Recommendations for EOHHS for Advancing Self-Direction in Massachusetts' Long-term Care Delivery Systems

Report Prepared by:

Laurie Burgess
Margaret Chow-Menzer
Jeff Keilson
Nilka Alvarez-Rodriguez
With input from the Systems Transformation Grant (STG) Diversion Subcommittee Financing Workgroup and STG project associate Wendy Trafton

July 25, 2008

Executive Summary

Over the past three decades, states have incorporated elements of self-determination into their long-term care delivery systems. This person-centered and person-directed approach to service delivery enables elders and persons with disabilities to direct the decision-making process for determining which supports they need, while ensuring access to information, services and supports, and providing flexibility to meet the unique needs of each individual. Elements of self-determination exist in several programs and pilots in Massachusetts.

This report outlines the programs in which each state agency believes there are elements of self-determination within their agency and their prioritized actions for further implementation of models of self-determination. This was revealed through meetings with senior staff at agencies and focus groups with consumers. It concludes with recommendations for activities for implementation at the Secretariat level as well as agency-specific actions to advance self-determination in the long-term care delivery system.

Agency-Specific Initiatives and Priorities

- **Department of Mental Health** (DMH) seeks to develop opportunities for self-direction in Day and Employment Services, Flexible Community Supports, Transition Age Youth Program, and 24-hour Residential Services Program. They prioritized employment services and Flexible Community Supports as programs to implement all elements of self-direction. Training is needed for agency staff to ensure a common understanding of self-direction and its components.
- **Department of Mental Retardation** (DMR) implemented three (3) programs with elements of self-direction: Self-directed program for adults, DMR/DOE Project, and the Autism waiver program. Objectives for improving the programs include increasing outreach and awareness of the programs and enabling more individuals to enroll in the programs through agency structural changes; as well as, providing self-directing individuals and their families with additional supports and tools.
- **Executive Office of Elder Affairs** (EOEA) currently offers a limited self-directed program, Home Care, which enables elders to hire and fire their own staff, participate in person-centered planning, and utilize fiscal intermediary services at ten (10) Aging Service Access Points (ASAPs). Future objectives include expansion of the program in terms of numbers of ASAPs and individuals enrolled and the scope of consumer-directed services. Initial ASAP staff trainings occurred and future trainings are planned.
- **Massachusetts Commission for the Blind** (MCB) seeks to develop opportunities for self-direction in Social Services Programs and the Deaf/Blind Multi-Handicapped Program. Priority areas include high need/high cost consumers in the social services program that receive close to $20,000 worth of services and individuals turning 22. Also, five individuals currently receive an individual budget and self-direct their residential services. MCB wants to develop an infrastructure to support this option for everyone receiving residential services.
- **Massachusetts Commission for the Deaf and Hard of Hearing** (MCDHH) is unique in that it does not provide programs or services in which individuals can enroll and self-direct. However, MCDHH has for years promoted self-determination and, in the course of the development of this report, indicated it intends to prioritize providing formal

training to its case managers in person-centered planning; as well as, providing training in self-direction to case managers from other agencies, clinicians and interpreters who work with people who are deaf. Other priorities include developing strategies for outreach and training on independence and self-direction for parents with deaf children and investigating and implementing optional peer supports for deaf individuals participating in person-centered planning and self-determination.

- **Massachusetts Rehabilitation Commission** (MRC) seeks to develop opportunities for self-direction within the Brain Injury and Statewide Specialized Community Services program and for people receiving residential services. In order to do this, MRC plans to develop training curriculums for consumers and service providers, create a methodology for establishing individual budgets, determine the role of a support broker and how to provide this service, and expand person-centered planning.

Recommendations for Advancing Self-Direction in Massachusetts

Whereas there is broad support and enthusiasm for promoting opportunities for self-direction in each agency, some statewide planning and implementation should be pursued at the Secretariat level. Recommendations include:

- *The Executive Office of Health and Human Services (EOHHS) should issue a policy statement announcing that our delivery systems will promote self-determination and provide multiple options for self-direction.*
- *The Executive Office of Health and Human Services should convene statewide conferences to promote self-determination.*
- *EOHHS should design and implement a statewide, broad-based and coherent self-determination and self-direction educational and awareness campaign.*
- *The Secretariat should leverage the EOHHS Purchasing Advisory Council and work with the provider trade organization affiliated with each agency to help build a self-direction focus into cross-agency purchasing efforts.*

Additionally, recommendations for activities that agencies can undertake to expand self-direction options include:

- *EOHHS and the identified agencies should take advantage of the numerous opportunities for learning and collaboration that currently exist in the Commonwealth to build agencies' capacity to support self-direction.*
- *Encourage each agency to be involved in the MABB-PCP grant project's activities pertaining to the development of a training curriculum and tools each agency can use to make service planning more person-centered and the expansion of aging and disability resource directories (e.g. MADIL) to include grass roots, culturally diverse and local community based organizations.*
- *Each state agency should develop and implement an outreach and educational campaign within the specific program area(s) identified by the agency for advancing self-determination.*

Conclusions

There is much excitement throughout the Commonwealth regarding self-determination. Through capacity building within the current service delivery system, Massachusetts can give consumers greater choice and control over their services and supports. In an improved system, consumers will be able to choose from a spectrum of supports and services, including traditional providers and non-traditional self-directed supports and services. The Secretariat and state agencies are tasked with defining self-directed service parameters and implementing activities that will result in increasing the available supports and services that can be self-directed. The recommendations outlined in this paper will assist in the efforts to expand self-direction options in long-term care delivery.

Table of Contents

I. Introduction

In October 2007, the Massachusetts Executive Office of Health and Human Services (EOHHS) was awarded a Massachusetts Building Blocks (MABB), Person-Centered Planning Implementation Grant from the federal Centers for Medicare and Medicaid Services (CMS). The purpose is to advance the use of person-centered planning, a key component of self-direction, in the Massachusetts long-term care delivery system. Around the same time, the Financing Workgroup of the CMS Systems Transformation Grant (STG) Diversion Subcommittee decided to develop a recommendation for EOHHS regarding how self-determination models might support effective alternative financing strategies for the long-term care system. In the spring of 2008, members of the Financing Workgroup[1] joined forces with the Person-Centered Planning Implementation Core Team (the authors of this report) to provide a comprehensive overview of the self-direction delivery system option and its advantages, and to develop a recommendation for the Secretariat regarding the implementation of all components of self-direction throughout the state's long-term care delivery system. This report represents their combined efforts, and contains recommendations on steps to aid the transformation of Massachusetts' long-term care delivery system into one that fosters self-direction. (See **Appendix A** for a list of all agency staff and other individuals external to state government who participated in the development of this report).

This report defines the components of self-direction and explains why the concept is important for Massachusetts as a whole. This is followed by a description of the current self-direction efforts identified by the six state agencies (the Department of Mental Health, the Department of Mental Retardation, the Executive Office of Elder Affairs, the Massachusetts Commission for the Blind, the Massachusetts Commission for the Deaf and Hard of Hearing, and the Massachusetts Rehabilitation Commission) and their hopes for further implementation of self-direction in their agencies. The report concludes with recommendations related to these agency-specific aims at the agency and Secretariat levels.

II. What are Self-direction and Self-determination? Why are these Important Concepts?

Self-determination is the fulfillment of elders' and persons with disabilities' desire to have control over their lives, including having control over support service decisions and the freedom to take risks.

By self-directing his/her long-term care services, an individual achieves self-determination. Self-direction in a long-term care delivery system includes the following features:

- The individual is central to and directs the decision-making process that will determine which supports are needed.
- The individual has easy access to information, options, services and supports to enable him or her to self-direct.

[1] The STG Diversion Subcommittee includes senior staff of EOHHS disability agencies and of EOEA including those involved in the person-centered planning grant implementation activities.

- The service system is flexible so that the individual can tailor his/her supports to meet his/her unique needs.[2]

A list of key terms and their definitions are provided in **Appendix B**.

Background

The movement to make self-determination in the social service systems a reality emerged in the 1960s, and had a particular focus on independent living and developmental disabilities service delivery. The demand, which was considered a civil rights issue, was to give individuals a choice to receive long-term supports in other than institutional settings. The concern was and continues to be that the long-term care delivery system compels individuals to receive services that others have determined are the "right" services for them. They believe decisions about how and when long-term supports are provided are restrictive, paternalistic and rely too heavily on medical opinion. Increasingly, individuals want the choice to self-direct their long-term services.

Nationally, state agencies began incorporating self-direction into their long-term care delivery systems in the 1990s. Initial efforts were in the developmental disabilities arena, in federal Medicaid Cash and Counseling demonstration programs focusing on community access, and in community-based supports for deinstitutionalization. Among the pilots, demonstration projects, and programs funded since the 1990's are:

- *Robert Wood Johnson Foundation's (RWJF) Self-Determination Initiative*: Nineteen states funded to explore ways persons with developmental disabilities can influence the character and configuration of the supports they receive through self-determination.[3]
- *RWJF's Cash and Counseling Model and Demonstration Project*: consumers received a budget to hire workers and buy care related goods and services.[4]
- *CMS's New Freedom Initiative and System Change Grants for Community Living*: states received funding to further CMS' vision of a person-centered long-term services and supports system. These initiatives focus on policies, programs and tools available to shape and carry out the vision. Programs include the Independence Plus home- and community-based waiver design, which allows states to use Medicaid to fund self-direction and other alternatives, in addition to more traditional services in the community.

More recently, promotion of self-direction nationally has expanded beyond the Independent Living and developmental disabilities delivery systems and into the aging and mental health service systems. This expansion has included: peer recovery supports, Medicaid programs in the areas of personal care, home and community-based waiver services, and the development of consumer-directed State Plan options authorized by the Deficit Reduction Act of 2005.

In Massachusetts, programmatic elements of self-determination were first implemented in the 1970's. Promoted by the Independent Living Centers, Personal Assistance Services (an optional Medicaid benefit Massachusetts calls Personal Care Attendant (PCA)) was implemented by the

[2] This definition was developed by the Massachusetts C-PASS Grant Coordinating Council, January 23, 2007.
[3] For more information, see The Robert Wood Johnson Foundation Self-Determination Initiative: Final Impact Assessment Report, November 2001 at www.hsri.org/docs/767aRWJFFinalImpactAssessmentReport.pdf
[4] For more information, visit www.mathematica-mpr.com

state using a self-determination model. Under the PCA program, people with disabilities do not manage an individual budget; instead, they hire and fire their own PCAs with the support of the fiscal intermediaries. Other ways in which the Commonwealth has implemented self-direction include:

- In the mid-1990's, Massachusetts was amongst the 19 states awarded a Robert Wood Johnson Foundation grant to implement a more cost-effective system that both served persons with developmental disabilities and gave them and their families more choice in determining the services they receive.
- In 2004, the Massachusetts Real Choice Flexible Supports and Services pilot was launched to examine the implementation of a Cash and Counseling model in the Commonwealth. This pilot was supported by a federal CMS Real Choice Systems Change grant and allowed participants to decide how to spend their budget allocation to meet those community service needs not typically covered by Medicare or Medicaid.
- A pending Community First 1115 Demonstration Waiver program will include a self-direction component that has been informed by the signification information provided by the Real Choice pilot, which will end in 2009.
- The Department of Mental Retardation and the Executive Office of Elder Affairs have each implemented some or all aspects of a self-direction delivery system option. (described in detail later in this report).
- Support for self-direction is identified in the Olmstead Plan currently in development and in pending legislation on self-determination.

Advantages of Providing the Self-Direction Delivery System Option

When a delivery system incorporates the principles of self-determination and individuals become empowered to choose, use, and control services, there are positive outcomes. A list of studies that support these conclusions is provided in **Appendix C**. These conclusions include:

- Individuals involved in such systems consistently report improved quality of life and, in some studies, improved health and an improved chance that changes in an individual's condition will not go undetected and will be addressed more quickly than in traditional systems.
- Individuals in such systems often rely on more informal supports which can decrease the use of traditional supports.
- Individuals' use of informal supports can lessen the burden on an overtaxed, traditional direct care workforce.
- Creation of delivery systems of supports for individuals employing self-direction often results in increased community awareness regarding the needs of persons with disabilities, an expansion of the network of informal supports, and a de-stigmatization of persons with disabilities.
- Individuals who are self-directing often choose employment and other activities over utilization of traditional services, which again decreases demand on the traditional health care delivery systems.
- When individuals have control over purchasing the services in the way they choose to meet their needs, there is often less over-utilization of services, in general.

In addition to the above reasons, it is also important to note that the Centers for Medicare and Medicaid Services (CMS) are encouraging states to incorporate self-determination into state long-term care and Medicaid delivery systems[5]. **Appendix D** contains examples of other states' recent successful innovations in self-direction.

Last, the principles of self-determination, especially the aspect of empowering individuals with disabilities to choose to live independently, with dignity, in the community, and in settings of their choice, are at the foundation of Governor Patrick's principles for the Massachusetts Long-Term Care delivery system. (EOHHS website, January 2007)

III. How Self-Direction is Implemented in Long-term Care Service Systems

Self-direction can be implemented in any service system. Self-direction is a service delivery approach that includes many of the following elements:

- Self-advocacy/skills training.
- Individual-directed, person-centered planning process enabling individuals to identify and access a personalized mix of paid and non-paid supports to meet unique needs and personally defined goals.
- Circle of support/team selected by the individual that meets regularly to help the individual accomplish their personal goals.
- Support broker to assist the individual to carry out a person-centered plan.
- An individual budget, that is a dollar amount for goods, services and supports specified in the person-centered plan that is under the control and direction of the individual.
- Availability of financial management services/fiscal intermediaries.
- Recruitment, hiring, firing, and training of direct support professionals and other staff.
- Attitude shift among state agency staff and provider staff (supporting individuals to make personal choices that staff might not agree with).

How a state implements delivery systems that foster self-direction can differ from one state agency to the other, and from service delivery network to service delivery network. Implementation may occur in varying degrees, in phases, along a continuum and over time, depending on the system.

In a system that *fully* incorporates the principles of self-determination, there are usually the following four elements:

[5] CMS has developed simplified model waiver and demonstration application templates intended to promote person-centered planning and self-directed service options. Most recently, CMS encouragement came in the form of guidance to state Medicaid directors on the implementation of the Deficit Reduction Act of 2005, section 8086: Expanded Access to Home and Community-Based Services for the Elderly and Disabled. Section 8086 added section 1915(i) to the Social Security Act, which offers states the option to amend their State plans to offer an individual (or the individual's representative) the option to self-direct Home and Community-Based Services (HCBS) without regard for statewideness or certain other Medicaid requirements. Under this same Public Law (Number 109-171), states are required to provide Individualized Care Plans that are person-centered.

- an enrollment process;
- a discrete benefit or set of services that individuals can be determined eligible for with a discrete budgeted amount attached;
- a service planning process that is directed by the individual; and
- support personnel available to the individual (referred to by any number of terms including service coordinator, peer monitor, case manager, care advisor, or support broker) whose purpose is to help the individual determine how and by whom their needs can be met and to help them monitor the receipt of services and quality of services.

Once eligible and enrolled in a system that fully incorporates the principles of self-determination, an individual can assess his/her own needs and access appropriate support staff he or she may need to:

- decide what services he or she wants.
- determine whether and how to use his/her individual budget to purchase services from traditional provider agencies and/or hire and purchase goods, services and supports directly.

There are significant differences in practice and in how individuals experience the service systems between systems that utilize a more traditional way of service plan development and administration and those that have incorporated the principles of self-determination. In a more traditional system and planning process, for example, typically, there is a professional case manager working with the individual to identify his/her needs, determine the providers that could meet those needs and presents them as the service options to the individual. The service plan is developed through this process with the individual selecting amongst the providers and services offered. The discussion and creation of the service plan might take place over the course of one visit with a case manager. At the annual review of the service plan, the case manager would typically convene a meeting and invite the service providers, the individual and often family members, to develop goals and objectives for the person and changes if any, to the service plan. The individual would participate in the meeting but would not direct it. The focus of the planning process in a traditional system is on the services that the system has to offer the individual and his or her family.

In contrast, in a system that utilizes a person-centered planning process, a support broker would likely first spend an initial meeting talking with the individual about what he/she wants and who he/she wants to include in their person-centered planning process. The support broker would make it clear to the individual that the process is to be directed by the individual and is intended to identify his or her strengths, capacities, preferences, needs and desired outcomes. The individual directs the planning process including deciding who to invite to participate. The invitees are the individual's identified team who works with the individual to help identify those supports he/she needs to attain his/her vision and all of the ways the individual might access those supports[6]. The focus of the planning process that is person-centered is to identify, organize

[6] Doug, an individual with significant mental health needs, before the PCP process is living alone, miserable and lonely, calling the police for attention, feeling disrespected and afraid to trust. He does not feel that he can control his circumstances. Those who are involved in the provision of his services react to his behaviors and try to get him to stop.

In the PCP process the support broker established a relationship with Doug and gained his trust. Doug then began to talk about what he really wanted and identified the kinds of supports that would help him feel less isolated and lonely and enable him to

and provide individualized supports that will enable the individual to achieve meaningful goals based on his or her strengths and preferences.

The following are examples of two Massachusetts delivery systems in which individuals have some capacity to self-direct. In the Department of Mental Retardation (DMR), which serves individuals with a developmental disability, there are three programs available through which individuals can self-direct. Among the three is DMR's Intermediary Service Organization (ISO) Program, which was established in the late 1990's. Participants can select from a menu of traditional services or choose to customize and direct the services they receive within a DMR approved funding allocation. This allocation is based on DMR's cost to provide the supports through traditional means. Each individual, with the help of friends, family and service coordinator/support broker, develops a service plan that will meet his/her support needs within the funding allocation. The funds are transferred to the ISO, which purchases the services and supports as directed by the individual.

In another Massachusetts example, the MassHealth Personal Care Attendant (PCA) program provides an opportunity for member self-direction in a different way. While the program does not provide individuals with a designated support broker or individual budgets, the principles of self-determination are incorporated into the delivery of PCA services (how services are obtained and managed). After MassHealth members are determined eligible for PCA services, the members are responsible for directing their services including hiring, firing, and training their PCAs as well as signing off on their PCAs' timesheets. Personal Care Management (PCM) agency staff assists members in understanding how to manage the program, if necessary.

IV. Process for Creating this Report

To collect and synthesize information for this report, the Core Team of the person-centered planning grant conducted a number of activities. First, a series of meetings was scheduled with the senior staff of each of the EOHHS long-term support agencies. In advance of the initial meeting at each agency, the core team distributed a set of key definitions related to the concepts of self-direction that were developed by the Financing Workgroup of the Diversion Subcommittee using nationally recognized definitions as the starting point. As noted above, these are provided in **Appendix B**. Forwarded to each agency was a list of key questions, also developed by the workgroup (and are provided in **Appendix E**). The purpose of the initial meeting with each agency was to gain an understanding of how the agency is already

---

continue to live independently. In Doug's case, the PCP process helped him to find and move into an in-law apartment in which he has his own space but can also interact with the family that lives there when he wants to be more social. He now feels he has control over his life.

Paul, is a 55 year old individual with MR. Before becoming involved in person-centered planning, he had been residing in a NF, in part, because his elderly mother who was also a resident there wanted to keep him close to her and feared that he couldn't make it in the community. A few years after she died, a support broker went to see him and asked him what he wanted for his life. He said he wanted to leave the NF and he engaged in a person-centered planning process. He identified who he wanted on his team, including his family members and guardians, and the support broker got them engaged. In the process, the family members expressed their fears about Paul living in the community but Paul was able to insist and with the assistance of the support broker, a network of supports were identified that could be put in place that made the family more comfortable about his safety and the prospect of his living in the community. Paul did move out of the NF and he is currently living in a home in the community.

implementing programs promoting self-direction and where each agency is hoping to expand on and improve opportunities for self-direction in the future. Section VI provides a detailed report of what the Core Team heard from each agency and recommendations regarding mechanisms for how each state agency can incorporate some or all of the elements of a self-direction approach within that agency. (**Appendix F** contains tables of Agency-specific findings from these discussions).

Second, the Core Team conducted research and compiled best practices nationwide using the resources of the System Transformation Grant and the expertise of the Person-Centered Implementation Grant consultant, who was also hired to facilitate the Financing Workgroup's activities related to this work.

Third, in an effort to gain at least an anecdotal perspective from consumers of self-direction within each of the agency's current long-term support service systems relative to the presence or absence of opportunities for self-direction, several small focus group meetings were conducted. **Appendix G** contains the set of questions that were asked of consumers and accounts of the ensuing discussions.

Fourth, after the initial meeting, the Core Team met several additional times with the senior managers of each agency to learn in greater detail what each agency is currently doing and hopes to do in the future to advance opportunities for self-direction. The summaries of the findings were distributed back to the agency staff for review, comment and confirmation.

Fifth, the Core Team reviewed with the STG Diversion Subcommittee's Financing Workgroup, the agency-specific summaries and those from the consumer groups within the context of best practices nationally. Together, the Core Team and Workgroup developed broad recommendations, including identifying cross-secretariat opportunities for fostering self-direction.

Sixth and last, after meeting with the commissioners of each of the six agencies, the Core Team found that all but MCDHH have at least one program that can lend itself to full implementation of self-direction. In the case of DMR, which already has significant programming with self-direction, there are areas in which the agency seeks to improve how it employs self-direction. In others, the agency staff sees the potential for broadening and making more comprehensive the employment of self-direction in certain key programs. In the case of MCDHH, agency staff believe that the agency will never be structured in such a way as to be able to employ all elements of self-directed programs, but that nonetheless there were opportunities for advancing some of the components of self-direction. The MCDHH goals in this regard are discussed in Section VI below.

V. What the Core Team Heard In Meetings with the Six State Agencies

Each of the state agencies—DMH, DMR, EOEA, MCB, MCDHH, MRC—is different in terms of who is eligible for its services, how case management[7] is provided, its individual service plan

[7] Some agencies use the term service coordination, but for the purposes of consistency in this report, the term case management is used.

process, its funding streams, the types of services it provides directly and the types of services it contracts. However, each agency shares a common interest and commitment to build on its experiences and promote opportunities for self-direction for elders and people with disabilities.

This section describes by agency ways in which each plans to evolve to expand self-direction. Summary tables containing the findings from each agency are provided in **Appendix F.**

Department of Mental Health (DMH)

DMH currently has no programs for consumers to self-direct their services. However, their support of recovery and peer specialists provides a solid foundation to support a philosophical shift in how services are provided and towards one that promotes self-direction for people with psychiatric disabilities.

There are four general program areas that DMH identified where the Department seeks to develop opportunities for people to self-direct. The four areas and the number of individuals currently served in them are:

- Day and Employment Services (currently providing services to more than 6,000 individuals).
- Flexible Community Supports - outreach and other non-24 hour services that support people in a variety of ways, including medication monitoring and shopping, to help them maintain their independence in their own home (currently providing services to more than 11,000 people across the State).
- Transition Age Youth program (currently providing services to 2,785 young adults 16 – 25 years of age).
- 24-hour Residential Services Program (currently providing services to close to 3,000 people).

Each of these program areas has in place many of the elements critical to self-direction. These include a clear enrollment process, a process for developing an individual service plan, and case management. In the case of these programs, there is a budget in the aggregate that would lend itself to the creation of individual budgets.

Across all four program areas, DMH is currently working with individuals to train other consumers to be stronger self-advocates. DMH has also expressed an interest in implementing self-direction for individuals with mental illness who are also deaf.

While DMH is committed to eventually offering opportunities for self-direction across all four program areas, the agency has prioritized employment services and Flexible Community Supports to implement all of the elements of self-direction including provision of individual budgets. After learning from those experiences, DMH would then look to expand self-direction into 24-hour residential services.

With employment services and community supports as the identified priority areas, the next step is to train DMH agency staff to ensure there is a common understanding of self-direction and its

key elements including support broker, individual budget, fiscal intermediaries, and person-centered planning. Following the development of a common understanding, DMH would then embark on developing a strategic/action plan that will serve as the blueprint for evolving service delivery in the prioritized areas to support self-direction. This would ensure that self-direction would be implemented in a thoughtful way that will be meaningful to individuals receiving supports from the Department.

Some of the specific next steps identified by DMH include:

- Develop and implement training for DMH and provider agency staff to ensure a common understanding of self-direction.
- Develop and implement an equitable methodology for creating individual budgets within each of the program areas discussed above.
- Develop a more person-centered planning process not only for people receiving services in the program areas discussed above but across all service areas.
- Implement a mechanism to provide consumers the supports they may need to direct the person-centered planning process, manage their individual budgets and make active decisions regarding how, and from whom, they will receive their services.
- Provide peer support for those who seek it for those who are self-directing their services.
- Make the structural changes needed to respond to an increased consumer demand for self-direction before comprehensive outreach efforts are undertaken to raise consumer awareness.

Department of Mental Retardation (DMR)

DMR has implemented three (3) programs offering self-direction in varying degrees to persons with mental retardation or, in some services developmental disabilities, and their families. These programs are:

- Self-directed program for adults
- DMR/DOE Project
- Autism waiver program

In each case, there is an enrollment process, case management (service coordination), individual service plan development, and an opportunity for an individual budget. What follows is a brief description of these programs.

Self-Directed Program for Adults with Intellectual Disabilities

DMR's pilot initiative supporting self-direction began in 1997 when Massachusetts was awarded one of 19 Self-Determination Demonstration Grants funded nationwide by the Robert Wood Johnson Foundation. A person-centered and person-directed approach was established to support consumers who wished to self-direct. It required new and modified mechanisms to enable consumers to direct service planning, manage resources and manage service delivery. This entailed person-centered planning, individual budgets, ISO (intermediary service organization that performed fiscal intermediary and other functions that enabled consumers to

exercise certain controls over their individual budget), and a quality assurance system to evaluate the impact of self-determination on the lives of the consumers. Today, this initiative continues as the ISO program and there are more than 280 participants directing almost $9 million annually in DMR funding. In the latest QA report by HSRI and PPL that looked at quality assurance outcomes and process improvements for the ISO through FY 2006, the survey of participants revealed the following results and trends in a comparison of the ISO participant population and DMR consumers not in the ISO: (1) demographically, the ISO participants were younger, more racially and ethnically diverse and less severely cognitively disabled; (2) ISO participants experienced significantly greater choice and decision making, particularly in deciding how to spend one's free time and choosing where to live; and (3) ISO participants were significantly more likely to feel safe in their homes and neighborhoods than DMR consumers not in the ISO.

DMR/DOE Project

The DOE/DMR (Department of Education/Department of Mental Retardation) Program is an interagency initiative that has enabled special education students, who have been placed or are eligible to be placed in a Chapter 766 residential program, to continue at their local school and remain at home with their family.

The DOE/DMR Program serves over 300 students annually and is funded at $8M/year. The DOE/DMR Program uses a self-directed model that provides flexibility in the delivery of services to young people who require intensive and coordinated special education services and residential support. It also provides the mechanism to pay for and deliver family support services and/or community-based residential services in a less restrictive setting at an equal or lower cost than services provided in residential special education schools.

Autism Waiver Program

The recently implemented Children's Autism Spectrum Disorders Home and Community-Based Services Waiver Program is a Medicaid home and community-based program (a $2M/year program offering up to $25K/individual) serving 80 children under age nine with an autism spectrum disorder who meet the eligibility criteria for the Waiver program. The Autism Waiver Program uses a service delivery model called Participant Direction in which the parent takes the lead in designing the program and selecting service providers based on the child's assessed level of need. Among the services offered through this Waiver is "Expanded Habilitation" which provides one-to-one behavioral, social, communication and related support services such as community integration activities and respite. Each family also receives assistance from an Autism Support Broker and a Targeted Case Manager.

Overall, DMR has two clear objectives regarding how it wishes the agency and its programs to evolve:

- Make more consumers aware of opportunities for self-direction and enable more to choose this option.
- Provide individuals and their families who choose to self-direct the supports and tools they need to be successful.

DMR is poised to build on its experiences with self-direction gained to-date and to increase the number of individuals or families who are self-directing across the Commonwealth. For those who are self-directing, DMR hopes to provide more supports and to improve on those currently provided to make the self-direction option even more valuable to the consumer. DMR needs to make sure that the agency makes the structural changes needed to respond to an increased consumer demand for self-direction and to do so *before* comprehensive outreach efforts to raise consumer awareness efforts are undertaken so that the staff and the agency are prepared for the increased demand. DMR has indicated that providing more self-direction options in the residential supports delivery system has significant challenges due to the current manner in which most residential services are procured. Helping this system evolve into one that supports self-direction will require concerted and strategic planning that ensures that the current system is not de-stabilized.

Key priority areas identified by DMR include:

- Conducting more outreach to promote self-direction to individuals and their families.
- Formalizing curriculum and beginning to provide education and training (including both peer to peer and family to family) on self-direction to all DMR clients and their families.
- Separating service coordination from the role of support broker for people whose funds are managed by the fiscal intermediary (ISO), where service coordination in the state provided targeted case management and support brokers are contracted staff supporting the consumer in self-direction. The role of support broker could include providing assistance with the hiring of staff, helping individuals decide how to allocate their individual budget, and helping individuals decide which agencies they want to purchase services from.
- Developing a more person-centered planning process for those individuals who are self-directing.
- Making the Individual Service Plan process more person-centered for all individuals receiving services from the Department.
- Providing more training to all DMR staff, particularly service coordinators, and to key provider contractors to facilitate the philosophical shift from paternalistic to person-centered thinking.[8] This will prepare those areas of the agency that don't immediately offer self-direction to be more prepared to do so when the infrastructure is in place.
- Ensuring that the two new 1915c Home and Community-Based Supports waivers being designed provide for opportunities for self-direction.

Executive Office of Elder Affairs (EOEA)

EOEA intends to expand self-direction (referred to as consumer direction in the aging community) as an option for all people enrolled in its Home Care, non-waiver program.

[8] Person-Centered Thinking: Every style of person-centered planning is rooted in a person-centered way of thinking. Person-centered thinking is essentially the fundamental concepts, values, and principles which underscore all PCP approaches; and, it is linked to a set of skills that results in seeing persons receiving services differently. Person-Centered Thinking also provides a way for acting on what is learned as reflected in the questions that follow.

The Home Care Program provides support services to approximately 35,000 elders with daily living needs to remain at home in their communities. Services provided by the program include homemaker, personal care, day care, home delivered meals, transportation, and other community support services to help maintain an elder in his/her home.

Within the Home Care program, there are two components:

- Basic Home Care (serving approximately 31,000)
- Enhanced Community Options Program (ECOP) (serving approximately 4,000)

In Home Care and ECOP, EOEA currently has many elements that can be modified to support self-direction for elders. There is an enrollment process, service plan development, and the availability of case management. Basic home care services are delivered or coordinated through the twenty-seven (27) Aging Services Access Points (ASAP) across the Commonwealth. For those who are participating in the home care services, case management is provided by the ASAPs.

Ten (10) of the ASAPs presently offer a limited consumer-directed program. Those participating in consumer-direction do not have an individual budget to manage and do not have the ability to spend funds in ways that are outside of the identified menu of services. They do, however, have the ability to hire and fire their own staff. Some also receive training on self-direction, participate in a more person-centered planning process that is developed with the elder and their family, and have access to fiscal intermediary supports.

There currently are approximately 120 individuals who are participating in the consumer-directed services within the Home Care Program.

EOEA has a strong commitment and desire to build on their experiences with their existing consumer-directed services program, and to not only expand the consumer-directed option to more elders across the state, but also to expand the scope of consumer-direction beyond just enabling the individual to hire their own staff (i.e., enable more people to have an individual budget and to be able to use the budget more flexibly).

As one step towards shifting the vision of the agency and the ASAP providers serving the agency's clients, EOEA engaged the services of UMASS Medical/CHPR to develop a training for all ASAP staff on the principles and philosophy of consumer-direction. That project is complete, and UMASS provided the training in May and June of this year in five regions across the state to a core group from every ASAP. Each ASAP is now responsible for ensuring that all staff receives the consumer-direction training, including new staff as part of the standard orientation process. Later this year, UMASS Medical/CHPR will conduct a train the trainer session for designated ASAP staff.

EOEA is looking to expand self-direction for elders in the Home Care program by:

- Supporting and expecting that, over a timeframe to be established, all 27 ASAPs will offer consumer-directed services (i.e., the ability to hire and fire staff and the option for an individual budget) to those they serve.
- Providing the opportunity for all elders to self-direct, have an allocated individual budget and receive the supports they need to manage the individual budget.

In order to move from 120 individuals self-directing to potentially thousands and to ensure successful state-wide implementation, the next step is for EOEA to develop a strategic development plan. Some of the key components include:

- Developing a methodology for an individual budget that would be allocated to each person participating in self-direction.
- Determining who will provide the support broker function for elders self-directing, either the existing case managers or by establishing a separate function distinct from case management.
- Expanding the availability of fiscal management services.
- Improving upon the current service planning process to become more person-centered.
- Developing and providing training for elders and their families on self-direction.
- Developing and providing training to management and staff of service providers on self-direction and on person-centered thinking.
- Expanding the training for ASAP case managers on self-direction and on person-centered thinking.
- Developing guidelines for the ASAPs on how they will manage the implementation of self-direction.
- Determining the process for enrollment and the pace for offering a consumer-direction option across the State.

Massachusetts Commission for the Blind (MCB)

MCB identified two program areas that they seek to develop new opportunities for people to self-direct. These two areas are delineated below:

- Social Services Programs

In the social services program, consumers are allocated services that cost an average of $6,000 - $10,000 with a range of $1,000 - $20,000 worth of services per year. There are 2,000 people receiving services. These specialized services include devices and techniques that can improve a legally blind person's quality of life.

- Deaf/Blind Multi-Handicapped Program

There are 600 people receiving services managed by the deaf/blind multi-handicapped unit. Of the 600, 74 people receive 24 hour residential services and the remaining people receive non-residential services, including day programs, respite and homemaker services. Services are very

individualized as MCB works with each individual to identify the type of services they desire and which provider agency they want to provide those services. MCB contracts with the residential provider to create and manage an allocated budget for those services.

Each of the two program areas has some elements that lend themselves to self-direction. There is an enrollment process, the provision of case management, and an individualized planning process. In the deaf/blind multi-handicapped program, there is also the option for an individual budget allocation. Five individuals that currently receive residential services have an individual budget and are, with their families, self-directing their services.

MCB is committed to learning from their experiences in the social services program and the deaf/blind multi-handicapped program to develop a more comprehensive approach to self-direction. Their overarching goals are:

- Support self-direction for high need/high cost consumers in the social services program. MCB has identified a group of consumers with multiple disabilities who need a continuum of supports (case management, PCA's, adaptive equipment, specialized training) to live and work in the community. MCB feels this is a logical group of people to begin with to develop an initiative supporting self-direction.
- Develop an infrastructure to support offering self-direction as an option for everyone currently receiving residential services.
- Offer self-direction as an option for everyone turning 22 (approximately 4 – 6 people each year) including those receiving both residential and non-residential services.

The common elements that would encompass all three goals include the development of an individual budget, implementation of a more dynamic person-centered planning process, and training of case managers, consumers, families and provider agencies on self-direction. MCB is also interested in learning more about the role of a support broker and of fiscal intermediary services.

In order to offer self-direction to the identified targeted groups, the priority tasks identified by MCB include:

- Develop methodology for an individual budget for individuals receiving social services or residential services and for those turning 22.
- Develop and implement training for case managers on self-direction and person-centered thinking.
- Develop training for MCB staff to learn more about the role of the support broker in order to decide who will provide the support broker function for those who choose self-direction.
- Provide further education to MCB staff on the role of an independent fiscal intermediary to determine if that is a tool MCB would like to make available to consumers who participate in self-direction.
- Develop and implement a more person-centered planning process not only for those who are self-directing, but for all persons receiving services from the Deaf/Blind Multi-handicapped Program.

- Develop strategy for outreach and education for people currently receiving either social services or residential services to promote self-direction as an option.
- Develop strategy for educating individuals and their families on the option of self-direction for those newly turning 22.

Massachusetts Commission for the Deaf and Hard of Hearing (MCDHH)

MCDHH was originally established to help promote the view that deafness is not something that needs to be fixed and to give persons who are deaf or hard of hearing a voice in state government and an opportunity to educate others regarding the various modes of communication employed by deaf and hard of hearing people as well as Deaf culture to help make the long-term care delivery system more accommodating to those who are deaf. While not an agency that provides or contracts for direct care services, for the most part, MCDHH provides some case management, particularly for those in greatest need, communication access, training and technology services, and interpreter referral services. MCDHH also supports very active consumer groups that are involved in monitoring services for people who are deaf.

While the agency itself does not directly enroll its clients into service programs which could be transformed into individual budgets for individuals to self-direct, the Commission is very interested in collaborating with the efforts of EOHHS and its sister agencies in promoting greater self-direction in ways that will support the opportunities for those who are deaf or hard of hearing to self-direct, across the long-term care delivery system. MCDHH believes it can support self-direction for its clients by training staff from other agencies, and within the independent living centers with which it has a contractual relationship, who work with people who are deaf and hard of hearing to understand both the formal aspects of self-direction and the deaf culture. MCDHH believes that it is critical that other agency staff and service providers understand the kinds of choices that persons who are deaf or hard of hearing may want to make as they may be surprisingly different from what hearing populations may choose and are equally legitimate. MCDHH also prioritized providing leadership in training parents with children who are deaf. Priority next steps, some of which are already underway, include:

- Developing and implementing training and periodic retraining for their case managers in person-centered planning and on self-determination.
- Working with EOHHS agencies in developing training on self-direction for case managers from their sister agencies who work with people who are deaf.
- Developing and implementing strategies for outreach and training on independence and self-direction for parents with children who are deaf.
- Developing and implementing training for staff providing services to people who are deaf, including interpreters and clinicians.
- Investigating and implementing ways in which peers are available to provide support for greater self-determination and self-advocacy to individuals who are deaf and provide support, when requested, in a person-centered planning process.

Massachusetts Rehabilitation Commission (MRC)

Consumer empowerment is at the core of MRC and the philosophy is reflected in the Independent Living Center and Supported Living Programs. MRC indicated that they intend to formally establish self-direction within the Brain Injury and Statewide Specialized Community Services (BISSCS) program. BISSCS is a state funded program that identifies, cultivates and develops resources and services for Massachusetts residents who have sustained an externally caused traumatic brain injury. Nine hundred and seventy four (974) people received services in Fiscal Year 2006.

BISSCS presently has many of the elements key to self-direction. There is an enrollment process, the availability of case management services, and an individual service planning process. While no one is self-directing their services at the present time, MRC contracted case managers and service providers work with consumers to develop services that are as responsive to their individual needs as possible. In the case of the non-24 hour regional services provided, though consumers are not able to self-direct services, some consumers have the option of choosing their private case manager who works with them to access services in their community.

MRC staff indicated a commitment to ultimately offer a self-direction option to consumers statewide. MRC will explore models for people with brain injury that afford greater flexibility and more choices in how and by whom consumers receive services.

In addition, MRC is interested in providing self-direction as an option for people presently receiving residential services or individuals who receive new funding for residential services.

In order to be successful in supporting self-direction for people with brain injuries, there are a number of key elements that MRC will first need to develop.

- Create a methodology for establishing individual budgets and a mechanism by which individuals, if they choose, can manage and receive the requisite assistance to manage individual budgets.
- Determine how to provide the necessary support broker role to assist individuals to self-direct, and to determine how this role should relate to MRC's existing case management infrastructure.
- Expand on the present service planning process and make it more person-centered. This may require developing and implementing tools to assist the service planning process. It will then be incumbent on MRC to provide training for all case managers, both state-employed and privately contracted, who will be assisting consumers with service planning so all service planning in the community services area will become more person-centered.
- Develop a curriculum to train consumers on management of an individual budget and implement a formal, comprehensive training for consumers on self-directing.
- Develop and implement training of service providers on self-direction and person-centered thinking.

Consumer Forums

In creating this Report, the Core Team felt that it would be helpful to gain the perspective, at least anecdotally, of the consumers in some of the agencies. The emphasis was on those who currently have the opportunity to self-direct and those who have not yet had the choice to do so. We were able to formally conduct three meetings with consumers of DMR and DMH services as well as to speak informally over the past several months with individuals receiving services in all of the agencies that are the focus of this study. Consumers and family members with whom we met included:

- Individuals and families participating in the DMR self-directed program for adults with intellectual disabilities in the Greater Boston Area.
- Family members of people with intellectual disabilities who are clients of DMR who do not have the option yet to self-direct.
- Individuals with psychiatric disabilities receiving services from DMH provider agencies in Western Massachusetts.
- Individuals and family members with whom the Core Team had spoken informally over the past several months and people interested in greater self-direction receiving or eligible for services from DMH, DMR, EOEA, MCB, and MRC.

In all cases, consumers were encouraged to talk about their thoughts on choice, control, and flexibility by way of sharing their experiences and to offer ideas for enhancing and furthering self-determination. The list of questions posed to consumers in the formal sessions is provided in **Appendix G**.

Universally, the Core Team heard that individuals with the opportunity to self-direct are very satisfied with their experiences. Individuals, and their families, who have not yet had the option were all interested but had a mix of questions. Some specific feedback follows:

- Among DMR consumers who are self-directing, participants agreed that the opportunity played an important role in helping them achieve personal autonomy and a higher quality of life. Individuals indicated that they were able to:
  - Overcome fear and felt in control for a change
  - See there was more to life
  - Meet new people
  - Develop a support network and/or get their own place to live
  - Pay for hobbies, like horseback riding
  - Receive support they needed to help them find and keep a job
  - Have a direct support worker schedule that met their needs.

- Among the family members of DMR consumers who do not yet self-direct, participants agreed that they were interested in learning more about self-direction. Some, however, were skeptical about how the option would benefit their family member's quality of life. Some of the families expressed the desire to continue to use provider agencies, but wanted the relationship to be more of an equal partnership.

- DMH consumers who are not yet self-directing expressed the same interest and had similar questions. They were also very interested in assisting in the creation of the DMH self-direction delivery system options. DMH consumers who have had exposure to the DMH-supported peer specialists indicated that there was not enough access to this support and that all providers should be expected to make them available as a support option.

- Individuals with whom the Core Team spoke over the past several months echoed these sentiments and questions.

Common Challenges Across the Six Agencies

One of the key outcomes from the meetings with each of the six agencies was the recognition that in order to be successful beyond a comparatively small pilot program, there are a number of common challenges identified that need to be addressed when the agencies seek to incorporate the principles of self-determination. These challenges included:

- Lack of a common language and understanding of self-determination and self-direction among and between state agency staff, consumers, the traditional provider and case management systems, and legislators and advocate groups.
- Lack of understanding of the changed role in self-directed systems of consumers, state agencies, providers and professionals.
- Concerns about adequate compensation to providers.
- Resistance on the part of formal caregivers and state agency staff to loss of control, and to allowing individuals with disabilities to take risks and to fail.
- Insufficient supervision of persons providing supports in self-directed delivery models which often results in caregivers taking control away from individuals.
- Concern that persons with disabilities will be exploited.
- Concern that costs will increase because when individuals are able to utilize their allocated budget more flexibly, they are likely to utilize more of it with creative strategies than they had with traditional approaches which relied on certain kinds of providers or staff that were insufficient for meeting their needs due to staff shortages.
- Currently, agencies are able to provide individual budgets for consumers through contracts with either fiscal intermediaries or providers directly. Agencies are concerned that the purchase of service rules that govern what constitute allowable expenses in this form of contracting may significantly restrict how individual budgets may be used.

VI. Recommendations for Advancing Self-Direction in Massachusetts

The Massachusetts long-term care system has been at the forefront in providing quality community-based services for elders and persons with disabilities for the past three decades. Over the past ten years, there have been initiatives undertaken by various state agencies that have enabled elders and persons with disabilities to exercise greater control over decisions affecting

their lives. The Massachusetts long-term care system, however, is still in its infancy relative to where and how individuals have the opportunity to self-direct services.

The Core Team clearly heard at the meetings with the executive staff at the Executive Office of Elder Affairs, the Department of Mental Health, the Department of Mental Retardation, the Massachusetts Rehabilitation Commission, the Massachusetts Commission for the Blind and the Massachusetts Commission for the Deaf and Hard of Hearing that they embrace the philosophy of self-determination. Each agency has expressed a desire to identify and implement ways to expand and enhance opportunities for self-direction for the individuals they support. EOEA Secretary Festa, DMH Commissioner Leadholm, DMR Commissioner Howe, MRC Commissioner Carr, MCB Commissioner LaBreck and MCDHH Commissioner Reed have committed agency resources to work collaboratively on actualizing self-direction within their respective agencies and across the Secretariat. There is clearly support and enthusiasm amongst the EOHHS agencies for pursuing change to the long-term care system that will promote opportunities for self-direction.

For such change to the statewide service system to succeed, the process for advancing self-determination must be a thoughtful one that recognizes that each state agency may require different strategies, direction, and technical assistance to advance self-direction. The process design must take into account the staff, provider community, consumer constituency and stakeholders of each state agency's different understandings of and experiences with the principles and values of self-determination and self-directed supports options. It must be a process that takes into account the different rules and financing that govern the programs administered by each state agency. It must also be a process that takes into account the infrastructure that must be in place within each state agency and the Secretariat to operationalize self-directed options.

Self-determination is both person-centered and person-directed and acknowledges the rights of elders and persons with disabilities to take charge of and take responsibility for their lives. Self-direction is a continuum of approaches based on the degree of decision making, control and autonomy allowed by the system in a particular situation. Advancing self-determination in the Massachusetts long-term care system will require a shift in how the Secretariat and the operating agencies conceptualize, design, deliver, and monitor supports to elders and persons with disabilities.

With these considerations in mind, the Core Team believes there are different strategies and actions that can be pursued over the course of the next 12 to 24 months. The Executive Office of Health and Human Services should take the lead on some of these strategies and actions because they require statewide planning and implementation. Others are activities that should be undertaken by state agencies after assessment of where the level of effort for shifting to more person-centered and person-directed approaches can be successful within their agency. The following are key recommendations for activities to be implemented at the Secretariat level. These are followed by recommendations for actions that should be undertaken by each agency and in the manner that is most effective for the particular agency and where they are in terms of readiness to promote self-direction options.

A. Recommendations for the Executive Office of Health and Human Services

Issue 1: To expand opportunities for self-direction in the EOHHS long-term care systems requires a coordinated effort that starts with an articulated policy that is disseminated across the agencies.

Recommendation 1A: ***The Executive Office of Health and Human Services should issue a policy statement announcing that our delivery systems will promote self-determination and provide multiple options for self-direction***. This policy statement will create the necessary environment to support the work of creating more of such options. The Core Team believes that there is no contention with the statement that the Commonwealth supports self-determination but the challenge is in how to design and implement self-directed options in ways that are feasible for the state agencies and providers while providing meaningful and accessible choices for consumers and their families. This is evident from the EOHHS cross agency work through the federal CMS Independence Plus, Real Choice Systems Change and Nursing Facility Transition Grants that are at the foundation of the Secretariat's Community First agenda. At this time, the Secretariat and the EOHHS agencies are working on the design of the Community First Waiver to include the elements of self-direction that will be available to waiver participants who wish to self-direct.

As part of this policy statement, the Secretariat can reiterate its support for expanding and improving opportunities for self-direction. This can be done by continuing to promote the development of the self-direction delivery system option – Independence Plus - within the Community First Waiver and actively supporting, through leadership and resources, the specific efforts that DMH, DMR, EOEA, MCB, MCDHH, and MRC intend to undertake to advance self-determination in their agencies. In addition, each agency should be encouraged to establish a work plan that will describe the goals, activities and timelines for creating opportunities for self-direction.

Recommendation 1B: ***The Executive Office of Health and Human Services should convene statewide conferences to promote self-determination.*** As agencies mature in how comprehensively they enable self-direction, EOHHS should consider convening statewide conferences on self-determination, at least annually, to provide opportunities for further education for and input by consumers, families, state and provider staff, as well as on-going communication and dialogue on strategies and actions for continuing the efforts to advance self-determination.

Issue 2: A common concern expressed at the state agency meetings was the need for a shared understanding on the parts of staff, providers and consumers of the meaning of self-determination, self-direction and related concepts, such as person-centered planning, support broker, individual budgets, and fiscal management services. This echoed a major finding from our recently concluded federally funded Mass C-PASS grant[9] regarding the need for cross-age,

[9] The Center for Medicare and Medicaid Services awarded the Mass-CPASS grant to the Commonwealth in 2003 to develop sustainable mechanisms to ensure consumer choice and consumer direction in personal assistance services and supports. The focus of the grant was to examine how culture influences self-determination. A major activity of

cross-disability and cross-cultural training and continuing education of elders, persons with disabilities, their families, service providers and local communities on self-determination and self-directed options.

Recommendation 2: ***EOHHS should design and implement a statewide, broad-based and coherent self-determination and self-direction educational and awareness campaign.*** This campaign will be for EOHHS and state agency staff, consumers (elders and persons with disabilities) and their families, provider staff, advocacy groups, unions, Executive Office of Administration and Finance, and the Legislature and the general public. The campaign will include trainings and public education efforts. The specific content and sequence of the trainings should be determined by each agency based on their respective state of readiness to both offer and publicize opportunities for self-direction, and to respond to the questions and demands of their consumer constituents. The trainings should start with agency staff to ensure that the agencies are knowledgeable about the principles and concepts behind self-determination and self-direction before offering new programming.

Information for the public campaign would be prepared and disseminated about the principles of self-determination and the possibilities, models, and arrangements involved. The information should address the changes in the roles in self-directed systems of consumers, state agencies, providers and professionals, and shift of control and responsibility to the consumers from the "professionals." State and provider staff will have different but still important roles in a self-directed system. With the shift in control and responsibility, a commensurate environmental adjustment will be necessary to support greater risk taking by consumers, families, provider and agency staff in a self-directed service system. The materials should be translated into multiple languages and formats. This campaign can be integrated into other EOHHS information dissemination efforts including the EOHHS Web Portal, MADIL,[10] and the ADRCs.[11]

The Core Team recommends that the Leadership Team created to direct the Massachusetts Building Blocks-Person Centered Planning Implementation (MABB-PCP) grant project be charged with the responsibility for directing and coordinating the educational and awareness campaign. The Leadership Team is composed of senior staff from EOHHS, EOEA, DMH, DMR, MCB, MCDHH and MRC with delegated authority to represent the commissioners. The Leadership Team is well poised to take on this task since the charge is within the scope of work expected to be performed under the MABB-PCP grant project.

Issue 3: One of the elements of the most comprehensive models for self-direction is the option that provides the consumer with a budget and the flexibility to use resources in ways that best meet their particular needs. Under this option the consumer decides, through an individual budget, how to best use the public dollars, including purchasing services from a traditional vendor, hiring a next door neighbor to help with activities of daily living, buying some type of

---

the grant was to gather information on barriers to self-determination and community inclusion from diverse geographical, racial, ethnic, and linguistic communities

[10] MADIL (Massachusetts Aging and Disability Information Locator) is a EOHHS web based public service that helps find information on services and programs supporting seniors and persons with disabilities.

[11] ADRCs (Aging and Disability Resource Centers) are single points of contact for information about programs and supports for seniors and persons with disabilities that are provided through partnerships of Aging Service Access Points and Independent Living Centers in Massachusetts.

assistive technology to enhance independence, or modifying their home to make it possible to remain in the community. For agencies that opt to offer this model, a supportive infrastructure for self-direction needs to be available across the Secretariat to support the consumers. The challenges will be in deciding which infrastructures work best and whether there are best practices that can only be used in certain agencies in certain circumstances and those that can and should be employed uniformly across agencies.

Recommendation 3: ***The Secretariat should leverage the EOHHS Purchasing Advisory Council and work with the provider trade organizations affiliated with each agency to help build a self-direction focus into cross-agency purchasing efforts.*** This activity would include fostering a shift away from using only traditional contracts for services (a slot-based system) to one that promotes provider system contracting arrangements that support individual budgets – consumer driven provider networks. The purchasing advisory council meetings present opportunities for the Secretariat and state agencies to discuss and process the impact that the promotion of self-directed options may have on the provider community. They would also allow EOHHS and agencies to gain input on how to implement self-directed options in ways that will not de-stabilize the present system of services, including the provision of technical assistance for providers that want to offer more self-directed options. This process will require that EOHHS work with the Office of the Comptroller, the State Auditor, Executive Office of Administration and Finance and the Operational Services Division to examine what changes to the statutes and regulations may be needed in order to support self-direction purchasing options more broadly. A different, less complicated and more flexible system may be needed to allocate, disperse and track funds.

B. Recommendations for DMH, DMR, EOEA, MCB, MCDHH and MRC

Issue 1: For the program area(s) identified by the state agency, basic elements, other than person-centered planning, may have to be established within the agency's infrastructure to support self-direction. Support brokers, fiscal management services, and individual budgets are a few of the elements of self-directed options that may not currently exist within the state agency.

Recommendation 1: ***EOHHS and the identified agencies should take advantage of the numerous opportunities for learning and collaboration that currently exist in the Commonwealth to build agencies' capacity to support self-direction***. The Systems Transformation Grant, the Person-Centered Planning Implementation Grant, the Community First Waiver, and the Real Choice Pilot, are all cross-agency activities that have created a wealth of information about how to develop a better self-direction support system.
For example, the Massachusetts Real Choice Pilot, launched in 2004, used federal grant funds to examine design issues, implementation barriers to self-direction, and financial impacts of the Pilot on Medicaid utilization. About a dozen participants (elders, persons with psychiatric disability, or cognitive disability, or physical disability) were given control in calculating an individual budget to purchase goods and services. This experience provides lessons learned for designing and implementing such a model on a larger scale.

Another example is the Mass C-PASS grant, with lessons learned from the consumer forums and its two mini demonstration pilots, which examined how culture, race, age, and geography influence self-determination. A key lesson learned from Mass C-PASS is the importance that the fabric and design of self-direction elements must incorporate cultural competency and cultural appropriateness into the supports that consumers can use to help them self-direct.

The work that will be required to build these elements within the state agencies will likely require funding from the Secretariat to support. We also recommend that agencies should plan to evaluate activities once they are implemented. EOHHS can also look to the Systems Transformation Grant to assist with agency-specific efforts in these areas. In addition, specifically, the Diversion Subcommittee Financing Workgroup might be a good resource for assisting agencies to develop individual budget methodologies.

Issue 2: Each state agency has expressed the desire to make the service planning process more person-centered and person-directed.

Recommendation 2: ***Encourage each agency to be involved in the MABB-PCP grant project's activities pertaining to the development of a training curriculum and tools each agency can use to make service planning more person-centered and the expansion of aging and disability resource directories (e.g. MADIL) to include grass roots, culturally diverse and local community based organizations.*** Person-centered planning is a central element of self-determination. We have learned from experience and other recent grants that a single strategy for self-direction and planning is not diverse enough to address the wide range of consumer preferences and needs, and the many different service delivery systems. Individuals of different ages and different cultures (including disability, race, ethnicity, language, creed, gender, and income) have markedly different preferences for planning and the level of control they wish to exercise. Plans and priorities also change as people age, learn, and change.

The MABB-PCP grant project will help the agencies shift existing service planning processes to be more person-centered and to ensure that they are also age-appropriate and culturally relevant. The grant will work together with agency staff to develop specific tools that each agency can use to enable it to properly respond to its diverse population's needs and preferences. The MABB-PCP grant project will produce the following building blocks for use by the state agencies and to support their efforts to advance self-direction:

1. Age appropriate and culturally-relevant PCP strategies and tools;
2. Assessments and intervention processes that strengthen culturally-relevant informal supports and community networks for consumers and their caregivers;
3. Culturally-relevant training for professionals and community leaders to support and nurture person-centered supports & strong community-based networks;
4. Culturally-relevant training for consumers, their families, caregivers, and PCP facilitators to ensure effective self-advocacy and understanding of self-direction and expected outcomes;
5. Strategies to identify, develop, and nurture community resources and natural supports for consumers and caregivers, including a web-based Community Resource Directory.

Issue 3: Within each state agency, there is an identified need to increase awareness and understanding of self-determination and self-directed options for agency staff as well as among consumers and the provider communities.

Recommendation 3: ***Each state agency should develop and implement an outreach and educational campaign within the specific program area(s) identified by the agency for advancing self-determination.*** This activity would include the development of culturally competent curriculum for education and training to help move the agency to make the service planning process more person-centered and person-directed. The Systems Transformation and Person-Centered Planning Implementation grants can support this effort. At least two agencies expressed interest in engaging consumers to assist in this process. And, as was clearly noted by the Mass CPASS grant, all educational materials must be translated into different languages and presented in different formats.

VII. Conclusion

As self-determination and opportunities for self-direction increase in Massachusetts' long-term care system, it is important to keep in mind that not everyone will necessarily want to direct all aspect of their services and supports but everyone should have the choice to decide whether and when they want to self-direct. The goal is to build capacity within the current service delivery system that will give the consumer greater choice and control over how, by whom, and to what ends they are served and supported. In a system in which self-determination is fully actualized, individuals will be able to choose to be served by traditional providers, choose to self-direct all aspects of their supports, or anything in between including changing their minds.

Advancing self-determination in EOHHS is the right thing to do. Furthermore, it is work that will support the Secretariat's efforts towards meeting the MassGOALS[12]. Through self-directed options, elders and persons with disabilities will have the freedom, authority, support and responsibility to decide what is necessary and desirable to create a satisfying and personally meaningful life. A self-directed service system will be a client-centered customer service system and will feature options that will enable individuals to engage in activities that accompany a meaningful life, including doing real work, living in a home in a community that is safe and welcoming, and being able to sustain and build relationships with chosen friends, family, neighbors and co-workers as part of an ordinary life.

What a self-directed service system means in Massachusetts will be the on-going work of the Secretariat and the state agencies in defining the parameters of what services can be "directed," the fiscal limits that will be allowed, and the options that will be available to support differing degrees of self-direction.

The Core Team hopes the implementation of these recommendations will further assist in EOHHS' aims for expanding self-direction options in long-term care delivery within the Secretariat in the future.

[12] MassGOALS represents Governor Patrick priorities: Affordable Housing, Civic Engagement, Clean Energy & Environment, Effective Government, Efficient Transportation & Mobility, Job Creation & Economic Growth, Safe Communities, Quality, Affordable Health Care for All, and World Class Education.

Recommendations for Advancing Self-Direction in Massachusetts' Long-Term Care Delivery Systems

Appendices

Appendix A

List of All Agency Staff and Others Who Participated in this Study

The following list of organizations and individuals collaborated with the Executive Office of Health & Human Services (EOHHS) to make this report possible.

EOHHS Agencies

Department of Mental Health (DMH)

Barbara Leadholm, Commissioner

Regina Marshall, Chief of Staff

Elaine Hill, Deputy Commissioner

Ellie Shea-Delaney, Assistant Commissioner of Program Development & Interagency Planning

Marcia Fowler, Assistant Commissioner of Mental Health Services

Beth Lucas, Director of Quality Improvement

Susan Wing, Area Director, Northeast Area

Department of Mental Retardation (DMR)

Elin Howe, Commissioner

Janet George, Assistant Commissioner for Policy Planning & Children Services

Jeanette Maillet, CFO

Gail Gillespie, Metro Regional Director

Rick O'Meara, Southeast Regional Director

Terry O'Hare, Central West Regional Director

Gail Grossman, Assistant Commissioner for Quality Assurance

Larry Tummino, Assistant Commissioner for Operations

Mandy Chalmers, Northeast Regional Director

Amy Nazaire, Northeast Service Coordinator

Executive Office of Elder Affairs (EOEA)

Michael F. Festa, Secretary

Sandra K. Albright, Under Secretary

Sue Thompson, Chief of Staff

Ruth Palombo, Assistant Secretary

Joe Quirk, Director of Home and Community Programs

Massachusetts Commission for the Blind (MCB)

Janet LaBreck, Commissioner

Phil Castonguay, Regional Director - Region 1

Bill Scully, Regional Director - Region 2

Rich Maley, Regional Director - Region 4

Rich Leland, Regional Director - Region 5

Trish Hart, Director of Program Development

Tom Lee, Fiscal Dept

Lynn Paulson, Deputy Commissioner of Services

Mike Dziokonski, Deputy Commissioner of Administration

Mitch Sanborn, Director of the DB/MH Unit

Massachusetts Commission for the Deaf and Hard of Hearing (MCDHH)

Heidi Reed, Commissioner

Tricia Ford, Deputy Commissioner for Programs & Policy

Stan Potrude, Case Management Director

Massachusetts Rehabilitation Commission (MRC)

Charles Carr, Commissioner

John Chappell, Deputy Commissioner, Community Services Division

Deb Kamen, BISSCS Director

Bob Ferris, SHIP Program

Cheryl Cormier, Statewide Employment Services (SES) Department, Supervisor

Jim Durant, T-22 Program Coordinator

Betty Maher, Home Care Assistance Program (HCAP) Director

Emeka Nwokeji, Consumer Involvement, Director

Joan Smith, Multicultural Outreach & Recreation Program Coordinator, (SHIP)

Cindy Wentz, Senior IL Program Coordinator

Caroline Christen, Supervisor or Residential Program Coordiantors, SHIP

Systems Transformation Diversion Subcommittee Financing Workgroup

Anne Fracht

Carol Suleski, Elder Services Plan North Shore

Deb Cutler, HEARTH

Deb Delman, M-Power

Eliza Lake, Diversion Subcommittee Lead

Elizabeth Fahey, Home and Health Care Association of Massachusetts

Emily Shea, Boston Partnership for Older Adults

Janet Gard, MassHealth Budget

Jeff Keilson, Consultant

Jessica Costantino, AARP of Massachusetts

John O'Neill, Somerville/Cambridge Elder Services

Keith Jones

Laurie Burgess, Principal Investigator

Lisa McDowell, Mass Health Office of Long-Term Care

Margaret Chow-Menzer, DMR

Mason Mitchell-Daniels, Project Director

May Shields, HEARTH

Nilka Alvarez-Rodriguez, DMR

Pat Kelleher, Home and Health Care Association of Massachusetts

Paul Spooner, Metrowest Center for Independent Living

Rob Sneirson, Consumer Co-Facilitator of Diversion Subcommittee

Scott Plumb, Massachusetts Extended Care Federation

Wendy Trafton, Project Associate

Appendix B

KEY TERMS AND DEFINITIONS

Introduction:

The Centers for Medicare and Medicaid Services (CMS) defines a self-directed program as "a state Medicaid program that presents individuals with the option to control and direct Medicaid funds identified in an individual budget." The CMS requirements for a comprehensive self-directed program, or Independence Plus, include:

- Person-centered planning
- Individual budgeting
- 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.

Model Types:

There are many *types* of consumer direction that can be implemented in a support system and its programs. Below are some of the most common types of consumer direction, with working definitions.

Agency-Delivered Services Model: Payer or provider decides what services are necessary, and when, how, and where the individual will receive them. Services are then provided by an agency-hired and supervised worker.

Cash and Counseling Model: The Cash & Counseling approach provides a flexible monthly allowance to recipients of Medicaid personal care services or home and community-based services. Participants use an individualized budget to make choices about the services they receive, hiring and firing of personal assistants and they are able to make sure these services address their own specific needs. In the Cash & Counseling program, the participant, instead of an agency, decides who to hire and what services they would like to receive. Participants also have the option of using their budget to purchase labor saving devices or to make home modifications to help them live independently. In addition, this innovative program offers counseling and fiscal assistance to help consumers manage their allowance and responsibilities by themselves or with the aid of a representative. These main features are adaptable to consumers of all ages with various types of disabilities and illnesses. Cash & Counseling intends to increase consumer satisfaction, quality, and efficiency in the provision of personal assistance services.

Cash Model: All recruitment, hiring, firing, and supervising responsibility is vested in the individual. Cash is provided to the individual and can be used for any services/products that the consumer determines.

Consumer Directed Service Model: Consumer decides which services to receive, who should provide them and when. Individual pays the rate established by the state for services provided and is responsible for the hiring, training, and firing of their worker. (E.g.: the Personal Care Attendant Program in Massachusetts)

Individual Budgeting Model: Individuals are given a budget which can be used to purchase services from a list provided by a traditional provider agency, community resources, do things themselves, or any combination of. Individuals can hire, fire, and supervise workers.

Participant Directed Agency Model: Individuals are offered a specific list of services provided by agency, from which they choose the specific services as well as the agency to provide them. Services may then be provided by a worker directed, hired, and supervised by the consumer.

Self-Directed Corporation Model (Micro-board): "A Microboard is formed when a small (micro) group of committed family and friends join together with a person who lives with challenges to create a non-profit society (board). Together this small group of people addresses the person's planning and support needs in an empowering and customized fashion. A Microboard comes out of the person centered planning philosophy and is therefore created for the sole support of one individual." ***(***Microboards and Microboard Association Design, Development and Implementation, David and Faye Wetherow, August 2004)

Overall Principles:

The **Self-Determination** movement has several over-arching principles:

1) Freedom: Choosing where and with whom to live, how to make a living, and with whom to develop relationships
2) Authority: Being in control of how one's long-term care dollars are spent
3) Support: Arranging public resources in a way that meet the individual needs of a person with a disability
4) Responsibility: Using public resource cost-effectively
5) Confirmation: Recognizing that individuals with disabilities must play a major role in the development and implementation of self-determination policies[13]

Definitions:

Circle of Support: A circle of support is a group of people who care about an individual and have a personal (and sometimes professional) commitment to the person. They will come together regularly and provide advice, guidance, and connections. Usually, a circle has a facilitator who helps to get it going and keep it running smoothly. A circle is a group of people who agree to meet on a regular basis to help the person with a disability accomplish certain visions or goals. It is one way of pulling other resources into a person's life. It helps connect the individual to natural supports in his or her community.

Fiscal Intermediary Service/Fiscal Agent/Financial Management Services: It is an independent person, designated agency or company that disburses a person's funds in accordance with their individual budget. These funds are based on an individual budget. The agency or company is responsible for the withholding, filing and depositing of federal, state, and local employment-related taxes, the preparation and distribution of payroll for support service workers

[13] Consumer Control and Choice: An Overview of Self-Determination Initiatives for Persons with Psychiatric Disabilities; NMHA Issue Brief, page 1

and others that provide services, paying for goods and other items that assist people to live more independently, sending regular reports to the individual on spending, and pays only those expenses and services that are incorporated in the individual's plan as directed by the individual or, where appropriate, the family.

Independent Living: Independent Living is having control over one's life. This means being able to make the decisions and choose the direction of one's life to the fullest extent possible.[14]

Individual Budget: It is the public funds for the purchase of the goods and services under the control and direction of the individual.

Person-Centered Planning: A critical component of self-determination. A person-centered plan describes the services and supports an individual will need to achieve their goals and are driven by the person's life goals. CMS defines person-centered planning as a process, directed by the participant, intended to identify the strengths, capacities, preferences, needs and desired outcomes of the participant. Person-centered planning is a comprehensive strategy for putting necessary services and supports in place to help people achieve their goals. Person centered planning is driven by the individual, but works best when it includes other people who can contribute valuable information to the process. Having a person-centered plan is the first step of self-directing services.[15]

Person-Centered Thinking: Every style of person centered planning is rooted in a person centered way of thinking. Person centered thinking is essentially the fundamental concepts, values, and principles which underscores all PCP approaches; and, it is linked to a set of skills that results in seeing persons receiving services differently. Person Centered Thinking also provides a way for acting on what is learned as reflected in the questions that follow. [16]

Is there a process for listening to what people supported and their families want? Does it lead to action?

- People are at the center of person centered planning and this entails having opportunity to lead their own plan.

What would you see at an individual/team level?

- Staff and managers separating what is important to from what is important for the people they support and finding a balance between them.
- Managers and staff defining their roles and responsibilities based on what is important to and for people who they support.

What would you see at an organizational level?

- People with learning disabilities are part of the implementation group.

---

[14] www.mrc.gov

[15] The Minnesota Governor's Council on Developmental Disabilities publication book "It's My Choice…" defines person-centered planning as "one way to figuring out where someone is going (life goals) and what kinds of support they need to get there." It is also about supporting people in the choices they make about their life. "What is Person-Centered Planning" by Marsha Forest, Jack Pearpoint and John O'Brien answered the question that "it is a constellation of tools developed to help a person who wants to make a meaningful change in their life."

[16] Amado, A.N. and McBride, M (2001) *Increasing Person Centered Thinking, Improving the Quality of Person Centered Planning: A Manual for Person Centered Planning Facilitators. Minneapolis, Minnesota: University of Minnesota, Institute for Community Integration.*

- Policy that reflects the organization's commitment to person centered thinking and planning and to people being at the center of their own lives.[17]

Support Broker/Personal Agent/Support Coordinator: Support broker is someone the person trusts to help them navigate the system, help with staff and act as an advocate. The primary aim of these supports is to assist the individual and, where appropriate their family, to capably use their funding allocation, and obtain the best services or supports to meet their needs. (From the State of Maryland, New Directions program) Some of the roles and responsibilities of a Support Broker are:

- The consumer can hire and train the support Broker. They work for the consumer;
- Assist to coordinate supports;
- Assist in developing and implementing the person-centered plan;
- Assists in developing and implementing the individual budget;
- Help to facilitate involvement of family, friends, co-workers, acquaintances and others;
- Helps in the understanding on what choices a consumer has;
- Assist the consumer in locating information on providers of services, such as location, quality of service and "fair market" costs;
- Provide technical assistance with implementing contractual agreements;
- Assist in conflict resolution and mediation;
- Monitor service arrangements;
- Identifying alternative services and supports when needed;
- Stimulate the development of new options for services and supports in the community; and
- Ensure that everything is in place to monitor the financial administration of individualized funding.

[17] Person Centered Thinking and Planning, www.helensanderassociate.co.uk

Appendix C

Studies Demonstrating Advantages of Providing the Self-Direction Delivery System Option

The following studies support the finding of positive outcomes from self-direction :

1. The Kaiser Commission on Medicaid and the Uninsured sponsored four focus groups with enrollees of CD-PAS, a consumer-directed Medicaid personal assistance services program. CD-Pas enrollees were able to hire and fire individuals who provide their personal care. A total of twenty-three (23) non-elderly adults with physical disabilities were interviewed in four cities, Denver, CO, Berkeley, CA, Alexandria, VA, and New York City, NY. The average interviewee had five (5) years of experience with the program and each consumer had at least one-year of experience with the program. Interviewees valued the independence and control that they achieved through consumer-direction. Many CD-PAS enrollees felt their physical and mental health and quality of life improved due to their ability to choose workers and set their schedules. Enrollee satisfaction with workers was greater and many attributed this to stronger relationships with the attendants they hired and higher level of supports that they received from the attendants.

Source: *Consumer Direction of Personal Assistance Services Programs in Medicaid Insights from Enrollees in Four States* prepared by Dulio, A., Perry, M., Lake Research Partners, Claypool, H., Paraprofessional Healthcare Institute and O'Malley, M., Kaiser Commission, March 2008

2. The Western New York Care Coordination Program, a collaborative initiative between six (6) county governments, the State Office of Mental Health, providers and consumers, uses a person-centered planning approach to increase quality of life and decrease Medicaid mental health cost and service utilization for adults with severe mental illness. The program, which began in 2003 and is now in its 5th year, provides training to care coordinators, clinicians, and others providing mental health services to consumers. Consumers, with the help of care coordinators and friends and family chosen by the consumer, use a person-centered planning approach to create unique service plans that include their goals and dreams. Each county receives a wrap around allocation to divide among all consumers to pay for items and services in the plans that are not reimbursed by Medicaid.

The program uses three instruments completed by Care Coordinators and consumers to measure outcomes: the Care Coordinator's Assessment of Functioning, a Periodic Reporting Form completed quarterly by the Care Coordinator, and a Quality of Life Self-Assessment. Yearly studies consistently found that quality of life increased and Medicaid-funded inpatient, emergency, and mental health outpatient service utilization decreased. For example, 2004 studies comparing 1st and 4th quarter data, showed a 56% decrease in number of clients with ER visits, 56% decrease in number of clients inpatient days, 60% decrease in number of clients with suicide attempt indicated, and 44% increase in number of clients involved in competitive

employment. In addition, 2007 self-reports showed that 79% dealt more effectively with daily problems, 75% were better able to control their lives, and 71% had improved housing situations. The average cost per person enrolled for Medicaid-paid mental health services during the first full year of enrollment (2003) decreased by $1730 per person when compared to costs in 2002, the year prior to enrollment. For this same population, the average Medicaid cost of inpatient services was down 48%, cost of emergency services was down 13% and mental health outpatient costs were down 8% as compared to the year prior to enrollment. Service utilization and fiscal outcomes were measured using the Minimum Data Set tool and Medicaid claims data.

Source: Western New York Care Coordination Program website. Retrieved on 6/24/08 from: http://www.carecoordination.org/. Phone conversation with Director, Adele Gorges on 6/24/08.

3. The Monadnock Self Determination (MDS) Project, which utilized individual budgets, personal agents chosen by the consumer, and fiscal intermediaries, proved that people with developmental disabilities have improved quality of life and state agency costs decrease when individuals are given greater control of their lives and resources. The project measured qualities of life and outcomes with the Personal Life Quality Protocol created by Jim Conroy. The project measured expenditures by changing the MDS accounting system to reflect individual budget tracking. Baseline costs were ascertained by determining individual costs from congregate costs. All cost data was converted to 1994-95 constant dollars. The quality of life measurements are designed to reflect identified issues from self-advocates and areas specified as central outcomes in the Developmental Disabilities Act Amendments of 1987: Independence, Productivity, Integration, and Satisfaction. The evaluation data is from a pre-post test completed at baseline and 18 months for 43 participants (38 completed pre and post test).

One component of the test is the Decision Control Inventory (DCI). The DCI measures 26 dimensions of everyday life, including items such as choice of foods, choice of case managers, and whether to have pets. There were 22 increases and 4 decreases, including 11 statistically significant increases and 1 statistically significant decrease. Interviews with consumers also measured satisfaction and quality of life. Consumers responded on a level of 0-5 and an overall score was computed from 0-100. There was a statistically significant increase of 6.7 points. A second part of the interview included an instrument called Quality of Life Changes. Every one of the nine dimensions showed improvement over the 18 month time period. The largest improvements were in the area of happiness, running my own life, and making my own choices. In addition, the average consumer statistically increased the amount of time spent in productive educational or vocational daytime activities.

Decision making power moved away from paid staff toward the individual and unpaid friends and family. At pre-test, 22.1% of the participant's involved in the Individual Service Plan were unpaid participants (the individual, friends, family, and peers). At post-test, a statistically significant increase occurred with 34.2% of participants not receiving compensation (the individual, friends, family, and peers).

Data was ascertained for residential program costs, day program costs, and the costs of coordination (case management, administrative, etc). Total state agency costs decreased between 12.4% and 15.5% from 1994-95 to 1996-97 after converting all MDS cost data into 1994-95 constant dollars.

Source: *Independent Evaluation of the Monadnock Self Determination Project*. The Center for Outcome Analysis, December 1996.

4. Florida Self-Directed Care (Florida SDC) is a program for people with serious mental illnesses that utilizes person-centered planning, support brokers, and a fiscal intermediary service to assist in identifying and securing traditional and nontraditional behavioral health goods and services.[18] Florida Law Chapter 2001-152 was established in 2000 following consumer and family advocacy to create and pass a Self-Directed Care Bill. Funding for the program is from the Alcohol, Drug Abuse and Mental Health Trust Fund in the Department of Children and Families, State General Revenue funds and a Community Mental Health Services Block Grant.

An evaluation was completed using client-level outcome data. Using a pre-post design, University of Illinois at Chicago researchers tested 106 participants enrolled in the program from November 2002 through June 2004. According to the study, participants spent significantly less time in psychiatric inpatient and criminal justice settings the year after joining the program then in the year prior to enrollment. Global Assessment of Functioning Scale scores were significantly higher in the year after enrollment. The Scale ranges from 0 to 100 in which a low score indicates a lower level of social, occupational, and psychological functioning. The mean score on follow-up was 58.3 and the mean score prior to enrollment was 50.9. Despite State concerns about overspending, consumers in the program spent only 32% of the money allocated to them.

Source: *Economic Ground Rounds: A Self-Directed Care Model for Mental Health Recover.* Psychiatric Services. June 2008, Vol. 59, No.6 and "Promoting Self-Determination for Individuals with Psychiatric Disabilities through Self-Directed Services," Judith Cook, Shawn Terrell, and Jessica Jonikas, US Department of Health and Human Services, March 2004.

5. The Center for Outcome Analysis evaluated consumer outcomes and costs in ten (10) states that implemented self-direction programs. First, researchers asked consumers and their allies to rate their control and power over resources through out the person-centered planning process using the Decision Control Inventory questionnaire. Consumers perceived and reported that their sense of control over their lives and services increased in all ten (10) states. In addition to providing more control over resources, consumer scores indicated that self-direction also improved the quality of life for consumers. Surveys were conducted at baseline and three (3) years into self-directing services. The survey measured fourteen (14) separate areas including: making choices, socializing, happiness, comfort, privacy, safety, health and family relationships. Consumers in all ten (10) states improved in all fourteen (14) areas. The largest increases were in the areas of "getting out," "making choices," "socializing," and "happiness."

Source: "Self-Determination Impacts on Qualities of Life in the U.S.: A Brief Progress Report." By James W. Conroy, Ph.D. Powerpoint presentation at National ASSID Conference in Adelaide, 2004.

[18] See Appendix D for more information about the Florida SDC Program.

6. A study of the Arkansas Cash and Counseling demonstration showed that Medicaid-funded consumer-directed personal care services (PCS) reduced Medicaid-funded nursing facility use and other Medicaid-funded medical costs to a greater extent than the traditional Medicaid system. This program provided flexible budgets to elders and consumers with disabilities to purchase goods and services to meet their personal care needs. Medicaid beneficiaries that were interested in the demonstration were randomly assigned to treatment (receiving an allowance for self-directed services) and control (traditional services) groups. 2008 consumers enrolled in the cohorts between December 1998 and April 2001. Using nursing facility data, PCS costs and Medicaid claims data, researchers determined that nursing facility use was 18% lower for the treatment group than for the control group during the 3 year follow-up.

Source: Dale, Stacy, and Randall Brown. *Reducing Nursing Home Use Through Consumer-Directed Personal Care Services.* Medical Care. 44(8):760-767, August 2006.

7. Mathematica Policy Research, Inc. conducted a study of the three Cash and Counseling demonstration states, New Jersey, Florida, and Arkansas. Through the program, consumers received a monthly allowance to hire workers and purchase goods and services for personal care, designated representatives to help make decisions about managing their care, and received fiscal intermediary services and counseling support. The evaluation used a pre-test post-test randomized control design and used an intent-to-treat analysis. Upon enrollment, consumers were randomly assigned to the treatment group or a control group that received agency-model services.

Outcome data was collected nine months after enrollment during thirty-minute telephone surveys. The study tested whether the program affected the types and amounts of care received, the consumers' unmet needs for care, their satisfaction with their care, their health and functioning, their quality of life, and the incidence of adverse outcomes, such as falls or pressure sores. All treatment group members in all states, except for elderly consumers in Florida, were much less likely than control group members to report unmet needs, more likely to report that their caregivers performed reliably and appropriately, and were more satisfied with the types of help they received. In addition, treatment group members were more satisfied with their care and were also much less likely to have remaining unmet needs for help with activities of daily living, household needs, and routine healthcare. The program enabled consumers to reduce unmet needs by ten to forty percent below the incidence of consumers in the control group.

Measures of health problems and adverse events were collected. None of the 11 measures showed worse outcomes for the treatment group in all states and age groups. The treatment group was significantly less likely to experience health problems for one-third of the 77 comparisons.

Quality of life was greater for the treatment group members. In fact, treatment group members were twenty-five to ninety percent more likely than control group members to report that they were very satisfied with how they were leading their lives, and generally half as likely to report that they were dissatisfied with their lives. The study also investigated abuse and neglect. Counselors contacted consumers regularly to ensure there were no problems of abuse or neglect. Only one incident of financial exploitation and one incident of self-neglect were reported.

Although magnitudes of cost differences varied widely per state, Medicaid personal care/waiver costs were substantially higher for the treatment group than for the control group. In Florida, the difference was fifteen percent between treatment and control groups after year one and two, while Arkansas costs were approximately double for the treatment group. Reasons cited for the difference in costs are that treatment group members were more likely than control group members to receive any paid care and because the treatment group had higher average Medicaid payments per month of benefits received.

Costs for Medicaid services other than personal care/waiver services were lower for the treatment group in all three states across age groups. Younger adults in Arkansas and Florida had the largest differences. The treatment group's costs were fifteen and seventeen percent lower, respectively. For all other age groups in each state, treatment group costs were approximately four to seven percent lower than control group costs.

Source: Brown, Randall, Barbara Lepidus Carlson, Stacy Dale, Leslie Foster, Barbara Phillips and Jennifer Schore. "Cash & Counseling: Improving the Lives of Medicaid Beneficiaries Who Need Personal Care or Home and Community-Based Services." Princeton, NJ: Mathematica Policy Research, Inc., August, 2007.

Appendix D

Examples of Other States' Innovations in Self-Determination

The following three states, Iowa, Florida and Wisconsin, were selected for presentation in this report as they are successfully implementing models of self-determination and are serving distinctly different populations.

Iowa

Through its Home and Community-Based Services waiver, Iowa offers residents with disabilities and the elderly the choice to control the supports that enable them to live in the community. The Consumer Choices Option provides individuals several tools to make informed decisions including independent support broker services, an individual budget and fiscal management services. This set of tools and services is offered to a diverse set of enrollees in the State's seven (7) HCBS waivers. The Iowa HCBS waivers include: an Ill and Handicapped Waiver, Mental Retardation Waiver, Brain Injury Waiver, Physical Disability Waiver, AIDS/HIV Waiver, Children's Mental Health Waiver, and Elderly Waiver. Funding for these services is provided through a combination of State, Federal and local sources.

Once it is determined that a consumer is eligible for waiver services, the case manager, consumer and, if they desire, a family member or friend work together to determine the budget. The individual budget amount is based on the service plan and a review of past service utilization. Trainings are provided and required by the Department of Human Services for all independent support brokers. Individuals may choose a family member or a friend to act as their support broker. In fact, consumers are encouraged to choose someone who knows them and their community well. In order to prevent conflict of interest, the support broker can not be a person that offers additional services to the consumer, can not be the parent or legal guardian of a consumer under age 18, and can not be the spouse, guardian or legal representative of a consumer over the age of 18. If the consumer can not identify an Independent support broker, the case manager will help contact trained Independent support brokers, schedule interviews and assist the consumer with preparing for the interview, if necessary. The waiver enrollee has the ability to hire and fire their independent support broker if they decide to choose a different person. Each individual will have unique needs that are served by the support broker; however, the maximum amount of compensated work is up to six (6) hours to develop the first Individual budget and up to twenty (20) hours per year after the budget is developed. The consumer establishes a pay rate that is capped at $15 per hour.

The waiver enrollee, support broker, and friends or family chosen by the enrollee work together to create an individual budget. The budget plan includes supports that are needed and wanted, the individual or company that will provide the service, when and how often the service will be provided, and how much it will cost. The plan can be changed or altered at any time if needed and must address how the individual's health and safety needs will be met. Services can be provided completely by agency providers, as a combination between agency and alternate service providers, or completely by non-traditional providers. The independent support broker helps to develop and implement the plan.

Once the plan is completed, the waiver enrollee must choose a financial management service provider from a list of community credit unions and banks supplied by the case manager. The financial management service provider works for the consumer and ensures that all federal and state laws are obeyed including payroll taxes. Once the consumer approves an invoice, the financial management service provider will provide payment to the service provider. The credit union or bank provides monthly statements and assists with tracking time cards and ensuring that providers follow an employer-employee agreement.

Florida

Florida's Self-Directed Care Program (Florida SDC) was designed to enable each participant to set and achieve personal mental wellness and productivity goals. The Florida SDC Program serves adults with psychiatric disabilities through funding from the Alcohol, Drug Abuse and Mental Health Trust Fund in the Department of Children and Families, State General Revenue funds, and Florida's Mental Health Block Grant. Each program enrollee receives an individual budget based on the average cost of services the prior year. For example, in 2004, Medicaid-eligible participants were allotted $1,673 and those not eligible for Medicaid were allotted $3,195. All enrollees are required to spend 48% of their budget on traditional behavioral health services such as medication or psychotherapy.

Each Florida SDC participant designs a recovery plan that is reviewed and approved by a senior quality advocate. Each enrollee is encouraged to hire a Recovery (non-peer) or Recovered (peer) Coach. Enrollees are in charge of implementing their plans by purchasing traditional and non-traditional services from vendors of their choice. Mental wellness services can be purchased from members of the Florida SDC Network that provide services within the participant's residential district. Participants have the ability to change services and providers. Additionally, match-funding opportunities are available to purchase tangible items such as clothing that will enhance community integration and enable the participant to return to work or another meaningful activity. Recovery plans are reviewed by program staff and the Fiscal Intermediary Service to ensure that all purchases are linked to a defined recovery goal and an identified need.

Florida State University acts as the Fiscal Intermediary Service and receives quarterly payments from the State for each participant. Behavioral health, medical and other professional services are billed directly to FSU. All other purchases from the approved plan are made by and reimbursed to the participant. Progress reports are provided to participants every three (3) months and new expenditures are pre-authorized for the upcoming three (3) months at this time. Funds are carried over into the next quarter if there is an available balance.

Wisconsin

Dane County, Wisconsin provides adults with developmental disabilities the opportunity to direct their own services. Individuals enrolled in the program receive an individualized budget, hire a support broker, and receive fiscal management services to purchase their own supports. Workers from the County Developmental Disabilities Unit use a formula to determine the set amount of the individual budget. The formula includes the number of service hours needed, rate of direct care, and a 35% indirect service rate. The formula varies if the consumer is in a paired working/living arrangement with another consumer. Final rates can be adjusted based on comparisons with other consumers with similar needs.

Utilization of a support broker is required and each broker receives a yearly fee per consumer. The individual can pick a support broker; however, they are initially assigned a worker based on their proximity to the seven (7) support broker agencies in the County. The selected support broker cannot be employed by one of the consumer's current support agencies, provide other types of support to the consumer, or act as a guardian or legal representative to the consumer. If the consumer chooses to hire a family member or friend as a support broker, the selected person can be trained by a brokerage firm. Two additionally ways of selecting support brokers are through broker fairs and individual interviews.

The support broker is responsible for assisting with the development and implementation of the person's plan. After receiving a budget from the intake worker, the individual and support broker create the individual and financial plan together and submit it to Dane County Adult Community Services for approval. Annual plans, fiscal paperwork, case notes, requests for adaptation modifications and DD system change forms must be completed by the support broker. Each individual can choose the frequency of contact with their support broker; however, face to face contact is required at least quarterly unless prior approval is obtained. A typical full-time broker serves twenty-one (21) individuals and works 5-8 hours per individual per month.

A fiscal assistance agency was formed as a non-profit human service agency to contract with Dane County Human Services to administer the functions of the program. The County submits the Individual Financial Plan to the agency to create and manage a customer account and make appropriate payments. Each payment must be approved through a Support and Services Agreement/Voucher signed by the individual and support broker. Monthly bills are sent directly to the fiscal assistance agency and payments are processed biweekly. In addition, spending allowances are provided to consumers based on their needs and budget. The support broker and individual are sent a monthly report that includes the account balance and all expenditures.

Appendix E

Agency Interview Tool

Diversion Subcommittee, Financing /PCP Workgroup
Questions Related to State Programs with Elements of Consumer-Direction

Please read the attached briefing document which provides the context and some definitions for our discussion.

General Overarching Questions:

1. Do you believe you are incorporating the elements of self-direction in your agency's service delivery system as we have described? If so, in which programs or generally, in which ways?
2. What are your hopes for advancing self-direction into your agency's delivery systems and processes?
3. What do you perceive are the challenges to advancing self-direction at your agency?

Specific Questions about the programs or processes in which you are currently incorporating elements of self-direction (Interviewers should ask commissioner to send any descriptive documents that exist describing these programs and processes):

Individual Assessment and Service Planning

1. Does your agency conduct assessment(s)? Describe the process.
2. Does your agency do service planning? Describe the process.
3. How is the consumer involved in the assessment process?
4. How are family members, other informal caregivers or guardians involved in the assessment process? In the service planning process?
5. Describe the role of the consumer in the service planning process in terms of his/her needs, preferences, and service options/providers. Please provide examples.
6. How is the consumer informed of consumer directed options available through your agency? Is this information shared with all eligible consumers? Do all consumers get to choose between consumer-directed and agency-directed services?

Case Manager, Service Coordinator, Support Broker

1. Is there a state-funded role such as a case manager, service coordinator, support broker, or something else whose job it is to assist the individual to plan and manage the services?
2. What is that role? Assessment? Planning? Monitoring?
3. Is this an independent entity? Is this role delivered through a contract or through state employees?
4. Do consumers (or, where appropriate, family members) have the right to choose their case manager/service coordinator or change their case manager if not satisfied? Do they know of this right and do they exercise it?

Budget Development and Flexible Funding

1. What is your agency's process for the allocation of resources/funding for individual consumers?

2. Is there an individual budget established for each service plan? Is the budget for all of the services in the service plan? Is there a fixed amount per consumer?
3. If individual budgeting is available to consumers, do the consumers direct/purchase/ choose from a specific list of services, or can they direct use of the funds for anything that the consumer feels would meet his/her needs (i.e., assistive technology, home adaptation, etc)?
4. If there is an individual budget, is training available to consumers on how to manage a budget?
5. If there is an individual budget, do you provide fiscal intermediary services in some way to assist individuals? What do they assist with?

Service Provision

If the individual has the authority to hire support workers,

1. How involved is the agency in the hiring and supervision process?
2. Who are the eligible caregivers (e.g. agency staff, friends, neighbors, family members, spouses, etc)? What is the hiring process? Hiring requirements? (CORI checks, etc)?
3. Are there surrogates available to individuals in your delivery system? If so, what is their role?
4. What supports exist for the individual in the hiring and supervision process?

Monitoring and Oversight of Self-Directed Services

1. How are programs monitored and who develops the monitoring measures, if any?
2. How are consumers involved in monitoring?
3. How does your agency determine whether a program is successful?

Appendix F

AGENCY INTERVIEW TABLES

In preparation for the development of the Recommendations for EOHHS for Advancing Self-Direction in Massachusetts' Long-term Care Delivery Systems Report, the Core Team of the Person-Centered Implementation Grant conducted an agency interview series. The participating agencies included DMH, DMR, EOEA, MCB, MCDHH and MRC. The purpose of the interviews with each agency was to gain an understanding of how the agency might already be implementing programs promoting self-direction and where each agency was hoping to expand on and improve opportunities for self-direction in the future. Information gathered from each agency was organized into Agency Interview Tables appearing in the subsequent pages.

Program: Day and Employment Services

DMH sponsors community-based programs to assist clients with achieving employment or educational objectives; both as a means of furthering a client's recovery process and his or her economic well-being. DMH delivers these services to clients primarily by contracting with private vendors. The major programs of this type are the Services for Education and Employment (SEE) and Community Support Clubhouses.

Self-Direction Element	Currently In Place	Future Plans/Hopes
▪ Individual budgets		X (priority area: employment)
▪ Provision of support broker		X (peer support a priority)
▪ Provision of fiscal intermediary		X (needs to be better understood)
▪ Person-centered planning		X
▪ Consumer involvement in monitoring their services	X	X (expansion)
▪ Training of consumers to self-direct	X (Through empowerment training of some people)	X (expansion)
▪ Consumers hire/fire pay service providers	X (some people participate in hiring staff for a program)	X (expansion)
▪ Training of service providers on self-direction	X (training on recovery and on some of the philosophy)	X (expansion)
▪ Training and ongoing supervision of case management staff re self-direction	X (training on recovery and on some of the philosophy)	X (expansion)

Program: Community Rehabilitation Support

Community Rehabilitation Support (CRS) provides general rehabilitation, support and assistance with medication. The emphasis of these interventions is on outreach and engagement for clients who may not utilize more traditional community-based services. In addition, DMH offers services focused on recovery and client empowerment. Most community- based programs provide both rehabilitative and supportive functions in a flexible manner to match the goals and needs of the individual client.

Self-Direction Element	Currently In Place	Future Plans/Hopes
▪ Individual budgets		X (priority area: supportive housing)
▪ Provision of support broker		X (peer support a priority)
▪ Provision of fiscal intermediary		X (needs to be better understood)
▪ Person-centered planning		X
▪ Consumer involvement in monitoring their services	X	X (expansion)
▪ Training of consumers to self-direct	X (Through empowerment training of some people)	X (expansion)
▪ Consumers hire/fire pay service providers		X (some people participate in hiring staff for a program)
▪ Training of service providers on self-direction	X (training on recovery and on some of the philosophy)	X (expansion)
▪ Training and ongoing supervision of case management staff re self-direction	X (training on recovery and on some of the philosophy)	X (expansion)

Program: Residential Services

DMH residential services are designed to ensure maximum flexibility to meet the changing needs of residents and provide support, supervision, treatment and rehabilitation to clients living in the community. Each individual receiving a residential rehabilitation and support are at the core of its programs. These include case management, residential services, clubhouses, Program of Assertive Community Treatment (PACT), service has a Program Specific Treatment Plan (PSTP) specifying the rehabilitative service components that will be provided and the outcomes these services are expected to achieve. In a shift towards consumer-directed care, DMH funds and supports a variety of consumer initiatives, including peer and family support, peer mentoring, warm-lines and recovery learning communities.

Self-Direction Element	Currently In Place	Future Plans/Hopes
▪ Individual budgets		X
▪ Provision of support broker		X (peer support a priority)
▪ Provision of fiscal intermediary		X (needs to be better understood)
▪ Person-centered planning		X
▪ Consumer involvement in monitoring their services		X
▪ Training of consumers to self-direct		X
▪ Consumers hire/fire pay service providers		X (some people participate in hiring staff for a program)
▪ Training of service providers on self-direction	X (some training on recovery and self-advocacy)	X
▪ Training and ongoing supervision of case management staff re self-direction	X (some training on recovery and self-advocacy)	X

Program: ISO (Intermediate Service Organization)

The ISO Program began in 1997 with the award to Massachusetts of one of 19 Self-Determination Demonstration Grants by the Robert Wood Johnson Foundation. Under the ISO, a person centered and person directed approach was established to support consumers who wished to self-direct. It required new and modified mechanisms to enable consumers to direct service planning, manage resources and manage service delivery. These included person centered planning, individual budgets, ISO (intermediary service organization that performed fiscal intermediary and other functions that enabled consumers to exercise certain controls over their DMR funded services), and a quality assurance system to evaluate the impact of self-determination on the lives of the consumers. Today, this initiative continues as the ISO program and there are more than 280 participants directing almost $9 million in DMR funding.

Self-Direction Element	Currently In Place	Future Plans/Hopes
▪ Individual budgets	X	
▪ Provision of support broker	X Limited. Support broker functions are primarily provided by service coordinators on voluntary basis	X Separate service coordination from service broker. Service coordination is state provided targeted case management and support brokers are contracted with vendor hired to oversee function (recruit, mentor, train)
▪ Provision of fiscal intermediary	X	
▪ Person-centered planning	X Combination of ISP and service planning combined with individual budgeting process.	X Change service planning process to be more person centered and person directed
▪ Consumer involvement in monitoring their services	X Process uses reporting to FI (complaints about payments) and service coordinator and random sampling on budget process	X Integrate with other citizen monitoring processes.
▪ Training of consumers to self-direct	X Basically, 1:1 orientation	X Need to do more outreach to promote self-direction (more marketing before training); on-going,

		broader spectrum of training, e.g. peer to peer/family to family discussions for support
▪ Consumers hire/fire pay service providers	X	X Implement system to qualify non-traditional providers as HCBS waiver providers
▪ Training of service providers on self-direction	X Some DMR training of agency providers.	X Need more regular outreach to providers
▪ Training and ongoing supervision of case management staff re self-direction	X No formal DMR training; peer modeling and on-going supervision provided to service coordinators	X

Program: Autism Waiver

The Office of Medicaid and the Department of Mental Retardation's Autism Division have received approval from the Federal Centers for Medicare and Medicaid Services (CMS) to implement an autism services program and receive federal matching funds for Medicaid eligible children diagnosed with an autism spectrum disorder. This three year model program is called the Children's Autism Spectrum Disorders Home and Community-Based Services Waiver Program. Waiver services are supplemental to special education services provided under IDEA (Individuals with Disabilities Education Act).

The Autism Waiver Program applies a service delivery model called Participant Direction in which the parent takes the lead in designing the program and selecting service providers based on the child's assessed level of need. Each family receives support from a designated staff person, an Autism Support Broker, at one of the seven DMR funded Autism Support Centers and from a Targeted Case Manager at the Autism Division.

Self-Direction Element	Currently In Place	Future Plans/Hopes
▪ Individual budgets	X	
▪ Provision of support broker	X	
▪ Provision of fiscal intermediary	X	
▪ Person-centered planning	X	
▪ Consumer involvement in monitoring their services	X	
▪ Training of consumers to self-direct	X	
▪ Consumers hire/fire pay service providers	X	
▪ Training of service providers on self-direction	X Autism Support Centers	X Expand to all providers
▪ Training and ongoing supervision of case management staff re self-direction	X	

Program: DOE/DMR

The Department of Mental Retardation, in conjunction with the Department of Education, is committed to exploring less restrictive, community-based options for public school students who are receiving special education services who are DMR-eligible consumers. This interagency initiative allows special education students who might otherwise need out-of-district residential programs to remain in their own homes with their own families at less cost to the state by allowing the Department of Mental Retardation to supply needed in-home supports to the students' families. In many cases, the Project has allowed students to return to their homes from residential placements.

Self-Direction Element	Currently In Place	Future Plans/Hopes
▪ Individual budgets	X All enrollees have individual budgets but not all have chosen to self- direct	
▪ Provision of support broker	X If enrolled in ISO; others have family support coordinators employed by family support providers	Under consideration to change rule and not have family support coordinators serve as support broker because of actual/potential conflict of interest
▪ Provision of fiscal intermediary	X If enrolled in ISO	Undecided whether to require FI or allow family support providers to perform some FI functions
▪ Person-centered planning	X More traditional assessment and service planning process	
▪ Consumer involvement in monitoring their services	X Families monitor	
▪ Training of consumers to self-direct	X Families receive information on ISO, support brokerage, direct hiring/firing staff	Need more formal/standardized training
▪ Consumers hire/fire pay service providers	X	
▪ Training of service providers on self-	X	More

direction	Providers understand importance of families having choice in other services.	formal/standardized training desired
▪ Training and ongoing supervision of case management staff re self-direction	X Particularly with regards to the importance of self-direction.	More desired to ensure plan meets child's needs

Basic Homecare – Non-Waiver

The Massachusetts Home Care Program provides support services to elders with daily living needs to remain at home in their communities. The services are designed to encourage independence and to ensure dignity. The program also supports families caring for elders in order to encourage and to relieve the ongoing care giving responsibilities. Eligibility for the Home Care Program is based on age (60 or older), financial status, and ability to carry our daily tasks such as bathing, dressing and meal preparation.

The Home Care Program is administered by the Executive Office of Elder Affairs in coordination with local Aging Services Access Points (ASAPs) located in communities throughout the Commonwealth of Massachusetts. Some of the services provided by the program include homemaker, personal care, day care, home deliver meals, transportation, and other community support services to help maintain an elder in his/her home. The ASAPs conduct comprehensive needs assessments to determine eligibly for the Home Care Program and other programs and services as appropriate. An individualized service plan is developed with the elder and his/her family and the ASAP reassesses the elders needs and monitors the services on an ongoing basis.

Self-Direction Element	Currently In Place	Future Plans/Hopes
▪ Individual budgets		X
▪ Provision of support broker	X The case managers perform some support broker functions for those who hire and fire direct support workers.	X
▪ Provision of fiscal intermediary	X For those who hire and fire direct support workers	X Make it available to all that self-direct.
▪ Person-centered planning	X For some who are hiring and firing direct support workers	X
▪ Consumer involvement in monitoring their services	X Individuals are encouraged to comment on the services they are	X

	receiving.	
▪ Training of consumers to self-direct	X How to be an employer training with no formal curriculum	X
▪ Consumers hire/fire pay service providers	X Only in 10 ASAPs.	X
▪ Training of service providers on self-direction		X Training of providers in ASAPs
▪ Training and ongoing supervision of case management staff re self-direction		X

Program: Social Services Programs

MCB is one of two Social Service Block Grant Agencies (the Department of Social Services being the other) in Massachusetts and, as such, is responsible for administering and providing social services to the blind. Independent Living Social Services, as all other services, are delivered primarily through offices serving six geographic regions.

Independent Living Social Services are provided for legally blind individuals who need assistance to become more independent. Specialized services, including some fairly simple devices and techniques, can often vastly improve a legally blind person's quality of life. Each consumer referred to the program works with a professional case manager. Services are planned and provided individually based on the person's unique needs.

Self-Direction Element	Currently In Place	Future Plans/Hopes
▪ Individual budgets		X Prioritize individuals with more intense needs.
▪ Provision of support broker		X
▪ Provision of fiscal intermediary		X
▪ Person-centered planning		X More person centered and person directed
▪ Consumer involvement in monitoring their services		X
▪ Training of consumers to self-direct		X
▪ Consumers hire/fire pay service providers		
▪ Training of service providers on self-direction		X
▪ Training and ongoing supervision of case management staff re self-direction		X

Program: Deaf/Blind Multi-Handicap Unit [19]

If a consumer is Deaf/Blind, or legally blind along with retardation, Commission for the Blind Services are available through specially trained counselors skilled in the use of American Sign Language or a variety of alternate communication methods. A range of Vocational Rehabilitation and Independent Living Social Services can be provided in a manner most suitable to the consumer. These may include job training, assistance in the development of independent living skills such as money management, cooking, the use of special equipment, help in developing new social contacts, or assistance with group home placement. In addition, the Deaf Blind Multi-Handicapped unit can help with the transition from school to work and life in the community, a process that often requires coordination with other service providers.

Self-Direction Element	Currently In Place	Future Plans/Hopes
▪ Individual budgets	X MCB contracts residential provider to create and manage individual budget	X
▪ Provision of support broker		X
▪ Provision of fiscal intermediary		
▪ Person-centered planning	X	X Improve and enhance it.
▪ Consumer involvement in monitoring their services		X
▪ Training of consumers to self-direct		X
▪ Consumers hire/fire pay service providers		X
▪ Training of service providers on self-direction		X
▪ Training and ongoing supervision of case management staff re self-direction		X

[19] Massachusetts State Legislature currently deliberating on funding allocation to pilot a SD program to expand on the D/MH Unit.

MCDHH

Massachusetts Commission for the Deaf and Hard of Hearing is the principal agency in the Commonwealth on behalf of people of all ages who are deaf and hard of hearing, established by Massachusetts General Laws, Chapter 6 §191-197: represents approximately 560,000 Deaf, late-deafened and hard-of-hearing people. As established, MCDHH contracts with 10 Independent Living Centers throughout the State.

All functions and services are carried out in order to enable deaf and hard of hearing individuals to have access to information, services, education, and opportunities which will be equal to those of able-bodied people who hear and which will enable each deaf and hard of hearing individual to live productively and independently while assuming fullest responsibilities as a citizen.

Self-Direction Element	Currently In Place	Future Plans/Hopes
▪ Individual budgets	N/A	
▪ Provision of support broker		
▪ Provision of fiscal intermediary	N/A	
▪ Person-centered planning		X
▪ Consumer involvement in monitoring their services		X Through peer support.
▪ Training of consumers to self-direct		X Interested in collaborating with EOHHS efforts. Especially in arranging for DHH adults to provide parent training – so parents can learn that their children can succeed and be independent.
▪ Consumers hire/fire pay service providers	N/A	
▪ Training of service providers on self-direction		Case managers and particularly interpreters and clinicians
▪ Training and ongoing supervision of case management staff re self-direction		MCDHH case managers could benefit from training on the self-determination terminology.

		MCDHH could play a role in assisting training of staff from other agencies that support people who are deaf.

Brain Injury & Specialized Community Services (BISCS)/SHIP

The Brain Injury and Statewide Specialized Community Services Program (BISSCS) is part of the Community Services of the Massachusetts Rehabilitation Commission. Formerly identified as the Statewide Head Injury Program (SHIP,) BISSCS is the public program in the Commonwealth of Massachusetts that identifies, cultivates and develops resources and services for Massachusetts residents who have sustained an externally caused traumatic brain injury. This has been accomplished since 1985, through training, program development, and program and service coordination activities.

BISSCS has been successful in creating a network of community-based services and supports that assists individuals in maintaining or increasing their level of independence at home, work and in their communities. BISSCS recognizes the significant role that families have in supporting the person who has sustained the brain injury, and their needs have been included in our program development efforts.

BISSCS is a completely state funded program whose budget is determined annually by the state legislature. BISSCS has experienced professionals working with individuals with head injuries and their families to access programs and obtain services necessary for rehabilitation and community life.

Self-Direction Element	Currently In Place	Future Plans/Hopes
▪ Individual budgets		
▪ Provision of support broker	X In some cases State case managers and private case managers perform functions of a support broker.	X
▪ Provision of fiscal intermediary		
▪ Person-centered planning		X
▪ Consumer involvement in monitoring their services	X	X
▪ Training of consumers to self-direct	X Only on an ad hoc basis with some case managers	X
▪ Consumers hire/fire pay service providers		X

▪ Training of service providers on self-direction		X
▪ Training of service provider agency staff including executives, managers, and direct care workers.		X

Appendix G

List of questions Asked of Consumers

- What services do you currently get from the agency you work with?
- What did you do to get your services from the agency you work with?
- Did you get to invite who you want to help plan your services?
- Did you have a say in what you get from the agency? Were you given choices and options?
- Did you get the services you asked for?
- Do you know what services are available?
- Do you have to call someone if you need help or does someone call you?
- What is your understanding of “self-determination” and “self-direction?”
- Do your friends, neighbors, and family give you help when you ask? On a regular basis?
- Is there anything that you would want to change in how your services are planned, arranged and/or provided?

Filename: EDED5BDB
Directory: C:\Users\Hernande\AppData\Local\Microsoft\Windows\Temporary Internet Files\Content.MSO
Template: C:\Users\Hernande\AppData\Roaming\Microsoft\Templates\Normal.dotm
Title: Self Determination in Massachusetts LTC delivery System
Subject:
Author: Preferred Customer
Keywords:
Comments:
Creation Date: 9/5/2014 8:36:00 AM
Change Number: 2
Last Saved On: 9/5/2014 8:36:00 AM
Last Saved By: Victor Hernandez
Total Editing Time: 1 Minute
Last Printed On: 9/5/2014 8:36:00 AM
As of Last Complete Printing
Number of Pages: 65
Number of Words: 21,296 (approx.)
Number of Characters: 121,388 (approx.)