

1 (red type and strikeouts show changes to original version)

2 A BILL TO BE ENTITLED

3 AN ACT

4 relating to the recognition of a supported health care decision-making agreement for adults with  
5 disabilities.

6 Sec. 1. SHORT TITLE. This act may be cited as the Supported Health Care Decision-  
7 Making Agreement Act.

8 Sec. 2. DEFINITIONS

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

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

12 (c) “Health care” means

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

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

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

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

20 (5) Palliative care,

21 (6) And a treatment plan;

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

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

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

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

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

1           Sec. 3. PURPOSE

2           The purpose of this Act is to create an alternative to guardianship, maximize autonomy, and  
3 improve health care outcomes for adults with disabilities by permitting adults with disabilities to  
4 name supporters to help them understand health-related information and options so they can  
5 make their own health care decisions.

6           Sec. 4. CONFLICT OF INTEREST

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

10           (a)    A person who has a financial interest in a lawsuit concerning or affecting the  
11 adult with a disability;

12           (b)    A person who has filed a pending petition for guardianship or conservatorship  
13 over the adult with a disability, when the adult with a disability was not previously subject to  
14 guardianship or conservatorship by that person, unless the person withdraws the petition;

15           (c)    A person who is indebted to the adult with a disability;

16           (d)    A person asserting a claim adverse to the adult's real or personal property;

17           (e)    A person or an immediate family member of a person who provides personal care  
18 or health care services to the adult with a disability for compensation, with the exception of a  
19 person who provides independent living or home health services to the adult with a disability in  
20 a home- and community-based setting, as defined at 42 C.F.R. § 441.301(b)(4), that is not a  
21 provider-owned or controlled residential setting as set forth at 42 C.F.R. § 441.301(b)(4)(vi);

22           (f)    A person or a relative of a person who is an employee of a nursing home, group  
23 home, or other facility in which the adult with a disability resides and through which the adult  
24 receives care or health care services. "Facility" shall not include a home- or community-based  
25 setting, as defined at 42 C.F.R. § 441.301(b)(4), that is not a provider-owned or controlled  
26 residential setting as set forth at 42 C.F.R. § 441.301(b)(4)(vi).

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

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

1           (1) To access, collect, or obtain or assist the adult in accessing, collecting or  
2 obtaining any information that is relevant to pending or future health care decision(s)  
3 from any person including, but not limited to, medical, psychological, financial,  
4 educational, or treatment records or research, as the adult’s personal representative  
5 pursuant to the Health Insurance Portability and Accountability Act (HIPAA), 42 C.F.R.  
6 § 164.502;

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

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

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

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

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



**Authority of Supporter**

1  
2  
3  
4  
5  
6  
7  
8  
9  
10  
11  
12  
13  
14  
15  
16  
17  
18  
19  
20  
21  
22  
23  
24  
25  
26  
27  
28  
29  
30

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;
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

1 preferences. My supporter's consent to providing or withholding treatment is not a substitute for  
2 my consent.

3

4

**Additional Authority or Limitations**

5

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

8

9

10

11

12

13

14

15

16

17

18

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

19

20

This agreement takes effect:

21

Immediately

22

On the following date: \_\_\_\_\_

23

24

This agreement ends:

25

When I cancel it

26

On the following date: \_\_\_\_\_

27

When the following event happens: \_\_\_\_\_

28

29

**Effect on Previous Supported Health Care Decision-Making Agreements**

30

1 I \_\_\_ DO \_\_\_ DO NOT want this agreement to take the place of any other supported health care  
2 decision-making agreements I have signed.

3

4

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

6

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

10

11

**Successor Supporter**

12

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

15

16 Name:

17 Address:

18 Phone Number:

19

20

**Consent of Supporter**

21

22 **I consent to act as a supporter.**

23

24

25 **(signature of supporter)**

**(printed name of supporter)**

26

27

**Signature**

28

29

30 **(your signature)**

**(your printed name)**

31

1  
2  
3  
4  
5  
6  
7  
8  
9  
10  
11  
12  
13  
14  
15  
16  
17  
18  
19  
20  
21  
22  
23  
24  
25  
26  
27  
28  
29  
30

(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 \_\_\_\_\_

(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.



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

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

7 (d) A supporter shall be subject to the same fiduciary obligations ordinarily  
8 applicable to similarly situated individuals acting pursuant to a grant of power of attorney.

9 (e) A supporter shall not be held liable for damages associated with decisions made by an  
10 individual without consulting the supporter or against the supporter's advice.

11

12 -

### 13 Sec. 7. ACCESS TO PERSONAL INFORMATION

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

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

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

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

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

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

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

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

13 (a) Any health care provider that respects and acts consistently with the authority  
14 given to a supporter by a duly executed supported health care decision-making agreement, shall  
15 be immune from any action alleging that the agreement was invalid unless the entity, custodian  
16 or organization had actual knowledge or **reasonable** notice that the adult had revoked such  
17 authorization; ~~that the agreement failed to meet any of the requirements of Sections 4, 5, or 9 of~~  
18 ~~this Act; was invalid, that the individual did not understand the purpose or scope of the~~  
19 ~~agreement at the time it was executed;~~ or that the supporter had committed abuse, neglect, or  
20 exploitation as described in Section 11 of this Act.

21 (b) ~~With respect to health care provided to a person with a disability who has~~  
22 ~~executed a~~ Any health care provider that provides health care **valid** ~~based on the consent of a~~  
23 ~~person with a disability, made with supports and services provided through a duly executed~~  
24 supported health care decision-making agreement, **a health care provider** shall be immune from  
25 any action alleging that the ~~person~~ **adult** with a disability lacked capacity to provide informed  
26 consent unless:

27 (1) ~~the~~ **The** entity, custodian or organization had actual knowledge or **reasonable**  
28 notice that the adult had revoked such authorization, that the agreement was invalid, or  
29 that the supporter had committed abuse, neglect, or exploitation as described in Section  
30 11 of this Act; **or**

1 (2) The adult with a disability had not given informed consent for the specific  
2 procedure or treatment, after taking into account accommodations and supports provided  
3 through the Supported Health Care Decision-Making Agreement. Existence of a  
4 disability or need for support shall not alone constitute a basis for finding absence of  
5 informed consent.:

6 (c) No part of this Act relieves a medical professional's obligation to assess whether  
7 or not a patient has provided informed consent to a specific medical intervention, procedure, or  
8 treatment, with or without support.

9 (d) Any public or private entity, custodian, or organization that discloses personal  
10 information about an adult with a disability to a supporter who is authorized to access, collect, or  
11 obtain or assist the adult with a disability in accessing, collecting or obtaining that information  
12 shall be immune from any action alleging that it improperly or unlawfully disclosed such  
13 information to the supporter unless the entity, custodian or organization had actual knowledge  
14 that the adult had revoked such authorization.

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

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

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

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

23 (4) Otherwise acted inconsistently with applicable law.

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

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

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

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

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

10 (d) **An individual's capacity to sign a** supported health care decision-making agreement  
11 **shall be evaluated on a situation-specific basis, based on the individual's understanding of and consent**  
12 **to the specific agreement. Such an agreement**~~that has been executed in accordance with this Section~~  
13 **shall be effective even if the individual:**

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

16 (2) Has been or would be found by a court to lack the capacity to independently  
17 execute ~~a contract~~**some other contract.**

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

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

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

#### 26 Sec. 11. REPORTING AND INVESTIGATING ABUSE, NEGLECT, AND 27 EXPLOITATION OF AN ADULT WITH A DISABILITY BY THE SUPPORTER

28 (a) **No part of this Act reduces or replaces any legal obligation to report a reasonable**  
29 **suspicion that an individual is experiencing abuse or neglect, including through undue influence**  
30 **by a supporter.**

31 (b) If a person is a mandatory reporter of suspected abuse, neglect, or exploitation of  
32 adults under [state law] receives a copy or is aware of the supported health care decision-making

1 agreement and has reason to believe that the adult with a disability is suffering from abuse,  
2 neglect, or exploitation caused by the supporter, that person shall report the alleged abuse,  
3 neglect or exploitation to the [Department of Family and Protective Services].

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

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

10 (1) the [Department of Family and Protective Services] may offer services to  
11 the adult with a disability pursuant to \_\_\_\_\_; and

12 (2) the supported health care decision-making agreement is terminated except  
13 if a successor supporter is appointed in the supported health care decision-making agreement.

14 (de)  
15 No part of this Act shall be construed to prevent health care providers from interviewing an  
16 individual with a disability outside the presence of the supporter for the purposes of ascertaining  
17 whether the individual with a disability is the victim of abuse or neglect, provided that such  
18 interview is otherwise in compliance with providers' obligation to make reasonable  
19 modifications for individuals with disabilities and to provide any necessary auxiliary aids or  
20 services necessary for effective communication.