

HOUSE No. 4167

The committee on Health Care Financing, reports, on House, No. 984, Bill to encourage responsibility, cost effectiveness and meaningful lives for individuals with disabilities (House, No. 4167). June 13, 2012. Steven M. Walsh, for the committee.

The Commonwealth of Massachusetts

In the Year Two Thousand Twelve

An Act to encourage responsibility, cost effectiveness and meaningful lives for individuals with disabilities.

1 Whereas, people with disabilities have the same rights and responsibilities as other citizens and
2 the Commonwealth must assist them to realize those rights and exercise those responsibilities as
3 contributing members of our communities;

4 Whereas, services should help people achieve quality outcomes regarding personal choices,
5 satisfaction, social integration and increased learning that may lead to rewarding occupations;

6 Whereas, the needs of the Commonwealth's citizens warrant increased flexibility and choice of
7 services;

8 Whereas, this body has previously endorsed providing opportunity for self-determination for
9 people with disabilities and their families through the provision of public services, supports, and
10 funding;

11 Whereas, self-determination is based on five principles: (1) FREEDOM, the ability for an
12 individual with disabilities, with chosen family and friends, to plan a life with necessary supports
13 rather than purchase a program; (2) AUTHORITY, the ability for an individual to control a

14 certain sum of dollars in order to purchase these supports, with the backing of a social network or
15 circle of friends, if needed; (3) SUPPORT, the arranging of resources and personnel, both formal
16 and informal, to assist an individual to live a life in the community, rich in community
17 associations and contributions, and; (4) RESPONSIBILITY, the acceptance of a valued role in
18 an individual's community through employment, affiliations, spiritual development, and general
19 caring for others, as well as accountability for spending public dollars in ways that are life-
20 enhancing; (5) CONFIRMATION, affirming the central role individuals have in leadership and
21 change;

22 Be it enacted by the Senate and House of Representatives in General Court assembled, and by
23 the authority of the same, as follows:

24 SECTION 1: Chapter 19B of the General Laws, as so appearing, is hereby amended by inserting
25 the following 3 sections:

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

27 (a) "Department", the Department of Disability Services.

28 "Fiscal intermediary", a financial management service or fiscal intermediary to assist an
29 individual who self-directs in disbursing funds allocated to an individual in their individual
30 budget at the individual's direction and in accordance with their person centered plan.

31 "Individual", an individual eligible to receive services through the Department of Disability
32 Services.

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

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

38 (1) the individual is central to and directs the decision making process that will determine which
39 supports are utilized;

40 (2) the individual has easy access to information, options, services and supports to enable the
41 individual to self-direct;

42 (3) the service system is flexible so that the individual can tailor their support to meet their
43 unique needs.

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

46 “Self determination domains”, for individuals who chose self-direction these are the domains to
47 be prioritized in their service planning:

48 (1) A place to call home with control over anyone who comes through the front door or
49 otherwise provides any services or supports with freely chosen assistance when necessary;

50 (2) Economic self-sufficiency through supports or funds as needed provided through jobs, self-
51 employment and active or passive pursuit of private dollars

52 (3) Family, friends and other significant relationships of the individual’s choosing and receive
53 assistance to develop or maintain these relationships;

54 (4)Community membership with real connections to citizens and memberships in vital
55 community organizations.

56 “Individual budget”, an allocation of resources determined through a person centered plan for the
57 purchase of goods, services and supports that is under the control of the individual.

58

59 (b) The Department shall promote the growth of self determination through a self-direction
60 model of service delivery for persons receiving services and supports funded through the
61 Department.

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

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

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

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

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

94 (f) The Department, in collaboration with the advocacy organizations represented on the Self-
95 Determination Advisory Council, shall hold meetings annually with providers to discuss self-
96 direction, how providers can participate, what it means to the present purchase of service system,

97 and how the Department can work with providers to establish self-directed choices within the
98 service system. The Department shall work with providers to help those interested in changing
99 their business model to offer services supporting persons who chose to self-direct. The
100 Department may offer introductory and on-going training to providers and provider staff on the
101 subjects of self-determination, self-direction and the related elements of person-centered
102 planning and individual budgeting.

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

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

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

117 (i)(1)(i)Individuals who chose to self-direct shall have access to a service broker to assist in the
118 development of a plan of service and a individual budget in the person centered planning

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

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

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

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

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

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

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

160 (b) Upon an individual or their guardian requesting a change of service or service provider for
161 their group residence of group living situation, the individual or their guardian and the provider
162 shall take steps to see if a resolution to the situation can be reached. If, at any time, the individual

163 feels that a resolution to the situation cannot be reached, the individual or their guardian can
164 request that the following provision be initiated within 7 days of the individual or their guardian
165 notifying the Department: (1) The Department shall assist the individual in developing an
166 alternative living situation, both the Department and the individual will make a good faith effort
167 to determine a suitable alternative; (2) The Department shall work in conjunction with the
168 individual to transfer to an available alternative; (3) As necessary, the Department will work with
169 the provider of the residence or group living situation to ensure stability including the use of the
170 contingency fund for mitigation established in Chapter 19B, Section 20.