

**HB**

**336**

<TARGET><BILL>HB 336</BILL><SUBJECT>HB  
336</SUBJECT><COMM>HJUD30</COMM></TARGET>

**Alaska Legislature  
Representative Charisse Millett**

**Session:**

State Capitol Building  
Juneau, AK 99801  
Phone (907) 465-3879  
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**Interim:**

Anchorage LIO  
1500 West Benson Blvd.  
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**MEMORANDUM**

**TO:** Rep. Matt Claman, Chair of the House Judiciary Committee

**FROM:** Rep. Charisse Millett, House Minority Leader

**DATE:** March 13, 2018

**RE:** Hearing Request for House Bill 336

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I respectfully request a hearing for House Bill 336, the Supported Decision-Making Agreements Act, before the House Judiciary Committee. If you have any questions about the bill, please feel free to contact my staff Hans Rodvik (his direct line is 907-465-4937).

Attached to this memo my staff has provided:

1. A copy of the bill in its current form, Version O
2. A sponsor statement of the bill
3. A sectional analysis of the bill
4. A fiscal note for the bill (Senior Disability Services has confirmed with us that it's going to be removed)
5. Various supporting documents
  - a. Letter of Support from Art Delaune
  - b. Letter of Support from AARP Alaska
  - c. Alaska Court Rule 402
  - d. SDMA Q&A
  - e. Time Magazine article on senior fraud
  - f. SDMA Pilot Program Evaluation Human Services Research Institute
  - g. Updated guardianship numbers in AK
  - h. Governor's Council on Disabilities and Special Education talking points
  - i. OPA/Public Guardian Challenges
  - j. ThinkWork! Paper on guardianship
  - k. National Core Indicators 2016 survey
  - l. SDMA example from Texas
  - m. SDMA example from Autistic Self Advocacy Network

- n. SDMA examples from Nonotuck
  - o. SDMA bill from Delaware
  - p. SDMA bill from Texas
  - q. SDMA bill analysis from Texas
  - r. SDMA bill form Rhode Island
  - s. SDMA An Agenda for Action Paper
  - t. SDM In U.S. White Paper by Council on Quality and Leadership
6. The committee should expect testimony from:
- a. Anne Applegate, Governor's Council on Disabilities and Special Education
  - b. Patrick Reinhard, Governor's Council on Disabilities and Special Education
  - c. Community advocates for adults with intellectual and developmental disabilities

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**CS for House Bill 336 Version O: The Supported Decision-Making Agreements Act**

**Sectional Analysis**

Section One: Amending AS 13, which related to decedents' estates, guardianships, transfers, trusts and health care decisions, by adding a new chapter

13.56.010: Authorizes adults to enter into a supported decision-making agreement (SDMA) and spells out reasons why an adult may not enter a SDMA.

13.56.020: Describes the requirements adults must meet to be qualified as supporters in SDMAs.

13.56.030: Sets the parameters for what a SDMA must contain to be legitimate. Also deals with alternate supporters and sharing of information amongst supporters.

13.56.040: This section lays out the precise requirements for a SDMA to be valid, and how the principal and supporter(s) may formalize the signing of the SDMA.

13.56.050: Mandates that each supporter acknowledge their relationship with the principal and their responsibilities to support the principal.

13.56.060: Delineates who a witness to the signing of the SDMA can and cannot be.

13.56.070: Clarifies when a SDMA becomes effective and how long they last.

13.56.080: This section details how either a principal or supporter(s) of a SDMA may terminate all or portions of a SDMA. Likewise, explains what happens to a SDMA if only portions of it are terminated.

13.56.090: States the general duties of supporters.

13.56.100: Outlines the areas of a principal's life, including health, finances, education and communication, that a supporter may provide support in. Also provides a way for supporters to help the principal deal with health information covered under federal healthcare privacy laws.

13.56.110: Prohibits supporters from wrongfully guiding and influencing the principal in a harmful manner. This section also prohibits supporters from using or obtaining the principal's personal information without their consent.

13.56.120: Requires the supporter(s) of a principal to keep all information related to the principal confidential, protected and shielded from unauthorized use.

13.56.130: Directs people who interact with principals/supporter(s) to recognize the communication, requests and decisions made by the principal (with support from the supporter(s)) as if that communication, request or decision was made solely by the principal.

13.56.140: This section absolves a person (for three distinct reasons) from civil or criminal liability or discipline for unprofessional conduct if they either comply or decline to comply with an authorization in a SDMA.

13.56.150: Delineates the circumstances in which a principal is capable and has capacity. A principal doesn't lack capacity based on how they communicate. Likewise, a principal may make decisions without the support of a supporter(s). Lastly, the existence of a SDMA doesn't mean a principal lacks capacity.

13.56.160: Deals entirely with the affairs of a principal that a SDMA may cover. Work, healthcare, support services education, finances, living arrangements and more are all discussed.

13.56.170: This section spells out the multitude of support services, as referenced in 13.56.160, that supporters may provide the principal as agreed upon in the SDMA.

13.56.190: Definitions

13.56.195: The short title of House Bill 336 is the Supported Decision-Making Agreements Act.

Section 2: Amends Alaska Court Rule 402, Alaska Rules of Evidence, to clarify that the execution of a SDMA cannot be used as evidence of a principal's incapacity.

Section 3: Amends the uncodified law of Alaska by amending Court Rule 402 and clarifies the two-thirds majority vote of each house needed to achieve such action.

# Fiscal Note

State of Alaska  
2018 Legislative Session

Bill Version: HB 336  
Fiscal Note Number: \_\_\_\_\_  
( ) Publish Date: \_\_\_\_\_

Identifier: HB336-DHSS-SDSA-2-23-18  
Title: SUPPORTIVE DECISION-MAKING  
AGREEMENTS  
Sponsor: MILLETT  
Requester: House HSS

Department: Department of Health and Social Services  
Appropriation: Senior and Disabilities Services  
Allocation: Senior and Disabilities Services Administration  
OMB Component Number: 2663

**Expenditures/Revenues**

Note: Amounts do not include inflation unless otherwise noted below. (Thousands of Dollars)

	FY2019	Included in	Out-Year Cost Estimates						
	Appropriation Requested	Governor's FY2019 Request	FY 2019	FY 2019	FY 2020	FY 2021	FY 2022	FY 2023	FY 2024
<b>OPERATING EXPENDITURES</b>	<b>FY 2019</b>	<b>FY 2019</b>	<b>FY 2020</b>	<b>FY 2021</b>	<b>FY 2022</b>	<b>FY 2023</b>	<b>FY 2024</b>	<b>FY 2024</b>	<b>FY 2024</b>
Personal Services									
Travel									
Services	15.0								
Commodities									
Capital Outlay									
Grants & Benefits									
Miscellaneous									
<b>Total Operating</b>	<b>15.0</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>

**Fund Source (Operating Only)**

1004 Gen Fund (UGF)	15.0								
<b>Total</b>	<b>15.0</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>

**Positions**

Full-time									
Part-time									
Temporary									

**Change in Revenues**

None									
<b>Total</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>

**Estimated SUPPLEMENTAL (FY2018) cost:** 0.0 (separate supplemental appropriation required)  
(discuss reasons and fund source(s) in analysis section)

**Estimated CAPITAL (FY2019) cost:** 0.0 (separate capital appropriation required)  
(discuss reasons and fund source(s) in analysis section)

**ASSOCIATED REGULATIONS**

Does the bill direct, or will the bill result in, regulation changes adopted by your agency? Yes  
If yes, by what date are the regulations to be adopted, amended or repealed? 07/01/19

**Why this fiscal note differs from previous version/comments:**

Not applicable; initial version.

Prepared By:	Duane Mayes, Director	Phone:	(907)269-2083
Division:	Senior and Disabilities Services	Date:	02/23/2018
Approved By:	Shawnda O'Brien, Asst. Commissioner	Date:	02/23/18
Agency:	Health and Social Services		

## FISCAL NOTE ANALYSIS

STATE OF ALASKA  
2018 LEGISLATIVE SESSION

BILL NO. HB336

### Analysis

**HB336 version "D"** amends AS 13 to add a new Chapter 56 *Supported Decision-Making Agreements*. A supportive decision-making agreement, created by this bill, formalizes the relationship between an individual requiring supportive decision-making and the individual providing the support.

The supported decision-making agreement supports individuals to make significant decisions and exercise their legal capacity. The specific decisions with which the supporter may assist the person include: medical, psychological, financial, and educational.

Potential supporters may be friends, family, volunteers, and community members. These unpaid supporters may help the person to gather, understand and consider relevant information about the decision in question, assist the person to weigh pros and cons, predict likely outcomes and consequences or evaluate the available options. With this support, the person then makes the decision themselves.

Authority is granted to the department to establish the regulations and forms required to implement the statute. The department would require technical assistance from the Department of Law to create regulations and forms.

In FY2019, associated time for form and regulatory drafting will include an estimated 40 hours legal and paralegal support, which is equivalent to \$15.0.

30-LS1239\U  
Bannister  
3/29/18

**CS FOR HOUSE BILL NO. 336( )**  
**IN THE LEGISLATURE OF THE STATE OF ALASKA**  
**THIRTIETH LEGISLATURE - SECOND SESSION**

**BY**

**Offered:**  
**Referred:**

**Sponsor(s): REPRESENTATIVES MILLETT, Saddler, Spohnholz, Kopp, Tuck, Gara, Grenn, LeDoux, Kito, Johnston, Claman**

**A BILL**  
**FOR AN ACT ENTITLED**

**"An Act relating to supported decision-making agreements to provide for decision-making assistance; and amending Rule 402, Alaska Rules of Evidence."**

**BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF ALASKA:**

**\* Section 1.** AS 13 is amended by adding a new chapter to read:

**Chapter 56. Supported Decision-Making Agreements.**

**Sec. 13.56.010. Agreements authorized.** (a) Except as provided in (b) and (c) of this section, an adult may enter into a supported decision-making agreement. A supported decision-making agreement allows an adult to receive decision-making assistance with the adult's affairs from one or more other adults.

(b) The adult wanting to receive decision-making assistance may not enter into a supported decision-making agreement unless the adult

(1) enters into the agreement voluntarily and without coercion or undue influence; and

(2) understands the nature and effect of the agreement.

1 (c) An adult may not enter into a supported decision-making agreement under  
 2 this section if the agreement encroaches on the authority of a guardian or conservator  
 3 of the adult, unless the guardian or conservator approves in writing the adult entering  
 4 into the supported decision-making agreement.

5 **Sec. 13.56.020. Eligibility of supporters.** A supporter must be an adult, but  
 6 may not be

7 (1) an employer or employee of the principal, unless the employer or  
 8 employee is an immediate family member of the principal;

9 (2) a person who provides paid support services, except decision-  
 10 making assistance, directly to the principal, unless the person is an immediate family  
 11 member of the principal; or

12 (3) a person against whom a protective order or restraining order has  
 13 been entered by a court on request of or on behalf of the principal.

14 **Sec. 13.56.030. Contents of agreement.** (a) A supported decision-making  
 15 agreement must

16 (1) name one or more adults to provide a principal with decision-  
 17 making assistance; and

18 (2) describe the decision-making assistance that each supporter may  
 19 provide the principal.

20 (b) A supported decision-making agreement must contain a notice to third  
 21 parties that summarizes the rights and obligations of the supporter under this chapter  
 22 and expressly identifies this chapter.

23 (c) A supported decision-making agreement may

24 (1) name an alternate supporter to act in the place of a supporter and  
 25 the circumstances under which the alternate supporter may act;

26 (2) authorize a supporter to share information with another supporter  
 27 named in the agreement, including an alternate supporter.

28 **Sec. 13.56.040. Requirements for validity.** A supported decision-making  
 29 agreement is valid if

30 (1) the agreement is dated and in writing;

31 (2) the agreement satisfies the requirements of AS 13.56.010 -

1 13.56.030 and 13.56.050;

2 (3) the agreement has been signed by the principal and each named  
3 supporter, including any alternate supporter, and the

4 (A) signing takes place in the presence of two witnesses who  
5 also sign the agreement; or

6 (B) signatures of the principal and each named supporter,  
7 including any alternate supporter, are notarized; and

8 (4) when the principal has a guardian or conservator, the principal has  
9 notified the guardian or conservator of the agreement.

10 **Sec. 13.56.050. Declarations by supporters.** A supported decision-making  
11 agreement must contain a separate declaration for each supporter that states the  
12 supporter's relationship with the principal, states the willingness of the supporter to act  
13 as a supporter for the principal, and indicates that the supporter acknowledges the  
14 duties of a supporter under this chapter. Each declaration must be signed by the  
15 supporter making the declaration.

16 **Sec. 13.56.060. Witnesses.** (a) Each witness under AS 13.56.040 must be an  
17 adult who understands the means of communication used by the principal, except, if  
18 there is an individual who understands the principal's means of communication present  
19 to assist during the execution of the supported decision-making agreement, the  
20 witnesses are not required to understand the means of communication used by the  
21 principal.

22 (b) A witness under AS 13.56.040 may not be a supporter named in the  
23 supported decision-making agreement or an employee or agent of a supporter named  
24 in the supported decision-making agreement.

25 **Sec. 13.56.070. Term of agreement.** A supported decision-making agreement  
26 may indicate the date it becomes effective and its duration. If the supported decision-  
27 making agreement does not indicate the date it becomes effective, the supported  
28 decision-making agreement becomes effective immediately. If a supported decision-  
29 making agreement does not indicate its duration, the supported decision-making  
30 agreement remains effective until terminated under AS 13.56.080.

31 **Sec. 13.56.080. Termination of agreement.** (a) A principal may at any time

1 terminate all or a portion of a supported decision-making agreement. A supporter may  
2 at any time terminate all or a portion of the supporter's obligations under a supported  
3 decision-making agreement, including the declaration of support described in  
4 AS 13.56.050.

5 (b) A termination under (a) of this section must be in writing and signed, and

6 (1) the signing must take place in the presence of two witnesses who  
7 also sign the termination; or

8 (2) the signature must be notarized.

9 (c) A principal or supporter terminating all or a portion of a supported  
10 decision-making agreement shall notify, in person, by certified mail, or by electronic  
11 means, the other party to the agreement that the agreement has been terminated.

12 (d) If all or a portion of a supported decision-making agreement is terminated  
13 under this section and the termination is consistent with this section, the remainder of  
14 the agreement remains in effect.

15 **Sec. 13.56.090. Duties of supporter.** A supporter shall act with the care,  
16 competence, and diligence ordinarily exercised by individuals in similar  
17 circumstances.

18 **Sec. 13.56.100. Decision-making assistance of supporter.** (a) Except as  
19 limited by a supported decision-making agreement, a supporter may provide to a  
20 principal the following decision-making assistance about the principal's affairs:

21 (1) assisting with making decisions, communicating decisions, and  
22 understanding information about, options for, the responsibilities of, and the  
23 consequences of decisions;

24 (2) accessing, obtaining, and understanding information that is relevant  
25 to decisions necessary for the principal to manage the principal's affairs, including  
26 medical, psychological, financial, and educational information, medical treatment  
27 records, and other records;

28 (3) ascertaining the wishes and decisions of the principal, assisting in  
29 communicating those wishes and decisions to other persons, and advocating to ensure  
30 the implementation of the principal's wishes and decisions; and

31 (4) accompanying the principal and participating in discussions with

1 other persons when the principal is making decisions or attempting to obtain  
2 information for decisions.

3 (b) Under (a)(2) of this section, a supporter may use the principal's dated  
4 consent to assist the principal in obtaining protected health information under the  
5 Health Insurance Portability and Accountability Act of 1996 (P.L. 104-191) or  
6 educational records under 20 U.S.C. 1232g (Family Educational Rights and Privacy  
7 Act of 1974).

8 **Sec. 13.56.110. Prohibited activities.** A supporter may not

- 9 (1) exert undue influence on the principal;  
10 (2) make decisions for or on behalf of the principal;  
11 (3) sign for the principal or provide an electronic signature of the  
12 principal to a third party;  
13 (4) obtain, without the consent of the principal, information that is not  
14 reasonably related to matters with which the supporter may assist the principal under  
15 the supported decision-making agreement; or  
16 (5) use, without the consent of the principal, information acquired for a  
17 purpose authorized by this chapter for a purpose other than assisting the principal to  
18 make a decision under the supported decision-making agreement.

19 **Sec. 13.56.120. Confidentiality, handling, and disposal of information.** A  
20 supporter shall keep the information collected by the supporter on behalf of the  
21 principal under this chapter confidential, may not use the information for a use that is  
22 not authorized by the principal, shall protect the information from unauthorized  
23 access, use, or disclosure, and shall dispose of the information properly when  
24 appropriate.

25 **Sec. 13.56.130. Recognition of decisions and requests.** A person shall  
26 recognize a decision or request made or communicated with the decision-making  
27 assistance of a supporter under this chapter as the decision or request of the principal  
28 for the purposes of a provision of law, and the principal or supporter may enforce the  
29 decision or request in law or equity on the same basis as a decision or request of the  
30 principal.

31 **Sec. 13.56.140. Limitation of liability.** (a) A person who, in good faith, either

1 acts in reliance on an authorization in a supported decision-making agreement or  
2 declines to honor an authorization in a supported decision-making agreement is not  
3 subject to civil or criminal liability or to discipline for unprofessional conduct for

4 (1) complying with an authorization in a supported decision-making  
5 agreement, if the person is complying based on an assumption that the underlying  
6 supported decision-making agreement was valid when made and has not been  
7 terminated under AS 13.56.080;

8 (2) declining to comply with an authorization in a supported decision-  
9 making agreement if the person is declining based on actual knowledge that the  
10 supported decision-making agreement is invalid or has been terminated under  
11 AS 13.56.080;

12 (3) declining to comply with an authorization related to health care in a  
13 supported decision-making agreement, if the person is declining because the action  
14 proposed to be taken under the supported decision-making agreement is contrary to  
15 the good faith medical judgment of the person or to a written policy of a health care  
16 institution that is based on reasons of conscience.

17 (b) In this section, "good faith" means honesty in fact and the observance of  
18 reasonable standards of fair dealing.

19 **Sec. 13.56.150. Capability and capacity.** (a) In the application of this chapter,  
20 a decision that a principal is incapable of managing the principal's affairs may not be  
21 based on the manner in which the principal communicates with others.

22 (b) An adult who enters into a supported decision-making agreement may act  
23 without the decision-making assistance of the supporter.

24 (c) A person may not use the execution of a supported decision-making  
25 agreement as evidence that the principal does not have capacity.

26 (d) In this chapter, a principal is considered to have capacity even if the  
27 capacity is achieved by the principal receiving decision-making assistance.

28 **Sec. 13.56.160. Principal's affairs.** This chapter applies to decisions related to  
29 the following affairs of a principal:

30 (1) monitoring health, obtaining, scheduling, implementing, and  
31 coordinating health and support services, understanding health care information and

1 options, providing for care and comfort, and other health care and personal matters in  
2 which the principal makes decisions about the principal's health care;

3 (2) managing income and assets and the use of income and assets for  
4 clothing, support, care, comfort, education, shelter, and payment of other liabilities of  
5 the principal;

6 (3) handling personal, health care, and financial matters that arise in  
7 the course of daily living;

8 (4) monitoring information about the principal's support services,  
9 including future necessary or recommended support services;

10 (5) living arrangements, including where and with whom the principal  
11 wants to live; and

12 (6) working arrangements, including where the principal wants to  
13 work.

14 **Sec. 13.56.170. Support services.** The following are considered support  
15 services under this chapter:

16 (1) house repair, home cleaning, laundry, shopping, and providing  
17 meals;

18 (2) transportation, accompanying a principal, and facilitating a  
19 principal's written, oral, and electronic communication;

20 (3) nurse visitations and attendant care;

21 (4) provision of health care;

22 (5) physical and psychosocial assessments;

23 (6) financial assessments and advice on banking, taxes, loans,  
24 investments, and management of real property;

25 (7) legal assessments and advice;

26 (8) education and educational assessments and advice;

27 (9) assistance with bathing, dressing, eating, range of motion, toileting,  
28 transferring, ambulation, and other direct assistance with the activities of daily living;

29 (10) care planning;

30 (11) services that assist in maintaining the independence of a principal.

31 **Sec. 13.56.180. Form for supported decision-making agreement. A**

supported decision-making agreement must be in substantially the following form:

STATUTORY FORM FOR  
SUPPORTED DECISION-MAKING AGREEMENT

(1) INTRODUCTION. I, \_\_\_\_\_, want to have one or more persons I trust help me make decisions, obtain and understand the information I need to make my decisions, and tell other people about my decisions. The people who will help me are my "supporters."

I can name three supporters in this form. If I want to have more than three supporters, I can use a form that is substantially similar to this form to enter into a supported decision-making agreement with the additional supporters.

This is a written agreement between me ("principal") and each of my supporters. I can say in this agreement what kind of help each of my supporters will give me. A SUPPORTER APPOINTED UNDER THIS AGREEMENT DOES NOT MAKE DECISIONS FOR ME.

My supporters may share information with each other (select one of the following):

Yes [ ]                      No [ ]

(2) SUPPORTERS. These are my supporters:

SUPPORTER NO. 1

Name: \_\_\_\_\_

Address: \_\_\_\_\_

Telephone number: \_\_\_\_\_

Electronic mail address: \_\_\_\_\_

I want this supporter to help me with (mark any of the following you want):

- [ ] Making choices about food and clothing
- [ ] Making choices about where and with whom I live
- [ ] Making choices about my health and health care
- [ ] Making choices about how I spend my time

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- Making choices about where I work
- Making choices about my support services
- Making choices about how I spend my money and how I

save my money

- Making choices about legal matters
- Making choices about (list other areas the supporter will

help you with):

---



---

I do not want this supporter to help me with:

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SUPPORTER NO. 2

Name: \_\_\_\_\_

Address: \_\_\_\_\_

Telephone number: \_\_\_\_\_

Electronic mail address: \_\_\_\_\_

I want this supporter to help me with (mark any of the following you want):

- Making choices about food and clothing
- Making choices about where and with whom I live
- Making choices about my health and health care
- Making choices about how I spend my time
- Making choices about where I work
- Making choices about my support services
- Making choices about how I spend my money and how I

save my money

- Making choices about legal matters
- Making choices about (list other areas the supporter will

help you with):

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\_\_\_\_\_  
I do not want this supporter to help me with:

\_\_\_\_\_  
\_\_\_\_\_

SUPPORTER NO. 3

Name: \_\_\_\_\_

Address: \_\_\_\_\_

Telephone number: \_\_\_\_\_

Electronic mail address: \_\_\_\_\_

I want this supporter to help me with (mark any of the following you want):

- Making choices about food and clothing
- Making choices about where and with whom I live
- Making choices about my health and health care
- Making choices about how I spend my time
- Making choices about where I work
- Making choices about my support services
- Making choices about how I spend my money and how I

save my money

- Making choices about legal matters
- Making choices about (list other areas the supporter will

help you with):

\_\_\_\_\_  
\_\_\_\_\_

I do not want this supporter to help me with:

\_\_\_\_\_  
\_\_\_\_\_

ALTERNATE SUPPORTER. If one of my supporters dies, becomes unable to act as my supporter, refuses to act as my supporter, or terminates the supporter's part of this agreement, I want the following person to become my supporter and help me with the areas the original

1 supporter was helping me with:

2 Name: \_\_\_\_\_

3 Address: \_\_\_\_\_

4 Telephone number: \_\_\_\_\_

5 Electronic mail address: \_\_\_\_\_

6 (3) INFORMATION ACCESS FORMS. I am attaching to this  
7 agreement (mark yes or no for each choice below):

8 A form that lets my supporter(s) obtain my health information  
9 under the Health Insurance Portability and Accountability Act

10 Yes [ ] No [ ]

11 A form that lets my supporter(s) see my educational records  
12 under the Family Educational Rights and Privacy Act of 1974

13 Yes [ ] No [ ]

14 (4) GUARDIANS AND CONSERVATORS. If I have a  
15 guardian or conservator, I must notify the guardian or conservator  
16 about this agreement. If this agreement encroaches on the authority of  
17 that guardian or conservator, the guardian or conservator must approve  
18 this agreement in writing.

19 [ ] I have a guardian, and I have notified the guardian about  
20 this agreement.

21 [ ] I am attaching a signed statement by my guardian approving  
22 my use of this agreement.

23 [ ] I have a conservator, and I have notified the conservator  
24 about this agreement.

25 [ ] I am attaching a signed statement by my conservator  
26 approving my use of this agreement.

27 (5) NOTICE TO THIRD PARTIES. This is a summary of the  
28 rights and obligations of a supporter under AS 13.56, the chapter that  
29 authorizes making this agreement. A supporter does not make decisions  
30 for the principal, but a supporter may provide a principal with help  
31 when making decisions, obtaining information for decision,

1 communicating decisions, and understanding the options,  
 2 responsibilities, and consequences of decisions. A supporter may  
 3 accompany the principal and participate in discussions with other  
 4 persons. The principal sets out in this agreement the areas in which the  
 5 supporter may help the principal with decisions.

6 A third party must recognize a decision or request of the  
 7 principal that is made or communicated with the assistance of a  
 8 supporter as the decision or request of the principal (AS 13.56.130).  
 9 The principal or supporter may enforce the decision or request in law or  
 10 equity. A principal may act without the help of the supporter.

11 (6) DURATION AND TERMINATION OF AGREEMENT. I  
 12 can end all or part of this agreement at any time by giving notice to my  
 13 supporter(s). My termination must be signed and notarized or witnessed  
 14 like this agreement. This agreement starts \_\_\_\_\_ (date) and will  
 15 continue until the agreement is terminated by me or my supporter(s).

16 (7) SIGNATURE OF PRINCIPAL. I know that I do not have to  
 17 sign this agreement. I am entering into this agreement voluntarily and  
 18 without coercion or undue influence. I understand the nature and effect  
 19 of this agreement. I know that I can change this agreement at any time.

20 Signature: \_\_\_\_\_

21 Printed name: \_\_\_\_\_

22 Telephone number: \_\_\_\_\_

23 Electronic mail address: \_\_\_\_\_

24 Date: \_\_\_\_\_

25 (8) SIGNATURES OF SUPPORTERS.

26 Signature of Supporter No. 1

27 Signature: \_\_\_\_\_

28 Printed name: \_\_\_\_\_

29 Name: \_\_\_\_\_

30 Address: \_\_\_\_\_

31 Telephone number: \_\_\_\_\_

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Telephone number: \_\_\_\_\_

Electronic mail address: \_\_\_\_\_

Date: \_\_\_\_\_

Signature of Supporter No. 2

Signature \_\_\_\_\_

Printed name: \_\_\_\_\_

Date: \_\_\_\_\_

Signature of Supporter No. 3

Signature: \_\_\_\_\_

Printed name: \_\_\_\_\_

Date: \_\_\_\_\_

Signature of Alternate Supporter

Signature: \_\_\_\_\_

Printed name: \_\_\_\_\_

Date: \_\_\_\_\_

(9) DECLARATIONS OF SUPPORTERS.

DECLARATION OF SUPPORTER NO. 1. I, \_\_\_\_\_,  
am the principal's \_\_\_\_\_ (relationship to the  
principal). I am willing to act as the principal's supporter. I  
acknowledge my duties as a supporter under AS 13.56.

I understand that my job as a supporter is to help the principal  
make decisions, obtain and understand information for decisions,  
communicate decisions, and understand the options, responsibilities,  
and consequences of decisions. My support may include giving the  
principal information in a way that the principal can understand,  
discussing pros and cons of decisions, and helping the principal  
communicate the principal's decisions.

I will act with care, competence, and diligence. I know that I

1 may not make decisions for the principal. I will not exert undue  
 2 influence on the principal. I will not sign for the principal or provide an  
 3 electronic signature of the principal to a third party. I will keep the  
 4 principal's information confidential. I will not use information I receive  
 5 under this agreement for a purpose other than as authorized by the  
 6 principal for decision making, unless the principal consents to another  
 7 use.

8 Signature: \_\_\_\_\_

9 Printed name: \_\_\_\_\_

10 Date: \_\_\_\_\_

11 DECLARATION OF SUPPORTER NO. 2. I, \_\_\_\_\_,  
 12 am the principal's \_\_\_\_\_ (relationship to the  
 13 principal). I am willing to act as the principal's supporter. I  
 14 acknowledge my duties as a supporter under AS 13.56.

15 I understand that my job as a supporter is to help the principal  
 16 make decisions, obtain and understand information for decisions,  
 17 communicate decisions, and understand the options, responsibilities,  
 18 and consequences of decisions. My support may include giving the  
 19 principal information in a way that the principal can understand,  
 20 discussing pros and cons of decisions, and helping the principal  
 21 communicate the principal's decisions.

22 I will act with care, competence, and diligence. I know that I  
 23 may not make decisions for the principal. I will not exert undue  
 24 influence on the principal. I will not sign for the principal or provide an  
 25 electronic signature of the principal to a third party. I will keep the  
 26 principal's information confidential. I will not use information I receive  
 27 under this agreement for a purpose other than as authorized by the  
 28 principal for decision making, unless the principal consents to another  
 29 use.

30 Signature: \_\_\_\_\_

31 Printed name: \_\_\_\_\_

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DECLARATION OF SUPPORTER NO. 3. I, \_\_\_\_\_,  
am the principal's \_\_\_\_\_ (relationship to the  
principal). I am willing to act as the principal's supporter. I  
acknowledge my duties as a supporter under AS 13.56.

I understand that my job as a supporter is to help the principal  
make decisions, obtain and understand information for decisions,  
communicate decisions, and understand the options, responsibilities,  
and consequences of decisions. My support may include giving the  
principal information in a way that the principal can understand,  
discussing pros and cons of decisions, and helping the principal  
communicate the principal's decisions.

I will act with care, competence, and diligence. I know that I  
may not make decisions for the principal. I will not exert undue  
influence on the principal. I will not sign for the principal or provide an  
electronic signature of the principal to a third party. I will keep the  
principal's information confidential. I will not use information I receive  
under this agreement for a purpose other than as authorized by the  
principal for decision making, unless the principal consents to another  
use.

Signature: \_\_\_\_\_

Printed name: \_\_\_\_\_

Date: \_\_\_\_\_

DECLARATION OF ALTERNATE SUPPORTER. I,  
\_\_\_\_\_, am the principal's \_\_\_\_\_  
(relationship to the principal). I am willing to act as the principal's  
supporter in the place of another supporter. I acknowledge the duties as  
a supporter under AS 13.56.

I understand that my job as a supporter would be to help the  
principal make decisions, obtain and understand information for  
decisions, communicate decisions, and understand the options,

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1 responsibilities, and consequences of decisions. My support may  
 2 include giving the principal information in a way that the principal can  
 3 understand, discussing pros and cons of decisions, and helping the  
 4 principal communicate the principal's decisions.

5 I will act with care, competence, and diligence. I know that I  
 6 may not make decisions for the principal. I will not exert undue  
 7 influence on the principal. I will not sign for the principal or provide an  
 8 electronic signature of the principal to a third party. I will keep the  
 9 principal's information confidential. I will not use information I receive  
 10 under this agreement for a purpose other than as authorized by the  
 11 principal for decision making, unless the principal consents to another  
 12 use.

13 Signature: \_\_\_\_\_

14 Printed name: \_\_\_\_\_

15 Date: \_\_\_\_\_

16 (10) NOTARIZATION OR WITNESSING. The signatures on  
 17 this agreement must be either (1) notarized, or (2) witnessed by two  
 18 witnesses.

19 NOTARIZATION

20 State of \_\_\_\_\_

21 \_\_\_\_\_ Judicial District

22 On this \_\_\_\_ day of \_\_\_\_, in the year \_\_\_\_, before me,  
 23 \_\_\_\_\_ (name of notary public), appeared  
 24 \_\_\_\_\_ (name of principal), and  
 25 \_\_\_\_\_ (name of each supporter and alternate  
 26 supporter named in the agreement), personally known to me to be the  
 27 persons who executed this agreement, and each acknowledged to me  
 28 that each executed the agreement as the person's free and voluntary act  
 29 and deed for the uses and purposes under this agreement.

30 Witness my hand and official seal the day and year written  
 31 above.

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(Signature of notary public)

(Seal, if any)

\_\_\_\_\_

(Title and rank)

My commission expires: \_\_\_\_\_

WITNESSING

If the signatures are not notarized, two adults must witness the signatures of the principal, the supporter(s), and any alternate supporter, and all must sign together in the presence of the witnesses. A witness CANNOT be a supporter named in this agreement. The witnesses CANNOT be employees or agents of the supporter(s) named in this agreement. Unless a person who understands the principal's means of communication is present to assist when the agreement is signed, each witness must understand the means of communication used by the principal.

1. Witness signature: \_\_\_\_\_

Printed name: \_\_\_\_\_

Date: \_\_\_\_\_

2. Witness signature: \_\_\_\_\_

Printed name: \_\_\_\_\_

Date: \_\_\_\_\_

(11) APPROVAL BY GUARDIAN. I am the guardian of \_\_\_\_\_, I have read and understand the nature and effect of this agreement. I approve the use of this agreement by \_\_\_\_\_ (name of principal) to obtain support in making decisions.

Signature: \_\_\_\_\_

Printed name: \_\_\_\_\_

Date: \_\_\_\_\_

(12) APPROVAL BY CONSERVATOR. I am the conservator

1 of \_\_\_\_\_. I have read and understand the nature  
 2 and effect of this agreement. I approve the use of this agreement by  
 3 \_\_\_\_\_ (name of principal) to obtain support in  
 4 making decisions.

5 Signature: \_\_\_\_\_

6 Printed name: \_\_\_\_\_

7 Date: \_\_\_\_\_

8 **Sec. 13.56.190. Definitions.** In this chapter, unless the context indicates  
 9 otherwise,

10 (1) "adult" means an individual who is 18 years of age or older;

11 (2) "affairs" means the affairs described in AS 13.56.160;

12 (3) "capacity" means the ability to understand and appreciate the  
 13 nature and consequences of a decision and the ability to reach and communicate an  
 14 informed decision;

15 (4) "conservator" means a person appointed a conservator under  
 16 AS 13.26.401 - 13.26.595 or a similar law of another state;

17 (5) "decision" means a decision relating to the affairs of a principal;

18 (6) "decision-making assistance" means the decision-making  
 19 assistance described in AS 13.56.100;

20 (7) "guardian" means a person appointed a guardian under  
 21 AS 13.26.201 - 13.26.316 or a similar law of another state;

22 (8) "immediate family member" means a spouse, child, sibling, parent,  
 23 grandparent, grandchild, stepparent, stepchild, or stepsibling;

24 (9) "person" means an individual, health care institution, health care  
 25 provider, corporation, partnership, limited liability company, association, joint  
 26 venture, government, governmental subdivision, governmental agency, governmental  
 27 instrumentality, public corporation, or another legal or commercial entity;

28 (10) "principal" means an adult who enters into a supported decision-  
 29 making agreement under this chapter to receive decision-making assistance;

30 (11) "supported decision-making agreement" means an agreement  
 31 authorized under AS 13.56.010;

1 (12) "supporter" means an adult who enters a supported decision-  
2 making agreement and provides decision-making assistance;

3 (13) "support services" means the support services described in  
4 AS 13.56.170.

5 **Sec. 13.56.195. Short title.** This chapter may be cited as the Supported  
6 Decision-Making Agreements Act.

7 \* **Sec. 2.** The uncodified law of the State of Alaska is amended by adding a new section to  
8 read:

9 INDIRECT COURT RULE AMENDMENT. AS 13.56.150(c), added by sec. 1 of this  
10 Act, has the effect of changing Rule 402, Alaska Rules of Evidence, by prohibiting the  
11 execution of a supported decision-making agreement from being used as evidence of a  
12 principal's incapacity. In this section, "principal" and "supported decision-making agreement"  
13 have the meanings given in AS 13.56.190, added by sec. 1 of this Act.

14 \* **Sec. 3.** The uncodified law of the State of Alaska is amended by adding a new section to  
15 read:

16 CONDITIONAL EFFECT. AS 13.56.150(c), added by sec. 1 of this Act, takes effect  
17 only if sec. 2 of this Act receives the two-thirds majority vote of each house required by art.  
18 IV, sec. 15, Constitution of the State of Alaska.

**Alaska Legislature  
Representative Charisse Millett**

Session:  
State Capitol Building  
Juneau, AK 99801  
Phone (907) 465-3879  
Fax (907) 465-2069  
Toll free (888) 269-3879



Interim:  
Anchorage LIO  
1500 West Benson Blvd.  
Anchorage, AK 99501  
Phone (907) 269-0222  
Fax (907) 269-0223

**Sponsor Statement for House Bill 336**

**“Supported Decision-Making Agreements Act”**

With over 100 wards per public guardian Alaska has one of the highest rates of full guardianship in the nation. Studies concerning individuals under full guardianship have found that such individuals were significantly less likely to have any kind of paid employment and are less likely to be integrated into their community, than people provided less restrictive options to full guardianship.

Policy makers should engage in efforts to provide adults with intellectual and developmental disabilities (IDD) the needed tools to experience lives with the most autonomy, freedom and independence as possible. The Supported Decision-Making Agreements Act does just that.

Designed as a mechanism to enable adults with IDD to enter into newly created legal structures called supported decision-making agreements (SDMA), House Bill 336 will provide a less-restrictive alternative to full guardianship for adults with IDD. Guided by the experience of other states, HB 336 will enable adults with disabilities to maintain their rights to make decisions currently being taken away from them by guardianship orders.

The philosophy underpinning HB 336 contends that adults with IDD do have and should retain their constitutional and civil rights to live as freely and autonomously as possible. HB 336 will help change the current system in which one person tends to make every decision for adults with IDD, even though those adults have capacity to make many decisions on their own; to a system where adults who can make life decisions with support from others no longer have the right to make those decisions taken away from them by the government.

HB 336 will enable OPA to focus its efforts on adults who truly need full guardianship, while providing Alaskans experiencing varying levels of IDD an avenue to live happier and healthier lives.

Alaska Legislature  
Representative Charisse Millett

Session:

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**Explanation of Changes for House Bill 336 Version O to U**

Under the new CS (Version U) the only substantive change made was to insert a statutory form for supported decision-making agreements into the bill. The form is lengthy, but meets the requirements and stipulations laid out in the rest of the bill.

**Sec. 13.56.180, Page 7 on line 31 through page 18 line 7:**

Adds new section stating that a supported decision-making agreement must substantially adhere to the criteria spelled out under the 12 new subsections. Creates a standard statutory form for supported decision-making agreements.

**Alaska Legislature  
Representative Charisse Millett**

Session:  
State Capitol Building  
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**Sectional Analysis of CS for House Bill 336 Version U**

Section One: Amending AS 13, which related to decedents' estates, guardianships, transfers, trusts and health care decisions, by adding a new chapter – chapter 56

13.56.010: Authorizes adults to enter into a supported decision-making agreement (SDMA) and spells out reasons why an adult may not enter a SDMA.

13.56.020: Describes the requirements adults must meet to be qualified as supporters in SDMAs.

13.56.030: Sets the parameters for what a SDMA must contain to be legitimate. Also deals with alternate supporters and sharing of information amongst supporters.

13.56.040: This section lays out the precise requirements for a SDMA to be valid, and how the principal and supporter(s) may formalize the signing of the SDMA.

13.56.050: Mandates that each supporter acknowledge their relationship with the principal and their responsibilities to support the principal.

13.56.060: Delineates who a witness to the signing of the SDMA can and cannot be.

13.56.070: Clarifies when a SDMA becomes effective and how long they last.

13.56.080: This section details how either a principal or supporter(s) of a SDMA may terminate all or portions of a SDMA. Likewise, explains what happens to a SDMA if only portions of it are terminated.

13.56.090: States the general duties of supporters.

13.56.100: Outlines the areas of a principal's life, including health, finances, education and communication, that a supporter may provide support in. Also provides a way for supporters to help the principal deal with health information covered under federal healthcare privacy laws.

13.56.110: Prohibits supporters from wrongfully guiding and influencing the principal in a harmful manner. This section also prohibits supporters from using or obtaining the principal's personal information without their consent.

13.56.120: Requires the supporter(s) of a principal to keep all information related to the principal confidential, protected and shielded from unauthorized use.

13.56.130: Directs people who interact with principals/supporter(s) to recognize the communication, requests and decisions made by the principal (with support from the supporter(s)) as if that communication, request or decision was made solely by the principal.

13.56.140: This section absolves a person (for three distinct reasons) from civil or criminal liability or discipline for unprofessional conduct if they either comply or decline to comply with an authorization in a SDMA.

13.56.150: Delineates the circumstances in which a principal is capable and has capacity. A principal doesn't lack capacity based on how they communicate. Likewise, a principal may make decisions without the support of a supporter(s). Lastly, the existence of a SDMA doesn't mean a principal lacks capacity.

13.56.160: Deals entirely with the affairs of a principal that a SDMA may cover. Work, healthcare, support services education, finances, living arrangements and more are all discussed.

13.56.170: This section spells out the multitude of support services, as referenced in 13.56.160, that supporters may provide the principal as agreed upon in the SDMA.

**New Section: 13.56.180:** This section creates a statutory form for supported decision-making agreements as prescribed in the other sections of HB 336.

- 1) Introduction: Principal declares their desire to enter a SDMA.
- 2) Supporters: Supporters fill out their information and select what they will be helping the principal with. Provides for an alternate supporter to enter the SDMA.
- 3) Information Access Forms: Enables supporters to obtain the principal's private information.
- 4) Guardians and Conservators: Principal must declare whether they have a guardian or conservator.
- 5) Notice to Third Parties: Outlines the rights and obligations of supporters and ensures that a third party must recognize a principal's request or decision as declared under AS 13.56.130.
- 6) Duration and Termination of Agreement: Principals may end the agreement at any time by giving notice to their supporters.

- 7) Signature of Principal: Recognition of voluntary signature of the principal to enter the SDMA
- 8) Signatures of Supporters: Self explanatory
- 9) Declaration of Supporters: Supporters and possible alternate supporter sign again and acknowledge their role to help the principal with the mutually agreed upon terms.
- 10) Notarization or Witnessing: Provides area for notary or two witnesses to sign and make the SDMA official.
- 11) Approval by Guardian: Space for the guardian to approve the principal entering the SDMA.
- 12) Approval by Conservator: Space for a conservator to approve the principal entering the SDMA.

13.56.190: Definitions

13.56.195: The short title of House Bill 336 is the Supported Decision-Making Agreements Act.

Section 2: Amends Alaska Court Rule 402, Alaska Rules of Evidence, to clarify that the execution of a SDMA cannot be used as evidence of a principal's incapacity.

Section 3: Amends the uncodified law of Alaska by amending Court Rule 402 and clarifies the two-thirds majority vote of each house needed to achieve such action.

# Fiscal Note

State of Alaska  
2018 Legislative Session

Bill Version: HB 336  
Fiscal Note Number: \_\_\_\_\_  
( ) Publish Date: \_\_\_\_\_

Identifier: HB336CS(HSS)-DHSS-SDSA-4-6-18  
Title: SUPPORTIVE DECISION-MAKING  
AGREEMENTS  
Sponsor: MILLETT  
Requester: House JUD

Department: Department of Health and Social Services  
Appropriation: Senior and Disabilities Services  
Allocation: Senior and Disabilities Services Administration  
OMB Component Number: 2663

**Expenditures/Revenues**

Note: Amounts do not include inflation unless otherwise noted below. (Thousands of Dollars)

	FY2019	Included in	Out-Year Cost Estimates				
	Appropriation Requested	Governor's FY2019 Request	FY 2020	FY 2021	FY 2022	FY 2023	FY 2024
<b>OPERATING EXPENDITURES</b>	<b>FY 2019</b>	<b>FY 2019</b>					
Personal Services							
Travel							
Services							
Commodities							
Capital Outlay							
Grants & Benefits							
Miscellaneous							
<b>Total Operating</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>

**Fund Source (Operating Only)**

None							
<b>Total</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>

**Positions**

Full-time							
Part-time							
Temporary							

**Change in Revenues**

None							
<b>Total</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>

**Estimated SUPPLEMENTAL (FY2018) cost:** 0.0 *(separate supplemental appropriation required)*  
*(discuss reasons and fund source(s) in analysis section)*

**Estimated CAPITAL (FY2019) cost:** 0.0 *(separate capital appropriation required)*  
*(discuss reasons and fund source(s) in analysis section)*

**ASSOCIATED REGULATIONS**

Does the bill direct, or will the bill result in, regulation changes adopted by your agency? No  
If yes, by what date are the regulations to be adopted, amended or repealed? n/a

**Why this fiscal note differs from previous version/comments:**

The committee substitute removed the regulatory authority of the Department; and no longer requires the Department to develop the supported decision-making agreement form.

Prepared By: Duane Mayes, Director	Phone: (907)269-2083
Division: Senior and Disabilities Services	Date: 03/12/2018 09:56 AM
Approved By: Shawnda O'Brien, Asst. Commissioner	Date: 03/13/18
Agency: Health and Social Services	

FISCAL NOTE ANALYSIS

STATE OF ALASKA  
2018 LEGISLATIVE SESSION

BILL NO. CSHB336(HSS)

Analysis

**HB336 version "O"** amends AS 13 to add a new Chapter 56 *Supported Decision-Making Agreements*. A supported decision-making agreement, created by this bill, formalizes the relationship between an individual requiring supported decision-making and the individual providing the support.

The purpose of this bill is to support and respect the independence of Alaskans who are elderly and persons with disabilities. The supported decision-making agreement allows individuals to make significant decisions and exercise their legal capacity with the assistance of designated "supporters." Similar to executing a power of attorney, a supported decision-making agreement is an informal agreement that does not require court involvement or the associated costs, is voluntary, and may be terminated by either party at any time.

The committee substitute no longer expressly grants regulatory authority to the Department; and no longer requires the Department to develop the supported decision-making agreement form.

No significant fiscal impact to the Division of Senior and Disabilities Services is anticipated.

1841 Chelton Lane  
Fairbanks, Alaska 99709  
February 12, 2018

To Whom It May Concern,

I support House Bill 336, a bill that adds Supported Decision Making (SDM) agreements as an option to guardianship in Alaska. SDM agreements are planned and written by a set process, with supporters that are chosen by the person who wants support. These valid agreements will have specific ways that supporters will help with decisions and will have safeguards to protect the well-being and independence of adults with disabilities.

SDM agreements are planned and written by a set process, using supporters that are chosen by the person who wants support. These valid agreements will have specific ways that supporters will help with decisions and will have safeguards to protect the well-being and independence of adults with disabilities. There will be a basic template form for the SDM agreements, but each agreement will be individualized to convey the directions of the person who wants support, and the ways they want to be supported

I have full guardian and conservatorship for my 24 year old son who experiences both a developmental and a mental health disability. Although I have the authority to make decisions for him, he and I have always discussed decisions and come to an agreement before a decision is made. This process has always worked well works well for us as well as several other guardians I know. SDM would be a great option for my son. It would empower him and give him more control of his life. Our public guardians, working under the Office of Public Advocacy, are overwhelmed because each public guardian has over 100 wards for whom they make decisions. Inserting SDM agreements as a third option in Alaska Guardianships would take some of that burden from Public Guardians.

The passage of HB336 will allow a person the opportunity to have a voice in how they live their lives. Research shows that people who make more decisions about their lives are more involved in the community, more likely to have supported employment, and more likely to report satisfaction with their lives Control of your life brings about empowerment, self-determination, and a positive mindset. I encourage legislators to work to move HB336 through the legislative process as soon as possible.

Sincerely,



Art Delaune  
907-479-2838  
[Adelaune555@gmail.com](mailto:Adelaune555@gmail.com)

## **Supported Decision Making Act**

### **Our Position**

AARP Alaska endorses the Supported Decision Making Act. HB 336

### **GOALS**

1. Adults who are vulnerable or live with disabilities have support from people for making life decisions. Supporters agree, in writing, to take direction from these adults on getting information, talking about outcomes, telling other people about a person's choices and doing other things that the adults want for support when they are making life decisions.
2. Adults with Supported Decision Making (SDM) Agreements do not have their rights to make decisions taken away from them like they would with guardianship orders. They have the information and support that they need about their choices to exercise the same rights that others have to choose where to live, what services they get, how to spend their money, and who they spend time with.
3. Supported Decision Making continues familiar and lifelong ways of making choices. It is very common throughout life to confer with family, friends, a physician, a financial planner, or a member of the clergy when big decisions are made. SDMA's formalize that familiar process as needs and capacity change.

### **WHAT**

1. Supported Decision Making Agreements are planned and written by a set process, with supporters that are chosen by the person (the principal) who wants support.
2. Valid agreements will have specific ways that supporters will help with decisions and will have safeguards to protect the well-being and independence of vulnerable adults and those who live with disabilities.

3. There will be a basic template form for the SDM Agreements, but each Agreement will be individualized to express the directions of the person who wants support, and the ways they want to be supported to make decisions.
4. This Bill does not:
  - A. Interfere or change the established law regarding legal capacity to make decisions or the court processes on petitions for guardianship or conservatorship. It is just another option for people to use.
  - B. Take the place of other legally established documents such as powers of attorney or advance directives.
  - C. Alter or change a person's responsibility for their own actions
  - D. Cost much; additional funding to implement these changes is estimated to be minimal

#### ***WHY IS IT NEEDED?***

1. People who can make life decisions with support from others around them should not have the right to make those decisions taken away from them by unnecessary government (court) involvement.
2. Alaska has one of the highest rates of full guardianship in the country. The number of guardianships in the state has doubled in the last 7 years. The courts can't keep up with monitoring all the guardianships to make sure rules and guidance are followed. The Office of Public Advocacy (public guardians) is overwhelmed and has too many wards to supervise. Many of the guardianships would be unnecessary if there were an option for a formalized SDM Agreement.
3. Research shows that people who make more decisions about their lives through alternatives to full guardianship are more involved in their community, more likely to maintain their own health, more likely to feel respected and dignified, and more likely to report satisfaction with their own lives.
4. Even people experiencing declining abilities due to a condition like Alzheimer's disease, still can and should maintain remaining skills by

exercising them with support and encouragement. Identity does not have to be lost with memory.

**ASK**

***Please support the Supported Decision Making Act – HB 336***

**Court Rule 402. Relevant Evidence Admissible— Exceptions — Irrelevant Evidence Inadmissible.**

All relevant evidence is admissible, except as otherwise provided by the Constitution of the United States or of this state, by enactments of the Alaska Legislature, by these rules, or by other rules adopted by the Alaska Supreme Court. Evidence which is not relevant is not admissible. (Added by SCO 364 effective August 1, 1979; amended by SCO 1841 effective October 6, 2014)

Note: Chapter 110 SLA 04 (HB 285) adopts the Uniform Electronic Transactions Act. According to Section 3 of the Act, AS 09.80.100, enacted in Section 1, has the effect of amending Evidence Rule 402 by adding a provision that prevents electronic evidence of a record or signature from being inadmissible as evidence just because it is in electronic form.

Note: Chapter 62, SLA 2014 (HB 250), effective October 6, 2014, enacted various changes, including a new section AS 09.55.544 restricting the evidence that is admissible in medical malpractice actions.

# **HB 336: THE SUPPORTED DECISION-MAKING AGREEMENT ACT**

## **Who Can Enter into the Agreement?**

A supported decision-making agreement may be entered into by an adult who wants assistance with getting information, weighing options, identifying possible outcomes, or communicating decisions to others. It is a tool that can help seniors who have an early diagnosis of dementia and who want a commitment of support from multiple caregivers, rather than relying only on their spouse or an adult child. Adults who want to continue the support and advice of family and friends but who don't want to lose responsibility for their choices can avoid unnecessary guardianships with supported decision-making agreements. And those adults who have guardians, but who understand the nature and effect of an agreement, can use the agreements to build their capacity by experiencing shared responsibility for making decisions – while still having the oversight of a guardian.

The individual should have the ability to understand that a supporter will be assisting him or her with particular decisions, and to be able to make decisions with the help of supporters.

## **Who Can Be a Supporter?**

A supporter may be any adult, and is usually a family member or friend. The adult who wants a supported decision making agreement has the free will to choose who will serve as their supporters. The individual chooses people they trust, as trust is the foundation of the process. A supporter must agree to serve in that capacity, and must be willing to provide the time and commitment necessary to carry out the agreement. A supporter should be able to clearly understand and communicate with the person to be supported. Each supporter makes a signed declaration to provide the assistance that is described in the agreement.

## **What is the Scope of the Agreement?**

The agreement will be individualized to the needs and strengths of the adult, who is called a "principal". It may be customized to fit the circumstances or situation that the principal is in.

The principal may allow their supporter to help gather information needed for a life decision, support the decision-making process by helping the adult evaluate and understand the options and consequences, and communicate that decision to other parties. The agreement may be established for one specific decision or for many decisions.

The agreement allows the individual to decide which decisions they would like assistance with:

- Obtaining food, clothing and shelter
- Taking care of physical or mental health
- Managing financial affairs
- Obtaining education or training
- Choosing and maintaining supports and services
- Finding a job

The individual may authorize a supporter to do any or all of the following:

- provide supported decision-making, including assistance in understanding the options, responsibilities, and consequences of the adult's life decisions, without making those decisions on behalf of the adult;

- assist the adult in accessing, collecting, and obtaining information that is relevant to a given life decision;
- assist the adult with understanding the information relevant to a decision; and
- assist the adult in communicating the adult's decisions to others.

### **What Authority Does A Supporter Have?**

A supporter has no authority to make the decisions for the principal. A supporter is only allowed to assist the individual with whatever is specified in the agreement. Supporters help the individual gather information and process that information in order to make an informed decision. A supporter can also assist in communicating the decision to the necessary third parties. A supporter merely assists the individual -- the individual is "the decider." A supporter does not have the authority to make financial transactions on behalf of the principal.

### **What Rights Are Maintained By The Principal?**

The agreements do not change any of the principal's existing rights to make decisions. If there is a guardianship order that overlaps with an area of decision-making described in the agreement, the guardian must approve of the agreement. The principal can reject the advice of a supporter.

### **What are the Execution Requirements?**

The adult must sign the agreement voluntarily, with no coercion or undue influence. A supporter must indicate consent to serve in that capacity by signing the agreement and making a declaration, as well. The adult and each supporter must sign in the presence of either two witnesses or a notary public. If the principal has a guardian, notice must be given to the guardian and the guardian must approve in writing.

One of the advantages of the use of supported decision-making agreements is that the parties do not necessarily need an attorney, and no court involvement is required. It is therefore less expensive and may be more accessible to parties with limited financial means. It may also be less stressful to the parties than a guardianship proceeding.

### **How Does It Differ From a Power of Attorney?**

A power of attorney grants an agent the authority to make decisions and handle matters without input from the individual. A supported decision-making agreement does not give supporters the power to make decisions—the principal retains right to make decisions for himself or herself.

### **How Long Does The Agreement Last?**

The agreement may specify an expiration date; otherwise it is effective until the adult or a supporter terminates the agreement. The agreement will also become invalid if the principal is subsequently found to need a guardian or a conservator.

### **Is Personal Information Protected?**

The agreement allows a supporter to access private information only as needed to assist the adult with disabilities in obtaining or accessing information relevant to making the decision authorized by the agreement. If a supporter needs access to medical or other records protected by the Health Insurance Portability and Accountability Act of 1996 ("HIPAA"), the adult must sign a HIPAA release giving the supporter that access. If the adult would like the supporter to access educational records, he or she must sign a release under the Family Educational Rights and Privacy Act of 1974 (20 U.S.C. § 1232g).

The supporter is required to ensure that the information is kept confidential and privileged and must protect the information from unauthorized access. The supported decision-making agreement does not prevent the individual from seeking their own personal information without assistance of supporter. The individual's right to their own information is preserved.

### **What Are the Liability Risks for Someone Relying on the Agreement?**

The bill provides that a person shall rely upon the original or copy of the supported decision-making agreement. The bill absolves someone of liability for acting in good faith while relying on a supported decision-making agreement.

### **What about Abuse?**

Because supported decision-making agreements are informal, there is no court supervision over supporters. The agreement is entered into in private and supporters are not subject to formal accountability through the bill. However, protections already exist by operation of other statutes. Principals who have free agency are protected by the laws that protect all of us from fraud, exploitation, abuse and other criminal acts. They are also protected from changes to their own legal capacity to make decisions. The availability of emergency petitions for temporary guardianship, Title 47 commitments, and the role of mandatory reporters of crimes against vulnerable adults are all unaffected by the bill or the agreements. For principals who have a guardian, there is also the additional oversight of court supervision of the guardian's actions. The bill and the agreements do not change any of those existing protections.

### **Can Supported Decision-Making Be Used With Guardianship and Other Alternatives?**

A supported decision-making agreement theoretically could be used in conjunction with guardianship alternatives such as powers of attorney or a representative payee contract. It is possible that it could be used with a limited guardianship if the right to make the specific decision is retained by the ward. This use should be consistent, however, with the goal of promoting self-determination of the principal and avoiding a full guardianship. Other tools like Able Act accounts, Powers of Attorney, and Advanced Health Care Directives can also be used with the agreements.

## **CONCLUSION**

Supported decision-making agreements can be an excellent tool to allow people to make their own decisions with the support they need. The supported decision-making agreement does not protect an individual from bad decisions. We all have the freedom to make bad decisions—this is known as the “dignity of risk.” Every life experience has some degree of risk, and we can learn from our mistakes as well as our successes. We often grow the most from our failures. People want to have responsibility for themselves and take on that risk.

There is a careful balance between supporting independence and protecting someone against risk. But the Supported Decision-Making Agreement Act would be a positive move away from paternalistic substitute decision-making and toward self-determination and equal access to choices about one's life.

# FRAUD

## In The Family

Who is most likely to cheat or swindle you, or steal from you? The people you know best. Here's how it happens, why police stay mostly uninvolved and what you can do to protect yourself **By Gary Weiss**

**W**HEN YOU think of the villains who defraud older people, you might picture crooks hacking into bank accounts or selling bogus stocks. But don't be misled. The real scoundrels might be sitting at your next family gathering, looking as innocent as folks in a Norman Rockwell painting. Roughly 6 out of 10 cases of elder financial abuse are committed by relatives, according to a large-scale 2014 study. And about 3 out of 10 instances can be traced to friends, neighbors or home care aides. In other words, 90 percent of perpetrators of fraud are known to their victims.

Even scarier: The closer the tie between perpetrator and victim, the greater the damage. A detailed study of elder financial abuse in Utah found that the amount stolen by people who knew their victim averaged \$116,000—nearly triple the haul taken by strangers. Criminals within the family got even more: \$148,000. And the thieves who stole the most money—\$262,000, on average—were the victims' children.

Maybe you thought such thefts occurred only among the rich and famous—think of Brooke Astor, the New York heiress whose son was convicted of swindling her.

But elder-abuse experts say this crime infects a wide range of households. You just don't hear about it. Only 1 in 44 cases of elder financial abuse get reported, estimates the National Adult Protective Services Association. Why? Victims are embarrassed. Families don't want to air conflicts. People doubt money will be recovered. They also fear the perpetrator.

What follows is an attempt to spotlight this scourge—with true stories of exploitation, plus advice for preventing and remedying it. Our narratives are based on witness interviews, legal records and other documents. Due to some sources' fear of retaliation, some identities have been disguised.

### 1 The Distant Son

In 2005, 88-year-old Francine Maloney was suffering from dementia and about to move to an Orange County, California, assisted living facility. (All names in this family have been changed.) Maloney had given her daughter, Amy,



power of attorney to handle her affairs in 2000, a year after Francine's husband had died. Amy, also from California, put her mother's home up for sale.

Then Amy's only sibling, Randy, got involved. His relationship with their parents had always been strained, and he had an alcohol problem they were slow to recognize, Amy says. In 2005, Randy was living with his wife, Madeline, in Westchester County, New York, and hadn't been around much. But when he learned the house had to be sold, he became attentive—fast, Amy recalls. Unbeknownst to Amy, he flew west and got Francine to sign a new power of attorney giving him total control over her finances. Amy consulted a lawyer about fighting back, but the \$10,000 retainer was too much. She and her brother stopped talking.

Once the house was sold, the \$450,000 proceeds went into a trust for Francine's benefit, controlled by Randy. In theory, Francine had plenty of money. Amy, however, suspected something was amiss. Yet a lawyer was too expensive, and she doubted social service agencies could help. So she communicated her concerns to Randy via his attorney and left it at that.

That is, until she visited her mother in May 2010 and found a fraud-alert notice for a Bank of America credit card in her mother's name. The letter listed more than two dozen suspicious charges, including \$1,135 from a Boston hotel, a \$372 Boston car rental and a \$250 dry cleaning bill in Maryland where Randy then lived. Amy later determined that Randy had additionally revived a dormant Citibank credit card of Francine's and was using it to pay for his living expenses. Payments to that account, Amy concluded, were coming from her mother's trust account. By mid-2010, the account that had been seeded with \$450,000 from the sale of Francine's home had dwindled to \$158.51—and the assisted living facility was owed nearly \$9,500. Francine was broke.

After Amy filed a police report in June 2010, the local California sheriff's office subpoenaed checks drawn on the trust account. One expenditure: \$9,100 to a luxury-car dealer. Checks made out to Randy's wife totaled \$35,000.

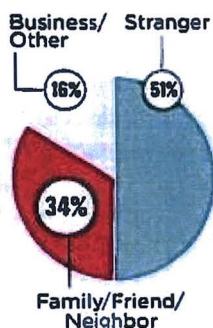
"I wasn't shocked," Amy says.

Contacted for this article, Randy said he is 14 years

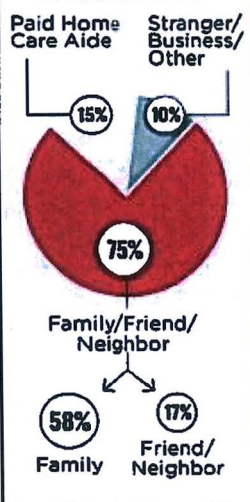
## WHO RAIDED OUR SAVINGS?

Strangers, sure, but family and friends are the more likely culprits

### Perception WHO COMMITS FRAUD IN MEDIA REPORTS



### Reality WHO ACTUALLY COMMITS FRAUD



sober. He disputed the overall amount Amy alleges he took from Francine's account, asserting it was in the "low-six-figure range." But he admitted via email that he took the money for his personal expenses and expressed remorse, terming his behavior "the most regrettable thing in my life." He wrote, "I was under some financial pressures that I was too weak to stand up to. ... The intention was always that the money would be returned from future realized gains."

In the end, he got away with it. The sheriff in California told Amy the prosecutor had declined to pursue the case; the D.A., contacted for this article, has no record of the sheriff's referral. Prosecutors in Maryland passed as well, suggesting Francine wouldn't be able to fly east to testify. The FBI said no, too. Amy could not afford to file a civil suit against her brother. "He is dead to me," she says. "How can you do that—steal from your mother for luxuries?"

Eventually, Francine had to leave the assisted living facility. Because she couldn't afford a nursing home, Amy placed her mother in a Social Security-financed small-scale custodial-care facility, a converted private home. Care was barely adequate. Francine died in February 2016, at age 99. "None of us would want to live like that," Amy says.

### FRAUD TAINTED BY EMOTION

Elder financial abuse, as in Francine's case, doesn't appear out of the blue, experts say. It may be the result of long-festering family issues. Sometimes a big dose of rationalization is involved. "One of the things I've heard is, 'It's OK to steal or take this money from Mom and Dad because it's my inheritance,'" says Jilene Gunther, director of AARP's BankSafe initiative.

Substance abuse may also play a role, Gunther says. The perpetrator may be a child or friend with a drug addiction.

Once someone close to you gets over the moral hurdles, the logistics are easy. A relative or friend, unlike a larcenous stranger, knows or can quickly find out exactly what you own and where it is. Most important, that person has your trust. Once a fraudster has that, experts say, getting you to agree to requests is relatively simple.

"This is the easiest crime to commit," says Karen Sundstrom, who works for the Lexington County, South Carolina, Recreation and Aging Commission as an advocate for older adults who experience abuse. "It's a piece of cake."

PERCEPTION CHART NOTE: TOTAL DOES NOT EQUAL 100 PERCENT BECAUSE OF ROUNDING. CHARTS SOURCES: "THE NET USE STUDY OF ELDER FINANCIAL ABUSE," JUNE 2016; FINANCIAL EXPLOITATION OF OLDER ADULTS: A POPULATION-BASED PREVALENCE STUDY," JULY 2014



## 2 The Family Friend

Ethel Simmons, now 87, expected to live out her life in comfort. She had pension income, Social Security and money in the bank. And, above all, a home.

She and her late husband, Elgie, bought their house in 1962 and raised their three sons there. It's a green one-story dwelling with a large detached garage, located in south-central Los Angeles. Ethel was a full-time homemaker; Elgie worked as a mechanic in a factory. Johanna Holmes, whose parents were friends with the Simmonses, remembers the two families picnicking together when she was a kid. Johanna's "Aunt Ethel" was active in the Church of God in Christ; she was, Johanna says, "fun loving, kind and caring."

After Elgie died, in 2011, Ethel continued to live in the house, which had three rental units. One was occupied by her middle son, Wayne. (Ethel's oldest child, who was born disabled, lives in a group home; her youngest son doesn't figure in this story.) Wayne, who Johanna says was Ethel's favorite, had been in trouble with the law over the years—a conviction for car theft, for one, and convictions or guilty pleas for drug possession and possession with intent to sell. "He was an addict," says Johanna.

Wayne also had some worrisome friends, including one we'll call Alfred.

Alfred grew close to Ethel after Elgie died. He shopped for her groceries. Ethel grew to trust him. Johanna didn't. Around 2012, Ethel told her that Alfred wanted to buy her house for \$200,000. Johanna, who suspected that Wayne was involved, was stunned. "I said, 'How is he going to afford \$200,000 when he doesn't even have a job?'" she remembers. Ethel declined the offer.

In 2015, Alfred moved onto the property. He soon went with Ethel to the bank and became joint owner of her only account. The balance wasn't high—maybe \$2,500—notes Nicholas Levenhagen, a lawyer with Bet Tzedek Legal Services who later got involved in Ethel's case. Money, however, was flowing in from Social Security and Elgie's pension.

Early in 2016, after a stroke put Ethel in the hospital, Alfred had her meet with a man he said was an attorney, supposedly to discuss what Ethel understood were tax and insurance issues. Ethel didn't remember signing a thing. It's not clear even now who the "attorney" was, according to subsequent litigation. But somehow Alfred got the title to Ethel's home, and Ethel never got a penny.

Ethel didn't tell Johanna about any of this. But by March 2016, Alfred had begun intercepting Johanna's calls to Ethel, making excuses for why she wasn't available. Once, when Johanna got through, Ethel sounded frightened. "Why are you whispering? This is your phone," Johanna recalls saying. By this time, according to court documents, Alfred controlled Ethel's life, physically and financially. He used the joint account as a piggy bank, spending Ethel's money for restaurant meals and gas bills. He drove around in a Mercedes. The City of Los Angeles alleged that narcotics were being sold out of Ethel's garage.

Johanna, increasingly worried, recalls that on Good

### PREVENT IT

Protect your loved ones from financial abuse with these steps

**STAY IN TOUCH**  
Isolation is the exploiter's friend, says prosecutor Paul R. Greenwood. If you can't visit regularly, buy your relative a device with Skype or FaceTime so you can see his or her face, and check in often.

**BEWARE OF THE FOG**  
Mental impairment raises the risk of abuse. At the first signs of a person's dementia or other cognitive decline, go on high alert—and gently suggest getting help with finances.

**BE CAREFUL OF CAREGIVERS**  
Interview them and check references, even if their agency says they've been screened. Make unannounced visits. Inventory valuables, and let the caregivers know you've done so.

**LOOK OVER SHOULDERS**  
If one sibling handles Dad's finances, give read-only access to his accounts to another relative. Set up automatic alerts to warn loved ones of unusual activity, such as large withdrawals.

Friday, March 25, 2016, she drove over to the now-shabby house and barged in. She was shocked to find drug addicts in the front room. Ethel's room was filthy, and she had been defecating in a pot.

Eventually, Los Angeles Adult Protective Services intervened, after Ethel was hospitalized following another stroke. She was placed in a nursing home, and an APS caseworker put Ethel and Johanna in touch with Bet Tzedek Legal Services, which filed suit to reverse the property transfer. Alfred did not contest the suit.

Ethel said, "I have money in the bank," Johanna recalls. But Alfred had taken it all. Ethel didn't even have any clothing. Hers were so foul that they had to be thrown out when she went to the hospital, Johanna says.

The house, with the title reverted back to Ethel, was sold in July for \$440,000, which can be used for Ethel's care. Johanna closely monitors the nursing home: "I have them on their toes when it comes to her."

Ethel is not pursuing further legal action. Alfred cannot be located. As for Wayne's role in what happened, Johanna is clear: "God forgive me, but I can't stand him," she says. "No way would I let anyone violate my parents."

#### WHERE'S JUSTICE?

Financial elder abuse is a crime. It's theft. Yet people who complain to law enforcement are frequently told that it's a "family" or "civil" matter or that the older person "won't press charges." These aren't valid reasons to avoid action, says Paul R. Greenwood, head of the San Diego District Attorney's Office Elder Abuse Prosecution Unit. Child-abuse victims, he notes, don't decide whether abusers are charged.

Another excuse for not prosecuting is a victim's inability to testify. But Peter A. Lichtenberg, director of the Institute of Gerontology at Wayne State University in Detroit, says that elder-abuse cases rely on forensic examination of financial records more than they do on witness testimony.

An added hurdle: Police and prosecutors may be suspicious about those who make accusations. "I often get these calls from adult family members who want me to prosecute the other sibling," Greenwood says. "I interrupt and say, 'Now, where were you when all this was going on?'"

Plus, a victim might say the money was a gift, says Greenwood: "He's a nice boy, and he's been helping me around the house.' Those arguments are very difficult to overcome."

There's one more reason these crimes are rarely prosecuted. People who have been robbed won't admit it. "It's

## TAKE ACTION

If you suspect exploitation of a loved one, do this

### GATHER EVIDENCE

Have a low-key talk with the suspected victim to see if he'll provide evidence (or at least clues) of abuse you can relay to authorities.

### BLOW THE WHISTLE

Contact adult protective services. (To find your closest APS agency, go to [napsa-now.org](http://napsa-now.org) and click Get Help.) You don't need a full-blown case—just a well-grounded suspicion.

### CALL THE COPS

Have clear evidence of theft? File a report with the police, and make their job easier by compiling and organizing the paperwork yourself.

hard to get victims of elder abuse to talk," says Lori Delagrammatikas, a longtime specialist in elder abuse and the incoming president of the National Adult Protective Services Association. "They're so embarrassed."

## 3 The Housekeeper

Lori Delagrammatikas is quite familiar with the embarrassment caused by elder financial abuse. It happened to her mother. Janet Dermay had a doctorate in education and spent her life as a teacher, at one time running a small technical college. She was a tough, hardheaded woman. She was perfectly fine—self-sufficient and healthy—when, at 76, she moved into an independent-living facility north of Phoenix in 2009.

Janet, like other residents, had an apartment with a small kitchen. On-staff housekeepers tidied up every day. While residents could get rides to local places, Janet drove herself in a late-model four-door sedan.

One day in 2012, Janet told Lori—who lived a seven-hour drive away—that she had a new car. Janet also told Lori that months before, she had sold the previous car to her housekeeper. The housekeeper (let's call her Mary) had been chatting daily with Janet about her marriage. "She said she was a victim of domestic violence, her husband didn't work, and he was pushing her to work more and more hours," Lori says. Mary told Janet that she needed a car because her old one wasn't working.

Janet, taking pity on Mary, sold her car to her for monthly payments of about \$100. Lori never learned how much Mary promised to pay in total. There was no paperwork. All she discovered was that not long after Mary made her first (and only) payment, she vanished. She was dismissed for borrowing money from residents.

Janet had been conned. "I see it so much at work that I wasn't surprised," Lori admits. "But I was frustrated my mom wasn't willing to do anything about it," such as file a complaint. Janet died last year. "It's humiliating when you get ripped off," Lori adds. "It hits people in the deepest level of their self-image."

Lori was developing a training program for protective services workers when her mother was swindled. "I talked to my mom a lot about the work I do—'Oh, let me tell you about the latest scam that's happening,'" Lori says. "Didn't make a bit of difference."

*Gary Weiss, a longtime investigative reporter, was formerly at BusinessWeek and Condé Nast Portfolio. He has contributed to Barron's and other magazines and has written three books*

# SUPPORTED DECISION MAKING PILOT: Pilot Program Evaluation Year 2 Report

Prepared for the Center for Public Representation  
and Nonotuck Resource Associates, Inc.

*Authors: Elizabeth Pell, MSW, LICSW, and Virginia Mulkern, PhD*



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A selection of HSRI's evaluation findings are presented below.

- Regardless of age, diagnoses, or life histories, these SDM adopters understand that SDM means making their own decisions and receiving decision help when they want help. All adopters reported that SDM is a positive experience.
- Decisions made reflected the preferences of SDM adopters.
- SDM adopters and decision supporters were satisfied with the process of providing decision assistance as well as with the decisions made.
- A variety of decisions were made—from everyday decisions to very important decisions. SDM was most frequently used for health care decisions followed by financial decisions, areas of concern that often lead to use of guardianship and conservatorship.
- Involved community members acted on the expressed preferences of SDM adopters, and did so without documentation of decisional capacity or decision supporter role.
- Having multiple supporters worked well in this pilot. Decision supporters were committed to regular and ongoing communication.
- SDM adoption and use made a definite and positive impact on the lives of adopters. One individual's right to make decisions was restored when the probate court discharged his guardianship.
- Observable differences were noticed in the personal growth of SDM adopters, along with increased self-esteem and self-advocacy, more engagement in decision making, and increased happiness.
- SDM adopters did not experience abuse, neglect or financial exploitation as a consequence of SDM. Many pilot participants believe that the structure of SDM—selecting people one trusts to help make decisions and having more than one decision supporter—reduces such risks.
- For the SDM adopters, additional opportunities for expansion of decision making authorities exist, such as utilizing the self-directed services option for services funded through the state developmental disabilities agency.
- Decision supporters, care managers and CPR staff believe this intentional SDM pilot demonstrated that SDM is a viable means to provide people with I/DD and other disabilities customized decision making assistance that allows people to keep their decision making rights, has a positive impact on their self-respect, and can reduce society's use of guardianship.
- Pilot participants believe SDM would be helpful for other populations whose decision making rights are often removed—specifically older adults with early stage dementias, adults with psychiatric disabilities, and youth with I/DD who become legally recognized adults at age 18, an age when many families are counseled to secure guardianship.
- This pilot was faithful to the values and principles of SDM.

## Alaska Guardianship by the Numbers

- Petitions increased 59% between 2010-2016
  - Total for 2016 was 723 petitions
  - Approximately doubled the number in the last seven years
- Nat'l Core Indicators data shows 96% of Alaskan respondents had full guardianship
  - NCI average = 55% had full guardianship
- Assets controlled by guardians = \$100 million in the annual reporting (2017)

## Alaska Guardianship by the Numbers, cont'd

- Elder population doubling between 2012-2042
- Average life expectancy for person who experiences I/DD
  - 22 years old in 1930s; now 70 years old
- Office of Public Advocacy (1500 wards (2017) statewide)
  - "Fully staffed": 1 guardian to 90 ward
  - 2/2017 report: 1 guardian to 100 wards
    - 1:109+ as of 1/2018
  - Lawsuit alleging failure to visit wards

Nationally recommended  
Maximum: 1:40  
(Nat'l Guardianship Assn.)

## Legal Capacity in Alaska

- **“Incapacitated person”**
  - **Impairment of ability**
    - to receive and evaluate information or
    - to communicate decisions
  
  - **That causes a lack of ability**
    - to provide the essential requirements
    - for physical health or safety
    - without court-ordered assistance

## Legal Capacity in Alaska, cont'd

- **“essential requirements” for health and safety**
  - health care, food, shelter, clothing, personal hygiene and protection
  
  - without which serious physical injury or illness is more likely than not to occur

## Alaska Guardians' Authority

- A full guardian of an incapacitated person has the same powers and duties respecting the ward that a parent has respecting an unemancipated minor
- Except:
  - Least-restrictive abode
  - Institutionalize w/o commitment proceedings
  - Abortion, sterilization, removal of organs
  - Withhold life-saving procedures
  - Prohibit voting
  - Terminate parental rights
  - Prohibit marriage or divorce
  - others



## **Please Join the Council in Supporting HB ?**

### **The Supported Decision Making Act**

#### **WHAT IS IT?**

This bill provides equal access to decision making for adults with disabilities by authorizing written agreements between an adult and supporters which describe a process for making life decisions; including decisions related to a person's finances, where and with whom the person wants to live, the services, supports, and medical care the person wants to receive, and where the person wants to work. Supported Decision Making Agreements would be a legal alternative to full or partial guardianship. This alternative actively engages people with disabilities in creating the decision-making structures and tools that serve their lives and autonomy. This bill formalizes a support process, describes eligible supporters, creates a blueprint for valid written agreements, and provides safeguards to protect the well-being and independence of adults with disabilities.

Supported Decision Making (SDM) is a constitutional and civil rights idea which recognizes that full guardianship is often not the least-restrictive alternative for adults who experience intellectual or developmental disabilities, communication impairment, or dementia. All people use support for making the important decisions of life; needing more, different, or structured help with getting information, setting goals, weighing options, exploring outcomes does not justify unequal treatment and removal of all rights to make a decision.

#### **WHY IS IT NEEDED?**

Alaska has one of the highest rates of full guardianship in the nation. The Office of Public Advocacy (OPA) reports that public guardians are currently each responsible for over 100 wards. The recommended national maximum is a ratio of 1:40. Guardians in Alaska have control over \$100 million of assets of wards, with private guardianships having little or no practical oversight. Guardianship orders in Alaska have doubled in the last seven years, and will likely increase as our senior population grows.

Many good guardians encourage their wards to engage in making decisions about their lives and act on the preferences and choices made by their wards. However, research shows that adults under guardianship orders are less likely to have supported employment, and less likely to be integrated into the community than adults with less-restrictive alternatives to guardianship. Guardianship can lead to a cycle of learned helplessness, where the lack of authority to make decisions leads to increased withdrawal from planning or taking responsibility for adult decisions. Individuals with disabilities who are wards in Alaska report on the loss of independence, self-expression, and dignity that comes from being able to make choices about their lives. It is also important to note that Alaska has recently had an increase of the number of cases of financial exploitation by abusive guardians, problems that stem from the isolation of wards, the number of unexamined guardianship reports, and lack of required monitoring

by the courts.

## HOW WILL IT WORK?

Supported decision-making empowers people with disabilities to use available support to make their own choices so they can live more independent and self-directed lives. So, how does this work? People with disabilities who want to use supported decision-making will:

1. Choose people they trust to help them make decisions.
2. Ask these individuals to be their supporters.
3. Think about the type of decisions they need help making.
4. Complete a written plan called a supported decision-making agreement
5. Provide the agreement to people like doctors and service providers

Then, when people with disabilities need to make a decision and want some extra support, they can call upon their supporters to help them through the process. Supported decision-making agreements are an excellent self-advocacy tool that people with disabilities can use to advocate for the right to make their own decisions, and to have the support they need to make those decisions. This process can be used to help plan for future decision making and avoid the need for a restrictive guardianship.

## COMMUNITY SUPPORT FOR SDM AGREEMENTS:

With the Council's work and vision, Alaska has joined fourteen other states and the District of Columbia in implementing SDM at varying levels. The momentum toward legal recognition of written Supported Decision Making Agreements has been championed by the American Bar Association. Texas and Delaware have enacted Supported Decision Making statutes, and the New York Supreme Court has required SDM Agreements to be legally recognized by lower courts. The U.S. Administration on Community Living supports nation-wide adoption of Supported Decision Making Agreements through state WINGS grants. The Council supported the successful WINGS grant application for Alaska, and is a lead stakeholder in that collaboration along with the court system, the Long-Term Care Ombudsman, and the Office of Public Advocacy. Within the Council, there is also a work group that is facilitating a pilot project to develop and implement written SDM Agreements for several adults to replace or prevent full guardianship orders. The Council has presented on SDM Agreements to a wide variety of audiences and stakeholders this fall, and is creating more training for professional groups and agencies that are involved in adult guardianship or decision making for others. The Council will continue to work with the legislature, the court system, self-advocates community partners, and state agencies to create processes, forms, professional standards, and institutional support for legally recognized SDM Agreements.

## RESOURCES:

- National Resource Center for Supported Decision Making  
<http://supporteddecisionmaking.org>
- American Bar Association Resolution on SDM  
[https://www.americanbar.org/content/dam/aba/administrative/law\\_aging/2017\\_SDM\\_%20Resolution\\_Fin\\_al.authcheckdam.pdf](https://www.americanbar.org/content/dam/aba/administrative/law_aging/2017_SDM_%20Resolution_Fin_al.authcheckdam.pdf)
- Videos of individuals and their families implementing SDM Agreements:  
<http://youtu.be/wfsMAM781Xk>  
<https://www.youtube.com/watch?v=wfsMAM781Xk>  
<https://www.youtube.com/watch?v=DwnJ1nRR0Hs>

## **Talking Points:**

### **Supported Decision Making Act**

#### **ASK**

Please join the Council in supporting the Supported Decision Making Act.

#### **GOALS**

1. Adults with disabilities have support from people for making life decisions. Supporters agree, in writing, to take direction from these adults on getting information, talking about outcomes, telling other people about a person's choices, and doing other things that the adults want for support when they are making life decisions.
2. Adults with Supported Decision Making (SDM) Agreements do not have their rights to make decisions taken away from them by guardianship orders. They have the information and support that they need about their choices to exercise the same rights that others have to choose where to live, where to work, what services they get, how to spend their money, and who they spend time with.

#### **WHAT**

1. Supported Decision Making Agreements are planned and written by a set process, with supporters that are chosen by the person who wants support.
2. Valid agreements will have specific ways that supporters will help with decisions and will have safeguards to protect the well-being and independence of adults with disabilities.
3. There will be a basic template form for the SDM Agreements, but each Agreement will be individualized to express the directions of the person who wants support, and the ways they want to be supported to make decisions.

**4. This Bill does not:**

- A. Interfere or change the established law regarding legal capacity to make decisions or the court processes on petitions for guardianship or conservatorship. It is just another option for people to use.
- B. Alter or change a person's responsibility for their own actions
- C. Cost much; additional funding to implement these changes is estimated to be minimal

**WHY IS IT NEEDED?**

1. People who can make life decisions with support from others around them should not have the rights to make those decisions taken away from them by the government.
2. Alaska has one of the highest rates of full guardianship in the country. The number of guardianships in the state has doubled in the last 7 years. The courts can't keep up with monitoring all the guardianships to make sure rules and guidance are followed. The Office of Public Advocacy (public guardians) is overwhelmed and has too many wards to supervise. Many of the guardianships would be unnecessary if there was an option for a formalized SDM Agreement.
3. Research shows that people who make more decisions about their lives through alternatives to full guardianship are more involved in the community, more likely to have supported employment, and more likely to report satisfaction with their lives.

**SHARE**

A personal story or someone else's story about why this bill is necessary.

**ASK**

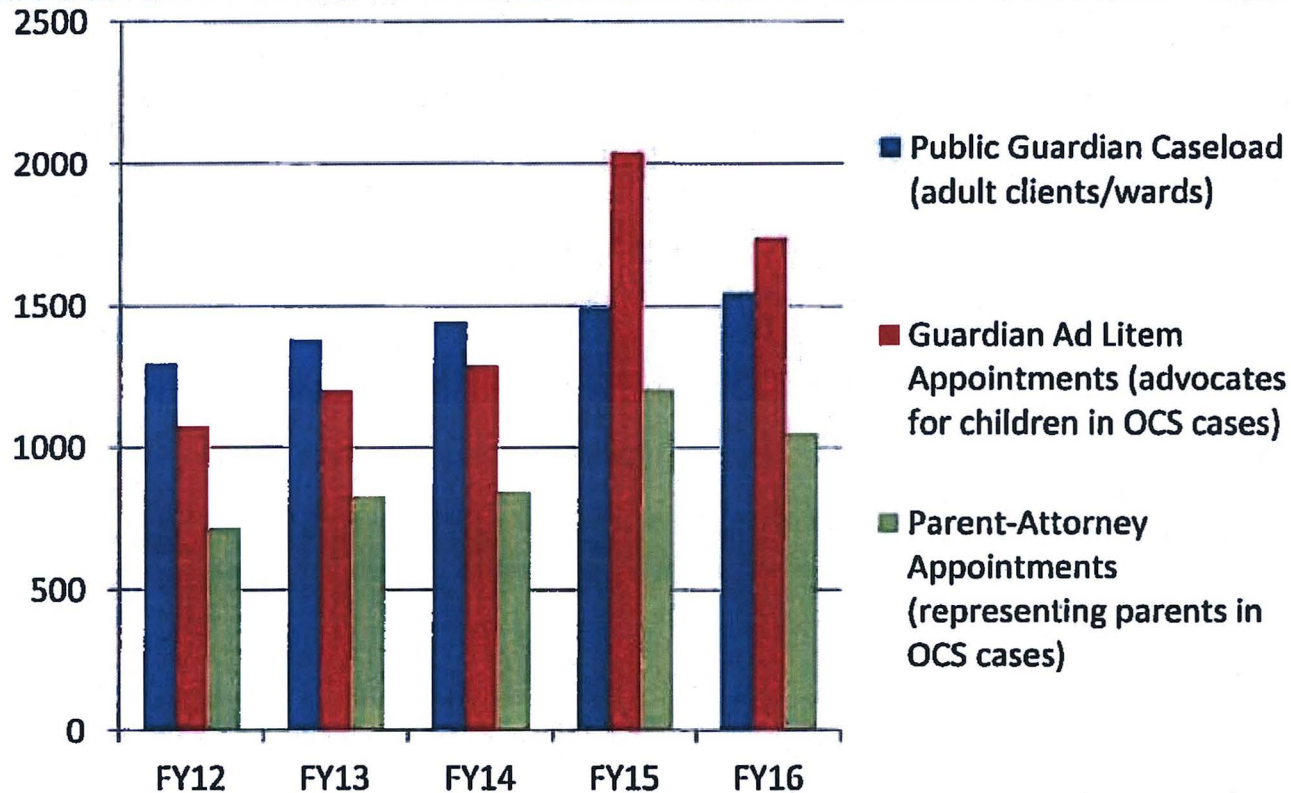
**Please support the Supported Decision Making Act.**

## OPA Challenges – Public Guardian

---

- 90 Wards per Public Guardian when at full staff - recommended National Maximum is 40
- Crushing workload is causing low morale and difficulty in filling open positions resulting in over 100 wards per Public Guardian while positions remain vacant
- Lack of public resources to support wards requires increasing amount of time to deal with bureaucracy and acquire resources
- Ongoing lawsuit alleging that the Public Guardian is violating statutory duties to visit wards – a direct result of case overload

# OPA Caseloads/Appointments



U.S.:  
between  
1.5 million -  
3 million

2030 - estimate  
- several million  
w/ disab over  
60

M:



## How is guardianship status related to employment status for people with IDD? Findings from the National Core Indicators Adult Consumer Survey.

### Key Findings from the RRTC on Advancing Employment

By Kelly Nye-Lengerman, Cara Narby, and Sandra Pettingell

### Introduction

Many individuals with intellectual and developmental disabilities, or IDD, have a legal guardian who assists them in making life decisions about housing, health, and employment. A recent analysis of data from the National Core Indicators (NCI) Adult Consumer Survey has found that people with IDD who were represented by a legal guardian were less likely to have paid employment than people who were their own legal guardians.

This finding may help us understand the role that legal guardians play in access to employment. If guardianship is a potential barrier to community-based work, then guardians need to be directly engaged in efforts to promote integrated employment.

### Overview

This study examined data from a sample of 12,213 people with IDD who responded to the NCI Adult Consumer Survey in 2012–2013. The sample captures data from respondents in 26 states. The purpose of the study was to observe and describe different demographic characteristics among the respondents, and how those characteristics correlated to different outcomes.

One of the characteristics examined was whether or not an individual was represented by a legal guardian. In the NCI survey, this was a single-item question with three response categories: yes, full guardianship; yes, limited guardianship; and no, person is independent. For the purposes of this study, responses to the question were collapsed into two groups: has a guardian or does not have a guardian.

Four categories of employment settings were included in the data analysis for this study. These employment settings were 1) individual employment in the community, 2) group employment in the community, 3) facility-based work, and 4) no paid job.

The setting categories were created by combining two items from the NCI survey. The background information section of the survey includes a question about whether

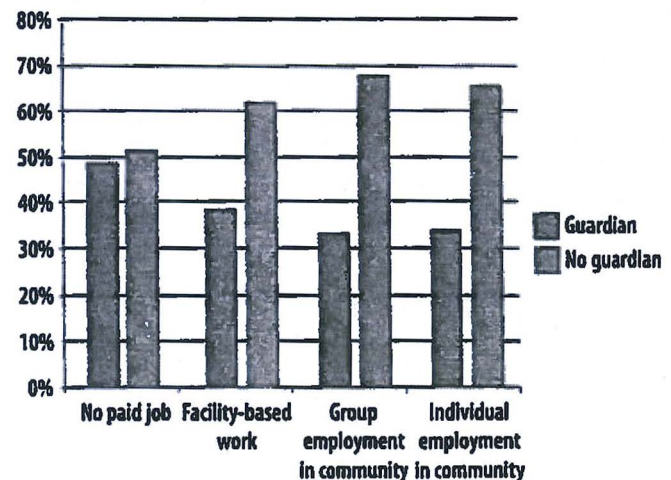
an individual has engaged in a paid job in a community setting, and this is followed up by another question about whether the job activity was done primarily by a group of people with disabilities.

If “yes” is marked for both questions, the individual was deemed to have a job in the community in a group setting. If the questions were marked “yes” to engaging in a paid community setting job, but not primarily with a group of individuals with disabilities, they were categorized as having an individual job in the community. If “engagement in facility work only” was selected, they were included in the facility-based work setting group. If the question did not indicate engagement in any of the employment groups, the individual was classified as not having a paid job.

### Findings

The findings of this study showed a correlation between legal guardianship and employment setting for individuals with IDD. People who have a legal guardian were significantly less likely than people who were independent to have any kind of paid employment. Among those individuals without a paid job, there was an even split in guardianship status: 48.7% had a guardian, and 51.3% did not have a guardian.

Employment Setting and Guardianship



RRTC on Advancing Employment for Individuals with Intellectual and Developmental Disabilities

A project of

**ThinkWork!**  
at the Institute for Community Inclusion, University of Massachusetts Boston



In the paid employment groups, the rate of people represented by a legal guardian decreased significantly by comparison. People with a guardian represented about 39.1% of individuals in facility-based employment, and comprised only about a third of respondents who were employed in the community. About 32.8% of people in group community-based work settings and 33.7% of people in individual community-based work settings were represented by a legal guardian.

## Discussion

In addition to employment and guardianship, this study included a metric for capturing the respondents' degree of intellectual impairment, on a scale of five categories: none, mild, moderate, severe, and profound. Like guardianship status, severity of intellectual impairment had a negative correlation with the likelihood of having paid employment. Individuals who experienced a higher degree of intellectual impairment were also less likely to have any kind of paid job.

However, guardianship for people with IDD is a complex issue. In general, guardianship does not necessarily reflect or neatly correspond to an individual's degree of intellectual impairment. The current data set shows that rates of guardianship for people with IDD vary significantly across different states (Pettingell, 2017), and the requirements for guardianship vary according to state law (Whitenack, n.d.). Whether and why a guardian might be appointed depends on a given individual's circumstances, and may be dependent on the discretion and biases of the court system (Morgan, 2015; Jameson et al., 2015).

Guardians often have significant influence over the lives of people with IDD. Legal guardianship should be considered as a distinct phenomenon that potentially influences individuals' access to employment. To improve employment outcomes for all individuals with IDD, it may be necessary to explore whether and where legal guardians are able to access information about integrated employment, and whether there might be observable gaps or misalignment between guardians' expectations and individuals' employment goals.

## Conclusion

The findings of this study highlight an important correlation between legal guardianship and employment for people with IDD. More research is needed to understand why people with legal guardians are less likely to attain community-based employment. Understanding why guardianship may represent a barrier to integrated employment can help providers, policymakers, and guardians engage with guardians to support improved employment outcomes for individuals with IDD.

## References

- Jameson, J. M., Riesen, T., Polychronis, S., Trader, B., Mizner, S., Martinis, J., & Hoyle, D. (2015). Guardianship and the potential of supported decision making with individuals with disabilities. *Research and Practice for Persons with Severe Disabilities*, 40 (1), 36-51.
- Morgan, M. (2015). Alternatives to guardianship for adult Texans with intellectual and developmental disabilities. Austin, TX: The Arc of Texas.
- Nye-Lengerman, K., Pettingell, S., Nord, D., & Hewitt, A. (Under review). Utilization of employment services by people with IDD: An analysis of National Core Indicator data. *Intellectual and Developmental Disabilities*.
- Pettingell, S. (2017). Analysis of 2012-2103 National Core Indicator Data - Adult Consumer Survey.
- Whitenack, S. B. (n.d.). Guardianship and developmental disabilities. Retrieved from <http://www.specialneeds.com/children-and-parents/autism/guardianship-and-developmental-disabilities>.

## ThinkWork!

ADVANCING EMPLOYMENT AND OPPORTUNITY FOR PEOPLE WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

The Rehabilitation Research and Training Center on Advancing Employment for Individuals with Intellectual and Developmental Disabilities is a project of ThinkWork! at the Institute for Community Inclusion at UMass Boston. ThinkWork! is a resource portal offering data, personal stories, and tools related to improving employment outcomes for people with intellectual and developmental disabilities.

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[www.ThinkWork.org/rrtc](http://www.ThinkWork.org/rrtc)

This brief was developed in collaboration with the RRTC on Community Living, Institute on Community Integration at the University of Minnesota. The study used data that was collected by the National Core Indicators Project.

Research & Training Center on Community Living

UNIVERSITY OF MINNESOTA



Supported Decision Making is a constitutional and civil rights concept which recognizes that full guardianship is often not the least-restrictive alternative for adults who experience intellectual or developmental disabilities, communication impairment, or dementia. SDM can be best defined as relationships, practices, arrangements, and agreements of more or less formality and intensity that are designed to assist an individual with a disability to make and communicate to others decisions about the individual's life. The equal rights philosophy underlying SDM is that all people use support for making the important decisions of life; needing more, different, or structured help with getting information, setting goals, weighing options, exploring outcomes does not justify unequal treatment and removal of all rights to make a decision.

With the Council's work and vision, Alaska has joined 18 other states and the District of Columbia in implementing SDM at varying levels. The momentum toward legal recognition of written Supported Decision Making Agreements (SDMAs) has been championed by the American Bar Association and the U.S. Administration on Community Living through state WINGS grants. The Council supported the successful WINGS grant application for Alaska, and is a lead stakeholder in that collaboration along with the court system, the Long-Term Care Ombudsman, and the Office of Public Advocacy. The WINGS project objectives are to reform guardianship, improve court processes, and to provide less-restrictive alternatives to ensure that Alaskans with disabilities have as many options as possible to lead person-directed lives. Within the Council, there is also a work group that is facilitating a pilot project to develop and implement written SDMAs for several adults to replace or prevent full guardianship orders. The Council has presented on SDMAs to a wide variety of audiences and stakeholders this fall, and is creating more training for professional groups and agencies that are involved in adult guardianship or decision-making for others. The Council will also be working with the legislature, the court system, self-advocates, community partners, and state agencies to create processes, forms, professional standards, and institutional support for legally recognized SDMAs.

The American Bar Association considers SDM is constitutional right, under *Shelton v. Tucker* as articulated by *O'Conner v. Donaldson*; and a civil right under the "integration mandate" of *Olmstead v. L.C.* In August of 2017, the ABA adopted a Resolution on Supported Decision Making, at: [https://www.americanbar.org/content/dam/aba/administrative/law\\_aging/2017\\_SDM\\_%20Resolution\\_Final.authcheckdam.pdf](https://www.americanbar.org/content/dam/aba/administrative/law_aging/2017_SDM_%20Resolution_Final.authcheckdam.pdf)

Two states have enacted statutes providing legal requirements and recognition of SDMAs. An SDMA statute has passed both houses in a third state, and is awaiting enactment in 2018.

Table 7. Family Member's Preferred Means of Communication

State	Spoken	Gestures or Body Language	Sign Language or Finger Spelling	Communication Aid or Device	Other	N
AK	84%	7%	4%	2%	3%	123
AZ	80%	13%	1%	3%	3%	328
DC	74%	18%	4%	1%	3%	231
FL	71%	18%	3%	3%	6%	430
GA	76%	17%	2%	1%	5%	437
HI	78%	17%	1%	2%	3%	218
LA	77%	15%	1%	1%	7%	391
MD	78%	17%	2%	1%	3%	730
MS	69%	22%	1%	0%	7%	449
NC	72%	22%	2%	2%	2%	251
NH	84%	10%	4%	1%	1%	447
OK	75%	19%	2%	0%	3%	472
PA	85%	10%	1%	2%	3%	442
VA	65%	29%	1%	1%	4%	150
WA	76%	13%	2%	1%	8%	432
NCI Average	75%	16%	2%	1%	4%	5,531

Table 8. Family Member Has Legal Court Appointed Guardian of Conservator

*— guardianship doubled in AK in last 7 years*

State	None	Limited	Full	Has Guardianship, Level is Unknown	N
AK	0%	4%	96%	0%	138
AZ	25%	8%	65%	1%	320
DC	29%	11%	50%	10%	217
FL	36%	18%	42%	4%	400
GA	40%	15%	40%	5%	397
HI	17%	10%	71%	2%	206
LA	63%	6%	22%	9%	336
MD	50%	12%	32%	6%	671
MS	35%	10%	49%	6%	433
NC	15%	13%	67%	6%	248
NH	16%	9%	72%	2%	445
OK	22%	8%	66%	4%	460
PA	50%	10%	36%	4%	399
VA	22%	12%	64%	2%	153
WA	28%	11%	56%	4%	412
NCI Average	30%	10%	55%	4%	5,235

# Adult Family Survey

2015-16 Final Report

*Edited 2/15/17*



**NATIONAL  
CORE  
INDICATORS™**

**A Collaboration of**

**The National Association of State Directors of  
Developmental Disabilities Services  
and  
Human Services Research Institute**

SDM Agreement Created by Disability Rights Texas  
**Supported Decision-Making Agreement**

This agreement is governed by the Supported Decision-Making Act, Chapter 1357 of the Texas Estates Code. This supported decision-making agreement is to support and accommodate an individual with a disability to make life decisions, including decisions related to where and with whom the individual wants to live, the services, supports, and medical care the individual wants to receive, and where the individual wants to work, without impeding the self-determination of the individual with a disability. This agreement may be revoked by the individual with a disability or his or her supporter at any time. If either the individual with a disability or his or her supporter has any questions about the agreement, he or she should speak with a lawyer before signing this supported decision-making agreement.

**Appointment of Supporter:**

I (Name of Adult with Disability), \_\_\_\_\_ am entering into this agreement voluntarily.

I choose (Name of Supporter) \_\_\_\_\_ to be my Supporter.

Supporter's Address: \_\_\_\_\_

Phone Number: \_\_\_\_\_

E-mail Address: \_\_\_\_\_

**My Supporter may help me with life decisions about:**

- Yes \_\_\_ No \_\_\_ obtaining food, clothing and a place to live
- Yes \_\_\_ No \_\_\_ my physical health
- Yes \_\_\_ No \_\_\_ my mental health
- Yes \_\_\_ No \_\_\_ managing my money or property
- Yes \_\_\_ No \_\_\_ getting an education or other training
- Yes \_\_\_ No \_\_\_ choosing and maintaining my services and supports
- Yes \_\_\_ No \_\_\_ finding a job
- Yes \_\_\_ No \_\_\_ Other: \_\_\_\_\_

**My Supporter does not make decisions for me. To help me make decisions, my Supporter may:**

1. Help me get the information I need to make medical, psychological, financial, or educational decisions;
2. Help me understand my choices so I can make the best decision for me; or
3. Help me communicate my decision to the right people.

Yes \_\_\_ No \_\_\_ My Supporter may see my private health information under the Health Insurance Portability and Accountability Act of 1996. I will provide a signed release.

Yes \_\_\_ No \_\_\_ My Supporter may see my educational records under the Family Educational Rights and Privacy Act of 1974 (20 U.S.C. Section 1232g). I will provide a signed release.

This agreement starts when signed and will continue until \_\_\_\_\_ (date) or until my Supporter or I end the agreement or the agreement ends by law.

Signed this \_\_\_\_\_ (day) of \_\_\_\_\_ (month), \_\_\_\_\_ (year)

\_\_\_\_\_  
(Signature of Adult with Disability)

\_\_\_\_\_  
(Printed Name of Adult with Disability)

SDM Agreement Created by Disability Rights Texas  
**CONSENT OF SUPPORTER**

I (Name of Supporter), \_\_\_\_\_ consent to act as a Supporter under this agreement.

\_\_\_\_\_  
(Signature of Supporter)

\_\_\_\_\_  
(Printed Name of Supporter)

**This agreement must be signed in front of two witnesses or a Notary Public.**

\_\_\_\_\_  
(Witness 1 Signature)

\_\_\_\_\_  
(Printed Name of Witness 1)

\_\_\_\_\_  
(Witness 2 Signature)

\_\_\_\_\_  
(Printed Name of Witness 2)

OR

Notary Public

State of \_\_\_\_\_

County of \_\_\_\_\_

This document was acknowledged before me on \_\_\_\_\_ (date)

By \_\_\_\_\_ and \_\_\_\_\_  
(Name of Adult with a Disability) (Name of Supporter)

\_\_\_\_\_  
(Signature of Notary)

\_\_\_\_\_  
(Printed Name of Notary)

(Seal, if any, of notary)

My commission expires: \_\_\_\_\_

**WARNING: PROTECTION FOR THE ADULT WITH A DISABILITY**

If a person who receives a copy of this agreement or is aware of the existence of this agreement has cause to believe that the adult with a disability is being abused, neglected, or exploited by the supporter, the person shall report the alleged abuse, neglect, or exploitation to the Department of Family and Protective Services by calling the Abuse Hotline at 1-800-252-5400 or online at [www.txabusehotline.org](http://www.txabusehotline.org).

**DUTY OF CERTAIN PERSONS WITH RESPECT TO AGREEMENT**

A person who receives the original or a copy of a supported decision-making agreement shall rely on the agreement. A person is not subject to criminal or civil liability and has not engaged in professional misconduct for an act or omission if the act or omission is done in good faith and in reliance on a supported decision-making agreement



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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;**



Nothing about us without us!

- 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  
156

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

158  
159 This agreement takes effect:

160    Immediately

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

162  
163 This agreement ends:

164    When I cancel it

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



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

167  
168 **Third Party Rights Under the Supported Health Care Decision-Making Agreement**

169 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  
188 (signature of supporter)

(printed name of supporter)

189  
190 **Signature**

191  
192 (your signature)

(your printed name)

193  
194 (witness signature)

(printed name of witness)

195  
196 Signed this \_\_\_\_\_ day of \_\_\_\_\_, 20\_\_\_\_

\_\_\_\_\_  
(your signature)

197  
198 State of \_\_\_\_\_

199 County of \_\_\_\_\_

200 This document was acknowledged before me on

201 \_\_\_\_\_ (date) by \_\_\_\_\_



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202 (name of adult with a disability)  
203

\_\_\_\_\_  
(signature of notary)

(seal, if any, of notary)

\_\_\_\_\_  
(printed name)

My commission expires: \_\_\_\_\_

204 **WARNING: PROTECTION FOR THE ADULT WITH A DISABILITY**  
205

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

**Nonotuck Resource Associates and  
Center for Public Representation  
Supported Decision-Making Agreement**

---

**This is the Supported Decision-Making Agreement of**

**Name :** \_\_\_\_\_ **Date of birth:** \_\_\_\_\_

**Address:** \_\_\_\_\_

**Telephone:** \_\_\_\_\_ **Email:** \_\_\_\_\_

**A. I need supporter(s) to help me make decisions about:**

- Taking care of my financial affairs, like banking
- Hiring a lawyer if I need one and working with the lawyer
- My health care, including large and small health care decisions
- Personal care (like where I live, the support services I need, managing the people who work with me, my diet, exercise, education, safety and activities)
- Other matters: \_\_\_\_\_

**B. I expect my supporter(s) to help me in the following ways:**

- Giving me information in a way I can understand
- Discussing the good things and bad things (pros and cons) that could happen if I make one decision or another
- Telling other people my wishes
- \_\_\_\_\_

C. I express myself and show what I want in the following ways:

- Telling people my likes and dislikes.
- Telling people what I do and do not want to do.
- \_\_\_\_\_
- \_\_\_\_\_

D. I designate the following individual(s) to be part of my Supported Decision-Making Network to assist me in making decisions.

**Network Supporter #1**

Name: \_\_\_\_\_ Date of birth: \_\_\_\_\_

Address: \_\_\_\_\_

Telephone: \_\_\_\_\_ Email: \_\_\_\_\_

Relationship: \_\_\_\_\_

**Areas of Assistance for Supporter #1:** *Check all that apply.*

- Finances     Healthcare     Living Arrangements
- Relationships/Social     Employment     Legal Matters
- Other (*please specify*):

**Areas I don't want Supporter #1 to assist me with:**

**Network Supporter #2**

Name: \_\_\_\_\_ Date of birth: \_\_\_\_\_

Address: \_\_\_\_\_

Telephone: \_\_\_\_\_ Email: \_\_\_\_\_

Relationship: \_\_\_\_\_

**Areas of Assistance for Supporter #2:** *Check all that apply.*

- Finances     Healthcare     Living Arrangements  
 Relationships/Social     Employment     Legal Matters  
 Other (*please specify*):

**Areas I don't want Supporter #2 to assist me with:**

**Network Supporter #3**

Name: \_\_\_\_\_ Date of birth: \_\_\_\_\_

Address: \_\_\_\_\_

Telephone: \_\_\_\_\_ Email: \_\_\_\_\_

Relationship: \_\_\_\_\_

**Areas of Assistance for Supporter #3:** *Check all that apply.*

- Finances     Healthcare     Living Arrangements  
 Relationships/Social     Employment     Legal Matters  
 Other (*please specify*):

**Areas I don't want Supporter #3 to assist me with:**

*Use the reverse side of this document to list additional supporters.*

**E. If I have more than one Supporter (Optional, but if you do not fill out this section, your Supporters will act "Successively".)**

My Supporters will act (*choose one*)

Jointly (work together to help me)

OR

Successively (For example: Supporter #2 helps me if Supporter #1 is not available)

**F. I understand I can contact the Supported Decision-Making Project at any time to end this agreement or to add, replace or remove a network supporter.**

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

**G. Notary Certification**

Commonwealth of Massachusetts, County of \_\_\_\_\_

On this \_\_\_\_\_ day of \_\_\_\_\_, 20\_\_\_\_, before me, the undersigned notary public, personally appeared \_\_\_\_\_ proved to me through satisfactory evidence of identification, which were \_\_\_\_\_, to be the person whose name is signed on the preceding or attached document in my presence.

(seal)

\_\_\_\_\_  
Notary Public Signature

The Supported Decision-Making Project can be reached at 413-586-6024.

**H. Network Supporters' Statements**

**Network Supporter #1**

I understand that as \_\_\_\_\_'s supporter, my job is to honor and present his/her expressed wishes. In the event I cannot perform my job under this agreement, I will contact the Supported Decision-Making Coordinator.

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

**Network Supporter #2**

I understand that as \_\_\_\_\_'s supporter, my job is to honor and present his/her expressed wishes. In the event I cannot perform my job under this agreement, I will contact the Supported Decision-Making Coordinator.

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

**Network Supporter #3**

I understand that as \_\_\_\_\_'s supporter, my job is to honor and present his/her expressed wishes. In the event I cannot perform my job under this agreement, I will contact the Supported Decision-Making Coordinator.

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

Delaware

## TITLE 16

# Health and Safety

## Individuals with Disabilities

### CHAPTER 94A. SUPPORTED DECISION-MAKING

#### § 9401A Short title.

This chapter may be cited as the "Supported Decision-Making Act."

80 Del. Laws, c. 427, § 1.;

#### § 9402A Purpose; interpretation.

(a) The purpose of this chapter is to do all of the following:

- (1) Provide assistance in gathering and assessing information, making informed decisions, and communicating decisions to adults who do not need a guardian or other substitute decision maker for such activities, but who would benefit from decision-making assistance.
- (2) Give supporters legal status to be with the adult and participate in discussions with others when the adult is making decisions or attempting to obtain information.
- (3) Enable supporters to assist in making and communicating decisions for the adult but not substitute as the decision maker for that adult.

(b) This chapter is to be administered and interpreted in accordance with all of the following principles:

- (1) All adults should be able to live in the manner they wish and to accept or refuse support, assistance, or protection as long as they do not harm others and are capable of making decisions about those matters.
- (2) All adults should be able to be informed about and, to the best of their ability, participate in the management of their affairs.
- (3) All adults should receive the most effective yet least restrictive and intrusive form of support, assistance, or protection when they are unable to care for themselves or manage their affairs alone.
- (4) The values, beliefs, wishes, cultural norms, and traditions that an adult holds should be respected in managing an adult's affairs.

80 Del. Laws, c. 427, § 1.;

**§ 9403A Definitions.**

For the purposes of this chapter:

- (1) "Adult" means an individual who is 18 years of age or older.
- (2) "Affairs" means personal, health care, and financial matters arising in the course of activities of daily living and includes all of the following:
  - a. Those health-care and personal affairs in which an adult makes his or her own health-care decisions, including monitoring his or her own health; obtaining, scheduling, and coordinating health and support services; understanding health-care information and options; and making personal decisions, including those to provide for his or her own care and comfort.
  - b. Those financial affairs in which an adult manages his or her income and assets and its use for clothing, support, care, comfort, education, shelter, and payment of other liabilities of the individual.
- (3) "Good faith" means honesty in fact and the observance of reasonable standards of fair dealing.
- (4) "Health-care institution" means "health-care institution" as defined in § 2501 of this title.
- (5) "Health-care provider" means "health-care provider" as defined in § 2501 of this title.
- (6) "Immediate family member" means a spouse, child, sibling, parent, grandparent, grandchild, stepparent, stepchild, or stepsibling.
- (7) "Person" means an adult; health-care institution; health-care provider; corporation; partnership; limited liability company; association; joint venture; government; governmental subdivision, agency, or instrumentality; public corporation; or any other legal or commercial entity.
- (8) "Principal" means an adult who seeks to enter, or has entered, into a supported decision-making agreement with a supporter under this chapter.
- (9) "Supported decision-making agreement" or "the agreement" means an agreement between a principal and a supporter entered into under this chapter.
- (10) "Supporter" means a person who is named in a supported decision-making agreement and is not prohibited from acting under § 9406A(b) of this title or under regulations enacted under § 9410A of this title.
- (11) "Support services" means a coordinated system of social and other services supplied by private, state, institutional, or community providers designed to help maintain the independence of an adult, including any of the following:
  - a. Homemaker-type services, including house repair, home cleaning, laundry, shopping, and meal-provision.

- b. Companion-type services, including transportation, escort, and facilitation of written, oral, and electronic communication.
- c. Visiting nurse and attendant care.
- d. Health-care provider.
- e. Physical and psychosocial assessments.
- f. Financial assessments and advisement on banking, taxes, loans, investments, and management of real property.
- g. Legal assessments and advisement.
- h. Education and educational assessment and advisement.
- i. Hands-on treatment or care, including assistance with activities of daily living such as bathing, dressing, eating, range of motion, toileting, transferring, and ambulation.
- j. Care planning.
- k. Other services needed to maintain the independence of an adult.

80 Del. Laws, c. 427, § 1; 70 Del. Laws, c. 186, § 1.;

**§ 9404A Presumption of capability.**

- (a) All adults are presumed to be capable of managing their affairs and to have capacity unless otherwise determined by the Court of Chancery.
- (b) The manner in which an adult communicates with others is not grounds for deciding that the adult is incapable of managing the adult's affairs.
- (c) Execution of a supported decision-making agreement may not be used as evidence of incapacity and does not preclude the ability of the adult who has entered into such an agreement to act independently of the agreement.

80 Del. Laws, c. 427, § 1.;

**§ 9405A Supported decision-making agreements.**

- (a) An adult may enter into a supported decision-making agreement if all of the following apply:
  - (1) The adult enters into the agreement voluntarily and without coercion or undue influence.
  - (2) The adult understands the nature and effect of the agreement.
- (b) A supported decision-making agreement must include all of the following:
  - (1) Designation of at least 1 supporter.
  - (2) The types of decisions for which the supporter is authorized to assist.
  - (3) The types of decisions, if any, for which the supporter may not assist.
- (c) A supported decision-making agreement may include any of the following:

- (1) Designation of more than 1 supporter.
  - (2) Provision for an alternate to act in the place of a supporter in such circumstances as may be specified in the agreement.
  - (3) Authorization for a supporter to share information with any other supporter named in the agreement, as a supporter believes is necessary.
- (d) A supported decision-making agreement is valid only if all of the following occur:
- (1) The agreement is in a writing that contains the elements of the form developed by the Department of Health and Social Services as required under § 9410A(a) of this title.
  - (2) The agreement is dated.
  - (3) Each party to the agreement signed the agreement in the presence of 2 adult witnesses.
- (e) The 2 adult witnesses required by paragraph (d)(3) of this section may not be any of the following:
- (1) A supporter for the principal.
  - (2) An employee or agent of a supporter named in the supported decision-making agreement.
  - (3) Any person who does not understand the type of communication the principal uses, unless an individual who understands the principal's means of communication is present to assist during the execution of the supported decision-making agreement.
- (f) A supported decision-making agreement must contain a separate declaration signed by each supporter named in the agreement indicating all of the following:
- (1) The supporter's relationship to the principal.
  - (2) The supporter's willingness to act as a supporter.
  - (3) The supporter's acknowledgement of the duties of a supporter under this chapter.
- (g) A supported decision-making agreement may authorize a supporter to assist the principal to decide whether to give or refuse consent to care within the meaning of Chapter 25 of this title.
- (h) A principal or a supporter may revoke a supported decision-making agreement at any time in writing and with notice to the other parties to the agreement.
- (i) An authorization in a supported decision-making agreement may be prospectively limited or abrogated, in whole or part, by a judicial determination that the principal lacks the capacity to engage in the making of specific decisions covered by the agreement despite the assistance of a supporter.

80 Del. Laws, c. 427, § 1.;

#### § 9406A Supporters.

- (a) Except as otherwise provided by a supported decision-making agreement, a supporter

may do all of the following:

- (1) Assist the principal in understanding information, options, responsibilities, and consequences of the principal's life decisions, including those decisions relating to the principal's affairs or support services.
- (2) Help the principal access, obtain, and understand any information that is relevant to any given life decision, including medical, psychological, financial, or educational decisions, or any treatment records or records necessary to manage the principal's affairs or support services.
- (3) Assist the principal in finding, obtaining, making appointments for, and implementing the principal's support services or plans for support services.
- (4) Help the principal monitor information about the principal's affairs or support services, including keeping track of future necessary or recommended services.
- (5) Ascertain the wishes and decisions of the principal, assist in communicating those wishes and decisions to other persons, and advocate to ensure that the wishes and decisions of the principal are implemented.

(b) Except as permitted by regulation promulgated under § 9410A of this title, any of the following are disqualified from acting as a supporter:

- (1) A person who is an employer or employee of the principal, unless the person is an immediate family member of the principal.
- (2) A person directly providing paid support services to the principal, with the exception of supported decision-making services, unless the person is an immediate family member of the principal.
- (3) An individual against whom the principal has obtained an order of protection from abuse or an individual who is the subject of a civil or criminal order prohibiting contact with the principal.

(c) A supporter is prohibited from doing any of the following:

- (1) Exerting undue influence upon, or making decisions on behalf of, the principal.
- (2) Obtaining, without the consent of the principal, information that is not reasonably related to matters with which the supporter is authorized to assist under the supported decision-making agreement.
- (3) Using, without the consent of the principal, information acquired for a purpose other than assisting the principal to make a decision under the supported decision-making agreement.

(d) A supporter shall act with the care, competence, and diligence ordinarily exercised by individuals in similar circumstances, with due regard either to the possession of, or lack of, special skills or expertise.

80 Del. Laws, c. 427, § 1.;

**§ 9407A Recognition of supporters.**

A decision or request made or communicated with the assistance of a supporter in conformity with this chapter shall be recognized for the purposes of any provision of law as the decision or request of the principal and may be enforced by the principal or supporter in law or equity on the same basis as a decision or request of the principal.

80 Del. Laws, c. 427, § 1.;

**§ 9408A Limitation of liability.**

A person who in good faith acts in reliance on an authorization in a supported decision-making agreement, or who in good faith declines to honor an authorization in a supported decision-making agreement, is not subject to civil or criminal liability or to discipline for unprofessional conduct for any of the following:

- (1) Complying with an authorization in a supported decision-making agreement based on an assumption that the underlying supported decision-making agreement was valid when made and has not been revoked or abrogated under § 9405A of this title.
- (2) Declining to comply with an authorization in a supported decision-making agreement based on actual knowledge that the agreement is invalid or has been revoked or abrogated under § 9405A of this title.
- (3) Declining to comply with an authorization related to health care in a supported decision-making agreement because the action proposed to be taken under the agreement is contrary to the conscience or good faith medical judgment of the person or to a written policy of a health-care institution that is based on reasons of conscience.

80 Del. Laws, c. 427, § 1.;

**§ 9409A Access to information.**

(a) A supporter may assist the principal with obtaining any information to which the principal is entitled, including, with a signed and dated specific consent, protected health information under the Health Insurance Portability and Accountability Act of 1996 (P.L. 104-191) or educational records under the Family Educational Rights and Privacy Act of 1974 (20 U.S.C. § 1232g).

(b) The supporter shall ensure all information collected on behalf of the principal under this section is kept privileged and confidential, as applicable; is not subject to unauthorized access, use, or disclosure; and is properly disposed of when appropriate.

80 Del. Laws, c. 427, § 1.;

**§ 9410A Forms; regulatory authority.**

(a) The Department of Health and Social Services shall develop the forms necessary to implement this chapter.

(b) The Secretary of the Department of Health and Social Services may promulgate regulations necessary to implement this chapter.

80 Del. Laws, c. 427, § 1.;

Texas

## ESTATES CODE

## TITLE 3. GUARDIANSHIP AND RELATED PROCEDURES

## SUBTITLE I. OTHER SPECIAL PROCEEDINGS AND SUBSTITUTES FOR GUARDIANSHIP

## CHAPTER 1357. SUPPORTED DECISION-MAKING AGREEMENT ACT

## SUBCHAPTER A. GENERAL PROVISIONS

Sec. 1357.001. SHORT TITLE. This chapter may be cited as the Supported Decision-Making Agreement Act.


Added by Acts 2015, 84th Leg., R.S., Ch. 214 (H.B. 39), Sec. 23, eff. September 1, 2015.

Added by Acts 2015, 84th Leg., R.S., Ch. 1224 (S.B. 1881), Sec. 1, eff. June 19, 2015.

Sec. 1357.002. DEFINITIONS. In this chapter:

(1) "Adult" means an individual 18 years of age or older or an individual under 18 years of age who has had the disabilities of minority removed.

(2) "Disability" means, with respect to an individual, a physical or mental impairment that substantially limits one or more major life activities.

 (3) "Supported decision-making" means a process of supporting and accommodating an adult with a disability to enable the adult to make life decisions, including decisions related to where the adult wants to live, the services, supports, and medical care the adult wants to receive, whom the adult wants to live with, and where the adult wants to work, without impeding the self-determination of the adult.

(4) "Supported decision-making agreement" is an agreement between an adult with a disability and a supporter entered into under this chapter.

(5) "Supporter" means an adult who has entered into a supported decision-making agreement with an adult with a disability.

Added by Acts 2015, 84th Leg., R.S., Ch. 214 (H.B. 39), Sec. 23, eff. September 1, 2015.

Added by Acts 2015, 84th Leg., R.S., Ch. 1224 (S.B. 1881), Sec. 1, eff. June 19, 2015.

Text of section as added by Acts 2015, 84th Leg., R.S., Ch. 214, Sec. 23

Sec. 1357.003. PURPOSE. The purpose of this chapter is to recognize a less restrictive substitute for guardianship for adults with disabilities who need assistance with decisions regarding daily living but who are not considered incapacitated persons for purposes of establishing a guardianship under this title.

Added by Acts 2015, 84th Leg., R.S., Ch. 214 (H.B. 39), Sec. 23, eff. September 1, 2015.

Text of section as added by Acts 2015, 84th Leg., R.S., Ch. 1224, Sec. 1

Sec. 1357.003. PURPOSE. The purpose of this chapter is to recognize a less restrictive alternative to guardianship for adults with disabilities who need assistance with decisions regarding daily living but who are not considered incapacitated persons for purposes of establishing a guardianship under this title.

Added by Acts 2015, 84th Leg., R.S., Ch. 1224 (S.B. 1881), Sec. 1, eff. June 19, 2015.

#### SUBCHAPTER B. SCOPE OF AGREEMENT AND AGREEMENT REQUIREMENTS

Sec. 1357.051. SCOPE OF SUPPORTED DECISION-MAKING AGREEMENT. An adult with a disability may voluntarily, without undue influence or coercion, enter into a supported decision-making agreement with a supporter under which the adult with a disability authorizes the supporter to do any or all of the following:

- (1) provide supported decision-making, including assistance in understanding the options, responsibilities, and consequences of the adult's life decisions, without making those decisions on behalf of the adult with a disability;
- (2) subject to Section 1357.054, assist the adult in accessing, collecting, and obtaining information that is relevant to a given life decision, including medical, psychological, financial, educational, or treatment records, from any person;
- (3) assist the adult with a disability in understanding the information described by Subdivision (2); and
- (4) assist the adult in communicating the adult's decisions to appropriate persons.

Added by Acts 2015, 84th Leg., R.S., Ch. 214 (H.B. 39), Sec. 23, eff. September 1, 2015.

Added by Acts 2015, 84th Leg., R.S., Ch. 1224 (S.B. 1881), Sec. 1, eff. June 19, 2015.

Sec. 1357.052. AUTHORITY OF SUPPORTER. A supporter may exercise the authority granted to the supporter in the supported decision-making agreement.

Added by Acts 2015, 84th Leg., R.S., Ch. 214 (H.B. 39), Sec. 23, eff. September 1, 2015.

Added by Acts 2015, 84th Leg., R.S., Ch. 1224 (S.B. 1881), Sec. 1, eff. June 19, 2015.

Sec. 1357.053. TERM OF AGREEMENT. (a) Except as provided by Subsection (b), the supported decision-making agreement extends until terminated by either party or by the terms of the agreement.

(b) The supported decision-making agreement is terminated if:

(1) the Department of Family and Protective Services finds that the adult with a disability has been abused, neglected, or exploited by the supporter; or

(2) the supporter is found criminally liable for conduct described by Subdivision (1).

Added by Acts 2015, 84th Leg., R.S., Ch. 214 (H.B. 39), Sec. 23, eff. September 1, 2015.

Added by Acts 2015, 84th Leg., R.S., Ch. 1224 (S.B. 1881), Sec. 1, eff. June 19, 2015.

Sec. 1357.054. ACCESS TO PERSONAL INFORMATION. (a) A supporter is only authorized to assist the adult with a disability in accessing, collecting, or obtaining information that is relevant to a decision authorized under the supported decision-making agreement.

(b) If a supporter assists an adult with a disability in accessing, collecting, or obtaining personal information, including protected health information under the Health Insurance Portability and Accountability Act of 1996 (Pub. L. No. 104-191) or educational records under the Family Educational Rights and Privacy Act of 1974 (20 U.S.C. Section 1232g), the supporter shall ensure the information is kept privileged and confidential, as applicable, and is not subject to unauthorized access, use, or disclosure.

(c) The existence of a supported decision-making agreement does not preclude an adult with a disability from seeking personal information without the assistance of a supporter.

Added by Acts 2015, 84th Leg., R.S., Ch. 214 (H.B. 39), Sec. 23, eff. September 1, 2015.

Added by Acts 2015, 84th Leg., R.S., Ch. 1224 (S.B. 1881), Sec. 1, eff. June 19, 2015.

Sec. 1357.055. AUTHORIZING AND WITNESSING OF SUPPORTED DECISION-MAKING AGREEMENT. (a) A supported 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 two or more subscribing witnesses or a notary public.

(b) If signed before two witnesses, the attesting witnesses must be at least 14 years of age.

Added by Acts 2015, 84th Leg., R.S., Ch. 214 (H.B. 39), Sec. 23, eff. September 1, 2015.

Added by Acts 2015, 84th Leg., R.S., Ch. 1224 (S.B. 1881), Sec. 1, eff. June 19, 2015.

Sec. 1357.056. FORM OF SUPPORTED DECISION-MAKING AGREEMENT. (a) Subject to Subsection (b), a supported decision-making agreement is valid only if it is in substantially the following form:

SUPPORTED DECISION-MAKING AGREEMENT

Appointment of Supporter

I, (insert your name), make this agreement of my own free will.

I agree and designate that:

Name:

Address:

Phone Number:

E-mail Address:

is my supporter. My supporter may help me with making everyday life decisions relating to the following:

Y/N obtaining food, clothing, and shelter

Y/N taking care of my physical health

Y/N managing my financial affairs.

My supporter is not allowed to make decisions for me. To help me with my decisions, my supporter may:

1. Help me access, collect, or obtain information that is relevant to a decision, including medical, psychological, financial, educational, or treatment records;

2. Help me understand my options so I can make an informed decision; or

3. Help me communicate my decision to appropriate persons.

Y/N A release allowing my supporter to see protected health information under the Health Insurance Portability and Accountability Act of 1996 (Pub. L. No. 104-191) is attached.

Y/N A release allowing my supporter to see educational records under the Family Educational Rights and Privacy Act of 1974 (20 U.S.C. Section 1232g) is attached.

Effective Date of Supported Decision-Making Agreement

This supported decision-making agreement is effective immediately and will continue until (insert date) or until the agreement is terminated by my supporter or me or by operation of law.

Signed this \_\_\_\_\_ day of \_\_\_\_\_, 20\_\_\_\_

Consent of Supporter

I, (name of supporter), consent to act as a supporter under this agreement.

(signature of supporter)

(printed name of supporter)

Signature

(my signature)

(my printed name)

(witness 1 signature)

(printed name of witness 1)

(witness 2 signature)

(printed name of witness 2)

State of

County of

This document was acknowledged before me

on \_\_\_\_\_ (date)

by \_\_\_\_\_ and \_\_\_\_\_

(name of adult with a disability)

(name of supporter)

(signature of notarial officer)

(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 OF THIS AGREEMENT OR IS AWARE OF THE EXISTENCE OF THIS AGREEMENT HAS CAUSE TO BELIEVE THAT THE ADULT WITH A

DISABILITY IS BEING ABUSED, NEGLECTED, OR EXPLOITED BY THE SUPPORTER, THE PERSON SHALL REPORT THE ALLEGED ABUSE, NEGLECT, OR EXPLOITATION TO THE DEPARTMENT OF FAMILY AND PROTECTIVE SERVICES BY CALLING THE ABUSE HOTLINE AT 1-800-252-5400 OR ONLINE AT WWW.TXABUSEHOTLINE.ORG.

(b) A supported decision-making agreement may be in any form not inconsistent with Subsection (a) and the other requirements of this chapter.

Added by Acts 2015, 84th Leg., R.S., Ch. 214 (H.B. 39), Sec. 23, eff. September 1, 2015.

Added by Acts 2015, 84th Leg., R.S., Ch. 1224 (S.B. 1881), Sec. 1, eff. June 19, 2015.

#### SUBCHAPTER C. DUTY OF CERTAIN PERSONS WITH RESPECT TO AGREEMENT

Sec. 1357.101. RELIANCE ON AGREEMENT; LIMITATION OF LIABILITY. (a) A person who receives the original or a copy of a supported decision-making agreement shall rely on the agreement.

(b) A person is not subject to criminal or civil liability and has not engaged in professional misconduct for an act or omission if the act or omission is done in good faith and in reliance on a supported decision-making agreement.

Added by Acts 2015, 84th Leg., R.S., Ch. 214 (H.B. 39), Sec. 23, eff. September 1, 2015.

Added by Acts 2015, 84th Leg., R.S., Ch. 1224 (S.B. 1881), Sec. 1, eff. June 19, 2015.

Sec. 1357.102. REPORTING OF SUSPECTED ABUSE, NEGLECT, OR EXPLOITATION. If a person who receives a copy of a supported decision-making agreement or is aware of the existence of a supported decision-making agreement has cause to believe that the adult with a disability is being abused, neglected, or exploited by the supporter, the person shall report the alleged abuse, neglect, or exploitation to the Department of Family and Protective Services in accordance with Section 48.051, Human Resources Code.

Added by Acts 2015, 84th Leg., R.S., Ch. 214 (H.B. 39), Sec. 23, eff. September 1, 2015.

Added by Acts 2015, 84th Leg., R.S., Ch. 1224 (S.B. 1881), Sec. 1, eff. June 19, 2015.

**BILL ANALYSIS**

Senate Research Center

~~S.B. 1882~~

By: Zaffirini

Health &amp; Human Services

7/6/2015

Enrolled

**AUTHOR'S / SPONSOR'S STATEMENT OF INTENT**

The purpose of this legislation is to ensure that persons under guardianship understand their rights. Persons under guardianship often retain many legal and civil rights, depending on the court order. Unfortunately, often times they are not informed of the rights they get to keep and presume they have no rights whatsoever. Incidentally, some guardians are under the same assumption. There are few legal processes more restrictive of citizens in a free society than guardianship. It is important that the persons under guardianship know the rights that they get to keep, unless the court has determined otherwise.

~~S.B. 1882~~ codifies in the Estates Code the 24 rights that already are granted for persons under guardianship. The rights include: to participate in social, religious, and recreational activities, training, employment, education, habilitation, and rehabilitation of the person who is under guardianship in the most integrated setting of his or her choice; to visit with people of his or her choice; to contact the Department of Family and Protective Services he or she feels abused or neglected; and the right to vote.

What's more, the bill will allow a person under guardianship to request a hearing to remove restrictions imposed by a guardian regarding communication and visitation; require attorneys representing a person in guardianship matters to be certified in guardianship law; require a guardian or his or her designee to visit the person under guardianship every three months; provide a person under guardianship the right to receive notice regarding court proceedings to continue, change, or terminate the guardianship, as well as matters that involve the real and personal property of a person under guardianship; and clarify that a person under guardianship is allowed to petition the court to enforce the rights under this subsection.

~~S.B. 1882~~ amends current law relating to a bill of rights for wards under guardianship.

**RULEMAKING AUTHORITY**

This bill does not expressly grant any additional rulemaking authority to a state officer, institution, or agency.

**SECTION BY SECTION ANALYSIS**

SECTION 1. Amends Chapter 1151, Estates Code, by adding Subchapter H, as follows:

**SUBCHAPTER H. RIGHTS OF WARDS**

Sec. 1151.351. BILL OF RIGHTS FOR WARDS. (a) Provides that a ward has all the rights, benefits, responsibilities, and privileges granted by the constitution and laws of this state and the

(12) to have a court investigator, guardian ad litem, or attorney ad litem appointed by the court to investigate a complaint received from the ward or any person about the guardianship;

(13) to participate in social, religious, and recreational activities, training, employment, education, habilitation, and rehabilitation of the ward's choice in the most integrated setting;

(14) to self-determination in the substantial maintenance, disposition, and management of real and personal property after essential living expenses and health needs are met, including the right to receive notice and object about the substantial maintenance, disposition, or management of clothing, furniture, vehicles, and other personal effects;

(15) to personal privacy and confidentiality in personal matters, subject to state and federal law;

(16) to unimpeded, private, and uncensored communication and visitation with persons of the ward's choice, except that if the guardian determines that certain communication or visitation causes substantial harm to the ward:

(A) the guardian may limit, supervise, or restrict communication or visitation, but only to the extent necessary to protect the ward from substantial harm; and

(B) the ward may request a hearing to remove any restrictions on communication or visitation imposed by the guardian under Paragraph (A);

(17) to petition the court and retain counsel of the ward's choice who holds a certificate required by Subchapter E (Qualifications to Serve as Court-Appointed Attorney), Chapter 1054, to represent the ward's interest for capacity restoration, modification of the guardianship, the appointment of a different guardian, or for other appropriate relief under this subchapter, including a transition to a supported decision-making agreement, except as limited by Section 1054.006 (Representation of Ward or Proposed Ward by Attorney);

(18) to vote in a public election, marry, and retain a license to operate a motor vehicle, unless restricted by the court;

(19) to personal visits from the guardian or the guardian's designee at least once every three months, but more often, if necessary, unless the court orders otherwise;

(20) to be informed of the name, address, phone number, and purpose of Disability Rights Texas, an organization whose mission is to protect the rights of, and advocate for, persons with disabilities, and to communicate and meet privately with representatives of that organization;

**BILL ANALYSIS**

Senate Research Center

**S.B. 1881**  
By: Zaffirini et al.  
Health & Human Services  
6/29/2015  
Enrolled**AUTHOR'S / SPONSOR'S STATEMENT OF INTENT**

The purpose of this legislation is to support and respect the independence of Texans who are elderly and persons with disabilities. Persons with disabilities are being placed into guardianship before they have the opportunity to exercise their civil rights and liberties and time to learn decision-making.

State law directs courts to encourage the development or maintenance of maximum self-reliance and independence but unfortunately it is not uncommon for courts to create full guardianships that deprive persons with disabilities and seniors of the right to make fundamental decisions about their lives. An alternative option to guardianships are supported decision-making agreements which support protections of civil rights and well-being of people to make important decisions. Similar to executing a power of attorney, a supported decision-making agreement is an informal agreement that does not require court involvement or the associated costs, is voluntary and may be terminated by either party at any time. These types of agreements could delay or negate the need for guardianship as a legal tool used to allow a person to make decisions for another person.

**S.B. 1881** adds supported decision-making agreements to the Estate Code as an informal alternative to guardianship to maximize the autonomy and rights by people with a disability.

The committee substitute would strike unnecessary and confusing language; provide a technical clarification; and align language with other code.

**S.B. 1881** amends current law relating to authorizing supported decision-making agreements for certain adults with disabilities.

**RULEMAKING AUTHORITY**

This bill does not expressly grant any additional rulemaking authority to a state officer, institution, or agency.

**SECTION BY SECTION ANALYSIS**

SECTION 1. Amends Subtitle I, Title 3, Estates Code, by adding Chapter 1357, as follows:

**CHAPTER 1357. SUPPORTED DECISION-MAKING AGREEMENT ACT****SUBCHAPTER A. GENERAL PROVISIONS**

Sec. 1357.001. SHORT TITLE. Authorizes this chapter to be cited as the Supported Decision-Making Agreement Act.

as applicable, and is not subject to unauthorized access, use, or disclosure, if a supporter assists an adult with a disability in accessing, collecting, or obtaining personal information, including protected health information under the Health Insurance Portability and Accountability Act of 1996 (Pub. L. No. 104-191) or educational records under the Family Educational Rights and Privacy Act of 1974 (20 U.S.C. Section 1232g).

(c) Provides that the existence of a supported decision-making agreement does not preclude an adult with a disability from seeking personal information without the assistance of a supporter.

**Sec. 1357.055. AUTHORIZING AND WITNESSING OF SUPPORTED DECISION-MAKING AGREEMENT.** (a) Requires a supported decision-making agreement to be signed voluntarily, without coercion or undue influence, by the adult with a disability and the supporter in the presence of two or more subscribing witnesses or a notary public.

(b) Requires the attesting witnesses to be at least 14 years of age if signed before two witnesses.

**Sec. 1357.056. FORM OF SUPPORTED DECISION-MAKING AGREEMENT.** (a) Provides that a supported decision-making agreement, subject to Subsection (b), is only valid if it is substantially a certain form as set forth.

(b) Authorizes a supported decision-making agreement to be in any form not inconsistent with Subsection (a) and the other requirements of this chapter.

#### **SUBCHAPTER C. DUTY OF CERTAIN PERSONS WITH RESPECT TO AGREEMENT**

**Sec. 1357.101. RELIANCE ON AGREEMENT; LIMITATION OF LIABILITY.** (a) Requires a person who receives the original or a copy of a supported decision-making agreement to rely on the agreement.

(b) Provides that a person is not subject to criminal or civil liability and has not engaged in professional misconduct for an act or omission if the act or omission is done in good faith and in reliance on a supported decision-making agreement.

**Sec. 1357.102. REPORTING OF SUSPECTED ABUSE, NEGLECT, OR EXPLOITATION.** Requires a person, if a person who receives a copy of a supported decision-making agreement or is aware of the existence of a supported decision-making agreement has cause to believe that the adult with a disability is being abused, neglected, or exploited by the supporter, to report the alleged abuse, neglect, or exploitation to DFPS in accordance with Section 48.051 (Report), Human Resources Code.

**SECTION 2.** Effective date: upon passage or September 1, 2015.

In essence, we all seek our own circles of support and engage in supported decision-making. Depending on the issue, we reach out to families or friends, colleagues or classmates, mechanics or mentors before we decide to go on a blind date, buy a used car, change jobs, renew a lease, sign up for a hot yoga class or undergo cataract surgery. We confer and consult with others, and then we decide on our own. Likewise, people with disabilities may need assistance making decisions about living arrangements, health care, lifestyles and financial matters, but they don't necessarily need a guardian to make those decisions for them. What they might need instead is a trusted network of supporters to field their questions and review their options so they too can confer and consult, and then reach their own decisions. Supporters can be family members, co-workers, friends, and past or present providers (though many SDM models discourage paid staff on support networks). It is critically important that the individual select supporters who know and respect his or her will and preferences, and will honor the choices and decisions the individual makes.  
Source: <http://supporteddecisions.org/about-sdm/>

**DRAFT SUPPORTED DECISION-MAKING ACT**  
**2018 – H/S -----**

LC

**STATE OF RHODE ISLAND  
IN GENERAL ASSEMBLY  
JANUARY SESSION, A.D. 2018**

**AN ACT**  
**RELATING TO SUPPORTED DECISION-MAKING**

**Introduced By:**

**Date Introduced:**

**Referred To:**

It is enacted by the General Assembly as follows:

- 1 Section 1. Title \_ of the General Laws entitled " \_\_\_ " is hereby amended by adding the following chapter  
2 Chapter T.C.<sup>1</sup>
- 3 **T.C.1: Title**  
4 **This Act may be cited as the Supported Decision-Making Act.**
- 5 **T.C. 2: Purpose/Interpretation**  
6 **(a) The purpose of this chapter is to do all of the following:**  
7 **(1) Provide assistance in gathering and assessing information, making informed decisions, and**  
8 **communicating decisions for adults who would benefit from decision-making assistance;**  
9 **(2) Give supporters legal status to be with the adult and participate in discussions with others**  
10 **when the adult is making decisions or attempting to obtain information;**  
11 **(3) Enable supporters to assist in making and communicating decisions for the adult but not**  
12 **substitute as the decision maker for that adult; and**  
13 **(4) Establish the use of Supported Decision-Making as an alternative to guardianship.**
- 14 **(b) This chapter is to be administered and interpreted in accordance with all of the following principles:**  
15 **(1) All adults should be able to choose to live in the manner they wish and to accept or refuse**  
16 **support, assistance, or protection;**

<sup>1</sup> T.C. will be replaced by the Title # and Chapter #

17 (2) All adults should be able to be informed about and participate in the management of their  
18 affairs; and

19 (4) The values, beliefs, wishes, cultural norms, and traditions that an adult holds should be  
20 respected in supporting an adult to manage his or her affairs.

21 **T.C. 3: Definitions**

22 **For the purposes of this chapter:**

23 **(1) "Adult" means an individual who is 18 years of age or older.**

24 **(2) "Affairs" means personal, health care, and financial matters arising in the course of activities of daily**  
25 **living and includes all of the following:**

26 **a. Those health-care and personal affairs in which an adult makes his or her own health-care**  
27 **decisions, including monitoring his or her own health; obtaining, scheduling, and coordinating**  
28 **health and support services; understanding health-care information and options; and making**  
29 **personal decisions, including those to provide for his or her own care and comfort; and**

30 **b. Those financial affairs in which an adult manages his or her income and assets and its use for**  
31 **clothing, support, care, comfort, education, shelter, and payment of other liabilities of the**  
32 **individual.**

33 **(3) "Good faith" means honesty in fact and the observance of reasonable standards of fair dealing.**

34 **(4) "Health-care institution" means "health-care institution" as defined in § \_\_\_\_\_ of this title.**

35 **(5) "Health-care provider" means "health-care provider" as defined in § \_\_\_\_\_ of this title.**

36 **(6) "Immediate family member" means a spouse, child, sibling, parent, grandparent, grandchild,**  
37 **stepparent, stepchild, or stepsibling.**

38 **(7) "Person" means an adult; health-care institution; health-care provider; corporation; partnership;**  
39 **limited liability company; association; joint venture; government; governmental subdivision, agency, or**  
40 **instrumentality; public corporation; or any other legal or commercial entity.**

41 **(8) "Principal" means an adult who seeks to enter, or has entered, into a supported decision-making**  
42 **agreement with a supporter under this chapter.**

43 **(9) "Supported decision-making" means a process of supporting and accommodating an adult with a**  
44 **disability to enable the adult to make life decisions, including decisions related to where the adult wants**  
45 **to live, the services, supports, and medical care the adult wants to receive, whom the adult wants to live**  
46 **with, where the adult wants to work, how the adult wants to manage finances, without impeding the**  
47 **self-determination of the adult.**

48 **(10) "Supported decision-making agreement" or "the agreement" means an agreement between a**  
49 **principal and a supporter entered into under this chapter.**

50 **(11) "Supporter" means a person who is named in a supported decision-making agreement and is not**  
51 **prohibited from acting under § \_\_\_\_\_ of this title.**

52 **(12) "Support services" means a coordinated system of social and other services supplied by private,**  
53 **state, institutional, or community providers designed to help maintain the independence of an adult,**  
54 **including any of the following:**

55 **a. Homemaker-type services, including house repair, home cleaning, laundry, shopping, and**  
56 **meal-provision;**

57 **b. Companion-type services, including transportation, escort, and facilitation of written, oral, and**  
58 **electronic communication;**

59 **c. Visiting nurse and attendant) care;**

60 **d. Health-care provider;**

61 **e. Physical and psychosocial assessments;**

62 **f. Financial assessments and advisement on banking, taxes, loans, investments, and management**  
63 **of real property;**

- 64 g. Legal assessments and advisement;
- 65 h. Education and educational assessment and advisement;
- 66 i. Hands-on treatment or care, including assistance with activities of daily living such as bathing,
- 67 dressing, eating, range of motion, toileting, transferring, and ambulation;
- 68 j. Care planning; and
- 69 k. Other services needed to maintain the independence of an adult.

70 **T.C. 4: Presumption of Capacity**

- 71 (a) All adults are presumed to be capable of managing their affairs and to have legal capacity.
- 72 (b) The manner in which an adult communicates with others is not grounds for deciding that the adult is
- 73 incapable of managing the adult's affairs.
- 74 (c) Execution of a supported decision-making agreement may not be used as evidence of incapacity and
- 75 does not preclude the ability of the adult who has entered into such an agreement to act independently
- 76 of the agreement.

77 **T.C. 5: Supported Decision-Making Agreements**

- 78 (a) A supported decision-making agreement must include all of the following:
- 79 (1) Designation of at least 1 supporter;
- 80 (2) The types of decisions for which the supporter is authorized to assist; and
- 81 (3) The types of decisions, if any, for which the supporter may not assist.
- 82 (b) A supported decision-making agreement may include any of the following:
- 83 (1) Designation of more than 1 supporter;
- 84 (2) Provision for an alternate to act in the place of a supporter in such circumstances as may be
- 85 specified in the agreement; and
- 86 (3) Authorization for a supporter to share information with any other supporter named in the
- 87 agreement, as a supporter believes is necessary.
- 88 (c) A supported decision-making agreement is valid only if all of the following occur:
- 89 (1) The agreement is in a writing that contains the elements of the form at § \_\_\_\_\_;
- 90 (2) The agreement is dated; and
- 91 (3) Each party to the agreement signed the agreement in the presence of 2 adult witnesses, or
- 92 before a notary public.
- 93 (d) The 2 adult witnesses required by paragraph (d)(3) of this section may not be any of the following:
- 94 (1) A supporter for the principal;
- 95 (2) An employee or agent of a supporter named in the supported decision-making agreement;
- 96 (3) a paid provider of services to the principal; and
- 97 (4) Any person who does not understand the type of communication the principal uses, unless
- 98 an individual who understands the principal's means of communication is present to assist
- 99 during the execution of the supported decision-making agreement.
- 100 (e) A supported decision-making agreement must contain a separate declaration signed by each
- 101 supporter named in the agreement indicating all of the following:
- 102 (1) The supporter's relationship to the principal;
- 103 (2) The supporter's willingness to act as a supporter; and
- 104 (3) The supporter's acknowledgement of the role of a supporter under this chapter.
- 105 (f) A supported decision-making agreement may authorize a supporter to assist the principal to decide
- 106 whether to give or refuse consent to a life sustaining procedure within the meaning of Chapter 4.11 of
- 107 Title 23.
- 108 (g) A principal or a supporter may revoke a supported decision-making agreement at any time in writing
- 109 and with notice to the other parties to the agreement

110 **T.C. 6: Supporters**

111 a) Except as otherwise provided by a supported decision-making agreement, a supporter may do all of  
112 the following:  
113 (1) Assist the principal in understanding information, options, responsibilities, and consequences  
114 of the principal's life decisions, including those decisions relating to the principal's affairs or  
115 support services;  
116 (2) Help the principal access, obtain, and understand any information that is relevant to any  
117 given life decision, including medical, psychological, financial, or educational decisions, or any  
118 treatment records or records necessary to manage the principal's affairs or support services;  
119 (3) Assist the principal in finding, obtaining, making appointments for, and implementing the  
120 principal's support services or plans for support services;  
121 (4) Help the principal monitor information about the principal's affairs or support services,  
122 including keeping track of future necessary or recommended services; and  
123 (5) Ascertain the wishes and decisions of the principal, assist in communicating those wishes and  
124 decisions to other persons, and advocate to ensure that the wishes and decisions of the principal  
125 are implemented.

126 (b) Any of the following are disqualified from acting as a supporter:  
127 (1) A person who is an employer or employee of the principal, unless the person is an immediate  
128 family member of the principal;  
129 (2) A person directly providing paid support or health services to the principal, with the  
130 exception of supported decision-making services, unless the person is an immediate family  
131 member of the principal; and  
132 (3) An individual against whom the principal has obtained an order of protection from abuse or  
133 an individual who is the subject of a civil or criminal order prohibiting contact with the principal

134 (d) A supporter shall act with the care, competence, and diligence ordinarily exercised by individuals in  
135 similar circumstances, with due regard either to the possession of, or lack of, special skills or expertise.  
136 **T.C. 7: Recognition of Supporters**  
137 A decision or request made or communicated with the assistance of a supporter in conformity with this  
138 chapter shall be recognized for the purposes of any provision of law as the decision or request of the  
139 principal and may be enforced by the principal or supporter in law or equity on the same basis as a  
140 decision or request of the principal.

141 **T.C. 8: Limitation of Liability**  
142 A person, who in good faith acts in reliance on an authorization in a supported decision-making  
143 agreement, or who in good faith declines to honor an authorization in a supported decision-making  
144 agreement, is not subject to civil or criminal liability or to discipline for unprofessional conduct for any  
145 of the following:  
146 (1) Complying with an authorization in a supported decision-making agreement based on an  
147 assumption that the underlying supported decision-making agreement was valid when made and  
148 has not been revoked;  
149 (2) Declining to comply with an authorization in a supported decision-making agreement based  
150 on actual knowledge that the agreement is invalid.

151 **T.C. 9: Access to Information**  
152 (a) A supporter may assist the principal with obtaining any information to which the principal is entitled,  
153 including, with a signed and dated specific consent, protected health information under the Health  
154 Insurance Portability and Accountability Act of 1996 [P. L. 104-191], educational records under the  
155 Family Educational Rights and Privacy Act of 1974 [20 U.S.C. § 1232g], or information protected by 42  
156 C.F.R Part 2.

157 (b) The supporter shall ensure all information collected on behalf of the principal under this section is  
158 kept privileged and confidential, as applicable; is not subject to unauthorized access, use, or disclosure;  
159 and is properly disposed of when appropriate.

160 **T.C. 9: Reporting of Suspected Abuse, Neglect, or Exploitation**

161 If a person who receives a copy of a supported decision-making agreement or is aware of the existence  
162 of a supported decision-making agreement has cause to believe that the principal, who is adult with a  
163 developmental disability or an elder, is being abused, neglected, or exploited by the supporter, the  
164 person shall report the alleged abuse, neglect, or exploitation pursuant to RI Gen. Laws §40.1-27-02,  
165 and §42-66-8 [add others that are facility-based?].

166 **T.C. 10: Form of Supported Decision-Making Agreement**

167 (a) Subject to Subsection (b), a supported decision-making agreement is valid only if it is in substantially  
168 the following form:

169 **SUPPORTED DECISION-MAKING AGREEMENT**

170 **Appointment of Supporter**

171 I, \_\_\_\_\_(insert your name), make this agreement of my own free will.

172 I agree and designate that: \_\_\_\_\_

173 Name: \_\_\_\_\_

174 Address: \_\_\_\_\_

175 Phone Number: \_\_\_\_\_

176 E-mail Address: \_\_\_\_\_

177 is my supporter. My supporter may help me with making everyday life decisions relating to the  
178 following:

179 Y/N obtaining food, clothing, and shelter

180 Y/N taking care of my physical health

181 Y/N managing my financial affairs.

182 My supporter is not allowed to make decisions for me. To help me with my decisions, my supporter  
183 may:

184 1. Help me access, collect, or obtain information that is relevant to a decision, including medical,  
185 psychological, financial, educational, or treatment records;

186 2. Help me understand my options so I can make an informed decision; or

187 3. Help me communicate my decision to appropriate persons.

188 Y/N A release allowing my supporter to see protected health information under the Health  
189 Insurance Portability and Accountability Act of 1996 (Pub. L. No. 104-191) is attached.

190 Y/N A release allowing my supporter to see educational records under the Family Educational  
191 Rights and Privacy Act of 1974 (20 U.S.C. Section 1232g) is attached.

192 [Y/N A declaration pursuant to § 23-4.11-3 or 3.1 – does this really belong here?]

193 **Effective Date of Supported Decision-Making Agreement**

194 This supported decision-making agreement is effective immediately and will continue until \_\_\_\_\_  
195 (insert date) or until the agreement is terminated by my supporter or me or by operation of law.

196 Signed this \_\_\_\_\_ day of \_\_\_\_\_, 20\_\_\_\_

197 **Consent of Supporter**

198 I, \_\_\_\_\_ (name of supporter), consent to act as a supporter under this agreement, and  
199 acknowledge my responsibilities under [this chapter].

200 \_\_\_\_\_

201 (signature of supporter) \_\_\_\_\_ (printed name of supporter)

202 My relationship to the principal is: \_\_\_\_\_

203 I, ..... (name of supporter), consent to act as a supporter under this agreement,  
204 and acknowledge my responsibilities under [this chapter].

205 .....  
206 (signature of supporter) ..... (printed name of supporter)

207 My relationship to the principal is: .....

208 Consent of the Principal  
209 .....  
210 (my signature) ..... (my printed name)

211 Witnesses or Notary  
212 .....  
213 (witness 1 signature) ..... (printed name of witness1)

214 .....  
215 (witness 2 signature) ..... (printed name of witness 2)

216 Or  
217 State of .....  
218 County of .....

219 This document was acknowledged before me on ..... (date)  
220 by ..... and.....  
221 (name of adult with a disability) ..... (name of supporter)

222 .....  
223 (signature of notarial officer)

224 (Seal, if any, of notary)  
225 .....  
226 (printed name)

227 My commission expires: .....

228  
229 (b) A supported decision-making agreement may be in any form not inconsistent with Subsection (a)  
230 and the other requirements of this chapter.

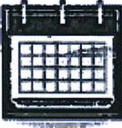

231 Part B Amend Chapter 15 of Title 33, Section 47 as follows  
232 STATE OF RHODE ISLAND PROBATE COURT OF THE  
233 COUNTY OF .....  
234 No.  
235 ESTATE OF .....  
236 PERSONAL ESTATE ESTIMATED AT \$..... CITY/TOWN OF  
237 PETITION FOR LIMITED GUARDIANSHIP OR GUARDIANSHIP  
238 hereby petitions the Probate Court of the  
239 Petitioner  
240 city/town of ..... to appoint a limited guardian/guardian for ..... who currently resides at  
241 .....

242 Address  
243 ....., in the city/town of ....., and whose date of birth is .....

244 Based upon an assessment conducted by ..... on, which Date  
245 functional assessment reflects the current level of functioning of ....., it has been determined  
246 that Respondent lacks decision-making ability in one or more of the following areas as indicated:

- 247 .... health care  
248 .... financial matters  
249 .... residence

- 250 .... association
- 251 .... other
- 252 Regarding each area indicated, please describe the specific assistance needed:
- 253 Indicate which of the following less restrictive alternatives to guardianship have been explored and
- 254 deemed inappropriate as indicated:
- 255 .... Durable Power of Attorney for Health Care
- 256 .... Living Will
- 257 .... Power of Attorney
- 258 .... Durable Power of Attorney
- 259 .... Trusts
- 260 .... Joint Property Arrangements
- 261 .... Representative Payee
- 262 .... Money Management
- 263 .... Single Court Transactions
- 264 .... Government Benefit and Social Service Programs
- 265 .... Housing Options
- 266 ... Supported Decision-Making Agreement
- 267 .... Other<sup><add></sup>
- 268 Section 2. This act shall take effect on \_\_\_\_\_

	<p><b><i>4:25 Agenda for the Next Meeting, Linda Ward, Chair</i></b></p> <p><b>Purpose/Goal: To set the agenda for the next meeting.</b></p> <p><b>Discussion:</b>          The next meeting of the Legislation Committee is on Tuesday November 7<sup>th</sup>.</p> <ul style="list-style-type: none"> <li>• Reviewing the 2017 Legislative Package and deciding which items to recommend working on in 2018</li> <li>• Supported Decision Making</li> <li>• Adding new items to the 2018 Legislative Package from the concerns raised at the public forums.</li> <li>• Recommending the 2018 scope of review (categories of bills to be reviewed and commented on during the 2018 General Assembly session.</li> </ul>
	<p><b><i>4:30 Adjournment, Linda Ward, Chair</i></b></p> <p><b>Potential MOTION: To adjourn at 4:39 PM</b>  <b>Motion moved by KH, seconded by RCo, <i>passed unanimously</i></b></p>

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# Supported Decision-Making: An Agenda for Action

February 2014

## Introduction

Historically, people with cognitive disabilities have been placed under legal guardianship regimes, losing the right to make their own choices about life issues such as where to live and whether to work, marry, or receive health care. Supported Decision-Making (SDM), by contrast, offers an opportunity for many adults with disabilities to make their own decisions, consistent with fundamental human and legal rights, and an emerging international consensus.

SDM is a process in which adults who need assistance with decision-making – for instance, some people with intellectual or developmental disabilities (I/DD) – receive the help they need and want to understand the situations and choices they face, so they can make life decisions for themselves, without the need for undue or overbroad guardianship. Introduced as part of the United Nations Convention on the Rights of Persons with Disabilities (CRPD), SDM can be a key element for improving experiences and opportunities for many people with different life conditions (Kohn, N., Blumenthal, J. & Campbell, A. 2012).

Since the Middle Ages, society has too often responded to people who need help making some decisions by taking away their right to make any decisions through the use of plenary or “full” guardianship (O’Sullivan, J., 2002; Salzman, L., 2010). In the United States, adult guardianship is a legal process governed by state law with different rules and systems in each state. In general, guardianship is ordered when a court determines that a person cannot make some or all decisions and is in need of “protection”; and that there are no less restrictive options for decision-making than guardianship.<sup>1</sup> This is considered a “substituted” decision-making approach because the court appoints a third party to make some or all decisions for the person. In the majority of cases, courts order full or “plenary” guardianship, where the guardian makes all decisions for the person with a disability. (Teaster, P., Wood, E., Lawrence, S., & Schmidt, W., 2007).

Article 12 of the CRPD challenges the existing system of substituted decision-making, including guardianship. It pushes us to move toward a new framework where people are supported to be their own decision-makers. Article 12 recognizes that all people have legal capacity and that governments must take appropriate action to provide people with access to the supports they

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<sup>1</sup> “Less restrictive” options mean other ways of making decisions that protect the person’s rights and self-determination better than guardianship.

need and want to make their own decisions and order their own lives to the maximum of their capabilities (Dinerstein, R., 2012).

While there is no “one-size-fits-all” model of SDM, it generally occurs when people receive assistance from one or more trusted friends, family members, professionals or advocates - to help them understand the situations they face and choices and options they have, so they can make their own decisions. This process mirrors what happens for most adults when they make decisions such as whether to get car repairs, sign legal documents and consent to medical procedures: they seek advice, input and information from friends, family or professionals who are knowledgeable about those issues, so they can make their own well-informed choices.

This paper outlines actions taken and being taken to advance SDM as an alternative to guardianship, culminating in the findings and recommendations of the First Annual Symposium on Supported Decision-Making, held at the American University Washington College of Law on October 24, 2013.

## Building the Agenda

The first step toward an Action Agenda was a one-day conversation (Roundtable) held in New York City in October 2012, where stakeholders met to discuss the rights of people with intellectual disabilities to make their own decisions, including the impact of the CPRD. Organized and supported by the American Bar Association and the Administration on Intellectual and Developmental Disabilities, the goal of the meeting was to explore concrete ways to move from a model of substituted decision-making, like guardianship, to one of SDM, consistent with an assumption of capacity for all adults. Roundtable participants included experts and stakeholders from a variety of disciplines and organizations, including lawyers; physicians; educators; services providers; siblings; parents; advocates; members of the judiciary; representatives from national and state organizations and participants from several government agencies.

In the summer of 2013, a 29 year old woman named Margaret “Jenny” Hatch won a landmark legal battle protecting her right to make her own life decisions using SDM, instead of being subjected to guardianship. Like many people with disabilities, Jenny faced a guardianship petition challenging her right to make decisions -- choices she had always made for herself, like where to live, what to do and who to see. At the request of her parents, the court put Jenny under a temporary guardianship and placed her in a group home, where they took away her cell phone and laptop and wouldn't let her see her friends. However, after a year of litigation, Jenny won the right to make her own decisions and now lives and works where she wants, has the friends she chooses, and encourages others to do the same.

The trial Court in Jenny's case was the first to order the use of SDM instead of a guardianship for a person with a disability, and received national and international attention for highlighting "an individual's right to choose how to live and the government's progress in providing the help needed to integrate even those with the most profound needs into the community."<sup>2</sup>

On October 24, 2013, a group sixty five participants was convened for an Invitational Symposium on Supported Decision-Making.<sup>3</sup> The meeting was planned and coordinated by Quality Trust for Individuals with Disabilities, The Council on Quality and Leadership (CQL) and the Burton Blatt Institute (BBI), and hosted by the American University Washington College of Law. This event was also supported, in part, by funding from the Administration on Intellectual and Developmental Disabilities, Administration for Community Living, U.S. Department of Health and Human Services.<sup>4</sup> National and international stakeholders and opinion leaders were invited to come together and outline an action agenda for moving forward to advance and implement SDM. Ms. Hatch and her supporters were invited to frame the issues from the perspective of the person needing assistance. Stakeholder representatives included advocates with disabilities, families, guardians, lawyers, researchers, government policy makers, providers and other professionals. This document reflects the conclusions and recommendations from the participants.

## Challenges and Opportunities

It's an important time to have this conversation. This generation of people with disabilities is the first to grow up with the rights and opportunities protected and promoted by the Americans with Disabilities Act (ADA). There is growing recognition that over-reliance on formal systems of substituted decision-making can hinder or prevent inclusion, self-determination and community integration, in violation of the ADA and other federal laws (Salzman, L., 2010).

The 2012 Roundtable included conversation about needed legal and other reforms and changes that may lead to the end of guardianship as we know it. Roundtable participants brought many

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<sup>2</sup> [http://articles.washingtonpost.com/2013-07-20/local/40695386\\_1\\_group-home-guardianship-jim-talbert](http://articles.washingtonpost.com/2013-07-20/local/40695386_1_group-home-guardianship-jim-talbert)

See, also, [http://articles.washingtonpost.com/2013-08-02/local/41002259\\_1\\_morris-and-talbert-jim-talbert-jenny-hatch](http://articles.washingtonpost.com/2013-08-02/local/41002259_1_morris-and-talbert-jim-talbert-jenny-hatch) ; <http://www.wavy.com/news/local/newport-news/jenny-hatch-in-her-new-life>

<sup>3</sup> Symposium participants included the Administration on Intellectual and Developmental Disabilities, Open Society, Collaboration to Promote Self-Determination, Elizabeth Boggs Center, and the Autistic Self Advocacy Network.

<sup>4</sup> Organizations receiving funding that undertake projects under government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official Administration on Intellectual and Developmental Disabilities policy.

backgrounds and experiences and raised a number of important and difficult questions, including:

- Should we build a bridge between the existing guardianship laws and full SDM?
- Can we revise current standards for guardianship to stress independent decision-making and the supports needed?
- Should implementation take place somewhere other than the judicial system?
- How would decision-making supporters be appointed?
  - What process would be needed to have them legally recognized?
- Where and how do we find the resources needed to create networks of support and trust for individuals?
- How do we prevent abuse and undue influence without denying legal capacity?
- How can we protect the integrity of the decision-making process?
  - Do we need standards and expectations for supporters? Should there be a reporting system?
  - Should supporters be required to keep records?
  - What kind of monitoring would be required?
  - Should monitoring differ for different kinds of decisions?
  - How should disputes between supporters and the person with a disability be resolved?
- How would SDM work for other populations? For example, what differences would we find in applying the idea to older individuals with dementia or to those with episodic mental health conditions?

## **An Agenda for Future Action**

At the October 2013 Invitational Symposium, participants were divided into four workgroups: (1) People with disabilities, families and support networks; (2) Legal; (3) Policy and practice; and (4) Research. People from all stakeholder groups were represented in each working group to ensure that all perspectives were represented. Each group was provided with a standard framework, a facilitator and some general questions to start. The groups were challenged to come up with action steps and strategies to ensure SDM is used as a primary approach for assisting people with multiple types of challenges to make choices in various circumstances. The results of the group work are as follows:

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## **GROUP 1 - People with Disabilities, Families, Support Network Issues**

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Woven through all of this group's discussion, was the idea that we need to re-evaluate everything we do (research/legal/policy/practice) from the perspective of the person with a disability. There are many good ideas (e.g., person-centered planning and self-determination) that have yet to be fully brought to life and translated to practice in a way that results in achieving the outcomes desired. Therefore, an effort to move SDM from theory to practice could help us to define and operationalize many of these ideas.

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### **GROUP 1 Action Steps**

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1. Start with a focus on education. There should be an expectation that all children with disabilities will develop as decision-makers. SDM should be a basic expectation for everyone – not a “thing” or a “technology”.
  - Create a public awareness campaign about SDM options.
  - Track who is getting, understanding and implementing the message.
2. Frame decision-making as a basic human right and natural part of the human experience. From an early age, the expressed interests of children with disabilities should be heard, respected and considered in every activity that involves decisions about their life.
  - Create a “toolbox” that will help people explore the options for support.
  - Create a one stop resource center for information on SDM.
3. Focus on rights and expectations to set basic standards.
  - Identify and promote one uniform standard of good and ethical practice that would cut across all professions and job titles.
  - Identify ways to support and spread high expectations – perhaps using peer to peer support strategies and parent to parent support groups.
  - Identify and implement ways to help people explore different issues and circumstances – so that everyone can understand how people with very different abilities can take charge of their lives.
  - Recruit professionals (psychology/speech/OT/PT/Social work/lawyers and others) to embrace the expectation that people with disabilities should and will develop into their own decision-makers – so that people not directing their own lives becomes the exception instead of the norm.

**4. Address the elephant in the room – SAFETY.**

- Need a process for attacking the “myth” that safety in life can be achieved for anyone.
- Define what it means to be “safe”.
- Answer the burning questions that too often steer the conversation and action away from how to support the person:
  - Can we really keep people safe?
  - When does trying to keep people safe become abusive or coercive?
  - When does the cost of safety (loss of freedom and access to life) outweigh the benefits?
- Create a way for people to tell their stories of how they balance safety, autonomy, and dignity and risk in real life situations.
- Use real-life examples of people taking different paths and using different decision-making methods so the discussion moves away from being “hypothetical.”
- Share stories that illustrate what worked and did not work in different situations.

**5. Create a way for people working on this issue throughout the country (and world) to link to and communicate with one another for the purpose of building momentum and advancing practice:**

- Sharing resources;
- Telling stories;
- Networking with other professionals doing similar work;
- Getting technical assistance;
- Accessing sample tools and documents; and
- Forming strategic partnerships to address and advocate for specific issues, infuse SDM into everyday life, across the ADA, CRPD, Individuals with Disabilities Education Act (IDEA), Vocational Rehabilitation and other policy statements and laws.

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**GROUP 2 - Legal Issues**

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The legal group identified action steps necessary to advance SDM in the courts and the practice of law. There was consensus that SDM, with adequate resources, must be put in place before guardianship and that guardianship should only be considered if SDM has not succeeded. It

was acknowledged that SDM is generally not known to the general public, policymakers, the judiciary and many lawyers. Part of the legal challenge is to make this strategy known and understood. One of the best ways that we can do that, whether we are in court or talking to policymakers or parents and friends is to associate the right to make decisions, through SDM or otherwise, through known rights. A person's right to make his or her own decisions is inherent in the U.S. and state Constitutions and other laws, and therefore should be legally enforceable. That right should not be dependent on the quality of any decision made.

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## **GROUP 2 Action Steps**

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1. Ensure that there is a bedrock human, legal and enforceable right to make your own decisions.
2. Ensure that this right is not contingent upon the quality of decisions you make, the process by which you make those decisions or the ways in which you communicate them.
3. If a person chooses to use accommodation or support to make decisions, this request for assistance should be recognized as a fundamental human right. The use of assistance should not be used as a pretext to take away any person's right to make decisions.
4. These rights should be communicated in policy, practice and law, and utilized throughout the lifespan (and be recognized and respected by third parties).
5. Communicate and advocate for these rights whenever possible. Whenever possible, preferably always, associate them with known rights. This will take the "mystery" out of SDM and allow it to be applied across the lifespan and life experiences – in courts, employment situations, educational settings and other areas.
6. Focus outreach and advocacy on third parties who have traditionally steered people toward guardianship. Stress that third parties have an affirmative duty to accommodate people's need or desire for SDM.
7. Pursue administrative and legal remedies against third parties that do not support a person's right to make his or her own decisions.
8. Outreach should also be targeted to the general public—strategic communication illustrating people's right, ability and legal capacity to make their own decisions.
9. Define this right, and disability in general, as a diversity issue, to make people with disabilities more visible and included in their communities.

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### **GROUP 3 - Policy and Practice Issues (International, Federal, State, Local)**

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The policy and practice group began with a focus on critical principles and strategies to guide best practice. They generated a list of principles that are known, but not always reflected, in policy or day-to-day practice such as:

- Everyone has a right to make their own decision(s).
- People with disabilities have a right to be their primary decision maker.
- Good decision making is a skill that can be learned.
- SDM should be available to all who choose to use it.
- Everyone has a right to fail without serious injury or loss of rights.
- With good SDM, guardianship should be a last resort. With effective use of SDM, guardianship should not be needed. Relationships need to be valued, created, mentored and supported.
- All people need help making decisions. We are all diverse, we all make decisions individually and with support, at different times in life.

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### **GROUP 3 Action Steps**

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1. Finalize a set of guiding principles that everyone will support.
2. Redefine disabled to differently abled.
3. People should have the right to maintain relationships with supporters while maximizing inclusion and rights.
4. Policies should facilitate community and personal relationship(s) with a focus on rights and choice.
5. Add SDM and the right to make one's own decisions to any statement of rights associated with programs or services.
6. Develop policies and strategies to support people to exercise their legal rights
7. Develop better guidance about what constitutes informed decision making.
8. Identify promising practices from CRPD implementation globally.

#### ***What specific policy changes are needed in Supported Decision-Making?***

- All people should have the right to make their own decisions, as consistent with the integration mandate set out in the Olmstead decision.

- Require information on alternatives to guardianship to be provided as part of federal regulations (e.g., Medicaid, Older Americans Act, IDEA).
- Require IDEA regulations on transition planning to specifically address procedures for implementing SDM.
- Strengthen Preadmission Screening and Resident Review (PASRR) regulations to specifically address and implement SDM.

***How can Supported Decision-Making be advanced in practice?***

**Training:**

- Waiver and community providers must be trained to respect and implement SDM.
- Special education providers must be trained to respect and implement SDM.

**Education:**

- State and Federal Departments of Education must provide interpretive guidance on alternatives to guardianship and information on SDM.
- Inform judges, hearing officers and administrative law judges about SDM.

**Structure and Process:**

- Incentivize supporters to utilize SDM.
- Implement Employment First policies to get people integrated into their communities where they can make decisions and build relationships.
- Ensure that Medicaid decision processes for services are in accessible formats.
- Review state guardianship laws and suggested appropriate changes to recognize less-restrictive alternatives including SDM.
- Create and implement a campaign by people with disabilities advocating for SDM.
- Ensure that SDM becomes a cornerstone in all service provision.
- Monitor systems specific to SDM and government supports to identify best practices.
- Strive for total system change in thinking and implementation.

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**GROUP 4 - Research Issues**

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The research group addressed critical questions regarding ways research can assist with advancing knowledge about SDM. The list of research questions generated reflects that much work is needed to better define both the current status and the scope of current practice.

While some initial research has been done in this area, more is needed to create a body of evidence that will support new practices. This basic research will inform what quality indicators can be used to measure progress and impacts over time.

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#### **GROUP 4 Action Steps**

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##### ***What are the priority questions related to policy and practice evaluation?***

- What is the problem? Examine size, cause, scope, impact of guardianship. Identify who are the typical guardians, what funding mechanisms are perpetuating guardianship, and what legal provisions are perpetuating it.
- Do we know how many people live in segregated settings and who are under guardianship? How many people live with their parents / family and are under guardianship?
- How many service agencies have a policy (unwritten or otherwise) that “requires” guardianship before service provision / coordination? Why are such policies and practices utilized?
- What are public schools / VR systems advising parents during the transition process? How can students and their parents/supporters be better prepared for the transition process?

##### ***What interventions should be tested to enhance Supported Decision-Making?***

- Teaching self-advocacy and SDM to students in special education, at least by the time of transition planning.
- What, exactly, constitutes SDM in particular circumstances? What are the best practices for implementing SDM?
- Identify the elements of responsibility, including duty, freedom, rationality and, accountability.
- What constitutes “consent capacity”?

#### **Conclusions**

There is significant agreement on what should and needs to be done. Because the traditions around protection and support are strong, creating significant change will require consistent and coordinated effort. The challenge for leaders is to identify the steps they can take within their scope of influence AND work collaboratively with others to create new policies, systems and practices.

These fundamental principles reflect the clear consensus on what is needed to guide future action:

- ❖ Uniform standards and guiding principles that can be universally adopted.
- ❖ The need to compile existing information in one place, and track new information and efforts as they emerge in the U.S.
- ❖ The need for research, including studies into how SDM is working in the U.S. and abroad.
- ❖ The need to identify barriers to needed reform in guardianship and other support practices.
- ❖ The need to develop alternatives for people under guardianship now as well as those who are or may be facing guardianship.
- ❖ The importance of sharing stories – both success and real life challenges.

Additionally, the following three principles should also be reflected in all actions:

1. Recognize and respect that everyone has an equal right to make their own decisions, regardless of their diagnosis or functional challenges
2. Be respectful of the various opinions and deeply held beliefs that have led parents and advocates to choose different options for decision-making support, including SDM.
3. Promote the use and development of practices that will provide people in need of support with individualized decision-making assistance in a way that imposes the absolute minimum restriction of rights.

This report is the beginning of a long-term effort to promote the use of SDM. The Jenny Hatch Justice Project<sup>5</sup>, formed by Quality Trust for Individuals with Disabilities is committed to serving as a link to connect people and projects working on these issues throughout the country and abroad. We will reconvene stakeholders annually to take stock of progress and continue to advance SDM policy and practice, now and in the future.

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<sup>5</sup> You can contact the Jenny Hatch Justice Project (JHJP) by phone at 202-448-1448, through email at [JHJP@dcqualitytrust.org](mailto:JHJP@dcqualitytrust.org), or on the web at <http://jennvhatchproject.info/>.

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The First Annual Symposium on Best Practices in Supported Decision Making was organized by:



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[www.c-q-l.org](http://www.c-q-l.org)



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I support  
HB 336!  
JOE  
CARR

Senator Chenault  
145 main st  
Loop Room 223  
Kenai, AK 99601

Fishing with Tom Beatty at Kayaker's Cove 2007



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I support HB 376

I write/call to support the  
Supported Decision Making Act (HB336)  
that empowers Alaskans w/ disabilities  
to form individualized supported decisions  
making agreements to foster greater independence  
for adults with disabilities

Nick Jordan (Seward, Alaska)

Fishing with Tom Beatty at Kayaker's Cove 2007

Peter Miccicho  
145 Main St. Loop  
Ste. 226  
Kenai, AK 99611



# DISABILITY LAW CENTER

3330 Arctic Boulevard, Suite 103  
Anchorage, AK 99503

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April 8, 2018

The Honorable Matt Claman, Chair  
House Judiciary Committee  
Alaska State Legislature, Room 118  
Juneau, Alaska 99801

RE: Letter of Support for HB 336 - An Act relating to supported decision-making agreements to provide for decision-making assistance.

Dear Representative Claman:

The Disability Law Center of Alaska thanks the House Judiciary Committee for considering HB 336, and through this letter lends support for this important legislation.

"An individual's right to make decisions about his or her life is a fundamental value in American law."<sup>1</sup> However, many individuals with intellectual or cognitive disabilities have been stripped of this fundamental right. Exercising its *parens patriae* authority, the State appoints a guardian for these individuals. When considering the impact of the appointment of a guardian on the life of an individual with a disability, U.S. Representative Claude Pepper observed:

The typical ward has fewer rights than the typical convicted felon—they no longer receive money or pay their bills. They cannot marry or divorce. By appointing a guardian, the court entrusts to someone else the power to choose where they live, what medical treatment they will get and, in rare cases, when they will die. It is, in one short sentence, the most punitive civil penalty that can be levied against an American citizen, with the exception, of course, of the death penalty.<sup>2</sup>

<sup>1</sup> The American Bar Association, Resolution 113 (2017).

RESOLVED, That the American Bar Association urges state, territorial, and tribal legislatures to amend their guardianship statutes to require that supported decision-making be identified and fully considered as a less restrictive alternative before guardianship is imposed; and urges courts to consider supported decision making as a less restrictive alternative to guardianship; and

FURTHER RESOLVED, That the American Bar Association urges state, territorial, and tribal legislatures to amend their guardianship statutes to require that decision-making supports that would meet the individual's needs be identified and fully considered in proceedings for termination of guardianship and restoration of rights; and urges all courts to consider available decision-making supports that would meet the individual's needs as grounds for termination of a guardianship and restoration of rights.

<sup>2</sup> Abuses in Guardianship of the Elderly and Infirm: A National Disgrace, H.R.641, Subcommittee on Health and Long-Term Care, House Special Committee on Aging, 100th Cong., 1st Sess. (Sept. 25, 1987) (Comm. Pub. 100-641).

THE PROTECTION AND ADVOCACY SYSTEM FOR THE STATE OF ALASKA

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Guardianship is a significant deprivation of individual rights and therefore should only be used as a last resort. Supported decision-making is a meaningful alternative. Rather than extinguishing a fundamental right, supported decision-making recognizes an individual's 'legal capacity' — the right to make decisions and have those decisions respected. "All persons with disability have the right to develop a full human life and such development cannot happen without the opportunity to exercise capacity. To deny this opportunity to any group of persons is to perpetuate exclusion and to legitimize discrimination."<sup>3</sup>

The United Nations Convention on the Rights of Persons with Disabilities further describes this right in Article 12 -- *Equal Recognition Before the Law*:

1. States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.
2. States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.
3. States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.

Recognizing the legal capacity of individuals with disabilities through supported decision-making is in consonance with the integration mandate of the Americans with Disabilities Act and the U.S. Supreme Court's decision in *Olmstead v. L.C.* "[B]y limiting an individual's right to make his or her own decisions, guardianship marginalizes the individual and often imposes a form of segregation that is not only bad policy, but also violates the Act's mandate to provide services in the most integrated and least restrictive manner."<sup>4</sup>

Supported decision-making has been formally recognized as a less restrictive alternative by the Uniform Law Commission that revised the Uniform Guardianship, Conservatorship, and Other Protective Arrangements Act<sup>5</sup> in July of 2017.

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<sup>3</sup> Office of the United Nations High Commissioner for Human Rights, Legal Capacity, 20 (n.d.).

<sup>4</sup> Leslie Salzman, *Rethinking Guardianship (Again): Substituted Decision Making as a Violation of the Integration Mandate of Title II of the Americans with Disabilities Act*, 81 University of Colorado Law Review 157 (2010).

<sup>5</sup> "The Uniform Guardianship, Conservatorship, and other Protective Arrangements Act (UGCOPAA) is a comprehensive guardianship statute for the twenty-first century. It was drafted with extensive input from experienced guardianship judges and organizations that advocate for guardianship reform. UGCOPAA promotes person-centered planning to incorporate an individual's preferences and values into a guardianship order, and requires courts to order the least-restrictive means necessary for protection of persons who are unable to fully care for themselves."

<http://www.uniformlaws.org/Act.aspx?title=Guardianship,%20Conservatorship,%20and%20Other%20Protective%20Arrangements%20Act>

[T]he Act recognizes the role of, and encourages the use of, less restrictive alternatives, including supported decision-making and single-issue court orders instead of guardianship and conservatorship. To this end, the Act provides that neither guardianship nor conservatorship is appropriate where an adult's needs can be met with technological assistance or supported decision-making.

In closing, it is important to remember during deliberations on HB 336 that legal capacity – the right to make decisions - is a fundamental human right. “Whether an individual has the cognitive ability to understand and appreciate consequences of her decisions—the traditional threshold of the common law—is simply not determinative of whether she has legal capacity. Even if she does not possess those decision-making abilities, she cannot be stripped of her legal capacity.”<sup>6</sup>

Alaskans have a right to maximize their autonomy and independence through the use of the supports described in HB336. The Disability Law Center of Alaska fully supports HB 336 as it is consistent with the legislative, judicial and scholarly authorities cited herein.

Sincerely,

DISABILITY LAW CENTER OF ALASKA



David C. Fleurant  
Executive Director

The Disability Law Center of Alaska is an independent, non-profit law firm and is the designated Protection & Advocacy system for the State of Alaska. Our mission is to vigorously enforce and advance the rights and interests of people with disabilities.

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<sup>6</sup> Rebekah Diller, *Legal Capacity for All: Including Older Persons in the Shift from Adult Guardianship to Supported Decision-Making*, 43 *Fordham Urb. L.J.* 495 (2016). Available at: <https://ir.lawnet.fordham.edu/ulj/vol43/iss3/2>



**AADD**  
**ALASKA ASSOCIATION ON**  
**DEVELOPMENTAL DISABILITIES**  
**P.O. Box 241742**  
**Anchorage, Alaska 99524**

*To facilitate a united provider voice for best practices, advocacy, partnerships and networking.*

April 5, 2018

Dear Representative Claman,

AADD, the Alaska Association on Developmental Disabilities, is the professional association that represents the voice of forty seven organizations in Alaska that provide home and community based services to individuals who experience intellectual and developmental disabilities. The Association is a strong supporter of HB 336 on Supportive Decision-Making Agreements.

AADD is pleased to be involved with WINGS (Working Interdisciplinary Network of Guardianship Stakeholders) which is a valuable project working on ways to improve our state's guardianship system. The group recognizes the difficulty Alaska faces with the high percentage of full guardianships awarded in Alaska compared to other states. Supported Decision Making Agreements (SDMA) is one of the alternatives that can support individuals that experience developmental disabilities to direct their lives and services. SMDA's provide a legal written framework for decision making in which a vulnerable adult may select persons of his or her own choosing to assist in life choices where decisions are complex for that individual. We all turn to experts in fields where we lack expertise such as taxes, health, legal affairs. HB 336 provides a legal framework for this commonplace practice for individuals who experience disabilities but who can and want to make decision about their own life.

AADD is grateful for leadership from Representative Millett in championing this bill. We believe that individuals who experience developmental disabilities will benefit from SMDA in supporting their choices and rights to direct their services. We look forward to the passage, enactment and implementation of SMDA in Alaska.

Sincerely,

Lizette Stiehr  
Executive Director  
AADD