

**Real Lives**

Ms. Clark, Ms. Spilka, Ms. O'Connor Ives and Ms. Chang-Diaz and Mr. Joyce moved that the proposed new text be amended by inserting, after section 24, the following new sections:-

“SECTION XX. Chapter 19B of the General Laws, as appearing in the 2010 Official Edition, is hereby amended by inserting the following three sections:

Section 19. As used in this section, the following words shall have the following meanings:-

(a)“Department”, the Department of Developmental Services.

“Fiscal intermediary”, a financial management service or fiscal intermediary to assist an individual who self-directs in disbursing funds allocated to an individual in their individual budget and in accordance with their person-centered plan. The intermediary shall work at the direction of the individual or an appointed designee identified in the person-centered plan.

“Individual”, an individual eligible to receive services through the Department of Developmental Services.

“Individual budget”, a dollar amount for goods, services and supports specified in the person-centered plan that is under the control and direction of the individual.

“Person-centered plan”, a plan of service for individuals who chose to participate in self-direction.

“Self-determination,” an approach to providing services that underpins a self-direction model of service delivery. Self-determination is based on five principles:

- (1) Freedom, the ability for an individual with disabilities, with chosen family and friends, to plan a life with necessary supports rather than purchase a program;
- (2) Authority, the ability for an individual to control a certain sum of dollars in order to purchase these supports, with the backing of a social network or circle of friends, if needed;
- (3) Support, the arranging of resources and personnel, both formal and informal, to assist an individual to live a life in the community, rich in community associations and contributions, and;
- (4) Responsibility, the acceptance of a valued role in an individual's community through employment, affiliations, spiritual development, and general caring for others, as well as accountability for spending public dollars in ways that are life-enhancing;
- (5) Confirmation, affirming the central role individuals have in leadership and change.

"Self-determination domains", for individuals who choose self-direction these are the domains to be prioritized in their service planning:

- (1) A place to call home with control over anyone who comes through the front door or otherwise provides any services or supports with freely chosen assistance when necessary;
- (2) Economic self-sufficiency through supports or funds as needed provided through jobs, self-employment and active or passive pursuit of private dollars
- (3) Family, friends and other significant relationships of the individual's choosing and receive assistance to develop or maintain these relationships;
- (4) Community membership with real connections to citizens and memberships in vital community organizations.

“Self-direction”, a model of service delivery in which services and supports are person-centered, person-defined and person-controlled. Self-direction in a service delivery system includes features ensuring that:

- (1) the individual is central to and directs the decision making process that will determine which supports are utilized;
- (2) the individual has easy access to information, options, services and supports to enable the individual to self-direct;
- (3) the service system is flexible so that the individual can tailor their support to meet their unique needs.

“Support broker”, a person chosen by an individual participating in self-direction to assist as dictated by the individual in the development and execution of the person-center plan. This role can include but is not limited to adviser, advocate, facilitator and support staff.

(b) The general court finds that people with disabilities have the same rights and responsibilities as other citizens and the Commonwealth must assist them to realize those rights and exercise those responsibilities as contributing members of our communities. Further, the general court finds that services should help people achieve quality outcomes regarding personal choices, satisfaction, social integration and increased learning that may lead to rewarding occupations. In order to increase flexibility and choice of services, the Department shall promote the growth of self-determination through a self-direction model of service delivery for persons receiving services and supports funded through the Department.

(c) The Department shall establish a Self-Determination Advisory Board to evaluate and to advise the Department on efforts to implement self-direction and to participate in educational outreach efforts on self-direction. The Self-Determination Advisory Board shall include individuals participating in self-direction, family members of individuals participating in self-direction, providers, service brokers, and representatives of advocacy organizations, including but not limited to: The Arc of Massachusetts, Massachusetts Developmental Disabilities Council, Massachusetts Families Organizing for Change, Massachusetts Advocates Standing Strong, Advocates for Autism of Massachusetts, Massachusetts Down Syndrome Congress, Disability Law Center and the Association of Developmental Disabilities Providers.

(d) All persons eligible for services through the Department shall be eligible for self-direction, including persons with complex medical or behavioral conditions, persons with profound intellectual impairments and persons eligible for services through special eligibility.

(d) The Department shall provide information about self-direction to all persons eligible for services through the Department. (1) The Department shall provide information about self-direction to a person eligible for services upon: (i) the notification to a person of their priority for services; (ii) the beginning of the development of an individual support plan; (iii) the beginning of the renewal of an individual support plan; (iv) the annual notification of persons who have declined an individual support plan of their option to participate in the individual support plan process. (2) The Department shall encourage individuals entering their Turning 22 program that are prioritized for services to pursue self-direction.

(e)(1)The Department shall publish information on the self-determination concept and self-direction options annually and shall make this information available to the public on the Department's website. (2) The Department shall email information on the self-determination concept and self-direction options annually to any organization or interested party that agrees to forward or post the information on their website and who provides their email address.

Organizations include: The Arc of Massachusetts, Massachusetts Developmental Disabilities Council, Massachusetts Families Organizing for Change, Massachusetts Advocates Standing Strong, Advocates for Autism of Massachusetts, Massachusetts Down Syndrome Congress, Disability Law Center and the Association of Developmental Disabilities Providers. (3) The Department, in collaboration with the advocacy organizations represented on the Self-Determination Advisory Council, shall hold educational forums with families and individuals to provide information about self-direction no less than four times annually in each service region.

(f) The Department, in collaboration with the advocacy organizations represented on the Self-Determination Advisory Council, shall hold meetings annually with providers to discuss self-direction, how providers can participate, what it means to the present purchase of service system, and how the Department can work with providers to establish self-directed choices within the service system. The Department shall work with providers to help those interested in changing their business model to offer services supporting persons who choose to self-direct. The Department may offer introductory and on-going training to providers and provider staff on the subjects of self-determination, self-direction and the related elements of person-centered planning and individual budgeting.

(g)The Department shall educate all staff, except for staff classified as janitorial, maintenance, or secretarial, on self-direction not less than two times annually.

(g) For individuals who choose self-direction, the Department shall implement a person-centered planning process. The individual shall direct the development of the person-centered plan and shall direct who is involved in the planning process. The person-centered plan shall be designed around the self-determination domains.

(h) Individuals who choose to self-direct shall receive an allocation of resources based on their assessed needs. The amount of allocation and development of an individual budget shall be determined through a person-centered plan. The Department shall determine an individual's prioritization for services and the amount allocated for an individual's services in a transparent manner. The individual or a legal representative designated by the individual shall be able to utilize resources allocated to them through the individual budget to choose which services and supports best serve the individual's needs and are consistent with meeting goals developed in line with the self-determination domains.

(i)(1) Individuals who choose to self-direct shall have access to a support broker to assist in the development of a plan of service and an individual budget in the person-centered planning process, to assist in the purchase of services and to assist in monitoring expenditures through the year. The support broker shall be made available through the Department or through a qualified private sector broker of the individual's choice. (ii) The Department shall establish basic competencies that must be met in order to qualify private sector or public sector support brokers in consultation with the Self-Determination Advisory Board. (2) Individuals who choose to self-direct shall have access to a state-designated or other qualified fiscal intermediary of the individual's choice to assist in the execution of the purchase of services. (3) If an individual chooses to utilize a private sector support broker, an allocation for the purchase of this service shall be included in the individual's budget. If an individual chooses to utilize a private sector fiscal intermediary, an allocation for the purchase of this service shall be included in the individual's budget.

(j) Providers and employees providing services to individuals through self-direction shall be eligible for a proportional amount of any additional appropriation designated for the increase of salary for workers employed by the Department or its providers.

(k) Individuals who choose to self-direct shall be surveyed at least once annually about their experiences with self-direction and potential improvements to the self-direction model and its overall operation.

(l) The Department shall provide an annual report, after consultation with the Self-Determination Advisory Board, to the Joint Committee on Children, Families, and Persons with Disabilities documenting progress in terms of numbers served through self-direction, ongoing improvements to the Department's self-direction program and challenges related to the Department's self-direction programs. The annual report shall include an analysis of the annual survey of individuals participating in self-direction mandated in section K and strategies to address the issues identified in these surveys.

(m) The Department shall utilize the Home and Community Based Waivers to maximize federal reimbursement for services rendered through self-direction and related models. As necessary, the Department and Executive Office of Health and Human Services shall amend the waiver and take any other steps to ensure that activities or services can be implemented to achieve goals under self-determination domains for individuals.

Section 20. (a) The Department shall establish a contingency fund to assist: (1) Individuals in need of services; (2) Individuals who participate or wish to participate in self-direction or self-determination; (3) Individuals with unanticipated, emergency or changing needs; (4) In the case of an individual who chooses to leave a group living arrangement, in order to mitigate impact to providers. (b) The fund shall be comprised of 40% of the savings from the closure of Monson, Glavin and Templeton and other funds as they may be available within the Department's budget and at its discretion. The Department shall make every effort to ensure that the pool will retain sufficient funds for individuals utilizing self-determination and provider mitigation throughout the fiscal year. (c) The Department shall develop a policy related to the fund for individuals utilizing self-direction with the assistance of the Self-Determination Advisory Board.

Section 21. (a) Individuals and their guardians shall have choice of Department services or qualified providers and shall be free to change the individual's services or service provider. When an individual or their guardian requests a change, the Department shall initiate the process for requested changes without delay.

(b) Upon an individual or their guardian requesting a change of service or service provider for their group residence or group living situation, the individual or their guardian and the provider shall take steps to see if a resolution to the situation can be reached. If, at any time, the individual feels that a resolution to the situation cannot be reached, the individual or their guardian can request that the following provision be initiated within 7 days of the individual or their guardian notifying the Department: (1) The Department shall assist the individual in developing an alternative living situation, both the Department and the individual will make a good faith effort to determine a suitable alternative; (2) The Department shall work in conjunction with the individual to transfer to an available alternative as expeditiously as possible and taking no longer than 90 days; (3) As necessary, the Department will work with the provider

of the residence or group living situation to ensure stability including the use of the contingency fund for mitigation established in Chapter 19B, Section 20.

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