# Supported Decision Making Appendix

#### TITLE 16

### **Health and Safety**

#### Individuals with Disabilities

#### CHAPTER 94A. SUPPORTED DECISION-MAKING

#### § 9401A Short title.

This chapter may be cited as the "Supported Decision-Making Act." 80 Del. Laws, c. 427, § 1.;

#### § 9402A Purpose; interpretation.

- (a) The purpose of this chapter is to do all of the following:
  - (1) Provide assistance in gathering and assessing information, making informed decisions, and communicating decisions to adults who do not need a guardian or other substitute decision maker for such activities, but who would benefit from decision-making assistance.
  - (2) Give supporters legal status to be with the adult and participate in discussions with others when the adult is making decisions or attempting to obtain information.
  - (3) Enable supporters to assist in making and communicating decisions for the adult but not substitute as the decision maker for that adult.
- (b) This chapter is to be administered and interpreted in accordance with all of the following principles:
  - (1) All adults should be able to live in the manner they wish and to accept or refuse support, assistance, or protection as long as they do not harm others and are capable of making decisions about those matters.
  - (2) All adults should be able to be informed about and, to the best of their ability, participate in the management of their affairs.
  - (3) All adults should receive the most effective yet least restrictive and intrusive form of support, assistance, or protection when they are unable to care for themselves or manage their affairs alone.
  - (4) The values, beliefs, wishes, cultural norms, and traditions that an adult holds should be respected in managing an adult's affairs.

80 Del. Laws, c. 427, § 1.;

#### § 9403A Definitions.

For the purposes of this chapter:

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

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

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

#### § 9404A Presumption of capability.

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

80 Del. Laws, c. 427, § 1.;

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

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

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

80 Del. Laws, c. 427, § 1.;

#### § 9406A Supporters.

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

may do all of the following:

- (1) Assist the principal in understanding information, options, responsibilities, and consequences of the principal's life decisions, including those decisions relating to the principal's affairs or support services.
- (2) Help the principal access, obtain, and understand any information that is relevant to any given life decision, including medical, psychological, financial, or educational decisions, or any treatment records or records necessary to manage the principal's affairs or support services.
- (3) Assist the principal in finding, obtaining, making appointments for, and implementing the principal's support services or plans for support services.
- (4) Help the principal monitor information about the principal's affairs or support services, including keeping track of future necessary or recommended services.
- (5) Ascertain the wishes and decisions of the principal, assist in communicating those wishes and decisions to other persons, and advocate to ensure that the wishes and decisions of the principal are implemented.
- (b) Except as permitted by regulation promulgated under § 9410A of this title, any of the following are disqualified from acting as a supporter:
  - (1) A person who is an employer or employee of the principal, unless the person is an immediate family member of the principal.
  - (2) A person directly providing paid support services to the principal, with the exception of supported decision-making services, unless the person is an immediate family member of the principal.
  - (3) An individual against whom the principal has obtained an order of protection from abuse or an individual who is the subject of a civil or criminal order prohibiting contact with the principal.
- (c) A supporter is prohibited from doing any of the following:
  - (1) Exerting undue influence upon, or making decisions on behalf of, the principal.
  - (2) Obtaining, without the consent of the principal, information that is not reasonably related to matters with which the supporter is authorized to assist under the supported decision-making agreement.
  - (3) Using, without the consent of the principal, information acquired for a purpose other than assisting the principal to make a decision under the supported decision-making agreement.
- (d) A supporter shall act with the care, competence, and diligence ordinarily exercised by individuals in similar circumstances, with due regard either to the possession of, or lack of, special skills or expertise.

80 Del. Laws, c. 427, § 1.;

#### § 9407A Recognition of supporters.

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

80 Del. Laws, c. 427, § 1.;

#### § 9408A Limitation of liability.

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

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

80 Del. Laws, c. 427, § 1.;

#### § 9409A Access to information.

- (a) A supporter may assist the principal with obtaining any information to which the principal is entitled, including, with a signed and dated specific consent, protected health information under the Health Insurance Portability and Accountability Act of 1996 (P.L. 104-191) or educational records under the Family Educational Rights and Privacy Act of 1974 (20 U.S.C. § 1232g).
- (b) The supporter shall ensure all information collected on behalf of the principal under this section is kept privileged and confidential, as applicable; is not subject to unauthorized access, use, or disclosure; and is properly disposed of when appropriate.

80 Del. Laws, c. 427, § 1.;

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

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

80 Del. Laws, c. 427, § 1.;

#### SUPPORTED DECISION-MAKING AGREEMENT

#### Delaware Code Title 16, Chapter 94A, Section 9401A

This form is to be read aloud or otherwise communicated, in the presence of the witnesses and parties to the agreement. The form of communication shall be appropriate to the needs of the individual with the disability, that individual's language (an interpreter must be present for foreign languages and alternative forms of communication) and sensory processing wants or needs.

This form is to be used for the appointment of a person(s) to help me make decisions. A Supported Decision-Making Agreement is a written agreement between me and my appointed person(s). The person(s) I appoint helps me make decisions. My appointed person(s) does not make decisions for me. A Supported Decision-Making Agreement is effective if I am at least 18 years of age and able to understand the nature and effect of this agreement. I can revoke this agreement at any time and with notice to the appointed Supported Decision-Maker(s). This agreement takes effect as soon as it is signed by all the required individuals. This agreement supersedes any other Supported Decision-Making Agreement made by me. This agreement is not durable and would not survive a determination of incapacity under Delaware Code.

This is the Supported Decision-Making Agreement of:

Name		Date of Birth	
Phone			
2. My Supported	l Decision-Maker		
	person(s) to be my Supporte	ed Decision-Maker(s):	
Supported Decision-M		(8).	
Name			
		(cell)	
out this section.  If my Supported Decis	ion-Maker named above de	Optional) – if there is no Alternate, please of eclines to help me or is unable or unavailable to wing person to help me as my Supported Dec	o help
Maker:			ASTOIL
Maker:			ision
Maker: Name			
Maker: NameAddress		(cell)	

1.

4. Areas I Want My Supported Decision-Maker to Help Me			
I want my Supported Decision-Maker(s) to help me make decisions in the following areas:			
a) Health Affairsinitials			
Access or obtain any information that will help me make decisions. Help me make appointments			
with health care providers. Help me keep track of information about my health care in a life with health care providers.			
with health care providers. Help me keep track of information about my health care, including my medic			
records and help me with creating my health care plan and activities of daily living. Help me understand			
information about health care decisions I have to make, now or in the future, so that I can make my own			
decisions about my health care. Communicate or assist me in communicating my decision to other persons.			
My Supporter may see my private health information under the Health Insurance Portability and			
Accountability Act of 1996, and I will provide a signed release.			
Add any additional information:			
b) Supportive Services initials			
Defined as a coordinated system of social and others services supplied by private, state,			
institutional, or community providers designed to help maintain the independence of an adult.			
Communicate or assist me in communicating my decision to other persons. For more specifics see DE			
Code, Title 16, Ch. 94A. Access or obtain any information that will help me make decisions. My Supporter			
may see my educational records under the Family Education Rights and Privacy Act of 1974 (20 U.S.C.			
Section 1232g), and I will provide a signed release.			
Add any additional information:			
c) Financial Affairs initials			
Access or obtain any information that will help me make decisions. Help me obtain information			
and understand information about financial affairs, including but not limited to assets and resources and			
their use and management for my clothing, support, care, comfort, education, health care and shelter.			
Communicate or assist me in communicating my decision to other persons.			
Add any additional information:			
5. Areas I DO NOT Want My Supported Decision-Maker(s) To Help Me (if any)			
supported 2 constant intended (in any)			
I do not want my Supported Decision-Maker(s) to help me in making these kinds of decisions:			
Page 2 of 4			

Adult		
I am at least 18 years of age ar	nd I understand the nature and effect of this agre	eement.
Print Name	Signature	Date
Supported Decision-Make	r #1	
Print Name	Signature	Date
Alternate Supported Decisi section.	on-Maker (optional) - <u>if there is no Alterna</u>	te, please cross out this
Print Name	Signature	Date
Two adults must witness my sit together in my presence. The also CANNOT be an employed be a spouse, child or parent of	ignature and the signature(s) of my Supported I witnesses CANNOT be a Supported Decision-N e or an agent of the Supported Decision-Maker. the Supported Decision-Maker or an employee	Maker of the adult. They As well, they CANNOT
together in my presence. The also CANNOT be an employed	witnesses CANNOT be a Supported Decision-Ne or an agent of the Supported Decision-Maker.	Maker of the adult. They As well, they CANNOT
Two adults must witness my sit together in my presence. The also CANNOT be an employed be a spouse, child or parent of Maker.	witnesses CANNOT be a Supported Decision-Ne or an agent of the Supported Decision-Maker. the Supported Decision-Maker or an employee	Maker of the adult. They As well, they CANNOT of the Supported Decision-
Two adults must witness my sit together in my presence. The salso CANNOT be an employed be a spouse, child or parent of Maker.  Print Name  Print Name  Concerns about adults who me	witnesses CANNOT be a Supported Decision-Maker. e or an agent of the Supported Decision-Maker. the Supported Decision-Maker or an employee  Witness Signature  Witness Signature  asy be in need of protective services should be	Maker of the adult. They As well, they CANNOT of the Supported Decision-  Date  Date
Two adults must witness my sit together in my presence. The salso CANNOT be an employed be a spouse, child or parent of Maker.  Print Name  Concerns about adults who maccordance with Title 31 chapt A person, who in good faith accordance who in good faith declines to the sale of the	witnesses CANNOT be a Supported Decision-Maker. e or an agent of the Supported Decision-Maker. the Supported Decision-Maker or an employee  Witness Signature  Witness Signature  asy be in need of protective services should be	Maker of the adult. They As well, they CANNOT of the Supported Decision-  Date  Date  De evaluated and reported in decision-making agreement, on-making agreement, is not

## SUPPORTED DECISION-MAKING AGREEMENT DECLARATION

am willing to act as a suppo-	rter.	
acknowledge the duties of a	supporter under DE Code Title 16, Chapter	94A.
Supported Decision-Make	er #1	
Print Name	Signature	Date
Alternate Supported Decis	ion-Maker (optional) <u>if there is no Alterr</u>	nate please cross out thi
	in there is no riteri	are, please cross out th
section.		

#### **ABA Materials**

These materials are provided to indicate the position of the American Bar Association on Supported Decision Making. They should not be construed as an endorsement of the Delaware Model, merely as the ABA position on Supported Decision Making. They were obtained from Westlaw and from the website for the American Bar Association.

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### ABA URGES SUPPORTED DECISION MAKING AS LESS-RESTRICTIVE ALTERNATIVE TO GUARDIANSHIP

On August 14, 2017, the American Bar Association's (ABA) House of Delegates adopted Resolution 113, urging state, territorial, and tribal legislatures to (1) amend their guardianship statutes to require that supported decision making be identified and fully considered as a less restrictive alternative, before guardianship is imposed, and (2) require that decision-making supports that would meet the individual's needs be identified and fully considered in proceedings for termination of guardianship and restoration of rights.

The Resolution further urges courts to consider (1) supported decision making as a less-restrictive alternative to guardianship and (2) decision making supports that would meet the individual's needs as grounds for termination of a guardianship and restoration of rights.

An individual's right to make decisions about his or her life is a fundamental value in American law. Sponsored by the ABA Commission on Disability Rights, the Commission on Law and Aging, and the Sections of Civil Rights and Social Justice (Disability Rights Committee), and Real Property, Trust and Estate Law, this Resolution continues and furthers the ABA's long-standing interest in, and commitment to, ensuring that guardianship is a "last resort," after other, less-restrictive options have been considered. The Resolution recognizes the newly denominated modality of supported decision making—in which people with disabilities make their own decisions with supports, rather than rely on a surrogate—and urges that it be explicitly included in guardianship statutes requiring consideration of less-restrictive alternatives.

Supported decision making is a process by which individuals with disabilities choose a trusted person or persons to support them in making their own decisions and exercising their legal capacity. Supporters can be friends, family, professionals, advocates, peers, community members, or any other trusted person. They may gather and present relevant information; help the person to understand and communicate the decision to third parties such as health care professionals and financial institutions; and/or assist in implementing the decision.

Notably, the Uniform Law Commission recently revised the uniform law relating to guardianship, the Uniform Guardianship, Conservatorship, and Other Protective Arrangements Act (UGCOPAA), and, in doing so, recognized supported decision-making as a less-restrictive alternative to guardianship.

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#### AMERICAN BAR ASSOCIATION

# COMMISSION ON DISABILITY RIGHTS SECTION OF CIVIL RIGHTS AND SOCIAL JUSTICE SECTION OF REAL PROPERTY, TRUST AND ESTATE LAW COMMISSION ON LAW AND AGING

#### REPORT TO THE HOUSE OF DELEGATES

#### RESOLUTION

1	RESOLVED, That the American Bar Association urges state, territorial, and tribal legislatures to
2	amend their guardianship statutes to require that supported decision-making be identified and
3	fully considered as a less restrictive alternative before guardianship is imposed; and urges courts
4	to consider supported decision-making as a less restrictive alternative to guardianship; and
5	g autuminip, and
6	FURTHER RESOLVED, That the American Bar Association urges state, territorial, and tribal
7	legislatures to amend their guardianship statutes to require that decision-making supports that
8	would meet the individual's needs be identified and fully considered in proceedings for
9	termination of guardianship and restoration of rights; and urges all courts to consider available
10	decision-making supports that would meet the individual's needs as grounds for termination of a
11	guardianship and restoration of rights.

#### REPORT

An individual's right to make decisions about his or her life is a fundamental value in American law. Guardianship is a legal means by which a court appoints a third party (guardian) to make some or all decisions on behalf of an adult whom the court finds is not able to make decisions for him or herself. While guardianship can be an important protective device, it results in loss of an individual's right to make life choices. Accordingly, because of the significant liberty and property interests at stake, less restrictive alternatives must be considered before a guardianship is imposed. Most state statutes have recognized this important concept.

This resolution does several things. First, it continues and furthers the American Bar Association's (ABA) long-standing interest in, and commitment to, ensuring that guardianship is a "last resort" after other, less restrictive options have been considered. Second, the resolution recognizes the newly denominated modality of supported decision-making-in which people make their own decisions with supports, rather than rely on a surrogate—and urges that it be explicitly included in guardianship statutes requiring consideration of less restrictive alternatives. Supported decision-making is a process by which individuals 1 choose a trusted person or persons to support them in making their own decisions and exercising their legal capacity. Supporters can be friends, family, professionals, advocates, peers, community members, or any other trusted person. They may gather and present relevant information; help the person to understand and weigh decisions, including potential risks, options, and likely outcomes and consequences; communicate the decision to third parties such as health care professionals and financial institutions; and/or assist in implementing the decision. Finally, the resolution further urges courts reviewing already existing guardianships to consider decision-making supports as appropriate grounds for terminating guardianship and restoring the rights of the person who was subject to the guardianship.

This report provides background on adult guardianship and the legal principle of the least restrictive alternative; examines the concept of supported decision-making; summarizes relevant ABA involvement and policy; and explains the need for this resolution.

#### Background

Guardianship<sup>2</sup> has been employed since Roman times to "protect" persons who are unable to manage their personal or financial affairs because of "incapacity" by removing their right to make decisions and giving legal power to another person, the guardian.<sup>3</sup> In the United States,

<sup>&</sup>lt;sup>1</sup> Individuals with psychosocial disabilities, intellectual and developmental disabilities, traumatic brain injury, and older individuals with cognitive limitations.

<sup>&</sup>lt;sup>2</sup> Terminology differs by state. Many states use the terms "guardianship of the person" and "guardianship of the estate" or "guardianship of property," while other states (and the Uniform Guardianship, Conservatorship, and Other Protective Arrangements Act [UGCOPAA]) use the term "guardianship" to refer to guardianship of the person and "conservatorship" to refer to financial matters. A few states do not use the term "guardianship" for adults, but use the term "conservatorship" exclusively for the person and for the estate of adults. In this report, the generic term "guardianship" refers to guardians of the person, as well as guardians of property or "conservators," unless otherwise indicated.

<sup>&</sup>lt;sup>3</sup> See, e.g., Kristin Booth Glen, Changing Paradigms: Mental Capacity, Legal Capacity, Guardianship and Beyond, 44 COLUM. HUM. RTS. L. REV. 93, 102-06 (2012).

guardianship is a matter of state law. Before a guardian may be appointed, an individual must be determined to lack the ability to meet essential requirements for physical health, safety, or self-care because he or she is unable to receive and evaluate information or make or communicate decisions, even with appropriate supportive services, technological assistance, or supported decision making and his or her identified needs cannot be met by less restrictive alternatives.<sup>4</sup>

In most jurisdictions, a single guardianship statute covers all incapacitated adults, regardless of the cause of their incapacity, which often is cognitive impairment due to aging. Six states—California, Connecticut, Idaho, Kentucky, Michigan, and New York—have a separate statute or provision that covers guardianship of persons with intellectual or developmental disabilities.<sup>5</sup>

Guardianships may be plenary (full), removing all decision-making rights from the person subject to guardianship, or limited, taking away decisions in those areas in which the person is found to lack capacity. Although virtually all statutes include a strong preference for limited guardianships, what empirical data exists suggests that the vast majority of guardians appointed are given total, or plenary power, to substitute their decisions for those of the persons under guardianship, often referred to as "wards" or "incapacitated persons."

Few states collect information on guardianship in ways that make it possible to make accurate statements about its prevalence. The National Center for State Courts estimated that, based on the average of active pending adult-guardianship cases in four states for 2008, the number of active cases in the United States is 1.5 million, but could range from less than 1 million to more than 3 million due to the variance between the states.<sup>7</sup> With the growing number of aging baby boomers,<sup>8</sup> that number is expected to increase significantly.

It is estimated that between seven and eight million Americans of all ages, or three percent of the general population, experience intellectual or developmental disabilities. According to a 2014-

<sup>&</sup>lt;sup>4</sup> Uniform Guardianship, Conservatorship, and Other Protective Arrangements Act (UGPPA) (2017) Art. 3, § 301(a)(1)(A) & (B)...

<sup>&</sup>lt;sup>5</sup> CAL. PROB. CODE § 1801(d); CONN. GEN. STAT. ANN. § 45a-669 et seq.; IDAHO CODE ANN. § 15-5-301 et seq.; KY. REV. STAT. ANN. § 387.500 et seq.; MICH. COMP. LAWS ANN. ch. 330 (Mental Health Code), §330.1600 et seq.; N.Y. SURR. CT. PROC. ACT art. 17-A.

<sup>&</sup>lt;sup>6</sup> See, e.g., Pamela B. Teaster et al., Wards of the State: A National Study of Public Guardianship, 37 STETSON L. REV. 193, 219 (2007) (noting that a 2005 study of public guardianship programs revealed that court orders only limited guardianships in 0 to 7 percent of cases). See also Lawrence A. Frolik, Promoting Judicial Acceptance and Use of Limited Guardianship, 31 STETSON L. REV. 735-55 (2002).

<sup>&</sup>lt;sup>7</sup> Brenda K. Uekert & Richard Van Duizend, *Adult Guardianships: A "Best Guess" National Estimate and the Momentum for Reform, in* FUTURE TRENDS IN STATE COURTS 2011 107-08 (National Center for State Courts, 2011). *State Court Leaders Strive to Improve Guardianship and Conservatorship Oversight*, NCSC Backgrounder, Nov. 30, 2016, <a href="http://www.ncsc.org/Newsroom/Backgrounder/2016/Guardianship.aspx">http://www.ncsc.org/Newsroom/Backgrounder/2016/Guardianship.aspx</a> (the National Center for State Courts stated that, based on data from a handful of state courts in 2015, there were an estimated 1.3 million open guardianship or conservatorship cases).

<sup>&</sup>lt;sup>8</sup> A Profile of Older Americans: 2015 (Administration on Aging, Administration on Community Living, U.S. Department of Health and Human Services).

<sup>&</sup>lt;sup>9</sup> Administration on Intellectual and Developmental Disabilities, Fact Sheet: President's Committee for People with Intellectual Disabilities (2016), <a href="https://acl.gov/Programs/AIDD/Programs/PCPID/index.aspx">https://acl.gov/Programs/AIDD/Programs/PCPID/index.aspx</a>.

15 National Core Indicators (NCI) survey, 42 percent of adults with intellectual disability across 46 states and the District of Columbia have some kind of guardianship arrangement in place. 10

Because guardianship intrudes substantially on a person's liberty, self-determination, and autonomy, it has been the subject of successive reform efforts that have significantly increased the statutorily required (though often ignored in practice) due process protections afforded an "alleged incapacitated person." These reforms have also attempted to ensure that the substituted decision-making regime of guardianship is the "last resort" or, as a constitutional matter, the "least restrictive alternative" available to protect a person who is unable to care for him or herself.

The "least restrictive alternative" principle was first recognized by the U.S. Supreme Court in *Shelton v. Tucker*, <sup>11</sup> and has been applied in a number of contexts, including institutionalization and guardianship, to limit state deprivation of individual rights and liberties only to the extent necessary to achieve the state's legitimate purposes. The Uniform Guardianship, Conservatorship, and Other Protective Arrangements Act (UGCOPAA) provides that guardianship should be viewed as a "last resort," and provides that guardianship may not be imposed if less restrictive alternatives will meet the individual's needs. <sup>12</sup>

The *National Probate Court Standards*<sup>13</sup> require that a guardianship petition include "representations that less intrusive alternatives to guardianship or conservatorship have been examined"<sup>14</sup>; provide that a court "should encourage the appropriate use of less intrusive alternatives to formal guardianship and conservatorship proceedings"<sup>15</sup>; and specify that a court visitor report should state "whether less intrusive alternatives are available."<sup>16</sup> Many state statutes prioritize less restrictive options to guardianship, such as joint accounts, durable and health care powers of attorney, trusts, representative payment for public benefits for financial decisions, and advance directives, living wills, and use of state default consent laws for personal and health decisions.

http://www.nationalcoreindicators.org/upload/aidd/Guardianship Case Study formatted1.pdf.

<sup>&</sup>lt;sup>10</sup> NCI, Guardianship Reform,

There is no comprehensive study on how many people with intellectual or developmental disabilities have guardians nationwide. NCI is an effort by public developmental disabilities agencies to track and measure their own performance.

<sup>11 364</sup> U.S. 479, 493-94 (1960).

<sup>&</sup>lt;sup>12</sup> UGPPA (1997) Prefatory Note 1-2.

<sup>&</sup>lt;sup>13</sup> National Center for State Courts, <a href="http://ncsc.contentdm.oclc.org/cdm/ref/collection/spcts/id/240">http://ncsc.contentdm.oclc.org/cdm/ref/collection/spcts/id/240</a>.

<sup>&</sup>lt;sup>14</sup> Id. at Standard 3.3.1(C)(9) at p. 44-45 (Petition).

<sup>&</sup>lt;sup>15</sup> Id. at Standard 3.3.2 at 46-47 (Initial Screening).

<sup>&</sup>lt;sup>16</sup> Id. at Standard 3.3.4 at 49-50 (Commentary).

#### The Emergence and Meaning of Supported Decision-Making

ABA policy, federal <sup>17</sup> and state <sup>18</sup> constitutions, the UGCOPAA, <sup>19</sup> most state guardianship statutes, and, quite possibly, the Americans with Disabilities Act (ADA) <sup>20</sup> embrace the principle of the least restrictive alternative. In the guardianship context, the principle requires all alternatives that might enable older persons, persons with cognitive limitations, and persons with intellectual disability, of whatever origin, <sup>21</sup> to make their own decisions about personal and/or financial matters be considered and exhausted prior to the imposition of the "last resort" of guardianship. However, as a keynote speaker at the 2001 Wingspan Conference noted, the problem is "the failure of available alternatives to obviate the need and demand for guardianship and conservatorships." <sup>22</sup> Or, to put it in a more favorable light, "[t]he greater the availability of and access to alternatives, the better the dignity and freedoms of people needing protection will be preserved."

Over the past several years, a recent shift in the decision-making landscape is the advent of "supported decision-making," which has been gaining recognition internationally, <sup>24</sup> as well as academically <sup>25</sup> and legislatively in the United States, <sup>26</sup> as a less restrictive alternative to the

<sup>&</sup>lt;sup>17</sup> See Shelton v. Tucker, 364 U.S. 479, 493-94 (1960); O'Connor v. Donaldson, 422 U.S. 563 (1975); Wyatt v. Aderholt, 503 F.2d 1305 (5th Cir. 1974), aff'g Wyatt v. Stickney, 325 F. Supp. 781 (M.D. Ala. 1971); New York State Ass'n for Retarded Children, Inc. v. Carey, 393 F. Supp. 715 (E.D.N.Y. 1975).

<sup>&</sup>lt;sup>18</sup> See, e.g., Keselbrenner v. Anonymous, 33 N.Y.2d 161, 165 (N.Y. 1973) (ruling "To subject a person to a greater deprivation of his personal liberty than necessary to achieve the purpose for which he is being confined is, it is clear, violative of due process.").

<sup>19</sup> UGCOPAA (2017), Art. 1, Definitions § 102 (13), Art. 3, § 313 (Duties of Guardian for Adult).

<sup>&</sup>lt;sup>20</sup> Professor Leslie Saltzman has persuasively argued that the ADA's *Olmstead* mandate applies to guardianship. See Leslie Saltzman, Rethinking Guardianship(Again): Substituted Decision Making as a Violation of the Integration Mandate of Title II of the Americans With Disabilities Act, 81 U. COLO. L. Rev. 157 (2010); Leslie Saltzman, New Perspectives on Guardianship and Mental Illness: Guardianship for Persons with Mental Illness—A Legal and Appropriate Alternative?, 4 St. Louis U. L. J. Health L. & Pol'y 279 (2011).

<sup>&</sup>lt;sup>21</sup> AMERICAN ASSOCIATION ON INTELLECTUAL AND DEVELOPMENTAL DISABILITIES, DEFINITION OF INTELLECTUAL DISABILITY, <a href="http://aaidd.org/intellectual-disability/definition#">http://aaidd.org/intellectual-disability/definition#</a>. WIojwVMrKHs (defining "intellectual disability" as "a disability characterized by significant limitations in both intellectual functioning and adaptive behavior, which covers many everyday social and practical skills. This disability originates before the age of 18.").

A. Frank Johns & Charles P. Sabatino, *Introduction: The Second National Guardianship Conference*, 31 STETSON
 L. REV. 575 (2002) (*quoting* Richard Van Duizend, Executive Director of the National Center of State Courts).
 Id. at 581.

<sup>&</sup>lt;sup>24</sup> See, e.g., Czech Republic (Czech Civil Code, Supportive Measures for Decreased Legal Capacity Advanced Directives, § 38), <a href="http://www.mdac.org/en/news/czech-republic-enacts-legal-capacity-law-reform">http://www.mdac.org/en/news/czech-republic-enacts-legal-capacity-law-reform</a>; Israel (Capacity and Guardianship (Amendment No. 18) Law, 5776-2016 (Mar. 29, 2016) (addition of Section 67B), <a href="http://www.supporteddecisionmaking.org/node/393">http://www.supporteddecisionmaking.org/node/393</a>; Latvia, <a href="http://supporteddecisionmaking.org/legal-resource/latvia-abolishes-plenary-guardianship">http://supporteddecisionmaking.org/legal-resource/latvia-abolishes-plenary-guardianship">http://supporteddecisionmaking.org/legal-resource/latvia-abolishes-plenary-guardianship</a>.

<sup>&</sup>lt;sup>25</sup> See, e.g., Saltzman, New Perspectives, supra note 20, at 281 (stating supported decision-making is an extension of the integration mandate); Nina Kohn et al., Supported Decision-Making: A Viable Alternative to Guardianship, 117 PENN ST. L. REV. 1111 (2013) (stating supported decision-making in lieu of guardianship or in addition to the guardianship system has the potential to promote self-determination); Jonathan Martinis, Supported Decision-Making: Protecting Rights, Ensuring Choices, 36 A.B.A. BIFOCAL 107, 107-10 n.5 (2015); Kristin Booth Glen, Supported Decision-Making and the Human Right of Legal Capacity, 3 INCLUSION 2, 2-16 n.1 (2015); Robert Dinerstein et al., Emerging International Trends and Practices in Guardianship Law for People with Disabilities, 22 ILSA J. INT'L & COMPARATIVE L. 435 (Winter 2016).

<sup>&</sup>lt;sup>26</sup> Supported Decision-Making Agreement Act, TEX. ESTATES CODE ANN. § 1357 (West 2015).

surrogate decision-making model embodied in guardianship.<sup>27</sup> Guardianship practice involves a third party, the guardian, making decisions *for* the individual subject to guardianship, using a variety of standards.<sup>28</sup> By contrast, supported decision-making focuses on *supporting* the individual's own decisions.

Supported decision-making constitutes an important new resource or tool to promote and ensure the constitutional requirement of the least restrictive alternative. As a practical matter, supported decision-making builds on the understanding that no one, however abled, makes decisions in a vacuum or without the input of other persons. Whether the issue is what kind of car to buy, which medical treatment to select, or who to marry, a person inevitably consults friends, family, coworkers, experts, or others before making a decision. Supported decision-making recognizes that older persons, persons with cognitive limitations, and persons with intellectual disability will also make decisions with the assistance of others, although the kinds of assistance necessary may vary or be greater than those used by persons without disabilities.

Such assistance or "supports" may be formal or informal, and may come from individuals such as family members, friends, professionals, advocates, peers and community members. Supports may also involve accommodations such as communication aids and devices and modification of practices or procedures, as well as an array of community services and supports such as those provided under the Older Americans Act (OAA).<sup>29</sup> These supports help individuals understand relevant information and available choices so they can make their own decisions. Individuals serving as supporters can assist the decision-maker in other ways; for example, when a person cannot communicate verbally, a family member may interpret and communicate the person's decisions. An emergent form of support is the "Supported Decision-Making Agreement," by which the person with a disability chooses individuals to support him or her in various areas, such as finances, health care, and employment, and the "supporters" agree to support the person in his or her decisions, rather than substituting their own.

<sup>&</sup>lt;sup>27</sup>See, e.g., Saltzman, New Perspectives, supra note 20, at 306-07; Dinerstein et al., supra note 25. For a useful and concise summary of the history of supported decision-making, see Michelle Browning et al., Supported Decision Making: Understanding How Its Conceptual Link to Legal Capacity Is Influencing the Development of Practice, 1:1 ROUTLEDGE RESEARCH AND PRACTICE IN INTELLECTUAL AND DEVELOPMENTAL DISABILITIES 34-35 (2014), <a href="http://dx.doi.org/10.1080/23297018.2014.902726">http://dx.doi.org/10.1080/23297018.2014.902726</a>. For a discussion of the extension of supported decision-making to older persons with cognitive decline, see Rebekah Diller, Legal Capacity for All: What the Shift from Adult Guardianship to Supported Decision-Making Has to Offer Older Adults, 43 FORDHAM URBAN L.J. (forthcoming 2017) (on file with authors).

<sup>&</sup>lt;sup>28</sup> Linda S. Whitton & Lawrence A. Frolik, Surrogate Decision-Making Standards for Guardians: Theory and Reality, Symposium on Third National Guardianship Summit: Standards of Excellence, 3 UTAH L. REV. 1491-540 (2012).

<sup>&</sup>lt;sup>29</sup> 42 U.S.C. §§ 3001-3058ee.

<sup>&</sup>lt;sup>30</sup> The supported decision-making agreement, designated a "Representation Agreement," was first legislatively recognized in British Columbia 30 years ago. Representation Agreement Act, R.S.B.C., ch.405 (1996). That model has since been used in a number of other Canadian provinces, see Glen, supra note 3, at 145-53. Supported decision-making or representation agreements are used in supported decision-making pilot projects around the world, as well as in the first U.S. pilot project in Northampton, Massachusetts, Supported Decision-Making Pilot Project, a joint initiative of the Center for Public Representation and Nonotuck Resource Associates, Inc., <a href="http://supporteddecisions.org">http://supporteddecisions.org</a>. See Elizabeth Pell, Supported Decision Making Pilot: A Collaborative Approach, Pilot Evaluation Year 1 Report (Human Services Research Institute, Nov. 30, 2015), <a href="http://supporteddecisions.org/wp-content/uploads/2015/04/SDM-Evaluation-Report-Year-1">http://supporteddecisions.org/wp-content/uploads/2015/04/SDM-Evaluation-Report-Year-1</a> HSRI-2015, pdf.

#### Support for, and Legal Recognition of, Supported Decision-making

As a legal, human rights, or theoretical matter, supported decision-making is the means by which a person with a disability exercises his or her right of legal capacity, as guaranteed by the United Nations Convention on the Rights of Persons with Disabilities (CRPD), which was adopted in 2006 and came into force in May 2008.<sup>31</sup> Article 12 embraces supported decision-making, stating that "persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life," and that "state parties [governments] shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity." Article 12 has been used to ensure self-determination and equality for people with cognitive, intellectual, and psychosocial disabilities. Supported decision-making is receiving increasing legislative and judicial support in a number of countries.<sup>34</sup>

In 2010, the ABA House of Delegates passed a resolution "urg[ing] the United States to ratify and implement United Nations Convention on the Rights of Persons with Disabilities." Although it has not yet been ratified by the Senate, the CRPD has provided inspiration and impetus for supported decision-making both nationally and more locally. 36

The federal agency responsible for overseeing the services and supports for both persons with intellectual disability and older persons—the Administration for Community Living (ACL) of the US Department of Health and Human Services (DHHS)—has embraced supported decision-making as an important modality in promoting and protecting autonomy and dignity. <sup>37</sup> In 2013, ACL funded a five-year grant to create a National Resource Center for Supported Decision-Making, <sup>38</sup> and has since authorized \$2.5 million for research on its practical impact. <sup>39</sup> ACL also

https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/convention-on-the-rights-of-persons-with-disabilities-2.html. In 2009, President Obama signed the treaty. As of January 2017, 172 countries have ratified the treaty. Although the Obama Administration submitted the CRPD to the Senate for ratification in the 112th Congress and again in the 113th, the Senate has yet to ratify the treaty.

<sup>&</sup>lt;sup>32</sup> Art. 12(2), G.A. Res. 61/106, U.N. Doc. A/RES/61/106 (Dec. 13, 2006).

<sup>33</sup> Id. at 12(3).

<sup>&</sup>lt;sup>34</sup> See SYMPOSIUM, INTERNATIONAL CONVENING TO SHARE EXPERIENCES ON IMPLEMENTATION OF CRPD ARTICLE 12 (Open Society Foundations & American University, Washington College of Law, Apr. 11-14, 2016) (convening representatives from, but not limited to, Argentina, Bulgaria, China, Columbia, India, Ireland, Israel, Lithuania, and Peru, in order to discuss the challenges and successes regarding implementation of supported decision-making throughout the world).

<sup>35</sup> ABA Resolution 2010M108B,

http://www.americanbar.org/content/dam/aba/directories/policy/2010 my 108b.authcheckdam.pdf.

<sup>&</sup>lt;sup>36</sup> The President's Committee for People with Intellectual Disabilities has recommended the U.S. Departments of Health and Human Services, Justice, Education and Labor encourage the study, integration, and promotion of supported decision-making in their policies and programs. See Report to the President: Strengthening an Inclusive Pathway for People with Intellectual Disabilities and their Families 61-69 (2016),

https://acl.gov/Programs/AIDD/Program Resource Search/docs/PCPID-Report-2016.pdf.

<sup>&</sup>lt;sup>37</sup> Aaron Bishop & Edwin Walker, *Preserving the Right to Self-Determination: Supported Decision Making*, U.S. Dep't. of Health and Human Services, Administration for Community Living Blog (Jan. 28, 2015), http://www.acl.gov/NewsRoom/blog/2015/2015 01 28.aspx.

<sup>&</sup>lt;sup>38</sup> The National Center, now three years old, has actively advanced supported decision-making through, *inter alia*, its website, webinars, printed materials, and numerous presentations to stakeholders groups of all kinds, <a href="http://www.supporteddecisionmaking.org/">http://www.supporteddecisionmaking.org/</a>.

<sup>39</sup> http://news.syr.edu/burton-blatt-institute-receives 2-5-million-grant-60460/.

funds state Developmental Disabilities Planning Councils (DDPC), which in turn have funded pilot programs on supported decision-making 40 and its use to restore rights to persons subject to guardianship. 41

The Uniform Law Commission recently revised the uniform law relating to guardianship, and, in doing so, recognized supported decision-making as a less restrictive alternative to guardianship. <sup>42</sup> The National Guardianship Association has recognized that "[s]upported decision-making should be considered for the person before guardianship. . . ."<sup>43</sup>

#### Legislation

Texas enacted the country's first law recognizing supported decision-making agreements. 44 Supported decision-making is defined as

a process of supporting and accommodating an adult with a disability to enable the adult to make life decisions, including decisions related to where the adult wants to live, the services, supports, and medical care the adult wants to receive, whom the adult wants to live with, and where the adult wants to work, without impeding the self-determination of the adult.<sup>45</sup>

The explicit purpose of the law is to serve as a less restrictive alternative for guardianship. 46 Delaware has recently enacted a similar law. 47

Further, in 2015 the District of Columbia enacted special education legislation providing that students with disabilities turning 18 years old "may receive support from another competent and willing adult to aid them in their decision-making" related to their individualized education program. <sup>48</sup> If a disagreement exists between the student and the supporter, the student's

<sup>&</sup>lt;sup>40</sup> See, e.g., New York State DDPC Funding Announcement, Supported Decision-making (soliciting proposals for two pilot projects utilizing supported decision-making, one to divert persons at risk of guardianship and one to restore rights to persons subject to guardianship), <a href="https://ddpc.ny.gov/supported-decision-making-0">https://ddpc.ny.gov/supported-decision-making-0</a>.
<a href="https://ddpc.ny.gov/supported-decision-making-0">https://ddpc.ny.gov/supported-decision-making-0</a>.

<sup>&</sup>lt;sup>42</sup> The revised UGPPA, retitled the Uniform Guardianship, Conservatorship, and Other Protective Arrangements Act (UGCOPAA), was approved by the Uniform Law Commission in July 2017. The Act provides that the guardianship order must clearly state the court's finding that the respondent's needs cannot be met by less restrictive means, including use of appropriate supportive services, technological assistance, and supported decision-making. Art. 3, § 301(a)(1)(A).

 $<sup>^{43}</sup>$  National Guardianship Association, Position Statement on Guardianship, Surrogate Decision Making and Supported Decision Making, at 2,

http://www.guardianshiporg/documents/NGA.Policy.Statement.052016.pdf.

44 Supported Decision-Making Agreement Act, Tex. Estates Code Ann. § 1357 (West 2015). The instant resolution does not, in any way, either endorse or propose adoption of such statutes before there is more experience with, and evaluation of, the use of supported decision-making agreements, as commentators have suggested. See, e.g., Nina A. Kohn et al., supra note 25 (proposing an empirical research agenda on how supported decision-making works in practice).

<sup>45</sup> Id. § 1357.002(3).

<sup>&</sup>lt;sup>46</sup> Id. § 1357.003.

<sup>&</sup>lt;sup>47</sup> DEL. CODE ANN. tit. 16, ch. 94A.

<sup>&</sup>lt;sup>48</sup> Special Education Procedural Protections Expansion Act of 2014, DC CODE § 38-2571.04(b).

decisional choice prevails.<sup>49</sup> In addition to the statute, the District of Columbia Public Schools has established policy and created a form that allows the student to designate the individual(s) who will serve as supporters, and to specify to which documents, such as requests for assessments or changes in placement or services, the student will permit supporters to gain access.<sup>50</sup>

#### Case Law

Courts, as well, are recognizing that an ongoing support system that enables persons with intellectual disability to make decisions constitutes a less restrictive alternative that eliminates the need for guardianship.<sup>51</sup> In one well-publicized case, a Virginia court appointed temporary guardians with the specific task of creating a supported decision-making system for Jenny Hatch, a 27-year-old woman with Down syndrome. The order indicated that the temporary guardianship would end in one year, which it did.<sup>52</sup> Similarly, courts have granted restoration of rights upon a showing that the person subject to guardianship now had a functioning support system,<sup>53</sup> or on proof of execution of a supported decision-making agreement.<sup>54</sup>

#### ABA Involvement and Policy

The ABA has played a leading role in these guardianship reform efforts, dating back almost four decades. Particularly notable in this almost forty-year history is the ABA's consistent focus on the need and obligation to exhaust other, less restrictive alternatives that would enable an incapacitated person to avoid guardianship. In 1977, the ABA House of Delegates passed a resolution embodying as "an explicit right and underlying premise" the doctrine of least restrictive alternative, namely "[t]he doctrine that mentally disabled persons cannot be deprived of basic rights in order to achieve state objectives that can be accomplished in less intrusive ways." In 1979, the ABA Commission on the Mentally Disabled (now the Commission on Disability Rights (CDR)) studied limited guardianship, public guardianship, and adult protective

<sup>49</sup> Id. § 104(b)(2).

<sup>&</sup>lt;sup>50</sup> D.C. Public Schools, Office of Teaching and Learning, Supported Decision Making Form, http://dcps.dc.gov/sites/default/files/dc/sites/dcps/publication/attachments/Supported%20Decision%20Making%20F orm.pdf.

<sup>&</sup>lt;sup>51</sup> See, e.g., In re D.D., 19 N.Y.S.3d 867, 876 (N.Y. Surr. Ct. 2015) (denying appointment of a mother and brother as co-guardians for their 29-year-old son/brother with Down syndrome on the grounds that his network of supported decision-making over the past 11 years "has yielded a safe and productive life where he has thrived and remained free from the need to wholly supplant the legal right to make his own decisions.").

<sup>&</sup>lt;sup>52</sup> Ross v. Hatch, No. CWF120000426P-03, slip op. (Va. Cir. Ct. Aug. 2, 2013).

<sup>&</sup>lt;sup>53</sup> In re Dameris L., 956 N.Y.S.2d 848, 856 (N.Y. Sur. Ct. 2012) (ruling that even if the court had jurisdiction over a woman with an intellectual disability, guardianship was no longer warranted because "she is able to exercise her legal capacity, to make and act on her own decisions, with the assistance of a support network."); In re Ryan Herbert King, No. 2003 INT 249 (D.C. Super. Ct. Probate Div., Oct. 11, 2016) (granting motion to terminate 15-year guardianship of an individual with intellectual disability based on existence of supported decision-making arrangement).

<sup>&</sup>lt;sup>54</sup> Guardianship of Cory C., Amended Findings of Fact and Rulings of Law, No. BE09PO253 (Berkshire Cnty. Mass. Dec. 7, 2015).

<sup>&</sup>lt;sup>55</sup> ABA Commission on the Mentally Disabled and Section Individual Rights and Responsibilities, Recommendation and Report, August 1077.

services in six states,<sup>56</sup> leading to its proposal of an extensive model guardianship statute,<sup>57</sup> which took as its basic premise the requirement of "least restrictive dispositional alternative," the following year. The Comment to Chapter 1, §3926 of the model statute provided:

The principle of the least restrictive alternative was explained in the report of the President's Committee on Mental Retardation [now the President's Committee on People with Intellectual Disabilities] as follows: when the government ... [has] a legitimate communal interest to serve by regulating human conduct it should use methods that curtail human freedom to no greater extent than is essential for securing that interest. In the context of the statute, no restriction should be placed on the legal capacity of an individual to act in his or her own behalf unless no combination of voluntary services or other alternatives to guardianship or conservatorship would be sufficient to permit the partially disabled or disabled person to meet the essential requirements for his or her physical health or safety and/or manage his or her financial resources. <sup>58</sup>

In 1986, the ABA Commission on Legal Problems of the Elderly (now Commission on Law and Aging (COLA)) hosted a National Conference of the Judiciary on Guardianship Proceedings for the Elderly, which produced a *Statement of Recommended Judicial Practices*, premised on the principle of the least restrictive alternative. The ABA House of Delegates adopted the *Statement* in 1987. <sup>59</sup>

In response to a nationwide Associated Press exposé of guardianship abuse, COLA and CDR convened in 1988 a multidisciplinary conference, the Wingspread National Guardianship Symposium, which reviewed the then-current guardianship system and developed an agenda for reform, generating thirty-one recommendations. In February 1989, the House of Delegates adopted all but two of the recommendations. The symposium's first recommendation was: "To encourage alternatives to and more appropriate uses of guardianship, the costs and benefits of various guardianship alternatives should be explored. . . . "61 The Commentary stated "alternatives should be explored first, and guardianship . . . should be relied on only as a last resort to provide needed services." "62

<sup>&</sup>lt;sup>56</sup> See Melvin T. Axilbund, Exercising Judgment for the Disabled: Report of an Inquiry into Limited Guardianship, Public Guardianship and Adult Protective Services in Six States: Executive Summary (American Bar Association, Commission on the Mentally Disabled, 1979).

<sup>&</sup>lt;sup>57</sup> See Model Guardianship and Conservatorship Act, Section ch.1, §3(26), in Bruce Dennis Sales, D. Matthew Powell & Van Duizend, Disabled Persons and the Law: State Legislative Issues (Plenum Press 1980).

<sup>&</sup>lt;sup>58</sup> *Id.* In its use of a functional rather than medical model, the Model Statute was far ahead of its time, rejecting a results-based model of incapacity, noting that "the [incapacity] standard should focus on the ability to engage in the decision-making process rather than on the resulting decision.... Individuals with disabilities should have no less right to be wrong than those without disabilities." Comment to Section 3(1).

<sup>59</sup> *See* 

http://www.americanbar.org/content/dam/aba/administrative/law\_aging/1987\_guardianship\_recommendation.authcheckdam.pdf.

<sup>60</sup> ABA Resolution 89M104,

http://www.americanbar.org/content/dam/aba/directories/policy/1989\_my\_104.authcheckdam.pdf.

<sup>&</sup>lt;sup>61</sup> Commission on the Mentally Disabled & Commission on Legal Problems of the Elderly, *Guardianship: An Agenda for Reform*, 1989, Recommendation I-A.

<sup>62</sup> Id. at Agenda Commentary, 3-4.

Two recommendations adopted by the House focused on terminating guardianships and restoring one's rights. One provided that "[c]ourt orders should make it relatively easy for the court to extend, limit *or dissolve* guardianships." (Emphasis added). The Commentary noted that "[i]n this way courts can monitor changing conditions and make sure the guardianship order *still represents the least restrictive alternative possible.*" (Emphasis added.) The other recommendation stated that "[u]pon a showing of favorable change in circumstances, the burden of proof should be imposed on those seeking to continue the guardianship." <sup>64</sup>

In August 1998, the House of Delegates approved the Uniform Guardianship and Protective Proceedings Act (UGPPA), 65 which is premised on the principle of the least restrictive alternative. In 2001, ABA entities with a host of other collaborating groups 66 convened Wingspan—The Second National Guardianship Conference, which produced recommendations in six separate areas. In 2002, approving these recommendations, the House explicitly "[s]upport[ed] the concept that guardianship should be a last resort and that less restrictive alternatives should be explored and exhausted prior to judicial intervention. . . ."67

A third invitational national convocation, the Third National Guardianship Summit in 2011, sponsored by the National Guardianship Network—including both the ABA Commission on Law and Aging and the Section of Real Property, Trust and Estate Law—produced recommendations, <sup>68</sup> which the House adopted in August 2012. <sup>69</sup> The House explicitly endorsed the obligation of a conservator [or guardian] "to assist the person [subject to guardianship] to develop *or regain* the ability to manage [his or her] affairs." <sup>70</sup> (Emphasis added.) Recommendation 2.2 encourages the court to issue orders that implement the least restrictive alternative and maximize the person's right to self-determination and autonomy. <sup>71</sup> Recommendation 2.3 encourages courts to "monitor the well-being of the person and status of the estate on an on-going basis, including, but not limited to: "Determining whether less restrictive alternatives will suffice."

http://www.americanbar.org/content/dam/aba/directories/policy/1998 am 116.authcheckdam.pdf. The revised UGPPA, retitled the Uniform Guardianship, Conservatorship and Other Protective Arrangement Act (UGCOPAA), was approved by the Uniform Law Commission in July 2017.

http://www.americanbar.org/content/dam/aba/directories/policy/2002 am 108b.authcheckdam.pdf,

http://www.americanbar.org/content/dam/aba/directories/policy/2012 hod annual meeting 106b.authcheckdam.do

<sup>63</sup> Id. at Recommendation III-D.

<sup>64</sup> Id. at Recommendation III-F.

<sup>65</sup> ABA Resolution 98A116.

<sup>&</sup>lt;sup>66</sup> The Wingspan Second National Guardianship Conference's primary sponsors were the National Academy of Elder Law Attorneys, Stetson University College of Law, and the Borchard Foundation Center on Law and Aging, with co-sponsors including the ABA Commission on Legal Problems of the Elderly, the National College of Probate Judges, the Supervisory Council of the ABA Section of Real Property, Probate and Trusts (currently the Section of Real Property, Trust and Estate Law), the National Guardianship Association, the Center for Medicare Advocacy, the Arc of the United States, and The Center for Social Gerontology, Inc.

<sup>67</sup> ABA Resolution 02A108B,

<sup>&</sup>lt;sup>68</sup> Symposium Third National Guardianship Summit: Standards of Excellence, 2012 UTAH L. REV. 1191.

<sup>69</sup> ABA Resolution 12A106B,

 $<sup>\</sup>frac{c}{70}$  *Id.* 

<sup>&</sup>lt;sup>71</sup> Symposium, supra note 68, 2012 UTAH L. REV. 1200.

<sup>72</sup> In

In October 2012, COLA and CDR hosted the first National Roundtable on Supported Decision-Making, with cooperation of the Agency for Community Living of the US Department of Health and Human Services, to explore concrete ways to move from a model of substitute decision-making to one of supported decision-making. As one consequence of that Roundtable, COLA, CDR, the ABA Section on Civil Rights and Social Justice) and the ABA Section of Real Property, Trust and Estate Law received an ABA Enterprise Grant to develop an instrument to help lawyers identify and implement decision-making options for persons with disabilities that are less restrictive than guardianship, including supported decision-making. That instrument, the PRACTICAL tool, offers concrete steps to implement the least restrictive alternative principle as a routine practice of law; it was rolled out in the summer of 2016.<sup>73</sup>

In September 2016, COLA held an invitational Roundtable on Restoration of Rights. It grew out of a cross-state guardianship file review supported by the Greenwall and Borchard Foundations.

#### Need for the Resolution

Although supported decision-making is increasingly understood and practiced, especially in the intellectual disability/developmental disability community, and clearly offers an additional, and potentially more readily available alternative to guardianship, <sup>74</sup> it may not be widely known among persons seeking guardianship. Legislation that requires supported decision-making to be identified and considered before guardianship is imposed <sup>75</sup> promotes self-determination. Such legislation directs petitioners (and their attorneys) to use the principles of supported decision-making before seeking guardianship—actions already proposed by the ABA's PRACTICAL tool. <sup>76</sup>

In the same way, courts may not be aware of supported decision-making or how it may constitute a statutorily required less restrictive alternative to guardianship. Accordingly, specifically naming supported decision-making as a modality that must be considered ensures that it will be part of the judicial toolbox available to avoid the unnecessary deprivation of liberty and/or property rights for persons with a variety of cognitive disabilities.

Furthermore, restoration of rights/termination of guardianship proceedings for persons currently subject to guardianship present additional, but equally important occasions for ensuring that

<sup>&</sup>lt;sup>73</sup> PRACTICAL is an acronym for Presume, Reason, Ask, Community, Team, Identify, Challenges, Ability, Limits. ABA Commission on Law and Aging et al.,

http://www.americanbar.org/content/dam/aba/administrative/law aging/PRACTICALGuide.authcheckdam.pdf.

74 The "least restrictive alternatives" most often mentioned in judicial decisions are trusts, advanced directives and/or powers of attorney, which generally require the services of an attorney, and may either be unknown or unavailable to persons of lower socio-economic status, minorities, and immigrants. It is, however, precisely members of these groups who have been recognized in the judicial decisions on supported decision-making to date.

75 Concomitant with a statutory requirement that supported decision-making must be considered, as the Resolution requires, would be a provision requiring that a guardianship petition contain a detailed statement about efforts already undertaken to utilize supported decision-making, and why those efforts were unsuccessful. The proposed revision of the UGPPA currently under consideration would require that the petition include a description of the alternative means of meeting the person's need that have been considered or implemented.

76 ABA Commission on Law and Aging et al., supra note 73.

guardianship is still the least restrictive available alternative. There is very little data on the number or results of restoration proceedings, but what data does exist suggests that these proceedings are few and far between. The suggests that these proceedings are few and far between.

Although ABA policy, the UGCOPAA, and a number of state statutes specifically require the proponent of continuing guardianship to prove that it is still required, there is a general misconception that the person subject to guardianship must prove that he or she has "recovered" capacity. By requiring courts to consider supported decision-making in restoration proceedings, the inquiry is properly returned to whether the existence of supporters who can assist the person in making his or her own decisions obviates the need for the deprivation of rights engendered by guardianship.

#### Conclusion

The proposed resolution will further existing ABA policy requiring that guardianship must be the least restrictive available alternative, by bringing the 21st century concept and practice of supported decision-making into legislation prescribing requirements for imposing guardianship and into judicial decision-making in proceedings for the restoration of rights of persons currently subject to guardianship.

Respectfully submitted,

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Honorable Judge Patricia Banks, Chair Commission on Law and Aging August 2017

<sup>77</sup> Id.

<sup>&</sup>lt;sup>78</sup> See Jenica Cassidy, Restoration of Rights in the Termination of Adult Guardianship, 23 IL. ELDER L.J. 83 (2015).