

# **HOUSE . . . . . No. 4151**

---

---

## The Commonwealth of Massachusetts

---

HOUSE OF REPRESENTATIVES, June 9, 2014.

The committee on Health Care Financing to whom was referred the Bill relative to real lives (House, No. 4063), reports recommending that the bill ought to pass with an amendment substituting therefor the accompanying bill (House, No. 4151) [Fiscal Note: Greater than \$100,000.00].

For the committee,

JENNIFER E. BENSON.

**The Commonwealth of Massachusetts**

\_\_\_\_\_  
**In the Year Two Thousand Fourteen**  
\_\_\_\_\_

An Act relative to real lives.

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

1 Chapter 19B of the General Laws, as appearing in the 2010 Official Edition, is  
2 hereby amended by inserting the following three sections:

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

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

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

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

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

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

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

19 (1) Freedom, the ability for an individual with disabilities, with chosen family  
20 and friends, to plan a life with necessary supports rather than purchase a program;

21 (2) Authority, the ability for an individual to control a certain sum of dollars in  
22 order to purchase these supports, with the backing of a social network or circle of friends, if  
23 needed;

24 (3) Support, the arranging of resources and personnel, both formal and informal,  
25 to assist an individual to live a life in the community, rich in community associations and  
26 contributions, and;

27 (4) Responsibility, the acceptance of a valued role in an individual's community  
28 through employment, affiliations, spiritual development, and general caring for others, as well as  
29 accountability for spending public dollars in ways that are life-enhancing;

30 (5) Confirmation, affirming the central role individuals have in leadership and  
31 change.

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

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

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

39 (3) Family, friends and other significant relationships of the individual's  
40 choosing and receive assistance to develop or maintain these relationships;

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

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

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

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

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

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

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

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

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

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

83 (e)(1) The Department shall publish information on the self-determination  
84 concept and self-direction options annually and shall make this information available to the  
85 public on the Department’s website. (2) The Department shall email information on the self-  
86 determination concept and self-direction options annually to any organization or interested party  
87 that agrees to forward or post the information on their website and who provides their email  
88 address. Organizations include: The Arc of Massachusetts, Massachusetts Developmental

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

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

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

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

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

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

126 individual's choice to assist in the execution of the purchase of services. (3) If an individual  
127 chooses to utilize a private sector support broker, an allocation for the purchase of this service  
128 shall be included in the individual's budget. If an individual chooses to utilize a private sector  
129 fiscal intermediary, an allocation for the purchase of this service shall be included in the  
130 individual's budget.

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

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

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

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

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

160 Section 21. (a) Individuals and their guardians shall have choice of Department  
161 services or qualified providers and shall be free to change the individual's services or service

162 provider. When an individual or their guardian requests a change, the Department shall initiate  
163 the process for requested changes without delay.

164 (b) Upon an individual or their guardian requesting a change of service or  
165 service provider for their group residence or group living situation, the individual or their  
166 guardian and the provider shall take steps to see if a resolution to the situation can be reached. If,  
167 at any time, the individual feels that a resolution to the situation cannot be reached, the individual  
168 or their guardian can request that the following provision be initiated within 7 days of the  
169 individual or their guardian notifying the Department: (1) The Department shall assist the  
170 individual in developing an alternative living situation, both the Department and the individual  
171 will make a good faith effort to determine a suitable alternative; (2) The Department shall work  
172 in conjunction with the individual to transfer to an available alternative as expeditiously as  
173 possible and taking no longer than 90 days; (3) As necessary, the Department will work with the  
174 provider of the residence or group living situation to ensure stability including the use of the  
175 contingency fund for mitigation established in Chapter 19B, Section 20.

176 to utilize a private sector support broker, an allocation for the purchase of this  
177 service shall be included in the individual's budget. If an individual chooses to utilize a private  
178 sector fiscal intermediary, an allocation for the purchase of this service shall be included in the  
179 individual's budget.

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

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

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

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

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

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

213 (b) Upon an individual or their guardian requesting a change of service or  
214 service provider for their group residence or group living situation, the individual or their  
215 guardian and the provider shall take steps to see if a resolution to the situation can be reached. If,  
216 at any time, the individual feels that a resolution to the situation cannot be reached, the individual  
217 or their guardian can request that the following provision be initiated within 7 days of the  
218 individual or their guardian notifying the Department: (1) The Department shall assist the  
219 individual in developing an alternative living situation, both the Department and the individual  
220 will make a good faith effort to determine a suitable alternative; (2) The Department shall work  
221 in conjunction with the individual to transfer to an available alternative as expeditiously as  
222 possible and taking no longer than 90 days; (3) As necessary, the Department will work with the  
223 provider of the residence or group living situation to ensure stability including the use of the  
224 contingency fund for mitigation established in Chapter 19B, Section 20.