

HOUSE No. 151

The Commonwealth of Massachusetts

PRESENTED BY:

Tom Sannicandro and Katherine M. Clark

To the Honorable Senate and House of Representatives of the Commonwealth of Massachusetts in General Court assembled:

The undersigned legislators and/or citizens respectfully petition for the passage of the accompanying bill:

An Act relative to real lives.

PETITION OF:

NAME:	DISTRICT/ADDRESS:
<i>Tom Sannicandro</i>	<i>7th Middlesex</i>
<i>Katherine M. Clark</i>	<i>Fifth Middlesex</i>
<i>Kimberly N. Ferguson</i>	<i>1st Worcester</i>
<i>Paul Brodeur</i>	<i>32nd Middlesex</i>
<i>Denise Andrews</i>	<i>2nd Franklin</i>
<i>James Arciero</i>	<i>2nd Middlesex</i>
<i>Cory Atkins</i>	<i>14th Middlesex</i>
<i>Bruce J. Ayers</i>	<i>1st Norfolk</i>
<i>Ruth B. Balsler</i>	<i>12th Middlesex</i>
<i>F. Jay Barrows</i>	<i>1st Bristol</i>
<i>Matthew A. Beaton</i>	<i>11th Worcester</i>
<i>Jennifer E. Benson</i>	<i>37th Middlesex</i>
<i>John J. Binienda</i>	<i>17th Worcester</i>
<i>Michael D. Brady</i>	<i>9th Plymouth</i>
<i>William N. Brownsberger</i>	<i>Second Suffolk and Middlesex</i>
<i>Antonio F. D. Cabral</i>	<i>13th Bristol</i>
<i>Thomas J. Calter</i>	<i>12th Plymouth</i>
<i>Christine E. Canavan</i>	<i>10th Plymouth</i>

<i>James M. Cantwell</i>	<i>4th Plymouth</i>
<i>Gailanne M. Cariddi</i>	<i>1st Berkshire</i>
<i>Tackey Chan</i>	<i>2nd Norfolk</i>
<i>Sonia Chang-Diaz</i>	<i>Second Suffolk</i>
<i>Thomas P. Conroy</i>	<i>13th Middlesex</i>
<i>Michael A. Costello</i>	<i>1st Essex</i>
<i>Sean Curran</i>	<i>9th Hampden</i>
<i>Mark J. Cusack</i>	<i>5th Norfolk</i>
<i>Josh S. Cutler</i>	<i>6th Plymouth</i>
<i>Marjorie C. Decker</i>	<i>25th Middlesex</i>
<i>Viriato Manuel deMacedo</i>	<i>1st Plymouth</i>
<i>Sal N. DiDomenico</i>	<i>Middlesex and Suffolk</i>
<i>Geoff Diehl</i>	<i>7th Plymouth</i>
<i>Stephen L. DiNatale</i>	<i>3rd Worcester</i>
<i>Diana DiZoglio</i>	<i>14th Essex</i>
<i>Paul J. Donato</i>	<i>35th Middlesex</i>
<i>James J. Dwyer</i>	<i>30th Middlesex</i>
<i>Carolyn C. Dykema</i>	<i>8th Middlesex</i>
<i>Lori A. Ehrlich</i>	<i>8th Essex</i>
<i>James B. Eldridge</i>	<i>Middlesex and Worcester</i>
<i>Tricia Farley-Bouvier</i>	<i>3rd Berkshire</i>
<i>Robert F. Fennell</i>	<i>10th Essex</i>
<i>John V. Fernandes</i>	<i>10th Worcester</i>
<i>Ann-Margaret Ferrante</i>	<i>5th Essex</i>
<i>Michael J. Finn</i>	<i>6th Hampden</i>
<i>Jennifer L. Flanagan</i>	<i>Worcester and Middlesex</i>
<i>William C. Galvin</i>	<i>6th Norfolk</i>
<i>Paul K. Frost</i>	<i>7th Worcester</i>
<i>Sean Garballey</i>	<i>23rd Middlesex</i>
<i>Denise C. Garlick</i>	<i>13th Norfolk</i>
<i>Kenneth I. Gordon</i>	<i>21st Middlesex</i>
<i>Danielle W. Gregoire</i>	<i>4th Middlesex</i>
<i>Patricia A. Haddad</i>	<i>5th Bristol</i>
<i>Sheila C. Harrington</i>	<i>1st Middlesex</i>
<i>Jonathan Hecht</i>	<i>29th Middlesex</i>
<i>Paul R. Heroux</i>	<i>2nd Bristol</i>
<i>Bradford Hill</i>	<i>4th Essex</i>
<i>Kate Hogan</i>	<i>3rd Middlesex</i>
<i>Kevin G. Honan</i>	<i>17th Suffolk</i>

<i>Donald F. Humason, Jr.</i>	<i>4th Hampden</i>
<i>Bradley H. Jones, Jr.</i>	<i>20th Middlesex</i>
<i>Brian A. Joyce</i>	<i>Norfolk, Bristol and Plymouth</i>
<i>Louis L. Kafka</i>	<i>8th Norfolk</i>
<i>Jay R. Kaufman</i>	<i>15th Middlesex</i>
<i>Mary S. Keefe</i>	<i>15th Worcester</i>
<i>John D. Keenan</i>	<i>7th Essex</i>
<i>Kay Khan</i>	<i>11th Middlesex</i>
<i>Robert M. Koczera</i>	<i>11th Bristol</i>
<i>John J. Lawn, Jr.</i>	<i>10th Middlesex</i>
<i>Jason M. Lewis</i>	<i>31st Middlesex</i>
<i>David Paul Linsky</i>	<i>5th Middlesex</i>
<i>James J. Lyons, Jr.</i>	<i>18th Essex</i>
<i>Timothy R. Madden</i>	<i>Barnstable, Dukes and Nantucket</i>
<i>John J. Mahoney</i>	<i>13th Worcester</i>
<i>Elizabeth A. Malia</i>	<i>11th Suffolk</i>
<i>Brian R. Mannel</i>	<i>2nd Barnstable</i>
<i>Paul W. Mark</i>	<i>2nd Berkshire</i>
<i>Christopher M. Markey</i>	<i>9th Bristol</i>
<i>Paul McMurtry</i>	<i>11th Norfolk</i>
<i>James R. Miceli</i>	<i>19th Middlesex</i>
<i>Leonard Mirra</i>	<i>2nd Essex</i>
<i>Michael O. Moore</i>	<i>Second Worcester</i>
<i>James M. Murphy</i>	<i>4th Norfolk</i>
<i>Kevin J. Murphy</i>	<i>18th Middlesex</i>
<i>Harold P. Naughton, Jr.</i>	<i>12th Worcester</i>
<i>Rhonda Nyman</i>	<i>5th Plymouth</i>
<i>Shaunna O'Connell</i>	<i>3rd Bristol</i>
<i>Kathleen O'Connor Ives</i>	<i>First Essex</i>
<i>James J. O'Day</i>	<i>14th Worcester</i>
<i>Eugene L. O'Flaherty</i>	<i>2nd Suffolk</i>
<i>Jerald A. Parisella</i>	<i>6th Essex</i>
<i>Sarah K. Peake</i>	<i>4th Barnstable</i>
<i>Alice Hanlon Peisch</i>	<i>14th Norfolk</i>
<i>William Smitty Pignatelli</i>	<i>4th Berkshire</i>
<i>Elizabeth A. Poirier</i>	<i>14th Bristol</i>
<i>Denise Provost</i>	<i>27th Middlesex</i>
<i>Angelo J. Puppolo, Jr.</i>	<i>12th Hampden</i>
<i>David M. Rogers</i>	<i>24th Middlesex</i>

<i>Dennis A. Rosa</i>	<i>4th Worcester</i>
<i>Jeffrey N. Roy</i>	<i>10th Norfolk</i>
<i>Jeffrey Sánchez</i>	<i>15th Suffolk</i>
<i>Paul A. Schmid, III</i>	<i>8th Bristol</i>
<i>John W. Scibak</i>	<i>2nd Hampshire</i>
<i>Carl M. Sciortino, Jr.</i>	<i>34th Middlesex</i>
<i>Theodore C. Speliotis</i>	<i>13th Essex</i>
<i>Karen E. Spilka</i>	<i>Second Middlesex and Norfolk</i>
<i>Thomas M. Stanley</i>	<i>9th Middlesex</i>
<i>Ellen Story</i>	<i>3rd Hampshire</i>
<i>William M. Straus</i>	<i>10th Bristol</i>
<i>Benjamin Swan</i>	<i>11th Hampden</i>
<i>James E. Timilty</i>	<i>Bristol and Norfolk</i>
<i>Timothy J. Toomey, Jr.</i>	<i>26th Middlesex</i>
<i>Cleon H. Turner</i>	<i>1st Barnstable</i>
<i>Chris Walsh</i>	<i>6th Middlesex</i>
<i>Martin J. Walsh</i>	<i>13th Suffolk</i>
<i>Daniel A. Wolf</i>	<i>Cape and Islands</i>
<i>Jonathan D. Zlotnik</i>	<i>2nd Worcester</i>

HOUSE No. 151

By Mr. Sannicandro of Ashland and Senator Clark, a joint petition (accompanied by bill, House, No. 151) of Tom Sannicandro and others for legislation to assist people with disabilities in realizing their rights and exercising their responsibilities. Children, Families and Persons with Disabilities.

The Commonwealth of Massachusetts

In the Year Two Thousand Thirteen

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

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

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

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

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

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

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

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

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

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

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

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

27 (4) Responsibility, the acceptance of a valued role in an individual’s community through
28 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 change.

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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