

Massachusetts CPASS Coordinating Council Self-Evaluation

*A self-evaluation by the Coordinating Council of the work conducted under the Massachusetts
Community-Based Personal Assistance Services and Supports (MASS CPASS) Grant*

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Prepared by: Emily Lauer

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Overview

The Coordinating Council was formed in the Fall of 2004. During the progression of the Massachusetts CPASS project, certain ex-officio members were added such as representatives from the demonstration projects. The Council met regularly throughout the grant and during the grant's one-year no-cost extension. The Council is set to sunset in September 2007, with voluntary participation offered in a proposed self-determination council. In the last two months of the CPASS grant, a survey was distributed to both official and ex-officio members of the Coordinating Council. The survey is attached in Appendix A.

The survey was sent to 25 members, 14 of which responded. Three requests were made for the surveys, and additional time was provided to encourage council members to respond.

Evaluator's Note:

This report is termed a 'self-evaluation' because council members were asked to evaluate their own performance. It is important to note that the duration and consistency of participation varied between members. In addition, some members participated in subcommittees for the project, providing them with a potentially expanded and different view of the grant activities than other members who were on different subcommittees or participated solely through council meetings and correspondence.

This 'self-evaluation' provides information on the majority of the different grant activities. It should be read in concert with the independent project evaluation, which focused on evaluating the demonstration projects. In some areas of this self-evaluation, council members have cited the need for additional or expanded work. It must be noted that some of this work was conducted during the grant period, but may not have been presented to the council, or was not presented during the member's period of participation. The comments expressed here are from the perspective of the council members, and should be read as such.

COORDINATING COUNCIL

Council Member Participation

Council members were asked if they felt that they were fully able to contribute to CPASS in their participation on the Coordinating Council (CC). One member was not able to due to personal and work obligations. All other responding members felt they were fully able to contribute. Some of the factors they cited as helping them to fully contribute were:

- Enthusiasm, welcoming-nature and commitment of CC members & chairperson
- Quality and engaging nature of member discussion
- Involvement in grant activities that built upon Council members' experience and expertise (ex. Development of a particular community forum)
- Having access to staff members who could clarify and provide further information
- Supportive nature of the project team allowed participants not to feel pressured and valued all levels of participation
- Materials were always made available in electronic format
- Meetings:
 - Scheduling of meetings well in advance and with input from council members
 - Central meeting locations, convenient meeting times
 - Some phone access to meetings for those who couldn't physically be present
 - Provided transportation to meetings and events for those needing assistance
 - Reimbursements for travel and baby-sitting
 - Directions provided to the site
 - Meeting locations were always accessible

Members were also asked what could have enabled them to participate more. Some members responded that all their needs were met, while others mentioned the following factors. It should be noted that the majority of the respondents to the survey were those members that were still regularly active in the second half of the project period.

- **More time to attend meetings and provide more input and fewer work conflicts** (most frequently reported)
- More staff resources
- Consistent phone access to meetings
- Start meetings more promptly at scheduled start time
- For those of us who came in late in the process, having a full understanding of the work being done from beginning to end. Also, a clear understanding of our roles.
- Transportation to go to more forums
- Closer meeting locations

Consumer-driven Coordinating Council

The original project management plan for CPASS called for a “consumer-driven C-PASS Coordinating Council.” Most responding Council members (ten) felt this was achieved; four were mixed on this topic or unsure whether it had been achieved. Of those that were mixed, most felt that while the Council had a lot of consumer participation, it could have better engaged some consumers.

Members cited aspects of the Council to support their opinion that it was consumer-driven. The council had a majority of people with disabilities and family members, which many cited as a real strength of the Council. It involved both actual unpaid consumer-participants and state and service providers who were also consumers.

Some respondents appeared to look at the project as a whole, rather than just the Council and cited other areas where the project was consumer-driven. One respondent remarked: *“The community forum format coordinated and conducted by bilingual and bicultural staff from various communities has enabled the direct participation of consumers and families in talking openly about issues that are most important to them.”*

Some felt that while the council strongly recruited consumers, there were times when consumers could have been more engaged. *“Opportunities for discussion at Council meetings were open to everyone, but I am not sure the agenda and goals of the Council were clearly understood by all consumers. Therefore, there were many meetings where the discussions did not seem to engage the majority of consumers.”*

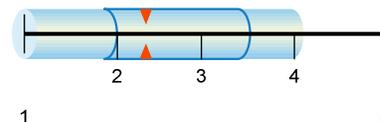
Coordinating Council Duties

Members were asked to rate how well they felt the Council accomplished each of the duties assigned to it at the start of the grant.

Next to each duty, a graph of responses is presented. The numbers represent a continuum where 1 represents “well accomplished” and 5 represents “not accomplished”. The circular bar represents the range of responses. The triangular point represents the average of responses, and the outline on the bar shows one standard deviation on either side of the average. If this outline is wide, the responses were more dispersed. If it is closer to the average, the responses were more similar.

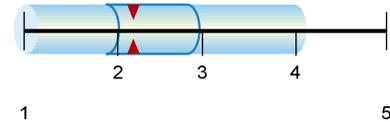
1. Establish rules of procedure and meeting schedules

The average response was moderately accomplished (2.4). Responses were most mixed on this duty; members felt meeting schedules were more established than rules of procedure. Four people rated this duty as not well accomplished (4), and ten rated this as well accomplished (1 or 2).



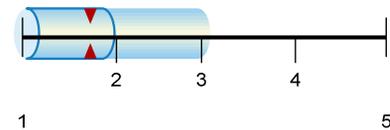
2. Organization within Council meetings

The average response was accomplished (2.2). Eleven people rated this as accomplished, or well accomplished (1 or 2), with two providing lower ratings. One person did not respond.



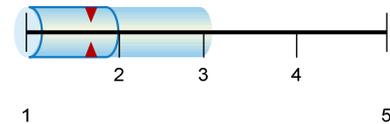
3. Develop and modify project work plan as appropriate

The average response was accomplished (1.9), many felt it was done well. One person remarked that they were unaware that this happened.



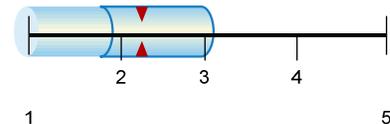
4. Selection of subcontractors/subgrantees

The average response was accomplished (1.9), many felt it was done well.



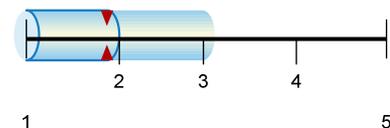
5. Maintaining linkages to the other state initiatives (ex. Systems Change grants)

The average response was accomplished (2.3), most giving it a score of (2).



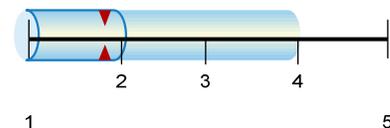
6. Maintaining coordination across subcommittees

The average response was accomplished (1.9), most scoring it as 1 or 2. One person was unsure.



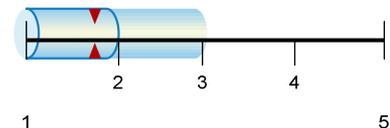
7. Monitor progress on goals and objectives

The average response was accomplished (1.9), most scores were well accomplished (1 or 2), but one person did not feel it was not well accomplished (4).



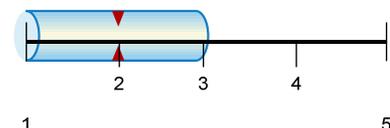
8. Facilitating implementation of demonstration projects

The average response was well accomplished (1.8). Responses were almost all in agreement that this goal was well-accomplished (1). This was the highest score of all duties.



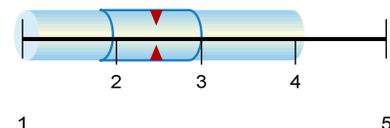
9. Management of demonstration projects

The average response was accomplished (2.0). Most responded with a 2 or 3 to this response.



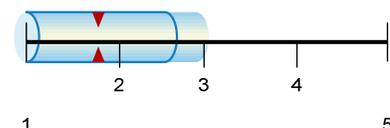
10. Dissemination of successful models from CPASS

The average response was moderately accomplished (2.5). Responses were mostly 3, followed by 2. This appears to be an area CPASS could reexamine in the last portion of the grant.



11. Draft changes in regulatory, budget and policy language to sustain the project's success

The average response was accomplished (1.9), responses were mixed between 1, 2 and 3.



Comments on these duties from members:

"I think the bill that was filed and the involvement of legislators was a great achievement of CPASS, but it remains unclear how such legislation, if passed, will "trickle down" to the state agencies and providers and what the actual outcome will be."

"[It's] not clear what components from grant will be directly sustained."

“There also was little discussion about recommendations for regulatory changes (for example, PCA program was a big focus but very little recommendations or discussions for policy or regulatory changes were made to the funding agency (MassHealth)); and little discussions about budget. To my knowledge, CPASS has not been in discussion with EOHS, where the locus of most of these changes would need to originate, about any of its findings/recommendations.”

Board Development Skills

Members were asked whether they felt additional board development skills would have benefited the Coordinating Council. Most members did not feel additional board development skills would have benefited the Council. Many felt that because it wasn't a governing board, they were not necessary. Many felt that most Council members had a relevant skill set before coming to the board.

Some members mentioned that perhaps some additional one-on-one work with consumers and family members would have been beneficial. While efforts were made in this area, members felt some consumers still appeared to lack confidence in some areas about their skills, participation or knowledge. Instead of board development skills, members made other suggestions of training on cultural understanding and support in order to affect true systems change.

Representation on the Council

Members were asked whether other groups should have been represented on the CC. Four felt that a good job was done recruiting several different groups. Of these, one remarked that the original membership had more ideal representation and that for those that became inactive, efforts should have been made to replace those representations.

The following additions were suggested by members: more self-advocates, more elder representation, more minorities to represent other cultures, languages and ethnicities and other disability groups to balance out the over-representation by developmental disability (DD) groups. Members acknowledged that in some cases more representatives had been invited, but did not accept and that a larger budget would have been needed to add more groups. It was also mentioned that input from service providers would be helpful to inform efforts to implement legislation & recommendations, even if not part of the Council.

Role of the Council: Advisory vs. Active Management

Members were asked whether they felt the Council had only an advisory role to the project, an active management role with decisive power or both. They were also asked to discuss the strengths and weaknesses of the Council's role. Five members felt the Council had both roles. Six felt it had an active management/decision-making role, and two thought it was only advisory.

Strengths:

- Dedicated, committed members. Members did an incredible job participating and contributing despite having other responsibilities and obligations.
- Strong support and facilitation from project coordinator;
- Members willing to do the work to move the project forward;
- Excellent model for future collaboration of interagency, cross-disability, cross-age, cross-culture
- Diversity and scope of views and experiences
- Committee had an active role with language, next steps, brainstorming and how to make CPASS make a difference and not just be a committee where any work or results don't go anywhere
- Cross disciplines, cross disability, cross age representation, also cross cultural and cross agency
- Consumer participation

Weakness:

- Given the late start in CPASS, it appears to have taken a while to develop a “team” where people felt comfortable sharing thoughts and ideas.
- The time in bringing everyone to the same level of understanding
- Grant seemed to be less connected to active policy work
- No decision-making by the Council on funding

Time Commitment for Council Members

Members were asked how reasonable the expected time commitment was to participate in the Council. Of those that responded, all felt it was reasonable. Some commented that the time requirement was significant, but reasonable for the task/project. Members valued that their time was usually well-spent, and that any level of participation was appreciated with work or life challenges arose.

CPASS PROJECT

CPASS Management Model

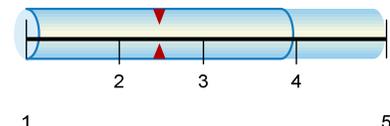
One of the goals of the Council was to break the vertical management model and adopt a more collaborative management model. Members were asked how well this was achieved. Most (10) felt that it was achieved and done well. Some felt certain members who were reluctant to speak up could have been more engaged to balance some discussions. Three felt the management model was still vertical, mostly because breaking the vertical management model would be politically-charged and would involve State agencies and service delivery organizations. Skepticism was expressed by some as to whether it was possible for the Council to break that model on its own.

CPASS Project Goals

Members were asked how well they felt the Council met each of the original project goals, and what the strengths and weaknesses of the Council’s approach were to the goal. *Each goal was scored on a rating scale where 1 represents “well accomplished” and 5 represents “not accomplished”.* See the box on page 2 for an explanation of the graphs to the right.

Goal 1: Develop and test quality assurance and safeguard procedures that will ensure the scope and quality of services are consistent with need and are delivered in a coherent, timely manner.

The average response was that this goal was moderately achieved (2.5). Responses were mixed for this goal, with some members feeling it was very well-achieved and others felt it wasn’t achieved at all. One member felt they weren’t able to comment.

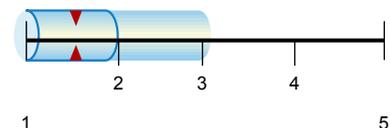


A portion of members did not feel that the Council developed a mechanism for testing the quality and appropriateness of services being delivered by mini-grantees. While grant activities such as the public forums and outreach/education raised consumer expectations, it did not rigorously test these factors.

Members felt that frequent communication from the demonstration projects enabled the CC to monitor the goal well. Members who felt this goal was satisfied pointed to evidence from the demonstration results, together with a review of literature and building upon the foundation of quality assurance work from the Real Choices grant.

Goal 2: Develop and fund consumer-directed demonstration projects that explore maximum opportunity for self-direction and flexible use and allocation of supports across age and disability categories.

The average response was that this goal was well-achieved (1.6). Members were mostly in agreement on this goal, often giving scores of 1 or 2.

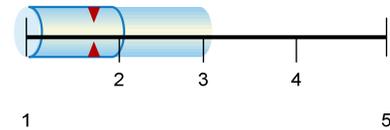


Members identified the design of the RFR and provision of decisive power to the Council to select the demonstration grant recipients as strengths in the approach to this goal. Also consumer participation, inclusion of diversity of race and disability, and a consistent and strong emphasis on the need for services to be supportive of self-determination and self-direction were identified as strengths. Members felt that having past projects to build on (such as C-PIG) aided this goal. Some felt that the demonstration projects could have used more time, especially to show sustainability.

Some members felt that the demonstrations could have been more innovative and done more to differentiate themselves from other grants and pilot projects. Although members felt the demonstration projects were well-run, some felt they mostly re-demonstrated what was already known in Massachusetts. Some members were hoping that demonstration applicants would use the opportunity to try more things that are not currently allowed under the existing system.

Goal 3: Identify/develop and field test various models to prepare, support and empower consumers and/or surrogates to select from a menu of options that allow differing levels of self-determination and control over the type and format of services desired.

The average response was that this goal was well-achieved (1.8). Members were mostly in agreement on the achievement level for this goal, often giving scores of 1 or 2.



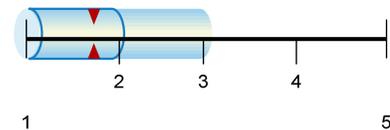
Many members commented that the flexibility of the project was a strength when testing models. The project had an awareness of cultural and ethnic differences, and allowed for diversity across cultures and disabilities in consumer choices. A member commented that the ability of the Council to give subgrantees some clarity around the desired overarching goals to be achieved via the demonstration projects was also a strength. Members also felt the strong consumer participation was a positive part of the Council's approach.

"[The] combination of mini-grants and policy subcommittees and consumer forums provided information from various sources and with different perspectives. It was a multi-dimensional approach that yielded valuable and useful information."

A small portion of members were not clear on the actual models that were tested, outside of supplemental funding to traditional services. Numerous members commented that demonstration projects could have used more time to gather more information. It was also commented that less paperwork would have been appreciated.

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.

The average response was that this goal was well-achieved (1.8). Members were mostly in agreement on this goal, often giving scores of 1 or 2.



Numerous members listed the evaluation and the change in selected evaluators as a strength. Also, the CC made a commitment early on to seek sustainable options. Members cited a very active Project Evaluation Subcommittee, and many members positively reviewed the Committee's choice to change evaluators. Members listed the evaluation, with CC involvement, as a strength.

The community-based and culturally sensitive approach to seeking sustainable options for self-determination was also discussed. *"The interpersonal relations and networks nurtured by CPASS and CC will have a long lasting and profound impact on transforming the long term care service and support system in Massachusetts."*

"Commitment of CC to continue the work started by CPASS even if funding is not assured speaks volumes about the successful collaboration and potent structure consisting of the many stakeholders"

(including consumer coalitions from the consumer forums, state agency representatives, providers, and legislators) who will volunteer their time to advance self-determination."

"Involving other providers, not as Council members but as persons the Council could interview about consumer direction, may have made this more achievable." While the Council did develop a long-range plan, some members felt the plan could have been stronger, including more clarification around the self-determination model for the state. Members expressed that the legislation and the program should be advertised in communities outside of DMR and the agency's related groups.

Challenges and Successes

Members were asked their opinion about the 2 largest challenges faced by CPASS during the grant period. The following challenges were cited by multiple members:

- Organization of and communication within the Coordinating Council. Members discussed challenges in getting the members to coalesce as a steering body, ensuring members were on the same page and understood what CPASS was trying to achieve, and overcoming early delays and organizational challenges in the grant work.
- Sustaining full and on-going participation over a multi-year process. At some points, it was challenging to keep members from all groups engaged and interested.
- Need to change evaluators.

Other challenges that were mentioned included:

- The time needed for coordinating and assisting with the implementation of the pilot projects
- Money and high level support beyond the PI to implement the changes needed to services the populations focused on by this grant
- There was a learning curve not anticipated since most of the people were veteran disability service workers or advocates.
- The length of time of the grant
- Agreeing on key definitions, like "self-determination"
- Lack of clarity pertaining to target for change;
- Broad definition/population focus while working within DD model/community perspective
- State system that was pretty unfamiliar with Person-centered planning, which was hard to do in a short time period
- Paperwork
- Lack of fund control by the CC

Members were also asked their opinion about CPASS's two biggest successes during the grant period. The following challenges were cited by multiple members:

- Self-determination legislation and the engagement and education of legislators on consumer direction and self-determination
- Development of the community forums and marketing through these forums
- Development of Mini-Projects that provided evidence of the effectiveness of, and satisfaction with, consumer driven services.
- Establishment of a stakeholder network (both grassroots and professional)
- Engaging people from various cultures, particularly those in historically underserved communities, and maintaining cultural sensitivity throughout the project

Other successes mentioned include:

- The marketing at the national and political level
- Grass roots needs assessment
- Flexibility in project administration
- More options for folks and broadening of options that were not prescribed

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- The broad representation on the CC reflected the philosophy of entire project: cross-cultural, cross disability
 - Consumer/family participation

Consumer Participation throughout CPASS

Members were asked if they felt there was enough consumer involvement in the CPASS project and whether they felt consumers had a powerful voice. The large majority of members that responded, including some consumers themselves, felt that there was a lot of consumer involvement in the project, and that the consumers had a voice. In addition, a significant amount of the grant budget went to support consumers' participation.

The members agreed that the clearest and strongest consumer voice was through the community forums. A member expressed that the consumer involvement that was not uniform, stating that some consumers contributed more than others. Some consumers were not as vocal, "possibly because they did not understand what CPASS was all about or had never heard of self-determination. It was helpful to have consumers who understood the current system and the legislative process, but not all consumers do." Some members commented that the consumer involvement in the forums was much stronger than the consumer involvement at the Council level. A few members also expressed that there should have been "voices raised by people with a larger variety of disabilities (deaf, blind, etc.)."

Reflection:

Usefulness of Pre-grant Organizational Period

Members were asked whether they felt that 6 months to 1 year of organizational time before the start of the demonstration projects and forums would have been helpful.

The response across members was mixed. About half of the members felt that this would have been useful to aid grant organization. Others felt that any additional time would not have been useful. Some members suggested involving consumers (through forums) earlier in the process. Many acknowledged that it does take time to build a council who has organization, coherence and feels comfortable working together. Some suggested that taking some time during the grant for the Council to do more self-evaluation and reflection on goal progress would have been more useful than a larger period at the beginning.

Agenda for an Additional Grant Year

When members were asked what they would prioritize during an additional grant year. The two most common responses were to focus on ensuring the Self Determination legislation is passed and implemented in the state, and to explore ways to sustain the Statewide Grassroots Network of coalitions and continue community linkages and engagements.

Other suggestions included:

- Strengthening and extending the pilot projects
- Adding more diversity to the Council
- Create more opportunities for field-testing systems change
- Continue training and support for consumers to self-direct
- Finish the work to make consumer direction possible in the state system: state contracting processes, developing state budgets, hearing from provider community on ideas for implementation, etc.
- Join forces with other systems change groups to develop and sell to the new administration a cohesive, comprehensive plan to make state-funded services more responsive to consumers needs.
- Work on building more ethnic community buy-ins
- Concentrate on assurances and safeguards to protect access to supports that allow the greatest amount of consumer control

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- Spend time strategizing an approach to provider organizations, likely the most powerful opponent to a system that would change the locus of control

What would members change?

- Engage legislators earlier
- In the RFR for the project evaluator, require that applicants provide an evaluation design before awarding a contract to the consultant. The group first hired was non-responsive causing further delays in implementation. Today we know better what specific type of evaluator is needed for demonstrations like C-PASS.
- Provide greater structure to the mini-projects, and ensure the project design was creative and innovative in contrast to past efforts. In practice, the projects requested and required more structure than anticipated.
- Spend more time analyzing existing projects and systems in other states may have better-enabled the project to address deficiencies other programs encountered and were unable to follow through on, rather than creating two more “Cash and Counseling” models.
- Set up a process to analyze obstacles to self-determination, first, then invite proposals for pilot projects that specifically sought solutions to those obstacles.
- Develop stronger connections between what was happening at the grassroots committee level to what is happening at the state policy design level

Should Consumer Forums Be Sustained?

The members were basically in agreement that the community forums were a great source of gathering a great deal of consumer input. However, the members were mixed as whether the groups should be sustained and what their role might be. Most members felt that they should be continued if they could have a concrete role that could be tapped for consumer input on current issues. Many members acknowledged that maintaining the forums would require the identification of a consistent funding source, and would require manpower to maintain the groups. In most cases, the groups would require work to transition from the initial groups into something more sustainable over the long-term. Members were concerned about maintaining the groups without a clear role, agenda and purpose for them. Some members cautioned against holding community groups without also putting in the time to respond to their concerns and needs directly and provide feedback to the groups. With the right support the groups would be very useful, but without that support, the forums may be more detrimental to the relationships with communities than beneficial.

Demonstration Project Design

Members agreed that the demonstration projects yielded valuable information, including the identification of many important barriers, in particular, the identification of barriers created when individuals from other cultures, languages, and ethnicities become engaged with the systems of services. More time for these projects would have been beneficial to examine barriers to sustainability as well.

However, some members felt that the projects did not completely systematically test barriers. Some also felt that barriers for consumers in general were missed by the narrow focus of the projects. For example, the funding given to consumers was largely supplemental to other services. While this showed benefits, it did not necessary test barriers within the resources provided by the current service system for all consumers.

Sustaining the Work of the Council

Members were asked how to best sustain the work of the grant and the Council after the end of the grant period. The most popular answer among member was to see to the **realization of the Self-Determination legislation** and continue working with policymakers.

Other Recommendations include:

- The Council should continue to serve as the coordinating engine for system change to better reflect diverse communities served by the Commonwealth of MA
- Market the project at the national level
- Advocate for systems change at the local political level, using C-PASS as a more efficient model that respects human rights
- Support the continued existence of the Statewide Grassroots Network across different ethnicities.
- Find additional funding sources to pursue implementation of findings and recommendations and community first initiatives
- Ensuring policy change within administration
- Imbue the drive for self-determination in existing advocacy groups and help them find the support they need to sustain the work.
- Define clearly what the intervention was for each pilot area and develop ways to sustain interventions in larger system
- Get "flexible" and "self-determination" language in new 1115 waiver as well as all other HCBS services (not just the self-directed programs).
- Training statewide with financial support for consumers, family, staff, state agency, personnel
- Flexible control with empowerment

Special Project Focuses

Members were asked how well they think the project explored each of the following special focus areas.

1. Understanding and addressing the needs of under represented groups

Most members felt the project explored this focus well throughout a wide span of groups in the consumer forums, and with a narrower focus in the demonstration projects. A strength of the project was the way it reached out to various groups that are traditionally underserved and did so in a way that invited people to participate and feel a part of the solution.

Members would have also liked to see involvement from the following under-represented groups:

- GLASS community; greater voice from elder community
- More minority groups, including Vietnamese, Portuguese and Russian communities
- Those with learning disabilities, blindness, deaf and hard of hearing and more representation for those with brain injuries

2. Exploring adaptations necessary for cultural awareness and encouraging this awareness in service planning

Most members felt that CPASS did well in the area of cultural awareness, as evidenced by the findings in the demonstration projects and consumer forums. A few members felt that a clearer pathway for the application of this information is needed.

3. Emphasizing the adaptation of approaches to accommodate an individual's culture, while attempting to move away from administrative cultures

Most members felt CPASS did well emphasizing the need to accommodate an individual's culture during the grant, although a couple members were unsure or felt that more work was needed in this area. Members felt the consumer forums helped emphasize cultural awareness. It will be important for the project to continue to emphasize this adaptation after the end of the project.

4. Designing services to address participants needs instead of forcing people to choose from available defined services

All members who provided feedback felt CPASS did very well addressing the needs of participants in the demonstration projects. However, some members would like to see more clarification about how these service designs will be carried over into the existing system and sustained. In addition, a member

brought up the need for affordable housing options that would allow one to continue to belong to their community.

5. Develop political awareness and strengths across cultural, age & disability groups

Many members felt that political awareness was well achieved across these groups within CPASS through the grassroots approach, consumer forums with guest speakers and by encouraging legislative advocacy. Some members remarked that they would like to see this very important political awareness include additional groups as the movement grows.