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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

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

Sec. 4. CONFLICT OF INTEREST.

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

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

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

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

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

records or research, as the adult's personal representative pursuant to the Health Insurance Portability and Accountability Act (HIPAA), 42 C.F.R. § 164.502;

(2) To assist the adult with a disability in understanding that information;

(3) To assist the adult with a disability in understanding the options, responsibilities and consequences of the health care decision(s) to be made so the adult can make his or her own decision(s); and

(4) To communicate or to assist the adult in communicating his or her decisions to other persons, including health care providers.

(b) A supporter may assist the adult with a disability in understanding the options, responsibilities and consequences in order to make health care appointments and to make major and minor health care decisions, but is not authorized to make such decisions on behalf of the adult with a disability or to exert undue influence over the person's decision-making. The supporter must ensure that the decision reflects the adult's preferences and/or expressed interests, even if the supporter feels that the adult's decision is not in his or her best interests.

(c) The following form is known as a "supported health care decision-making agreement." An adult with a disability may use a supported health care decision-making agreement to name a supporter and grant some or all of the authority set out in this chapter to that supporter. A supported health care decision-making agreement in substantially the following form demonstrates the intent of the adult with a disability to enter into a supported health care decision-making agreement with the supporter and has the meaning and effect prescribed by this subchapter. The following form is not exclusive, and other forms of supported health care decision-making agreements may be used so long as they demonstrate the adult's intent to enter into a such an agreement, name a supporter and grant some or all of the authority set out in this chapter to that supporter:



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SUPPORTED HEALTH CARE DECISION-MAKING AGREEMENT

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

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

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

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

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

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

Appointment of Supporter

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

Name:

Address:

Phone Number:

is my supporter.

Authority of Supporter

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

1. 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, as my personal representative under the Health Insurance Portability and Accountability Act (HIPAA), 42 C.F.R. § 164.502;

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

I ☐ DO ☐ DO NOT give my supporter permission to talk to doctors when I am not present or when I am temporarily unable to communicate.

I ☐ DO ☐ DO NOT give my supporter permission to access psychotherapy notes or other information about conversations I have had during mental health counseling, substance abuse counseling, or group or family therapy.

This agreement does not give my supporter the authority to make decisions about my health care for me, or to influence me to make decisions that do not reflect my expressed wishes and preferences. My supporter's consent to providing or withholding treatment is not a substitute for my consent.

Additional Authority or Limitations

ON THE FOLLOWING LINES YOU MAY GIVE SPECIAL INSTRUCTIONS LIMITING OR ADDING TO THE RIGHTS GRANTED TO YOUR SUPPORTER.

Effective Date of Supported Health Care Decision-Making Agreement

This agreement takes effect:

☐ Immediately

☐ On the following date: _____

This agreement ends:

☐ When I cancel it

☐ On the following date: _____



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___ When the following event happens: _____

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

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

Successor Supporter

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

Name:

Address:

Phone Number:

Consent of Supporter

I consent to act as a supporter.

(signature of supporter)

(printed name of supporter)

Signature

(your signature)

(your printed name)

(witness signature)

(printed name of witness)

Signed this _____ day of _____, 20____

(your signature)

State of _____

County of _____

This document was acknowledged before me on

_____ (date) by _____



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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 _____.

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

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

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

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

Sec. 7. ACCESS TO PERSONAL INFORMATION.

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

(4) Otherwise acted inconsistently with applicable law.

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

(1) the [Department of Family and Protective Services] may offer services to the adult 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.