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

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Purpose

- To provide a comprehensive overview of the self-direction delivery system option and its advantages and provide recommendations for the Secretariat regarding the implementation of all components of self-direction throughout the state's long-term care delivery system.

What are Self-Direction and Self-Determination?

- 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.

- Self-determination can be achieved by self-directing one's long-term care services.

What are Self-Direction and 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.
  - The service system is **flexible** so that the individual can tailor his/her supports to meet his/her unique needs.

Key Terminology

- **Fiscal Intermediary:** An independent person, designated agency or company that disburses a person's funds in accordance with their individual budget. They are responsible for:
  - employment-related taxes,
  - payroll for workers and service providers,
  - paying for goods and services incorporated in the individuals' plan,
  - reporting to the individual on spending.
- **Person-Centered Planning:** 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. Person-Centered Planning is a comprehensive strategy for putting necessary services and supports in place to help people achieve their goal. It is driven by the individual, but works best when it includes other people who can contribute valuable information to the process.
- **Person-Centered Thinking:** The fundamental values, principles and concepts which underscores all Person-Centered Planning approaches.

Background

- Since the 1960s, the self-determination movement has worked to provide individuals the choice to receive long-term supports outside institutional settings.

- In the 1990s, self-direction was implemented in many states. The Robert Wood Johnson Foundation's (RWJF) Self-Determination Initiative, the Cash and Counseling Model and Demonstration Project, and CMS's New Freedom Initiative and System Change Grants for Community Living are all examples of funded programs to increase self-direction opportunities.

- In MA in the 1970s, elements of self-determination were implemented through the Personal Care Attendant Program. Other ways in which MA has implemented self-direction include:
  - A RWJF grant to implement a system that gave persons with DD more choice in determining the services they receive.
  - MA Real Choice Flexible Supports and Services pilot allowed participants to decide how to spend a budget allocation to meet their needs.
  - The pending Community First 1115 Demonstration Waiver.
  - Options through EOEA and DMR.

Advantages of Providing the Self-Direction Delivery System Option

- Positive outcomes of self-determination include:
  - reported improved quality of life and, in some studies, improved health;
  - increased use of informal supports;
  - decreased use of overtaxed direct care workforce;
  - increased awareness about the needs of persons with disabilities, an expansion of the network of informal supports and de-stigmatization;
  - increased employment and other activities over utilization of traditional services;
  - Decreased utilization of services in general.

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

- In a system that fully incorporates the principles of self-determination, the following elements usually exist:
  - an enrollment process;
  - a discrete benefit or set of services with a budgeted amount attached;
  - a service planning process that is directed by the individual;
  - support personnel available to help the individual determine how and by who their needs can be met and to help them monitor the services.

Process for Creating Report

- Meetings were held with senior staff at each agency to learn how the agency is implementing programs promoting self-direction and how each agency hopes to expand on and improve these opportunities.
- Research on self-direction was conducted and best practices nationwide were compiled.
- Several small consumer focus group meetings were conducted.
- Additional meetings with senior managers occurred and findings were reviewed and confirmed.
- Broad recommendations were developed with the assistance of the STG Diversion Subcommittee's Financing Workgroup.

What the Core Team Heard in Meetings with the Six State Agencies

- Each agency is different in terms of:
  - who is eligible for services;
  - how case management is provided;
  - the individual service plan process;
  - funding streams;
  - the types of services provided; and
  - the types of services it contracts.
- Each agency shares an interest and commitment to promote opportunities for self-directions.

Department of Mental Health

- DMH identified four general programs areas to develop opportunities for self-direction. These programs are:
  - Day and Employment Services
  - Flexibly Community Supports
  - Transition Age Youth Program
  - 24-hour Residential Services Program
- Next steps include:
  - Training DMH agency staff about self-direction and its key elements.
  - Developing a strategic/action plan as the blueprint for change.

Department of Mental Retardation

- DMR currently has three programs offering self-direction in varying degrees:
  - Self-directed program for adults
  - DMR/DOE Project
  - Autism waiver program
- Their goals include:
  - Increasing awareness among consumers about these opportunities and enabling more to choose the option.
  - Providing consumers and their families the supports and tools necessary for success.

Executive Office of Elder Affairs

- EOEA currently offers opportunities for self-direction through its Home Care Program.
  - 120 individuals are participating at 10 ASAPs and have the ability to hire and fire their own staff, utilize fiscal intermediaries, and participate in person-centered planning.
  - EOEA is committed to expanding the option to elders at all 27 ASAPs; as well as, expanding the scope to provide an individual budget, the supports needed to manage the budget, and the ability to use the budget more flexibly.
- EOEA engaged the services of UMMS/CHPR to develop and conduct trainings on the principles and philosophy of self-direction for groups of staff from all ASAPs.

Massachusetts Commission for the Blind

- MCB identified two program areas for developing opportunities for self-direction:
  - Social Services Program
  - Deaf/Blind Multi-Handicapped Program
- Their goals include:
  - supporting self-direction for high need/high cost consumers in the social services program,
  - developing an infrastructure to support self-direction as an option for everyone receiving residential services,
  - offering self-direction for everyone turning 22.

Massachusetts Commission for the Deaf and Hard of Hearing

- MCDHH does not provide or contract direct care services; however, they are interested in supporting opportunities to self-direct for deaf and hard-of-hearing people. They intend to do this by:
  - training staff from other agencies and ILCs about self-direction and Deaf culture, and
  - providing leadership in training parents with deaf children.

Massachusetts Rehabilitation Commission

- MRC intends to implement self-direction within the Brain Injury and Statewide Community Services (BISSCS) program.
  - Next steps include exploring and implementing models that afford greater flexibility and more choices in how and by whom consumers receive services.
- MRC is also interested in providing self-direction as an option for people receiving residential services.

Recommendations for Advancing Self-Direction in Massachusetts

Recommendations for EOHHS

- EOHHS should issue a policy statement announcing that our delivery systems will promote self-determination and provide multiple options for self-direction.
- EOHHS 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 organizations affiliated with each agency to help build a self-direction focus into cross-agency purchasing efforts.

Recommendations for Advancing Self-Direction in Massachusetts

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

- 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.
- EOHHS should 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.

Conclusion

- There is great excitement to improve the Commonwealth's long-term care system to allow consumers to choose from a spectrum of supports and services, including traditional and non-traditional sources.
- The Secretariat and state agencies are tasked with defining service parameters and implementing activities to increase the availability of self-directed supports and services.
- The Recommendations will assist in these efforts to expand self-direction options in long-term care delivery.