

**DEPARTMENT OF DEVELOPMENTAL SERVICES
REPORT TO GOVERNOR AND LEGISLATURE
Implementation of a Self-Determination Model at the
Department of Developmental Services**

I. Introduction

Chapter 4 of the Resolves of 2008 directed the Commissioner of the Department of Mental Retardation (now known as the Department of Developmental Services or “DDS”) to investigate and study for implementation, a self-determination model for funding services and supports for individuals served by the Department. The model to be studied is to include (a) an individual budget for each individual’s service and support plan; (b) appropriate assistance for each individual to design, implement and control a unique service and support plan; (c) the arrangement of unique services and supports preferred by the individual; and (d) a system of accountability for the use of public funds. A report of the study with recommendations is to be submitted to the Governor and the Legislature by June 30, 2009. (See Appendix A for a copy of the legislation.)

From February through June 2009, the DDS Self-Determination Advisory Committee met to assist the Commissioner with the study and recommendations. The Committee was composed of individuals with first hand knowledge and experience with self-determination models for funding services and supports. They included individuals and families served by the Department, representation from Massachusetts Advocates Standing Strong, Families Organizing for Change, Coalition of Families and Advocates for the Retarded, ARC of Massachusetts, the Department’s Statewide Advisory Council, the Association of Developmental Disabilities Providers, Service Employees International Union and DDS staff. (See Appendix B for a list of the Committee members.)

This report is from the Commissioner of Developmental Services building upon the recommendations from the DDS Self-Determination Advisory Committee on how the Department could address several of the policy, resource and operational challenges discussed in the course of the investigation and study mandated by this legislation.

II. Department of Developmental Services' Policy on Self-Determination

To implement a system of services that supports self-determination, the Self-Determination Advisory Committee members agreed that a common understanding of both self-determination and self-direction shared by individuals, families, provider and state agency staff and others must be established in the first instance.

Towards that end, one of the first and an important step taken by the Department of Developmental Services was the issuance of the Policy on Self-Determination on March 9, 2009. (See Appendix C for a copy of Policy #2009-1.)

As discussed at the Advisory Committee's meetings, self-determination can be described as the fulfillment of individuals with intellectual disabilities' desire to have control over decisions on supports and services, and the freedom to take risks. The principles (in bold) underlying self-determination are the **freedom** of a person to choose where and with whom one lives as well as how one organizes all important aspects of one's life with freely chosen assistance as needed, the **authority** of a person (with a support network or circle, if needed) to control a targeted amount of public dollars in order to purchase services, with the **supports** organized in ways that are unique to the individual, the **responsibility** to use public dollars wisely and to contribute to one's community. Along with freedom and choice is the responsibility of the person to follow and honor the ordinary rules of citizenship and **confirmation** that the person must be a major part of the redesign of the human service system of long-term care.¹ Self-Determination is organized around a set of principles rather than a set of human service interventions or environments. These principles are not human service categories – they are based on each individual receiving supports at a very personal level.

Self-direction, on the other hand, is a vehicle by which an individual can achieve self-determination. Self-direction is an alternative to provider management of services that promotes personal choice and control over an individual's services and how they are delivered. Self-direction in a service delivery system includes features ensuring that: (a) the individual is central to and directs the decision making process that will determine

¹ The basic principles and values of self-determination and self-direction were established with the initial Robert Wood Johnson Foundation grants in the mid-1990's and have been reinforced at the federal and state levels through the President's New Freedom Initiative, the Home and Community Based Waivers and the CMS System Change grants.

what supports are needed; (b) the individual has easy access to information, options, services and supports to enable him or her to self-direct; and (c) the service system is flexible so that the individual can tailor his/her supports to meet his/her unique needs.² Individual budgets, support brokerage and fiscal intermediaries are valuable tools that help people self-direct their services and supports.

The Policy on Self-Determination makes clear that self-determination is a high priority and that the Department is committed to promoting self-determination by expanding opportunities for self-direction in its service delivery system. The expansion will be accomplished by offering to individuals, guardians and families (hereafter referred to collectively as “individuals”) a range of service options where, on one end of the spectrum, they can choose to be served by traditional agency providers through arrangements by the Department; or, they can choose the other end of the spectrum and assume the responsibility and risk of self-directing all aspects of their supports including who to hire and what to buy to meet their support needs; or, they can choose any combination of both options.

These service options will give individuals greater control to decide and direct what supports and services to use, when and where to receive them and from whom. The service options will include assistance designed to help those individuals who wish to self-direct and will be individualized, sensitive and culturally appropriate. They include clinical and functional **assessments, individual-directed, person-centered approach to service planning, circle of support or team** selected by the individual to help him or her meet their goals, **support brokerage services** to help develop and carry out a person-centered service plan, **an individual budget** with a dollar amount for goods, services and supports specified in a service plan that is under the control of the individual, **fiscal intermediary or financial management services** to disburse funds in accordance with the individual’s support plan and individual budget, **recruitment, hiring, training, and firing of direct support professionals and other staff by the**

² This definition was developed by the Massachusetts C-PASS Grant Coordinating Council, January 23, 2007. MA C-PASS was a 3 year federally funded project awarded to the Department of Mental Retardation to demonstrate in Massachusetts consumer directed flexible supports service delivery models to improve the quality of life for persons with disabilities and elders and to enable them to become more fully integrated in the community of choice.

individual, and **training on self-advocacy and consumer choice** of differing levels of authority and responsibility for exercising self-direction.

III. Advancing Self-Determination

There are several major initiatives currently being undertaken by the Department of Developmental Services to advance self-determination. One is the three year Children's Autism Spectrum Disorders Home and Community Based Waiver Program which was implemented in November 2008. This Waiver Program uses a participant directed service model where the parent takes the lead in designing the program and selecting the service providers based on the child's assessed level of need. The others are the participant direction opportunities built into the three proposed Home and Community based Waiver Programs which are scheduled to start in the second half of Fiscal Year 2010.

These Home and Community Based Waiver Programs are federal Medicaid programs³ that help pay for a comprehensive range of home and community services for individuals as alternatives to institutional care. As Medicaid programs, the new Waiver Programs must meet with the following specific program requirements:

- that waiver services provided to a target population is no more costly than the cost of services these individuals would receive in an institution;
- that measures will be taken to protect the health and welfare of consumers;
- that provider standards are adequate and reasonable to meet the needs of the target population; and,
- that the services are provided in accordance with a plan of care.

The Department of Developmental Services is working with our state Medicaid agency in finalizing the home and community based waiver program applications for submission to and approval by the federal Centers for Medicare and Medicaid Services (CMS). Included in the three applications are descriptions of who will be served, what services the state will offer, who will be allowed to provide those services, and how the Department will make sure people are safe and assured of their rights.

For the individuals enrolled in these proposed waivers (hereafter referred to as "waiver participants") who are self-directing their services, they may choose to have

³ Medicaid is a partnership between the states and the federal government. The state and the federal government share the costs of providing services under the Medicaid program.

either or both **employer authority** and **budget authority**. Participant employer authority means the waiver participant is supported to recruit, hire, supervise and discharge workers who provide supports. The waiver participant may function as the common law employer or co-employer of his or her worker. Budget authority means the waiver participant has authority and accepts the responsibility to manage an individual budget and makes decisions about the purchase of goods and services that are authorized in the individual service plan.

The elements for self-direction set forth in the Department's Policy on Self-Determination are, as discussed below, built into the participant direction opportunities in the proposed waivers. These elements are the tools that the Department will put in place to help waiver participants design, implement, and exercise control over their services and supports, including processes for arranging the services and supports preferred by the individual.

Individuals can decide to self-direct their services at any time and will be asked specifically each year at the time of the annual service planning process whether they wish to self-direct if they are not doing so already. The waiver participant's team will assess his or her ability to self-direct and determine what supports will be needed to enable the waiver participant to self-direct. The waiver participants will have the opportunity to choose a DDS service coordinator or a qualified independent agent to provide **support brokerage** services. There will be a **service planning process** that will include the waiver participant, responsible legal representative, DDS service coordinator, clinicians and supporters, as appropriate, support broker if identified at the time, and any other individuals of the participant's choosing. There will be an annual **individual service plan** that will describe the type, frequency, and duration of the waiver services necessary to address the waiver participant's support needs. The waiver participant will be able to direct some or all services that are identified in the specific waiver as allowable for self-direction. The waiver participant will have an **individual budget** that is determined as part of the **person-centered approach to service planning** and is based on the outcome of the assessment of needs, the cost of the selected services and the cost limits and certain service limits specified in the waiver that the participant is enrolled in.

Individuals who choose to have **employer authority** may choose to be the **direct employer** of the workers that provide the waiver services or may use an **agency with choice**. The **agency with choice** is the employer of record for workers hired to provide waiver services with the waiver participant maintaining the ability to select, train, and supervise the workers. The waiver participant may select workers already employed by the agency with choice or may refer prospective workers to the agency with choice for employment. In both arrangements, the waiver participant (and/or family) is responsible for managing the services they choose to direct. Where the waiver participant (and/or family) chooses to be the **direct employer** and hire their own workers (known as the “common law employer”), the waiver participant has the authority to recruit, hire, verify qualifications, determine the worker’s duties, set the worker’s wages and benefits within established guidelines, approve time sheets, provide training and supervision, evaluate the worker’s job performance and terminate the worker’s employment. For waiver participants (and/or families) that choose to be the **direct employer**, they are required to use the **fiscal intermediary or financial management services** (hereafter referred to as “financial management services”). The financial management services would be responsible for providing the fiscal services related to payroll, income and social security tax withholding and state worker compensation taxes of the workers hired by the participant and/or family. The financial management services would also be responsible for processing the Criminal Offense Record Inquiries on the prospective workers to be hired.

Under the proposed waivers, the use of **financial management services** is also required for waiver participants (and/or families) that choose to have **budget authority** and self-direct waiver services that are in the individual service plans.⁴ Under the proposed waivers, once the waiver participant’s service plan and individual budget are complete, the budget is then forwarded to the financial management services for implementation of the service plan and individual budget. The waiver participant decides in what manner and from whom the self-directed waiver services in the service plan will

⁴ Not all waiver services offered in a waiver can be self-directed. For example, participant direction opportunities are available in the Community Living Supports waiver for many waiver covered services such as homemaker services, physical therapy, respite, home modifications, and assistive technology, but are not available for group or center-based day services or day habilitation.

be purchased. The financial management service performs the payment, accounting, and reporting tasks associated with the purchase of waiver services.

Lastly, the proposed waivers include new waiver services, such as **peer support and family training**, which can assist individuals and families to self-direct their services. Peer support is the provision of **training, instruction and mentoring to individuals about self-advocacy, participant direction, civic participation, leadership, benefits and participation in the community. Family training includes the provision of training on family leadership, support of self-advocacy and independence for their family member.** (See Appendix D for a list of the waiver services that can be self-directed.)

IV. Lessons Learned

For over a decade and a half, the Department has incorporated elements of self-direction into parts of its service delivery system and supporting individuals to have greater control over decisions impacting their lives. The experiences gained through the Robert Wood Johnson Foundation Self Determination Grant and the ISO program,⁵ the Family Support Program, the DESE/DDS Program (Department of Elementary and Secondary Education/Department of Developmental Services Program formerly known as the DOE/DMR Program),⁶ the Children's Autism Spectrum Disorder waiver program and the federal Systems Change grants (Real Choice Systems Change grant, Community Integrated Personal Assistance Supports and Services [MASS CPASS] grant and the Person Centered Planning Implementation [MABB-PCP] grant), have created a strong foundation for advancing and expanding self-direction and self-determination through the creation of the proposed waiver programs for individuals and families served by the Department. These programs demonstrate the value and importance of including the elements of self-direction in a service delivery system offering self-directed options.

⁵ The ISO Program is the DDS self-directed program that was first started as a result of the Robert Wood Johnson Foundation grant in 1996 to Massachusetts to develop and implement a Self-Determination approach to supporting people with developmental disabilities. In the ISO program, participants have an individual budget and self-direct their services with the help of service coordinators who serve as support brokers and a fiscal intermediary that provides the financial management services.

⁶ The DESE/DDS (Department of Elementary and Secondary Education/Department of Developmental Services) program helps prevent out of home placement of children with special needs by allowing families to self direct services.

A person-centered approach to service planning is a central element of a self-determination model. Using a more person-centered approach to service planning should be the first step towards self-directing services. The Department has learned that a single strategy is not diverse enough to address the wide range of individual preferences and needs. Individuals of different ages and different cultures (including disability, race, ethnicity, language, creed, gender and income) have markedly different preferences for planning and different levels of control they want to exercise. Plans and priorities change as people age, learn, and change. The planning process is enhanced with the inclusion of a skilled facilitator who is trained in person-centered planning and can apply the principles of self-determination. Goals must be personalized with facilitators helping the individual to identify the steps towards achieving the goals.

The circle of support or team supporting the individual should involve people, in addition to paid staff, who know and care about the individual. Invitations to participate in the planning process should be at the discretion of the individual. There are individuals served by the Department who need assistance in creating a larger circle of supports that can support the hopes and dreams of the individual.

Support brokers are important in helping individuals and families navigate the service system, help them manage their budgets and/or workers, and help them use their funding allocations to get the services and supports to meet their needs. There are service coordinators at the DDS Greater Boston Area Office, Merrimack Valley Area Office and Plymouth Area Office who are currently providing both service coordination and support brokerage services to DDS consumers enrolled in the self directed ISO program. They are a dedicated group of state employed case managers who have been trained on the role of support brokers and how it differs from the role of the service coordinators, and they are managed by area directors and service coordinator supervisors familiar with and supportive of self-direction. They are great examples of service coordinators doing support brokering. Based on these experiences, the Department has built into the proposed waivers the option for waiver participants to select a DDS service coordinator to serve as their support broker.

Individual budgeting enables people needing assistance to have some control over how the funds used for their supports are to be spent. An individual budget gives the

individual the freedom and responsibility to purchase supports from a provider or from any community resources that might be available. To expand self directed support options, there is a need for a policy and process to be established for determining individual budget allocations that are fair, equitable and transparent. There is a need to transition to a more rate based service system to make it easier for individuals and families to purchase goods and services in accordance with their service plan and individual budget.

Fiscal intermediary or financial management services are important to help individuals and families track and monitor individual budgets, perform payroll services and handle their billing and documentation for purchases made in accordance with an individual's service plan in self-directed service models. Experience has taught the Department that the agencies or companies providing the financial management services need to be consumer friendly in responding to the needs of individuals and families in terms of communications and timeliness in paying bills, providing understandable, accurate and regular reports regarding their individual budget and expenditures, and be cost effective in the delivery of the services.

Consumer education and outreach are important to help individuals, guardians and families make an informed decision as to whether greater self-direction is something they want to explore. Experiences through DDS programs, such as the ISO and the DESE/DDS programs, and from other states reveal that more people will choose self-direction as awareness is increased through training and outreach. On-going state and provider staff education and training are important too. Their knowledge and understanding of the underlying principles of self-determination and the elements of self-direction are important in creating the environment and building blocks to advance self-determination and an appreciation of the importance of self-determination in their own lives.

V. Challenges to Advancing Self-Determination

Drawing from the lessons learned from the Department's pilots and programs employing self-direction, the framework and many of the details for operationalizing self-direction have been built into the three new home and community based waiver programs. At this point in time, the challenge facing the Department is how to address

the policy, resource and implementation questions listed below, that will ensure the growth, success and sustainability of self-determination. It was the consensus of the Self-Determination Advisory Committee that this can be best achieved by staying true to the self-determination principles of freedom, authority, support, responsibility and confirmation and the self-determination values of respect, choice, ownership, support and opportunity.

The specific questions that the Department asked the Self-Determination Advisory Committee for advice on included:

1. How can the current Individual Service Planning process become more person-centered?
2. What are the important competencies (experience, knowledge and skill set) that a facilitator of a more person-centered approach to service planning possess?
3. What are the important skills and competencies that support brokers should have to educate and help participants, as needed, to design and manage their self-directed plan and individual budget?
4. When an individual chooses to have budget authority to self-direct services, what are the rules to separate “wants” from “needs?”
5. What should be the methodology for determining individual allocations?
6. What must individuals, families, DDS and provider staff, and the general public understand about self-determination and self-direction?
7. Why is self-advocacy important to self-determination and success of individuals who self-direct their services and supports?
8. What are effective strategies for training and education on self-determination and self-direction?

Throughout the Committee’s discussions, the members understood that the recommendations they offered had to not only reflect the principles and values of self-determination, but also be cognizant of the legal, fiscal and practical constraints to implementing self direction through the proposed waivers.

At the **March 27, 2009** meeting, the Committee tackled the questions of how to make the current Individual Service Plan (ISP) more person-centered; what are important qualities and competencies that support brokers and facilitators should possess; and

whether support brokerage be provided by service coordinators or should support brokers be independent agents? The Committee agreed that the service planning process should be based on the person's view and voice, and that appropriate tools and supports should be in place to help those who wish to self-direct. The Committee recommended that the person facilitating the planning process should have listening skills, speak the language of the individual, embrace the principles and values of self-determination, be able to help individuals balance choice with risk and be able to properly conduct an ISP using a more person-centered approach. The Committee generally supported service coordinators serving as support brokers and understood that the Department is engaged in on-going discussions with the labor union and others on how to expand the number of service coordinators serving as support brokers statewide. The Committee stressed the importance for support brokers to be trained on person-centered planning, given practical instruments to help with thoughtful planning, be able to think outside the box and help the individual build partnerships, and be able to facilitate the abilities of an individual to develop a vision and identify resources to realize the vision. This work means looking at the best value for Department funding and resources, as well as the resources and money the individual and family have to contribute.

At the **April 24, 2009** meeting, the Committee addressed the subjects of individual budget, individual allocation and the question of "want v. need," and employer authority.

The Committee agreed that optimally an individual's allocation should be based on an assessment that is individualized and takes into account the individual's or family's situation. There should be a process for assessing the needed supports and its relationship to resource uses. Standards and criteria should be established over time that will allow for creativity in how resources can be used to assure the goods and services address what is important to the individual while ensuring there is statewide fairness and consistency and minimize cultural and other biases in the decision making. The Committee noted that creating self-directed opportunities would be easier for populations with sources of new funding, such as for Turning 22 individuals and Rolland class members, while acknowledging that the Department is committed to building self-direction opportunities for everyone served by the Department. Using existing funding to

reshape the service delivery system built on individual budgets and allocations is more challenging and will require more deliberate planning to shift the purchase of services system to a rate based system without destabilizing the provider management system or adversely impacting individuals supported in provider managed services where funding is tied to programs slots in contracts. In addition, the Committee believed it was important to emphasize that an allocation is not disposable income for the individual but public resources to be used to meet the individual's services needs. The Committee recognized that where there is a limited pool of funds, the budgeted items should be consistent with established guidelines on individual budgeting. The Committee also noted that the process by which individuals prioritize the goals in their service plans will further define how the individual budget will fund the supports to meet their assessed needs.

The Committee proceeded to discuss the concept of employer authority, specifically with respect to a new tool known as Agency with Choice. The Department plans to issue an RFR for entities interested in becoming an Agency with Choice. The Committee members agreed that education is needed to help individuals and families understand how Agency with Choice can be helpful and education is needed to help providers understand this new business model and how they might build such a business within their organization.

At the **May 22, 2009** meeting, the Committee addressed the topics of education and training for individuals, guardians, families, provider and state staff. There was agreement that these and other stakeholders should be educated and trained on the concepts of self-determination and self-direction, employer authority and budget authority, on a more person-centered approach to service planning, support brokers, financial management services, individual budget, agency with choice and how these concepts are built into the participant direction opportunities offered in the three proposed home and community based waiver programs. The Committee emphasized the importance of getting all stakeholders to understand that self-determination is an evolutionary process that will change the way things are done and change the roles and responsibilities for many. Self- advocacy is important to self-determination insofar as it will help individuals find their voice and have that voice heard in decisions over the substance of their lives, and if they are self-directing, in decisions about their service plan

and individual budget. The Committee believed that DDS and provider staff can support self-advocacy by acknowledging that the service system should create and support opportunities for individuals to experience a variety of different things. Exposure to new experiences will help individuals make more informed decisions about opportunities and service options.

VI. Recommendations for the Self-Determination Model in the Proposed Home and Community Based Waiver Programs

The following recommendations come from the Self-Determination Advisory Committee deliberations and advice shared at the June 12, 2009 meeting on how the Department of Developmental Services can address several of the policy, resource and operational questions remaining to fully implement self-directed options within the three proposed home and community based waivers. The Department adopts these recommendations and will establish an implementation schedule that will be aligned with the Department's plans to submit the three waiver applications to the federal Centers for Medicare and Medicaid Services for approval in the summer of 2009 and to implement in the second half of fiscal year 2010.

A. Design Recommendations Adopted By the Department

1. The Department needs to continue its efforts in developing a plan for increasing support brokerage capacity throughout the state. The Department is committed to expanding the provision of support brokerage services through service coordinators. The Department will work on identifying current service coordinators who are interested in taking on support brokerage functions and will continue the Labor-Management discussions with SEIU (the bargaining unit representing service coordinators) to address the issues of caseload, supervision, support and training and conflict of interest. The Department is also working on strategies for building a roster of independent and qualified support brokers as an alternative to service coordinators that waiver participants can choose to provide the support brokerage services.

2. The Department should continue its efforts to review the current ISP (Individual Service Planning Process) and to consider ways in which it could be made more person-centered. The Department established a workgroup several months ago to study this question and plans to submit to the Commissioner shortly its recommendations for making the ISP more person-centered. The Department is also the recipient of the federal Person-Centered Planning Implementation Grant where person-centered planning tools and processes are being developed that may assist waiver participants, particularly those who are self-directing. It is not contemplated at this time that all waiver participants will be required to use a comprehensive person-centered planning process, however it will be an option. Guidance is under consideration for recommending that the more comprehensive person-centered planning process be used when the individual is experiencing a major life event or going through a transition (e.g. Turning 22 individual leaving the special education system for adult services system). The guidance would include a strong recommendation that there be a circle of support involved to help ensure that the choices and preferences of the individual are respected and strategies are built in the plan to assure the health and safety of the individuals. The person-centered planning tools and manuals developed through the grant have been drafted and are currently being tested in pilots.
3. Over time and in a well planned process, the Department will need to change the way it allocates, disperses and tracks funds. Self-direction in the proposed waivers presents a business model with different rules and processes for allocating funds, paying for services, and developing budgets on an individual basis. Guidance and tools will need to be established for how services are procured, how to determine and track individual allocations, and what assessment methods to use to establish budget ranges for the allocations. The Department has several internal workgroups tackling these items and developing design recommendations for further review and comments by individuals, guardians, families, DDS and provider staff, and other stakeholders. Members of the Self-Determination Advisory Committee, including representatives from ADDP and ARC of Massachusetts have volunteered to join several of these workgroups.

4. The Department has internal workgroups working on recommendations for how to establish or develop rates for the new waiver services that can be self-directed. Questions to be answered include how to assign costs to the services and what are the variables that must be considered. Members of the Self-Determination Advisory Committee, including the ADDP representative have volunteered to join and serve on these workgroups.

B. Implementation Recommendations Adopted by the Department

The Department's plan to operationalize the implementation recommendations described below will reflect the collective thinking of the Self-Determination Advisory Committee that self-direction is a fluid and evolving process and that the people involved (including individuals, guardians, families, caring supporters, support brokers, DDS and provider staff) will be at varied levels of understanding of how a self-determination model is different from a provider managed model that is predominant in the current service delivery system. As a result, the approach and timing of the communications and trainings in the implementation plan will take into account the readiness of the different stakeholders to implement self-direction.

1. Communications Plan - The Self-Determination Advisory Committee members were unanimous in their strong recommendation that a communication plan on self-determination and participant direction opportunities in the proposed waivers be developed and implemented as soon as possible. The Committee noted that there should be regular conversations and discussions with individuals and in groups. The Department should start planning and scheduling initial sessions to introduce the principles underlying self-determination and self-direction to the greater DDS community, and then follow-up with sessions specifically for individuals, guardians and families interested in self-direction where they can learn and develop a deeper understanding of self-directed options available through the Department. In advance of these sessions, the Department must be prepared to answer the question of "How will self-determination and self-directed options affect me?" Literature notes that people are often reluctant to ask such a personal question, but it is an issue that can significantly impact on the willingness of people to participate in changing the service system to one that is

grounded in self-determination and the redesign of the service system to include participant direction opportunities in the three proposed waivers. In addition, there should be manuals, booklets, leaflets and other educational and informational materials to explain self-determination and self-direction including a glossary of the terms and concepts. (There was a suggestion that the term “support budget” rather than “individual budget” be used because the latter created confusion in suggesting by its name that the budget covered not only the funds allocated by the Department for the individual but also the individual’s personal funds). There should also be guidance for DDS and provider staff on how to manage risk and for individuals to understand the risk of taking control of their services and supports. The Committee also strongly urged that the Department publish regular updates with information on the three proposed waivers, a glossary of the terms used in connection with self-determination and self-direction, and personal stories showing in concrete terms how self-direction can work and make a positive difference in people’s lives,

2. DDS Staff Training – Members of the Self-Determination Advisory offered the following recommendations for training of DDS staff.
 - (a) For all DDS staff, and in particular area office staff that include service coordinators and service coordinator supervisors, there should be introductory and on-going training on the subjects of self-determination, self-direction and participant direction in the waivers. In each regional office and area office, consideration should be given to the identification of key personnel as the “go to” resource that DDS staff can access for answers to questions on self-determination, self-direction, and participant direction in the waivers.
 - (b) For the service coordinators and service coordinator supervisors, there should be on-going training and opportunities for peer support that will help them acquire and enhance their knowledge and skills to facilitate a more person-centered planning process and on performing the work of a support broker, including how to work with an individual to develop an individual budget based on the individual’s service plan.

- (c) For the DDS senior management, one of the DDS Commissioner's meetings should be dedicated to the topic of Self-Determination. The meeting would be a forum for consciously communicating a clear message about how the Department and its senior management team will lead the effort for advancing self-determination in the service system with honest discussions on changing rules, roles, responsibilities, and expectations. The language and behavior of senior management in promoting and supporting self-determination are important ingredients to achieving a successful outcome.
 - (d) The Department should create opportunities and vehicles for all DDS staff to share and exchange ideas, problem-solve, and provide support and technical assistance to each other on how to make self-direction work better on an individual and system-wide basis.
3. Provider Staff Training and Assistance – Members of the Self-Determination Advisory Committee offered the following recommendations for training and assistance to the providers.
- (a) The Department, the Association of Developmental Disabilities Providers (ADDP), the ARC of Massachusetts and others should convene provider forums to share and discuss the Department's Policy on Self-Determination, how it will be operationalized, the impact of self-direction on the current purchase of service system, and how the Department will partner and work with the provider community to establish self-directed questions within the service system. Providers with experience with self-direction should be asked to share their stories of the challenges and successes in supporting people who self-direct. Self-advocates from Massachusetts Advocates Standing Strong and representatives from the ARC of Massachusetts should be invited to participate in the forums and share their perspectives.
 - (b) The Department should offer introductory and on-going training to providers and provider staff on the subjects of self-determination, self-direction and participant direction and the related elements of person-centered planning, circle of support and individual budgeting. More specific training should be offered on the business model of "agency with choice," on financial

management services, support brokerage and on the new waiver services, such as, homemaker, chore, individualized home supports, live-in caregiver, and peer support and family training.

- (c) The Department should work with providers to establish a formal structure for the provision of technical assistance that includes help to those interested in changing their business model to offer services supporting individuals who are self-directing.
 - (d) The Department should produce manuals and guidance on self-determination, self-direction and participant direction opportunities in the waiver and what it means for providers.
4. Individuals, Guardians and Family Training and Assistance – Members of the Self-Determination Advisory Committee offered the following recommendations for training and assistance to individuals, guardians and families. In implementing these recommendations, the Department recognizes that self-direction is a fluid and evolving process and
- (a) The Department, Massachusetts Advocates Standing Strong, Massachusetts Families Organizing for Change, the Coalition of Families of the Retarded and the ARC of Massachusetts should collaborate to convene forums and discussion groups where self-determination, self-direction and participant direction opportunities in the proposed waivers are covered, what they mean to individuals, guardians and families are discussed, and where concrete plans for advancing self-determination within the service system are shared. Consideration should be given to inviting the Association of Developmental Disabilities Providers and others to participate and share their perspectives on how providers can partner with all stakeholders to bring about the change.
 - (b) The Department should consider convening an annual conference when fiscal resources permit as well as scheduling regular consumer forums and discussion groups on self-determination and self-direction towards building understanding and support for bringing about system change. These meetings will provide opportunities for individuals, guardians and families to share

information and problem-solve and for the Department to provide updates on its activities towards advancing self-determination within the service system.

- (c) The Department should produce user friendly leaflets and booklets on self-determination, self-direction and participant direction opportunities in the waivers and what it means for individuals, guardians and families. These materials should be produced with the help and input of Massachusetts Advocates Standing Strong, Massachusetts Families Organizing for Change, ARC of Massachusetts and the Coalition of Families for the Retarded.
- 5. The Department should regularly bring stakeholders together in coalitions towards building new partnerships and providing cross-fertilization training on implementing self-directed options.
- 6. The Department should issue solicitations (RFRs) for financial management services, support brokerage services, and agency with choice. These services will need to be in place to support the participant directed options available through the proposed waivers. Prior to issuance, the Department should hold informational sessions to explain what these services are and how they are different.
- 7. The Department should develop information systems to facilitate and support the new work required of DDS staff and providers to implement self-directed options that are offered through the proposed waivers. For self-direction to be realized in the service system, DDS will need additional information technology capabilities to handle the complexities of a self-determination model involving individualized assessments, individual allocations of funds, and individual budgets. The Department is planning to procure with federal funding the additional information technology capabilities that will support the work associated with self-direction in a service system.

Implementation of self-direction will require change in the culture, attitudes, rules, roles, programs, processes and practices of how individuals and families served by the Department can be supported. The core question is whether the Department of Developmental Services is ready to make such changes. The answer is a resounding YES. Starting with the issuance of the Policy on Self-Determination and continuing with

the ongoing work including more participation direction opportunities in the proposed waivers, the Department of Developmental Services has demonstrated its readiness to implement a self-determination model. Over time, everyone served by the Department throughout the Commonwealth of Massachusetts will have the opportunity to choose amongst a range of self-directed options. In a self-determination model, an individual will have many options, including the choice to assume total control of fiscal resources and self direct all their services and supports, the choice to be supported through traditional services, and all options in between.

The Self-Determination Advisory Committee has been invaluable in helping with this study and shaping the recommendations for this report. As we move forward with implementation, the members have accepted the Commissioner's invitation to continue to meet quarterly. The Committee will help evaluate the successes, challenges and progress made by the Department in advancing self-determination and advise on how the systems, processes and tools can be improved to better support self-direction by individuals, guardians, and families.

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