Supported Decision Making: An Alternative to Limited Conservatorship

By Ellen Cookman Esq.

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Welfare and Institutions Code Division 11.5 Sections 21000-21008

§ 21000

The Legislature finds and declares all of the following:

- (a) Adults with disabilities, including older adults with disabilities, are presumed competent and to have the capacity to make decisions regarding their day-to-day health, safety, welfare, and social and financial affairs, unless otherwise determined through legal proceedings.
- (b) All adults, to the best of their ability and with supports they choose, should be able to be informed about, and participate in, the management of their affairs.
- (c) Like adults without disabilities, adults with disabilities may use a wide range of voluntary supports to help them understand, make, and communicate their own decisions. These voluntary arrangements should be encouraged and recognized as a valid way for people with disabilities to strengthen their capacity and maintain their autonomy.
- (d) The capacity of an adult should be assessed with any supports, including supported decisionmaking, that the person is using or could use.
- (e) Supported decisionmaking offers adults with disabilities a flexible way to maintain autonomy and decisionmaking authority over their own lives by developing and maintaining voluntary supports to assist them in understanding, making, communicating, and implementing their own informed choices.
- (f) Supported decisionmaking can be a way to strengthen the capacity

of an adult with a disability.

(g) Supported decisionmaking is one of several options available to adults with disabilities to understand, make, and communicate decisions and to express preferences, including, but not limited to, medical and financial powers of attorney, authorized representative forms, health care directives, release of information forms, and representative payees.

Added by Stats. 2022, Ch. 894, Sec. 16. (AB 1663) Effective January 1, 2023.

§ 21001

The following definitions apply for purposes of this division:

- (a) "Adult with a disability" means an adult with any disability, including an older adult with a disability or an age-related disability. Disability includes, but is not limited to, an intellectual or developmental disability, cognitive disability, communication disability, psychiatric disability, physical disability, sensory disability, learning disability, dementia, cognitive impairment, Alzheimer's disease, major neurocognitive disorder, or chronic illness or condition.
- (b) "Life decision" means any decision that affects the adult with a disability, including, but not limited to, a decision regarding any medical, psychological, financial, educational, living arrangement, access to home and community-based services, social, sexual, religious, or occupational matter.
- (c) "Supported decisionmaking" means an individualized process of supporting and accommodating an adult with a disability to enable them to make life decisions without impeding the self-determination of the adult.
- (d) "Supported decisionmaking agreement" means a voluntary, written agreement, written in plain language accessible to the adult with a disability and in conformance with Section 21005. A supported decisionmaking agreement shall be signed in conformance with subdivision (b) of Section 21005 and may be revoked orally or in writing at any time by either party. A supported decisionmaking agreement may include images, be read aloud, or be video or audio recorded, in addition to the written version.
- (e) "Supporter" means one or more adults who meet the requirements in **Section 21002** and who enter into a supported decisionmaking agreement to help the adult with a disability make decisions.

Added by Stats. 2022, Ch. 894, Sec. 16. (AB 1663) Effective January 1, 2023.

§ 21002

(a) A supporter is bound by all existing obligations and prohibitions otherwise applicable by law that protect adults with disabilities and the elderly from fraud, abuse, neglect, coercion, or mistreatment. This division does not limit a supporter's civil or criminal liability for prohibited conduct against the adult with a disability, including liability for fraud, abuse, neglect, breach of fiduciary duty, if any exists, coercion, or mistreatment, including liability under the Elder Abuse and Dependent Adult Civil

Protection Act (Chapter 11 (commencing with **Section 15600**) of Part 3 of Division 9), including, but not limited to, **Sections 15656** and **15657**.

- (b) An individual shall not be selected as a supporter or continue as a supporter of an adult with a disability in any of the following circumstances:
 - (l) The adult with a disability previously made, or makes, an allegation against the supporter under the Elder Abuse and Dependent Adult Civil Protection Act.
 - (2) The adult with a disability has obtained, or obtains, an order of protection from abuse against the supporter.
 - (3) The supporter is the subject of a civil or criminal order prohibiting contact with the adult with the disability, or is subject to a restraining order with respect to the adult with a disability.
 - (4) The supporter has been removed as the conservator of the adult with a disability, based upon a finding that they did not act in the conservatee's best interest.
 - (5) The supporter is found criminally, civilly, or administratively liable for abuse, neglect, mistreatment, coercion, or fraud.
- (c) A supporter shall do all of the following:
 - (1) Support and implement the direction, will, and preferences of the adult with a disability.
 - (2) Respect the values, beliefs, and preferences of the adult with a disability.
 - (3) Act honestly, diligently, and in good faith.
 - (4) Act within the scope identified by the adult with a disability.
 - (5) Maintain confidentiality of any information obtained by a supporter, unless the adult with a disability specifically authorizes its disclosure.
- (d)
- (1) A supporter shall not coerce an adult with a disability.

- (2) Unless the supporter has a valid legal authorization to do so and the action is within the scope of their authority, a supporter shall not do either of the following:
 - (A) Make decisions for, or on behalf of, the adult with a disability.
 - (B) Sign documents on behalf of the adult with a disability.
- (3) A supporter shall not obtain information not reasonably related to matters with which the adult with a disability has requested assistance, and shall not use or disclose information for any purpose other than supporting the adult with a disability.
- (4) A supporter shall not participate in any life decision in which they have a conflict of interest. This includes, but is not limited to, any decision in which the supporter has a financial or other tangible stake in the outcome.

Added by Stats. 2022, Ch. 894, Sec. 16. (AB 1663) Effective January 1, 2023.

§ 21003

- (a) An adult with a disability may choose to enter into a supported decisionmaking agreement with one or more chosen supporters. Support may include, but is not limited to, helping the adult with a disability obtain and understand information related to a life decision, communicating the decision to others, and assisting the individual to ensure their preferences and decisions are honored.
- (b) An adult with a disability's signing of a supported decisionmaking agreement does not preclude the adult with the disability from acting independently of a supported decisionmaking agreement and shall not be used by a court or other entity as evidence of incapacity. This subdivision does not limit the admissibility of evidence pursuant to Section 28 of Article 1 of the California Constitution.

Added by Stats. 2022, Ch. 894, Sec. 16. (AB 1663) Effective January 1, 2023.

§ 21004

(a) Notwithstanding any other provision of this division, an adult with a disability is entitled to have present one or more other adults, including supporters, in any meeting or discussion, or to participate in any written communication, including, but not limited to, individual planning meetings required by state or federal law, service and care planning meetings, discharge planning meetings, meetings with health care providers and individuals who provide residential services or long-term services and supports, and communications with a bank, financial institution, or financial planner.

- (b) An adult with a disability may indicate that they wish to have one or more adults attend a meeting or discussion or participate in any written communication through oral statement, gesture, or any augmentative or alternative communication method used by the adult with a disability.
- (c) A third party may only refuse the presence of one of more adults, including supporters, if the third party reasonably believes that there is fraud, coercion, abuse, or other action by the individuals requested to be included that the third party is required to report pursuant to the Elder Abuse and Dependent Adult Civil Protection Act (Chapter 11 (commencing with Section 15600) of Part 3 of Division 9).

(d) The Legislature finds and declares that this section is declaratory of existing law. *Added by Stats. 2022, Ch. 894, Sec. 16. (AB 1663) Effective January 1, 2023.*

§ 21005

- (a) A supported decisionmaking agreement shall be written in plain language accessible to the adult with the disability and shall include, but not be limited to, all of the following:
 - (1) A list of the areas in which the adult with a disability requests support.
 - (2) A list of the areas in which the supporter agrees to provide the support.
 - (3) The supporter's agreement that they meet each of the requirements specified in Section 21002.
 - (4) Information advising the adult with a disability about their right to file a report under the Elder Abuse and Dependent Adult Civil Protection Act (Chapter 11 (commencing with Section 15600) of Part 3 of Division 9), including, but not limited to, Sections 15656 and 15657.
 - (5) Information and copies of other supported or substituted decisionmaking documents the adult with a disability has in place, including, but not limited to, powers of attorney, authorizations to share medical or educational information, authorized representative forms, or representative payee agreements.
- (b) A supported decisionmaking agreement shall be signed by the adult with a disability and each supporter, in the presence of two or more attesting and disinterested witnesses who are at least 18 years of age, or a notary public. The adult with a disability may use reasonable

modifications, such as assistive technology or physical assistance, to sign the agreement.

Welfare and Institutions Code (Section 21000-21008) - California Code 2023 - CEB

(c) A supported decisionmaking agreement should be reviewed by all supporters and the adult with a disability every two years and updated as needed. An updated agreement shall be signed as required in subdivision (b).

Added by Stats. 2022, Ch. 894, Sec. 16. (AB 1663) Effective January 1, 2023.

§ 21006

(a)

- A supported decisionmaking agreement is effective until it is terminated in one of the following ways:
 - (A) By the adult with a disability.
 - (B) By all supporters.
 - (C) By the terms of the agreement.
 - (D) By the death of the adult with a disability.
 - (E) All supporters are no longer eligible to serve pursuant to Section 21002.
- (2) Any party may choose to terminate their participation in the agreement at any time by providing written or oral notice of the termination to all parties to the agreement. An adult with a disability may terminate a supported decisionmaking agreement by other conduct intended to communicate termination, including by canceling, defacing, obliterating, burning, tearing, or otherwise destroying the supported decisionmaking agreement or directing another in the presence of the adult with a disability to destroy the supported decisionmaking agreement.
- (b) If there is more than one supporter, the termination by one supporter does not terminate the supported decisionmaking agreement with respect to other supporters.

Added by Stats. 2022, Ch. 894, Sec. 16. (AB 1663) Effective January 1, 2023.

§ 21007

This division does not apply to CARE court proceedings or to a CARE supporter trained and appointed under the Community Assistance, Recovery, and Empowerment (CARE) Act (Part 8 (commencing with Section 5970) of Division 5).

Added by Stats. 2022, Ch. 894, Sec. 16. (AB 1663) Effective January 1, 2023.

§ 21008

In developing educational information or training materials on supported decisionmaking or supported decisionmaking agreements, the California Health and Human Services Agency or any departments under its jurisdiction shall do all of the following:

- (a) Consider the needs of individuals who have been underserved, including, but not limited to, immigrants, individuals whose preferred language is not English, individuals from rural communities, and individuals living in long-term care facilities.
- (b) Consider existing materials and resources on supported decisionmaking and best practices developed nationwide.
- (c) Consult with stakeholders to provide input about the information, materials, and training being developed. The stakeholders shall include persons with a disability, including an older adult with a disability, family members of a person with a disability and family members of an older adult living in a long-term care facility, and one representative of each of the following: the State Council on Developmental Disabilities; the protection and advocacy agency described in **subdivision (i) of Section 4900**; the client's rights advocate described in **Section 4433**; a disability organization; the California Health and Human Services Agency's Alzheimer's and Related Disorders Advisory Committee, the departments' ombudsperson offices; and an organization representing older adults.

Added by Stats. 2022, Ch. 894, Sec. 16. (AB 1663) Effective January 1, 2023.

Supported Decision-Making Agreement

This agreement must be read out loud or otherwise communicated to all parties to the agreement in the presence of <u>either</u> a notary <u>or</u> two witnesses. The form of communication shall be appropriate to the needs and preferences of the person with a disability.

My name is: _____.

I want to have people I trust help me make decisions. The people who will help me are called **supporters.**

My supporters are not allowed to make choices for me. I will make my own choices, with support. I am called the **decider**.

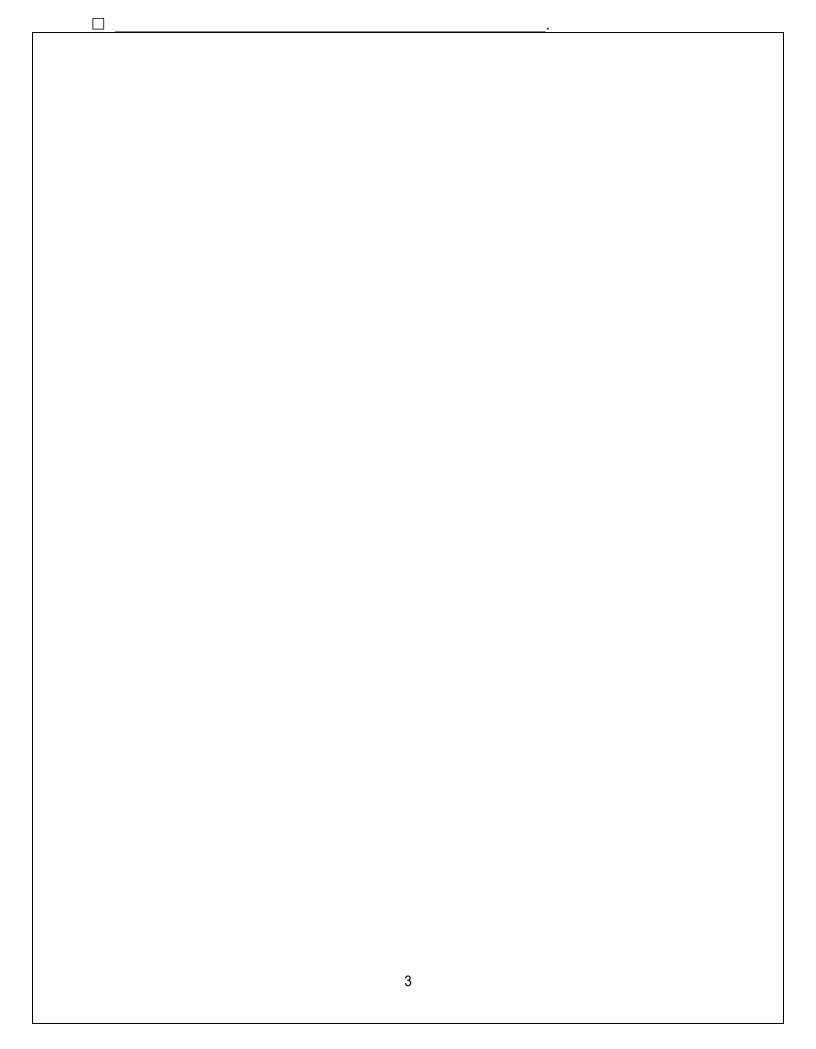
This agreement can be changed at any time. I can change it by crossing out words and writing my initials next to the changes. Or I can change it by writing new information on another piece of paper, signing that paper, and attaching it to this agreement.

Signature of Decider

I am signing this supported decision-making agreement because I want people to help me make choices. I know that I do not have to sign this agreement. I know that I can change this agreement at any time.

My printed name:		
My address:		
My phone number:		
My email address:		
Today's date is:		
Wait to sign your name ι	until a notary or two witnesses are there	to watch you sign.
My signature:		

ACLU DISABILITY RIGHTS PROGRAM SUPPORTED DECISION-MAKING AGREEMENT		
	<u>Supporters</u>	
Supporter #1		
Name:	Address:	
Phone Number:	Email address:	
I want this person to h Personal Care:	elp me with these choices: (check as many boxes as you want)	
 Making choices abo Making choices abo Taking care of perso Remembering to tak 	out clothing onal hygiene (showering, bathing)	
Staying Safe:		
□ Understanding and	s around the house (for example, fire alarms, turning stove off) getting help if I am being treated badly (abused) ut alcohol and drugs	
Home, Work, and Friends		
 Making choices about the second second	out where I live and who I live with out where to work or what activities to go to o in my free time vices, hiring and firing staff	
Health Choices:		
 Making medical cho Making choices abo 	jo to the doctor or dentist pices for everyday things (for example, check-up, small injury, taking aspirin) put major medical care (for example, big injuries, surgery) put medical care in emergencies	
Partners:		
Making choices aboMaking choices abo	out dating, sex, birth control, and pregnancy ut marriage	
<u>Money</u> :		
Keeping track of my	ime and keeping a budget money and making sure no one steals my money s about money (for example, opening a bank account, signing a lease)	
Other: (write any other are	eas where you want support):	
	2	



Supporter #2

Name: _____Address: _____

Phone Number: Email address:

I want this person to help me with these choices: (check as many boxes as you want)

Personal Care:

- Making choices about food
- Making choices about clothing
- □ Taking care of personal hygiene (showering, bathing)
- □ Remembering to take medicine

Staying Safe:

- □ Making safe choices around the house (for example, fire alarms, turning stove off)
- □ Understanding and getting help if I am being treated badly (abused)
- Making choices about alcohol and drugs

Home, Work, and Friends:

- □ Making choices about where I live and who I live with
- □ Making choices about where to work or what activities to go to
- \Box Choosing what to do in my free time
- □ Finding support services, hiring and firing staff

Health Choices:

- □ Choosing when to go to the doctor or dentist
- □ Making medical choices for everyday things (for example, check-up, small injury, taking aspirin)
- □ Making choices about major medical care (for example, big injuries, surgery)
- □ Making choices about medical care in emergencies

Partners:

- □ Making choices about dating, sex, birth control, and pregnancy
- □ Making choices about marriage

Money:

- □ Paying the bills on time and keeping a budget
- □ Keeping track of my money and making sure no one steals my money
- □ Making big decisions about money (for example, opening a bank account, signing a lease)

Other: (write any other areas where you want support):

Supporter #3

Name: _____Address: _____

Phone Number: Email address:

I want this person to help me with these choices: (check as many boxes as you want)

Personal Care:

- Making choices about food
- Making choices about clothing
- □ Taking care of personal hygiene (showering, bathing)
- □ Remembering to take medicine

Staying Safe:

- □ Making safe choices around the house (for example, fire alarms, turning stove off)
- □ Understanding and getting help if I am being treated badly (abused)
- Making choices about alcohol and drugs

Home, Work, and Friends:

- □ Making choices about where I live and who I live with
- □ Making choices about where to work or what activities to go to
- \Box Choosing what to do in my free time
- □ Finding support services, hiring and firing staff

Health Choices:

- □ Choosing when to go to the doctor or dentist
- □ Making medical choices for everyday things (for example, check-up, small injury, taking aspirin)
- □ Making choices about major medical care (for example, big injuries, surgery)
- □ Making choices about medical care in emergencies

Partners:

- □ Making choices about dating, sex, birth control, and pregnancy
- □ Making choices about marriage

Money:

- □ Paying the bills on time and keeping a budget
- □ Keeping track of my money and making sure no one steals my money
- □ Making big decisions about money (for example, opening a bank account, signing a lease)

Other: (write any other areas where you want support):

When My Supporters Can Talk About Me

Check one box:

- \Box My supporters can talk to each other about me <u>only when I say it is OK</u>
- □ With this agreement, I am saying it is OK for my supporters to talk to each other about me whenever they want

Meeting with My Support Team

I can talk to my supporters anytime I want to. But my whole team might meet together sometimes to talk about how we are doing. *Check one box:*

 $\Box\,$ I do not want my support team to meet on a regular basis.

Special Directions and Other Information

I can write any other information or special directions here. I can also write more information on a separate piece of paper and attach it to this agreement.

<u>Monitor</u>

If I want someone to help me make choices about money, I <u>must</u> also choose someone to make sure my supporters are being honest and using good judgment in helping me with my money. This person is called a **monitor**. The monitor cannot also be a supporter.

I do not have to write anything here if I am not asking anyone to help me with money.

My monitor is:

Name:

Address:

Email address: _____

Other Forms

I am including the following forms to this agreement:

(circle yes or no for each choice below)

Yes / No A form that lets my supporters see my medical records (*HIPAA Authorization*)

Yes / No A form that lets my supporters see my school information (Authorization to Disclose Educational Information)

This supported decision-making agreement starts right now and will continue until the agreement is stopped by me or my supporters.

Consent of Supporters

Signature of supporter

Date

Ι,

____consent to act as _____

's

supporter under this agreement. I understand that my job as a supporter is to honor and express his/her wishes. My support might include giving this person information in a way he/she can understand; discussing pros and cons of decisions; and helping this person communicate his/her choice. I know that I may *not* make decisions for this person. I agree to support this person's decisions to the best of my ability, honestly, and in good faith.

Signature of supporter

Date

Signature of supporter

Date

Consent of Monitor

A monitor must be appointed to oversee financial supporters.

I, ______ consent to act as a monitor for financial decisions under this agreement. I agree to review the financial records of the person with a disability when provided by the supporters every month. I agree to make reasonable efforts to ensure that the supporters under this agreement are acting honestly, in good faith, and in accordance with the choices of the person with a disability. If I suspect financial abuse, misuse of funds, bad faith, or failure to comply with the decisions of the person with a disability, I will require the supporters to explain their actions. If the supporter fails to provide this information or if I continue to have reason to believe that the supporter is abusing or failing to comply with the wishes of the person with a disability, I will promptly inform Adult Protective Services.

Monitor's signature:	

Date:	

Signature of Notary or Witnesses

	orginatare of notary of	
	st be read in front of <u>either</u> a not be named in this agreement as a	•• —
	Signature of Not	ary
State of California	County of	
On	(<i>date</i>), before me	, personally appeared
		e on the basis of satisfactory evidence of is Supported Decision-Making agreement.
The text of this agreen	nent was communicated to the person	with a disability in my presence by:
	I agreement aloud municating the agreement to the perso on used):	•
Seal of notary:	My comr	nission expires:
	<u>OR</u>	
	Signature of Witne	<u>ISSES</u>
	, swear that this Sup resence to the decider (the person wit	oported Decision-Making agreement was h a disability).
Signature	Date	
	, swear that this Sup resence to the decider (the person wit	oported Decision-Making agreement was h a disability).
Signature	Date	
	10	

SUPPORTED DECISION-MAKING AGREEMENT

Pursuant to the Disability Services Reform Amendment Act of 2018 D.C. Law 22-93, D.C. Official Code §§ 7-2131 to 7-2134

NOTE: According to D.C. Official Code § 7-2133, a person or a District agency who receives a supported decision-making agreement shall rely on the agreement, unless the person or District agency has substantial cause to believe that the supported person is an adult in need of protective services. Neither a person nor a District agency shall be subject to criminal or civil liability, nor shall a person be considered to have engaged in professional misconduct, for an act or omission done in good faith and in reasonable reliance on a supported decision-making agreement.

PART 1: Appointment of Supporter

I,	_(printed name of supported
person), make this agreement of my own free wil	Ι.
I agree to designate the following person as my sup	porter:
Name:	

Address	1
---------	---

Phone Number: () Email:	
	/	

My supporter may help me with making everyday life decisions relating to the following (circle Y for Yes and N for No):

Y / N Applying for and maintaining supports and services including District

government assistance

 $Y\,/\,N\,$ Obtaining food, clothing, and shelter

Y / N Taking care of my physical health

Y / N Taking care of my mental/behavioral health

Y / N Managing my financial affairs

Y/N Managing real property transactions

Any other duties as listed below:

NOTHING IN THIS DOCUMENT GIVES MY SUPPORTER PERMISSION TO MAKE DECISIONS FOR ME.

Nothing in this document prevents my supporter from also serving as a power of attorney or as a healthcare decision-maker.

To help me with decisions, my supporter may (circle Y for Yes and N for No):

- Y/N Help me obtain information that is relevant to a decision, including medical, psychological, financial, educational, or treatment records;
- Y/N When requested by me, be present to help me make my own decisions;
- Y / N Help me understand my options so that I can make an informed decision; and
- Y / N Help me communicate my decision to appropriate persons.

- Y/N A release allowing my supporter to see and obtain protected health information under the Health Insurance Portability and Accountability Act of 1996 is attached.
- Y / N A release allowing my supporter to see and obtain educational records under the Family Educational Rights and Privacy Act of 1974 is attached.

PART 3: 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.

PART 4: Signatures

Signed this _____day of _____(month), 20___(year)

Consent and Attestation of Supporter

I, _____(name of supporter), consent to act as a supporter under this agreement and affirm that:

- I have not been found to have abused, neglected, or exploited (printed name of supported person) by a government agency;
- 2. I have not been found to have inflicted harm upon a child, elderly individual, or person with a disability by an investigation of a government agency;

- 3. In the last 7 years, I have not been convicted of any sexual offense where the victim was a child, elderly individual, or person with a disability;
- 4. In the last 7 years, I have not been convicted of aggravated assault where the victim was a child, elderly individual, or person with a disability; and
- 5. In the last 7 years, I have not been convicted of fraud, theft in the first degree, forgery or extortion.

Signature of	
Supporter	
Printed Name of	
Supporter	
Signature of Supported Person	
I,	(name of
supported person), consent to have	
	_(name of supporter) act
as my supporter under this Agreement.	
Signature of	
Person	
Printed Name of	
Person	
Signature of Two Witnesses	
Signature of First Witness	
Printed Name of First Witness	

Printed Name of Second Witness

NOTARY PUBLIC (Not required if signed by 2 witnesses)

This document was acknowledged before me on this	day of
	(month and year) by
	_(name of person supported)
and	(name
of supporter).	
Signature of Notary Public and notary seal, if any	
Printed Name of Notary Public	
My commission expires:	

WARNING: PROTECTION FOR PERSON SUPPORTED 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 NAMED AS A SUPPORTED PERSON IS BEING ABUSED, NEGLECTED, OR EXPLOITED BY THE SUPPORTER, THE PERSON MAY REPORT THE ALLEGED ABUSE, NEGLECT, OR EXPLOITATION TO THE CITYWIDE CALL CENTER AT 311, METROPOLITAN POLICE DEPARTMENT AT 911, OR ADULT PROTECTIVE SERVICES AT (202) 541-3950.

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),agreement voluntarily.	_ am entering into this				
I choose (Name of Supporters) my Supporter.	to be				
Supporters' Address:					
Phone Number:					
E-mail Address:					
My Supporters may help me with life decisions about:					
Yes <u>No</u> obtaining food, clothing and a place to live					
Yes <u>No</u> my physical health					
Yes <u>No</u> my mental health					
Yes <u>No</u> managing my money or property					
Yes <u> </u>					
Yes <u>No</u> choosing and maintaining my services and supports					
Yes No finding a job					
Yes <u>No</u> Other:					
My Supporters do not make decisions for me. To help me make decisions, my Supp	porters may:				
 Help me get the information I need to make medical, psychological, fina decisions; 	ancial, or educational				
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 Supporters may see my private health information under Portability and Accountability Act of 1996. I will provide a signed release.	the Health Insurance				
Yes <u>No</u> My Supporters may see my educational records under the Family 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 Supporters				

or I end the agreement or the agreement ends by law.

Signed this _____ (day) of _____ (month), _____ (year)

IMPORTANT INFORMATION FOR SUPPORTERS:

When you agree to provide support to an adult with a disability under this supported decision-making agreement, you have a duty to:

- 1. Act in good faith
- 2. Act loyally and without self-interest; and
- 3. Avoid conflicts of interest.

CONSENT OF SUPPORTER

consent to act as a Supporter under this	
(Printed Name of Supporter)	
consent to act as a Supporter under this	
(Printed Name of Supporter)	
esses or a Notary Public.	
(Printed Name of Witness 1)	
(Printed Name of Witness 2)	
(date)	
Name of Supporter)	
(Printed Name of Notary)	
nission 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.

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

Supported Decision-Making Agreement developed by Center for Public Representation

This is the Supported Decision-Making Agreement of					
Nam	Name : Date of birth:				
Addı	ress:				
Telephone: Email:					
Α.	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				

С.	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.	lesignate the following individual(s) to be part of my upported Decision-Making Network to assist me in making ecisions.				
Netw	ork Supporter #1				
Name	Name: Date of birth:				
Addre	ess:				
Telep	hone: Email:				
Relat	ionship:				
Area	s of Assistance for Supporter #1: Check all that apply:				
🗌 Fi	nances Healthcare Living Arrangements				
Relationships/Social Employment Legal Matters					
□ 0	ther (please specify):				
Areas I don't want Supporter #1 to assist me with:					
Netw	ork Supporter #2				
Name	e: Date of birth:				
Addre	ess:				

Telephone:		Email: _		
Relationship:			-	
Areas of Assist	ance for Sup	oorter #2:	Check all that apply:	
Finances	Healthca	re Livi	ng Arrangements	
Relationship	s/Social	Employmer	nt Legal Matters	
Other (pleas	e specify):			
Areas I don't wa	ant Supporter	[•] #2 to assist	me with:	
Network Suppo	rter #3			
Name:		Da	ate of birth:	
Address:				
Telephone:		Email:		
Relationship:				
Areas of Assist	ance for Sup	oorter #3:	Check all that apply:	
Finances	Healthca	re Livi	ng Arrangements	
Relationship	s/Social	Employmer	nt Legal Matters	
Other (pleas	se specify):			
Areas I doubt wort Cuppenter #2 to cost the with				

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 that at any time I can choose to end this agreement. I understand that at any time I can choose 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

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 _____.

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 _____.

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 _____.

Signature

Date

This form was developed by Center for Public Representation www.supporteddecisions.org



ESUME Cianship EASON. rly identify easons for oncern.



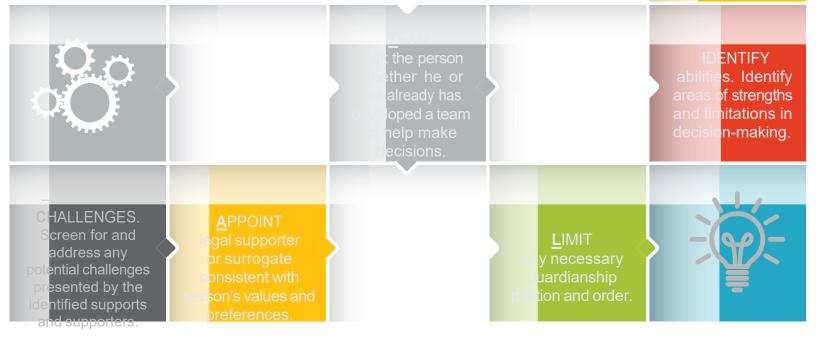
PRACTICAL Tool for Lawyers:

Steps in Supporting Decision-Making

if a triggering concern may be caused by temporary or reversible conditions.

<mark>G</mark>OMMUNITY

Determine if concerns can be addressed by connecting the individual to family or community resources and making accommodations.



Jointly produced by the Commission on Law and Aging; Commission on Disability Rights; Section on Civil Rights and Social Justice; and



Section on Real Property, Trust and Estate Law

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PRACTICAL Tool for Lawyers: Steps in Supporting Decision-Making

The PRACTICAL Tool aims to help lawyers identify and implement decision-making options for persons with disabilities that are less restrictive than guardianship. It is a joint product of four American Bar Association entities – the Commission on Law and Aging, Commission on Disability Rights, Section on Civil Rights and Social Justice, and Section on Real Property, Trust and Estate Law, with assistance from the National Resource Center for Supported Decision-Making. Learn more about the PRACTICAL Tool and Resource Guide at <u>www.ambar.org/practicaltool</u>.

PRESUME guardianship is not needed.

€ Consider less restrictive options like financial or health care power of attorney, advance directive, trust, or supported decision-making

Observations and Notes:

 \in Review state statute for requirements about considering such options

REASON. Clearly identify the reasons for concern.

Consider whether the individual can meet some or all of the following needs:*

Money Management:

- € Managing accounts, assets, and benefits
- € Recognizing exploitation

Health Care:

- € Making decisions about medical treatment
- € Taking medications as needed
- € Maintaining hygiene and diet
- € Avoiding high-risk behaviors

Relationships:

- € Behaving appropriately with friends, family, and workers
- € Making safe decisions about sexual relationships

Community Living:

- € Living independently
- € Maintaining habitable conditions
- € Accessing community resources

Personal Decision-Making:

- € Understanding legal documents (contracts, lease, powers of attorney)
- € Communicating wishes
- € Understanding legal consequences of behavior

Employment:

€ Looking for, gaining, and retaining employment

Personal Safety:

- € Avoiding common dangers
- € Recognizing and avoiding abuse
- € Knowing what to do in an emergency

*Adapted from University of Missouri Kansas City, Institute for Human Development, "MO Guardianship: Understanding Your Options & Alternatives," <u>http://moguardianship.com</u>. Observations and Notes (List supports needed.):

ASK if a triggering concern may be caused by temporary or reversible conditions.

Look for steps to reverse the condition or postpone a decision until the condition improves.

Are concerns the result of or related to temporary or reversible conditions such **Observations and Notes:** as:

- € **Medical conditions:** Infections, dehydration, delirium, poor dental care, malnutrition, pain
- € Sensory deficits: hearing or vision loss
- € Medication side effects
- € Psychological conditions: stress, grief, depression, disorientation
- € Stereotypes or cultural barriers

COMMUNITY. Determine if concerns can be addressed by connecting the individual to family or community resources and making accommodations.

Ask "what would it take?" to enable the person to make the needed decision(s) or address the presenting concern.

Might any of the following supports meet the needs:

Community Supports:

- € In-home care, adult day care, personal attendant, congregate and home delivered meals, transportation
- € Care management, counseling, mediation
- € Professional money management

Informal Supports from Family/Friends:

- € Assistance with medical and money management
- € Communication assistance
- € Identifying potential abuse

Accommodations:

- € Assistive technology
- € Home modifications

Residential Setting:

€ Supported housing or group home

Observations and Notes:

- € Senior residential building
- € Assisted living or nursing home

2 • <u>www.ambar.org/practicaltool</u>

TEAM. Ask the person whether he or she already has developed a team to help make decisions.	
 € Does the person have friends, family members, or professionals available to help? € Has the person appointed a surrogate to help make decisions? 	Observations and Notes:
DENTIFY abilities. Identify areas of strengths and limitations in decision-making if the person does not have an existing team and has difficulty with specific types of decisions.	
 Can the individual: € Make decisions and explain his/her reasoning € Maintain consistent decisions and primary values over time € Understand the consequences of decisions 	Observations and Notes:
CHALLENGES. Screen for and address any potential challenges presented by the identified supports and supporters.	
Screen for any of the following challenges: Possible challenges to identified supports: € Eligibility, cost, timing or location € Risk to public benefits	Observations and Notes:
 Possible concerns about supporters: € Risk of undue influence € Risk of abuse, neglect, exploitation (report suspected abuse to adult protective services) € Lack of understanding of person's medical/mental health needs € Lack of stability, or cognitive limitations of supporters € Disputes with family members 	

APPOINT legal supporter or surrogate consistent with person's values and preferences.

Could any of these appointments meet the needs:

- € Social Security representative payee
- € Health care surrogate under state law

€ Agent under health care power

of attorney or advance directive

- € Agent under financial power of attorney
- € Trustee

- € VA fiduciary
 € Supporter under representation
- agreement, legally or informally recognized

LIMIT any necessary guardianship petition and order.

If a guardian is needed:

- € Limit guardianship to what is absolutely necessary, such as:
 - Only specific property/financial decisions
 - Only property/finances
 - Only specific personal/health care decisions
 - Only personal/health care decisions
- € State how guardian will engage and involve person in decision-making
- € Develop proposed person-centered plan
- € Reassess periodically for modification or restoration of rights

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Observations and Notes:

Observations and Notes:

PRACTICAL Resource Guide

The **PRACTICAL Tool** for lawyers is a joint product of four American Bar Association entities—the Commission on Law and Aging; Commission on Disability Rights; Section on Real Property, Trust and Estate Law; and Section on Civil Rights and Social Justice, with assistance from the National Resource Center for Supported Decision-Making. These four ABA entities recognize the need to raise the awareness of lawyers about decision-making options for persons with disabilities that are less restrictive than guardianship.¹

"PRACTICAL" is an acronym for nine steps for lawyers to identify these options. The lawyer can use the PRACTICAL checklist of steps during the client interview and immediately after to assist in case analysis. The steps blend in naturally with the case interview process. Lawyers serving in different roles may use the steps differently.

- A lawyer **representing a potential petitioner** for guardianship can go through the steps with the client to screen for other options, including creative ways to target concerns and prevent harm that could moot the need for guardianship.
- A lawyer **representing a respondent** in a guardianship proceeding can use the steps to contest the petition if the client wishes to do so. For example, the lawyer could ask for a continuance to address reversible conditions or put in place community supports that might make guardianship unnecessary. The lawyer could use the steps in preparing hearing arguments identifying the person's abilities and supports.
- A lawyer **serving as guardian ad litem** can use the steps in interviewing the person and preparing a report for the court.
- A lawyer **serving as guardian** can use the steps to enhance the self-determination of the individual and assess for possible modification of the order or restoration of rights.

Background

Lawyers increasingly encounter the need for decision-making by and on behalf of adults with disabilities—as an advisor to clients who are considering a guardianship petition; as counsel for petitioner or respondent or as a guardian ad litem in a guardianship proceeding; as guardian or conservator; when counseling clients on legal and financial planning; and when advising families on the transition of a minor with disabilities to adult status. With the <u>aging of the population</u>² and the <u>increase in individuals with disabilities</u>,³ lawyers practicing in any area of the law increasingly may encounter issues of consent and capacity when clients need to execute contracts, transfer property or give informed consent for treatment.

¹ In this guide, the generic term "guardianship" refers to guardians of the person as well as guardians of the property, frequently called "conservators," unless otherwise specified.

² Jennifer M. Ortman, Victoria A. Velkoff, and Howard Hogan, *An Aging Nation: The Older Population in the United States* (May 2014), U.S. Department of Commerce, Economics and Statistics Administration, *available at* <u>https://www.census.gov/prod/2014pubs/p25-1140.pdf</u>.

³ *Disability and Health*, World Health Organization Fact Sheet No 352 (December 2015), *available at* <u>http://www.who.int/</u>mediacentre/factsheets/fs352/en/.

Guardianship is one of society's most drastic interventions, protecting individuals yet infringing upon fundamental human rights and opportunities for self-determination. Many state statutes prioritize less restrictive legal options such as: for financial decisions, appropriate use of joint accounts, durable powers of attorney, trusts, and representative payment for public benefits; and for personal and health decisions, advance directives, living wills, and use of state default consent laws.

If a guardian is appointed, it should be as a last resort, and the order limited to only those areas in which the individual needs decision-making assistance. The importance of limited guardianship is a major theme of the Uniform Guardianship and Protective Proceedings Act (<u>UGPPA</u>).⁴ Limited guardianship, participation of the individual in decision-making, and use of the person's values and preferences are key concepts in many state guardianship laws.

A recent shift in the decision-making landscape is the advent of "supported decision-making." The United Nations Convention on the Rights of Persons with Disabilities (<u>CRPD</u>),⁵ adopted in 2006,⁶ recognizes in Article 12 that persons with disabilities have the "legal capacity" and the right to make their own decisions, and that governments have the obligation to support them in doing so. For people with cognitive, intellectual, or psychosocial disabilities, Article 12 is critical to self-determination and equality. It calls for a switch in perception from a focus on disabilities to abilities, and from protection to support. Supported decision-making can be viewed as a key part of the "least restrictive alternative" spectrum; and has been called "<u>a critically important alternative</u>"⁷ to the guardianship model. Also, supported decision-making precepts can guide guardians in maximizing the voice of individuals they serve.

Despite the strong mandates in statute and standards, use of the least restrictive alternative principle in practice appears uneven at best—and "supported decision-making" is still in the early stages of recognition. While statistics are scant, anecdotal evidence and numerous press accounts confirm that guardianship orders are frequently overly broad or perhaps unnecessary; and that guardians regularly are appointed when practical supports and/or a less drastic legal intervention would have sufficed.

The *PRACTICAL Tool* offers concrete steps to implement the least restrictive alternative principle as a routine practice of law. The *PRACTICAL Tool Resource Guide* describes each of the nine steps, offering examples and including hyperlinks to key materials and community resources.

⁶ Ratification of the CRPD currently is pending with the U.S. Senate.

⁴ Uniform Guardianship and Protective Proceedings Act (1997/1998), drafted by the National Conference of Commissioners on Uniform State Laws, available at <u>http://www.uniformlaws.org/shared/docs/guardianship%20and%20protective%20</u> proceedings/UGPPA_2011_Final%20Act_2014sep9.pdf.

⁵ United Nations Convention on the Rights of Persons with Disabilities, available at <u>http://www.un.org/disabilities/</u> <u>convention/conventionfull.shtml</u>.

⁷ Leslie Salzman, *Guardianship for Persons with Mental Illness—A Legal and Appropriate Alternative?*, Saint Louis University Journal of Health Law & Policy (Vol. 4, No. 271), *available at <u>http://supporteddecisionmaking.org/sites/default/files/</u> guardianship for persons with mi.pdf.*

PRESUME guardianship is not needed. Notably, such a presumption

is typically required by state statutes allowing guardianship only where a person's needs cannot be met by less restrictive means.

Guardianship historically has been a protective device, rooted in the ancient concept of *parens patriae,* in which the state must care for people who cannot care for themselves. In guardianship, an individual's powers, rights, and authority are transferred from the person to a surrogate in the name of protection from harm—a process that has been said to "<u>unperson</u>"⁸ an individual.

When a client presents a situation in which someone seems at risk and unable to protect him or herself, a natural and well-meaning impulse, compounded by collective legal practice over many years, may be for the lawyer to begin to draw up a requested guardianship petition to prevent harm and maximize safety.

In the PRACTICAL approach, the lawyer *stops*—and uses as a starting point that there may be other practical and legal options that can address needs and challenges at hand. Best practice requires that the lawyer thoroughly examine these options *before* proceeding with the guardianship petition.

In effect, the PRACTICAL approach confirms and operationalizes the presumption that guardianship is not the answer, yet retains it in the most limited form as a last resort option if needed. Consider the following rationales:

Statutory Mandate

The "<u>least restrictive alternative</u>"⁹ principle was first established by the U.S. Supreme Court in 1960, limiting state intervention in individual rights and liberties to only what is necessary for the health and welfare of individuals. This principle has been statutorily applied to the state's intervention in the form of guardianship proceedings. The Uniform Guardianship and Protective Proceedings Act requires a court visitor report to specify "whether less restrictive means of intervention are available." Most state guardianship laws similarly emphasize exploration of less restrictive decisional options before the filing for, and appointment of, a guardian. Finding less restrictive options is not only good practice; it is generally a state statutory mandate. Check requirements for your state.¹⁰

⁹ Shelton v. Tucker, 364 U.S. 479 (1960), available at <u>https://www.law.cornell.edu/supremecourt/text/364/479</u>.

¹⁰ Adult Guardianship Statutory Table of Authorities, American Bar Association Commission on Law and Aging, *available at* <u>http://www.americanbar.org/content/dam/aba/administrative/law_aging/2014_</u> AdultGuardianshipStatutoryTableofAuthorities.authcheckdam.pdf.

⁸ Fred Bayles and Scott McCartny, Guardians of the Elderly: An Ailing System Part I: Declared 'Legally Dead' by a Troubled System, Associated Press (Sep. 19, 1987), *available at <u>http://www.apnewsarchive.com/1987/Guardians-of-the-Elderly-An-Ailing-System-Part-I-Declared-Legally-Dead-by-a-Troubled-System/id-1198f64bb05d9c1ec690035983c02f9f.*</u>

Moreover, a compelling argument can be made that unnecessary guardianship without the examination of workable alternatives violates the 1999 Supreme Court decision in the <u>Olmstead</u> <u>decision</u>¹¹ requiring community integration, in that it unnecessarily isolates and segregates individuals in efforts to protect them.

Practice Standards

The <u>National Probate Court Standards</u>¹² require that a guardianship petition include "representations that less intrusive alternatives to guardianship or conservatorship have been examined" (3.3.1); provide that a court "should encourage the appropriate use of less intrusive alternatives to formal guardianship and conservatorship proceedings" (3.3.2); and specify that a court visitor report should state "whether less intrusive alternatives are available" (3.3.4 commentary).

The 2013 *National Guardianship Association Standards of Practice*¹³ require that guardians provide a person "with every opportunity to exercise those individual rights that the person might be capable of exercising" (Std 9); "carefully evaluate alternatives that are available" (Std 8); and "identify and advocate for the person's goals, needs, and preferences" (Std 7).

Ethical Standards

<u>ABA Model Rules of Professional Conduct 1.14</u>¹⁴ instructs attorneys to recognize client selfdetermination, less restrictive alternatives, and the need for supports. If the lawyer suspects a client has "diminished capacity"¹⁵ that may inhibit the client's ability to make decisions regarding the attorney's representation, the lawyer must seek to maintain a "normal client-lawyer relationship." The Comment notes that this is based on the assumption that the client, "*when properly advised and assisted*, is capable of making decisions about important matters" (emphasis added). If the attorney believes that the client is at risk of substantial harm, the attorney may take "protective action," including seeking out and consulting with the client's support network or assisting the client in executing a power of attorney or another form of legal support.

In taking protective action, the lawyer should be guided by the person's "wishes and values" to the extent known, with the goal of "intruding into the client's decision-making autonomy to the least extent feasible, maximizing client capacities. . ." Further, in considering "appointment of a legal representative" the lawyer should "be aware of any law that requires the lawyer to advocate

¹⁴ Rule 1.14: Client with Diminished Capacity, Model Rules of Professional Conduct, American Bar Association, available at http://www.americanbar.org/groups/professional_responsibility/publications/model_rules_of_professional_conduct/ rule_1_14_client_with_diminished_capacity.html.

¹⁵ The Model Rules of Professional Conduct use the phrase "diminished capacity," and many state guardianship laws use the phrase "incapacitated person" or similar language based on capacity. Because the Convention on the Rights of Persons with Disabilities provides that individuals with disabilities have legal capacity and must be given decision support, this guide avoids these phrases.

¹¹ Olmstead v. L.C., 527 U.S. 581 (1999), available at <u>https://www.law.cornell.edu/supct/html/98-536.ZO.html</u>.

¹² National Probate Court Standards, National Center for State Courts, available at <u>http://ncsc.contentdm.oclc.org/cdm/ref/</u> collection/spcts/id/240.

¹³ National Guardianship Association Standards of Practice, National Guardianship Association, *available at* <u>http://www.</u> guardianship.org/documents/Standards_of_Practice.pdf.

the *least restrictive action* on behalf of the client." Most state ethics opinions also instruct the attorney to identify any less restrictive alternatives.

Mental Health and Quality of Life

Encouraging individuals to retain as much autonomy as possible and be "<u>causal agents</u>"¹⁶ in their lives is consistent with <u>gerontological findings</u>¹⁷ that maintaining opportunity for choice and control is an important component of mental health; and that loss of ability—or perceived ability—to control events can lead to or exacerbate physical or emotional illness. Complete loss of status as an adult member of society could in effect act as a self-fulfilling prophecy, intensifying any disability an older person may have. Similar <u>findings show that younger adults</u>¹⁸ with higher levels of self-determination have a more positive quality of life.

Expense and Delay

Identifying supportive arrangements that are less restrictive than guardianship can avoid expenses of legal and court fees, and the delays of court action.

REASON. Clearly identify the reasons for concern. Which of the individual's needs are not met?

State the specific triggering concern(s) in your own words (e.g., the person is being financially exploited; the person needs medical treatment requiring informed consent). Be as specific as possible. Use the following checklist of domains of functional needs¹⁹ (adapted from Missouri's tool on alternatives to guardianship²⁰) as a starting point. For each, consider whether the person can meet some or all of the needs:

Money Management

• Managing accounts, assets and benefits—including daily expenditures, paying bills, making change, and using a bank account

¹⁶ Wehmeyer, et al., *Promoting Causal Agency: The Self-Determined Learning Model of Instruction*, Exceptional Children (Vol. 66, No. 4, pp. 439-453), The Council for Exceptional Children, *available at* <u>http://supporteddecisionmaking.org/sites/</u> <u>default/files/promoting causal agency self-determined learning model instruction.pdf</u>.

¹⁷ Mallers, et al., *Perceived Control in the Lives of Older Adults: The Influence of Langer and Rodin's Work on Gerontological Theory, Policy, and Practice*, The Gerontologist (Vol. 54, No. 1), *available at http://gerontologist.oxfordjournals.org/* <u>content/54/1/67.full.pdf+html</u>.

¹⁸ Heller, et al., *Self-Determination Across the Life Span: Issues and Gaps*, National Gateway to Self Determination (2011), *available at <u>http://ngsd.org/news/self-determination-across-life-span-issues-and-gaps</u>.*

¹⁹ *MO Guardianship: Understanding Your Options & Alternatives*, at <u>http://moguardianship.com/#materials</u>, <u>sponsored</u>, revised and updated by Jane St. John & Rachel Hiles, Missouri Family to Family, UMKC-Institute for Human Development, sponsored by Missouri Planning Council for Developmental Disabilities, developed and produced by UMKC Institute for Human Development, in collaboration with the Missouri Protection and Advocacy Services & the Missouri Department of Mental Health, Appendix 3 (2013).

²⁰ *MO Guardianship: Understanding Your Options and Alternatives*, Institute for Human Development (Sep. 2013), *available at* <u>http://moguardianship.com/MO%20Guardianship%20RESOURCE%20GUIDE%20rev%20Sept%20%202013.pdf</u>.

• Recognizing exploitation

Health Care

- Making decisions about medical treatment
- Taking medications as needed
- Maintaining hygiene, dental care and diet
- Avoiding high-risk behaviors (such as substance abuse, overeating, high-risk sexual activities, wandering)

Relationships

- Behaving appropriately with different kinds of relationship partners: family, friends, coworkers, intimate partners
- Making safe decisions concerning marriage and sexual relationships

Community Living

- Living independently without risk of serious harm or injury
- Maintaining habitable conditions at home (cleanliness, maintenance, security)
- Accessing community resources (transportation, bank, stores, post office, restaurants, home repair, emergency services)

Personal Decision-Making

- Understanding and communicating consent concerning legal documents (contracts, lease, deed, power of attorney)
- Identifying someone to represent interests and support with decision-making
- Communicating wishes, including specific desire to participate in the voting process
- Understanding legal consequences of behavior

Employment

• Looking for, gaining, and retaining employment

Personal Safety

- Avoiding common dangers (traffic, problems in driving, sharp objects, hot stove, poisonous substances)
- Recognizing and avoiding abuse
- Knowing what to do in an emergency

Ask if a triggering concern may be caused by *temporary* or

reversible conditions. Look for steps to reverse the condition and postpone a decision until the condition improves.

Use the following list to systematically screen for conditions or environmental factors affecting decision-making ability that could be mitigated or reversed, mooting the need for a guardianship, or at least delaying the decision to seek guardianship.

Acute Temporary Medical Conditions

- <u>Urinary tract infections:</u>²¹ UTIs often can cause confusion in older people.
- <u>Delirium²²</u> (acute temporary disorientation): in older people often triggered by medical illness or post-operative stress.
- <u>Dehydration</u>,²³ <u>malnutrition</u>:²⁴ Inadequate nutrition, hydration, and vitamin deficiencies can lead to reversible cognitive changes.
- <u>Traumatic brain injury</u>.²⁵ may affect cognitive, social, physical, and psychological functioning but has a significant recovery rate.
- <u>Oral health:</u>²⁶ poor oral health has been linked to poor self-esteem, lack of nutrition, and diminished cognitive functioning.

²² When Patients Suddenly Become Confused, Harvard Women's Health Watch (May 2011), available at <u>http://www.health.</u> <u>harvard.edu/staying-healthy/when-patients-suddenly-become-confused</u>.

²³ David Benton, *Dehydration Influences Mood and Cognition: A Plausible Hypothesis?*, National Institutes of Health (May 2011), *available at <u>http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3257694/</u>.*

²⁴ M. Hickson, *Malnutrition and ageing*, National Institutes of Health (Jan. 2006), *available at <u>http://www.ncbi.nlm.nih.</u>* <u>gov/pmc/articles/PMC2563720/</u>.

²⁵ Basic Information about Traumatic Brain Injury and Concussion, Center for Disease Control and Prevention, available at <u>http://www.cdc.gov/traumaticbraininjury/basics.html</u>.

²⁶ Alan Mozes, *Could Poor Dental Health Signal a Faltering Mind?*, HealthDay (Dec. 2013), *available at* <u>http://consumer.</u> <u>healthday.com/senior-citizen-information-31/misc-aging-news-10/could-poor-dental-health-signal-a-faltering-mind-682728.html</u>.

²¹ Urinary tract infections (UTIs) and dementia, Alzheimer's Society, available at <u>http://www.alzheimers.org.uk/site/scripts/</u> <u>documents_info.php?documentID=1777</u>.

Sensory Deficits

- <u>Hearing loss:</u>²⁷ may be isolating and may be perceived as dementia or diminished understanding.
- <u>Vision loss:</u>²⁸ can be disorienting but is easily correctable.

Medication Effects; Polypharmacy

Prescription and over-the-counter medication, while potentially improving health, <u>may affect</u> <u>mental status</u>²⁹—especially if <u>multiple drugs are taken simultaneously</u>,³⁰ as is common for older persons, producing drug-to-drug interactions. In addition to the fact that older people take many drugs, as the body ages it may be less able to cope with <u>certain drugs and drug interactions</u>.³¹ <u>Careful review</u>³² of medications could identify changes that significantly improve mental functioning.

Pain

Chronic or acute pain can be associated with <u>cognitive impairment</u>.³³ Effective pain reduction or management could enhance mental status.

Emotional Conditions

- <u>Depression:</u>³⁴ Ongoing depression can impair judgment and cause fatigue.
- <u>Stress</u>; <u>grief</u>:³⁵ Grief and stress due to loss of a loved one are particularly common to older persons. Health problems or loss of employment can cause stress.

²⁷ Jeremy Shere, *Can Hearing Loss Predict—or Lead to—Cognitive Decline?*, The Dana Foundation (Aug. 2014), *available at* <u>http://www.dana.org/News/Can_Hearing_Loss_Predict%E2%80%94or_Lead_to%E2%80%94Cognitive_Decline_/</u>.

²⁸ Allen L. Pelletier and Jeremy Thomas, *Vision Loss in Older Persons*, American Family Physician (Jun. 2009), *available at* <u>http://www.aafp.org/afp/2009/0601/p963.html</u>.

²⁹ *Prescription Medication in the Elderly*, Net Wellness Consumer Health Information, *available at* <u>http://www.netwellness.</u> <u>org/healthtopics/aging/faq16.cfm</u>.

³⁰ Roni Caryn Rabin, *Cocktail of Popular Drugs May Cloud Brain*, Well Blog (Feb. 2012), The New York Times, *available at* <u>http://well.blogs.nytimes.com/2012/02/27/cocktail-of-popular-drugs-may-cloud-brain/?_r=0</u>.

³¹ *Medications & Older Adults*, Health in Aging Foundation (Oct. 2015), *available at <u>http://www.healthinaging.org/</u><u>medications-older-adults/</u>.*

³² Avoiding Overmedication and Harmful Drug Reactions, Health in Aging Foundation (Sep. 2015), available at <u>http://www.</u> <u>healthinaging.org/files/documents/tipsheets/Tip.Avoiding_OverMedication.pdf</u>.

³³ John Gever, *Chronic Pain Disrupts Resting Brain Dynamics*, MedPage Today (Feb. 2008), *available at <u>http://www.</u>medpagetoday.com/PainManagement/PainManagement/8225*.

³⁴ *Depression*, Mayo Foundation for Medical Education and Research (July 2015), *available at* <u>http://www.mayoclinic.org/</u> <u>diseases-conditions/depression/basics/symptoms/con-20032977</u>.

³⁵ Cell Press, *How repeated stress impairs memory*, ScienceDaily (Mar. 2012), *available at* <u>http://www.sciencedaily.com/</u> releases/2012/03/120307132202.htm. • <u>Transfer trauma:</u>³⁶ This is stress and confusion caused by a sudden and perhaps forced move, usually by a person with dementia, as from hospital to nursing home and perhaps back, or from home to assisted living or nursing home.

Age and Disability Discrimination

The trigger for a guardianship petition may well lie not in the person's abilities but the attitudes of others. Social workers, protective services, lawyers, and judges are not immune from the deeply entrenched societal belief that individuals with disabilities and older adults cannot live independently or make their own decisions.

- <u>Age & disability discrimination; stereotyping</u>.³⁷ Myths and stereotypes about <u>aging</u>³⁸ and <u>disability</u>³⁹ can cause skepticism about decision-making abilities, resulting in unnecessary guardianship. "Ageism" is systematic stereotyping and discriminating against individuals or groups on the basis of their age. It is important for lawyers to examine and confront <u>their</u> <u>own perceptions</u> and biases⁴⁰ to minimize unnecessary intrusive actions.
- <u>Cultural barriers</u>.⁴¹ Cultural variations and language differences may be a barrier to understanding a person's behaviors, but can be addressed by awareness and techniques for cultural competency, and sometimes by translation services.

Family Disputes

The trigger for a guardianship petition may lie in family disputes over care and control of finances, with long-standing sibling feuds re-emerging. In aggravated situations, one sibling may prevent visitation by another, isolating and perhaps neglecting the elder, or misusing powers of attorney. There are many <u>reasons why families may fight</u>⁴² over the care or support for the person, often leaving out the voice of the person him or herself. Family conflict may be addressed by mediation—especially by mediators skilled in elder care or guardianship cases.

³⁷ Are you ready? What you need to know about ageing, World Health Day Toolkit, World Health Organization, available at <u>http://www.who.int/world-health-day/2012/toolkit/background/en/index3.html</u>.

³⁶ Kate Jackson, Prevent Elder Transfer Trauma: Tips to Ease Relocation Stress, Social Work Today (Vol. 15, No. 1), available at http://www.socialworktoday.com/archive/011915p10.shtml.

³⁸ Melissa Dittmann, *Fighting ageism*, Monitor (May 2003), American Psychological Association, *available at* <u>http://www.apa.org/monitor/may03/fighting.aspx</u>.

³⁹ About Independent Living, National Council on Independent Living, available at <u>http://www.ncil.org/about/aboutil/</u>.

⁴⁰ Understanding the Four C's of Elder Law Ethics, American Bar Association Commission Law and Aging, available at <u>http://</u>www.americanbar.org/groups/law_aging/resources/ethics_and_counseling_older_clients.html.

⁴¹ Serena Patel, *Cultural Competency Training: Preparing Law Students for Practice in Our Multicultural World*, UCLA Law Review Discourse (Vol. 62, 2014), *available at* <u>http://www.uclalawreview.org/cultural-competency-training-preparing-law-students-for-practice-in-our-multicultural-world-2/</u>.

⁴² Jeff Anderson, *10 Reasons Families Fight about Senior Care*, Senior Living Blog (Mar. 2014), A Place for Mom, *available at* <u>http://www.aplaceformom.com/blog/reasons-families-fight-about-senior-care-02-27-2012/</u>.

COMMUNITY. Determine if concerns can be addressed by connecting the individual to family or community resources, and making accommodations in place.

At the heart of the PRACTICAL approach are practical actions that can be taken, connections that can be made, and creative accommodations that can be made to enhance decision-making ability. The PRACTICAL steps bring these essential non-legal solutions to the heart of the process. Rather than asking whether the person can make the decisions at hand, ask whether the person can make them with support.

Poor and inadequate social services and poor quality residential care can lead to a dire living situation, which may be the crux of the problem. A fix in social services or living arrangements may moot the need for a guardianship petition.

Community Supports

Lawyers can call on multiple networks of supportive community services for individuals with disabilities and older adults.

- Human Services. Most local jurisdictions have human services divisions, often with customer care or intake lines to help match the services to the needs. Some communities have an extensive set of supportive services for older persons and individuals with disabilities, while others have only the rudiments. Local resources may serve as an information or access point for state resources such as Medicaid. Find out about mental health resources, subsidized housing and rental assistance, assistive technology, home modification, supportive memory aids, training and education, and recreation/socialization opportunities that could support the person.
- Legal Services. Consider calling on the expertise of <u>legal services</u>,⁴³ especially those funded to help older people under the Older Americans Act, to access public benefits for low and moderate income individuals. Protection and Advocacy Programs (<u>P&As</u>)⁴⁴ in every state have the authority to provide legal representation and advocacy for individuals with disabilities. P&As represent individuals with disabilities on a wide variety of matters including employment and housing discrimination, as well as abuse and neglect.
- Agencies on Aging. Under the <u>Older Americans Act</u>⁴⁵ there is an established network of state and area agencies on aging either providing or contracting for key community-based aging services such as congregate or home delivered meals, senior centers, adult day health, care management, money management, transportation, in-home care, and assistance

⁴⁴ P&A/CAP Network, National Disability Rights Network, available at <u>http://www.ndrn.org/about/paacap-network.html</u>.

⁴³ Find Legal Aid, Legal Services Corporation, available at <u>http://www.lsc.gov/find-legal-aid</u>.

⁴⁵ Administration on Aging (AoA) Older Americans Act, Administration for Community Living, *available at* <u>http://www.aoa.</u> <u>gov/AoA_programs/OAA/</u>.

with Medicare problems. To find resources in your area quickly, use the <u>national Eldercare</u> <u>Locator</u>.⁴⁶

- ADRCs. The U.S. Administration on Community Living, with the Centers for Medicare & Medicaid Services (CMS) and the Veterans Health Administration has developed a "No Wrong Door" system of Aging and Disability Resource Centers (<u>ADRC</u>).⁴⁷ These centers streamline access to long-term services and support options and aim to simplify access.
- Independent Living Services. There is also a system of Independent Living Services— programs established under the Rehabilitation Act, currently based at the <u>Administration for</u> <u>Community</u> <u>Living</u>⁴⁸ in the U.S. Department of Health and Human Services. The independent living programs seek to maximize the independence, well-being, and health of people with disabilities across the lifespan.
- **Ombudsman Programs.** Each state and many localities have <u>long-term care ombudsman</u> <u>programs</u>.⁴⁹ Ombudsmen serve as advocates for residents in nursing homes, assisted living, and other residential settings. An ombudsman may be able to craft a resolution to problems in care or residents' rights that will meet the perceived need for a guardian.
- **Developmental Disability (DD) Councils.** <u>State Developmental Disability Councils</u>⁵⁰ receive federal funding to promote self-determination, inclusion, and integration for individuals with developmental disabilities.
- **Mediation.** There may be mediators in the community specially trained in elder or guardianship mediation. While there is no specific list of such mediators, contact your state mediation association or your area agency on aging. To be sure the mediator has the relevant experience and skills, review the Association for Conflict Resolution's (ACR) <u>Training</u> <u>Objectives for Eldercare Mediation.</u>⁵¹ In especially high conflict cases, find out if your court is piloting an "<u>eldercaring coordination</u>"⁵² program according to ACR guidelines.

⁴⁶ Eldercare Locator available at <u>http://www.eldercare.gov/Eldercare.NET/Public/Index.aspx</u>.

⁴⁷ Aging & Disability Resource Centers Program/No Wrong Door System, Center for Integrated Programs (CIP), Office of Consumer Access and Self Determination, available at <u>http://www.acl.gov/Programs/CIP/OCASD/ADRC/index.aspx</u>.

⁴⁸ Administration for Community Living website *available at* <u>http://www.acl.gov/</u>.

⁴⁹ National Consumer Voice for Quality Long-Term Care website available at <u>http://ltcombudsman.org/</u>.

⁵⁰ National Association of Councils on Developmental Disabilities website available at <u>http://www.nacdd.org/home/</u>.

⁵¹ Elder Care and Elder Family Decision-Making Mediation: Training Objectives and Commentary, ACR Section on Elder Decision-Making and Conflict Resolution Committee on Training Standards, available at <u>http://acreldersection.weebly.com/</u>uploads/3/0/1/0/30102619/eldercareobjectives 7 30 2012.pdf.

⁵² Guidelines for Eldercaring Coordination, Association for Conflict Resolution Task Force on Eldercaring Coordination (2014), available at <u>http://www.eldersandcourts.org/~/media/Microsites/Files/cec/ACR%20Guidelines%20for%20Elder%20</u> Caring%20Coordination%202014.ashx.

Informal Supports

Family caregivers⁵³ provide the bulk of long-term care in the U.S.

- Have all family members who could provide support been identified? Sometimes it takes a comprehensive search, and is worth digging.
- Is there a network of supportive friends able and ready to work with the individual on decisions in line with his or her values and preferences? Check for close friends over many years, neighbors, co-workers, providers who have become familiar with the person, volunteers, and members of faith-based communities.

Accommodations and Communication Techniques

It is the person's will and preference, plus support plus accommodations that equals legal capacity.⁵⁴

Finding the right combination of supports and accommodations can boost understanding and decision-making ability, and may alleviate the need for a guardianship. Start with the challenge at hand and ask "*what would it take*" to enable this person to make the needed decisions in a supportive environment.

There may be accommodations as required under the Americans with Disabilities Act (ADA) that can boost the person's functioning. But beyond the ADA there is a host of creative possibilities. While some involve funding, others are low-cost or no-cost, limited only by imagination. For example, an individual with an intellectual disability wanted to donate a kidney to his brother, but there were legal questions about his capacity to consent. Accommodations to aid understanding for such a person might include the use of drawings, a conversation with someone who has donated a kidney, a visit to the hospital, and communicating in plain language in a comfortable environment.⁵⁵

There are many <u>communication techniques</u>⁵⁶ that can markedly enhance understanding and response:

- Break information down into more manageable segments.
- Pay special attention to developing trust and confidence.
- Use paraphrasing and active listening.
- Don't make important points in passing, rephrase them.
- Use plain language, short sentences, active voice.
- Speak directly to the person, not "past" the person.
- Use hands and facial expressions to emphasize what you say.

⁵³ Caregiving, Family Caregiver Alliance (2009), available at <u>https://caregiver.org/caregiving</u>.

⁵⁴ Michael Bach, *A Disability-Inclusive Approach to the Right to Decide*, Developmental Disabilities Lecture Series (2013), *available at* <u>http://rwjms.rutgers.edu/boggscenter/documents/Bach5-3-13packet.pdf</u>.

⁵⁵ Kristin Booth Glen, Supported Decision-Making and the Human Right of Legal Capacity, Inclusion (Vol. 3, No. 1, 2015).

⁵⁶ Assessment of Older Adults with Diminished Capacity: A Handbook for Lawyers, American Bar Association Commission on Law and Aging and American Psychological Association (2005), available at <u>https://www.apa.org/pi/aging/resources/guides/</u> <u>diminished-capacity.pdf</u>.

TEAM. Ask the person whether he or she already has developed a "team" to help make decisions.

Ask if there are any people or entities already assisting the person in making decisions—and if the person wants such help. It is important the person is able to identify any supporters.

Network of Supporters

The person over time may have developed an informal system for making decisions with the help of a network of trusted supporters such as friends, relatives, colleagues, acquaintances from the community, supportive staff, or co-workers.

The person may have created—or may want to create—a structured "<u>circle of support</u>"⁵⁷ that includes trusted supporters who regularly meet as a group for planning, problem-solving, and decision-making. The circle members help the person with managing and budgeting goals, evaluating risks and consequences, and recognizing and making full use of abilities.

Appointed Surrogate

Guardianship may not be necessary if the person already has appointed a trusted surrogate authorized under state law to make decisions on his or her behalf, ideally with his or her participation.

- Is there already an appointed surrogate?
- Does the surrogate have authority to act in the situation at hand?
- Is the surrogate trustworthy?
- Will the surrogate act in accordance with the person's values and preferences, and with the person's involvement?

Legally authorized surrogates⁵⁸ could include:

- An agent under a financial power of attorney.
- A trustee under a revocable living trust.
- An agent under a health care power of attorney or advance directive.
- A family member or other person authorized to make health care decisions under a state default surrogate consent law.
- A representative payee for Social Security or other public benefits, or a VA fiduciary.
- While not a "surrogate," a supporter under a legally or informally recognized representation agreement can help the person make decisions.

⁵⁷ *NYS Self-Determination Consolidated Supports & Services Project*, Circle of Support (COS) Training, *available at* <u>http://</u><u>www3.opwdd.ny.gov/wp/images/cos_master_01_12.pdf</u>.

⁵⁸ See more information about legally authorized surrogates in the later section of this guide under "APPOINT."

DENTIFY abilities. If the person does not already have an existing team and has difficulty with specific types of decisions, identify areas of strengths and limitations in decision-making.

Determine whether:

- The person is able to make the specific decision(s) with support from a trusted friend, family member or someone else.
- The person is able to name one or more supporters to help in decision-making; or appoint a surrogate to make the decision(s) in question.

Without a system of decision-making support in place, there is a need to clearly assess the individual's abilities—both strengths and limitations—in the specific areas in which decisions are needed; as well as the ability to name a supporter or appoint a surrogate.

Sometimes this may be an informal assessment by the lawyer and others involved in the case about what the person is able to do and what support is necessary. The American Bar Association and the American Psychological Association have developed a <u>Handbook for Lawyers</u>⁵⁹ detailing the elements of such assessments for older clients, with a framework of factors including statutory provisions and ethical rules. Consider whether the person can:

- Articulate reasoning leading to a decision.
- Maintain consistent decisions and primary values over time;
- Appreciate consequences of decisions.

As explained in the *Handbook*, it is generally not appropriate for a lawyer to use formal clinical instruments such as the Mini-Mental Status Examination (MMSE). Lawyers are not trained to administer these tests or interpret the results. The test questions (such as clock drawing or counting backwards) have little direct bearing on understanding of the tasks or decisions at hand. Even for clinical professionals, the MMSE is simply a screening tool to determine whether further evaluation is needed, not an assessment tool itself.

In some cases, a lawyer may find that consultation with a *clinical specialist* would be helpful.

- The lawyer could **consult informally** with a clinician such as a geriatrician, geriatric psychiatrist, psychologist, neurologist or other mental health professional with experience in assessments.
- Or the lawyer could **seek a formal clinical assessment** with the individual's consent. Such an assessment can be a good tool in planning for needed supports, determining whether the person has the ability to either make certain decisions or to appoint a legal representative to

⁵⁹ Assessment of Older Adults with Diminished Capacity: A Handbook for Lawyers, American Bar Association Commission on Law and Aging and American Psychological Association (2005), available at <u>http://www.apa.org/pi/aging/resources/</u> guides/diminished-capacity.pdf.

assist. If there is a decision to file for limited guardianship, an assessment can help to clarify the specific powers that would be retained, making for a much more tailored court order.

• In seeking a formal assessment, be specific with the clinician about the reason for the referral, and the person's circumstances, history and values. Ask for opinions on supports in any areas of deficit, and approaches less restrictive than guardianship.

CHALLENGES. Screen for and address any potential challenges presented by the identified supports and supporters.

Once a support system or individual supporters are identified, the biggest challenge is making sure the situation remains viable and the supporters are trustworthy.

Challenges with Support Systems

- Are there challenges in accessing community or other support systems? Are there barriers in eligibility, cost, timing or location?
- Is an institutional support system—such as a community-based mental health agency or a homeless outreach organization—underfunded, overburdened with paperwork and bureaucratic delay?
- Does the individual receive public benefits that are at risk if not vigilantly protected?
- Are there certain prerequisites that the individual must establish in order to access the support systems?

Challenges with Supporters

- Do the identified supporters present any risk of substantial physical, emotional, or financial harm?
- Do you have any suspicion that the supporters may engage in abuse, neglect, exploitation or undue influence? Be sure to report any suspected abuse to <u>Adult Protective Services</u>.⁶⁰
- Do the supporters understand the individual's potentially complex medical and/or mental health needs?
- Are the supporters stable? Do they need an incentive to remain so?

Coercion; Undue Influence

It is important to consider whether concerns triggering a possible guardianship petition may be rooted in coercion, fraud, intimidation, or undue influence. Guardianship may be perceived as a key strategy in protecting an individual from the perpetrator. However, making a report to adult protective services and removing the cause of the undue influence—admittedly often not an

⁶⁰ National Adult Protective Services Association website available at <u>http://www.napsa-now.org/</u>.

easy task—may reduce the impetus for guardianship. Often the person will not recognize what is happening and will side with the perpetrator.

<u>Undue influence</u>⁶¹ has been defined as instances in which "people use their role and power to exploit the trust, dependency, and fear of others. They use this power to deceptively gain control over the decision-making of the second person" (psychologist Margaret Singer). <u>Legal</u> <u>definitions</u>⁶² vary, but often include factors relating to: (1) the relationship between the alleged influencer and the alleged victim; (2) the alleged victim's vulnerability to undue influence; (3) the alleged influencer's opportunity to gain control; and (4) whether the alleged victim's decisions were the outcome of the undue influence. Other definitions focus on the nature of the transaction(s) at hand, the mental condition of the individual, and the relationship of the parties. Be alert to the possibility that a supporter might potentially unduly influence the person in the guise of support.

Note that being subject to undue influence does not necessarily mean a person has "diminished capacity" as defined under state guardianship laws. Be careful to separate the external coercion from the individual's abilities.

APPOINT. If the person is able and wishes to select a trusted supporter to help make decisions and/or to appoint a legal surrogate, help the person do so in a way that is consistent with the person's values and preferences.

Consider the following options for clarifying or implementing a supporter relationship in a legally recognizable form that may help ensure the person's wishes are honored. The National Guardianship Network has a full <u>list of options</u>⁶³ for decision-making that are less restrictive than guardianship.

Health Care Advance Directive

The person may be able to name someone as an agent to make health care decisions in a written <u>advance directive document</u>,⁶⁴ which also could include statements of the person's wishes concerning medical treatment. The real challenge will be ensuring that the person effectively

⁶³ Decision Making Without Guardianship, National Guardianship Network, available at <u>http://www.naela.org/NGN/About_Guardianship/Decision_Making_Without_Guardianship/NGN/About_GuardianshipMain/Decision_Making.</u> aspx?hkey=eb9c2ced-35aa-4499-acd1-26cd208f02ac.

⁶⁴ Living Wills, Health Care Proxies, & Advance Health Care Directives, American Bar Association Section of Real Property, Trust and Estate Law, available at <u>http://www.americanbar.org/groups/real_property_trust_estate/resources/estate_</u> planning/living_wills_health_care_proxies_advance_health_care_directives.html.

⁶¹ Lisa Nerenberg, *Undue Influence: An Insidious Form of Elder Abuse*, NYC Elder Abuse Center website (2013), *available at* <u>http://nyceac.com/undue-influence-an-insidious-form-of-elder-abuse/</u>.

⁶² Lori A. Stiegel, *Legal Issues Related to Elder Abuse: A Pocket Guide for Law Enforcement*, Bureau of Justice Assistance (2014), *available at* <u>https://www.bja.gov/Publications/ABA-ElderAbuseGuide.pdf</u>.

communicates his or her values and wishes to the agent. Check your <u>state's laws</u>⁶⁵ for any specific requirements. Some <u>state laws</u>⁶⁶ also direct a guardian to comply with a health care advance directive if possible.

A health care agent may consent to or participate in discussion concerning two other kinds of advance care planning documents—a <u>Do Not Resuscitate (DNR) Order⁶⁷</u> directing a physician not to perform cardio-pulmonary resuscitation if an individual's breathing or heart stops; and in some states a Physician's Orders for Life-Sustaining Treatment (<u>POLST</u>)⁶⁸ in which a seriously ill patient can indicate and document his or her desired end of life care, which is translated into a physician's order.

Health Care Surrogate Under State Law

In the Uniform Health Care Decisions Act and <u>statutes in 44 states</u>,⁶⁹ if the person is not able to make health care decisions him or herself, the authority to make some or all health care decisions automatically devolves to a surrogate generally designated according to a hierarchy of family members. In over 20 of these states, a "close friend" familiar with the person's history and values can make decisions if there is no family, and in approximately 12 states some combination of physicians and ethics committee can decide if there is no one else. It is important to consider whether these legally authorized health care surrogates actually know or try to find out what the person wants or would have wanted and support the person in those choices. A surrogate could be a member of a support team assisting the person—or may be the only one on which the clinicians rely.

Financial Power of Attorney

The person may be able to execute a financial <u>power of attorney</u>,⁷⁰ a legal document assigning authority to make financial decisions to another party. Unlike the healthcare advance directive, a financial power of attorney can be effective while an individual has capacity. Or, it can become effective only if the individual loses capacity. It is helpful to delegate specific categories of authority, such as managing pensions, control over a checking account, or accountability for a lease.

⁶⁵ Links to State-Specific Advance Directive Forms, American Bar Association Commission on Law and Aging, available at <u>http://www.americanbar.org/content/dam/aba/administrative/law_aging/Links_to_State_Advance_Directive_Forms.</u> authcheckdam.pdf.

⁶⁶ Guardianship Law & Practice Resource Website, American Bar Association Commission on Law and Aging, available at <u>http://ambar.org/guardianship</u>.

⁶⁷ *Do-not-resuscitate order*, MedlinePlus, U.S. National Library of Medicine, *available at* <u>http://www.nlm.nih.gov/</u> medlineplus/ency/patientinstructions/000473.htm.

68 The National POLST website is available at http://www.polst.org/.

⁶⁹ Default Surrogate Consent Statutes, American Bar Association Commission on Law and Aging (July 2014), available at <u>http://www.americanbar.org/content/dam/aba/administrative/law_aging/2014_default_surrogate_consent_statutes.pdf</u>.

⁷⁰ *Power of Attorney*, American Bar Association Section of Real Property, Trust and Estate Law, *available at* <u>http://www.</u> <u>americanbar.org/groups/real_property_trust_estate/resources/estate_planning/power_of_attorney.html</u>.

Trustee

For complex or substantial assets, the person may be able to execute a document transferring title and authority to manage property to a <u>trustee</u>⁷¹ for the benefit of either the person or others as beneficiaries, under a revocable living trust.

Representative Payee

The Social Security Administration administers a <u>representative payment program</u>⁷² for recipients of Social Security and SSI who it deems "incapable" of managing their own funds. The representative payee receives and manages the payment, using it to pay for current and foreseeable needs such as rent, food and spending money. An individual can apply to Social Security to become a payee for a recipient, or designated organizations can serve as payees for many recipients. The representative payee has authority only over the benefits and cannot make any other decisions on the person's behalf. It is very difficult for an individual to revoke a payee's status once appointed.

The Veterans Administration can appoint a <u>VA Fiduciary</u>⁷³ upon a determination that a VA beneficiary is unable to manage his or her VA benefits. Generally, family members or friends serve as fiduciaries for beneficiaries, but when friends and family are not able to serve, VA looks for qualified individuals or organizations to serve. The VA fiduciary has authority only over VA benefits.

Legally Recognized Supporter

Law in selected Canadian and other jurisdictions allows individuals who require some decisionmaking assistance to enter into a "<u>representation agreement</u>"⁷⁴ with a support person or network, which is legally recognized by third parties. Under a representation agreement, an individual can authorize one or more "supporters" to assist in managing his or her affairs and help the person to make his or her own decisions. The agreement can be effective immediately or at a future date if circumstances change due to disability, age or another reason requiring support. The agreement can be revoked by the individual, and it can be supplanted by a legally appointed guardianship.

Under the Canadian model, an individual does not have to demonstrate "legal capacity" to enter into a representation agreement. The standard is that the individual has "trust" in the supporter/s in his or her network. This cutting edge alternative to guardianship is gaining international acceptance. Currently, the best resource to learn more about representation agreements is a Canadian nonprofit organization called <u>Nidus</u>, the Personal Planning and Resource Center <u>Registry</u>.⁷⁵ <u>Texas has enacted a legally recognized supported decision-making agreement</u>,⁷⁶ and in some areas in the U.S. such agreements are informally recognized.

⁷¹ *Revocable Trusts*, American Bar Association Section of Real Property, Trust and Estate Law, *available at* <u>http://www.americanbar.org/groups/real_property_trust_estate/resources/estate_planning/revocable_trusts.html</u>.

⁷² When People Need Help Managing Their Money, Social Security website, available at <u>http://www.socialsecurity.gov/payee/</u>.

⁷³ Fiduciary, U.S. Department of Veterans Affairs website, available at <u>http://benefits.va.gov/fiduciary/</u>.

⁷⁴ Representation Agreement, Nidus Personal Planning Resource Centre and Registry, available at <u>http://www.nidus.ca/?page_id=46</u>.

⁷⁵ The Nidus Personal Planning Resource Centre and Registry website is available at <u>http://www.nidus.ca/</u>.

⁷⁶ Supported Decision-Making: Alternatives to Guardianship, Texas Council for Developmental Disabilities, *available at* <u>http://</u><u>www.tcdd.texas.gov/resources/guardianship-alternatives/supported-decision-making/</u>.

LIMIT any necessary petition and order.

Judges are not like baseball umpires, calling strikes and balls or merely labeling someone competent or incompetent. Rather, the better analogy is that of a craftsman who carves staffs from tree branches. Although the end result—a wood staff—is similar, the process of creation is distinct to each staff. Just as the good wood-carver knows that within each tree branch there is a unique staff that can be "released" by the acts of the carver, so too a good judge understands that, within the facts surrounding each guardianship petition, there is an outcome that will best serve the needs of the incapacitated person, if only the judge and the litigants can find it ⁷⁷

If no less restrictive measures can reasonably meet the individual's need, and there is risk of significant harm, seek a limited guardianship order transferring authority to a surrogate only in those areas in which decision-making support is needed. A major theme of the UGPPA, is that "limited guardianship or conservatorship should be used whenever possible." Many <u>state laws</u>⁷⁸ reflect the emphasis on limited guardianship.

Through completing all of the foregoing PRACTICAL steps, you will gain a solid grasp of the individual's needs, strengths, and deficits—as well as actual or potential substantial harm, and any ways the harm could be addressed without a guardianship. If after this "due diligence" analysis you determine a guardianship is in fact needed as a last resort, aim to limit the scope of the order.

Specify Limits in Petition and Order

There are barriers to petitioning for limited guardianship. Some petition forms don't provide for it. Moreover, conditions change, and going back to court to petition again later for a modification of the order may be at significant cost to—or simply unaffordable for—your client. Some judges may not draft or approve limited orders, reasoning that a plenary order will give more flexibility without coming back to court. But despite these very real barriers, apply the statutory language concerning limited orders if possible.

- Use a good clinical assessment to clarify specific powers that should be retained
- Work with the court and bar to make petition and order forms acknowledge limitations. As a start, using <u>templates for limited orders</u>⁷⁹ in your court may work.

Seek Person's Participation in Decision-Making

Even though the guardian is a surrogate decision-maker, he or she should nonetheless consult with and allow the individual to lead in decisions when possible. Ideally, *the guardian is there as a support*, not as an authoritarian voice restricting self-determination.

⁷⁹ The form for the State of Rhode Island Petition for Limited Guardianship or Guardianship is available at <u>http://sos.</u> <u>ri.gov/documents/probate/PC2.3.pdf</u>.

⁷⁷ Lawrence A. Frolik, Promoting Judicial Acceptance and Use of Limited Guardianship, Stetson Law Review (Vol. 31, 2002), *available at* <u>http://papers.ssrn.com/sol3/papers.cfm?abstract_id=1348105</u>.

⁷⁸ Limited Guardianship of the Person, AARP Public Policy Institute, available at <u>http://www.americanbar.org/content/dam/</u> aba/administrative/law_aging/Limited_Guardianship_of_the_Person_Chart.authcheckdam.pdf.

- The UGPPA provides that "the guardian or conservator should always consult with [the individual] to the extent feasible, when making decisions."
- State laws frequently provide that a guardian must seek to maximize the participation of the person in decision-making and be guided by the person's values and preferences.
- Concepts of decision-making participation are embedded in court and guardian standards of practice (*National Probate Court Standards*⁸⁰ and *National Guardianship Association* <u>Standards of Practice</u>⁸¹).

Develop Plan to Maximize Self Determination

Some state laws require guardians to formulate forward-looking plans both as a practical tool and as a baseline of accountability for the courts. But even if a plan is not required, it is a good practice. The NGA *Standards of Practice* require the guardian to develop "a person-centered plan." A plan should not only show anticipated actions and services over the upcoming period, but the means by which the guardian will seek out and incorporate the person's voice.

Reassess for Restoration or Modification

Periodically reassess whether conditions have changed and <u>rights could be restored</u>.⁸² Under the NGA *Standards*, a guardian is to "assist the person under guardianship to develop or regain the capacity to manage his or her personal and financial affairs;" and should "seek termination or limitation of the guardianship: (A) When the person has developed or regained capacity . . . (B) when less restrictive alternatives exist; and (C) when the person expresses the desire to challenge the necessary of all or part of the guardianship" (Std #21).

A lawyer representing an individual in a restoration proceeding should:

- Thoroughly interview the person, seeking evidence of changes in abilities or circumstances that would make guardianship unnecessary. Interview those close to the person as well.
- Review evidence from the initial determination. Perhaps it was insufficient, inaccurate or overlooked at the time of the order.
- Ensure there is a solid clinical evaluation.
- Use evidence and testimony from third parties knowledgeable about the person's abilities.
- Articulate plans for overcoming deficits with supports.
- Show that supports are in place or ready.
- Thoroughly prepare the individual for the hearing; and secure any needed accommodations.
- If full restoration is not possible, consider a plan to progressively restore rights.

⁸⁰ National Probate Court Standards, National Center for State Courts, available at <u>http://ncsc.contentdm.oclc.org/cdm/ref/</u> <u>collection/spcts/id/240</u>.

⁸¹ National Guardianship Association Standards of Practice, National Guardianship Association, *available at* <u>http://www.guardianship.org/documents/Standards_of_Practice.pdf</u>.

⁸² Jenica Cassidy, *State Statutory Authority for Restoration of Rights in Termination of Adult Guardianship*, Bifocal (Vol. 34, No. 6), American Bar Association Commission on Law and Aging, *available at* <u>http://www.americanbar.org/publications/</u><u>bifocal/vol_34/issue_6_august2013/guardianship_restoration_of_rights.html</u>.

The PRACTICAL Tool aims to help lawyers identify and implement decision-making options for persons with disabilities that are less restrictive than guardianship. It is a joint product of four American Bar Association entities – the Commission on Law and Aging, Commission on Disability Rights, Section on Civil Rights and Social Justice, and Section on Real Property, Trust and Estate Law, with assistance from the National Resource Center for Supported Decision-Making.

Learn more about the ABA entities that produced this Tool:

- · Commission on Law and Aging: www.americanbar.org/aging
- Commission on Disability Rights: <u>www.americanbar.org/disability</u>
- · Section on Civil Rights and Social Justice: www.americanbar.org/crsj
- Section on Real Property, Trust and Estate Law: www.americanbar.org/rpte



The Right to Make Choices: International Laws and Decision-Making by People with Disabilities

Introduction

Freedom to make choices is a human right.

• International human rights laws protect people's right to decide how to spend their money, make their own health care decisions, work for a living, and have relationships with friends and family.

Adults without disabilities take freedom of choice for granted.

- But people with disabilities cannot take freedom of choice for granted. People with disabilities often do not make their own choices.
- People with disabilities especially people with intellectual, developmental, or mental health disabilities often do not get to make their own choices.
- Often, if a family member thinks the person with a disability cannot make good choices, the person with a disability is no longer in charge.

People with disabilities can make their own decisions with the right supports.

What is this guide?

This guide helps people with disabilities understand decision-making laws.

• Every country has different laws. This guide explains the different types of laws and how they work.

The guide explains how international law protects people with disabilities' freedom of choice.

- International laws are laws between countries.
- International law also involves agreements with international organizations, such as the United Nations and the European Union.
- International organizations create laws all member countries who vote for them must follow.
- Sometimes there is conflict between international law and a country's laws. Conflicts lead to lawsuits. This conflict can lead to changes in the laws.

What is Supported Decision-Making?

"Supported Decision-Making" gives people with disabilities the help they need to make choices about their own lives.

- These choices could be about where to live, what to do during the day, how to spend money, or when to see a doctor.
- Everyone needs supports to make decisions. But people with disabilities may need more or different kinds of supports.
- For example, people with disabilities may need help to understand information about choices we need to make.

• Examples of help include:

- 1. Plans for the future
- 2. Help us get our ideas across
- 3. Keep us on task.
- The person with a disability chooses a person that helps with decisions. This is supported decision-making.
- With supported decision-making, the supporter gives advice, but the person with a disability makes the final decision.
- A good supporter respects the wishes of the person with a disability.
- A good supporter listens and suggests ways to make the person's wishes happen.

Example - A good supporter

- For example, imagine that you want to find a place to live, but don't know how to make decisions about what you can afford, or what kind of house would be a good place to live.
- You ask your sister for help.
- Your sister comes to your house and asks you questions about what kind of apartment you want.
- She listens to you about how much money you get each month and how much you spend on other things like food and clothes.
- She helps you figure out how much money you can afford to pay in rent each month. Then she helps you look at apartments.
- Maybe she helps you understand that an apartment with all of the things you want for example, a big house close to the middle of town would be too expensive for you to afford.
- She helps you figure out which of the things you want in an apartment are most important to you.
- You visit apartments with your sister.
- You then decide which apartment you want and sign a lease.
- At the end of this process you have received a lot of support, but you still made all your decisions yourself.

How to name a supporter using a form

- Most supported decision-making happens without any special legal process. Your sister helps you find an apartment without a special form or going to the court.
- There are only a few states that have true supported decision-making laws on the books.
- But sometimes, people decide to sign a form that lets other people know that a supporter is helping them.

- There are a couple of different types of these forms, and they all do different things. Here, we're going to list a few of the different types of forms and what each of them do.
- The forms have names such as "Power of Attorney," "Health Care Proxy," "Representative Agreement," or "Supported Decision-Making Agreement."

"Power of Attorney" gives someone else the right to do things like take care of your money for you or make legal decisions for you.

- "Attorney" is a word that means "lawyer." But the person making decisions for you does not have to be a lawyer.
- This person can only make decisions at certain times. The times depend on the agreement.
- You can take this power away at any time.
- The person has the right to use the power of attorney to show that they can make decisions for you unless a court finds that you can't make decisions on your own anymore.
- The court might find that if you got really sick. So a power of attorney stops working if you can't make decisions by yourself, unless it's a special kind.

Durable power of attorney is that special kind of power of attorney.

- It keeps working even if you get sick.
- It keeps working even if you can't make decisions by yourself anymore.
- Sometimes it does not start working unless you stop being able to make decisions by yourself.

A "Health Care Proxy" is the same type of agreement for health care.

- A health care proxy or health care power of attorney puts someone else in charge of your health care decisions if you are unable to make them yourself.
- The document only takes effect if you are ill and can't make decisions by yourself. A team of doctors must determine if this is the case.
- Health care power of attorney is hard to cancel after you get sick.
- Even though these forms usually let people make decisions for you, you can sometimes write them in a way that lets you make all the final decisions.

"Representation Agreements" and "Supported Decision-Making Agreements" tell people who supports you.

- You remain in charge.
- The supporter helps.
 - The supporter takes these forms to doctors, bankers, landlords, or other people who might give services to a person with a disability.
 - Once the doctor, banker, landlord, or other person sees the form, they know that the supporter is helping the person with the disability.

If you are not interested in giving someone any decision-making power and are only interested in telling people what health care you want while you are sick, you can sign an advance directive.

- These are documents that tell people what you want them to do if you can't tell them what to do.
- They can be for medical care or for mental health care.
- However, these documents usually aren't **legally binding**.
 - This means that even though the advance directive tells the doctor what you *want* the doctor to do when you can't tell them (because you're sick or knocked out), the doctor **doesn't** legally have to do it.
 - An advance directive can be helpful if you trust your health care provider.

Powers of attorney and advance directives don't work if a court thinks the signer didn't understand what they were signing.

- This means that sometimes, a court will say a power of attorney or advance directive isn't valid because the signer had a disability.
- In those cases, the court will often put the person under **guardianship** instead.
- Sometimes the court will pick a guardian who is different from the person named in the power of attorney or advance directive.

How to name a supporter using a bank

- In most countries, people who need help with money can set up bank accounts that let another person help them.
- Bank accounts with partners give another person access to the account.
- You must trust the person because they can take money out of the account.

You can create an authorized signatory so that it takes two signatures – yours and your supporter – to take any money out.

• This works if you worry about money.

You can also create a trust.

- Other people help manage the trust. The managers are **trustees**.
- The trust has rules for when you can use the money.
- These rules are set when the trust is set up. The trustees have to follow the rules.
- These strategies let a person with a disability get help with money.
- Another person does not have full control with these strategies.

Guardianship is a system that allows one person to make decisions about another person's life.

- These decisions can include where you live, your friends, your money, and your health care.
- Sometimes, people under guardianship are not allowed to vote, get married, or take care of their children.
- In most countries, children have guardians. A parent takes responsibility for a child.
- Sometimes grandparents, step-parents, godparents, or someone else takes responsibility.
- Under the law, children cannot make important decisions without approval. As children grow older, they make their own decisions.
- Legal adults do not have guardians. Legal adults make their own choices.

People with disabilities under guardianship do not have the same rights as other adults.

- The person with a disability cannot make their own decisions under guardianship. **Another person is the guardian.**
- The guardian makes the decisions.
- For a guardianship you must go to court. A judge must declare guardianship.
- Full guardianship means the guardian makes every decision.
- Limited guardianship means the guardian only makes certain decisions. Examples include healthcare and money management.

Guardianship takes choices away from people with disabilities.

- For example, imagine that you want to find a place to live and are under guardianship.
- If you are using **supported decision-making** instead of guardianship, you could simply call up your sister and have her help you through the process.
- If you have a **guardian**, you could not get an apartment without your guardian's consent and assistance, even if you would rather have someone else help you instead of your guardian.
- Even if your guardian could only make decisions about how you spend your money, you wouldn't be able to pay the rent for your apartment without their help.
 - This means the guardian has a lot of power to say where you can or can't live.
 - Some countries' laws say that a guardian must consider your wishes when they make a decision.

It is hard to make sure your wishes are considered by a guardian.

- You may have to go to court to complain about your guardian's decisions.
- This may be expensive and hard.
- In some countries, you cannot even go to court on your own to complain about a guardian someone else has to make the complaint for you.
- Guardianship frustrates people because they cannot make their own

choices.

Guardianship VS Supported Decision-Making: An Illustration

DIFFERENCE BETWEEN GUARDIANSHIP SUPPORTED DECISION MAKING





Illustration by Pip Malone

Abuse can happen under guardianship.

- For example, a guardian might:
 - Refuse to let you spend time with friends or family
 - Force you into an institution or group home
 - Make healthcare choices you do not want
 - Steal or misuse money (this is illegal!)
 - Take away your right to marry or have children
 - People under guardianship cannot always protect themselves from what the guardian might do.
 - They may not know the situation they are in.
- Guardians can spend a person's money without telling them.
- Sometimes guardians have made health care decisions without telling the person under guardianship.

Guardians can make choices about a person without getting to know them.

- This is especially common if the guardian is the government itself or is a stranger appointed by the court.
- They may make the same choices for many people with disabilities under guardianship, even though those people all want different things.
- Even if the guardian knows the person very well, that guardian still has the power to do anything they want with that person's life without talking to the person at all.

Sometimes guardians can commit neglect.

- In this situation, the person with a disability cannot legally make decisions for himself or herself, but also cannot get the guardian to act on his or her behalf.
- As a result, the person may not be able to spend money to buy food or pay rent, and may face serious problems as a result.
- People with disabilities should have the right to make their own choices, rather than having someone else making choices for them.

Convention on the Rights of Persons with Disabilities

The Convention on the Rights of Persons with Disabilities (CRPD) is an agreement by many countries to respect the rights of people with disabilities.

- The word "convention" here means "treaty" or "agreement," not "conference."
- "Persons" is another word for "people."
- The CRPD includes:
 - the right to make choices.
- The CRPD also includes:
 - freedom from discrimination or violence,
 - the right to have a family,
 - the right to live and work in the community,
 - and the right to accessible roads, schools, information, housing, and other resources.

Article 12 of the CRPD says that:

- 1. Judges and courts must recognize people with disabilities as people.
- 2. Governments must recognize people with disabilities as people.
 - People with disabilities can make decisions for themselves.
- 3. People with disabilities need some help or supports. Governments must make sure that support is available.
- 4. Governments must protect people with disabilities from abuse.
 - Governments cannot give authority to someone who might abuse their power.
 - Governments need to respect a person's decisions.

5. Governments need to make sure that people with disabilities have the same right to:

- own money or property
- inherit money or property from their relatives
- and do all the same things with their money that people without disabilities can do.

For example, take out loans or use credit cards.

• People with disabilities should not have their money or property taken away from them for no reason.

Almost every country in the world has signed the CRPD.

- Almost every country in the world has signed the CRPD, and most countries have "ratified" it.
 - "Ratifying" something means that the country now has to follow the rules that are in the CRPD.
- Some countries have **signed** the CRPD but have not "**ratified**" it, which means that they agree with the idea of respecting the rights of people with disabilities but don't have to follow its rules.
- The names of the countries on the CRPD are here: <u>http://www.un.org/</u> <u>disabilities/countries.asp?navid=17&pid=166</u>
- Many of the countries that signed the CRPD have guardianship laws.

Many countries' guardianship laws break the CRPD, because they allow the court to take away the rights of people who could make their own decisions if they had the right supports.

- Some countries have already started trying to change their guardianship laws to respect people's rights under the CRPD.
- In other countries, people with disabilities have sued in court, saying that under the CRPD, they have the right to be free from guardianship.

The CRPD: An Illustration



Illustration by Pip Malone

Guardianship and Supported Decision-Making Laws

- All countries make their own laws.
 - In the United States and Canada, guardianship and supported decision-making laws vary by state or province.
 - Other countries have different laws.
 - Countries can have different types of laws about guardianship and supported decision-making.

Guardianship laws allow other people to make life choices for a person with a disability.

Supported decision-making laws allow people with disabilities to make their own choices with support.

- Some countries have **more specific laws** that allow people with disabilities to make some choices but not others, which will be discussed individually in the country sections.
- Often, countries have a combination of these three things.

The United States of America

- All 50 States have laws about guardianship. Each state has different laws.
 - Massachusetts, for example, might have very different rules about how the court decides who needs a guardian than Alabama does.

Different states have different rules about:

- How the court supervises the guardian
- How easy or hard it is for somebody to get put under guardianship in that state
- How the court decides who needs a guardian

Because different states have different laws about guardianship, which state a person with a disability lives in can change their whole life.

- For example, a person may be put under guardianship because they lived in a state where it was very easy to put someone under guardianship.
- If the person lived in a different state, they might not have been put under guardianship.
- Instead, they would be able to keep making their own choices. If a person with a disability moves from Virginia to Maryland and is under guardianship, the guardianship might change or completely disappear simply because of the move to Maryland.

Most states have laws saying that guardianships should be limited to just the parts of life that the person needs support with.

- But despite these laws, most people in most states get put under full guardianships like the ones described earlier.
- They lose the ability to make decisions for themselves.

Disability advocates want supported decision-making laws.

• These laws reduce the number of people under guardianship.

Supported Decision-Making Laws in the United States

Texas and Delaware have laws for supported decision-making.

- Texas and Delaware are the only states where these laws exist.
- In Texas, courts have to think about supported decision-making options for you before they can assign you a guardian.
- Guardianship is the final option if supported decision-making doesn't work.
- In Texas, an adult with a disability signs a **supported decision making agreement**.
- The agreement is legal as long as the person with a disability understands the agreement.
- You sign the agreement in front of people or witnesses.

Reform in the United States

Even though Texas and Delaware are the only US states which have passed a supported decision-making law, advocates across the United States are trying to get supported decision-making laws passed in their home states.

- There have also been many conferences on supported decision-making where people could talk about these laws.
- Many disability rights and disability self-advocacy groups have said that supported decision-making should be used whenever possible instead of guardianship.

ASAN wrote model supported decision-making laws that let people sign special supported decision-making agreements for health care.

- "Model laws" are designs for a law. A model law is not an actual law. People use model laws for ideas.
- ASAN's model law lets the person with a disability make decisions, with help from a supporter. ASAN's model law only works in healthcare situations.
- It is easy to prove you understand the agreement under ASAN's model law: you just have to say you want a supporter.

The Constitution and the Americans with Disabilities Act make guardianship hard.

- Guardianship takes away rights guaranteed by both the Constitution and the Americans With Disabilities Act.
- The Constitution says that freedom is a right. Guardianship takes away freedom.
- People with disabilities could also use the Americans with Disabilities Act to challenge guardianships.

It is possible to challenge guardianships and win.

- Jenny Hatch, a 29-year-old woman with Down Syndrome, went to live with friends after she won in court.
 - She chose her friends as her supporters. She has choices now.
 - Advocates hope more courts follow this decision.

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Canada

Several Canadian provinces have supported decision-making laws.

- In British Columbia, for example, people with disabilities enter a **Representation Agreement**.
- You name people you trust (or group of people) who help with the decisions.
 - This person is called the Representative.
 - You can sign a representation agreement even if the court says you cannot sign a power of attorney.
- You have control over the decisions you make.

The Representative sometimes makes decisions for a person with a disability in some special cases.

- This can happen when the Representative doesn't have the chance to talk to the person with a disability before making a decision.
- The Representative also can sometimes go against the person with a disability's wishes if their wishes do not seem "reasonable."

In most Representation Agreements, there are some choices that the Representative can't make for the person with a disability, no matter what.

- These include:
 - refusing medical treatments that you need to live,
 - abortion,
 - restraint,
 - experimental medical treatments,
 - forcing you to take medications,
 - using pain or unpleasant things to try and change the person's behavior,
 - making parenting decisions for a person with a disability who has children,
 - or buying or selling the person with a disability's house.

A Representation Agreement with Broader Powers lets the Representative make more decisions.

- But even in that case, a Representative can't consent to things like:
 - taking away the ability to have children (unless it's medically necessary)
 - or suicide with medical help.
- If a person with a disability signs a Representation Agreement, they have **legal capacity**.
 - **Legal capacity** means you can make decisions without your Representative.
- A person with a disability can stop or change a Representation Agreement any time.

Even without a Representation Agreement, you can get some kinds of help from your friends and family.

- They can remind you to do things you have to do, help you understand your choices, and come with you to the bank or doctor's office.
- Without a Representation Agreement, they cannot always do things like talk to your bank or your doctor when you can't talk to them yourself.
- Some Representation Agreements allow a Representative control over money.
- Special steps make sure the person with the disability is not taken advantage of:
 - You name a spouse as your Representative;
 - You name a group who serves as Representatives. The group must all agree before it can spend your money.
 - You name a **monitor**. The monitor make sure the representatives follow your wishes.

Anyone can report the representative for abuse and neglect. The government investigates.

- Yukon and Saskatchewan have similar Representation Agreement laws.
 - Only British Columbia's law allows people with significant disabilities to sign Representation Agreements.

In Canada, you can sign an Enduring Power of Attorney.

- An Enduring Power of Attorney is like a durable power of attorney in the United States.
- It is like a Representation Agreement, but not everyone can sign it.

A notary public puts a stamp on an Enduring Power Of Attorney. A notary republic makes a document legal.

- The notary public may choose not to make the document legal if the notary public believes you did not understand the document.
- Also, if another person believes you did not understand the document and complains to the court, and the court agrees, the court cancels the Enduring Power of Attorney.

Finally, Canada also has a guardianship system. A court appoints a guardian for you.

Sweden

Sweden has a supported decision-making law that is very different from Canada's.

- You must ask the court for a supporter in Sweden. The court appoints a legal mentor or administrator.
- No guardianship system exists in Sweden.

A legal mentor helps the person with a disability make decisions.

- The legal mentor can be a friend, family member, professional supporter, or even a community member such as a teacher or social worker.
- The legal mentor gives advice.
- If the person with a disability wants, the legal mentor manages money.
- If the person with a disability is ill, the legal mentor acts without approval.
- People with disabilities make decisions with the legal mentors, with or without help.
- The person with a disability can also cancel the legal mentorship at any time.

The court can also appoint an administrator, who acts more like a guardian.

- This only happens when appointing a legal mentor would not be enough to help the person make decisions.
- An administrator can make decisions for a person with a disability ithout first asking for the person's approval.
- The administrator can also undo decisions that a person with a disability made, if the administrator thinks they seemed wrong.
 - For example, if a person with a disability buys a car that the administrator thinks that the person cannot afford, the administrator can take the car back to the seller.
 - They can get the person's money back even if this means the seller will lose money.
- The person with a disability still has some decision-making rights, such as the right to vote.

Sweden also has programs to give people professional help to make decisions.

- For example, instead of choosing a person like a friend or family member, a person with a disability can get a professional supporter called a **Personal Ombudsman** from an agency.
- They do not have to go to court to get the Personal Ombudsman.
- The Personal Ombudsman (PO) spends a lot of time reaching out to and meeting with the disabled person.
- The PO cannot make any decisions for the person with a disability but can help the disabled person make his or her own choices.

Personal Ombudsmen work with people who have psychiatric disabilities, not intellectual or developmental disabilities.

- People with intellectual or developmental disabilities hire a personal assistant who helps with decisions and daily living.
 - The government pays for the assistant.

United Kingdom (England, Scotland, Wales, & N. Ireland)

- Guardianship and supported decision-making in England and Wales are now both governed by the same important law: **The Mental Capacity Act of 2005.**
- The United Kingdom is made up of England, Scotland, Wales, and Northern Ireland.
- The Mental Capacity Act of 2005 only is law in England and Wales. Northern Ireland and Scotland have different laws.

The Mental Capacity Act has a few important rules to follow.

- These rules are:
 - Assume a person with a disability makes their own decision unless proven otherwise.
 - The court must try supported decision-making before guardianship.
 - Bad decisions are not a reason for guardianship.
 - If people can't find any way for someone with a disability to communicate what choice they want to make or make a decision, all decisions made for the person must be in that person's "best interests."
 - Even a decision made in the best interest of a person with a disability must protect them and accomplish their goals.
 - This protection cannot restrict a person with a disability.

No guardianship under the Mental Capacity Act can take away your right to:

- Marry whoever you want
- Have relationships and friends
- Place a child up for adoption
- Vote
- People with disabilities who need support have options under The Mental Capacity Act.
- These options range from supported decision-making options to guardianship options.

Deputies

Deputies are the British term for guardians.

- A court appoints a deputy.
- The court appoints a deputy when the court thinks you cannot make decisions.
- A person must apply to the Court of Protection to be a deputy.
- The Office of the Public Guardian oversees deputies.
- The court order lists what the deputy is in charge of.
- The deputy must act in the best interests of the person with a disability.

A deputy must keep five things in mind with any decision.

- 1. Do not make assumptions about the person with a disability.
- 2. The deputy must wait to make a non-urgent decision if there is a chance the person with a disability will be able to decide for themselves later on.
- 3. The deputy must wait on any noncritical decision if there is a chance the person with a disability gets to make decisions themselves again.
- 4. The deputy must involve the person with a disability as much as possible in decisions.
- 5. Deputies cannot stop life-saving medical treatment.

Lasting Power of Attorney and Advance Decisions

In England when you create a power of attorney, you can create two types:

- an ordinary power of attorney and
- a Lasting Power of Attorney (LPA).
- An ordinary power of attorney gives someone the same kinds of powers as a normal power of attorney in the United States.

A Lasting Power of Attorney gives someone the power to make decisions for another person who is no longer able to make decisions for themselves.

• It is like a durable power of attorney in the United States or an enduring power of attorney in Canada.

Lasting Powers of Attorney grant a person (called the attorney, even if they are not a licensed attorney) the right to make one of two specific types of decisions on behalf of another.

- One type of decision is health care and welfare.
- The other type of decision is about property and financial decisions.
- These two types can't be combined.
- If someone wants to give another person the ability to make decisions about both health care and money, they would have to sign two different forms.
- Lasting powers of attorney can be **created** at any time when the person granting another power over their life is seen as having the ability to make their own decisions.
- The lasting power of attorney only **takes effect** when the person loses this ability.
- A lasting power of attorney could be used as a plan for how to make decisions in case of a future illness or disability.
- It can also be a way to appoint a supporter for times when you have more support needs than usual.

Advance statements say what you want in the future.

- Advance statements cover any subject.
- Advance statements are **not** legal documents.

An advance decision is like an advance statement, but specifically covers unwanted medical treatment.

- Unlike an advance statement, it is a legal document.
- It only works if it is signed when the person is seen as having the ability to make decisions.

- A doctor in England absolutely has to do what the **advance decision** says.
 - For example, an **advance statement** could say that the person with a disability doesn't want to go to a certain hospital but the person's doctors **don't have to listen.** They could still take the person to that hospital.
 - If an **advance decision** said that the person didn't want to go to that hospital, the doctors would have to not let that person go to that hospital no matter what.
 - This means that people have to think very carefully before signing an advance decision.

Independent Mental Capacity Advocates (IMCAs)

There are not many ways to use supported decision-making in the United Kingdom (U.K.).

- It is assumed that a family member or friend is your guardian, or that they can help you make decisions.
- England and Wales are part of the U.K. Some people in England or Wales do not have any family or friends that can help them. People in England or Wales may be able to get an Independent Mental Capacity Advocate, or IMCA.
- You cannot get an IMCA if you've been placed in a mental hospital under a law called the Mental Health Act of 1983.

British courts can decide that some people can't make important decisions on their own. IMCAs help these people.

- IMCAs can only help with health care, abuse and neglect, or when the person is changing where they live.
- The IMCAs know how to talk to people who have trouble communicating.
- The IMCA finds out from the person what they want and tells other people what they want.
 - For example, the IMCA tells the doctor what treatment the person wants.
- If the IMCA can't find out what the person wants, the IMCA makes a guess.
- The IMCA does not make the final decision. Whoever called the IMCA makes the final decision. This person is called the decision-maker.

- Sometimes an important decision has to be made. If there are no friends or family to help, the decision-maker **has** to give you an IMCA.
- The decision maker is chosen by the NHS or the local government. The NHS is the U.K. agency that does health care. Sometimes a doctor is the decision-maker.
- The IMCA can challenge the final decision if it is not what you want.
- They can also argue that you are able to make decisions, even if the British court said you can't.



Guardianship in Bulgaria

Guardianship in Bulgaria limits choices even more than guardianship does in other countries.

• Very few laws on guardianship exist in Bulgaria. The ones that do exist take most choices away from people with disabilities.

Advocates think guardianship in Bulgaria is outdated, used too much, and based on stereotypes about people with disabilities.

- About 7,000 people with disabilities are under guardianship in Bulgaria.
- Most of these are the "full" guardianships we explained earlier.
- There are "partial" guardianships in Bulgaria, but even these take away many rights.
- People under full or partial guardianships in Bulgaria can't sign a contract with someone else without help of the guardian.
- People under guardianship in Bulgaria don't have control over their property or where they live, either.

Bulgarian guardianship law grants the guardian the power to control the person under guardianship's property and the power to decide where the person under guardianship lives.

- The person cannot even complain to the court if they think they shouldn't have a guardian.
- Only their guardian can go to court to complain if the person is not getting any or enough services.
- This is a serious problem because sometimes the person's guardian does not want the same things the person wants.
- For example, if guardian takes a person's money away or puts them in an institution, the person can't go to court and complain unless the guardian agrees to let them go to court.

The European Court of Human Rights says Bulgaria's guardianship laws are illegal.

- The European Court on Human Rights hears cases inside the European Union.
- Bulgaria is a member of the European Union.
- Bulgaria must listen to the European Court on Human Rights.

In *Stankov v. Bulgaria* and *Stanev v. Bulgaria*, the European Court of Human Rights listened to complaints by people with disabilities who had been put into institutions by their guardians.

- The guardians had not asked them where they wanted to live.
- In Stanev's case, he had never even met his guardian.
- The conditions in the institutions were also very bad.

The European Court of Human Rights said that this violated European Convention on Human Rights.

- It was illegal because the people with disabilities had no way of arguing they shouldn't be institutionalized if that was what the guardian wanted.
- To obey these court decisions, Bulgaria will have to change its guardianship laws.

Supported Decision-Making in Bulgaria

- Right now, there are very few options in Bulgaria for people with disabilities who want to live independently but with supports.
- A national program called Assistants to People with Disabilities was created in 2003.
 - This program hires previously unemployed people and teaches them to support people with disabilities.
 - A program called **Help at Home** helps pay assistants or family members of people with disabilities to give people supports.

However, some advocates have said that these assistants sometimes don't have enough knowledge and experience about the needs of people with disabilities.

Reform Efforts in Bulgaria

Advocates in Bulgaria really want to make guardianship laws there better.

- Advocates created a supported decision-making model in Bulgaria.
- They're also trying to get laws passed that create supported decisionmaking for people with disabilities there.

The Minister of Justice wants to bring Bulgaria's laws in line with the CRPD.

- In Bulgaria, The Minister of Justice deals with human rights issues.
- The Minister of Justice wants supported decision-making.
- Progress is slow.

Reform Efforts in Bulgaria: An Illustration

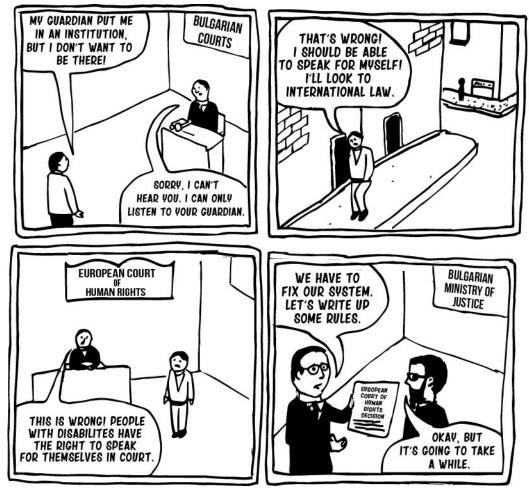


Illustration by Pip Malone

Israel

Guardianship

- Guardians in Israel are called *apotropos*, which is a legal term there.
- Originally, Israel made guardianship for the elderly.
- Now, Israel uses guardianship a lot.
 - In Israel, 50,000 people are under guardianship.
 - Guardians in Israel are always appointed by the courts.
 - They are often family members.

Guardianships in Israel are fairly similar to guardianships in other countries, in that the person with a disability loses power over their own decisions and daily life.

- The guardian gets the right to make those decisions.
- There is one interesting exception. In Israel, it is possible to be put under guardianship while still keeping the theoretical, legal ability to make your own decisions as well.
- This happens when a court appoints a guardian but does not specifically say that the person with a disability is "legally incompetent."

In this case, the person under guardianship can still make decisions about health care and money or sign contracts without telling the guardian, but the guardian in practice still controls the person's life.

• The guardian still does control the major choices that need to be made by the person with a disability because if people know you have a guardian, they probably won't ask for your opinion in Israel.

If the court says you cannot make choices, you can argue against guardianship in court.

Supported Decision-Making

- Israel just started to use supported decision-making.
- The first person in Israel moved from guardianship to supported decisionmaking two years ago.

Advocates want Israel's guardianship laws in line with the CRPD.

- **Bizchut** is a disability rights organization that helps with supported decision-making.
- Right now, 22 people with disabilities use supported decision-making.

Israel Unlimited gives people with disabilities a care coordinator and a mentor.

- The care coordinator and mentor help make decisions.
- The care coordinator and mentor also help the person with an independent living skills.

Israel agreed to the CRPD.

- This means that it should let people use supported decision-making instead of guardianship.
- But there is still no official government program to promote supported decision-making.

Other Guardianship Alternatives

- People in Israel can sign documents to name supporters.
- They can use a **power of attorney** to get support with health care and money.
- Powers of attorney in Israel are like powers of attorney in the US, Canada, or the UK.

A psychiatric advance directive says what mental health treatment you want if you have a mental health crisis.

• It is not a legal document. Doctors do not have to follow it.

- Some people who own property like a house worry that they will make a bad decision and sell the house.
- People can prevent this using something called a **caveat**.
 - A caveat prevents you from making certain kinds of decisions about land without the court's approval.
 - The caveat *can* also prevent a guardian or supporter from selling land without court approval too, although usually it isn't used like that.

A person can also name a trustee over his or her land, money, and other property.

- The person with a disability can put a bank account or land into a "**trust**." The **trustee** is the person who takes care of the **trust**.
- The trustee is like a power of attorney but can only make decisions about money or property in the trust.

The trust can have rules about what the trustee can or can't do.

- For example, the trustee may not be able to sell the land.
- For a bank account, the trustee may be allowed to spend only a certain amount every month.
- The person with a disability can put only some of their property in the trust.
- For example, they may put their house in a trust but keep control over their bank account.

Glossary

Advance decision (UK)

 An advance decision is like an advance directive, but specifically covers unwanted medical treatment. Unlike an advance directive, it is a legal document. It only works if it is signed when the person is seen as having the ability to make decisions. A doctor in England absolutely has to do what the advance decision says.

Advance directive

• A kind of form you can sign. Also called an Advance Statement in England. It tells people what you want if you become unable to make decisions or to tell them what you want. It is usually used to show the doctors what kind of health care you want, or what kind you don't want. An advance directive is usually not legally binding. This means that doctors don't always have to listen to what it says.

Advance statement

• see Advance directive

Apotropos (Israel)

• The word for guardians in Israel.

Assistants to People with Disabilities (Bulgaria)

• This program hires previously unemployed people and teaches them to support people with disabilities.

Bizchut (Israel)

• A disability rights organization that helps with supported decicion-making.

Caveat (Israel)

• A caveat in a legally-binding document can prevent a guardian from making certain kinds of decisions about land.

Convention on the Rights of Persons with Disabilities (CRPD)

• An agreement among countries about the rights of people with disabilities. It is an international law. Article 12 protects people's right to make decisions about their own lives. Most countries have agreed to follow the CRPD, but not all. Many countries that agreed to follow it are still not fully protecting the decision-making rights in Article 12. Those countries that have agreed to follow the CRPD, but are not following Article 12, may risk being taken to court. "Persons" is another word for "people."

Court of Protection (UK)

 A special kind of court in England. It can decide what kind of help a person needs to make decisions. It can appoint a deputy for a person with a disability.

Deputy

• The word for guardians in England.

Durable Power of Attorney

 A power of attorney that keeps working if you become unable to make decisions without help. Sometimes this kind of power of attorney only starts working if you become unable to make decisions without help. Usually, doctors have to say that you can't make decisions. Once you're seen as unable to make decisions, you may not be allowed to cancel the power of attorney.

Enduring Power of Attorney (Canada)

• see Durable Power of Attorney

European Court on Human Rights

• The European Court on Human Rights hears cases from countries that are inside the European Union.

Full Guardianship

 Guardianship where the guardian makes decisions involving every, or almost every, part of a person's life – including health care, money, where a person lives, and what a person does during the day.

Guardianship

 An arrangement where someone is appointed by law to make decisions about another person's life. In many countries, guardians will be appointed for disabled adults who are seen as unable to make their own decisions. Guardianship could be a Full Guardianship or a Limited Guardianship.

Help at Home (Bulgaria)

• This program helps pay assistants or family members of people with disabilities to give people supports.

Independent Mental Capacity Advocates (IMCAs) (UK)

 ICMAs are people paid to help the person who has trouble making important decisions on their own, like their future health care plans or their finances. The IMCAs receive training to help them communicate with the person they support and find out what that person wants to do.

Israel Unlimited (Israel)

• An organization that gives people with disabilities a care coordinator and a mentor. The care coordinator and mentor help the person with disabilities with independent living skills.

Lasting Power of Attorney (UK)

• see Durable Power of Attorney

Limited Guardianship

• Guardianship where the guardian makes decisions about some parts of a person's life, such as money and healthcare, but not others.

Legal capacity

 A person's ability to have their decisions recognized legally. This can include whether a person can sign a contract, set up a bank account, sue in court, or make a decision about health care. If a person does not have legal capacity, then a banker or a doctor would not be allowed to follow the person's decision alone. They would need permission from a guardian or family member. Different countries or states might have different rules about who has legal capacity and who does not.

Legal mentor

• The Swedish equivalent of a supporter. The mentor has some ability to make decisions for a person. The person with a disability can fire the mentor at any time. The mentor can make decisions for the person with a disability that person becomes unable to say what they want.

Mental Capacity Act of 2005 (UK)

 This law governs both guardianship and supported decision-making in England and Wales. The Mental Capacity Act has important rules to follow about when guardians can be assigned and what guardians can and cannot do.

Model Legislation

An idea for how a law could work. It is written to look like a real law.
 Lawmakers can use it as a model for laws to pass. It does not become a real law unless lawmakers vote to make it a law.

Notary or Notary Public

This word means different things in different countries. In many countries, notaries are people who have special stamps or seals. Sometimes they are also lawyers. A notary might need to put the stamp or seal on a power of attorney or health care proxy. The stamp or seal means that the notary is sure that the people signing the document are who they say they are. The notary may also make sure the person signing the document knows what they are signing. In some places, a power of attorney or health care proxy won't work unless a notary puts a stamp or seal on them.

Ordinary Power of Attorney

• A power of attorney that stops working if you become unable to make decisions without help. Also called Normal Power of Attorney.

Personal assistant or Personal Ombudsman

 A Swedish type of supporter. A person can get one from an agency. Usually a personal ombudsman works with people with psychiatric disabilities. A personal assistant works with people who have intellectual or developmental disabilities.

Psychiatric Advance Directive (Israel)

• An advance directive about mental health. For example, it can say that you don't want a certain medication. It is not a legal document. Doctors do not have to follow it.

Ratification

- This is what happens when a country agrees to follow the rules of an agreement or treaty created by multiple countries. If a country ratifies an agreement, they can be called into court if they break the rules of the agreement.
- Countries that agree with the treaty or agreement but don't want to follow the rules have not ratified it. They can't get called into court over it.

Representation Agreement (Canada)

- A kind of supported decision making agreement in British Columbia, Canada. It allows people with disabilities to name a Representative. The Representative helps make decisions. The person with a disability usually keeps the ability to make their own decisions.
- Sometimes a Representative may make decisions for the person with a disability. This can happen if the person with a disability can't make the decision for some reason. It could also happen if the Representative thinks the person with a disability is being "unreasonable."

Representation Agreement with Broader Powers (Canada)

 A special Representation Agreement. It gives a Representative the ability to do things that they normally could not. For example, the Representative could help make decisions about buying or selling a person's house. A person with a disability can't sign a Representation Agreement with Broader Powers if the court thinks they do not completely understand it.

Supported Decision-Making

 A way to make decisions. A person with a disability chooses someone to help them understand or communicate a decision. The person with a disability is free to make their own decision but has help from the supporter.

Supported Decision-Making Agreement

 An agreement that a person can make with a supporter. The supporter helps the person make decisions. The supporter usually can't make decisions for the person with a disability. In some places, an agreement just needs to be signed by the person with a disability and the supporter. In other places, they also need to be stamped by a Notary. In some places, they may even need to be approved by a court.

Trust

• A trust is a legal arrangement that lets someone else manage money or property. The manager, or trustee, has to follow special rules that you set. For example, there might be a rule that you get a certain amount of money each month. Or there can be a rule that the money can be spent for certain things. The trustee can only manage the money or property that's been put into the trust.

Trustee

• A trustee is someone who manages money or property that's in a trust. A trustee could be a person you know. Or it could be a bank or a lawyer. A trust can have more than one trustee.

No. You are not making the choices. You are helping this person make his or her own choices.

You will be asked to sign a document agreeing to support the person to the best of your ability and in good faith. This does not create legal liability for any choices the person makes.

Just like anyone else, you remain responsible for your *own* illegal acts, including fraud, abuse, or exploitation.

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Do I have to be a supporter forever?

No. You can stop at any time. But you should only agree to be a supporter if you expect to be able to support this person for at least a year. It takes a while to get into the swing of supported decision-making, so you want to have enough time to learn about it and really try it out. Where Can I Learn More About Supported Decision-Making?



ACLU Disability Rights Program

www.aclu.org/issues/disabilityrights/supported-decision-making

> 415-343-0781 smizner@aclu.org

> > જ જ જ

National Resource Center for Supported Decision-Making

www.supporteddecisionmaking.org

What is Supported Decision-Making and What Does a Supporter Do?

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A Guide To Supporting a Person With a Disability Using Supported Decision-Making



I've been asked to be a "supporter" in a "supported decision-making agreement." What does this mean?

Supported Decision-Making is a way for people with disabilities to get help in making their own choices. Unlike in conservatorship or guardianship, the person with a disability is still the ultimate decider. The person with a disability selects trusted family, friends, or staff to serve as supporters.

You have a choice about whether or not to be a supporter. You were asked to do this because the person with a disability trusts you and wants your help. But if you don't have time or don't want to be a supporter, you should say no.

If you do choose to be a supporter, you should talk with the person with a disability to learn more about what kind of support they want. They might want you to help in only some areas but not others. There are many kinds of support to help the person understand, make, and communicate choices.

You will probably be part of a team of supporters. You should ask the person with a disability who else is supporting them, and ask if you can meet the other supporters.

What does a supporter do?

Help, support, and advise the person with a disability. There are many ways that you might support a person.

Some examples of support are:

Information

- Providing **accessible information**, including plain language materials or spoken explanations
- Researching available choices
- Explaining and brainstorming options
- Classes to help the person learn about healthy decision-making and self-advocacy

Reminders and Logistics

- **Reminders** of important dates, appointments, and schedules
- Organizing visits and meetings to try out different options
- Attending appointments or meetings with the person with disabilities
- Arranging transportation for appointments

Advice

- Help in making lists of pros and cons
- Advising the person about her choice
- Reminding the person with disabilities about her values and preferences, and discussing how these values connect with the choices

Communication

- Making sure the person has **plenty of time** to think and talk about her choices
- Helping the person communicate her choice, making sure the choice is understood, recognized, and respected

The supporter is <u>not</u> making choices for the person with a disability, even if you think the person isn't making the best choice. People learn by making bad choices. They are safer and more protected if they can make their own choices. It is important to respect this.

If you think you would want to substitute your judgment, you should not be a supporter.

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Is this the same as becoming a guardian or conservator?

No. Only a judge can appoint a guardian or conservator, and the guardian or conservator makes choices <u>for</u> a person with a disability.

Being a supporter means helping the person with a disability understand, make, and communicate <u>his or her own</u> choices.