

MASS CPASS EVALUATION REPORT

**An independent evaluation of the work conducted under the
Massachusetts Community-Based Personal Assistance Services and
Supports (MASS CPASS) Grant**

**Presented to
The CPASS Coordinating Council**

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Executive Summary

Note: This evaluation focused on the Demonstration projects. Also see the Coordinating Council Self-Evaluation for more evaluative information about grant activities.

Introduction

In 2003, Center for Medicare and Medicaid Services (CMS) awarded a grant to the Massachusetts Department of Mental Retardation as part of their *Systems Change for Community Living Grant Categories*. The focus of the grant was to develop sustainable mechanisms to ensure consumer choice and consumer direction in personal assistance services and supports. A portion of the grant was devoted to the demonstration of a service delivery system based on the principle of self-determination that allows for self-direction of supports.

Specifically, the CPASS demonstration project in Massachusetts identified four major goals:

- *“Develop and test PASS quality assurance and safeguard procedures, including a consumer satisfaction survey process, that will ensure the scope and quality of services are consistent with need*
- *Develop and test consumer-directed demonstration projects that explore maximum opportunity for self-direction and flexible use and allocation of supports*
- *Identify and field test models to prepare, support, and empower consumers or surrogates to select from a menu of options allowing differing levels of self-determination*
- *Evaluate the effectiveness of the pilot projects and the achievement of all grant goals and objectives and develop a long-range plan for systems change to sustain MASS CPASS successes.”*

The grant committee chose to include a focus on cultural influences on self-determination. The pilot project centered specifically on Latino consumers, a large and fast-growing population in the Commonwealth of Massachusetts. Two agencies, the Multi-cultural Community Services of the Pioneer Valley, Inc. and the Association of Retarded Citizens of Massachusetts participated in the grant activities, and oversaw demonstration projects in three agency offices in Holyoke, Lawrence and Boston, Massachusetts.

This report independently evaluates the process and outcomes of the demonstration projects and the progress toward the goals of the grant. A consumer-driven model of evaluation was selected for the demonstration projects that places the individual receiving services in a central role as evaluator by empowering them to assess their services and planning process for themselves.

Findings

Structured interviews were conducted with almost 90% of participants and 100% of staff members involved in the demonstration project. Adaptations, including interpretation and picture cues, were incorporated into the interview process to address participants' communication needs. Over 90% of the participants and families interviewed were Latino.

Participants included both children and adults, and represented many disabilities including those affecting physical and intellectual abilities.

Satisfaction with the person-centered planning process was high among both participants and staff. For many participants, the freedom to design their own services has greatly improved their satisfaction and their ability to progress toward their goals. Most participants reported an increase in their happiness and satisfaction with life since participating in the CPASS demonstration project. Some consumers reported more confidence in themselves, and an increased perception that they could make decisions for themselves. To some consumers, independence was a learning process and it was important that the process was flexible enough to allow them to work through their own needs and change their mind as needed. Most participants felt their freedom of choice and decisive power increased in the pilot, as compared to their past experiences with supports and services.

Most staff felt that a family's culture has a large impact on their service needs. Language tends to be the most significance difference in working with consumers of a different culture to coordinate services.

Conclusion

Overall, it seems that the participating agencies were all able to understand and embrace the philosophy of self-determination in this project. The agencies' ability to assist consumers in their planning process and develop truly person-centered plans, in this evaluator's observations, met the project goals.

However, the agencies did encounter some barriers and hurdles during the demonstration project. Agencies invited consumers to participate in the demonstration project, some of which were met with more challenges than many of the consumers served by the agencies. Assisting these consumers challenged the agencies to the best of their abilities in the current service system. In many cases, the success of the planning process and the realization of the consumers' goals were due to the efforts and dedication of the agency staff. The staff guided many of these consumers to teach them how to consider their own independence and envision the process to get there. Person-centered planning as experienced in this pilot is truly a process, one that is done by attentive and skilled staff members that have earned the trust of the individuals they serve.

However, the person-centered plan is only the beginning of a system and a community that values self-determination and supports the self-direction of services. Once a consumer identifies their goals and accompanying milestones and pathways for achievement, the largest hurdles are currently encountered while trying to fulfill these plans.

The community and the current service systems could do a lot to ensure the realization of person-centered plans and to create an environment that nurtures self-direction. Consumers and their assistants are met with many of the largest challenges while trying to procure and consistently fund services to fulfill these plans.

A variety of current situations were identified in this demonstration project that can contribute to these challenges:

- Limited Resources in the community, especially culturally appropriate services

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- Problems within the PCA funding model including low wages, few benefits and odd/fragmented hours
 - Funding categories and current budget practices (annually) that do not support flexible funding and consumers can experience delays in the start of funding/services
 - Some consumers, regardless of the nature of their disability, and their families need time to adjust to self-direction. The concept of independence and choice can be 'foreign' initially or appear very abstract to some. However, in all cases within this project, a move toward self-direction had positive impacts on the consumers' quality of life.
 - Language is a real barrier to service and the ability of consumers to self-direct that must be addressed, as the problem is growing

Recommendations to the Coordinating Council

Short term Suggestions

- Create provider profiles to assist consumers and families in their choice of what they feel would be best for them. Have providers, DMR and consumers provide input into the content and include some sort of quality rating.
- Create additional materials that educate consumers and families and empower them in assisting themselves. Translate these materials into multiple languages
- Change area DMR (and other agency) budgets so that they are not by service group, or allow reallocation between these groups to accommodate changing needs of the area population. Budgets set at the start of the fiscal year may not appropriately address the needs of the area.
- Work to loosen funding categories to accommodate more individual needs
- Minimize the current delay between approved eligibility and the start in services
- Provide more emergency funding that agencies could access for consumers in crisis

Long-term Suggestions

- Create service options where consumers can participate in self-direction of their services and individual budgeting. A flexible system is needed that can support many degrees of self-direction
- Adjust the PCA funding system to allow for more competitive wages, regular benefits and more consistent hours. This would make the PCA position a more realistic job option for skilled workers.

As the Commonwealth moves toward Self-Determination:

- It is important that the agencies within the Executive Offices of Health and Human Services¹ work together to incorporate options for self-determination

¹ Agencies within the Executive Office of Health and Human Services: Massachusetts Commission for the Deaf and Hard of Hearing, Massachusetts Commission for the Blind, Massachusetts Rehabilitation

into their systems. Most consumers receive services from at least two agencies, and fractured efforts to incorporate self-determination options could be detrimental to consumer experiences and impede their ability to self-direct.

- Develop a longer-range pilot that involves more diverse agencies and follows more consumers for longer periods of time. The pilot should allow at least a portion of participants to completely self-direct their budgets. Focus the pilot on assessing the long-term support and educational needs of consumers who are self-directing a larger proportion of their supports.
- Choose a model for Person-Centered Planning or service planning that ensures some minimum standards for structure/content of the plans. The model should be flexible enough to support planning across disabilities (including consumers with and without intellectual disabilities).
- Develop educational materials for individuals and families before implementing this project and translate them into many languages. Evaluate the usefulness of these tools through input from consumers and families before statewide use.
- Increase the available community resources, and ensure skilled workers are available to individuals who are in need of personal assistants. Educate the community about the individual budgeting options as the system is rolled out. A centralized statewide listing of available skilled workers with information such as language and skills would benefit both consumers and workers.
- Ensure skilled facilitators are available to consumers and families to create and implement person-centered plans. Allow options for consumers to purchase additional support time as needed beyond average levels from staff with their service dollars to allow consumers to procure more assistance if they desire to do so.
- Ensure facilitators are available that can speak the individual's language and understand their culture.

Commission, Department of Mental Retardation, Department of Mental Health, Department of Public Health, MassHealth, Department of Social Services, Department of Youth Services, Department of Veterans' Services, Department of Elder Affairs, Soldiers' Homes, Office for Refugees and Immigrants, Department of Transitional Assistance, and Division of Health Care Finance and Policy.

Introduction

The Massachusetts CPASS Demonstration Project

In 2003, Center for Medicare and Medicaid Services (CMS) awarded a grant of \$579,178 to the Massachusetts Department of Mental Retardation as part of their *Systems Change for Community Living Grant Categories*.

The focus of the grant was to demonstrate a personal assistance support program based on the principle of self-determination that allows for self-direction of supports. Self-determination is the principle that individuals have the freedom and authority, balanced with responsibility, to create meaningful, culturally appropriate lives deeply embedded in their communities and suffused with real relationships.² To self-direct supports means that an individual has the freedom to control and direct their services, and often the funding for their support, themselves.

Massachusetts identified the overall goal of their CPASS project as an effort to:

“Make a significant and enduring difference in providing individuals with disabilities and elders with meaningful choices and enabling them to maximize their control in all models of personal assistance services and supports. The overall goal is to develop sustainable mechanisms that insure consumer choice and consumer direction of [Personal Assistance Services and Supports] PASS.”

Specifically, the CPASS demonstration project in Massachusetts identified four major goals:

- *“Develop and test PASS quality assurance and safeguard procedures, including a consumer satisfaction survey process, that will ensure the scope and quality of services are consistent with need*
- *Develop and test consumer-directed demonstration projects that explore maximum opportunity for self-direction and flexible use and allocation of supports*
- *Identify and field test models to prepare, support, and empower consumers or surrogates to select from a menu of options allowing differing levels of self-determination*
- *Evaluate the effectiveness of the pilot projects and the achievement of all grant goals and objectives and develop a long-range plan for systems change to sustain MASS CPASS successes.”*

Structure of the Demonstration Project

The Massachusetts DMR proposed two branches of work in the grant. The first is a series of pilot projects in Massachusetts regarding self-determination with a specific focus on person-centered planning and consumer-directed flexible funding supports (self-direction). The pilot projects were meant to produce and test new models of quality assurance, flexible supports and consumer direction. The second branch focused on conducting

² Center for Self-determination Policy Analysis of New Jersey’s Self-determination Effort. *Thomas Nerney with Kathy Harris, Esq.*

community forums throughout the Commonwealth to gather different cultural views on self-determination and the service climate in the state.

Grant team

The Central Office of the Department of Mental Retardation administered the grant and formed a Coordinating Council to manage the project with representation from state offices, provider agencies, consumers and family members. The Coordinating Council formed a variety of Subcommittees to focus on specific topics of Evaluation, Marketing & Outreach and Policy Development.

The Coordinating Council also hired an outside vendor to perform an independent evaluation of the demonstration project. This vendor worked with the Evaluation Subcommittee, and focused on evaluating the process and outcomes of the pilot projects. This report discusses the methods and findings from this evaluation process.

Project Evaluation Subcommittee

The Project Evaluation Subcommittee included state and agency representatives as well as consumers and family members. The Subcommittee worked with the evaluator to provide feedback at all major steps of the development of the evaluation methodology and the tools used to gather feedback.

Pilot Projects:

Through a public Request for Proposal (RFP) process, the Coordinating Council identified two agencies to participate in the self-determination pilot. The pilot included funding for agencies to dedicate staff time to the project, and also included flexible funding allocations to be directed and used by consumers involved in the pilot.

The Coordinating Council chose include a focus on cultural influences on self-determination. The pilot project centered specifically on Latino³ consumers, a large and fast-growing population in the Commonwealth of Massachusetts.

Two agencies, the Multi-cultural Community Services of the Pioneer Valley, Inc. and the Association of Retarded Citizens of Massachusetts, participated in the grant activities, and oversaw demonstration projects in three agency offices in Holyoke, Lawrence and Boston, Massachusetts.

Description of the sites

Multi-cultural Community Services of the Pioneer Valley, Inc. (MCS)

MCS is a non-profit organization located in Western Massachusetts, serving as a licensed provider of 24-hour residential, individual, family, respite and emergency support services for the Department of Mental Retardation. MCS is committed to providing culturally responsive supports to children and adults with developmental disabilities and their

³ "Latino" is used in this report to include anyone who identify their ethnicity as Hispanic or Latino, including those with European/Spanish, Central American or South American or indigenous roots. The term "Latino" identifies ethnicity only, and is not used here to define or connote race. A single term is used to identify this ethnic group for consistency throughout the report, although many terms were used interchangeably by consumers and staff to describe their roots and subgroups within the Latino ethnicity may have differences.

families in the Western part of the state. The agency began its Latino services informally, with the hire of its first bilingual staff person in 1981 to serve 14 Latino families. Currently, the agency supports over 100 Latino consumers with 35 bilingual family support staff. MCS serves 51 adults in residential supports, and more than 600 people, ranging from young children to elder adults in other services. MCS works in partnership with Padres Unidos en Accion (Parents United in Action), a Latino family-directed support project hosted by MCS.

Holyoke and its surrounding area have a large Latino population. According to 2000 census figures, Holyoke was 41.4% Latino, a majority of which are Puerto Rican. 43% of Holyoke residents over the age of 5 speak a language other than English in their home.

During the demonstration grant, a self-directed Personal Care Assistance (PCA) program was initiated at this site.

The Association of Retarded Citizens of Massachusetts (The Arc)

The Arc of Massachusetts is a non-profit organization with the mission of enhancing the lives of individuals with cognitive and developmental disabilities and their families. In addition, The Arc has a long history of advocacy for self-directed community services.

“Tools for Tomorrow” is a training program developed by a unique partnership among self-advocates⁴, families and advocacy organizations to help individuals determine their futures and achieve their dreams. The Arc led this development effort through a 3-year federally funded project on consumer direction.

The Arc oversaw two mini-site demonstration projects for the grant:

The Arc of Greater Lawrence (The Arc of GL)

The Arc of Greater Lawrence (The Arc of GL) was established in 2001 in order to develop services and support to individuals with disabilities and their families in the Greater Lawrence community. The group was formed by the Citizen’s League for Adult Special Services (CLASS, Inc.), a parent-formed organization in the Greater Lawrence area to provide community-based day activities and training to adult children with mental retardation.⁵

Today, The Arc of GL works with a predominately Latino population in Greater Lawrence. Recently, the Massachusetts Developmental Disabilities Council (MDDC) awarded a grant to The Arc of GL to create a Latino Leadership and Support Network, through which they have identified parents and children in need of services. The goal of the MDDC-funded project is to empower parents to advocate more independently for and learn how to secure resources necessary to meet the needs of their children with developmental disabilities. The project also identified individuals in need of services and assisted with the development of family-focused plans to respond to the family’s needs.⁵

⁴ In this context, a self-advocate is defined as an individual with a disability that pleads, defends or advocates their own needs and opinions. In some cases, self-advocates may also advocate the needs of individuals with disabilities on a larger scale (as a group or population).

⁵ The CLASS, Inc. & The Arc of GL website was used as a resource for background on the agency.
<http://www.classinc.org/>

The Boston Center for Independent Living (BCIL)

The Boston Center for Independent Living is a private nonprofit organization controlled and directed by persons with disabilities with the mission “to empower people with disabilities with the practical skills and self confidence to freely determine our own life choices in the community” and “to promote access and change within society, and to make full and equal participation by individuals with disabilities a reality.” In the early 70's, BCIL was founded to "open doors" for persons with disabilities so that living independently could become a reality for many who had either been institutionalized or limited to their home environment. BCIL provides services, community education, advocacy and employment for individuals with disabilities in the Greater Boston area. The organization operates a PCA program, provides independent living sources and has a long history for advocacy for and innovative work in providing community supports.⁶

Self-Direction: A Discussion of Components

To better understand the demonstration proposed by this grant, an understanding of ideas of self-direction and self-determination is required.

The Principle of Self-Determination

Self-determination is a principle that places decisive power about the design of a person's life in their own hands. The goal of self-determination can be summarized as: “the creation of meaningful, culturally appropriate lives deeply embedded in our communities and suffused with real relationships.”⁷ Service delivery systems that embrace this principle put the individual consumer in the primary decision making role regarding the design of services and the utilization of funding to support their needs.

Important Components of the Principle of Self-Determination⁸

Freedom to choose a meaningful life in the community

Authority over a targeted amount of dollars

Support to organize resources in ways that are life enhancing and meaningful to the individual with a disability

Responsibility for the wise use of public dollars and recognition of the contribution individuals with disabilities can make to their communities

Confirmation of the important leadership role that individuals with disabilities and their families must play in a newly re-designed system and support for the self-advocacy movement

⁶ The BCIL website was used as a resource for background on the agency. <http://www.bostoncil.org/>

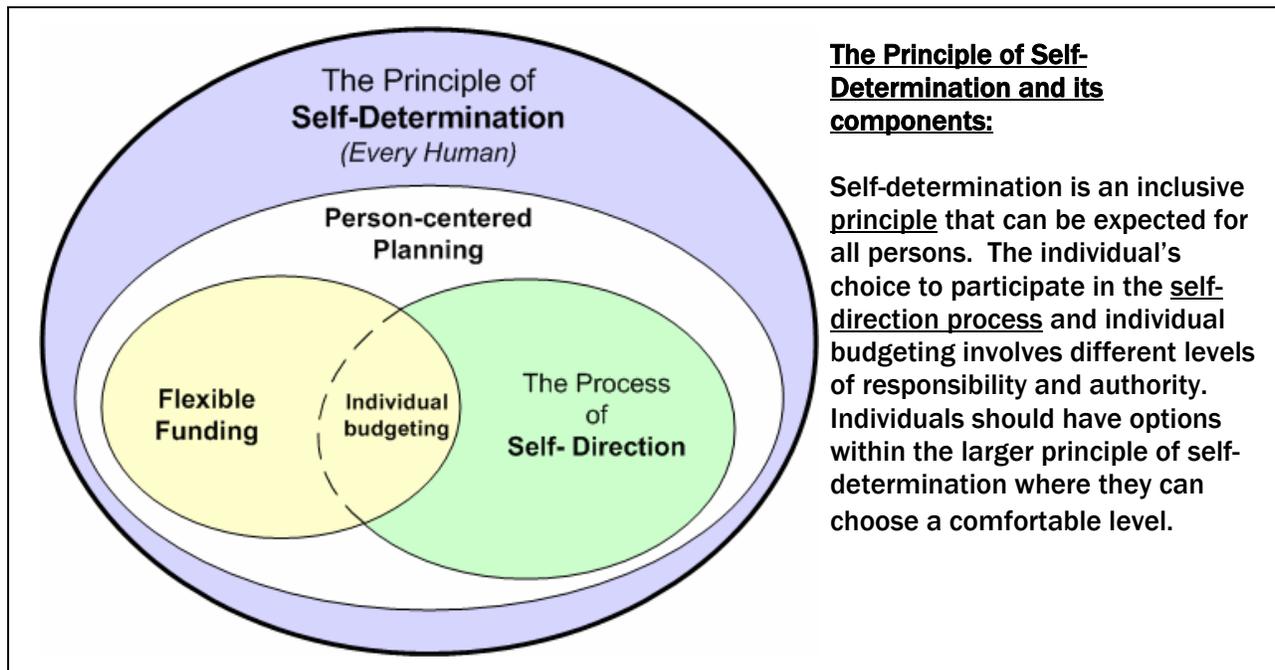
⁷ Center for Self-Determination Policy Analysis of New Jersey's Self-Determination Effort, Thomas Nerney with Kathy Harris, Esq., 2003

⁸ The Declaration of Freedom, Center for Self-Determination July 4, 2000. <http://www.self-determination.com/freedom.html>. Probably first defined in “Beyond Managed Care” (Nerney & Shumway, 1996)

CMS defines a self-directed state program as one that “presents individuals with the option to control and direct...funds identified in an individual budget.”⁹ The CMS requirements for a comprehensive self-directed program include:

- **Person-centered planning** - A process, directed by the participant, intended to identify the strengths, capacities, preferences, needs and desired outcomes of the participant.
- **Individual budgeting** - The total dollar value of the services and supports, as specified in the plan of care, under the control and direction of the program participant.
- **Self-directed services and supports** - A system of activities that assist the participant to develop, implement and manage the support services identified in his/her individual budget.
- **Quality assurance and quality improvement (QA/QI)** - The QA/QI model will build on the existing foundation, formally introduced under the CMS Quality Framework, of discovery, remediation and continuous improvement.

This programmatic structure, including these four essential elements, was designed from insights gathered in implementing self-directed programs and should be applied to each self-direction program.



⁹ <http://www.cms.hhs.gov/IndependencePlus/>

Person-Centered Planning

In this demonstration project, the CMS model of person-centered planning was applied. As defined by CMS:

“Person-centered planning is a process, directed by the participant, with assistance as needed from a representative. It is intended to identify the strengths, capacities, preferences, needs and desired outcomes of the participant. The process may include other individuals freely chosen by the participant who are able to serve as important contributors to the process.”¹⁰

“The person-centered planning process enables and assists the participant to identify and access a personalized mix of paid and non-paid services and supports that will assist him/her to achieve personally-defined outcomes in the most inclusive community settings. The identified personally-defined outcomes and the training, supports, therapies, treatments and/or other services become part of the person-centered plan.”¹⁰

Person-centered planning emphasizes important concepts in service provision including self-determination, community inclusion and individualized supports. The planning process has the ability to provide conceptual clarity to important foundations of independence such as personal autonomy.¹¹ As captured by S. Holburn et al., “person-centered planning is a prescriptive process to arrange circumstances by which a person’s aspirations can materialize.”¹¹ It is important to note that the person-centered planning process is not specific to individuals with intellectual disabilities. Instead, the process is highly flexible and should utilize individual abilities. Some individuals may require very little assistance and others may require more, however it is the availability of this support and the adherence to self-determination principles that are important about this planning ‘process’.

In the discussion of findings, this evaluation will assess the fidelity of the person-centered planning process used in this project to the principles of self-determination, and will also assess important indicators in the process and outcome of the person-centered plans.

The Process of Self-direction (Self-directed Supports)

Self-direction utilizes the principles of self-determination to deliver responsibility, authority and freedom in the design and control of their services to the consumer. As service coordinators, agency staff members teach the person to determine their own services and provide them with the supports necessary to allow them to succeed in this. Self-directed services should link the person with community resources and in many cases can enhance the person’s skills. Self-direction may look different across consumers, and varying levels of self-determination are possible which are linked to the consumer’s abilities and preferences.

¹⁰ *Independence Plus*, A CMS Initiative To Promote Self-Direction, July, 2003, Department of Health and Human Services (DHHS)

¹¹ Holburn S, et al. Quantifying the Process and Outcomes of Person-Centered Planning, *Am J Ment Ret*, 2000, 105(5): 402-416.

Flexible Funding and Individual budgeting

An individual budget is, as defined by CMS, “the total dollar value of the services and supports, as specified in the plan of care, under the control and direction of the program participant.” It is important to note that an individual budget is not a funding cap, and that in the CMS waiver, for example, participants can receive medically necessary services that exceed their individual budget if a medical circumstance arises that was not part of their plan of care (or person-centered plan).

The idea of flexible funding allows an allocated amount of service dollars to be utilized on the supports deemed best in the person-centered planning process. Consumers may choose to direct all or part of their individual budgets, allowing them to utilize the funding as they see fit. A flexible funding model would allow consumers, for instance, to hire community advisors to assist them in utilizing their allocated support funding to design their own services. An overall budget would be allocated to the consumer by the state and the consumer may choose, for instance, how many hours they receive from a PCA and how the rest of the funding is utilized. This level of self-determination involves some of the highest levels of responsibility on the part of the consumer, but also affords the consumer the most authority and freedom in their supports.

Self-Directed Quality Assurance and Improvement

A Quality Assurance and Improvement system is an essential piece of an overall state system to ensure that a Self-direction and Flexible funding program accomplishes its goals, minimizes risk to an acceptable level and adheres to the principles of self-determination for all individuals. Importantly, participant experiences must be a part of the data collected to inform improvement efforts. On a more personal level, participants should be encouraged and empowered to think critically about their services and their own decisions and apply similar assurance and improvement levels on an individual level.

For states participating in its waiver program, CMS mandates states have the following in their Quality Assurance and Improvement System:

- ❑ “System-wide procedures for receiving, reviewing, and acting upon critical incidents;
- ❑ System-wide emergency backup and/or emergency response capabilities;
- ❑ Criminal background checks of participants’ support workers;
- ❑ Procedures to assure that families and individuals have the requisite information and/or tools to participate in a family or person-centered planning approach; and
- ❑ Procedures that promote family or individual preferences;”¹⁰

An Evaluation of the MASS CPASS Demonstration Project

The goals of this evaluation are to examine the pilot of self-direction, with a focus on the four essential areas: person-centered planning, financial flexibility and individual budgeting, self-directed supports, and self-directed quality assurance and improvement. The evaluation seeks to identify strengths, successes and innovations of this model, as well as the obstacles and shortfalls encountered during its demonstration.

As the focus of this project is self-direction of supports and services, consumers drive the core of the evaluation. It is only with assistance from active consumers that the evaluation can identify the true obstacles, shortcomings, strengths and successes. It is the perceptions and experiences of the consumers participating in this demonstration project that will truly evaluate this model.

The evaluation design and evaluations tools received input from active consumers before their use in this project. Some of the staff members assisting consumers with person-centered planning, budgeting and self-direction also provided input regarding the design and the development of the tools.

The Importance and Use of Evaluation

The information gathered in the evaluation of this demonstration project will have importance for and will be of significant use to many of the stakeholders in this project. Evaluative feedback will be of interest to the Coordinating Council that oversaw the project to illustrate where and why they were able to meet or exceed their goals and where and why they may have fallen short.

Outside of the grant administrators, many other groups may have an interest in the evaluation of the project. The funding agency can utilize the evaluation to forge systems change. Agencies, Consumer groups, other states, and many other groups that were not involved as primary participants in the grant may be informed by a detailed evaluation. As a demonstration project that hopes to develop a model for use by the entire state, an evaluation is a key tool in assessing the fitness of the model and the idea for use beyond the demonstration.

As explained by the Coordinating Council:

“The development of consumer-directed supports, and development of consumer-driven evaluation, is new, challenging and potentially revolutionary. The development and implementation process along with its obstacles, shortfalls, successes and innovations is an essential element of record.”

The Role of the Evaluator

In demonstration projects such as this, it is important to conduct an independent evaluation of the process and outcomes of the project. Independence creates the potential for an objective analysis of the information collected through the evaluation process. In addition, independent evaluators can assure primary respondents in the evaluation process confidentiality and anonymity that would not be possible if a member of the grant team or the agencies involved were to conduct the evaluation.

It is the role of the evaluator to design an evaluation that encourages and empowers consumers, family members and staff to think critically about the demonstration project and the potential of the model for future application. It is also the role of the evaluator to provide a safe environment in which the respondents can feel confident in providing feedback without repercussion.

This evaluation was designed to obtain consumer-centered measures of individual outcomes and to discuss the success of the model in enabling consumers to reach their goals.

A 'Consumer-driven' Evaluation

How is this a consumer-driven evaluation?

The evaluation focuses on primary consumers¹² for feedback about the quality of the services they receive and how services can be improved.

While the evaluation did not use primary consumers to interview other consumers, individuals actively receiving support services were involved in the development process for the evaluation and the tools utilized during the evaluation period. The evaluation used a single evaluator due to the project's small size and the desire for consistency across interviews.

The interviews were semi-structured, but also involved open-ended portions. The evaluation avoided the use of close-ended surveys. Surveys were customized for each consumer, using minor modifications to questions to ask about their specific services. The interviewer asked all consumers a set of core customized questions in a conversational format. Follow-up questions and dialogue were created by the evaluator based upon the consumer's responses. In every case, the consumer could provide open-ended discussion and commentary on any one of the questions asked, or on separate thoughts. Consumers also had the option of not responding to a question if they so chose. The result was a dialogue with the interviewee that encouraged them to think constructively about their services, satisfaction and level of self-direction.

How do we compare individuals, while preserving individuality?

The process of person-centered planning, individual budgeting and self-direction, by definition and if done properly, will result in outcomes that differ among individuals. So then, how can outcomes and process be measured between consumers/families in a pilot of person centered planning and self-direction?

The process of developing a person-centered plan and individual budget should be driven by the consumer's self-identified goals. It is the progress toward these goals, through the identification of measurable milestones, which can be measured and compared, even though the goals may differ greatly between consumers. In addition, information about quality of life and the consumer's opinion on their freedom to "self-direct" and "make their own decisions" will transcend across consumers, as these are basic elements that should be present for all consumers.

Instead of using categories to group participants, the evaluation will use individual daily needs and goal components as a means of comparison. In the evaluation, the consumers are assisted in assessing for themselves how their supports allowed them to realize their own goals and where they would have liked things to have gone differently. Outcomes, as defined by the consumers, will be compared with clients of similar needs, and the consumers' progress toward their goals will be examined as a whole.

¹² A primary consumer is someone who directly consumes support services, in this context, usually a person with a disability.

How are consumers placed in a meaningful position to evaluate the services they are receiving?

Ideally, an evaluation of self-directed supports places the consumers in the central role as evaluator. Many service systems provided little opportunity to consumers to design and evaluate their personal supports. This approach can lead to services and evaluations that supplant judgment, and do not necessarily evaluate consumer satisfaction or the ability of the services to address the consumers' perceived needs.

Alternatively, consumer-driven evaluations generally lead to more valid and useful evaluation results and can also serve to empower the consumers. To truly enable consumers to fully participate in the evaluation of the project, a supportive evaluation environment must be created which enables the consumer to evaluate and participate to the fullest extent possible. Achieving full consumer participation involves respect for the consumers' voices and the formulation of an evaluation that has both the flexibility to address consumers' communication needs and the ability to encourage the consumers to think constructively about their supports. It is also essential to create an environment where the consumers feel they can express themselves without repercussion and have input into the content and scope of the evaluation.

To avoid the potential pitfalls mentioned above, the evaluation utilized tools to support consumers in thinking critically and constructively about their experience in the demonstration project. The tools used to gather feedback were designed with input from active consumers.

The Role of the Case Study

Case studies will be used in this report to illustrate the work of this grant in the context of an actual client. Person-centered planning and self-determination are built on the basis of adaptation to individual needs. The case studies in this report will be used to provide readers with a better sense of service experience in the context of a whole person.

Methods

Methods of the Self-Direction Demonstration

Each of the individual sites of the mini-project participated in the demonstration of self-directed services, including person-centered planning and flexible funding. In addition, each of the sites proposed areas of the self-direction model on which they would specifically like to focus.

The Arc of Massachusetts oversaw self-direction demonstrations at two sites: The Arc of Greater Lawrence and The Boston Center for Independent Living. The demonstration project involved a total of twelve consumers. In addition, The Arc also focused on gathering information to put together minimum competencies for 'community advisors' or 'community brokers', individuals who can assist consumers in self-directing and provide the tools, resources and information to allow the consumers to succeed in this process.

MCS created a project they termed *Otro Puente (Another Bridge)*, the goal of which was to prepare, support and empower individuals with developmental disabilities to increase access to, and control of, Personal Care Assistance (PCA) and Supports focusing on the Latino Community around Holyoke, Massachusetts.

Demonstration Project Overview

During the demonstration period, funding covered dedicated staffing costs, and supervisory staff to direct the project at the site and liaison with the Coordinating Council. At least 100 hours of staff support were allocated to each consumer during the demonstration. The amount of staff time available to the consumers in the demonstration project is typically more than agencies would be able to provide general consumers over the same time period. Some funding was also reserved for the training of staff in person-centered planning and self-direction. At MCS, about one-third of the grant funding was given directly to consumers, providing each consumer in the PCA pilot \$5000 in flexible funds. At BCIL and The Arc of GL, about \$1000 in flexible funding was available to consumers to allocate as they determined necessary. An additional \$2000 was given to The Arc of GL to serve an additional family with multiple children in need of services.

Agencies were asked to identify new or current consumers to participate in the pilot. Staff worked with consumers in a person-centered planning process to identify needed supports, such as PCA services, transportation, respite, child care, interpreters, etc. Because this was a project of limited time and scope, the demonstration did not delve into individual budgeting for all supports. Instead, staff assisted the consumers with budgets for the allocation in the project. Consumers may have also received services from other agencies or resources that did not participate in the flexible-funding model.

Staff members working with each consumer were asked to maintain qualitative and quantitative data about the consumers with whom they were working. Additionally, the staff agreed to participate in an interview process with the project evaluator. As part of the evaluation process, the staff members were asked to complete a consumer profile and were asked to work with the consumers to complete 'Goal Planning' worksheets. (See Appendix 3 for the consumer profile and Appendix 4 for the Goal Planning Worksheet.) The worksheets were designed by the evaluator to gather information about the self-

identified goals of the consumers and identified milestones in the progress of these goals of the consumer's choosing. These milestones, and the progress toward them, were used by the evaluator to assess completion of goals. Traditionally, case managers at these agencies will keep case notes on the consumers they serve; the reporting requirements imposed by the grant were, in most cases, more substantial than the information normally recorded. Some of the staff funding was used to support this work.

Person-centered Planning Model

As discussed in the introduction section on Person-centered Planning, there are a variety of different methodologies agencies can use during this planning process to assist consumers.

The Arc's 'Tools for Tomorrow' system¹³ was chosen as the person-centered planning model across all sites. A guide for this system has been created to aid consumers and their chosen advocates along with the staff assisting them. The staff members were trained on the use of this system by a "Tools for Tomorrow" Facilitator before working with consumers. The guide is created around the principle that:

"To truly individualize and build good humans services, people seeking supports, their families and those who know them best, must make the decisions about what supports must be and look like."

The system encourages the consumers to include family and/or people who are important to them so that these people can work with the individual in the planning process. The guide first asks the individual to envision their future and document their vision however they choose. Preference statements are then used to assist individuals in identifying their 'non-negotiables', principles and preferences that are most important to them and essential to their success and survival. In addition, the individual is asked to identify some pieces that are very important, or things that they may want, but are not non-negotiables. Preference questions under different categories within the guide can assist the individual in narrowing down what is most important about a topic such as "health care". The non-negotiables and preferences are then used to prioritize and design a system of supports with the consumer that fits their vision of their future.

All participating agencies reported that they already performed at least some aspects of person-centered planning before this demonstration project. However, all agencies reported some changes from their normal procedures during the pilot.

Evaluation Methods

The evaluation was designed by the evaluator in cooperation with the Project Evaluation Subcommittee created by the Coordinating Council. (See section in Introduction for description of the Evaluation Subcommittee.)

Part way into the grant, the Evaluation Subcommittee made the decision to change from the original independent evaluators and issued a second RFP for competitive bids. The period of work for the second evaluator started after most participants had begun working

¹³ Tools for Tomorrow, 2nd Edition. Developed in partnership between individuals and families: The Arc of Massachusetts, Mass Families Organizing for Change, Massachusetts Advocates Standings Strong and the Massachusetts Developmental Disabilities Council.

with the three agencies involved in the Demonstration project. Ideally, pre-participation interviews would have been conducted with consumers before the start of their participation in the demonstration project. However, because of the aforementioned change in evaluators and the timeline, pre-participation interviews were not feasible.

Most consumers were interviewed about three to six months into their participation in the demonstration project. In most cases, the progression toward consumer goals is a gradual process, and long-term follow-up with consumers would be ideal to garner how their supports and needs developed over a longer period of time. Unfortunately, long-term follow-up was not possible for this report given grant timelines. However, a follow-up study that asked similar evaluation questions to consumers at a later point would gather important information for the overall evaluation of this model and its potential for more widespread adoption.

One of the challenges in evaluating a demonstration project on person-centered planning is developing a method to gather meaningful data on process and outcomes while maintaining a consumer-driven focus and recognizing the wide variety of individual differences inherent to a project on person-centered planning.

A semi-structured interview format was proposed by the evaluator and approved by the Evaluation Subcommittee for use with both consumers and staff involved in the project. The content of the participant and staff interviews were presented to the Subcommittee and feedback from the members was incorporated into the structures before their use. The evaluation tools were also presented to and approved by the Coordinating Council in March 2006. In addition to a structured interview, participants were encouraged to share additional thoughts about their life, current situation and services where possible and permitted by the primary participant. Feedback was also solicited from family members who had frequent involvement in the consumer's life and from those who assist the consumer such as staff members, service coordinators, etc.

Special Adaptations to the Interview Process

The interview structure was developed with a wide variety of consumers in mind. It was important to this project that the evaluation have an emphasis on the empowerment of individuals to comment on and evaluate their own services and the creation of an environment where the participant is able to do this as easily as possible. During the design phase, it was anticipated that the evaluation would include individuals with intellectual disabilities ranging from mild to profound, individuals with learning disabilities, non-native English speakers and individuals who spoke no or limited English. Therefore the tools used in the evaluation process needed to be adaptable to the needs of the participants, and also easily understandable and consistent across translation.

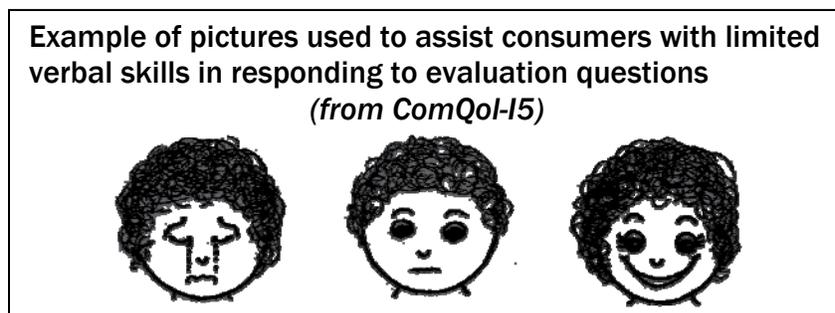
An attempt was made to maintain approximately a fourth-grade reading level in the questions, as this is slightly below the average reading level in the United States, and is also more easily translatable into other languages and understood by non-native English speakers. The use of Yes/No questions was avoided where possible. The use of True/False or numerical Likert scale¹⁴ questions was avoided completely. Responses on

¹⁴ A Likert scale is a response scale that allows respondents to select their level of agreement to a statement on a numerical scale, which can be confusing for individuals with learning or intellectual disabilities. (Likert, 1932).

these types of questions have been shown to be inconsistent in individuals with almost any level of intellectual disability or learning disability and can prove confusing for non-native English speakers.

An effort was made to avoid the use of questions that may change meaning across cultures or that had a potential for misinterpretation in prevalent ethnic and cultural groups in the area. Because the evaluation tools were to be used with primarily Latino consumers, Latino members and native Spanish-speakers of the project evaluation subcommittee were asked to review the tools specifically for content that may take on unintended meanings when translated into Spanish before they were used with staff or participants.

An important feature of the evaluation was the inclusion of the primary consumers in the evaluation. However, many of the consumers had intellectual disabilities, and ranged in the level of their disability and their ability to communicate verbally. In order to enable consumers with intellectual disabilities to evaluate their services to the best of their ability, adaptations to the consumer interview were necessary. In other interviews and evaluations, researchers have reported that some participants may respond similarly to all questions, despite their own opinion. In order to assess consistency and acquiescence, item-reversal techniques are used with an appropriate number of pairs of oppositely worded questions. Therefore, if the consumer responded with a “yes” or an affirmative answer to both, to all sets of these questions, it could be concluded that the consumer was influenced by other factors. These may include not understanding the question, wanting to please the interviewer, or other factors.



In addition, for consumers with limited verbal skills, picture cues¹⁵ were used with some questions. The pictures used were faces of emotions (shown above) that were introduced and explained to the consumer at the start of the evaluation. Consumers were asked to show the evaluator which face represented how they felt about different things in their life or during different activities. This method has been utilized in other evaluations of quality of life and services that were designed specifically for individuals with intellectual disabilities.

¹⁵ The Picture Cues used in the interviews and presented in this report are from the Testing Materials in Appendix E of the *Comprehensive Quality of Life Scale – Intellectual/Cognitive Disability, Fifth Edition (ComQol-I5)* by Robert A. Cummins.

During the Interviews:

The interviews were conducted by an independent evaluator unknown to the consumers and staff. Interviews with staff were conducted both over the phone and in person. Arrangements were made to interview all consumers in person. One consumer requested to be interviewed over the phone and arrangements were made to accommodate this request.

At the start of the interview, participants were informed that their comments were confidential and that their feedback would be presented in an aggregate report, but they would not be identified within this report and that their comments would not be relayed to anyone after the interview without their specific permission. Permission was asked of participants who were interviewed in person to record the audio from the interview for use in preparation of the evaluation report; all participants consented verbally. Some notes were also kept during the interview by the evaluator.

Translation & Language Barriers

Interviews were conducted in the language chosen by the consumer. Many participants natively spoke Spanish, and they were given the option to conduct the interview in English or to use an interpreter. For those that chose Spanish, independent interpreter services were arranged by the evaluator for the in-person interviews. These interpreters were from professional interpretation agencies, and interpreters were not previously known to the consumers, their family or to the staff working with the consumers. Interpreters were asked to provide literal interpretation between the participant and the interviewer, and were informed that the content of the interview was confidential.

[Note: In later sections of the report, quotes will be used from consumers and staff that participated in the evaluation process. In some cases, the quotes included may be the English interpretation of the participant's comment. It must be acknowledged that during the interpretation, slight variations from the actual statements of the participants may exist due to this process. However, due to the professional certifications of the interpreters, the amount of variation is expected to be minimized as much as possible.]

Customization of the Interview:

Using the consumer profiles gathered from the agencies, the content of the interviews was customized for each consumer. Questions may be restructured or focused on specific details about their services as appropriate. An effort was made to keep the interview in a conversational format, rather than a list of questions. In every interview, participants were encouraged to express their thoughts about anything related to their services or life plans that was not covered by the interview.

Note: the real names of consumers and staff have been withheld to maintain confidentiality. Any names appearing in this report have been created to protect their identity.

Results of the Evaluation Process & Consumer Demographics

Penetration of the Evaluation

In total, almost 90% of participants were interviewed for the evaluation. Efforts were made to interview all participants involved in the project, including two participants with whom the agency no longer had contact; unfortunately, arrangements could not be made to speak with these two participants. Table 1 shows the number of consumers participating at each agency and the percent of participants interviewed.

	<u>Primary Participants</u>	<u>Participants Interviewed</u>	<u>% interviewed</u>
Multicultural Community Services	5	5	100%
The Arc of Greater Lawrence	7	7	100%
Boston Center for Independent Living	6	4	67%
Total	18	16	89%

The average interview with a participant was at least 20 minutes in length. Interviews that used interpretation services tended to run longer, due to the time required for interpretation of questions and responses.

Age & Gender

In the current service system, there are three age categories that have particular significance for service planning. These include minors (under 18 years), those in a transitional age between adult and child services (18-22 years) and adult consumers (over 22 years). As shown in Table 2, the demonstration project included consumers from each of these three major age groups.

Table 2. Age & Gender Distribution of Participants

Age Group	<u>Primary Participants</u>		
	Male	Female	Total
Minors: Under 18	1	4	5
Turning 22: 18-21	2	2	4
Adults: Over 22	5	4	9
Total	8	10	18

The overall average age of participants was 25 years and the range of ages was from 3 years to about 55 years of age. There were more female children that participated than males; however the gender distribution was about even in the other age groups.

Race & Ethnicity

Race and ethnicity of the participants in the demonstration are presented in Table 3. The categories presented in this table come from the race and ethnicity structures utilized by the US Census. They are presented in these categories in order to aid in the comparison of this project to others. However, it is acknowledged that the separation of race and ethnicity may be artificial to some individuals. It should be noted that most participants in

this demonstration study that were of Latino ethnicity reported themselves to be “Hispanic” or “Latino” and did not specify both race and ethnicity, for example that they were “Hispanic Caucasian”.

Over 90% of the consumers and families interviewed were Latino.

About half of the 16 consumers interviewed required interpretation services in Spanish. See the description above under the Methods section to learn more about the independent interpretation services used in this evaluation.

Table 3. Race and Ethnicity of Participants

<u>Race</u>	Participants	Interviewed
African American	1	0
Caucasian	17	16
Total	18	16
<u>Ethnicity</u>	Participants	Interviewed
Latino	16	15
Non-Latino	2	1
Total	18	16

Family situations & social supports

Participants in the demonstration project represented a number of different family situations. These situations, in many cases, have a direct impact on the service needs of the individuals. Half of the participants interviewed were minors living in single-parent households. Below, the family and social situations at the start of each person’s participation in the project are listed.

- Independent adults, single (5), at least 3 of which had family involved
- Minor, lives with both married parents (3)
 - One consumer had a parent pass away during participation in the project
- Minor, lives with single parent (8)
- Young adult, parents deceased, some family involved in life (1)

At times, the family situation and the social supports for an individual can change with little warning. Some of the participants in this project experienced major life events that changed their family situations. The parent of one young adult consumer passed away during his participation in the project. Another young adult consumer learned his parents were planning to separate during the project. Lastly, an illness of a caretaker during participation in the project forced one participant to quickly transition to independent living for the first time. These life changes had required flexibility in the personal-centered support plan, and in some cases, a fast response by staff assisting the individual.

Disability

Participants in the demonstration project had a wide range of disabilities. A count of disabilities by generally utilized subgroups is presented below:

- Learning and/or Intellectual Disability (8)
- Physical Disability (4)
- Both (4)

Intellectual disabilities of participants ranged from none to profound mental retardation and an inability to verbally communicate. Physical Disabilities represented both mobility limitations and severe health complications. Four participants had both intellectual

disabilities and physical handicaps affecting their mobility. More specific information about disabilities in relation to their impact on service needs will be presented in the following section on Project Findings.

Staff Interviews

Of the four staff interviewed at MCS, two were staff hired by participants to support them in achieving their goals. Staff at all other sites were consumer advocates and their role in the grant was to assist the participants with their self-direction. In addition, the coordinators for the sites were also interviewed. Of these staff, about two-thirds identified themselves as Latino.

Table 4. Staff Interviewed by Agency	
	<u>Staff</u>
Multicultural Community Services	4
Arc of Greater Lawrence	3
Boston Center for Independent Living	3
Total	10

Project Findings

Person Centered Planning

Before individual results are examined, it is important to assess the fidelity of the person-centered planning process. In order for the planning process to be truly person-centered, it must adhere to the principles of self-determination. Similarly, the outcomes of the planning process should adhere to the individual's vision and be directed by the person and their selected team. S. Holburn et al. have researched the essential components of both the process and the outcomes associated with person-centered planning and have quantified these components to produce indices allowing for comparability of the process and outcomes to an ideal model.¹¹ First, the evaluation will examine person-centered planning process employed in this project to understand the integrity of the process before examining the results of that process.

Six variables represent a complete and robust person-centered planning process¹⁶. These variables are:

1. **Presence of strategic roles** including a skilled facilitator, a committed 'champion' who is dedicated to advocating with the individual, someone knowledgeable about the local community and also knowledgeable about community organizations, etc. It is also important that a member of the planning team has a relationship with an authority that can drive change in the individual's situation.
2. **Personal relationship with focus person**. The planning team must involve people who know and care about the individual.
3. **Desire for change** on the part of both the individual and the agency assisting them
4. **Creation of a personalized vision**. The planning process must focus on the preferences and capacities of the individual and must include their interests, strengths and capabilities. The plan should relate to and utilize resources within the community and should avoid system-oriented goals.
5. **Commitment to planning and follow-up**. Attendees at meetings should be committed to assisting the individual, at least some attendees should be unpaid, and attendance should be stable. Meetings should be a productive on-going process that assists the individual in reviewing their own progress toward their goals. Goals must be selected by the individual and should be measured objectively. The person and the people they choose should attend meetings.
6. **Flexible funding/resources**. Funding should be tailored to support an individualized service plan and be flexible enough to allow for changes in what is needed and desired. The person and the people they select should make decisions about both major and minor uses of resources and funding.

It is essential that the person be a direct part of this planning process.

¹⁶ Person-Centered Planning Process and Outcome Indicators Scales and Indices, New York State Institute for Basic Research in Developmental Disabilities. See Reference 11 for the publication that discusses the development of these scales and indices.

MASS CPASS Person-Centered Planning:

Assessment of Adherence to the Principles of Self-Determination

Overall, the person centered planning process implemented by the MASS CPASS demonstration project adhered well to the principles of self-determination and the accepted model of person-centered planning. Using the components outlined by S. Holburn et al. above, this section of the evaluation will examine how the MASS CPASS planning process compares to the process model.

1. Presence of strategic roles

The planning process for all individuals involved a skilled facilitator that had years of experience coordinating services for individuals with disabilities in Massachusetts. In addition, all facilitators were trained in the principles of self-determination and in person-centered planning before their interaction with participants. After interviewing each facilitator, it is the opinion of the evaluator that they were skilled in this process and could meaningfully apply the principles of self-determination in a person-centered planning process. Facilitators were also given the means by their agencies to assist the consumer in obtaining the services necessary to meet their goals. Facilitators were extremely knowledgeable about their local communities and organizations. In many cases, facilitators in this demonstration project met with community organizations to attempt to arrange services that had not previously been arranged by the agencies in an effort to fully realize participant's goals.

The components of the group involved in the planning process varied by individual, as would be expected. It was clear during the evaluation that an effort was made with each individual to involve in the planning process those close to and selected by the person. In a few cases, individuals did not have a personal advocate, or "champion", involved in their lives to bring to the meetings. All of these individuals were supported in self-advocacy by the facilitators.

2. Personal relationship with focus person

Wherever possible, the planning processes in this demonstration project involved people close to the individual. However, invitations to participate in the planning process were at the individual's discretion. A few individuals preferred to work directly with the facilitator and chose not to involve other people in their life.

3. Desire for change

It was clear during the evaluation process that all of the individuals participating and all three agencies had a clear desire for change. There was enthusiasm and commitment from both sides.

4. Creation of a personalized vision

Goals were personalized, and most individuals identified multiple goals. The facilitators were encouraged to ask individuals not only identify the goals, but also the milestones that would indicate progress *in their own opinion*.

In some cases, goals did involve system-related achievements, such as becoming eligible for family or individual supports. Because this was a demonstration project within the context of a larger system, it most likely would not have been possible to avoid some

system-related goals because they were essential to securing funding for services after the end of the demonstration project.

5. Commitment to planning and follow-up.

Because the evaluator was not present at the planning meetings, it was not possible to assess the productiveness of these meetings. However, at the completion of the planning process, the evaluation interviews with both individuals and staff demonstrated that all consumers emerged with personalized plans oriented toward their individual goals. In addition, some consumers had changes in their lives or changed their mind about their goals after the planning process. In these cases, the plans were modified through additional meetings as necessary. There was a very high level of satisfaction with the planning process from consumers.

6. Flexible funding & resources.

A component of the demonstration project allowed for some flexible funding, however, it was a capped amount targeted at a portion of the consumers' goals. Ideally, a longer-term pilot would be attempted that allowed for individual budgeting of all support resources to inform agencies how best to support consumers at this level of self-direction. A pilot of this nature would require participation across multiple agencies and resource sources.

Discussion of the Content of the Person-Centered Plans and the Planning Process

After staff were trained on the principles of self-direction and the person-centered planning process (described above), the first task of the staff participating in the mini-projects was to assist participants in the development of a person-centered plan. A goal-based system was encouraged, where consumers identify goals they would like to make progress on in their own lives. As the project involved consumers of a wide variety of ages and situations, the goals chosen by the consumers were also diverse. Common goals centered around educational or life skill training for younger consumers, finding alternative housing, health-related goals and goals related to gaining independence in the community. Participants reported needing help on a daily basis with services such as transportation, recreation and community activities and personal care assistance to assist with meal preparation, medication management and personal care.

All consumers were able to complete a person-centered plan with the assistance of the staff participating in the project. Most consumers selected at least two goals toward which to work. Consumers with more complex needs selected more goals for their plan. Staff encouraged consumers to choose at least two goals, but the number of goals selected was selected by the participant.

Satisfaction with the planning process was high among participants. Every participant reported that they felt that staff listened to their needs and desires during the planning process, and they all felt that the plans reflected goals of their own choice. Additionally, all participants felt the freedom to involve whoever they would like in their planning process. Younger individuals involved parents, and in some cases older siblings, to support them in their planning process. For some consumers, it was important to them that they had the opportunity to plan their services independently with the staff member and that they had control over who was involved in the planning process. Some consumers who were young adults or adults reported feeling more independence and freedom in the creation of the person-centered plan than they had when attempting to procure services in the past.

Plans were often completed with the individuals over a series of meetings. For consumers participating with MCS, person-centered plans were completed with about 5 hours of assistance from staff. For individuals and families who had not previously received services, about 10-20 hours of staff time were required before development of the person-centered plan to explain the current service system model, give an overview to the planning process and develop a relationship with the individual and the family.

Flexible Funding & Individual Budgeting

How was flexible funding utilized by participants?

The list below shows some examples of how participants spent the funding provided by the demonstration project. The list is split into two sections because some programs offered more funding than others (see site descriptions, above).

Those with up to \$5,000 in funding

- Tutoring [2]
- Gym membership and assistant or personal trainer [2]
- Individual Supports and/or Personal Assistance (many)

Those with approximately \$1,000 in funding

- Computer
- Couch (at a different height to allow utilization by physically disabled individual. Unable to transition from wheelchair to couch previously)
- Exercise bike to allow for physical therapy progression
- Transportation for physician visits in Boston
- Rent (covered back rent to prevent loss of current housing arrangement) [2]
- Art therapy for manual skill training
- Pediatric in-home nursing services
- Personal Assistance
- Clothing (consumer goes through clothing quickly because of condition)
- Travel costs
- Repairs/modifications to wheelchair accessible van

Sufficiency of funds

In all cases, sufficient funds were available to meet the needs of the consumers on the identified goals for the period of the project. For those services that did not involve one-time assistance, attempts were made to arrange for a continuation of the services if desired after the end of the demonstration project. In some cases, this was possible through applying for eligibility for family or individual support services from DMR or through PCA funding services. However, in cases where funding was utilized in a manner not currently supported by the current service systems, these services were scheduled to end if the agency is not able to continue funding them. Many participants expressed disappointment that the program could not continue, as they found the model and services it provided valuable and wanted them to continue.

In all consumer interviews, participants were asked how they would utilize additional flexible funding if it was made available to them. About 50% of participants did not feel they needed any additional funding. For those that could use additional funding, the following are examples of how participants would like to spend the funding:

- independent evaluations (for young consumers)
- additional hours from PCA (two consumers)
- winter clothes
- medication costs not covered by insurance
- staff time to assist with advocacy and coordination of services within the school system (multiple parents reported this, especially in Lawrence)

A portion of consumers expressed a desire to see all of their services provided on the flexible-funding model. They felt their needs would be better served if they could allocate support money to design the services they most needed instead of having to work within funding categories.

“I think that when you have a child that’s disabled, there are many other costs you have...I think people should have an option. Here’s [X amount]...how do you want to use the money? And I think I should be able to say, this is how I want to use the money.”

Self-Directed Supports

Consumer’s perception about their choice in the type of services they receive

Individuals receiving services as part of the demonstration project generally felt that they had a choice in the type of services they received and how were provided to them. Only one consumer did not feel that he had a choice in the person that provided services to him. The same participant also felt that he could not request another provider if he did not like the person providing services. However, he did note that he has been very happy with his service providers to date. Many consumers were able to provide examples of instances where they chose their service provider, or made a change when the service did not fit their needs well. For some, the demonstration built upon or enhanced a freedom of choice that consumers felt was present before the start of the project; for others, the project provided choices that they did not feel they had previously. All consumers receiving PCA services in the project chose the person to serve as their PCA.

Perceived flexibility in services:

Participants were asked about the perceived flexibility of their services and if they felt their services could change if their needs changed. All but one consumer felt that their services were flexible enough to change with their needs. The common opinion was that if their needs changed, participants could contact the agency to alter their services through the person-centered planning process. Most participants reported that they did not feel the freedom to adjust their services through the current systems (outside of the demonstration project).

"[My current agency] is more flexible than past agencies. I'm quite knowledgeable in this area and with other agencies. I've been doing this for 17 years with my son..."

Asked to a parent of a young participant: *As your daughter's needs changed, do you feel any new needs can be addressed or will you be back to your previous struggle? "No, I won't be back there. I don't know, I hope it will be different. Her needs change frequently... Hopefully I'll be ok. I think I have a good foundation. At least I know where to go now. Once this program ends, I think that [the community advisor] can still answer questions for me and provide support. The program definitely opened the door for me."*

Many of the parents of younger participants expressed frustration with obtaining and altering services within the school systems:

"At school there's nothing flexible, it's a constant fight. I don't have an IEP signed in the time that I have been here [over 1 year]. That's the way you can tell how much I've fought with them. I used to live in [another state] and in [that state] things are very different than here. When I brought the IEP from [my previous state] it was still active and they ignored everything here."

Many of the parents of young participants felt that the agencies could do little to sway the school systems about services for their children and that the burden of advocacy was placed upon them as parents. Unanimously, they felt that the services their child received were directly related to the success of their advocacy efforts.

Self-Directed Quality Assurance and Improvement

How did the program improve your supports?

Participants in the CPASS project were asked what they felt was better about their services since the start of their participation in the project. The consumers and their families had many positive things to say about the improvement to their services. Most participants stated that the help they received from the agency staff was "very good" and "helpful". Participants cited increased communication with staff, and more available hours from personal assistants and other services that were important to them.

"The agency is more involved with us. If it wasn't for this help, I wouldn't be able to survive."

In many cases, the agencies have helped to educate the participants and their families about programs and services of which they had no previous knowledge. One example of this is about the PCA program. Some consumers were struggling without the help of a PCA because, while eligible, they did not know the program existed. These consumers now receive daily assistance and have reported that it has greatly improved their lives. Agencies have also referred consumers to other resources such as the Mass Rehab Commission (MRC). Consumers in need of adaptive devices or training have been able to access these services through the MRC.

The additional staff time funded by the program has allowed the staff working with participants to spend more time working in detail with them. The staff has worked with

families to teach them how to advocate for themselves within the current systems. They have also worked on individual tasks specific to the family's needs, such as teaching them about the IEP process, or helping consumers create an organizational system where they can keep track of appointments, etc.

For many participants, the freedom to design their own services has greatly improved their satisfaction and their ability to progress toward their goals. Participants have been able to hire assistants to accompany them to the gym, or tutor them about life skills such as how to manage and pay their bills. Some of these consumers had identified but not met the goals addressed in the demonstration project far before the project started; the flexibility in this pilot that allowed them to design the right services to help them achieve these goals.

Receptiveness and Attentiveness of Staff in a Self-Directed System

Participants were asked whether they felt the project staff listened to their needs. All participants felt that their community advisors listened to their needs in the project. However, they did not always feel that staff at other resources, such as schools or job coaches always listened and responded to their needs.

"Yes, project staff are receptive. I feel they're more receptive than past staff at other agencies. I'm one parent who struggles to get the best for my children."

*"Oh yes. I think [my community advisor], not being a parent, the dedication she puts into this program is unsurpassed. She just doesn't stop. She's very responsive, and she has a big job." Have you found other staff to be responsive outside of this agency?
"No."*

*"Yes, they do. The school doesn't. I'm really angry with the school. I've decided that I might just take care of [my child] myself and teach her at home. Not this year, but maybe next year." So you had to fight for the services you received from the school?
"Yes! I've had to go with her and take her to therapy to make sure she's getting her therapy. I take her out of school and to [another town]."*

This parent discussed how she felt that she and her children fell in between the current service systems.

"They listen to me, but they don't have the tools to provide me the services."

She has multiple children, each with mental health challenges and/or intellectual disabilities. She feels that her children fall in between the gaps of Independent Living Centers, who primarily serve adults or young adults, and agencies that help children with more intellectual disabilities. She feels that her children are viewed as too independent to receive assistance from these latter agencies.

In addition, all participants felt that they could discuss their needs and be honest about their needs and opinions with their community advisors. However, some consumers reported "keeping things inside" when dealing with staff at other resources. The additional staff time with new consumers and cultural match of the advisors are two factors that appear to have allowed the staff to develop more trusting relationships with participants and their families.

Consumer Quality of Life

Daily Choices

During the evaluation, participants were asked whether they could choose what they wanted to do each day, and whether they felt this changed at all after their participation in the project. Most participants felt that they could choose what they would want to do each day. Three consumers felt that they could “sometimes” choose what they wanted to do. When asked what imposed limits on their freedom of choice, one participant cited limitations because of her medical condition, one participant was not sure, and one participant felt limited by his disability and his location in a rural area. This latter participant felt he had more choice before he moved from living in a major city.

Most participants felt they had adequate resources to “get where they want to go.” Of the participants that did not feel they had adequate resources, one consumer would like to be able to travel more independently within his community. Another consumer wanted more transportation resources, as he has to walk to appointments at times and feels like it is a long distance to walk.

Decision-making

Participants were asked if they felt they were able to make decisions on their own. The participants, especially younger adults, were also asked about their family’s role in the decision making process. After working in the CPASS program, all but one consumer reported that they felt they had the freedom to make decisions on their own.

This participant reported feeling more confidence to be independent since her work in the project. Are you limited at all in the decisions you can make? “Sometimes, yes. If I have to make a decision I would ask a friend what they thought and I would trust them to make the decision. But lately...I’m like No. I’m going to make my own decision. I’m going to go for it... So I do that now. I don’t depend on people... which is good.”

The consumer who did not feel independent in their decisions felt that she had made progress toward her independence in the program, but that her dependency on her family limited her freedom to make her own decisions. Another consumer reported feeling this freedom except in one portion of her life—and that involved moving out on her own. “My family won’t let me because they love me.” Some consumers expressed that they felt more able to make their own decisions after gaining independence through self-direction.

Friends

Consumers were asked if they felt that they had friends, and whether social activities to meet more people would interest them. All consumers, even those that reported having friends, reported without hesitation that they would like to meet more people and would like more social activities. About half of the consumers asked reported having friends. Some young adults reported having friends at work. Most did not report having a lot of friends, and wanted more and wanted to see their friends more. Most consumers were also able to discuss things they like to do in their free time.

Mental Health

Some participants, about one-quarter of participants, reported past struggles with depression, and one reported a past suicide attempt. However, all of these individuals reported they currently felt that had support networks upon which they could rely and people that they could talk to when they were feeling depressed. When asked who was in their support networks, participants mentioned family members, usually parents, religious figures in their community and psychiatrists. All who reported current problems with depression were under care from a professional.

[It is important to note that participants were not directly asked about depression or any other mental health challenges. This information came out through the questions in the survey (Appendix 1) and the discussions about their services.]

Improvements in Consumers lives

Most consumers reported an increase in their happiness and satisfaction with life since participating in the CPASS demonstration project. Three consumers reported making progress on their fitness related goals, stating that they felt healthier and lost weight, both of which were important to them.

Gaining Independence

Some consumers reported more confidence in themselves, and an increased perception that they could make decisions for themselves. To many consumers, independence was a learning process. Some initially felt they were not capable of the independence they later achieved in the program. Consumers reported feeling less dependent on others, which they state improved their quality of life.

“[The CPASS program] is helping because in some situations I didn’t know what to do before and it’s helped me a lot.”

Multiple consumers reported that the program greatly changed their lives.

What’s important in your life?

When asked what was important in their lives, about 90% of adult and young adult consumers reported that working was very important to them. This was consistent between consumers with physical disabilities and those with intellectual disabilities. Most consumers that were in jobs currently reported liking their jobs. Those that were not in jobs and wanted to work were working on job skills to make themselves more competitive and/or currently looking for employment. Two consumers reported difficulty with their job situations. One reported wanting to change jobs, but felt resistance from his job coach. Another had gone for four interviews at a local chain retailer, but was told the department was closing after going back for her fifth interview. Many consumers incorporated working into their goals, through a desire to work on job skills, the most common of which was learning how to use a computer.

Other consumers reported progress in their weight loss goals and visits from their friends as important to them.

Feedback from Staff

Staff members that participated in the Massachusetts CPASS demonstration projects were interviewed as part of the evaluation process. (See Appendix 2 for the structured interview used with staff members.) The interviews covered two main areas of the project:

- the staff's feedback on the process of person-centered planning, flexible funding and self-direction, and
- the impact of culture on the service and support needs of individuals and their families.

The feedback about these two components will be presented separately in the sections that follow. Afterwards, staff suggestions for systems changes are presented.

Feedback on the Main Components of the Demonstration Projects

Person-Centered Planning Process

An important aspect of the demonstration project was its provision of funding for additional staff time necessary in the beginning stages to develop a relationship with the consumer and in some cases, the family. This resulted in a service planning process that was more centered on the individual and uncovered and addressed their needs more aptly.

“PCP lets parents think of ‘what if I got sick’. The project has helped bring PCP into the agency.”

Regardless of nature of the disabilities the individuals experience, the concept of self-direction of services and supports may be new to potential consumers. Similarly, the concept of independence can be equally new. The availability of staff time is important for individuals that are not used to designing their own services. For almost all consumers in these demonstration projects, identifying their own needs and desires was a significant process. For both this identification stage and the subsequent process to realize these needs and goals, individuals required education on their options and support in talking through their ideal support systems.

Staff reported the ability of individuals and families to develop relationships directly with the agencies and the power of agencies to assist them immediately as a strength of the project. The individuals did not have to go through a larger service system like DMR; the result was more immediate change.

Feedback on ‘Tools for Tomorrow’:

Funding from the grant was utilized to translate the Tools for Tomorrow worksheets into five different languages to enable consumers to truly be a part of their own planning and enable them to use the tools.

Staff commented that person-centered planning, and specifically the “Tools for Tomorrow” system, represents a new concept for the families with which they work. Often, the families of children need a lot of guidance during the process of creating their first plan. Sometimes, the families of the younger children may not feel they're at the right stage to start thinking about their futures. One staff member commented:

“I think it’s a great tool for the transition kids because they’re thinking about the future. The families of younger kids aren’t seeing ‘where is my kid going to live’.”

In Latino families, the family members who are the primary caregivers are often concerned about making sure there is a family member that could care for that person if they were unable to do so in the future. To some, depending on systems outside of the family to provide some services to the person is a foreign concept, and not something they would automatically consider.

One staff member offered this insight:

...I think Tools for Tomorrow is a useful tool for people... Families sometimes don’t think they need to ask their son or daughter about what they want for the future. At least they start thinking about it [with the use of Tools for Tomorrow]. [Families may start to think:] ‘Maybe it is different. Maybe I should be thinking about what they like. Maybe I should be answering some of the questions in the book with their concerns.’

Staff reported that many families needed help procuring their non-negotiables identified in the planning process, often because of language barriers.

Self-Direction

Consumer Choice

Staff reported that self-direction provides consumers with “much more choice.” Staff commented that the system demonstrated by this project was much simpler than the current service system. They felt that they could ask what the individual wanted, and then simply deliver that service. Consumers that didn’t feel that the current service options were a good fit could design supports that were better suited to their needs.

“The choice of providers provided in CPASS would be really good for other consumers too and would increase their satisfaction.”

Some staff felt that it was hard to assess the impact of consumer choice in such a short period of time. All of the agencies involved in the demonstration had reached out into the generic service system, so some felt that they were already accomplishing the access to all possible available service that the program would help support.

Impact of the demonstration model on progression toward consumer goals

Individuals moved toward their goals more quickly in the demonstration project.

“The funding allows the staff to keep in better touch and change the goals as needed by the consumer.”

Staff reported that the planning process and Tools for Tomorrow were helpful in identifying realistic goals for the consumer. A “*person can be grandiose with their goals at first*” but the planning process helps individuals focus their goals and identify both services they really need from what they would desire. It is especially useful for younger consumers who may need more assistance in identifying what their needs are and separating these from desires. Staff reported that the self-directed supports from both agency staff and services changed consumers’ daily lives. *“The hours have really made a great impact in her life.”*

Staff also reported that participants have reached their goals much faster than they would have in the traditional service system. One agency staff person made the point that CPASS is “very focused”, especially on the individual. For example, the ability for the family to have someone they know be the PCA for their child and have the PCA hours start immediately means the individual can start working on the goals right away. The staff reported that for some of the participants in the demonstration project the progress of some goals plateaued across ISPs, but were reinvigorated in the demonstration project and showed much more progress. The participant’s ability to choose the service provider was essential to the effectiveness of the service in progressing the goals of the consumers.

The most common type of participant goals focused on independence. Goals of working in the community and having a consistent job were among the most popular for adult and young adult participants. For younger participants, goals often focused on procuring more and/or better services within their school system. Many participants were having problems with the school system, particularly in Lawrence, MA. The program supported parents in advocating for therapies or educational supports necessary for their children.

Flexible Funding

Staff reported that the flexible funding had many positive affects on the service availability, accessibility and appropriateness of services for individuals in the demonstration project and the ability of the individuals to self-direct these services. Staff felt the funding allowed participants to specify how the funding would help them most, and the impact on their quality of life was very positive, despite the small amount of funding available.

“We need flexible money for many other consumers. I don’t want to see the program end. It’s not a lot of money, but consumers think it’s a lot to help with the little things. The funding has definitely improved the quality of life of the consumers.”

The flexibility of the funding was important, as it allowed for services to be self-directed and allowed the individual to design the service to meet needs not addressed by the current service system. As a result, the funding enhanced the participants’ services and provided the agencies with a greater ability to serve more of the participant’s current needs. The ability to use the funding for things that do not fit in DMR’s current funding categories allowed the services to better fit some participant’s needs.

Example: In one example given by staff, DMR would fund a membership to a gym for a consumer, but they would not fund the person to supervise and assist the consumer at the gym. The result would render the gym membership useless to the consumer. In the CPASS program, funding could be allocated for both aspects of the service and the consumer now regularly attends the gym and has made progress toward his health-related goals.

Services provided with the flexible funding were reported to be “much more personalized” toward the needs of the consumers. The flexibility for the consumers to hire a person of their choice to provide the services, especially PCAs and tutors, was a positive aspect of the project. Individuals and families could choose people of the same culture, often from their local community, to assist them, which usually improved the individual’s satisfaction with the services and improved the progression toward their goals.

Maria and her family were able to choose a tutor to assist her in her educational goals. *“Maria wouldn’t have done nearly as well with a random tutor. The ability for her to pick a person she is comfortable with and had a relationship with has greatly helped her progress. She knows the tutor and listens to her. She starts right away when she gets home from school.”*

The funding in this demonstration project was also readily available to participants, requiring little paperwork and minimal waiting time for delivery. Staff contrasted this to the long waiting periods (often months) they regularly see for individuals in the current system. The funding was also available for the agency to provide emergency funding to families in immediate need. The staff reported that this emergency funding was needed, but not always available currently.

How was flexible funding used?

With the flexible funding, numerous participants purchased computers to assist with their personal goals. These purchases would not have been possible under the participant’s current service options, with the exception of one participant who had received a computer from the MRC for educational use. Consumers in the CPASS project used the computers to enhance their social interaction, to gain job skills, and to search for and access their own service resources such as housing and jobs.

The funding gave consumers more flexibility to prescribe how many hours they felt they needed from a PCA. The flexibility in the amount of hours made the staff more accessible to participants, and made them more available when the participants needed them.

The flexible funding was also often used as bridge money to stabilize and assist participants and/or families until services started. Some of the participants in the project were not receiving any services at the start of their participation in the project. Because there is a delay between the determination of eligibility and the start of services in the current service system, flexible funding was used in many instances to support the needs of the consumer and family until regular services started. In some cases, this funding stabilized the situation of consumers and families to prevent the need for crises supports. It prevented eviction for some, and brought in medical services to the home to prevent hospitalization for others.

Tutoring was also a common use of the flexible funding related to educational goals. Staff reported that for consumers in general, there is a large need for both life skills and some educational tutoring on school-related curriculum. For older consumers, life skills and job skills are the primary educational needs.

Staff also reported that funding for assistance with relocation and housing, moving assistance and language issues related obtaining housing would be readily utilized by consumers. Especially for consumers around the Boston area, homelessness can be a real issue.

Advantages of the CPASS program to consumers and families

All staff reported advantages for consumers and families under the CPASS program.

More hours of service

Staff reported that they felt consumers in the demonstration project received more hours of support services, from PCAs for example. Some consumers, they reported, did not have sufficient hours of support, but arranging for sufficient levels was easier in the demonstration.

Staff reported that consumers often experience a long wait for services and that there is a large amount of paperwork necessary to procure services in the current system. These barriers often result in discouragement in the consumers and can affect their quality of life. Staff discussed a consumer who had been waiting about one year for housing and other services, which was reported as typical. The consumer had a physical disability and was not able to independently get out of his apartment. The lack of accessibility of his apartment does not allow him to shower and mobilize independently. Staff felt that the demonstration project provided a different experience with less paperwork, faster service acquisition and more customized services to meet the actual needs of the consumers.

Another staff discussed a Latino child with learning disabilities who had made little education progress in her current school. After two months of one-to-one tutoring, she was able for the first time at 12 years old to read numbers and words and identify her own name.

The staff member commented after seeing her check her email: *“That really impacted me. I’ve been working with [her] since ‘97 in another agency and I see that she has made so much progress”*

It was reported by staff, the consumer’s family and her tutor that if she had these services earlier, they all felt she would have been much further along in her education. The current service system may have been able to provide her with 5-6 hours of assistance per month. In the demonstration program, she was able to get 5-6 hours per week from a tutor of her choosing. However, as with many of the consumers in the pilot, sustainability of the services at the end of the demonstration is a concern:

“One of my major concerns about [her] is that she’s doing so well with this and that she won’t be able to continue this after the grant ends.”

At a minimum, the demonstration project was reported to at least ‘enhance’ the services provided at all three of the agencies. Especially at smaller agencies, the model put forth in the demonstration model allowed the consumers to get more from the agencies than is normally available. Consumers receive ‘more individualized attention’ with the additional staff time and it has helped staff to ‘better serve’ consumers.

Training

The staff was asked to identify training needs for care providers working with the individuals they serve.

For PCAs & Other Care providers, consumer-specific training is important. CPR and First Aid training were also popular suggestions. Funding is needed to pay PCAs while they are in training. In the current system, PCAs are only funded for direct service hours with consumers. However, PCAs must be trained on the consumer’s specific needs. Additionally, staff at one agency involved in the pilot said that they were not paid for training the PCAs. Funding is needed for both staff.

For agency staff, or community advisors:

- Cultural training
 - For those working with Latino populations: the history of their native country and why they came to the US (example of Puerto Rico was given for staff working with individuals in Holyoke)
 - Also learn about the communities in the area that the agency serves. Visit local cultural organizations and learn who the trusted leaders are in the community (ex. Clergy, political leaders, etc.)
- Sign language, or have reliable access to someone in the office who knows sign language and the use of ASL syntax
- Training from a ‘mentor’ or a staff person who has experience working with the current systems
- Need the option to receive more specific training as topics arise. Examples given were immigration issues, political asylum, how to work with the Social Security office

For parents:

- Training about group homes and other living options and what they have to offer. Some staff members feel some of the individuals they serve would really thrive in a group home, but report that parents may have misconceptions about group homes. They feel that some families might want to try other options if they knew more about them, or knew that they existed.

“A list of what’s available would be really helpful. You might be taking away from creativity, but some families have no idea what to ask for. It’s important to train the families on the options when the child is at a younger age.”
- CPR & First-aid, offered in the parents’ native language, and offered with options for those parents who may not be literate
- Education about the legislative process
- Education about advocacy
- Education about IEPs and the process behind its formation

What staff would keep from the CPASS demonstration

When asked what parts of the demonstration project they would like to maintain and incorporate into their own programs, staff focused on two aspects of the demonstration. The first was the additional staff hours allocated to the consumers. The staff reported that having the time to spend with consumers to develop a relationship and really aid them in their initial person-centered planning process was essential to their success and progression toward their goals. In one of the participating agencies, it was their policy to respond to the consumer when the consumer reached out, but they would not actively follow the consumer. Some staff working at this agency reported that they really wanted to keep in touch with the consumers the way they were able to during the demonstration project. In some cases, both policy and funding constraints affect this ability. Staff also

stressed that it is important to have efficient and trained staff working with the consumers in order to have the staffing hours utilized efficiently to aid the consumer.

The second portion that staff really wished they could keep was the flexible funding available to consumers. They felt that the funding could really help consumers in a bind by allowing them to use it in ways that would most help them. The speed with which the funding was available was also important to assist the consumers when they needed help—not months down the line. In some cases the agency may already do person-centered planning with the consumers, however, flexible funding makes it easier and more likely that the consumers will reach their goals because the agency then has the resources and flexibility to design supports that will truly help the consumers when they need it.

In regards to person-centered planning, all three agencies reported that they did some form of it with consumers currently. Some leave the option to set goals up to the consumers. The agency can do life services planning with the consumers, but usually at the consumer's request. In general, it appears to currently be an informal process and may have been more emphasized during the demonstration than it would have otherwise been. (During the demonstration, participants were asked to identify at least two goals.)

Culture

One of the goals of the Massachusetts CPASS grant was to investigate the impact of culture on the service and support needs of individuals and their families. The staff members that participated in the project were asked about their perceptions on the impact of culture in the needs of the individuals they assist.

Impact of culture on service needs

Most staff felt that a family's culture, especially their language, had a large impact on their service needs.

"[The Spanish-speaking consumers and families] don't necessarily know what's available and the system is very difficult to navigate. It's not an easy thing for an English speaking parent, so when it's someone that doesn't speak English calling someone that doesn't speak Spanish; you have to run around a lot. It seems to me that families start to rely more on the social workers and the staff because they can't do it on their own necessarily. As much as you want to empower the families to do it on their own, the lack of a Spanish speaking person in the office would lead them to not do it on their own; someone else has to do it for them."

Another factor shared by all immigrant populations is the lack of knowledge about the service systems. In many cases, services were not available in their native country. Any services there were available may have come from very different systems. As some staff have explained, some non-native consumers are initially very happy to receive any services at all, so they may be more likely to accept services that aren't the best fit for them, or that don't cover all of their needs. Along with learning the service system, these families also need education about self-direction, advocacy and empowerment.

"...whatever you give [non-native consumers] is better [than what they previously received], so they're not going to advocate for anything that could be a whole lot better. I think it goes back to educating families about the services and how to advocate and empowering them to take over."

The immigrant-related issues are particularly important for the Latino population in Massachusetts as it tends to be a newer and less established population. Larger proportions of immigrants exist among the parents of consumers. Other areas such as New York or California have significant first and second generation populations. The Latino population in this area is not as established, resulting in more families without any English skills and with less familiarity with the service system.

The new immigration laws were also cited as an obstacle for Latinos. The laws make it more challenging for immigrants to become documented, and this can increase the number of undocumented people residing in the U.S. A lack of documentation makes it more challenging to procure services for these individuals. Additionally, some staff have reported coming across biases in the service system, where in some cases 'people are less likely to help non-natives with services.'

Stigmas about disability and the need for services can prevent some individuals and families from seeking assistance. Some individuals wanted to hide their disability and 'pretend it isn't there' or are they do not feel they have a disability. Also, some staff reported that the 'view of needs' may be different. These stigmas have been reported in some East Asian cultures and also in the Republic of Congo.

Stigmas may also exist in cultures about the service system. For instance, in many Hispanic and Latino populations in the US, a fear about family support agencies exists. Some families are very afraid of having their children taken away, or that there will be a price later on for services they receive now. As discussed in the results from the consumer interviews, these fears were confirmed during the evaluation and were expressed by more than one family. Consumers may not know the difference between agencies. Most fears exist about the Department of Social Services (DSS), but they may now know that a staff person from DMR is not associated with DSS. Latino families may also be scared to request services if they are dealing with immigration issues.

Cultural differences in service needs and acquirement

Language tends to be the most significance difference in working with consumers of a different culture to coordinate services. It can create a small barrier between the service coordinator and the consumer when the coordinator does not speak the consumer's language. Using a service such as the language line or an interpreter in the office puts a small distance between the coordinator and the consumer because the two are not directly communicating.

The service coordinator may also need to lend services that are not needed for English-speaking consumers. For instance, English speakers can make their own appointments over the phone, or express themselves to physicians, etc. Non-English-speaking Latino families face more challenges because they "can't go into the general community and be fully integrated." In many cases, staff needs to assist in activities that the consumers would otherwise be able to perform themselves.

Staff reported that some agencies they work with for PCA and other services are very willing to accommodate language issues; however, some agencies are not willing to accommodate language needs even if there is a large Latino population in the area. Limited access to interpreters can present a problem for these consumers both in service coordination and in utilizing services such as during medical appointments. Local

hospitals and doctors offices in the Holyoke area are reported to have recently stopped providing interpreters and now require consumers to bring their own translators to their appointments, creating a large barrier for some consumers.

A staff person remarked that agency staff assisting consumers may understand their disability, but may not understand the consumer's culture and values. This is equally important, and a lack of culturally-competent coordinators can create challenges for consumers. *"It's better for the consumers when they have staff of the same culture to coordinate their services."* One staff person suggested that quick fact sheets or short computer courses be compiled for different cultures so that if a consumer does need assistance and there is not someone in the office of their culture, the staff person can at least gain a small understanding of what the consumer's culture and value system may be like. Overall, openness to the consumers' values and opinions was stressed by all staff.

Another aspect of the challenges provided by language barriers exist in interpretation. In some cases consumers may bring in someone to interpret for them, such as a parent. It may be the case, as has been observed by some staff, that the parent is controlling or has a different opinion than the consumer. What is therefore translated may not be a verbatim account of the consumer's words, but may instead be modified or contradicted by what the parent says.

For cultural and/or financial reasons, some families feel they are not able to advocate for themselves as much as other families. One staff person remarked about serving Latino families:

"In this area, you are going to have to do a lot of advocacy to get what you need. I don't think it should be that way, but that's the way it is. Sometimes the more affluent families get more services because they do the most advocacy."

One advantage of the Latino population reported by staff is their strength in family and community. While many of those who have recently immigrated have a lack of knowledge about the services in this country, they educate the rest of their family and the neighborhood with what they've learned. Clients are often referred to the agencies by word of mouth—by friends and neighbors that are also served by the agency. While this does occur in other cultures, staff remarked that it is more pervasive in the Latino populations they serve. Many of the consumers in this pilot were referred by this method.

"A positive aspect of the Latino community is that they love to help each other out. If we could build upon that strength, we could probably be providing better services. If someone needs a ride, they'll do it if they can."

It was stated by many staff that it is important to work with community leaders of the culture if there is a population of that culture locally. Often community leaders and organizations are more successful about getting information to the local population about services, etc.

The role of family in the lives of consumers & the impact of culture

When entering into a Latino home to meet with a consumer, some staff said there are a few things to keep in mind. One staff person summarized it this way:

"You're not assigned an individual, you're assigned a family."

In Latino households, it is often the case that the whole family will get involved in the process of planning services for the consumer. The family will show you what is also important to them, what they may be working on, and they will tell you about assistance that other members of the family may need. The staff stated that you must appear involved in this process in order not to offend the family and gain their trust.

“People have to understand that it’s a whole family affair, even though they may not want it to be.” “The Anglo culture is very cold. There’s that professional role that you have to keep up with, and [Latino families] don’t necessarily see that.”

“Latino families may not trust you initially. They may feel that you’re there to take things away from them. In other cultures, you walk in and they’re not afraid of you. It’s always been like that in the Hispanic culture, for many, many years.”

“Families want to do stuff on their own; they want to be part of it. The Anglos may think that the Latino parents don’t want to be involved. Instead, it’s often that the system doesn’t really know how to involve them and really make it friendly so that they feel comfortable.”

In Latino families, the family is often involved heavily in the lives of consumers well into adulthood. Many consumers are not allowed to be fully independent by their family, especially young adults. As reported by staff and consumers, it can initially feel foreign to Latinos to be independent. Moving toward independence takes education, but *“once the consumer becomes independent they are very thankful for the change.”* (See case study 1) *“Independence improves the quality of life of the consumer. They go out, they have more freedom.”*

Moving toward independence appears to build confidence in consumers when they realize they are capable of more independent living. In some cases, staff members have seen that consumers may not trust themselves to be independent, which may be influenced by parental concerns. Sometimes a consumer is not used to making decisions by themselves and because of this can be unsure about decision-making. For some consumers, culture may not encourage them to be independent as young adults, especially for those with a disability.

Also, Latino families generally think the younger generations will care for them in the future. Some staff members reported that it can be hard to ask a parent of a consumer to help plan alternatives for the consumer if they were to pass away or become unable to assist the consumer. This was especially true for consumers with severe mental and physical handicaps. Some of the parents themselves reported in interviews that they could not imagine others caring for their child.

In contrast, families of some cultures may expect their children to move out of their house upon graduation and get a job. Especially if the child has a disability such as a learning disability or a physical handicap, this expectation may be put upon them despite any challenges they’re facing. A family may expect independence from a consumer that is not yet completely comfortable with the idea. For these consumers, the transition can appear swift and jarring without assistive transitional supports.

Ethnically-based Support Groups

Two of the three agencies offered Latino support groups for parents of the consumers supported by the agency. Through word of mouth, these parents also invite others they know struggling with similar issues with their children. Throughout the interviews with families involved in this pilot, the support groups were a very strong source of support, strength and empowerment for the parents of children and young adults with disabilities. After about 3.5 years, the parents of The Arc of GL support group are ready to take over the group from The Arc of GL staff and run it themselves. It has been a 'long process', but one that has demonstrated a strong potential for growth in these communities. Even for those families that were participating in the support groups, they all responded that they would be interested in learning about more opportunities for social activities with parents like themselves. Interestingly, staff reported that few men are involved in the support groups, which is reflective of the families they serve which are often run by women.

The support groups have covered a variety of topics—some to educate parents and give them the tools to help themselves, and others to support parents emotionally and assist them in expressing themselves. The groups have done workshops on topics such as letters of intent, navigating the IEP process, the transition into adulthood and 'turning 3'. Topics such as 'finding the joy in parenting' and a painting session where parents painted how they felt helped bring the group closer together. One planning session focused on a delicate topic—that of planning for the future:

"...I read this—Latinos don't plan. We just do things as it comes. We don't plan for the future or the day. It brings up a lot of different things for the parents to plan for child with disability, especially if the child doesn't have a long life expectancy. It's important that [discussions of planning are] really short-term and not focusing on death." It's the 'what if I get sick'. Identified someone who they would 'trust'. Many haven't thought about who that person would be because they do it.

–Comment from Latino staff involved in demonstration

Training staff to assist Latino consumers in planning services

Current staff and directors were asked what advice they would give a new staff member of a different culture during training to work with Latino consumers and families in the area. Patience was one of the first responses from staff across agencies and some mentioned it multiple times. (For the races and ethnicities represented by respondents, see above section) Many staff emphasized the need to develop trust in consumers. This is true for every ethnicity, but was emphasized for Latino consumers. It was also stressed that this can take time and multiple contacts and home visits.

"Above all you need trust. You will develop trust (more quickly) because of the language and similar cultures." –from a Latino staff member:

"Usually Hispanics won't tell you everything on the first visit, they're afraid of you, they feel intimidated. Wait until your 2nd or 3rd visit until you get trust from them and they'll tell you more." What tips would you give to improve the trust with the families? "Communication is essential: talk to the family about twice/week. Be social, check in, etc. This will greatly increase the trust they have in you."

–Comment from a Latino staff member involved in the demonstration

“They’re scared of DSS and that they’re going to take their kids, that’s partially why they don’t tell you everything. For intake, DMR needs to be very friendly and try to be open and get as much info as possible.”

“Be as open-minded as possible. Not all Latino cultures across the state are the same. Learn about the particular family. ‘Everyone comes in their own little box’. Sometimes as service providers, we want things to be done our way. We think our way is right, but it may not be. We have to try to listen to the family. There might be something we can take from them. Everyone, regardless of poverty level, has something that’s valuable.”

“It is ideal to hire staff members who speak the language and know the culture. Never use a family member to interpret if there is a language barrier. Always get an interpreter that will translate exactly what the consumer says.”

“Work on learning the family’s culture and understanding what is important to them. Remember that what may be offensive to you might not be offensive to them.”
(Example given: a kiss on the cheek as a greeting)

Many staff stated that meetings are a family thing. A half hour meeting quickly turns into an hour meeting. Appointments should not be made back to back.

Staff suggestions for proposed changes to the current service system

The ideas presented in this section are a report of the suggestions for change to the current service system made by staff interviewed during the evaluation. These changes were suggested in order to make the community more receptive to the service needs of the individuals served by the staff. Please see the Conclusion section for recommendations made by the evaluator.

- **Adjust the PCA system to make it easier for PCAs to achieve full-time, stable employment and offer personal assistants benefits.** *“Many people looking for employment can’t work with our individuals because they can’t do just 8 hours/month, since that’s only \$80. They have to work with many, many individuals to make it work. Currently not all of the caretakers get benefits.”* Allocations of more hours per consumer would make it easier to find PCAs and keep them employed.
- **Provide education to families about the family support process and the regulations.** Multiple staff expressed the need for education for families from DMR providers about the family support process. Explain what the program can support and what it can not. This understanding would enable families to be active in the planning process and assist them in advocating more efficiently. Staff reported that many families (of all cultures) are confused about what DMR is and what they can provide, especially when multiple agencies work with the families.
- **Improve cultural sensitivity and competency of services.** Services should be more culturally sensitive, given that the multi-cultural population is increasing. We need to talk to families to see what the families want & what would make their lives better, rather than assume our service system fits their needs.

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- Improve Cultural Competency of Group Homes. More group homes are needed that are oriented toward individuals that don't speak English, especially in areas with large immigrant/ethnic populations. A particular need for Spanish-speaking group homes emerged in areas with prevalent Latino populations, such as Lawrence and Holyoke. For example, some Spanish-speaking group homes do currently exist, but often they do not cook Spanish food and offer culturally comfortable settings.
 - Increase Spanish-speaking resources. Resources are lacking for Latino families in Western Massachusetts Hospitals, where interpretation services are reported to have been discontinued. Service agencies also need to have Spanish-speaking staff and access to Spanish-speaking professionals.
 - Large need for bilingual recreational activities in the Lawrence area for youth. The activities need to be low cost and located locally in the community. Many families do not have transportation resources to bring their children to activities. Recreational activities are needed for both after school and summer programs for children.

Example of a successful program: *The wellness program at The Arc of GL. There are 9 consumers actively participating from ages 14-21. Some parents and siblings participate with the consumers. "Even the parents and the siblings are losing weight."*

- Spanish-speaking day programs, especially in the Greater Lawrence area. There are very limited options for day programs for Spanish speakers.

One consumer, who does not speak English, is in a day program where no one speaks her language. Understandably, she does not like going to this program and would very much like a change. However, there are no resources in her area to support her.

- Need transportation services for Spanish-speakers. In general, the agencies did not report a lack of transportation services, but that there were few service providers that had Spanish-speaking transporters. Also, since many families do not have their own mode of transportation in Lawrence, agencies need to accommodate one or a couple of companions with the consumer. This is not always possible with the current systems.
- Additional DMR Funding in Greater Lawrence. Staff suggested the funding for the Greater Lawrence area be re-examined by DMR. Staff felt that the relative need (the amount of need and number of families needing assistance) made the area under-funded at its current support levels.
- More disability awareness needed in the community. The staff feels it would be great if consumers could access existing community resources like little league and the YMCA. However, the staff has encountered some misunderstanding about their consumers and at times resistance from community organizations. Staff made the point that it is easier to hire one staff person to support one or a few consumers in an existing community program than it is to start a completely new program for their consumers. Additionally, the consumers benefit from participating in

integrated programs. In order for it to be successful “everyone has to buy into the integration.”

- **MassHealth Services:** There is a current lack of services for individuals that do not have MassHealth¹⁷, either because they are not eligible or because they are experiencing immigration issues.
- **MassHealth billing rules for Therapy for Children.** If the child receives therapy (ex. PT) at the school, and MassHealth feels it’s being duplicated in the community, the child has to discontinue one of them. However, if the child can get more PT in the community to supplement the PT received at school to actually meet the IEP goals, they should not have to discontinue one of them. Often the schools can’t provide enough therapy to meet the professional prescriptions for the child. Also, the school will not do clinically-based therapy and this must be sought in the community.

Currently, many parents are seeking therapy outside of the city of Lawrence because of the challenges they’ve had in procuring adequate therapy services for their children. This requires that the parent transport the child, and often these families do not have their own car.

- **Lack of Services:** Services just don’t exist. Need someone to ‘reserve people’ who can really go in and help people who aren’t being served by any agency. This is often needed in nursing homes. Need a fail-safe method when people can’t speak for themselves.

¹⁷ MassHealth is the administrator of the Medicaid program, along with many other health care benefit programs for the Commonwealth of Massachusetts.

Case Studies

Child & Family participant

Serena is a 13 year old Puerto Rican girl who lives with her mother and brother in Massachusetts. Serena and her family speak Spanish. Serena understands some English but is not fluent and Spanish is spoken exclusively in their home. Serena experiences some developmental delays and struggles in her special education program at school, where she is taught only in English. At the age of 12, she was not able to write her own name or form letters independently. Serena is frustrated at school, where she is falling behind and seems uninterested in learning.

Serena's older brother and experiences some intellectual disabilities and has frequent behavioral problems, requiring a large amount of Serena's mother's daily effort. Serena's mother receives a lot of support from her nearby family, however, she still feels very overwhelmed. Serena needs some assistance when she's home from school and Serena's mother can not afford to pay someone to help her.

Through the demonstration project, Serena's family was able to hire a family friend to help Serena daily by tutoring her and teaching her about safety in her home and community (with family support from the current service system they could have only hired someone monthly). The agency working with Serena and her family purchased a computer for Serena to use with her tutor and also provided teaching materials regarding safety and some assistance with recreational activities.

Two months after the family friend started working with Serena, her mother noted 'a lot of changes' in Serena. Serena's enthusiasm for learning has increased greatly. She was able to spend more time on tasks, is more aware of safety in her home and can write her own name and knows and can write the letters of the alphabet. Serena is also more motivated to care for her room, where she's tutored, and has progressed to independently working on her for 2 days/week after school.

Adult participant

Estela is a woman in her 30's with a young a daughter living in Massachusetts who natively speaks Portuguese but is also fluent in English. She has physical disabilities and uses a wheelchair and also has some significant health challenges. She currently lives in accessible public housing in an urban area with her daughter. Estela does not have a job, but is interested in getting one. She is currently attending school locally, which she enjoys. She would also like to work, but does not feel she has many skills to offer. When Estela first started working with her current agency, the agency helped her arrange daily PCA services to help with her daily needs.

Estela loves her accessible apartment, but does not feel safe in her building. She has been stuck in the elevator multiple times and had to be rescued by the local fire department. Also, her neighbors and the noise at the complex make her feel unsafe. Currently, she goes to her mother's house for days and weeks at a time to get away from her apartment. She has sent the management notes, but does not feel the situation has improved.

After Estela began working with the agency, she remarked how much more independent she felt. For the first time, she started to take buses by herself around the city.

How has participating in this project changed your life? "It's really changed my life a lot... I've learned to be independent. I've learned to do a lot of things, like coming here. It's completely different. When I first learned about [the agency] I had no idea where it was. I came here and saw everyone [with disabilities] and how they were working so hard. I thought, I can do this, I can do that. Like taking buses by myself, I wouldn't do that."

As part of the demonstration project, she was able to purchase a computer.

"I was really in need of [a computer] because I was going to school for computer programming. I needed one to do my schoolwork."

The computer has afforded her freedom and flexibility that she did not have previously. It has helped her to research and access services over the internet, allowed her to sharpen her computer skills for a future job and has minimized her boredom.

Before working with the agency, Estela reported lacking the confidence to make her own decisions, and often relied on her mother or a close friend to help her most of her decisions. She now says that she feels more independent in her decisions.

Are you limited at all in the decisions you can make? "Sometime, yes. If I have to make a decision I would ask a friend what they thought and I would trust them to make the decision. But lately...I'm going to make my own decision[s]. I'm going to go for it... I don't depend on people, which is good."

Within the demonstration project, Estela has submitted an application for housing at a place where she would feel safer. In addition, she has started to volunteer at an agency to gain more job skills. She is using her computer to look for job opportunities and continue her education.

Conclusions

Considerations regarding the expansion of this model....

Would this work with other agencies?

The three agencies that participated in this project had pre-existing interests and philosophies that at least partially supported and attempted to incorporate the principles of self-determination to varying degrees. The project was aided by the fact that the principles of self-determination were not completely new to the agencies, and this familiarity assisted the development of the project within its short timeframe. It would be of interest to assess how successful this model will be in other agencies that are less familiar with these principles. Because of some of the hurdles met by these agencies in the area of community resources, implementing this model on a larger scale will most likely require a strong, united front in the presentation of these principles. Coordinated leadership from the state systems should greatly impact the success of this initiative in other agencies.

Management

The styles of management of the project differed between the three sites. In one site, the project coordinator was also heavily involved in service coordination for some participants. In other sites, the project coordinator was not involved with clients, and instead worked with representatives from two involved agencies. The variability within the demonstration project was informative and it was important to test the model in different organizational models. However, in a larger model, more consistency would be desirable around the management of the project and the roles of administrators versus service coordinators, etc.

Choose a model for the Person-Centered Plan

Each agency differed slightly in their implementation of the person-centered plan and the emphasis they placed on certain areas of the project. In addition minimum requirements for the planning method and a loose content structure would be helpful to define how a person-centered plan should be conducted and what information is essential to gather from and provide to consumers and their selected supporters.

Flexible-funding

This project was able to explore the area of flexible funding using a small amount of support funds over a short period of time (up to 1 year). This exercise was informative about the potential strengths and pitfalls of unstructured funding, especially as individuals and families already in the current statewide service system had the opportunity to rethink their current services and were presented with this type of choice for the first time. However, it was not possible to assess funding management over a long period of time or in a model that covered all services for the participants.

As a follow-up, a pilot of supported flexible-funding with a larger number of consumers for a longer period of time could be informative. More could be learned about the best models of education and support for consumers to enable them to embrace the freedom, responsibility and authority involved with flexible funding and individual budgeting.

Especially for those consumers just entering adulthood or who have had no experience with this authority, identifying the most assistive education and support models will be important to the programs success. This demonstration project was informative about many aspects of this program and can inform later efforts, but more analysis would be beneficial.

The Community Needs to Improve its Acceptance of Self-Determination

In the demonstration project, some individuals faced challenges when attempting to obtain the services in the community that would fulfill the goals and needs identified in their person-centered plans. The lack of available resources and resistance of a community can severely limit the ability of the individual to self-direct their own services.

Sustainability

This demonstration project contained many elements that showed a strong potential for sustainability. In addition, there were some elements of the project design that would most likely require some adjustment to ensure long-term success.

On an individual basis, there was a very high satisfaction rate with individuals who participated in the project. In addition, family members of minors involved in the project resonated this satisfaction. The demonstration project showed that it was possible to do the following:

- To train staff to assist individuals in creating a person-centered plan
- To assist consumers of all ages in creating a person-centered plan with which they were satisfied. None of these consumers had formally created a person-centered plan previously, and most had not formally set service goal previously.
- To coordinate and create services to fulfill these person-centered plans
- To adapt to services changes ranging from minor to major in the lives of the individuals to the satisfaction of the individuals experience these changes.

As this was a time-limited project, there are some questions that this project could not answer by the nature of its design. Longer-term follow-up of consumers in this model would show more about whether their services continued to provide the flexibility to meet their changing needs.

Overall conclusions

It seems that the participating agencies were all able to understand and embrace the philosophy of self-determination in this project. In fact, all three agencies had implemented some aspects of this philosophy into their daily work before the demonstration project. Their ability to assist consumers in their planning process and develop truly person-centered plans, in this evaluator's observations, met all of the project goals.

However, the agencies did encounter some barriers and hurdles during the demonstration project. Agencies invited consumers to participate in the demonstration project, some of which were met with more challenges than many of the consumers served by the agencies. Assisting these consumers challenged the agencies to the best of their abilities in the current service system. In many cases, the success of the planning process and the

realization of the consumers' goals were due to the efforts and dedication of the agency staff. The staff guided many of these consumers to teach them how to consider their own independence and envision the process to get there. Person-centered planning as experienced in this pilot is truly a process, one that is done by attentive and skilled staff people that have earned the trust of the individuals they serve.

However, the person-centered plan is only the beginning of a system and a community that values self-determination and supports the self-direction of services. Once a consumer identifies their goals and accompanying milestones and pathways for achievement, the largest hurdles are currently encountered while trying to fulfill these plans.

The community and the current service systems could do a lot to ensure the realization of person-centered plans and to create an environment that nurtures self-direction. Many of the largest challenges are met trying to procure and consistently fund services to fulfill these plans. A variety of current situations were identified in this demonstration project that can contribute to these challenges:

- Limited Resources in the community, especially culturally appropriate services
- Problems within the PCA funding model including low wages, few benefits and odd/fragmented hours
- Funding categories and current budget practices (annually) that do not support flexible funding and consumers can experience delays in the start of funding/services
- Some consumers, regardless of the nature of their disability, and their families need time to adjust to self-direction. The concept of independence and choice can be 'foreign' initially or appear very abstract to some. However, in all cases within this project, a move toward self-direction had positive impacts on the consumers' quality of life.
- Some consumers need a larger amount of staff time during their initial participation period than is allotted in the current service system. However, this need is usually reduced after the initial planning phases.
- Language is a real barrier to service and the ability of consumers to self-direct that must be addressed, as the problem is growing

Recommendations to the Coordinating Council

Short term Suggestions

- Create provider profiles to assist consumers and families in their choice of what they feel would be best for them. Have providers, DMR and consumers provide input into the content and include some sort of quality rating.
- Create additional materials that educate consumers and families and empower them in assisting themselves. Translate these materials into multiple languages
- Change area DMR (and other agency) budgets so that they are not by service group, or allow reallocation between these groups to accommodate changing needs of the area population. Budgets set at the start of the fiscal year may not appropriately address the needs of the area.

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- Work to loosen funding categories to accommodate more individual needs
 - Minimize the current delay between approved eligibility and the start in services
 - Provide more emergency funding that agencies could access for consumers in crisis

Long-term Suggestions

- Create service options where consumers can participate in self-direction of their services and individual budgeting. A flexible system is needed that can support many degrees of self-direction
- Adjust the PCA funding system to allow for more competitive wages, regular benefits and more consistent hours. This would make the PCA position a more realistic job option for skilled workers.

As the Commonwealth moves toward Self-Determination:

- It is important that the agencies within the Executive Offices of Health and Human Services¹⁸ work together to incorporate options for self-determination into their systems. Most consumers receive services from at least two agencies, and fractured efforts to incorporate self-determination options could be detrimental to consumer experiences and impede their ability to self-direct.
- Develop a longer-range pilot that involves more diverse agencies and follows more consumers for longer periods of time. The pilot should allow at least a portion of participants to completely self-direct their budgets. Focus the pilot on assessing the long-term support and educational needs of consumers who are self-directing a larger proportion of their supports.
- Choose a model for Person-Centered Planning or service planning that ensures some minimum standards for structure/content of the plans. The model should be flexible enough to support planning across disabilities (including consumers with and without intellectual disabilities).
- Develop educational materials for individuals and families before implementing this project and translate them into many languages. Evaluate the usefulness of these tools through input from consumers and families before statewide use.
- Increase the available community resources, and ensure skilled workers are available to individuals who are in need of personal assistants. Educate the community about the individual budgeting options as the system is rolled out. A centralized statewide listing of available skilled workers with information such as language and skills would benefit both consumers and workers.
- Ensure skilled facilitators are available to consumers and families to create and implement person-centered plans. Allow options for consumers to purchase

¹⁸ Agencies within the Executive Office of Health and Human Services: Massachusetts Commission for the Deaf and Hard of Hearing, Massachusetts Commission for the Blind, Massachusetts Rehabilitation Commission, Department of Mental Retardation, Department of Mental Health, Department of Public Health, MassHealth, Department of Social Services, Department of Youth Services, Department of Veterans' Services, Department of Elder Affairs, Soldiers' Homes, Office for Refugees and Immigrants, Department of Transitional Assistance, and Division of Health Care Finance and Policy.

additional support time as needed beyond average levels from staff with their service dollars to allow consumers to procure more assistance if they desire to do so.

- Ensure facilitators are available that can speak the individual's language and understand their culture.

Glossary

Self-determination	a principle that places decisive power about the design of a person's life in their own hands, with the goal of "the creation of meaningful, culturally appropriate lives deeply embedded in our communities and suffused with real relationships.
Self-directed services..... and supports	A system of activities that assist the participant to develop, implement and manage the support services identified in his/her individual budget.
Person-centered planning.....	A process directed by the participant, intended to identify the strengths, capacities, preferences, needs and desired outcomes of the participant.
CMS	Center for Medicare and Medicaid Services
MCS	Multicultural Community Services
PASS.....	Personal Assistance Services and Supports
BCIL	Boston Center for Independent Living
The ARC	The Association of Retarded Citizens
PCP	Person-Centered Planning
MASS CPASS.....	Massachusetts Community-Based Personal Assistance Services and Supports
DMR.....	Department of Mental Retardation
RFP	Response for Proposals
CLASS.....	Citizen's League for Adult Special Services
MDDC	Massachusetts Developmental Disabilities Council
QA/QI.....	Quality Assurance/Quality Improvement
PCA	Personal Care Assistance
DSS	Department of Social Services

Appendices

Appendix 1: Sample Consumer Semi-Structured Interview

Interview structure designed by evaluator with input from the Evaluation Subcommittee

Appendix 2: Sample Staff Semi-Structured Interview

Interview structure designed by evaluator with input from the Evaluation Subcommittee

Appendix 3: Consumer Profile

Completed by staff at the request of evaluator

Appendix 4: Goal Planning Worksheet

A worksheet staff used with consumers to identify goals and track the progression of these goals with consumer-identified milestones.

Appendix 1: Sample Consumer Semi-Structured Interview

Questions will be presented in a semi-structured interview and will be woven into a conversation with the consumer.

_____, I'm going to ask you some questions about yourself, your family and what your day is usually like. I'm also going to ask you how much you like different things in your life.

When I ask a question, I'd like you to tell me exactly how you're feeling. I will be the only one who hears what you say to these questions, and I won't tell anyone else what you say here (nor will the interpreter).

Would it be ok if I use a tape recorder to record what we say? I'd like to be able to listen to exactly what you said to the questions I ask you after I leave today.

General Data

1. Age
2. Gender
3. Race
4. Ethnicity
5. Primary language Spoken
6. Was translator used? Y/N
If so, who was translator?
7. Where do you live now? Who do you live with?
8. Can you describe the members of your family to me? How involved are they in your life? How often do you talk to them, how often do you see them?
9. Do you feel your family lets you make decisions for yourself?
(with yes or no, ask for an example)

Possibly add in questions about specific areas, based upon their services and ask them to choose the emotion face as to how they like each, similar to the tools for tomorrow questions

What is important to your home...where you live, who you live with, etc.?

Services and Supports

10. What do you feel you need help with on a daily basis?
11. What services and supports do you receive now? Ask opinion of each support, using face card if necessary. Ask if each service is as good as expected
(*Ex. Transportation, in-home assistance, day activities. Use follow-up questions to prompt as needed*)
12. Do you feel you have a choice about the type of services you can receive?
13. What is better about your services since you started participating in the CPASS program?
(*If unfamiliar with reference "CPASS program", use a timeframe or another term to refer to the program.*)

-
14. What do you not like about your current services?
 15. How flexible are your services? (Prompt: do you feel the services can change if your needs change?)
 16. What kind of help do your services provide to you? Do your services provide the type of help you thought they would?
 17. How much say do you have in who provides your services to you?

Can you choose who helps you?

Program evaluation (spread out these questions)

18. How has participating in this project changed your life? (Prompt: has it made it better, worse? Do you feel overwhelmed, or that you have more freedom?)
19. How do you feel about your participation in this project? (Prompt: Are you glad you participated, upset, etc.)
20. If you could go back in time, how would you feel about participating in this program again? (prompt: would you do it over again? Why, why not?)
21. If you could change the services you have, what would you do? (prompt: more, less services, different people, different type of service, different time of day, help with different things, etc.)
22. How well do project staff listen to your needs? (Prompt: If you don't like what staff are doing, or how they are doing it, do you feel you can say something and they will listen to you?)
23. Do you feel you can talk to project staff about your needs?

Quality of Life

24. What would you like to do in your life but can't currently?
25. Do you feel free to make your own decisions? (ask for example either way)
Could you make your own decisions before this project?
How often do you make your own decisions?
26. Do you feel you can choose what you want to do each day?
27. Can you get where you want to go?
28. How has working with CPASS improved your life, if at all?
29. How has it changed your life? (put in different sections from one above)
30. If problem with service is found: What got in the way of...

Training needs:

31. If you were to select a new person to help you every day, what would you want them to know? What would you want them to be able to do?
32. What do you like about what the person who currently assists you does? What do you not like?
33. What type of training/skills would you like to learn?

Appendix 2: Sample Staff Semi-Structured Interview

Would it be ok if we tape-recorded this session so that I may more accurately capture your responses in this interview?

1. What is your current job title, and what does that job entail?
2. How long have you been a _____?
3. How many consumers have you worked with in the CPASS project?

How have you worked with the CPASS consumers?

General questions about Latino-specific situation, current service system:

4. In your experience, how does a family's culture impact their service needs?
5. Specifically, how is your interaction and job different when working with a Latino family as opposed to a family of a different culture?
6. Do you feel that Latino families have unique difficulties finding appropriate services? How so? Do you feel they have unique advantages in finding services?
7. What aspects of Latino culture do you feel are important to understand when coordinating services for (or working with) them?
8. What obstacles to person-centered planning do Latino individuals experience that you do not see other individuals encountering?
9. If you could make a change in any system related to personal services to allow for more individual choice in services, what would you change?
10. How do the "important components" of an individual's life differ between cultures, if at all?
11. How is the family's role in the individual's life different between cultures in your experience? How is it similar? What is your experience with staff or agency's ability to adapt to these differences?
12. If you were training someone from a different culture to plan services for Latinos in the area, what advice would you give them?

CPASS Participation:

Think of an individual and their family involved in the CPASS project, and one that hasn't been involved in the CPASS project:

13. Has there been any advantage for the family in the CPASS project?
14. How has the flexible funding from CPASS influenced the service availability and accessibility for the individual and their family?
Has the additional flexible funding assisted the individual in receiving more personalized and/or appropriate services?
15. Have individuals participating in the CPASS project had more choice in their services than other consumers you serve? If so, what do you feel allowed for this greater choice?

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16. How has the progression toward individuals' goals been different between consumers in the CPASS project and other consumers? How do you feel each CPASS participants goal progression would differ without CPASS?
 17. If you could keep any part of the CPASS project, what would you keep? What parts of the project do you feel your agency already successfully employs?
 18. What aspects of an individual's life has CPASS improved?
 19. Has the Tools for Tomorrow system and CPASS enabled the individual and their family to express and act upon their choices more frequently and with greater ease?
 20. Do you feel most individuals and families can procure their "non-negotiables"? How, if at all, has CPASS changed this?
 21. Do you feel individuals have an easy time identifying what their "non-negotiables" are? Do you feel an individual's and their family's opinion of their non-negotiables often match? Does this differ by culture?

Do individuals need assistance in discovering their non-negotiables? What can aid them in this process?
 22. What type of services do you feel are needed in the area that you have trouble arranging for the individuals you serve? If you had a wish-list of additional services, what would be on it?
 23. Do you feel individuals in CPASS are more empowered to be the primary decision makers in their lives?
 24. How flexible do you feel the current services are to an individual's changing needs and non-negotiables?
 25. What did you like/not like about the Tools for Tomorrow guide?
 26. What advocacy strengths have you seen in families, where do they need assistance? Is this different between cultures?

–ask about short-term vs. long-term changes needed for the system

Inter-agency variability

27. Have you found any distinct differences between agencies? If so, what were these differences?
28. How have agencies been more or less helpful to Latino families?
29. What training needs do care providers have?

Appendix 3: Consumer Profile

Consumer Information Sheet

Date completed	
Consumer Name	
Age	
Ethnicity	
Gender	
Native language spoken	
Fluent in English?	Yes No
Translator needed for consumer interview?	Yes No
Can the consumer comfortable express themselves verbally?	Yes No
Coordinator name	
Date started working w/CPASS	
Current status in CPASS project	
Current Residential situation	
DMR client?	Yes No
What services does the consumer currently receive? (Also list any other agencies involved in service provision for the client)	
Description of services provided by CPASS (be specific)	
Description of the consumer's goals in relation to their participation in CPASS	
Involved Family & Advocates (name and role/level of involvement)	
Translator needed for any family member? (include native language)	

**Please attach person-centered plan and copy of current goal planning worksheet for each participant. Attach additional sheets as necessary

Appendix 4: Goal Planning Worksheet

Consumer Name	Date				
Staff or Family working with the Consumer on this form					
GOAL	Goal Number:				
<i>Instructions: Detail the consumer's personal goal. Be specific about the consumer's assessment of their current situation and how they would like to achieve their goal. Example goal: improve my reading skills in order to gain more independence in my home</i>					
GOAL MILESTONES					
<i>Instructions: Detail each milestone identified by the consumer that is necessary to achieve their goal. The question "how will we know?" can help to identify these milestones. The milestones <u>must</u> be identified by the consumer and should not be solely identified by staff or family. Each Goal should have at least 3 milestones (including completion) that include short-term and long-term measures. Examples of milestones for learning to read may be (1) identifying a tutor (2) scheduling the first session (3) completion of 5 lessons (4) ability to read a utility bill</i>					
Date work started on Goal	Date Goal Accomplished				
Date Milestones Achieved					
1	2	3	4	5	6