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MODEL LEGISLATION

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AN ACT RELATING TO THE RECOGNITION OF
A SUPPORTED HEALTH CARE DECISION-MAKING AGREEMENT
FOR ADULTS WITH DISABILITIES

1 **Sec. 1. SHORT TITLE.**

2 This act may be cited as the Supported Health Care Decision-Making Agreement Act.

3 **Sec. 2. DEFINITIONS.**

4 (a) “Adult” means anyone who has reached 18 years of age;

5 (b) “Disability” means a physical or mental impairment that substantially limits one or more
6 major life activities of such individual;

7 (c) “Health care” means

8 (1) Any examination, diagnosis, procedure, therapy, or treatment undertaken to prevent
9 or manage any disease, illness, ailment or physical or mental health condition,

10 (2) Any procedure undertaken for the purpose of an examination or a diagnosis,

11 (3) Any medical, surgical, obstetrical, psychiatric, or dental treatment,

12 (4) Anything done that is ancillary to any examination, diagnosis, procedure or
13 treatment,

14 (5) Palliative care,

15 (6) And a treatment plan;

16 (d) “Supported Health Care Decision-Making” means supports and services that help an adult
17 with a disability make his or her own health care decisions, including assistance monitoring health,
18 obtaining, scheduling, and coordinating health services, understanding health care information and
19 options, making decisions with respect to health care, and communicating those decisions to
20 others;

21 (e) “Supported Health Care Decision-Making Agreement” is an agreement between an adult
22 with a disability and a supporter or supporters entered into under this act;

23 (f) “Supporter” means an individual who:

24 (1) Is 18 years of age or older, and

25 (2) Does not have a conflict of interest included in Section 4.

26 **Sec. 3. PURPOSE.**

27 The purpose of this Act is to create an alternative to guardianship, maximize autonomy, and improve
28 health care outcomes for adults with disabilities by permitting adults with disabilities to name supporters

29 to help them understand health-related information and options so they can make their own health care
30 decisions.

31 **Sec. 4. CONFLICT OF INTEREST.**

32 The following individuals are considered to have a conflict of interest that disqualifies them from being
33 appointed or serving as a supporter in a supported health care decision-making agreement:

- 34 (a) A person who has a financial interest in a lawsuit concerning or affecting the adult with a
35 disability;
- 36 (b) A person who has filed a pending petition for guardianship or conservatorship over the
37 adult with a disability, when the adult with a disability was not previously subject to guardianship
38 or conservatorship by that person, unless the person withdraws the petition;
- 39 (c) A person who is indebted to the adult with a disability;
- 40 (d) A person asserting a claim adverse to the adult’s real or personal property;
- 41 (e) A person or an immediate family member of a person who provides personal care or health
42 care services to the adult with a disability for compensation, with the exception of a person who
43 provides independent living or home health services to the adult with a disability in a home- and
44 community-based setting, as defined at 42 C.F.R. § 441.301(b)(4), that is not a provider-owned or
45 controlled residential setting as set forth at 42 C.F.R. § 441.301(b)(4)(vi);
- 46 (f) A person or a relative of a person who is an employee of a nursing home, group home, or
47 other facility in which the adult with a disability resides and through which the adult receives care
48 or health care services. “Facility” shall not include a home- or community-based setting, as defined
49 at 42 C.F.R. § 441.301(b)(4), that is not a provider-owned or controlled residential setting as set
50 forth at 42 C.F.R. § 441.301(b)(4)(vi).

51 **Sec. 5. SCOPE OF SUPPORTED HEALTH CARE DECISION-MAKING AGREEMENT.**

52 (a) In a supported health care decision-making agreement, an adult with a disability may
53 voluntarily, without undue influence or coercion, authorize his or her supporter or supporters to do
54 any or all of the following:

- 55 (1) To access, collect, or obtain or assist the adult in accessing, collecting or obtaining
56 any information that is relevant to pending or future health care decision(s) from any person
57 including, but not limited to, medical, psychological, financial, educational, or treatment

- 58 records or research, as the adult’s personal representative pursuant to the Health Insurance
59 Portability and Accountability Act (HIPAA), 42 C.F.R. § 164.502;
- 60 (2) To assist the adult with a disability in understanding that information;
- 61 (3) To assist the adult with a disability in understanding the options, responsibilities
62 and consequences of the health care decision(s) to be made so the adult can make his or
63 her own decision(s); and
- 64 (4) To communicate or to assist the adult in communicating his or her decisions to
65 other persons, including health care providers.
- 66 (b) A supporter may assist the adult with a disability in understanding the options,
67 responsibilities and consequences in order to make health care appointments and to make major
68 and minor health care decisions, but is not authorized to make such decisions on behalf of the adult
69 with a disability or to exert undue influence over the person’s decision-making. The supporter
70 must ensure that the decision reflects the adult’s preferences and/or expressed interests, even if the
71 supporter feels that the adult’s decision is not in his or her best interests.
- 72 (c) The following form is known as a “supported health care decision-making agreement.” An
73 adult with a disability may use a supported health care decision-making agreement to name a
74 supporter and grant some or all of the authority set out in this chapter to that supporter. A supported
75 health care decision-making agreement in substantially the following form demonstrates the intent
76 of the adult with a disability to enter into a supported health care decision-making agreement with
77 the supporter and has the meaning and effect prescribed by this subchapter. The following form is
78 not exclusive, and other forms of supported health care decision-making agreements may be used
79 so long as they demonstrate the adult’s intent to enter into a such an agreement, name a supporter
80 and grant some or all of the authority set out in this chapter to that supporter:

81

SUPPORTED HEALTH CARE DECISION-MAKING AGREEMENT

82 **Notice of Rights: to be read aloud or otherwise communicated, in the presence of the notary,**
83 **to all parties to the agreement. The form of communication shall be appropriate to the needs of the**
84 **individual with the disability, including that individual’s language and sensory processing wants or**
85 **needs.**

86

This is a form that you can use to appoint a person to help you make health care decisions.

88

89 You have the right to make your own health care decisions and the right to decide who helps you
90 make those decisions. If you do not want the person named in this form to help you make health care
91 decisions, you do not have to sign this agreement.

92

93 If you sign this agreement, you still have the right to make the final decision about your health
94 care. Your health care supporter cannot force you to accept health care that you do not want, or take away
95 health care that you do want.

96

You can add another supporter by signing a new form appointing the other supporter.

98

99 You can cancel this agreement at any time. You can cancel this agreement in writing or by
100 otherwise making it clear to the supporter that you want the agreement to be canceled.

101

102

103

104

105

Appointment of Supporter

106

107 I, _____ (insert your name), agree that:

108

Name:

109

Address:

110

Phone Number:

111

112 is my supporter.

113

114

Authority of Supporter

115

116 My supporter has my permission to do the following things, except for the ones I have crossed out:

117

118 1. Access or obtain any information that will help me make health care decisions, including, but not
119 limited to, medical, psychological, financial, educational, or treatment records or research, as my
120 personal representative under the Health Insurance Portability and Accountability Act (HIPAA), 42
C.F.R. § 164.502;

121

122 2. Help me access or obtain any information that will help me make health care decisions, including,
but not limited to, medical, psychological, financial, educational, or treatment records or research;

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- 123 3. Help me make appointments with doctors, dentists, therapists, case managers, or other health care
- 124 providers;
- 125 4. Help me keep track of information about my health care, including my medical records, and
- 126 whether I have had recommended medical check-ups, tests and vaccines;
- 127 5. Help me with my health care plan, including, but not limited to, taking medications, monitoring
- 128 blood sugar, administering insulin, and refilling prescriptions;
- 129 6. Help me understand information about health care decisions I have to make, now or in the future,
- 130 so that I can make my own decisions about my health care;
- 131 7. Communicate or assist me in communicating my decision to other persons.
- 132

133 I DO DO NOT give my supporter permission to talk to doctors when I am not present or when I am

134 temporarily unable to communicate.

135

136 I DO DO NOT give my supporter permission to access psychotherapy notes or other information

137 about conversations I have had during mental health counseling, substance abuse counseling, or group or

138 family therapy.

139

140 This agreement does not give my supporter the authority to make decisions about my health care for me,

141 or to influence me to make decisions that do not reflect my expressed wishes and preferences. My

142 supporter's consent to providing or withholding treatment is not a substitute for my consent.

143

144 **Additional Authority or Limitations**

145

146 ON THE FOLLOWING LINES YOU MAY GIVE SPECIAL INSTRUCTIONS LIMITING OR

147 ADDING TO THE RIGHTS GRANTED TO YOUR SUPPORTER.

148

149 _____

150 _____

151 _____

152 _____

153 _____

154 _____

155 **Effective Date of Supported Health Care Decision-Making Agreement**

156

157 This agreement takes effect:

158 Immediately

159 On the following date: _____

160

161 This agreement ends:

162 When I cancel it

163 On the following date: _____

164

165

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166 ___ When the following event happens: _____
167

168 **Third Party Rights Under the Supported Health Care Decision-Making Agreement**
169

170 I agree that anyone who receives a copy of this document may act consistent with it and respect
171 my supporter's authority to help me make my own health care decisions, except when that person has
172 actual notice that I have cancelled this agreement or want to cancel it.
173

174 **Successor Supporter**
175

176 If my supporter dies, becomes unable to act as my supporter, resigns as my supporter, or refuses
177 to act as my supporter, I want the following person to become my supporter:
178

179 Name:

180 Address:

181 Phone Number:
182

183 **Consent of Supporter**
184

185 **I consent to act as a supporter.**
186

187 (signature of supporter)

(printed name of supporter)

189 **Signature**
190

191 (your signature)

(your printed name)

192 (witness signature)

(printed name of witness)

193 Signed this _____ day of _____, 20____
194

195 (your signature)

196 State of _____
197

County of _____

198 **This document was acknowledged before me on**
199

200 _____ (date) by _____
201



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(name of adult with a disability)

(signature of notary)

(seal, if any, of notary)

(printed name)

My commission expires: _____

WARNING: PROTECTION FOR THE ADULT WITH A DISABILITY

IF A PERSON WHO RECEIVES A COPY OR IS AWARE OF THE SUPPORTED HEALTH CARE DECISION-MAKING AGREEMENT HAS REASON TO BELIEVE THAT THE ADULT WITH A DISABILITY IS SUFFERING FROM ABUSE, NEGLECT, OR EXPLOITATION CAUSED BY THE SUPPORTER, THE PERSON MAY REPORT THE ALLEGED ABUSE, NEGLECT OR EXPLOITATION TO THE [DEPARTMENT OF FAMILY AND PROTECTIVE SERVICES] BY CALLING THE ABUSE HOTLINE AT _____ OR BY EMAIL AT _____.

212 **Sec. 6. DURATION AND EXERCISE OF SUPPORTED HEALTH CARE DECISION-MAKING**
213 **AGREEMENT.**

214 (a) A supporter may exercise the authority granted to the supporter in the supported health care
215 decision-making agreement.

216 (b) The supported health care decision-making agreement shall extend until terminated by
217 either party, until the expiration date or event specified in the agreement, or until it is terminated
218 pursuant to Section 11(b)(2) of this Chapter.

219 (c) Execution of a new supported health care decision-making agreement shall not operate to
220 revoke any prior health care decision-making agreements unless so specified in the new supported
221 health care decision-making agreement.

222 **Sec. 7. ACCESS TO PERSONAL INFORMATION.**

223 (a) A supporter who is authorized to access, collect, or obtain or assist the adult with a
224 disability in accessing, collecting, or obtaining information that is relevant to a decision referred
225 to in a supported health care decision-making agreement is entitled to access, collect, or obtain any
226 relevant information about the adult with a disability from any person, that is relevant to the
227 decision, as that adult's personal representative under the Health Insurance Portability and
228 Accountability Act (HIPAA), 42 C.F.R. § 164.502.

229 (b) A public or private entity, a custodian, or organization may disclose personal information
230 about an adult with a disability, to a supporter who is authorized under a supported health care
231 decision-making agreement to access, collect, or obtain or assist the adult with a disability in
232 accessing, collecting, or obtaining the information.

233 (c) No public or private entity, custodian, or organization shall require an adult with a
234 disability to complete a separate HIPAA release form or other authorization form prior to
235 disclosing personal information about an adult with a disability to a supporter who is authorized
236 under a supported health care decision-making agreement to access, collect, or obtain or assist the
237 adult with a disability in accessing, collecting, or obtaining the information.

238 (d) Where a supporter accesses, collects, or obtains personal information about an adult with
239 a disability under this section, the supporter

240 (1) May use and disclose the information only for the purpose of exercising the
241 authority granted to the supporter in the supported health care decision-making agreement,
242 and

243 (2) Shall take reasonable care to ensure the information is kept privileged and
244 confidential from unauthorized access, use, or disclosure.

245 (e) A supporter shall not attempt to access, collect, or obtain personal information about the
246 adult with a disability under this section from a public or private entity, custodian, or organization
247 other than the personal information that the supporter is entitled to access, collect, or obtain under
248 the supported health care decision-making agreement.

249 **Sec. 8. IMMUNITY FROM SUIT FOR HEALTH CARE PROVIDERS WHO ACT**
250 **CONSISTENTLY WITH A SUPPORTED HEALTH CARE DECISION-MAKING**
251 **AGREEMENT.**

252 (a) Any health care provider that respects and acts consistently with the authority given to a
253 supporter by a duly executed supported health care decision-making agreement, shall be immune
254 from any action alleging that the agreement was invalid unless the entity, custodian or organization
255 had actual knowledge or notice that the adult had revoked such authorization, that the agreement
256 was invalid, or that the supporter had committed abuse, neglect, or exploitation as described in
257 Section 11 of this Act.

258 (b) Any health care provider that provides health care based on the consent of a person with a
259 disability, made with supports and services provided through a duly executed supported health
260 care decision-making agreement, shall be immune from any action alleging that the person with a
261 disability lacked capacity to provide informed consent unless the entity, custodian or organization
262 had actual knowledge or notice that the adult had revoked such authorization, that the agreement
263 was invalid, or that the supporter had committed abuse, neglect, or exploitation as described in
264 Section 11 of this Act.

265 (c) Any public or private entity, custodian, or organization that discloses personal information
266 about an adult with a disability to a supporter who is authorized to access, collect, or obtain or
267 assist the adult with a disability in accessing, collecting or obtaining that information shall be
268 immune from any action alleging that it improperly or unlawfully disclosed such information to

269 the supporter unless the entity, custodian or organization had actual knowledge that the adult had
270 revoked such authorization.

271 (d) This Section shall not be construed to provide immunity from actions alleging that a health
272 care provider:

273 (1) Caused personal injury as a result of a negligent, reckless, or intentional act;

274 (2) Acted inconsistently with the expressed wishes of a person with a disability;

275 (3) Failed to provide information to either a person with a disability or his or her health
276 care supporter that would be necessary for informed consent; or

277 (4) Otherwise acted inconsistently with applicable law.

278 (e) The existence or availability of a supported decision-making agreement shall not relieve a
279 health care provider of any legal obligation to provide services to individuals with disabilities,
280 including the obligation to provide reasonable accommodations or auxiliary aids and services,
281 including interpretation services and communication supports, to individuals with disabilities
282 under the Americans with Disabilities Act, 42 U.S.C. § 12182 *et seq.*

283 **Sec. 9. FORM, SIGNING, AND WITNESSING OF SUPPORTED HEALTH CARE DECISION-**
284 **MAKING AGREEMENT.**

285 (a) A supported health care decision-making agreement must be signed voluntarily, without
286 coercion or undue influence, by the adult with a disability and the supporter in the presence of one
287 or more subscribing witnesses.

288 (b) A witness must be known to the adult with a disability and able to communicate with the
289 adult with a disability through the adult's preferred form of communication, which may include
290 use of alternative or augmentative communication devices or use of a signed language such as
291 American Sign Language (either with or without the assistance of a qualified interpreter).

292 (c) A witness may not, at the time of execution, be a person who would be ineligible to act as
293 the supporter of an adult with a disability according to Section 4 of this Act.

294 (d) A supported health care decision-making agreement that has been executed in accordance
295 with this Section shall be effective even if the individual:

296 (1) Requires significant assistance in order to manage his or her own health care,
297 personal care, financial affairs, or legal matters; or

298 (2) Has been or would be found by a court to lack the capacity to independently execute
299 a contract.

300 (e) [FOR STATES WITH ADVANCE DIRECTIVE OR HEALTH CARE PROXY
301 REGISTRIES] A copy of a supported health care decision-making agreement that has been
302 executed in accordance with this Section may be submitted to [STATE ADVANCE DIRECTIVE
303 REGISTRY]. Nevertheless, supported health-care decision-making agreements are effective even
304 if they have not been submitted to [STATE ADVANCE DIRECTIVE REGISTRY].

305 **Sec. 10. EFFECTIVE DATE OF SUPPORTED HEALTH CARE DECISION-MAKING**
306 **AGREEMENT.**

307 The agreement becomes effective on the date it is executed unless the agreement provides that it becomes
308 effective on a later date.

309 **Sec. 11. REPORTING AND INVESTIGATING ABUSE, NEGLECT, AND EXPLOITATION OF**
310 **AN ADULT WITH A DISABILITY BY THE SUPPORTER.**

311 (a) If a person is a mandatory reporter of suspected abuse, neglect, or exploitation of adults
312 under [state law] receives a copy or is aware of the supported health care decision-making
313 agreement and has reason to believe that the adult with a disability is suffering from abuse, neglect,
314 or exploitation caused by the supporter, that person shall report the alleged abuse, neglect or
315 exploitation to the [Department of Family and Protective Services].

316 (b) Any person not described in subsection 11(a) may voluntarily report suspected abuse,
317 neglect, or exploitation of an adult with a disability by his or her supporter under a supported health
318 care decision-making agreement.

319 (c) If the [Department of Family and Protective Services] makes a final finding, including a
320 disposition after an appeal, that the adult with a disability is suffering from abuse, neglect, or
321 exploitation caused by the supporter,

322 (1) the [Department of Family and Protective Services] may offer services to the adult
323 with a disability pursuant to _____; and

324 (2) the supported health care decision-making agreement is terminated except if a
325 successor supporter is appointed in the supported health care decision-making agreement.
326 (d) No part of this Act shall be construed to prevent health care providers from interviewing
327 an individual with a disability outside the presence of the supporter for the purposes of ascertaining
328 whether the individual with a disability is the victim of abuse or neglect, provided that such
329 interview is otherwise in compliance with providers' obligation to make reasonable modifications
330 for individuals with disabilities and to provide any necessary auxiliary aids or services necessary
331 for effective communication.