schools. She emphasized that the organizing and planning process customary to realize consumer forums was not followed in this instant. The invitation was extended to make the forum part of a three-day retreat organized by Urban Pride. The entire forum was a day long, since the participants first had to be brought up to speed with what C-PASS was looking to achieve and a great deal of time had to devoted to allowing the participants to vent over specific problems they had encountered. The Coordinator expressed the hope that the Greater Lawrence Consumer Forum would not be focused on chastising State agencies but rather on specific barriers to self-directed PASS.

In Montana, the three-day Conference was organized by CMS (Centers for Medicare and Medicaid Services) and focused on quality measures and recommendations for services to be rendered on Medicaid to ensure self-direction. The Coordinator was asked to make a presentation on the consumer forum series and its impact on gathering information and including traditionally underserved and un-served racial, cultural, and linguistic minorities. During her presentation it was clear that the responding to the traditionally underserved and un-served will not require a separate service system but making improving on the overall service delivery to attend to the unique features of all consumers. In other words, work from the premise that every consumer is not only a member of the disability culture but are also members of other social groups that affect their values and ideas about quality services. Overall, the participants in the Montana Conference were impressed with the work of Massachusetts' C-PASS.

III. Small Groups

The Small Groups Subcommittee which includes David Tagliaferri (DMH), Yajaira Blanco (AGL and Class), Wanda Cruz (MRC) and Jeanine Sanchez (MRC). They have been working the design and facilitation of the small discussion groups. David and Yajaira opened the discussion sharing the questions that will be asked in small groups to obtain information on barriers and recommendations. Consensus was reached on using the questions as proposed and outlined below.

- 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?

Discussion continued over what considerations should be made in breaking-up the forum participants into small discussion groups. Consensus was immediately reached to keep the groups small – allowing for no more than 10 people per group. The idea is to make certain everyone is heard from. The Committee also agreed to make an effort to break-up the groups into the following categories:

- Language (including deaf and hard of hearing)
- Disability
- Need
 - i. Elders
 - ii. Parent
 - iii. Youth
 - iv. Caregivers/Elders
 - v. Caregivers/Youth

Discussion on the category type of groups led to question how to plan or better facilitate the process for the break-out, small groups. Pre-registration of the participants became the most accepted idea; and, each member of the Committee made a commitment to recruit 10 consumers (including parents and caregivers). The Coordinator agreed to develop the pre-registration form and to distribute it immediately for the recruitment to move forward. Information gathered through the forms will be given to the Small Groups Subcommittee. It was determined that the pre-registration form ought to solicit information on necessary accommodations. The pre-registration should include the items in the following outline.

- Language
- Need area
- Childcare
- PCA
- Transportation
- Special Accommodations/Reasonable

Next important item revolved around who will facilitate and the need to have a preparation session to share strategies to acquire the desired data from the groups. Volunteers were requested and the following Committee members agreed to be facilitators: David, Yajaira, Wanda, Jeanine, Kevin, Maribel, Adalberto, Martina, Nikki, Francesliz and Josephine, as well as other facilitators recruited through Martha Velez, Assistant Director to Lawrence Senior Center. The Subcommittee Members agreed to get together with the volunteers at the end of the Meeting to agree on a date and time for the “prep” session.

IV. Outreach Flyer

Adalberto Escoto from the Lawrence Public Schools worked with a team (Francheliz and Josefina - the mother daughter dual) to develop several versions of an outreach flyer. At the beginning of the Meeting he distributed the three versions of the flyer for Committee Members to look over. At the time of Adalberto’s presentation Committee Members were prepared to offer feedback both orally and written. The bulk of the changes consist of placing the formal name of the organizations, including those missing, and on the layout itself. On the flyer Garden of Options has agreed to be the contact organization, NILP agreed to provide the TTY phone service, and C-PASS Coordinator e-mail address will be posted for the electronic inquiries.

Jan Burkholder from Senator Tucker’s Office asked why certain organizations in the area – such as American Training - were not on the Flyer. It was determined that she would reach out to those organizations so that they are included in this consumer forum project. Consensus was reached to combine two of the flyers containing the ideas expressed by the Committee. Adalberto will make the recommended changes and send the changed flyer electronically to everyone for final comments.

V. Outreach Strategies

Adalberto made the suggestions that an Outreach Subcommittee should be formed to develop outreach strategies including media. Jorge DeJesus from the Mayor's Office stated their work on composing a press release and generating an invitation to the legislators and other dignitaries could not be done until the program was secured. The Coordinator agreed to work with Jorge and other interested members to develop outreach strategies – a meeting will be called at the Mayor's Office. While the Subcommittee work will be focused mainly on media. Kevin will be connecting with NILP's Youth Program and Martina on the recruitment of youth with disabilities from the local high schools. Adalberto and Martina will continue to recruit parents. Everyone will reach out their consumer base to recruit and pre-register a minimum of 10 participants.

V. Next Steps

- Small Focus Group Subcommittee will be meeting Tuesday, September 5th, from 11:00 AM - 1:00 PM, at MRC, located at One Parker Street in Lawrence.
- Community Outreach Subcommittee will meet and develop outreach strategies. This meeting will actually be focusing on the media strategy (radio, TV, print).
- Adalberto will make the recommended changes to the outreach flyer and send it out to all.
- Jan will be reaching out to other area agencies to join our list of sponsors.
- Kevin will be connecting with NILP's Youth Program and Martina on the recruitment of youth with disabilities from the local high schools.
- Adalberto and Martina will continue to reach out to parents.
- Each Committee Member will recruit and pre-register a minimum of ten consumers.

Next Full Planning Committee Meeting
Wednesday, September 6th, from 10:00 A.M. to Noon
Lawrence Senior Center
145 Haverhill Street – Lawrence



Participant Contact Information

First Name		Last Name:	
Address:	City:	State:	Zip:
Telephone:		Email:	

Focus Group Discussion Enrollment

<p>Check The BOX that applies to you</p> <p><input type="checkbox"/> I am a Senior Citizen</p> <p><input type="checkbox"/> I am an Adult Person with a Disability</p> <p><input type="checkbox"/> I am a Youth with a Disability</p> <p><input type="checkbox"/> I am the Parent of a Child with a Disability</p> <p><input type="checkbox"/> I am the Parent of a Teen with a Disability</p> <p><input type="checkbox"/> I am the Parent of a Adult with a Disability</p> <p><input type="checkbox"/> I am the Caregiver for a Senior Citizen</p> <p><input type="checkbox"/> I am the Caregiver for a Child with a Disability</p> <p><input type="checkbox"/> I am the Caregiver for a Teen with a Disability</p> <p><input type="checkbox"/> Other _____</p>	<p>Check Preferred Language</p> <p><input type="checkbox"/> English</p> <p><input type="checkbox"/> Spanish</p> <p><input type="checkbox"/> Khmer</p> <p><input type="checkbox"/> Vietnamese</p> <p><input type="checkbox"/> Portuguese</p> <p><input type="checkbox"/> Deaf/Hard of Hearing</p> <p><input type="checkbox"/> Other _____</p>
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**Please Check Reasonable Accommodation Requests On This Form.
 Be Specific. We Will Do Our Best To Meet Your Needs.**

PCA Services Yes No

I will bring my PCA and they will join us for lunch Yes No

CART Reporter Yes No

Sign Language Interpreter Yes No

Braille Yes No

Large Print Yes No

Childcare Yes No

Other Needs, please describe:

Photograph/Video Disclaimer

Please note that video and photography will be used during this forum. By registering for this forum you give permission to the organizing committee and sponsoring organizations to take, retain, publish and use the pictures or images in whole or part of you and/or your dependents of age 18 or below. If you have any questions or concerns about this, please let us know either by writing to, e-mailing to, or calling us. Thank You.

Signature:	Date:
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