

**HB**

**336**

<TARGET><BILL>HB 336</BILL><SUBJECT>HB  
336</SUBJECT><COMM>HHSS30</COMM></TARGET>

# 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 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>
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>

**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>

**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? 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If yes, by what date are the regulations to be adopted, amended or repealed? 07/01/19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: <u>Duane Mayes, Director</u>	Phone: <u>(907)269-2083</u>
Division: <u>Senior and Disabilities Services</u>	Date: <u>02/23/2018</u>
Approved By: <u>Shawnda O'Brien, Asst. Commissioner</u>	Date: <u>02/23/18</u>
Agency: <u>Health and Social Services</u>	

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.

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**House Bill 336 (Version D) to Draft CS (Version J) Explanation of Changes**

**Unless noted, sections, pages and line numbers referenced below pertain to Draft CS for House Bill 336, Version J**

Section 13.56.010, Page 1, Line 9: Deleted "another adult" and added "one or more adults"

Section 13.56.010(c), Page 2, Line 1-4: Changed language to clarify that an adult cannot enter into a SDMA if that agreement infringes on the authority of any guardian or conservator – but still gives principal the ability to enter a SDMA IF the guardian/conservator approves of it in writing

Section 13.56.030(a)(2), Page 2, Line 18: Changed the word "the" after "assistance that" to "each" to clarify that a SDMA may have multiple supporters

Section 13.56.030(b), Page 2, Line 20-22: Inserted this new subsection to mandate that SMDAs contain 3<sup>rd</sup> party notification of the rights and obligations of supporters in SMDAs

Section 13.56.030(c), Page 2, Line 23-27: Renumbered the section, following insertion of subsection b

Section 13.56.040, Page 2, Line 30-31: Removed subsection 3 referencing a form provided by the Department of Health and Human Services. DHSS will not be required to create SDMA

forms. Governor's Council on Disabilities and Special Education has agreed to take this on. Also, under subsection 2, line 31 added language "the agreement..."

Section 13.56.040, Page 3, line 2-6: Renumbered subsection "4", to subsection "3."

Section 13.56.040, Page 3, line 8-9: Added new subsection "4," which provides safeguards by ensuring that a principal who also has a guardian or conservator must notify them of the SDMA for the agreement to be valid

Section 13.56.060(b), Page 3, line 22-24: Added "supported decision-making" before "agreement"

Section 13.56.070, Page 3, Line 25-30: Grammar edits in this section. Keeping consistency throughout bill, by adding "supported decision-making" before "agreement"

Section 13.56.080, Subsections A-D, Page 3, Line 31- Page 4, Line 14:

Removed subsection "c" referencing the superior court's ability to terminate or limit a SDMA, as these are private agreements and decision-making right are retained by the principal. Capacity is inherently retained by principals under SDMA's. SDMA's do not grant decision making authority away. Superior Court doesn't have authority over these agreements

- a) Clarifies that either a principal or supporter may terminate all, or a portion of a SDMA – at any time
- b) Termination process of all or part of a SDMA must be in writing, signed, and such signing must be presence of two witnesses who also sign the termination paperwork, or the signature must be notarized
- c) Renumbered as subsection "c" from "b" – includes language noting that a principal or supporter can terminate all or a portion of a SDMA
- d) New subsection. If certain parts of a SDMA are terminated, the entire SDMA is not terminated, and the untouched parts remain in effect

Section 13.56.100(2), Page 4, Line 24-25: Strikes out "to manage the principal's affairs", replaced with "for the principal to manage the principal's affairs". Supporter isn't managing

principal's affairs – principal is managing their own affairs with assistance by supporter in specific areas

Section 13.56.110, Page 5, Line 11: Inserted new subsection "3." Prohibits a supporter from signing or providing an electronic signature for the principal. Renumber other subsections accordingly

Section 13.56.140(3), Page 6, Line 14-15: Removed the language "conscience or" on concerns that this language might have been unconstitutional/discriminatory

Removed Section 13.56.150 "Principles for providing decision-making assistance," Page 6 of original bill (Version D), Line 11-24 – and renumbered sections accordingly. This language is stated better in the Shared Vision bill and shouldn't have to be stated -- we are talking about people with full agency, so these are already inherent rights

Section 13.56.150, Page 6, Line 19-27: Removed subsection "a" referencing the superior court for same reasons state previously, and renumbered subsections accordingly

Removed Section 13.56.185 "Regulatory authority; forms," Page 8 of original bill (Version D), Line 9-11: Deleted this section as DHSS won't be necessary to create forms or regulate these private capacity agreements. Governor's Council on Disabilities has offered to produce SDMA forms

Section 13.56.190 (4), Page 8, Line 7-8: Added new definition of "conservator" to include a conservator in another state

Section 13.56.190(6), Page 8, Line 10-11: Added new definition of "decision-making assistance"

Section 13.56.190(7), page 8, Line 12-13: Added new definition of "guardian" to include a guardian in another state

**Alaska Legislature**  
**Representative Charisse Millett**

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**Draft CS for House Bill 336: 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.

**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.

30-LS1239J  
Bannister  
2/26/18

**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**

**A BILL**

**FOR AN ACT ENTITLED**

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

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

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

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

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

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

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

14 (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, and 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. 13.56.190. Definitions.** In this chapter, unless the context indicates

1 otherwise,

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

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

4 (3) "capacity" means the ability to understand and appreciate the  
5 nature and consequences of a decision and the ability to reach and communicate an  
6 informed decision;

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

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

10 (6) "decision-making assistance" means the decision-making  
11 assistance described in AS 13.56.100;

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

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

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

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

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

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

26 (13) "support services" means the support services described in  
27 AS 13.56.170.

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

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

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

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

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

**Alaska Legislature  
Representative Charisse Millett**

**Session:**

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**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.



## **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\\_Resolution\\_Final.authcheckdam.pdf](https://www.americanbar.org/content/dam/aba/administrative/law_aging/2017_SDM_Resolution_Final.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**

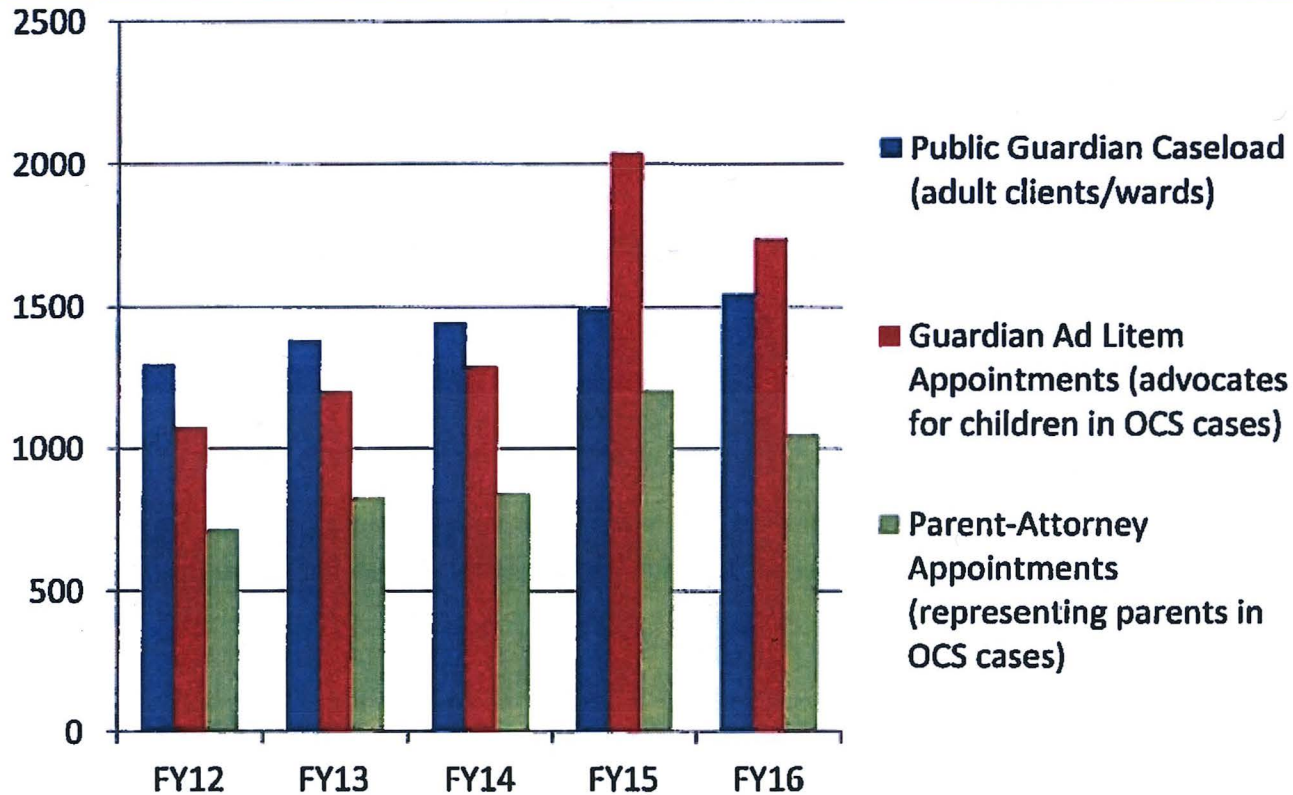
**Please support the Supported Decision Making Act.**

# OPA Challenges – Public Guardian

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- 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, Caro 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

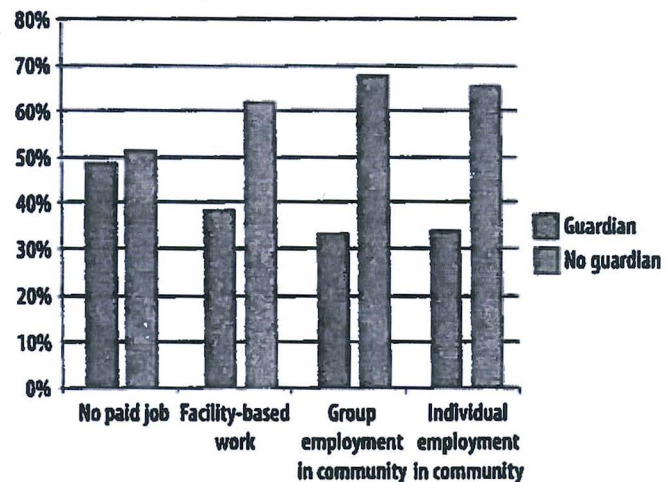
an individual has engaged in a paid job in a community setting, and this is followed up by another question about whether the job activity was done primarily by a group of people with disabilities.

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



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 advocates engage with guardians to support improved employment outcomes for individuals with IDD.

## References

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- Pettingell, S. (2017). Analysis of 2012-2103 National Core Indicator Data - Adult Consumer Survey.
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# 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.



Nothing about us without us!

**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 **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  
170 my supporter's authority to help me make my own health care decisions, except when that person has  
171 actual notice that I have cancelled this agreement or want to cancel it.

173 **Successor Supporter**

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

176 Name:  
177 Address:  
178 Phone Number:

182 **Consent of Supporter**

183 I consent to act as a supporter.

184  
185  
186  
187 (signature of supporter)

(printed name of supporter)

188  
189  
190 Signature

191  
192 (your signature)

(your printed name)

193  
194  
195 (witness signature)

(printed name of witness)

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

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

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

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

198 This document was acknowledged before me on

199 \_\_\_\_\_ (date) by \_\_\_\_\_  
200  
201



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202  
203

(name of adult with a disability)

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

(seal, if any, of notary)

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

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

204  
205

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

206  
207  
208  
209  
210  
211

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

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.

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

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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.

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

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**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

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	76%	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**

# 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.wavv.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:



*for Individuals with Disabilities*

[www.dcqualitytrust.org](http://www.dcqualitytrust.org)



The Council on Quality and Leadership

[www.c-q-l.org](http://www.c-q-l.org)



Burton Blatt Institute  
SYRACUSE UNIVERSITY

[www.bbi.syr.edu](http://www.bbi.syr.edu)

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**

**A N A C T**

**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 (add>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

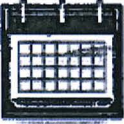
246 that Respondent lacks decision-making ability in one or more of the following areas as indicated:

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>addl</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>

269

**Texas****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 in 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.

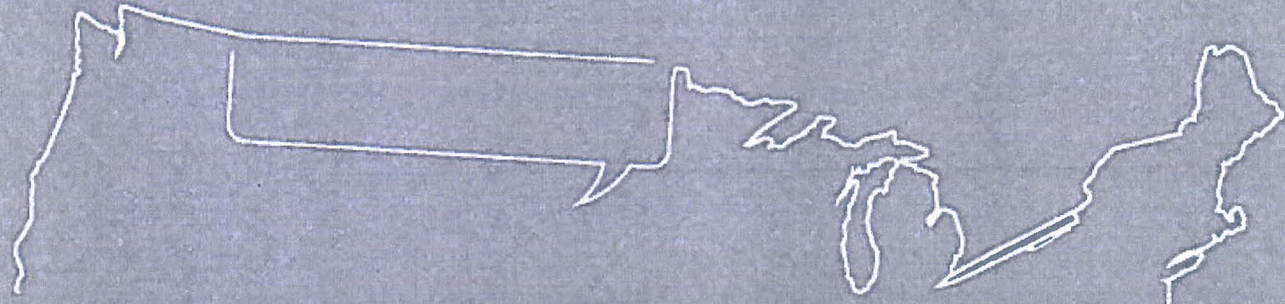
#### **SUBCHAPTER C. DUTY OF CERTAIN PERSONS WITH RESPECT TO AGREEMENT**

**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.

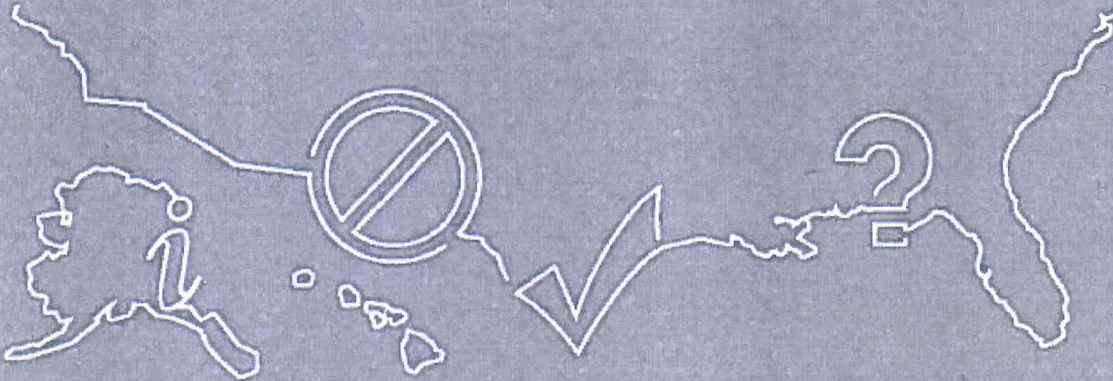
(b) Provides that a person is not subject to criminal or civil liability and has not engaged in professional misconduct for an act or omission if the act or omission is done in good faith and in reliance on a supported decision-making agreement.

**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.



**SUPPORTED DECISION MAKING IN THE UNITED STATES:  
A WHITE PAPER BY CQL | THE COUNCIL ON QUALITY AND LEADERSHIP**





For over 45 years CQL has provided international leadership in designing progressive practices in services for people with intellectual and developmental disabilities and people with mental illness. Our work remains focused on organizations and helping them make real change.

## MISSION

CQL is dedicated to the definition, measurement, and improvement of personal quality of life.

## VISION

A world of dignity, opportunity, and community for all people

## ACKNOWLEDGEMENTS



**Developmental  
Disabilities  
Planning Council**

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## RECOMMENDED CITATION

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## Executive Summary

Guardianship is a legal process “allowing a state court to appoint decision-making powers to another person on behalf of an individual based on a determination of impaired decision-making capacity” (Dinerstein, Grewal & Martinis, 2016, p. 436). Guardianship in various forms (full or partial), and other approaches such as substitute decision-making or power of attorney, presume a person is incapable of making decisions, or lacks the legal capacity to self-determine life choices because of a determination of reduced mental or cognitive capacity (Pathare & Shields, 2012).

Supported decision making (SDM) is a flexible alternative to guardianship which provides a process that recognizes people with disabilities as persons before the law, providing a pathway to exercise legal capacity by focusing on developing supports to enable autonomous decision-making. While there is growing interest from many stakeholder groups within the United States to implement SDM, there is little understanding or evidence that supports SDM, or identifies or describes best practice approaches. The laws and nature of guardianship are very unique to each country, and to understand how SDM might be applied in a United States legal system it is critical to explore the evidence of what exists within the constraints of the law of the land. Therefore, the main aim of this white paper was to synthesize published literature that might apply to use of SDM within the United States, describing policy, procedure, and practice approaches of SDM, as well as any pertinent empirical evidence to provide insight and inform stakeholder groups of best practices and benefits of SDM over other forms of legal representation.

Our findings reveal, using a social justice lens, SDM provides for a much greater pragmatic approach to legal determinations concerning an individual's personhood, legal, and human rights. However, opponents of SDM as well as advocates, and people with intellectual and developmental disabilities (IDD), voice serious concerns that without formalized mechanisms this approach has the potential to be abused. Concerns from across the literature echo a history of the conundrum courts face in determining what is best for a person with IDD when faced with balancing between concerns of safety and supervision versus allowing individuals to maintain control over their own decision-making and their own legal capacity. However, SDM upholds a philosophic view that all people are interdependent when making decisions; SDM also honors self-advocates' call for equality, autonomy, and self-determination to make decisions – and at times take risks – as a part of full personhood.

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# Supported Decision Making in the United States

## INTRODUCTION

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Guardianship is a legal process “allowing a state court to appoint decision-making powers to another person on behalf of an individual based on a determination of impaired decision-making capacity” (Dinerstein, Grewal & Martinis, 2016, p. 436). Guardianship in various forms (full or partial), and other approaches such as substitute decision-making or power of attorney, presume a person is incapable of making decisions, or lacks the legal capacity to self-determine life choices because of a determination of reduced mental or cognitive capacity (Pathare & Shields, 2012). Reduced mental or cognitive capacity is linked to the “assumption that people with intellectual or developmental disabilities (IDD) lack the ability to make informed decisions that may have long-term repercussions on their lives” (Jenkinson (1999) as quoted by Devi, 2013, p. 793). Guardianship is based on perceptions that people with disabilities, especially those with IDD or psychiatric disabilities, need guidance or advice from others on how best to reach a decision because they require counsel in making decisions on important matters. This arguably positions people with disabilities to inequitable standards compared to people without disabilities who also need outside support to make decisions in areas where their knowledge base is limited. Some advocates feel guardianship appointment, as an approach to providing support and services, violates a person’s constitutional rights as described in Title II of the Americans with Disabilities Act (ADA). As such, guardianship has been criticized by the disability community as an unnecessary and unjust approach to providing decision-making services and supports, especially when considered as the first option for people with IDD (ASAN, n.d.; Jameson et al., 2015).

People with disabilities are supported by the United States (US) Constitution and the Americans with Disabilities Act (ADA) to full inclusion in community living, and nondiscrimination in public policy. Despite this, socially accepted and routine practices persist throughout the US legal system that remove people with disabilities’ rights to full citizenship. Many advocates feel one of the most deeply imbedded of these practices is removing legal capacity through appointed guardianship, designed to ‘protect’ people with disabilities who are considered to “lack the cognitive capacity to understand the consequences and risks concerning life decision-making and incapable of managing life affairs” (People with Disability – Australia & Waldron, 2006, p. 11). Guardianship removes a person’s legal capacity to act in decision-making concerning finances, medical decisions, social choices, and living situations – the many choices and rights enjoyed by people without disabilities (Jameson et al., 2015, p. 37). The disability community recognizes this as another form of discrimination, stigmatization, and marginalization, and suggests a response of protest (International Disability Caucus, n.d.), similar to those in the past, which culminated in policy and legislative mandates such as *Olmstead v. L.C.* (1999), and the Developmental Disabilities and Bill of Rights Act (Public Law, 106-402). Each of these legislative mandates – and others – reinforce that people with disabilities must receive services and supports in the least restrictive manner to optimize community integration and self-determination (Americans with Disabilities Act (ADA), 1990; Developmental Disabilities and Bill of Rights Act, 2000; *Olmstead v. L.C.*, 1999; Rehabilitation Act of 1973, 1973). Despite this, entrenched legislative practices supporting guardianship that often unjustly and unnecessarily erase a person’s legal capacity for decision-making became the focus for a new mandate by the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (United Nations, 2006).

The UNCRPD was adopted by the United Nations General Assembly in 2006 as an international treaty of human rights for people with disabilities. One of the primary efforts of the UNCRPD is protecting the human rights of people with disabilities, with a focus on equality in the laws (Council of Europe Commissioner for Human Rights & Nilsson, 2012). Articles 12.1-12.3 of the UNCRPD state:

[12.1] States Parties reaffirm that people with disabilities have the right to recognition everywhere as persons before the law; 12.2 States Parties shall recognize that people with disabilities enjoy legal capacity on an equal basis with others in all aspects of life; 12.3 States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity. (United Nations, 2006)

These declarations by the UNCRPD effectively illustrate the concerns with substitute decision-making or guardianship practices, and call for a shift in the approaches nations and states use to provide services and supports in decision-making for those with IDD or other cognitive disabilities (Pathare & Shields, 2012). Supported decision-making (SDM) has emerged and is being embraced by the disability community as the replacement, and a least-restrictive alternative to guardianship and substitute decision-making practices – the most restrictive – to maintaining personhood and legal capacity for people with disabilities.

As an alternative to guardianship, SDM first emerged in Canada in 1993. A nonprofit group in British Columbia proposed that the Province should enact the first Representation Agreement Law for people with disabilities, and by 1995 the law was passed (RARC, 2006). This law in essence outlines SDM and provides a process that recognizes people with disabilities as persons before the law, providing a pathway to exercise legal capacity by focusing on developing supports to enable autonomous decision-making (Parker, 2016). SDM is clarified and defined in the UNCRPD Committee's Handbook for Parliamentarians as a flexible approach dependent on the specific needs of the individual where "support person(s) should enable the individual to exercise his/her legal capacity to the greatest extent possible, according to the wishes of the individual" (Gooding, 2013). Since the passage of the Canadian act as well as the UNCRPD articles, other countries – Australia, Canada, Germany, Ireland, Scotland, England, Norway, Sweden, and Israel – have adopted SDM nationally or within areas of their country. There is a growing momentum from these government actions trickling into other parts of the world through "academic journal articles, case law, formation of institutes, and presentation at conferences on SDM" (Parker, 2016, p. 5). Advocates of SDM describe the impact it has as a means to "empower people with disabilities by providing them with help in decision-making rather than offering up someone to make decisions for them," and coupling this with disability rights concepts of self-determination, and autonomy to help SDM gain political momentum (Kohn, Blumenthal & Campbell, 2012, p.1113).

## **Purpose**

While there is growing interest from many stakeholder groups within the United States to implement SDM models that align with these UNCRPD mandates, there is little understanding or evidence that supports SDM, or identifies or describes best practice approaches. To collect evidence, reviews of literature have been published but these focus on international SDM or have used broad diagnostic nets (Davidson et al., 2015; Kohn & Blumenthal, 2014; Pathare & Shields, 2012). The laws and nature of guardianship are unique to each country, and to the states or provinces within those countries, and to understand how SDM might be applied in a United States legal system it is critical to explore the evidence of what exists within the constraints of the law of the land. Therefore, the main aim of this white paper was to synthesize published literature that might apply to use of SDM within the United States, describing policy, procedure, and practice approaches of SDM, as well as any pertinent empirical evidence to provide insight and inform stakeholder groups of best practices and benefits of SDM over other forms of legal representation. Legal manuscripts, government documents, as well as grey literature were also included to expand the review.

## METHODS

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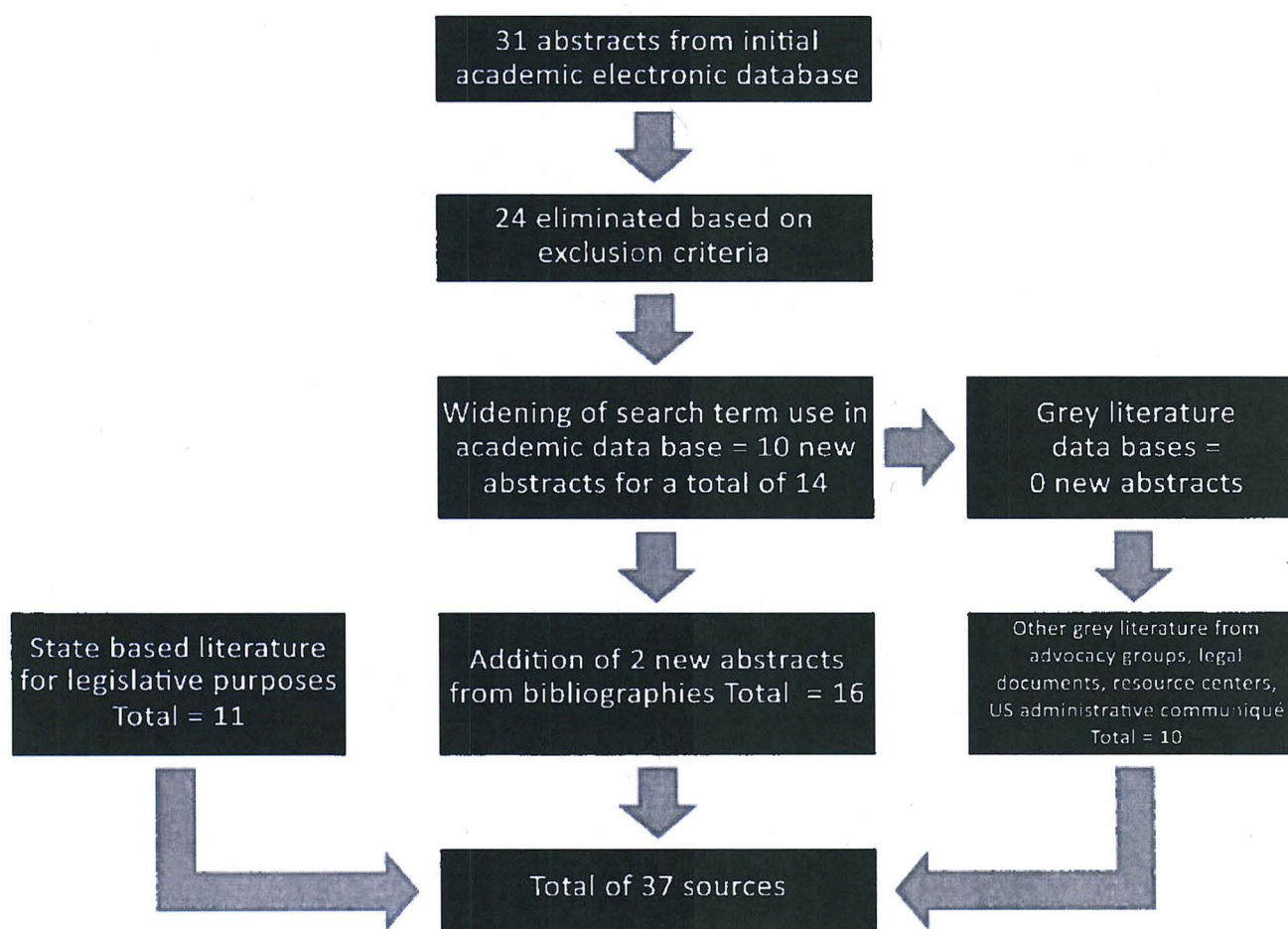
This review of the literature was performed to identify evidence for supported decision making (SDM) as well as reports on the current status of SDM in the United States. The goal for this search was to synthesize available academic literature describing processes, policy, and practice of SDM as well as any pertinent empirical evidence to provide descriptive insight and inform stakeholder groups of best practices, and perceived benefits of SDM over other forms of legal representation. Legal manuscripts as well as grey literature and advocacy group resources were also included to expand the review due to limited academic resources. Grey literature includes published and unpublished non-research literature, in print and electronic formats, and is considered important to include in literature reviews that might inform "policy and practice decision-making" (Benzies, Premji, Hayden, & Serrett, 2006, p. 55). Complementary search strategies were used as recommended by Cooper (2009) in order to identify "relevant studies from more than one channel of entry to the literature base" (p. 75). As suggested by Cooper (2009) this literature search explored primary and secondary "reference databases, relevant journals, review of references from previous syntheses" (p. 78) as well as grey literature – including advocacy group literature - and statewide legislation and policy recommendations. Inclusion and exclusion criteria were used to review the abstracts. A study was included if it described SDM as an approach for providing support and services to facilitate autonomy of an individual with intellectual disability, developmental disability, and/or psychiatric disability in decision-making. Abstracts were excluded if they focused solely on analysis of SDM policy or legislation processes from another country outside of the United States, or if they dealt with an approach to self-management of a chronic disease, illness, or condition. However, if an abstract was an internationally based analysis of SDM describing the supports, barriers, benefits or risks of SDM it was included as this directly informs the primary aim of this search. An exhaustive search of abstracts was used following the recommendations established by the Preferred Reporting Items for Systematic reviews and Meta-Analysis guidelines (PRISMA) (Moher et al., 2009).

The academic literature search databases used were PubMed, Cinhal, and Google Scholar. For all searches, search words used were: "supported decision-making" AND "intellectual disability" OR "disability" in addition to adding combinations of: "assisted decision-making" AND/OR "guardianship" AND "disability" OR "intellectual disability." "Supported decision-making" AND "intellectual disability" resulted in a total of 31 abstracts, 24 of which were eliminated as not pertinent because they explored other issues specifically around approaches such as: informed choice; shared decision making approaches used by providers with the people they support; substitute decision making; or self-determination. Abstracts were also rejected if they addressed supported decision making for women in fertility, prenatal testing, or genetic testing, or were concerned with legal consequences of choice processes (Nieboer, Cramm, van der Meij, & Huijsman, 2011), educational decisions (Nachshen & Minnes, 2005) or medical decisions made by families for a child (Diekema & Fost, 2010).

Finally, searches were made using only "supported decision-making" and using variations in the phrase "supported decision-making" found while searching the literature to apply a wider net for literature abstraction. Variations included "shared decision-making" and "inter-dependent decision-making." Using "supported decision-making" alone, 10 additional abstracts were identified. However, no new relevant literature was identified using the variations in terminology. The combination of abstracts using search terms totaled 14 publications from the academic literature.

Grey literature databases including Open Access, ClinicalTrials.gov (US National Institute of Health (NIH)) showed no additional studies addressing SDM as defined. Review of relevant journals - using the same search words described previously - were also explored and contributed no new abstracts. Reference lists of all selected articles, including previously published literature reviews on SDM, were hand searched and key researchers' names were searched for related studies providing two new abstracts not previously found (figure 1). This provided a total of 16 academic articles found to be relevant for inclusion in this review. Extraction of themes came from identifying and summarizing the major findings of each article to determine priority concerns from the academic literature to inform the primary gaps that exist, evidence of best practice, as well as suggestions for future research.

Other grey literature searches were done through searching the Internet using the term “supported decision-making” and included policy documents, national research and assistance centers, legislative reports, presentations, and advocacy group educational literature. An abundance of literature can be found describing SDM with the intended audience including legal scholars and practitioners, mental healthcare providers, legislators, advocates with IDD, and family members and individuals with IDD. The literature explored from this category required its own inclusion criteria. It was determined that literature would be included if it was considered a primary informational resource (e.g., advocacy group, national resource center), or critical legislative document from within the identified academic literature. Finally, eleven US states are in different stages of evaluating, implementing, or recently passing legislation on SDM. Each state’s documentation on this process provides insight into the social and political considerations leading up to formally recognizing SDM as an alternative to guardianship and maintaining human and legal rights to personhood. This literature was also included to provide valuable insight into best practices, benefits, and risks of SDM.



**Figure 1. Search Strategy**

Taken and adapted from: Moher et al. (2009)

## RESULTS

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### Academic Literature

The abstracted academic literature included three literature reviews (Davidson et al., 2015; Kohn & Blumenthal, 2014; Pathare & Shields, 2012), one editorial (Kripke, 2016), nine analyses or descriptions of concepts and practices of SDM (Agoratus, 2016; Coleman, 2016; Devi, 2013; Dwyer, 2016; Gooding, 2013; Gordon, 2000; Jamieson, Theodore & Raczka, 2016; Parker, 2016; Salzman, 2010), and three qualitative studies (Jamieson et al., 2016; Mitchell, 2015; Werner & Chabany, 2016).

There were three primary themes that emerged from this extracted academic literature: 1) a need for mechanisms of oversight; 2) concern over the lack of evidence for process and outcomes of SDM; and, 3) belief that SDM is a viable alternative to guardianship. The most common theme was concern regarding limited or non-existent legal mechanisms for protection or oversight for the individual (Coleman, 2016; Davidson et al., 2015; Dwyer, 2016; Jameson et al., 2015; Kripke, 2016; Mitchell, 2015; Salzman, 2010). This argument identified that various levels of SDM can occur – from very formal court appointed contracts to informal family and community social networks – however, arguments exist recommending that SDM should have formalized court appointed mechanisms as precedent to protect the individual, reduce potential for risk, and facilitate the support networks of the individual (Coleman, 2015; Dwyer, 2016).

A second theme found in the majority of the manuscripts of amplified concern was the lack of evidence on SDM approaches and the urgency for research on best-practices (Pathare & Shields, 2012) in order to develop guidelines for SDM practice and processes (Davidson et al., 2015; Jameson et al., 2015). In this theme was recognition of the dearth of literature on substantive outcomes of the decisions individuals make (Kohn & Blumenthal, 2014), and a paucity of any descriptions of demographics, individual factors, and characteristics that impact outcomes for the decision-maker as well as supporters (Davidson et al., 2015; Salzman, 2010). Jamieson et al. (2016) highlighted the need for more research on how individual differences and contextual factors can impact satisfaction and outcomes with SDM. In Jamieson et al.'s (2016) study on support networks and decision-making of women with IDD and pregnancy, the researchers found that individual differences between the woman with IDD, and the support providers made a significant difference in both satisfaction and decision-making process. One individual factor for both groups was whether a past service support relationship was perceived as being positive or negative - this appeared to lay a foundation for trust, open communication, and greater flexibility in support processes (Jamieson et al., 2016). Kohn and Blumenthal (2014) cite the need to understand and describe processes that supporters might use to best facilitate truly autonomous decision-making to stay true to the goals of empowering the individual through SDM.

Finally, a third major theme that was found in the academic literature - even by opponents of SDM - was the acknowledgement that SDM does appear to provide a viable alternative to more restrictive guardianship laws (Agoratus, 2016; Devi, 2013; Gooding, 2013) and appears better aligned with conceptual elements of autonomy, self-determination, and dignity of risk (Gooding, 2013) than guardianship or substitute decision-making approaches. Werner and Chabany (2016) suggest that SDM is important conceptually in that it shifts perceptions away from the idea that people with disabilities are utterly dependent, and incapable of making life decisions to the idea that people with disabilities are capable of living inter-dependently.

Unique findings from two of the extracted pieces of academic literature identify some possible early evidence to inform practice and application of SDM. The qualitative study by Mitchell (2015) exploring self-directed support skills of adolescents in transition to adult services found that skills in decision making were stronger if fostered over time, and that young adults with IDD are at risk for potentially internalizing low expectations of capacity for decision-making skills from parents, and significant caretakers. Similar findings were described by Werner and Chabany (2016) of parents' and professionals' lack of understanding of distinctions between parenting responsibilities, and guardianship designation, as a casual factor for guardianship appointment for a young adult. These researchers also noted that individuals with IDD elected to choose guardianship over SDM, possibly as a result of internalized parental beliefs of incapacity for supported decision-making. Both of these research studies recommend that early introduction of SDM approaches for children may provide for greater autonomy in decision-making in transition into and in adulthood. Additionally, results from a nationwide survey recommend that SDM be initiated in school curriculums for students with IDD and include financial, medical, career, living and contract supports for individuals with IDD as a means of adhering to self-determination principles (Jameson et al., 2015).

Lastly, of interest was the conceptual and philosophic implications of formalizing SDM as an alternative to guardianship (Gordon, 2000). Gordon (2000) recognizes that supported or assisted decision-making has historically been provided informally and through assistance of family and community networks. By legitimizing it with court orders, Gordon feels, the essence of what makes this approach work - "informal arrangements involving caring and trusting individuals" - may be destroyed (p. 73). Literature on the development of self-advocacy skills describes the critical role of life-long learning through informal relationships (Alper, Schloss, & Schloss, 1995). Gordon also reflects on possible ethical and moral struggles supporters might face in adhering in practice to a dignity of risk (Perske, 1972) when honoring the decisions of the individual. Lastly, Gordon worries that people with IDD should be, but likely will not be, at the table if and when formalized mechanisms for the approach are determined (Gordon, 2000).

### **Precedent-Setting Court Decisions**

Although legal battles may not traditionally be used as evidence for best practice approaches, precedent setting court decisions can stand as examples of single case studies. Two well-documented cases of an individual seeking to avoid or remove guardianship appointments can be found in the cases of Dameris L., and Margaret "Jenny" Hatch. The Matter of the Guardianship of Dameris L. (No. 2009-0892, December 28, 2012) is an example of how SDM can be the better alternative for a person with IDD who has been assigned guardianship. Dameris was a 29-year-old woman diagnosed with mild to moderate cognitive impairment, and at the time of petition for guardianship by her mother Maria, attended adult day habilitation. Shortly after this petition Dameris married and became pregnant, motivating her husband to seek guardianship. A lawyer was appointed by the court as a temporary guardian. Following legal counsel and mediation, it was decided that her husband and mother would act as co-guardians. Over time Dameris and her husband acquired a reliable and comprehensive support network including family, and a strong community of neighbors to assist the entire family, including Dameris, to live independently and make decisions. Following a second pregnancy Dameris began exploring birth control methods and believed the decision was hers to make. Subsequently, she initiated the process to terminate guardianship. During the trial, the court was provided with evidence that Dameris had a documented history of, and was capable of, making her own decisions if provided with support. Dameris was able to terminate the guardianship roles of her mother and husband, allowing her to use them instead as supporters in her decision-making. This termination occurred primarily because of; 1) a documented system of informal supported decision-making in place with a demonstrated history of success, as well as, 2) documented mechanisms in place to continue to provide for SDM as a less restrictive alternative to guardianship.

The second notable court case began in 2012 when Margaret “Jenny” Hatch petitioned to terminate guardianship in favor of SDM (Terrill, Campanella, & Melda, 2014). Jenny’s parents – believing she needed greater supervision in everyday life following a bicycle accident – petitioned the court for guardianship before she was discharged from the hospital. The court admitted Jenny into a group home under temporary guardianship while they deliberated the case (Dinerstein et al., 2016). Despite a long history of living and working in the community with support, her parents petitioned for guardianship, which would give them authority to make all decisions for Jenny, including where she lived, who she saw, whether or not she received medical care. Jenny argued that she understood her need for support and services and to live in the community, and because of this had established a rich network of both professional service supporters, and trusted friends to support her. The case was highly publicized and concluded with the court determining that Jenny should live with guardians of her choice – individuals that would come from her standing network of supporters. The court also limited this guardianship to only two facets of her life that would be terminated after a one year period at which time Jenny would regain all decision-making authority (Ross v. Hatch, 2013; The Justice for Jenny Project, n.d.). During this year and while in this temporary guardianship, the court held that informal SDM approaches should be implemented and practiced to allow for a smooth transition to Jenny having guardianship totally removed.

It is arguable that the primary reason the court made this determination was that the lawyers representing Jenny demonstrated that Jenny was not, as her guardians claimed, an incapacitated person. In fact, the court evidence showed a long history of Jenny using supporters to make informed decisions regarding healthcare and living arrangements. Jenny’s lawyers provided statements from individuals dedicated to providing individualized supports and services, available to Jenny whenever she needed them in order to live independently. They offered evidence of past and current supporters for health and financial decisions and application and adherence to protocols for receipt of Medicaid Waiver services and supports. The lawyers also provided documentation of training and tailored support specific to Jenny’s needs. Finally, the lawyers provided evidence of the oversight mechanisms in place to safe guard Jenny against abuses or risks that the court might worry would occur without the oversight of a guardian. They provided a record that Jenny had a history of not taking risk or making poor decisions, and they provided testimony that Jenny was happier and healthier living in a supported environment versus under guardianship. The lawyers did not deny that Jenny needed supporters to assist her, and described Jenny’s own recognition of this, but emphasized that she did not need someone to make decisions for her, but rather to support her.

### **Advocacy Group Efforts**

A surge in interest from advocacy groups and individuals with IDD, national organizations (United States Administration on Community Living), states (Massachusetts, North Carolina, Texas), advocacy networks (Autistic Self Advocacy Network), and non-profit organizations (CQL | The Council on Quality and Leadership; Burton Blatt Institute) have resulted in various activities around SDM, including grant projects and pilot studies to identify how best to advance SDM, and develop evidence-based recommendations for best practice or model approaches.

One of the leading advocacy groups in the United States for promoting SDM as an alternative to guardianship is the Autistic Self Advocacy Network (ASAN). This organization has worked to develop and provide supports and structures to guide individuals, families, and other advocacy organizations on guardianship options. ASAN has developed a toolkit that includes SDM Model Laws<sup>1</sup> that let people sign SDM agreements specific for health care (ASAN, 2014).

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<sup>1</sup> Model Laws are designs for a law, not an actual law.

The ASAN model provides a formalized process for individuals who only need support in healthcare decision making. The ADA and US Constitution make plenary or full guardianship designation a difficult and lengthy legal process specifically because this determination removes individual freedoms and constitutional rights (ASAN, n.d.). Judges often welcome alternatives if any exist and make sense for the individual, such as limited guardianship designation. The ASAN Model Law, developed in collaboration with Quality Trust for Individuals with Disabilities, creates an alternative that maximizes autonomy by permitting adults with disabilities to name supporters to help them understand health-related information, and so they can make their own decisions.

The ASAN Model Law also provides a framework for legal counsel to develop alternatives to court orders of guardianship, and a platform for advocates to use in working with state legislators on alternatives that might be developed to guardianship (ASAN, 2014). The ASAN Model Law is informed by SDM legislation in other countries (i.e., Canada, Sweden, United Kingdom) and has created formalized support arrangements as well as introduced mechanisms of oversight and guidelines for process (Kripke, 2016). ASAN has used its knowledge and this Model Law in advocacy efforts with states regarding legal recognition of SDM.

In 2014, a small two-year pilot study was conducted by The Human Services Research Institute (HSRI), the Center for Public Representation (non-profit law firm), and Nonotuck Resources (a service provider of residential supports contracted with the HSRI) to offer SDM to a group of 10 individuals (Pell & Mulkern, 2015). In the pilot, participants – people under or at risk of guardianship – were provided with a structured approach to SDM (Pell & Mulkern, 2015). Year one of this pilot described the process of establishing SDM and offered recommendations for developing a comprehensive approach to successful SDM. One of the ‘lessons-learned’ in the development and implementation of the pilot was the need to educate providers of the background and philosophy of SDM in order to get ‘buy-in’ for use of the approach. Education efforts targeted families as well as judges that would typically be assigned guardianship cases. Recommendations from the implementation phase of the pilot indicated the need to have a well-defined process of pilot safeguards that included: an advisory committee; independent monitoring; and, regulations to define SDM concepts in addition to widespread community education. The administrative team for the pilot included two attorneys (one a senior attorney in guardianship law), one legal advocate, three program directors, one vice president of Clinical Services, and five care managers. Recommendations included starting with a small group of adopters, simplifying the SDM representation agreement (as well as all adopter documentation) into plain language, formalizing the SDM agreements (with a notary public), and ongoing community awareness and education (Pell & Mulkern, 2015). Supporters in the project were used flexibly and SDM was most frequently used for healthcare decisions followed by financial, social and leisure, employment/volunteer work/day supports, relationships, and legal matters. Less frequent were SDM arrangement decisions such as changing a decision supporter (Pell & Mulkern, 2016). The overall results indicated the model had positive outcomes and participants were satisfied with the approach. Changes that were documented in the SDM adopters (decision makers) were increased self-esteem and self-advocacy, more engagement in decision-making and increased happiness (Pell & Mulkern, 2016). Researchers concluded that SDM was a viable alternative to guardianship.

The Administration on Community Living (ACL) and the Quality Trust for Individuals with Disabilities have worked to build a national training, technical assistance, and resource center to explore, develop, and extend SDM as an alternative to guardianship (Bishop & Walker, 2015). This resource evolved from the court case of Margaret “Jenny” Hatch (The Jenny Hatch Justice Project, n.d.), which resulted in empowering national and international stakeholders and opinion leaders to advance SDM as a viable legal alternative to guardianship (Terrill, Campanella, & Melda, 2014). The Jenny Hatch Justice Project, the Quality Trust for Individuals with Disabilities, and ACL created the National Resource Center for Supporting Decision-Making (NRC-SDM) (Supported Decision Making Pilot Project, n.d.) funding five pilot projects in different states (i.e., Delaware, Wisconsin, Maine, North Carolina, and Indiana) to explore and fill the gaps in the SDM evidence. These pilot projects, advocacy campaigns, and legal court orders and opinions have stimulated a small avalanche of change across the US on how guardianship decisions are viewed.

## **State-Level Efforts**

In the US, legal guardianship legislation is controlled at the state level and “across the fifty states there exist many various processes and standards” for determining guardianship (Dinerstein et al., 2016, p. 436). This state flexibility has spurred at least eleven US states [Delaware, Indiana, Maine, Maryland, Massachusetts, Michigan, New York, North Carolina, Texas, Wisconsin, and Virginia] to begin implementing or examining SDM as a possible alternative to guardianship for people with IDD. These are: Two of these states have recently passed legislation on SDM as a viable alternative to guardianship while others, such as Wisconsin, are in early phases of community education and surveys. Some states have options for SDM for support in specific context areas, and others have introduced SDM into parts of informed consent.

### **Texas**

In 2009, the 81st Texas Legislature H.B. 1454 established a pilot volunteer-supporter decision-making advocacy program, run by the Department of Aging and Disability Services for people with IDD who live in a community setting. With a working group consisting of individuals with IDD and family members, rules, processes, and structures of the pilot were developed. These included criteria for volunteer supporters and as well as those adopters of support. Early challenges with recruitment - in part due to negative provider perspectives of SDM - caused the pilot to shift focus from implementing the intervention to educating and increasing understanding of how SDM aligns with shared beliefs in the philosophies of self-determination for people with disabilities. The pilot ultimately identified positive evidence for SDM used by the 84th Texas Legislative session in 2015 to make Texas the first state to recognize that courts must consider SDM agreements as an alternative to guardianship prior to guardianship appointments (S.B.1881, 2015 Leg., 84 Session (Tex. 2015)). Texas provides formal guidelines, documentation, and suggested mechanisms of monitoring a SDM agreement but allows for flexibility and customization within the statutory guidelines on an individual basis (Disability Rights Texas, n.d.).

### **Delaware**

Delaware became the second state to pass legislation enacting SDM into state law in July of 2016. Senate bill No. 230 allows people with disabilities in Delaware to form legally recognized SDM agreements (Delaware Supported Decision Making Act, 2016). Delaware’s Working Group used ASAN’s Model Law, recent legislation passed in Texas, as well as models from Canada to inform and draft their own bill. Through knowledge gained from past advocacy groups’ efforts this pilot project focused on extending the level of awareness of SDM as an option to guardianship through educational experiences directed at the community, as well as individuals who would be supporters, providers, professionals providing services (and referral), legislators, and the general public.

### **Indiana**

Indiana’s Arc of Indiana Foundation, in conjunction with the National Resource Center (NRC) for SDM, has been actively working within the state to educate and inform legislators on the benefits of SDM (Indiana, 2016). These advocacy groups funded and implemented a pilot study of SDM in 2016 to gather and document support to move SDM into Indiana legislative code. On April 18th, 2017 the Indiana 120th General Assembly adopted Senate Resolution No. 44 to assign a committee to study the topic of SDM as an alternative to adult guardianship (S. Res. 44, Ind. 2017). Advocates hope that Indiana will be the third state, following Texas and Delaware, to formalize SDM as a legal process. The current focus for the State is to target new cases considering guardianship – students with individualized education plans (IEPs) as they begin transitioning to adult life, and who are at risk for having guardianship appointments. The state’s SDM working group feels schools are the gatekeepers of guardianship information, including alternatives to guardianship. They argue that SDM has benefits for individuals with IDD as well as the potential for a positive impact on the state budget, but that gaining the support of judges, legislators, schools and families is currently the biggest challenge. The current efforts are on education of these communities on the background and benefits of SDM as an alternative to guardianship.

## **Maine**

As a recipient of the National Resource Center's (NRC) SDM grant award, Maine is also piloting a two-year project to educate and provide resources to community members on SDM. The most recent report from this pilot identified major 'lessons-learned' in the process toward establishing SDM. Of primary concern (but not the only obstacle) to educating individuals and families on SDM was a lack of understanding of guardianship procedures, and implications that exist making distinguishing SDM from guardianship complicated. This pilot found initial first steps had to occur in educating the community on broader issues of legal capacity (Disability Rights Maine, 2016).

## **Massachusetts**

Despite the pilot project of The Human Services Research Institute (HSRI), The Center for Public Representation, and Nonotuck Resources based in an organization within the State, Massachusetts currently only provides for SDM in the context of medical decision making at the time of this publication.

## **Maryland and Michigan**

While both Maryland and Michigan have made some recognition or passed measures on SDM, they have done so in small ways. Michigan has recognized SDM as a fundamental human right, similar to the approach taken by New York, and Maryland recognizes SDM only as an auxiliary aid in medical decision making at this time.

## **New York**

New York has approached SDM differently than other states. In the court decision of *Dameris* described earlier (In re *Dameris L*, 956 N.Y.S. 2d 848, NY Cty., 2012) a precedent was established "affirming *Dameris's* constitutional and human rights" that upheld SDM as, in fact, a logical first choice that should be considered when interpreting laws concerning guardianship (Glen, 2012).

## **North Carolina**

The First in Families of North Carolina (FIFNC) is one of the grant recipients of the National Resource Center for Supported Decision-Making's State Grant Program. North Carolina has initiated a pilot project in conjunction with The Arc of North Carolina to identify and train individuals with IDD and their families on a tool to increase self-directedness in decision-making (First in Families of North Carolina, 2016). Reports on the early uses of the tool describe broadly an increase in skill development and help in making financial decisions. Significant obstacles and lack of follow through with use of the decision-making tool were described as causal factors in poor outcomes (Secor, Torres, & MacMichael, 2016). Limited understanding by participants of the rationale behind the tool was also described. Some of these outcomes appear similar to many of the factors identified in the academic literature, specifically individual factors on the part of supporters and those receiving support, and contextual factors such as timing and readiness of initiating the intervention. One limitation of this report was that many of the adopters had no social network or individuals they felt they could trust and rely upon to build a SDM team.

**Virginia**

In the case of Jenny Hatch, which took place in Virginia, the practice of SDM was presented as a rational, ethical, and most healthy psychological approach for assisting people with IDD to be as autonomous as possible (Commonwealth of Virginia H.J. Res. 190 Reg. Sess., 2014). Despite the court finding in favor of Jenny Hatch and establishing judicial precedent, no formal position on the use of SDM exists in Virginia at this time. Recommendations by the court were to initiate exploration of a method for measuring decision-making capacity of an individual as a first step toward developing a program to support SDM at the state level (Commonwealth of Virginia H.J. Res. 190 Reg. Sess., 2014).

**Wisconsin**

As another of the five NRC-SDM grant award states, Wisconsin has partnered with Minnesota on working to expand the Center for Excellence in Supported Decision Making (CESDM). A fact sheet distributed throughout the State and on the Internet directs interested individuals to social workers who are available to provide assessments regarding guardianship and alternatives. Legal and technical advice, as well as an introduction to SDM agreements (based on documents from Texas law) and other concerns on guardianship, is also provided (Center for Excellence in Supported Decision Making, n.d.).

## DISCUSSION

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While individual opinions may vary or be neutral when asked about SDM, among the loudest voices that emerge from this review are two distinct groups with a clear divide between: those that support SDM, including individuals, families and advocates of the community of IDD; and those that oppose, including lawyers, businesses and professionals that have some interest in maintaining the status quo of established guardianship laws. Both groups point to the obvious gaps that exist in evidence and the absence of guidelines for processes in establishing SDM as well as monitoring to avoid abuses and risk (Kohn & Blumenthal, 2014). Although evidence gaps and monitoring for risks and abuses in SDM are major concerns for opponents of SDM, the literature recognizes that in fact formalized guardianship approaches have poorly established evidence and a history of recorded abuses (Kohn et al., 2012) as well as higher incidence of institutionalization (Lachs et al., 2002). However, the conclusions each side makes are substantially different. Those that support SDM critically evaluate the paucity of literature and are exploring methods to strengthen the evidence and establish guidelines. Suggestions that come from the academic literature include furthering the depth and breadth of research and investigating multiple aspects of SDM to improve its effectiveness for autonomy in decision making, developing guidelines and mechanisms for processes, as well as monitoring, with a recognition of the need to maintain individualism and flexibility (Gooding, 2013). The legislative decisions and pilot interventions echo these recommendations as essential elements of a successful SDM contract. The proponents of SDM do not appear to be deterred by the challenges and, in fact, appear to welcome suggestions for future research as a pathway to building credibility of SDM as the necessary first choice when guardianship options are being considered (Kohn & Blumenthal, 2014; Pathare & Shields, 2012).

Those that criticize SDM are convinced that revising and improving monitoring of guardianship laws is the better path, and argue that guardianship is too entrenched in our system for attitudes and behaviors to change (Coleman, 2015). Guardianship however, is so “deeply rooted in a culture of paternalistic practices toward people with disabilities” (Johns, 2012, p. 3) that it extends beyond determining legal capacity to make decisions, but permeates every context a person with IDD might encounter when making those choices. History shows that norms and cultural attitudes “can either promote equal status and positive attitudes or unequal status and negative attitudes” toward minority groups including people with disabilities (Yuker, 1988, p. 273). The voices that claim that guardianship over SDM is for the individual with disabilities’ “own safety” or in their “best interest” is an old debate the disability community and advocacy groups have much experience with (Perske, 1972). Understanding that people with disabilities are entitled to rights as citizens, including the notion that least restrictive supports and services, should be used demands a re-evaluation of established practices.

Of significance are the reports of challenges and obstacles from the pilot studies and NRC-SDM grant funded projects. There are significant similarities in the reported barriers across studies in implementation of SDM. One of the most significant of these barriers appears to be a limited knowledge of the processes and impact of guardianship itself, and limited understanding of the differences between SDM and guardianship. Some of these outcomes were also found as incidental factors within the academic literature and potential factors of poor satisfaction with SDM (Jamieson et al., 2016; Werner & Chabany, 2016). It may be that best practices for implementing SDM models in practice begin with exploring the culture and readiness for change (Wensing, Bosch & Grol, 2013) by those that must buy into this approach, versus guardianship.

In fact, service provider, family and legal ‘buy-in’ appear to be a major contributor to successful implementation of SDM approaches for pilot projects with the community of individuals with IDD. Acceptance by these communities, through exposure to the background and philosophy of SDM as well as education on how it functions as an alternative to guardianship, was identified in the majority of the literature as a critical component to implementing SDM for individual cases (Dameris, 2012; The Jenny Hatch Justice Project, n.d.) as well as in pilot studies (ASAN, Maine, North Carolina). Best practice approaches that emerged from these pilot studies and that were used as evidence to influence individual court cases include:

- An established record of trained/known supporters and their roles;
- A documented history of informal supported decision making by the people with disabilities;
- Formalization through use of legal SDM agreements;
- Documentation of mechanisms for how SDM would occur while simultaneously providing for flexibility; and
- Customization of SDM agreements to individual needs.

According to academic research, there is another major determinant in the court cases. Werner and Chabany (2015) emphasized the perceptions of parents or caregivers of individuals with IDD’s capacity to participate in SDM. Individuals with IDD and their families had strong beliefs that guardianship was the best and only option. The researchers proposed that children with IDD may internalize others’ beliefs that they are incapable of making autonomous decisions based on years of low expectations from families and professionals (Werner & Chabany, 2015). Jameson et al.’s (2015) national survey on guardianship and people with IDD posits that the impact of guardianship has long lasting effects that directly influences the persons’ capacity for autonomy or self-determined decision-making. More importantly, they found that the IEP process, based on their responders, appeared to cultivate the person toward choosing guardianship as a first option. In examining the court documents of Dameris L. (2012) and Ross v. Hatch (2013) it is clear that each of these individuals had been offered opportunities to explore and learn from supported decision-making experiences over time. It is also evident that this documented history of “learning SDM” was important to the court decision to terminate guardianship in these cases. The current pilot project that the state of Indiana is pursuing, implementing SDM into IEPs, may provide a future model of IEPs as a method for supporting and enhancing long-term positive outcomes in community living by nurturing self-determined decision-makers from an early age.

Lastly, when weighing guardianship and SDM, two states - New York and Michigan - are approaching SDM cases from the perspective of community advocacy efforts that emphasize SDM versus guardianship as a civil rights issue. Legislation from the ADA, specifically Title II regulations, requires that public entities “administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities” (ADA, 1990, n.p.; Pub. L. No. 101-336). Guardianship is recognized by the American Bar Association as well as the disability community as the most restrictive form of providing necessary supports and decision making for people with IDD (Jameson et al., 2015). SDM attends to Title II to provide autonomy and the least restrictions to people with IDD and allows for maintenance of legal capacity as well as personhood.

## CONCLUSION

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Using a social justice lens, SDM provides for a much greater pragmatic approach to legal determinations concerning an individual's personhood, legal and human rights. However, opponents of SDM (as well as advocates, and people with IDD) voice serious concerns that without formalized mechanisms this approach has the potential to be abused in many of the same ways as reported in guardianship appointments. While SDM may benefit from Model Laws and evidence for best practice, for it to stay true to its foundation in autonomy and self-determination, each community and every individual must be provided with the opportunity to maintain flexibility in determining when, and in what manner, supports are identified, provided, and modified.

To support the commitment of deinstitutionalization and success of living in the community requires personalization of services and supports - as no two people, including people with IDD are the same - and therefore individualization of supports is needed (McConkey & Keogh, 2016). The academic literature that does exist identifies that SDM lacks the necessary evidence vital for advocates to argue for its adoption as an alternative to guardianship. There is a dearth of evidence in every respect of the approach including issues related to the supporter, guidelines, and mechanisms for process, and of monitoring outcomes. Lastly, SDM is recognized conceptually as a 'good-thing' but implementation can present a challenge. This challenge, in part, is due to the entrenched stigmas surrounding people with IDD as well as a system where guardianship is the default. The advocacy, state wide legislative policy, and grey literature describe that SDM can be, and should be, used to uphold the constitutional laws and human rights of people with IDD, and that elements of the ADA can be used to do so. Pilot projects and studies report common frustrations and challenges with a lack of 'buy-in' and adoption by communities, such as the projects in Maine and North Carolina. However, evidence of successful model projects, such as the two-year pilot from HSRI, the Center for Public Representation, and Nonotuck Resources, and the ASAN Model Law, can serve as frameworks to guide others. The ASAN Model Law and the advocacy efforts of ASAN have assisted two states to implement SDM into law. Other states are hoping to take the lessons learned from these early initiatives, and incorporate them into their activities. Concerns from across the literature echo a history of the conundrum courts face in determining what is best for a person with IDD when faced with balancing between concerns of safety and supervision versus allowing individuals to maintain control over their own decision-making and their own legal capacity. This is primarily because people with IDD fall outside of the normative cognitive parameters society identifies as having the capacity for sound decision-making. However, SDM upholds a philosophic view that all people are interdependent when making decisions; SDM also honors the disability communities' call for equality, autonomy, and self-determination to make decisions - and at times take risks - as a part of full personhood.

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## **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***

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,



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