

SENATE No. 2640

The Commonwealth of Massachusetts

—
**In the One Hundred and Ninety-Third General Court
(2023-2024)**
—

SENATE, March 14, 2024.

The committee on Financial Services, to whom was referred the petitions (accompanied by bill, Senate, No. 678) of Liz Miranda and Lydia Edwards for legislation to improve sickle cell care, report the accompanying bill (Senate, No. 2640).

For the committee,
Paul R. Feeney

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An Act to improve sickle cell care.

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

1 SECTION 1. (a)(1) Notwithstanding any general or special law to the contrary, there is
2 hereby established a Statewide Steering Committee on Sickle Cell Disease within the department
3 of public health.

4 (2) The Steering Committee under this section shall consist of:

5 (A) two representatives from the Massachusetts Sickle Cell Disease Association
6 including the Executive Director or their designee;

7 (B) three medical professionals from major Sickle Cell Disease treatment centers in the
8 commonwealth who shall be appointed by the commissioner;

9 (C) the Executive Director of the Massachusetts Association of Community Health
10 Workers or their designee;

11 (D) the President of the Massachusetts Chapter of the National Association of Social
12 Workers or their designee;

13 (E) two members who shall be appointed by the commissioner, one of whom shall be an
14 expert on the biology of the disease, and one of whom shall be an expert on the psycho-social
15 aspect of the disease;

16 (F) two representatives of the department of elementary and secondary education who
17 shall be appointed by the commissioner, including one of whom is knowledgeable about the right
18 to comparable education, supportive services and accommodations under section 504 of the
19 Rehabilitation Act of 1973;

20 (G) one representative of the Black and Latino Caucus who shall be appointed by the
21 commissioner;

22 (H) one representative of the Asian Caucus who shall be appointed by the commissioner;

23 (I) two sickle cell disease patients who shall be appointed by the Governor, one of which
24 shall be over 25 years in age and the other shall be between 18 and 25 years in age;

25 (J) a parent of a minor child with sickle cell disease who shall be appointed by the
26 Governor;

27 (K) a parent of a secondary or post-secondary school age youth with sickle cell disease
28 who shall be appointed by the commissioner; and

29 (L) one representative who has a background in racial health disparities who shall be
30 appointed by the Governor.

31 The representatives of nongovernmental organizations shall serve staggered 3-year
32 terms. Vacancies of unexpired terms shall be filled within 60 days by the appropriate appointing
33 authority.

34 (3) The Steering Committee under this section shall:

35 (A) establish institution and community partnerships, including hospitals, and institutions
36 of higher education;

37 (B) establish a statewide network of stakeholders, including parents, home health care
38 providers, school-based nurses, and the Massachusetts Sickle Cell Disease Association who are
39 committed to care for individuals with sickle cell disease collaboratively in an inclusive setting;

40 (C) establish a statewide network of racially and culturally competent stakeholders who
41 include general and special education administrators and teachers and paraprofessionals;

42 (D) oversee the development of educational materials for individuals with sickle cell
43 disease, the public, and health care providers about the assistance available to such individuals in
44 the commonwealth, including local school district responsibilities for care of such individuals;

45 (E) identify funding sources for implementing or supporting the actions, studies, policies
46 required by federal and state laws and regulations, or recommended by the Steering Committee,
47 including funding from:

48 (i) state, federal, and local government sources; and

49 (ii) private sources;

50 (F) investigate and report on a standard of basic, multidisciplinary care for patients across
51 the commonwealth; and

52 (G) establish subcommittees as appropriate.

53 (4) The department may, in consultation with the Statewide Steering Committee, provide
54 services relating to sickle cell disease, including:

55 (A) educational programs on sickle cell disease for individuals affected by the disease,
56 including:

57 (i) education on the rights of individuals with sickle cell disease, such as, without
58 limitation, the right not to be discriminated against and the right to receive appropriate
59 educational programming, health related services and accommodations necessary to access such
60 programming and services;

61 (ii) expectations, options, and responsibilities of families of individuals with sickle cell
62 disease;

63 (iii) challenges and responsibilities of caregivers of individuals with sickle cell disease;

64 (iv) obligations of employees at primary and secondary schools; and

65 (v) challenges and responsibilities of health care providers;

66 (B) social services support to individuals with sickle cell disease, including support from
67 social workers and community health workers to provide information on services that may be
68 available to the individual;

69 (C) hemoglobin electrophoresis or genetic testing for the presence of sickle cell disease;

70 (D) genetic counseling;

71 (E) assistance with any available reimbursement for medical expenses related to sickle
72 cell disease;

73 (F) education and counseling services for parents and other family members and
74 caretakers after the receipt of sickle cell trait test results from the Newborn Screening Program as
75 required by section 270.006(A)(2)(e) of chapter 105, Code of Massachusetts Regulations,
76 provided that, with the consent of parents and other family members and caretakers, such
77 services may be provided in whole or in part by the Massachusetts Sickle Cell Disease
78 Association; and

79 (G) any other programs or services that are necessary to decrease the use of acute care
80 services by individuals who have sickle cell disease.

81 (5) The department shall, in consultation with any other agency of the commonwealth as
82 the department determines appropriate, provide the services in paragraph (4) through
83 community-based organizations, including specifically, pre-K, elementary and secondary
84 schools as well as institutions for higher education for all affected school-age children, youth,
85 and older students to the extent practicable.

86 (6) The Steering Committee, in conjunction with the department and other relevant
87 stakeholders, shall study and make recommendations on:

88 (A) how to enhance access to services for individuals with sickle cell disease with a focus
89 on areas in the commonwealth where there is a statistically high number of individuals with
90 sickle cell disease or in areas where there is a lack of providers with expertise in treating sickle
91 cell disease;

92 (B) whether to establish a sickle cell disease registry, and if recommended, the process
93 and guidelines for establishing a registry and obtaining information consistent with informed
94 consent and protecting data privacy;

95 (C) how to enhance the coordination of health care services for individuals with sickle
96 cell disease who are transitioning from pediatric to adult health care, including the identification
97 of available resources for individuals who are transitioning; and

98 (D) how to engage with community-based health fairs and other community-sponsored
99 events in areas with a statistically high number of individuals with sickle cell disease to provide
100 outreach and education on living with sickle cell disease and how to access health care services.

101 (b) The department shall, in consultation with the Steering Committee, establish and
102 implement a system that provides information on the sickle cell trait to any individual who has
103 the sickle cell trait and, if the individual is a minor, to the individual's family.

104 (c) The department shall include the following in the information provided under
105 subsection (b):

106 (1) how the sickle cell trait impacts the health of an individual with the trait;

107 (2) how the sickle cell trait is passed from a parent to a child; and

108 (3) implications for pregnancy.

109 (d) The department shall maintain in a conspicuous location on its website a list of
110 resources for health care practitioners to use to improve their understanding and clinical
111 treatment of individuals with sickle cell disease or the sickle cell trait, including information on
112 the health impacts of carrying the sickle cell trait.

113 (e) For the purposes of this section, the following word shall, unless the context clearly
114 requires otherwise, have the following meaning:-

115 “Steering Committee”, the Statewide Steering Committee on Sickle Cell Disease.

116 SECTION 2. (a) Notwithstanding any general or special law to the contrary, there is
117 hereby established within the department of public health the sickle cell disease detection and
118 education program to: (1) promote screening and detection of sickle cell disease, especially
119 among unserved or underserved populations; (2) educate the public regarding sickle cell disease
120 and the benefits of early detection; and (3) provide counseling and referral services.

121 (b) The program under this section shall include:

122 (1) establishment of a statewide public education and outreach campaign to publicize
123 evidence-based sickle cell disease screening, detection and education services. The campaign
124 shall include: general community education, outreach to specific underserved populations,
125 evidence based clinical sickle cell disease screening services, and an informational summary that
126 shall include an explanation of the importance of clinical examinations and what to expect during
127 clinical examinations and sickle cell disease screening services;

128 (2) provision of grants to approved organizations pursuant to subsection (c) and for
129 community based organizations pursuant to subsection (d);

130 (3) compilation of data concerning the program and dissemination of such data to the
131 public; and

132 (4) development of health care professional education programs including the benefits of
133 early detection of sickle cell disease and clinical examinations, the recommended frequency of
134 clinical examinations and sickle cell disease screening services, and professionally recognized
135 best practices guidelines.

136 (c)(1) Under the program, the commissioner of public health shall make grants in
137 amounts appropriated to approved organizations for the provision of services relating to the
138 evidence-based screening and detection of sickle cell disease as part of this program. The
139 services required to be provided under such grants shall include:

140 (A) promotion and provision of early detection of sickle cell disease, including clinical
141 examinations and sickle cell disease screening services;

142 (B) provision of counseling and information on treatment options and referral for
143 appropriate medical treatment;

144 (C) dissemination of information to unserved and underserved populations as determined
145 by the commissioner, to the general public and to health care professionals concerning sickle cell
146 disease, the benefits of early detection and treatment, and the availability of sickle cell disease
147 screening services at no cost to such populations;

148 (D) identification of local sickle cell disease screening services within the approved
149 organization's region;

150 (E) provision of information, counseling and referral services to individuals diagnosed
151 with sickle cell disease; and

152 (F) provision of information regarding the availability of medical assistance, including
153 medical assistance for an individual who is eligible for such assistance pursuant to section 9 of
154 chapter 118E of the General Laws, to an individual who requires treatment for sickle cell
155 disease.

156 (2) The commissioner shall give notice and provide opportunity to submit applications
157 for grants under the program. In order to be considered for a grant, an applicant must show
158 evidence of the following, relating to the services the applicant proposes to provide:

159 (A) ability to provide and to ensure consistent and quality services under the program;

160 (B) expertise in providing the service;

161 (C) capacity to coordinate services with physicians, hospitals and other appropriate local
162 institutions or agencies;

163 (D) ability to provide the service to unserved or underserved populations; and

164 (E) ability to provide the service in accordance with the standards specified in
165 subdivision three of this section.

166 Applications shall be made on forms provided by the commissioner.

167 (3) The commissioner shall develop standards for the implementation of grants under the
168 program by approved organizations, which shall ensure the following:

169 (A) integration of the approved organization with existing health care providers;

170 (B) maximizing third party reimbursement; and

171 (C) provision of services to unserved or underserved populations.

172 (4) Within the amounts of state or federal funds appropriated for the program, approved
173 organizations may be authorized by the department to provide such services for populations

174 served under this title. Services may include evidence based screening, patient education,
175 counseling, follow-up and referral.

176 (5) Every organization receiving grants under this subsection shall submit to the
177 commissioner, on or before October first of each year, a report of such organization's activities,
178 including an assessment of the organization's programs and such data as the commissioner deems
179 relevant and necessary to accomplish the purposes of the program

180 (d)(1) Under the program, the commissioner shall make grants within amounts
181 appropriated for community based organizations to provide post-diagnosis counseling, education
182 and outreach programs for persons diagnosed with sickle cell disease based upon criteria to be
183 developed by the commissioner.

184 (2) The commissioner shall provide notice and opportunity for community-based
185 organizations to submit applications to provide post-diagnosis sickle cell disease counseling,
186 education and outreach programs. Such applications shall be on forms established by the
187 commissioner.

188 (e) The commissioner shall submit, on or before December first of each year, an annual
189 report to the governor and the legislature concerning the operation of the program. The reports
190 shall include the experience of the program in providing services under this act. The annual
191 report shall include strategies for implementation of the sickle cell disease awareness program
192 and for promoting the awareness program to the general public, state and local elected officials,
193 and various public and private organizations, associations, businesses, industries, and agencies.
194 Organizations receiving grants under this act shall provide data and assessments as the

195 commissioner may require for the report. The report shall include any recommendations for
196 additional action to respond to the incidence of sickle cell disease in the commonwealth.

197 (f) For the purposes of this section, the following words shall, unless the context clearly
198 requires otherwise, have the following meanings:-

199 “Community-based organizations”, free-standing organizations in which sickle cell
200 disease survivors hold significant decision-making responsibility, and which offer a broad range
201 of sickle cell disease education and support services free of charge.

202 “Program”, sickle cell disease detection and education program.

203 “Unserved or underserved populations”, people having inadequate access and financial
204 resources to obtain sickle cell disease screening and detection services, including people who
205 lack health coverage or whose health coverage is inadequate or who cannot meet the financial
206 requirements of their coverage for accessing detection services.

207 SECTION 3. (a)(1) Notwithstanding any general or special law to the contrary, the
208 commissioner of public health or designee shall, in accordance with regulations adopted by the
209 department of public health pursuant to subsection (b), and in consultation with the
210 Massachusetts Sickle Cell Disease Association, establish and maintain a system for the reporting
211 of information on sickle cell disease and its variants. Said system shall include a record of the
212 cases of sickle cell disease and its variants which occur in the commonwealth along with such
213 information concerning the cases as may be appropriate to form the basis for: (A) conducting
214 comprehensive epidemiologic surveys of sickle cell disease and its variants in the
215 commonwealth; and (B) evaluating the appropriateness of measures for the treatment of sickle
216 cell disease and its variants.

217 (2) Hospitals, medical laboratories, and other facilities that provide screening, diagnostic
218 or therapeutic services to patients with respect to sickle cell disease and its variants shall report
219 the information prescribed by the regulation promulgated pursuant to subsection (b).

220 (3) Any provider of health care who diagnoses or provides treatment for sickle cell
221 disease and its variants, except for cases directly referred to the provider or cases that have been
222 previously admitted to a hospital, medical laboratory or other facility described in paragraph (2),
223 shall report the information prescribed by the regulation adopted pursuant to subsection (b).

224 (b) The department of public health shall, by regulation:

225 (1) prescribe the form and manner in which information on cases of sickle cell disease
226 and its variants must be reported in compliance with any applicable federal privacy law;

227 (2) prescribe the information that must be included in each report, which must include,
228 without limitation: (A) the name, address, age and ethnicity of the patient; (B) the variant of
229 sickle cell disease with which the person has been diagnosed; (C) the method of treatment; (D)
230 any other diseases from which the patient suffers; (E) information concerning the usage of and
231 access to health care services by the patient; and (F) if a patient diagnosed with sickle cell
232 disease and its variants dies, his or her age at death and cause of death; and

233 (3) establish a protocol for allowing appropriate access to and preserving the
234 confidentiality of the records of patients needed for research into sickle cell disease and its
235 variants;

236 (4) establish a protocol for allowing information, in accordance with the preceding
237 subsections, to be communicated with Statewide Steering Committee on Sickle Cell Disease, the

238 sickle cell disease services program, and within the department as determined appropriate by the
239 commissioner.

240 (c) The chief administrative officer of each health care facility in the commonwealth shall
241 make available to the commissioner or designee the records of the health care facility for each
242 case of sickle cell disease and its variants. The department of public health shall abstract from
243 the records of a health care facility or shall require a health care facility to abstract from its own
244 records such information as is required by regulations promulgated pursuant to subsection (b).
245 The department shall compile the information in a timely manner and not later than 6 months
246 after receipt of the abstracted information from the health care facility. The department shall by
247 regulation adopt a schedule of fees which must be assessed to a health care facility for each case
248 from which information is abstracted by the department. Any person who violates this section is
249 subject to an administrative penalty established by regulation by the department.

250 (d) The department shall publish reports based upon the information obtained pursuant to
251 subsections (a), (b), and (c) and shall make other appropriate uses of the information to report
252 and assess trends in the usage of and access to health care services by patients with sickle cell
253 disease and its variants in a particular area or population, advance research and education
254 concerning sickle cell disease and its variants and improve treatment of sickle cell disease and its
255 variants and associated disorders. The reports must include, without limitation:

256 (1) information concerning the locations in which patients diagnosed with sickle cell
257 disease and its variants reside, the demographics of such patients and the utilization of health
258 care services by such patients;

259 (2) the information described in paragraph (1), specific to patients diagnosed with sickle
260 cell disease and its variants who are over 60 years of age or less than 5 years of age; and

261 (3) information on the transition of patients diagnosed with sickle cell disease and its
262 variants from pediatric to adult care upon reaching 18 years of age.

263 (e) The department shall provide any qualified researcher whom the department
264 determines is conducting valid scientific research with data from the reported information upon
265 the researcher's: (1) compliance with appropriate conditions as established under the regulations
266 of the department; and (2) payment of a fee established by the department by regulation to cover
267 the cost of providing the data.

268 (f) The commissioner or designee shall analyze the information obtained pursuant to
269 subsections (a), (b) and (c) and the reports published pursuant to subsection (d) to determine
270 whether any trends exist in the usage of and access to health care services by patients with sickle
271 cell disease and its variants in a particular area or population.

272 (g) If the commissioner or designee determines that a trend exists in the usage of and
273 access to health care services by patients with sickle cell disease and its variants in a particular
274 area or population, the commissioner or designee shall work with appropriate governmental,
275 educational and research entities to investigate the trend, advance research in the trend and
276 facilitate the treatment of sickle cell disease and its variants and associated disorders.

277 (h) The department shall not reveal the identity of any patient, physician, or health care
278 facility which is involved in any reporting required by this section unless the patient, physician
279 or health care facility gives prior written consent to such a disclosure. A person or governmental
280 entity that provides information to the department pursuant to this section shall not be held liable

281 in a civil or criminal action for sharing confidential information unless the person or organization
282 has done so in bad faith or with malicious purpose.

283 (i) For the purposes of this section, the following words shall, unless the context clearly
284 requires otherwise, have the following meanings:-

285 “Sickle cell disease and its variants”, an inherited disease caused by a mutation in a gene
286 for hemoglobin in which red blood cells have an abnormal crescent shape that causes them to
287 block small blood cells and die sooner than normal.

288 SECTION 4. (a)(1) Notwithstanding any general or special law to the contrary, if a
289 newborn screening for hereditary disorders performed pursuant to section 270.006(A)(2)(e) of
290 chapter 105, Code of Massachusetts Regulations detects the presence of sickle cell trait, the
291 laboratory performing the screening shall notify the physician responsible for the newborn’s care
292 and shall document the patient’s information in the central registry established pursuant to
293 paragraph (2) in a manner and on forms prescribed by the department of public health.

294 (2) The physician responsible for such newborn’s care shall provide the patient’s parents
295 with information concerning the availability, benefits, and role of genetic counseling performed
296 by a genetic counselor licensed pursuant to section 253 of chapter 112 of the General Laws,
297 including a document available in multiple languages (as determined by the department) that
298 identifies at least 10 genetic counselors and the public health care payers and private health care
299 payers which contract with each such genetic counselor. In the case a physician described in the
300 preceding sentence is not identified, the laboratory described in paragraph (1) shall provide the
301 patient’s parents with such information relating to genetic counseling. Genetic counseling
302 concerning a diagnosis of sickle cell trait shall include, but not be limited to, information

303 concerning the fact that one or both of the parents carries sickle cell trait and the risk that other
304 children born to the parents may carry sickle cell trait or may be born with sickle cell disease.

305 (b)(1) The commissioner of public health shall establish a central registry of patients
306 diagnosed with sickle cell trait. The information in the central registry shall be used for the
307 purposes of compiling statistical information and assisting the provision of follow-up counseling,
308 intervention, and educational services to patients and to the parents of patients who are listed in
309 the registry including, but not limited to, information concerning the availability and benefits of
310 genetic counseling performed by a genetic counselor licensed pursuant to section 253 of chapter
311 112 of the General Laws.

312 (2) The commissioner shall establish a system to notify the parents of patients who are
313 listed in the registry that follow-up consultations with a physician are recommended for children
314 diagnosed with sickle cell trait. Such notifications shall be provided: at least once when the
315 patient is in early adolescence, when the patient may begin to participate in strenuous athletic
316 activities that could result in adverse symptoms for a person with sickle cell trait; at least once
317 during later adolescence, when the patient should be made aware of the reproductive
318 implications of sickle cell trait; and at such other intervals as the commissioner may require.

319 (3) The commissioner shall establish a system under which the department shall make
320 reasonable efforts to notify patients listed in the registry who reach the age of 18 years of the
321 patient's inclusion in the registry and of the availability of educational services, genetic
322 counseling, and other resources that may be beneficial to the patient.

323 (4) Information on newborn infants and their families compiled pursuant to this section
324 may be used by the department and agencies designated by the commissioner of public health for

325 the purposes of carrying out this act, but otherwise the information shall not be a public record
326 and shall be confidential and not divulged or made public so as to disclose the identity of any
327 person to whom it relates, except as exempted or consented in accordance with section 10 of
328 chapter 66 or section 70G of chapter 111 of the General Laws, respectively.

329 SECTION 5. (a) Notwithstanding any general or special law to the contrary, the division
330 of medical assistance shall ensure the availability of accessible, quality health care for
331 individuals with sickle cell disease who are enrolled in Medicaid managed care organizations or
332 accountable care organizations that have a contract with the division to provide services to
333 individuals enrolled under MassHealth pursuant to section 9 of chapter 118E of the General
334 Laws. Such health care shall include, but not be limited to the following:

335 (1) comprehensive integrated care management for sickle cell disease, including primary
336 care, specialized care, and mental health services;

337 (2) sickle cell trait testing and genetic counseling;

338 (3) social work services as well as education on disease management to patients,
339 caregivers, and providers; and

340 (4) support navigating health insurance coverage and support with transportation to
341 treatment centers.

342 (b) Not later than the fiscal year 2024 contract year, the division of medical assistance
343 shall require Medicaid managed care or accountable care organizations to implement a sickle cell
344 disease quality strategy for children and adults with sickle cell disease that includes, but is not
345 limited to, the following components:

346 (1) measurable goals to improve the identification of members with sickle cell disease
347 within 90 days after enrolling in the contracted health plan;

348 (2) to the extent practicable, adequate provider network capacity to ensure timely access
349 to sickle cell disease specialty service providers, including, but not limited to, hematologists;

350 (3) care coordination strategies and supports to help members with sickle cell disease
351 access sickle cell disease specialists and other related care supports;

352 (4) delivery of a training curriculum approved by the division of medical assistance to
353 educate primary care providers on sickle cell disease, including information on emergency
354 warning signs and complications, evidence-based practices and treatment guidelines, and when
355 to make referrals to specialty sickle cell disease treatment providers; and

356 (5) in the case of an individual who is diagnosed with sick cell disease, exceptions to
357 otherwise applicable prior authorization or dispensing limits for pain medications that are
358 designed to reduce barriers for such an individual to be able to obtain the appropriate dosage and
359 amount of a pain medication in a timely manner.

360 (c) The division of medical assistance shall also do the following:

361 (1) Not later than the fiscal year 2025 contract year, require each Medicaid managed care
362 organization and accountable care organization to report, on a quarterly basis, an unduplicated
363 count of children and adults identified as having sickle cell disease enrolled with the contracted
364 plan during the quarter. The department shall publish these reports, by contracted plan, on the
365 department's website.

366 (2) Not later than January 1, 2025, and in partnership with Medicaid managed care
367 organizations and accountable care organizations, identify, document, and share best practices
368 regarding sickle cell disease care management and care coordination with Medicaid-enrolled
369 primary care and sickle cell disease specialty providers with a goal of improving services for
370 members with sickle cell disease and their families.

371 (3) Enter into a contract not later than January 1, 2025, with a publicly funded university
372 to develop a sickle cell disease-focused comprehensive assessment tool or a supplement to an
373 existing comprehensive assessment tool to screen members identified with sickle cell disease for
374 comorbidities, medical history for the treatment of sickle cell disease including disease-
375 modifying medications and pain management, psychosocial history, barriers to accessing or
376 completing treatments, social supports, other care coordinators working with the member,
377 community resources being used or needed, quality of life, and personal preferences for
378 engagement with a care coordinator.

379 (4) Not later than the fiscal year 2025 contract year, establish performance measures
380 relative to access to care and available therapies, engagement in treatment, and outcomes for
381 individuals with sickle cell disease, with the metrics to be reported annually by the
382 comprehensive health care program to Medicaid managed care organizations and accountable
383 care organizations and with incentive payments attached to the measures.

384 (5) Not later than January 1, 2025, develop a plan for improving the transition from
385 pediatric care to adult care for adolescents with sickle cell disease who are aging out of the
386 Medicaid program, and a plan for helping qualified beneficiaries maintain Medicaid coverage
387 under another eligibility category, in order to maintain continuity of care.

388 (d) The division of medical assistance shall provide an annual sickle cell disease
389 management and accountability report to the senate and house committees on ways and means,
390 including the status of sickle cell disease-focused access to care, quality of services, health
391 outcomes, and disparities in the commonwealth.

392 (e) The division of medical assistance shall incorporate the sickle cell disease
393 management and accountability standards into its contracts with managed care plans and
394 accountable care organizations, including financial or administrative penalties for lack of
395 performance. Contracted plan rates must be adjusted to reflect enhanced care or other provisions
396 that are shifted to the contracted plans.