

Supported Decision-Making as an Alternative to Guardianship

A Nevada Conversation

November 28, 2017

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Materials

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A Nevada Conversation

November 28, 2017

University of Nevada Cooperative Extension

Las Vegas, Nevada

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Second Judicial District Court, State of Nevada, County of Washoe
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-A Nevada Conversation-
November 28, 2017
Las Vegas, Nevada

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Agenda

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PROGRAM

8:30 – 9:00/(1:00-1:30)	Sign in at each location
9:00 – 9:10/(1:30-1:40)	Opening - Judge Frances Doherty
9:10-10:00/(1:40-2:30)	Supported Decision-Making: From Justice for Jenny to Justice for All! Jonathan Martinis, Esq., J.D.
10:00-10:10/(2:30-2:40)	Break
10:10-11:00/(2:40-3:30)	Supported Decision-Making: Where We Are and Where We Can Go Jonathan Martinis, Esq., J.D.
11:00-11:10/(3:30-3:40)	Break
11:10-11:30/(3:40-4:00)	Panelists introductions and comments Facilitator, Mallory Nelson, J.D., Debra Bookout, Esq. Dr. Elaine Brown Mary Bryant Judge Frances Doherty Jonathan Martinis, Esq.
11:30-11:55/(4:00-4:25)	Questions - Panel
11:55-12:00/ (4:25-4:30)	Closing – Judge Frances Doherty

PLEASE COMPLETE SURVEYS!

Presenter Biographies

Presenters

Debra Bookout, J.D., Legal Aid Center of Southern Nevada, Las Vegas, Nevada

Debra Bookout joined the staff of Legal Aid Center of Southern Nevada in the Consumer Rights Project in October of 2013, after more than nine years with the Federal Public Defender's Office in Las Vegas. Debra currently handles foreclosure, general consumer, and guardianship cases. Debra earned a bachelor's degree from the University of Houston in 1986 and received her J.D. from the University of Texas, School of Law in 1992.

Dr. Elaine C. Brown, Ph.D., Chief Psychologist for State of Nevada Developmental Services, Aging and Disabilities Services Division, Reno, Nevada

Elaine C. Brown, Ph.D. serves as the Chief Psychologist for State of Nevada Developmental Services, Aging and Disabilities Services Division. She is an adjunct faculty at the University of Nevada, Reno and oversees the extern program at Sierra Regional Center. She received her doctorate in psychology from The Ohio State University and has specialized in the field of intellectual/developmental disabilities for over 20 years. Her early research focused on the assessment and identification of mental health needs in children with intellectual and developmental disabilities. She has conducted numerous trainings and consultations for families, schools, and agencies in areas of child development, behavioral/emotional disorders, and systems of support for children and adults with intellectual/developmental disabilities. She participated in the state-wide development and expansion of Positive Behavior Support-Nevada and served for a number of years as a state-wide instructor. She is a Fellow of the American Association for Intellectual and Developmental Disabilities.

Mary Bryant, University of Nevada, Reno, Reno, Nevada

Mary Bryant is the founder and director of the Path to Independence (P2I) program at the University of Nevada Reno. P2I is an inclusive two-year, non-degree, certificate program for students with intellectual disabilities. She serves on the Nevada Guardianship Commission and the Nevada Special Education Advisory Committee. Previously, she served as chair of the Nevada Governor's Council in Developmental Disabilities and vice-chair of the Nevada Commission on Services for People with Disabilities. She has two daughters, one of whom has Down syndrome.

Judge Frances M. Doherty, Second Judicial District Court, Reno, Nevada

Judge Doherty currently presides in Department 12 - Family Division of the Second Judicial District Court in Washoe County, Nevada. She oversees civil family court cases including dissolution of marriage, custody, adoption and all adult guardianship matters. She was elected in 2002 and was re-elected in 2008 and 2014. Judge Doherty has spoken and trained nationally and in Nevada on issues affecting children and families. Prior to her election, Judge Doherty worked as a family court master, a legal services attorney and a deputy attorney general for the Nevada Commission on Ethics, the Consumer Protection Division, and the Nevada Domestic Violence Task Force.

Jonathan Martinis, Esq., J.D., The Burton Blatt Institute at Syracuse University, Syracuse, New York. Jonathan Martinis is the senior director for law and policy at The Burton Blatt Institute (BBI) at Syracuse University. Jonathan leads BBI's national and international efforts to ensure that people with disabilities have access to the supports they want and need to live full, independent and inclusive lives. He has more than 20 years of experience representing people with disabilities to protect their legal and human rights, including precedent-setting cases securing access to critical community-based services. In 2013, he represented Margaret "Jenny" Hatch in the "Justice for Jenny" case— the first to hold that a person has the right to use Supported Decision-Making to make her own life choices instead of being subjected to a permanent, plenary guardianship. Since then, he has spoken to and trained thousands of people, families, attorneys, advocates, judges, teachers, health care workers, and other professionals across the country about everyone's Right to Make Choices and direct their own lives.

Mallory Nelson, J.D., Second Judicial District Court, Reno, Nevada

Mallory Nelson is the Adult Guardianship Case Compliance Specialist at the Second Judicial District Court in Washoe County, Nevada. She works closely with court administration and the Honorable Frances Doherty, who oversees the adult guardianship caseload, to ensure case compliance with state and federal law. Ms. Nelson contributes to the development of case management protocols to highlight and address non-compliant cases. In July 2017, Ms. Nelson joined Judge Doherty on an outreach tour across Northern Nevada to educate communities on supported decision-making as a less restrictive alternative to guardianship. Ms. Nelson previously worked in the Family Division as law clerk to the Honorable Linda Gardner from 2011-2014.

Ms. Nelson devoted most of her legal career to advocacy on behalf of vulnerable and marginalized communities. Prior to joining her current team at Second Judicial District Court, she represented survivors of domestic violence and indigent defendants in the State of Washington. Ms. Nelson obtained her Bachelor of Arts in International Relations from the College of William and Mary and received her law degree from Seattle University School of Law. She is dually licensed in the State of Washington and Nevada.

From Justice for Jenny to Justice for All!

Supported Decision-Making: From Justice for Jenny to Justice for All!

Jonathan
Martinis

Senior Director for
Law and Policy

*The Burton Blatt
Institute at Syracuse
University*

Co-Project Director,
*National Resource
Center for Supported
Decision-Making*

THERE ARE STUPID QUESTIONS

What's Your Favorite
Right?

RIGHTS=CHOICES

“I am my choices. I cannot not choose. If I do not choose, that is still a choice. If faced with inevitable circumstances, we still choose *how we are* in those circumstances.”

- Jean Paul Sartre

RIGHTS=CHOICES

CHOICES=SELF DETERMINATION

- Life control
- People's ability and opportunity to be "causal agents . . . actors in their lives instead of being acted upon"
- Wehmeyer, Palmer, Agran, Mithaug, & Martin, 2000

BENEFITS OF SELF-DETERMINATION

People with greater self determination are:

- Healthier
 - More independent
 - More well-adjusted
 - Better able to recognize and resist abuse
- Khemka, Hickson, & Reynolds, 2005; O'Connor & Vallerand, 1994; Wehmeyer & Schwartz, 1998

ANOTHER STUPID QUESTION

Are Your Rights Worth
ANYTHING If You're Not
Allowed to Use Them?

AND YET: 2,000 YEARS AND COUNTING

- **Ancient Rome:** “Curators” appointed for older adults and people with disabilities.
- **5th Century Visigothic Code:** “people insane from infancy or in need from any age . . . cannot testify or enter into a contract”
- **Feudal Britain:** divided people with decision-making challenges into “idiots” and “lunatics” and appointed “committees” to make their decisions

GUARDIANSHIP IN THE U.S.

“Plenary” or “Full” Guardianship

- Gives the Guardian power to make ALL decisions for the person.
- Used in the **VAST** Majority of cases
- “As long as the law permits plenary guardianship, **courts will prefer to use it.**”

- Frolik, 1998

IN NEVADA

A guardian of the person has the power to decide:

- Where the person lives
- What health care the person receives
- What education the person receives
- Whether and where the person works
- Who sees the person's medical and other records

NV Rev Stat § 159.079

AS A RESULT

Guardians have “substantial and often complete authority over the lives of vulnerable [people].”

4 NAELA J. 1, 7 (2008).

This includes power to make the most basic health, personal, and financial decisions.

AARP, Guardianship Monitoring: A National Survey of Court Practices 1-2 (2006).

WHEN PEOPLE ARE DENIED LIFE CONTROL

Study after Study shows:

- “[F]eel helpless, hopeless, and self-critical”
- Deci, 1975
- Experience “low self-esteem, passivity, and feelings of inadequacy and incompetency,”
decreasing their ability to function
- Winick, 1995

THE PROBLEM

“The typical ward has fewer rights than the typical convicted felon By appointing a guardian, the court entrusts to someone else the power to choose where they will live, what medical treatment they will get and, in rare cases, when they will die. It is, in one short sentence, the most punitive civil penalty that can be levied against an American citizen.”

- House Select Committee on Aging, H.R. Rpt. 100-641 (opening statement of Chairman Claude Pepper)

WHERE DO WE GO FROM HERE?

Guardianship **MAY** be Needed:

- In emergency situations when
 - The person is incapacitated and cannot give consent
 - The person did not previously identify how decisions should be made in that situation
 - There is no one else available in the person's life to provide consent through a Power of Attorney, Advanced Directive, or other means
- To support People:
 - Who face critical decisions and have no interest in or ability to make decisions
 - Who need immediate protection from exploitation or abuse

GUARDIANSHIP IS NEVER NEEDED

JUST

- “Because you have ____”
- “Because you’re ____ years old”
- “Because you need help”
- “Because that’s the way its always been”
- “For your own good”

BUT WE MEANT WELL

“Experience should teach us to be most on our guard to protect liberty when the Government’s purposes are beneficent. . . . The greatest dangers to liberty lurk in insidious encroachment by men of zeal, well-meaning but without understanding.”

Olmstead v. U.S., 277 U.S. 438 (1928)

WE MUST'VE MEANT REALLY WELL

Estimated number of adults under guardianship has **tripled** since 1995

- Reynolds, 2002; Schmidt, 1995; Uekert & Van Duizend, 2011.

RESEARCH

People under guardianship can experience a “**significant negative impact** on their physical and mental health, longevity, ability to function, and reports of subjective well-being”

- Wright, 2010

ON THE OTHER HAND

People with disabilities who exercise greater self-determination have a **better quality of life**, more independence, and more community integration.

- Powers et al., 2012; Shogren, Wehmeyer, Palmer, Rifenbark, & Little, 2014; Wehmeyer and Schwartz, 1997; Wehmeyer & Palmer, 2003

AND

Women with intellectual disabilities exercising more self-determination are **less likely to be abused**

- Khemka, Hickson, and Reynolds, 2005

AND

People with Intellectual and Developmental Disabilities who do **NOT** have a guardian are more likely to:

- Have a paid job
- Live independently
- Have friends other than staff or family
- Go on dates and socialize in the community
- Practice the Religion of their choice

2013-2014



NATIONAL
CORE
INDICATORS™

SO, WHERE DO WE GO FROM HERE?

If:

- We **KNOW** that some people need more support as they age or due to disability
- We **KNOW** that guardianship can result in decreased quality of life and
- We **KNOW** that increased self-determination leads to improved quality of life

Then we need a means of **INCREASING** self-determination while **STILL** providing support

MARGARET “JENNY” HATCH

Margaret “Jenny” Hatch

Twenty-Nine year old woman with Down syndrome.

- High School graduate
- Lived independently
- Employed for 5 years
- Politically active



THE SITUATION: FEBRUARY 2013

- Court Order putting Jenny in a “temporary guardianship”
- Living in a segregated group home
- No cell phone or computer, Facebook password changed
- Guardians controlled all access to her
- Working up to 5 days a week for 8 months
– made less than \$1000

Jenny's Rights In One Sentence

Guardians had the power:

“[T]o make decisions regarding visitation of individuals with Respondent, Respondent's support, care, health, safety, habilitation, education, therapeutic treatment and, if not inconsistent with an order of commitment, residence.”

WHY?

FROM THEIR EXPERT

On Jenny's:

- Independent Living Skills: **“If she had assistance, she may be able to do that”**
- Legal Skills: **“she would need assistance to understand a legal document”**
- Money Management: **She needs “assistance with [a] bank account.”**

THEREFORE...

“She’s going to need assistance to make decisions regarding her healthcare, her living arrangements and such like that, she will need someone to guide her and give her assistance.”

AND...

“I believe what would be beneficial to Jenny is that she is afforded the opportunity to have individuals around her who support and love her, who give her the assistance she needs.”

PETITIONERS' SWORN STATEMENT

How could Jenny execute a Power of Attorney?

“[N]ot only did Jenny have an opportunity to review the documents, but also the attorney had the opportunity to get to know Jenny and understand her capabilities and limitations in understanding legal documents. Based on this series of observations over several visits, the attorney concluded, and we concurred, that Jenny was capable of understanding these documents.”

WHAT THAT ALL ADDS UP TO

Jenny Needs Support:

- To Understand Legal Issues
- To Understand Medical Issues
- To Understand Monetary Issues
 - In her Day to Day Life

IN OTHER WORDS

JENNY IS A PERSON

We Are All Jenny Hatch

A WAY FORWARD: SUPPORTED DECISION-MAKING

“a recognized alternative to guardianship through which people with disabilities use friends, family members, and professionals to help them understand the situations and choices they face, so they may make their own decisions without the “need” for a guardian.”

- Blanck & Martinis, 2015

THINK ABOUT IT

How do you make decisions?

What do you do if you're not familiar with the issue?

- Taxes?
- Medical Care?
- Auto Repairs?

What Do You Do?

**SO, SUPPORTED DECISION-MAKING IS A
LOT OF WORDS FOR**

Getting help when its needed

Just like you and me

AND JUST LIKE YOU AND ME:

Decisions Jenny had made with Support

- Sign Power of Attorney
 - Consent to Surgery
- Medicaid Waiver Individual Service Plan
 - Application for Paratransit
- Authorization to share medical records
- Assignment of a Representative Payee

FINAL ORDER

- First 4 pages justify guardianship.

“However”

- Guardians to be who she wants
- She lives where she wants
- Guardianship for only 1 year – Expired August, 2014
- Only over 2 things – medical and safety

FINAL ORDER

EVEN DURING the 1 year limited guardianship:

“Guardians shall assist Respondent in making and implementing decisions we have termed ‘supported decision making.’”

JENNY GOT JUSTICE



Jenny Hatch and her attorney celebrate after the court victory. (TWP)

‘I’m so happy to go home today’

Theresa Vargas

Jenny Hatch, a 29-year-old-woman with Down syndrome, can live the life she wants after a judge rules she can reside with friends.

WHY?

**Jenny is Strong, Smart, Determined
AND**

She had support from:

- Friends and professionals
- National Organizations and Leaders
- Media
- A Judge who was willing to Listen and Learn

IN OTHER WORDS

Jenny Got Lucky

THE LESSON JENNY TEACHES US

Justice and Self-Determination should:

- **NEVER** depend on luck or who you know.
- **ALWAYS** Be the Rule **NOT** the Exception

So, WHERE DO GO FROM HERE?

When is a Person “Incompetent?”

Incompetent means an adult person who, by reason of mental illness, mental deficiency, disease, weakness of mind or any other cause, is **unable, without assistance, properly** to manage and take care of himself or herself or his or her property, or both. The term includes a person who is mentally incapacitated.

NV Rev Stat § 159.019

WHEN IS A GUARDIAN APPOINTED

- If the court finds the proposed ward to be of limited capacity and **in need** of a special guardian, the court shall enter an order accordingly and specify the powers and duties of the special guardian.
- If the court finds that appointment of a general guardian is **required**, the court shall appoint a general guardian of the ward's person, estate, or person and estate.

NV Rev Stat § 159.054

THINK ABOUT IT

WHAT DOES IT MEAN TO BE “INCAPABLE”

- People may be able “capable” of making some decisions but not others.
 - Or be able to “take care of himself or herself person or property” only with assistance.
 - Or be unable to “provide for [his or her] family” unless they get help understanding them.
- e.g. Salzman, 2010

Capacity to take medication is not the same as capacity to prescribe it!

So...

If a person can “take care of himself or herself” or “take care of his or her property” **with assistance or support**, is a guardianship necessary?

**IS IT NECESSARY
FOR YOU?**

WHICH MEANS: ASK A QUESTION

BEFORE seeking or recommending
guardianship:

**What ELSE Have You
Tried?**

OR, AS THE NATIONAL GUARDIANSHIP ASSOCIATION SAYS

“Alternatives to guardianship, including supported decision making, should always be identified and considered whenever possible prior to the commencement of guardianship proceedings.”

- National Guardianship Association Position Statement on Guardianship, Surrogate Decision Making and Supported Decision Making, 2015

SUPPORTED DECISION-MAKING CAN HELP PEOPLE “TAKE CARE OF” THEMSELVES AND THEIR PROPERTY

Supported Decision-Making can help people:

- Understand information, issues, and choices;
- Focus attention in decision-making;
- Weigh options;
- Ensure that decisions are based on their own preferences
- Interpret and/or communicate decisions to other parties.

- Salzman, 2011

IT'S A PARADIGM, NOT A PROCESS

There is no “one size fits all” method of Supported Decision-Making.

Can include, as appropriate

- Informal support
 - Written agreements, like Powers of Attorney, identifying the support needed and who will give it
 - Formal Micro-Boards and Circles of Support
- Martinis, Blanck, and Gonzalez, 2015.

IN COMMON

ALL Forms of Supported Decision-Making recognize:

- That **EVERYONE** has the Right to Make Choices to the Maximum of Their Ability;
 - That you can get help exercising your Right to Make Choices without giving it up; and
 - That there are as many ways to give and get help as there are people
- Dinerstein, 2012.

SUPPORTED DECISION-MAKING AND SELF DETERMINATION

“Supported Decision-Making has the potential to increase the self-determination of older adults and people with disabilities, encouraging and empowering them to reap the benefits from increased life control, independence, employment, and community integration”
- Blanck & Martinis, 2015

BUT

Supported Decision-Making
ONLY works if we recognize,
respect, and protect
EVERYONE'S
Right to Make Choices.

REMEMBER THE CHALLENGE

EVERY great advance in civil rights fundamentally changed the way “things have always been”

REMEMBER THE OBSTACLES

Change is **HARD**

“We were not promised ease. The purpose of life . . . is not ease. **It is to choose, and to act upon the choice.** In that task, we are not measured by outcomes. We are measured only by daring and effort and resolve.”

- Stephen R. Donaldson

CHANGE THE CULTURE, CHANGE THE WORLD!

- We will ALL be part of the “System”
- What kind of “System” do you want to be in?

“People with disabilities will have the same opportunities for success and security as their nondisabled peers. If we change the culture, we will change the world!”

Gustin & Martinis, 2016

JOIN THE CONVERSATION

National Resource Center for Supported Decision-Making:

SupportedDecisionMaking.Org

The Burton Blatt Institute at Syracuse University: BBI.Syr.Edu

Jonathan Martinis, Senior Director for Law and Policy, JGMartin@Law.Syr.Edu

Where We Are and Where We Can Go

Supported Decision-Making: Where We Are and Where We Can Go

Jonathan
Martinis

Senior Director for
Law and Policy

*The Burton Blatt
Institute at Syracuse
University*

Project Director,
*National Resource
Center for Supported
Decision-Making*

SUPPORTED DECISION-MAKING

Part II

Where We Are

WHY SUPPORTED DECISION-MAKING?

Endorsed by:

- US Department on Health and Human Services
- American Bar Association
- National Guardianship Association
- ASAN
- The Arc
- NAMI

PRECEDENT

In re Peery, 727 A.2d 539 (Pa. 1999).

In re Dameris L., 956 N.Y.S.2d 848 (N.Y. Sur. Ct. 2012).

Ross v. Hatch, No. CWF120000426P-03 (Va. Cir. Ct., 2013)

WASHINGTON DC

IN RE: KING

In re: Ryan Herbert King, Case No. 2003 INT 249 (DC Sp Ct (Probate), 2016).

- Ryan and his parents always worked together so he could make his own decisions
- Ryan's parents told he had to get guardianship when he turned 18
- Court refused to terminate guardianship in 2007

IN RE: KING

- In 2016, presented new evidence to the court including new functional evaluation
- Submitted affidavits showing use of SDM
- Submitted draft Power of Attorney if guardianship terminated
- Held: because Ryan uses SDM to make his own decisions he is not “incapacitated.”
- Guardianship terminated

VERMONT:

IN RE: CB

In re: CB, Docket No. 4-9-16 OsGS, Sp Ct (Family Division)

- CB was under guardianship of grandmother
- Grandmother moved to resign as guardian, public guardian was to be appointed
- Public guardian raised possibility of using SDM instead of guardianship for CB
- Court ordered public guardian to meet with CB's support team to explore possibility

IN RE: CB

- Supporters met to develop SDM plan
- Submitted SDM plan to the Court for consideration
- Court terminated guardianship finding SDM plan was “step down” from guardianship because all parties agreed to follow SDM plan

NEW YORK:

IN RE: DD

In re: DD, File No. 2014-2185, Surrogate's Court (Kings)

- DD was 29 years old with Down syndrome and full scale IQ of 54
- Two doctors certified that bc of his ID, he could not make his own decisions
- Evidence showed he worked, managed his own transportation, social life, personal hygiene

IN RE: DD

- DD said he wanted to get married
- Mother moved for guardianship
- GAL investigated, said he could make his own decisions with support, recommended alternatives to guardianship
- Held: guardianship denied. There was no evidence that he couldn't make his own decisions, with support.

IN RE: DD

- Held: alternatives to guardianship like SDM “enable individuals with disabilities to maintain as much control over their own life decisions as they are capable to make in the least restrictive setting.”
- “the standard here is not whether the petitioners can make better decisions than DD, it is whether or not DD has the capacity to make decisions for himself with the support he abundantly has.”

LEGISLATION: TEXAS

- “Supports and Services” - formal and informal resources that help people meet their needs, manage their health and finances, and make decisions – Tex. Estates Code §1002.031(2015)
- Before placing people under guardianship, Court must find by clear and convincing evidence they cannot make their own decisions using “Supports and Services” -Tex. Est. Code Ann. §1101.101(2015)

LEGISLATION: TEXAS

- Recognizes SDM Agreements where people appoint supporters to help them make decisions – Tex. Estates Code
- Provides a form to appoint supporters. In order to be legally enforceable, SDM agreement must be in substantial compliance with the form – Tex. Estates Code 1357.056
- Other model forms available including one by DD Council at:
<http://www.tcdd.texas.gov/resources/guardianship-alternatives/supported-decision-making/>

LEGISLATION: DELAWARE

- Recognizes SDM Agreements
- People can enter into legally enforceable SDM agreements that:
 - (1) Designate at least 1 supporter.
 - (2) ID the types of decisions for which the supporter is authorized to assist.
 - (3) ID the types of decisions, if any, for which the supporter may not assist.

Delaware Code, Title 16, Section 9405A

LEGISLATION: DELAWARE

- SDM Agreements must be “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.” – Delaware Code, Title 16, Section 9405A

SDM PROJECT: NATIONAL RESOURCE CENTER FOR SUPPORTED DECISION-MAKING

- www.SupportedDecisionMaking.Org
- Provide information, training, and technical assistance regarding SDM
- Model forms, research materials, educational material, SDM news
- Conduct research to determine links between SDM, self-determination, and quality of life

SDM PROJECTS: VERMONT

- Vermont Task Force “to create solutions and initiatives that transform practices in a way that brings a culture of collaboration”
- Includes consumers, families, and representatives of the Provider, Legal, Educational, Employment, Advocacy, Mental Health, Aging, and Developmental Disabilities communities

VERMONT PROJECTS

- Pilot project between DD Provider and Public Guardian to identify people who could “take care of themselves’ with appropriate supports, plan for and provide the supports, and move to terminate guardianship
- Project between Self-Advocate Group, Schools, VR, State P&A and State DD Agency to identify students at risk of guardianship and help them receive appropriate supports and services

VERMONT PROJECTS

- Collaboration between Public Guardian, State DD Agency, and State Evaluators to review competency evaluation guidelines to examine whether people are able to make their own decisions if they have appropriate supports
- Education of people, families, judges, attorneys, and others about alternatives to guardianship

SDM PROJECT: MY CHOICE KENTUCKY

- Identify 5-7 people under guardianship or at risk
- Help them implement SDM plans to avoid or be restored from guardianship
- Analyze impact on quality of life

SDM PROJECT: CENTER FOR PUBLIC REPRESENTATION

- Work with people with Intellectual and Developmental Disabilities who are in or at risk of guardianship
- Help them identify supporters and create SDM agreements
- Create model forms
- www.SupportedDecisions.Org

SDM PROJECT: SAKS INSTITUTE FOR MENTAL HEALTH LAW

- Work with cohort of people with mental illness
- Help them identify supporters and create SDM agreements
- Analyze impact on their quality of life

SUPPORTED DECISION-MAKING

Part III

Where Can We Go?

OPPORTUNITIES FOR SDM ARE ALL AROUND US

- “Student Led” IEPs and Transition Planning
- “Informed Choice” in Vocational Rehabilitation
- “Person Centered Planning” in Medicare/Medicaid
- Powers of Attorney/Advanced Directives

Supported Decision-Making Opportunity: Special Education

Purpose of the IDEA:

“to ensure that all children with disabilities have available to them a free appropriate public education that emphasizes special education and related services designed to meet their unique needs and **prepare them for further education, employment, and independent living.**”

20 U.S.C. § 1400(d)(1)(A) (emphasis added).

AND YET:

- The school IEP process is usually the first “prompt” for parents to seek guardianship
- School personnel are the most frequent source of recommendations that parents seek guardianship

- Jameson, et al, 2015

Best Practices: The Student Led IEP

THE STUDENT actually engages in self-determination

THE STUDENT can practice different decision-making methods in a “safe environment”

THE STUDENT leads meeting

THE STUDENT Identifies goals and objectives with assistance from professionals and people **THE STUDENT** invites

- Mason, Mcgahee-Kovac, Johnson, L., & Stillerman, S. (2002)

Doesn't That Sound Like Supported Decision-Making?

“people with disabilities use friends, family members, and professionals to help them understand the situations and choices they face, so they may make their own decisions.”

- Blanck & Martinis, 2015

Supported Decision-Making: SpEd Transition Services

Transition services:

- “[F]acilitate the child’s movement from school to post-school activities, including post-secondary education, vocational education, integrated employment (including supported employment), continuing and adult education, adult services, independent living, or community participation;”
- **Are “based on the individual child’s needs, taking into account the child’s strengths, preferences, and interests; and**

20 USC 1401(34)

SUPPORTED DECISION-MAKING: VOCATIONAL REHABILITATION

VR program provides services and supports to help people with disabilities:

“prepare for, secure, retain, advance in, or regain employment”

Rehabilitation Act, 2006, § 722 (a)(1)

VR SERVICES

Some services that are available:

- Assessments
- Counseling
- Job search and retention services
- Education
- Assistive technology
- Medical and mental health care
- On the job training
- Job coaches
- Transportation
- Services to family members (like Day Care!)
 - 34 CFR 361.48

“INFORMED CHOICE”

VR Agencies must ensure that the person can exercise “informed choice”

“Informing each applicant and eligible individual . . . through appropriate modes of communication, about the availability of and opportunities to exercise informed choice, including the availability of support services for individuals with cognitive or other disabilities who require assistance in exercising informed choice throughout the vocational rehabilitation process”

Doesn't That Sound Like

**Supported Decision-
Making?**

SUPPORTED DECISION-MAKING: PERSON CENTERED PLANNING

Person Centered Plan MUST:

- Address “health and long-term services and support needs in a manner that reflects individual preferences and goals.”
- Result “in a person-centered plan with individually identified goals and preferences, including those related community participation, employment, income and savings, health care and wellness, education and others.”

www.medicaid.gov/medicaid-chip-program-information/by-topics/long-term-services-and-supports/home-and-community-based-services/downloads/1915c-fact-sheet.pdf

PERSON CENTERED PLANNING FOCUSES ON

What is:

- Important TO the Person
- Important FOR the Person

Where the Person is and where the Person wants to be

- What needs to change and what needs to stay the same to get there

DOESN'T THAT SOUND LIKE...

Supported Decision-Making can
address planning and
implementation in all those areas
whether as part of an HCBS Waiver
or Not!

SUPPORTED DECISION-MAKING

POWER OF ATTORNEY

Power of Attorney giving agent decision-making authority:

“It is my and my agent’s intent that we will work together to implement this Power of Attorney. That means that I should retain as much control over my life and make my own decisions, with my agents support, to the maximum of my abilities. I am **giving my agent the power to make certain decisions on my behalf, but my agent agrees to give primary consideration to my express wishes in the way she makes those decisions.”**

SUPPORTED DECISION-MAKING: MEDICAL ADVANCED DIRECTIVE

“My agent will work with me to make decisions and give me the support I need and want to make my own health care decisions. This means my agent will help me understand the situations I face and the decisions I have to make. Therefore, at times when my agent does not have full power to make health care decisions for me, my agent will provide support to make sure I am able to make health care decisions to the maximum of my ability, with me being the final decision maker.”

ETHICAL CONSIDERATIONS: YOU'RE ALREADY USING IT

Nevada Rules of Professional Conduct, Rule 1.14(a)

“When a client’s capacity to make adequately considered decisions in connection with a representation is diminished, whether because of minority, mental impairment or for some other reason, the lawyer shall, as far as reasonably possible, maintain a normal client-lawyer relationship with the client.”

ETHICAL CONSIDERATIONS: REALLY, YOU SHOULD BE USING IT

ABA Model Rules of Professional Conduct,
Comment to Rule 1.14(a) – may be used to
interpret Nevada Rule 1.14 per Rule 1.0A

“The normal client-lawyer relationship is based on the assumption that the client, when properly advised and assisted, is capable of making decisions about important matters. . . . [A] client with diminished mental capacity often has the ability to understand, deliberate upon, and reach conclusions about matters affecting the client's own well-being.”

ETHICAL CONSIDERATIONS: YOU SHOULD BE USING IT

ABA Rules of Professional Conduct

Comment to Rule 1.14 - – may be used to interpret Nevada Rule 1.14 per Rule 1.0A

“The client may wish to have family members or other persons participate in discussions with the lawyer. . . . Nevertheless, the lawyer must keep the client's interests foremost and, except for protective action authorized under paragraph (b), must look to the client, and not family members, to make decisions on the client's behalf.”

ETHICAL CONSIDERATION

PLEASE, USE IT!

ABA Rules of Professional Conduct

Comment to Rule 1.14 - – may be used to interpret Nevada Rule 1.14 per Rule 1.0A

“If a lawyer reasonably believes that a client is at risk of substantial physical, financial or other harm unless action is taken . . . such measures could include: **consulting with family members, using a reconsideration period to permit clarification or improvement of circumstances, using voluntary surrogate decisionmaking tools such as durable powers of attorney or consulting with support groups, professional services, adult-protective agencies or other individuals or entities** that have the ability to protect the client. In taking any protective action, the lawyer should be guided by such factors as the **wishes and values of the client** to the extent known, the client's best interests and **the goals of intruding into the client's decisionmaking autonomy to the least extent feasible**, maximizing client capacities and respecting the client's family and social connections.”

CHANGE THE CULTURE, CHANGE THE WORLD!

“Long after the schools, Vocational Rehabilitation, early interventionist, behavioral consultants, and para-educators have gone. the students will be adults. . . We [are] ethically, morally, and fiscally responsible for supporting their lives of success and meaning. . . . We have the tools, we have the means . . . we have the vision.”

Gustin, 2015

JOIN THE CONVERSATION

National Resource Center for Supported Decision-Making:

SupportedDecisionMaking.Org

The Burton Blatt Institute at Syracuse University: BBI.Syr.Edu

Jonathan Martinis, Senior Director for Law and Policy: JGMartin@Law.Syr.Edu

About this Project

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ABA Proposal 113

American Bar Association
Policy on
Supported Decision Making
August 2017
Proposal 113

ADOPTED
RESOLUTION

RESOLVED, That the American Bar Association urges state, territorial, and tribal legislatures to amend their guardianship statutes to require that supported decision-making be identified and fully considered as a less restrictive alternative before guardianship is imposed; and urges courts to consider supported decision making as a less restrictive alternative to guardianship; and

FURTHER RESOLVED, That the American Bar Association urges state, territorial, and tribal legislatures to amend their guardianship statutes to require that decision-making supports that would meet the individual's needs be identified and fully considered in proceedings for termination of guardianship and restoration of rights; and urges all courts to consider available decision-making supports that would meet the individual's needs as grounds for termination of a guardianship and restoration of rights.

ABA Practical Tool for Lawyers



PRESUME
guardianship
is not needed.

REASON.
Clearly identify
the reasons for
concern.



PRACTICAL Tool for Lawyers:

Steps in Supporting Decision-Making

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

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



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

IDENTIFY
abilities. Identify
areas of strengths
and limitations in
decision-making.

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

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

LIMIT
any necessary
guardianship
petition and order.



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

ABA
Defending Liberty
Pursuing Justice

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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 www.ambar.org/practicaltool.

PRESUME guardianship is not needed.

- ☐ Consider less restrictive options like financial or health care power of attorney, advance directive, trust, or supported decision-making
- ☐ Review state statute for requirements about considering such options

Observations and Notes:

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

Observations and Notes
(List supports needed.):

*Adapted from University of Missouri Kansas City, Institute for Human Development, "MO Guardianship: Understanding Your Options & Alternatives," <http://moguardianship.com>.

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 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**

Observations and Notes:

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

Observations and Notes:

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:

IDENTIFY 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

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

Observations and Notes:

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

Could any of these appointments meet the needs:

- ☐ Agent under health care power of attorney or advance directive
- ☐ Health care surrogate under state law
- ☐ Agent under financial power of attorney
- ☐ Trustee
- ☐ Social Security representative payee
- ☐ VA fiduciary
- ☐ Supporter under representation agreement, legally or informally recognized

Observations and Notes:

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

Observations and Notes:

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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 aging of the population² and the increase in individuals with disabilities,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 <https://www.census.gov/prod/2014pubs/p25-1140.pdf>.

³ *Disability and Health*, World Health Organization Fact Sheet No 352 (December 2015), available at <http://www.who.int/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 (UGPPA).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 (CRPD),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 "a critically important alternative"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.

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

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

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

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 http://supporteddecisionmaking.org/sites/default/files/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 “unperson”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 “least restrictive alternative”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

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

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

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

Moreover, a compelling argument can be made that unnecessary guardianship without the examination of workable alternatives violates the 1999 Supreme Court decision in the *Olmstead* decision¹¹ requiring community integration, in that it unnecessarily isolates and segregates individuals in efforts to protect them.

Practice Standards

The *National Probate Court Standards*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

ABA Model Rules of Professional Conduct 1.14¹⁴ instructs attorneys to recognize client self-determination, 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

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

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

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

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.

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 “causal agents”¹⁶ in their lives is consistent with gerontological findings¹⁷ 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 findings show that younger adults¹⁸ 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 http://supporteddecisionmaking.org/sites/default/files/promoting_causal_agency_self-determined_learning_model_instruction.pdf.

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/content/54/1/67.full.pdf+html>.

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

¹⁹ *MO Guardianship: Understanding Your Options & Alternatives*, at <http://moguardianship.com/#materials>, sponsored, 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 <http://moguardianship.com/MO%20Guardianship%20RESOURCE%20GUIDE%20rev%20Sept%20%202013.pdf>.

- 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, co-workers, 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, mooted the need for a guardianship, or at least delaying the decision to seek guardianship.

Acute Temporary Medical Conditions

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

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

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

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

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

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

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

Sensory Deficits

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

Medication Effects; Polypharmacy

Prescription and over-the-counter medication, while potentially improving health, may affect mental status²⁹—especially if multiple drugs are taken simultaneously,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 certain drugs and drug interactions.³¹ Careful review³² of medications could identify changes that significantly improve mental functioning.

Pain

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

Emotional Conditions

- Depression:³⁴ Ongoing depression can impair judgment and cause fatigue.
- Stress; grief: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 http://www.dana.org/News/Can_Hearing_Loss_Predict%E2%80%94or_Lead_to%E2%80%94Cognitive_Decline/.

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

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

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

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

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

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

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

³⁵ Cell Press, *How repeated stress impairs memory*, ScienceDaily (Mar. 2012), available at <http://www.sciencedaily.com/releases/2012/03/120307132202.htm>.

- Transfer trauma.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.

- Age & disability discrimination; stereotyping.³⁷ Myths and stereotypes about aging³⁸ and disability³⁹ 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 their own perceptions and biases⁴⁰ to minimize unnecessary intrusive actions.
- Cultural barriers.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 reasons why families may fight⁴² 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.

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>.

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

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

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

⁴⁰ *Understanding the Four C's of Elder Law Ethics*, American Bar Association Commission Law and Aging, available at http://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 <http://www.uclalawreview.org/cultural-competency-training-preparing-law-students-for-practice-in-our-multicultural-world-2/>.

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

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 legal services,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 (P&As)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 Older Americans Act⁴⁵ 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

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

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

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

with Medicare problems. To find resources in your area quickly, use the [national Eldercare Locator](#).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 ([ADRC](#)).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 [Administration for Community Living](#)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 [long-term care ombudsman programs](#).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.** State Developmental Disability Councils⁵⁰ 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) [Training Objectives for Eldercare Mediation](#).⁵¹ In especially high conflict cases, find out if your court is piloting an “[eldercaring coordination](#)”⁵² program according to ACR guidelines.

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

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

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

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

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

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 http://acrelldersection.weebly.com/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 <http://www.eldersandcourts.org/~media/Microsites/Files/cec/ACR%20Guidelines%20for%20Elder%20Caring%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 communication techniques⁵⁶ 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 <https://caregiver.org/caregiving>.

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

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 <https://www.apa.org/pi/aging/resources/guides/diminished-capacity.pdf>.

TTEAM. 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 “circle of support”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 http://www3.opwdd.ny.gov/wp/images/cos_master_01_12.pdf.

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

IDENTIFY 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 Handbook for Lawyers⁵⁹ 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 <http://www.apa.org/pi/aging/resources/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 Adult Protective Services.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 <http://www.napsa-now.org/>.

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

Undue influence⁶¹ 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). Legal definitions⁶² 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 list of options⁶³ 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 advance directive document,⁶⁴ which also could include statements of the person’s wishes concerning medical treatment. The real challenge will be ensuring that the person effectively

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

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

⁶³ *Decision Making Without Guardianship*, National Guardianship Network, available at [http://www.naela.org/NGN/About Guardianship/Decision Making Without Guardianship/NGN/About GuardianshipMain/Decision Making.aspx?hkey=eb9c2ced-35aa-4499-acd1-26cd208f02ac](http://www.naela.org/NGN/About%20Guardianship/Decision%20Making%20Without%20Guardianship/NGN/About%20GuardianshipMain/Decision%20Making.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 http://www.americanbar.org/groups/real_property_trust_estate/resources/estate_planning/living_wills_health_care_proxies_advance_health_care_directives.html.

communicates his or her values and wishes to the agent. Check your state's laws⁶⁵ for any specific requirements. Some state laws⁶⁶ 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 Do Not Resuscitate (DNR) Order⁶⁷ 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 (POLST)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 statutes in 44 states,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 power of attorney,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 http://www.americanbar.org/content/dam/aba/administrative/law_aging/Links_to_State_Advance_Directive_Forms_authcheckdam.pdf.

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

⁶⁷ *Do-not-resuscitate order*, MedlinePlus, U.S. National Library of Medicine, available at <http://www.nlm.nih.gov/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 http://www.americanbar.org/content/dam/aba/administrative/law_aging/2014_default_surrogate_consent_statutes.pdf.

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

Trustee

For complex or substantial assets, the person may be able to execute a document transferring title and authority to manage property to a trustee⁷¹ for the benefit of either the person or others as beneficiaries, under a revocable living trust.

Representative Payee

The Social Security Administration administers a representative payment program⁷² 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 VA Fiduciary⁷³ 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 decision-making assistance to enter into a “representation agreement”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 Nidus, the Personal Planning and Resource Center Registry.⁷⁵ Texas has enacted a legally recognized supported decision-making agreement,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 http://www.americanbar.org/groups/real_property_trust_estate/resources/estate_planning/revocable_trusts.html.

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

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

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

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

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

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 state laws⁷⁸ 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 templates for limited orders⁷⁹ 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.

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

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

⁷⁹ The form for the State of Rhode Island Petition for Limited Guardianship or Guardianship is available at <http://sos.ri.gov/documents/probate/PC2.3.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 Standards of Practice*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 rights could be restored.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 necessity 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 <http://ncsc.contentdm.oclc.org/cdm/ref/collection/spcts/id/240>.

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

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 http://www.americanbar.org/publications/bifocal/vol_34/issue_6_august2013/guardianship_restoration_of_rights.html.



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: www.americanbar.org/disability
 - Section on Civil Rights and Social Justice: www.americanbar.org/crsj
 - Section on Real Property, Trust and Estate Law: www.americanbar.org/rpte
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Defining Supported Decision Making

Defining Supported Decision Making—SDM in Advance Care Planning

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Supported decision making (SDM) is a Person driven, or Person-centered model, that empowers a Person with limited or declining capacity to make choices, with guidance and advice from trusted advisors. SDM starts with the principle that all individuals, as long as they are able to communicate, have a fundamental ability and right to make choices, that adults normally engage advisors to assist with life's decisions and that choices of the individual should be honored.² SDM gained traction in advocacy for adults with disabilities³ and is expanding as a model for helping older adults experiencing changes in memory and cognition.

SDM is a balancing point between leaving a Person totally on their own, and someone taking control of the Person's life.⁴ SMD requires advisors or a supportive circle to work with the Person to offer advice and guidance to assist the Person in making choices. The advisors are tasked with explaining the facts and issues, offering advice, making recommendations, and helping the Person communicate his or her choices – always in consultation with the Person -- and then honoring those choices.

We all practice SDM in our daily lives. When we are sick, we ask medical professionals for a diagnosis and advice and make a choice on the treatment we want or do not want based on that information. When we take our cars in for service, the “service advisor” makes recommendations on work to be done, and we make choices based on that advice. We select advisors -- be they doctors, mechanics, bankers or plumbers based -- on how they treat us and how we feel about their advice. As adults we engage in supported decision making all of the time.⁵ We also have a right to ignore the advice and make what others may see as bad choices. At one time or another most of us have ignored the advice of a doctor, or chosen not to have that 30,000 mile scheduled service done on our car. We have all spent money in ways that others considered imprudent – as adults we are allowed to do that. These are rights and choices that should not be taken away from a Person just because the world perceives the Person as being different.

Yet, for adults with disabilities and for adults experiencing changes in memory or cognition or developing dementia,



Person or person

The focus of supported decision making is on the individual. If I referred to the individual as David or Mary, I would capitalize the first letter of the name, recognizing that I am referring to an individual human being. I capitalize Person, to remind us that the focus is on an individual human being. While this usage may seem awkward, or grammatically incorrect, the goal is to focus the readers on the humanity of the Person.

the norm has been to take over decision making for them. All too often this is an overreaction – taking away all choice in an effort to protect the Person from their choices. Utilizing the SDM model empowers the adult to remain active in the decisions impacting their lives. For adults experiencing changes in memory and cognition, the SDM model can play an important role in planning, selecting advisors and legally empowering advisors. After all, research has correlated self-determination with improved quality of life for older adults including improved physical and mental health.⁶

Capacity

When we think about capacity, it is easy to think that some people are fully capable and others totally lack capacity due to intellectual challenges or dementia. But the reality is, we all lack some—perhaps significant--capacity. While I may lack the capacity to fly an airplane, I might be able to learn how to fly one with the help of advisors. It was demonstrated in an episode of “Myth Busters” that a non-pilot may be talked through landing an airliner by breaking the landing process down into small steps and with simple easy-to-follow choices and instructions.⁷ Very complex challenges can be broken down into simple understandable steps.

Early Diagnosis → Early Planning

Early diagnosis of dementia improves options for legal planning and treatment. A Person can have a lot of residual capacity at the time of diagnosis. As understanding of the causes of dementia expand and treatment options emerge for some causes, there is an expanded push for early diagnosis.⁸

While we urge every adult to plan for incapacity, planning becomes critically important for a Person experiencing changes in memory and cognition. Planning must take place while a Person has the ability to understand and make choices, so that he or she can be engaged in the planning process. Dementia will progress to the point that planning is impossible. The early diagnosis of dementia needs to be a trigger point for selecting and legally empowering advisors to assist with personal, health and financial decisions. The sooner the Person engages in planning, the greater the likelihood that the Person will have the legal capacity needed to do so.

The Challenge of Communicating

One of the challenges to SDM is communicating effectively. Communicating across the spectrum of ability and life experience is more complex than communicating with someone of equal or greater life experience and ability, but it can be done. Basic ethics and morals obligate professionals to communicate in a manner that the Person can understand, as does the Americans with Disabilities Act’ requirement to accommodate the sensory loss and cognitive impairments that people who are older may face.⁹ A starting point is explaining, offering options, and advice and asking the person what do they want to do, or how do they feel. Open ended questions are harder to answer, but if the Person is able to answer them the answer will offer greatest insight into the persons values, goals and choices. When the person has less experience or less ability, multiple choice questions, breaking the major issue down into smaller parts that add up to the overall choice may be more useful.

Let me offer an example of taking a complex question and breaking it down into simple choices. Start with a standard deck of 52 playing cards. Shuffle and have someone draw a card. You can determine what card the person is holding in six simple steps, without asking them what card they are holding.

1. Ask if the card they are holding a face card (Jack, Queen, King or Ace) or a number card, (two through nine)?
2. If it is a face card, ask if it is a high face card Ace-King, or a low face card Jack-Queen; If it is a number card ask if it is a high number card six through nine, or low number card two through five.
3. Ask if it is Red or Black?
4. If it is Red ask if it is a queen or heart, if it is black ask if it is a spade or club

5. If it is a number card, ask if it is odd or even.
6. You have now narrowed it down to two cards, ask if it is one of them,
7. If it is not the card you guessed, it is the other one.

You didn't have to ask 52 questions, the first four questions can be asked in any order. If it is a face card, you have one less question. You are asking simple multiple-choice questions. At no point did you ask what card the person is holding. But in small steps you deduced the ultimate answer. Any person who is familiar with the cards in a deck can answer these questions. If the person was unfamiliar with the cards in a deck of cards, you could use illustrations to ask – does it look like this or this (red or black,) face or number, high or low, odd or even?

This kind of logic can be used to break nearly any question down into small parts anyone who can express a choice can make. When people say it is too complicated to ask a person to make a choice, what they are saying is they don't want to take the time and put the effort into helping the person understand the options, to help them arrive at a choice.

How Does SDM Impact Advance Care Planning?

Traditional advance care planning focusses on the “who” by naming an agent to make decisions. With Supported Decision Making, the focus is on “how” decisions are made, in addition to who the agents or advisors are. You do this by selecting agents who understand and are willing to commit to the principles of person driven decision making using SDM. You then train the agents in the principles of SDM and legally empower them to support the person.

Selecting agents/advisors, sometimes known as supporters or the supportive circle, is very much like selecting agents for powers of attorney or selecting a health care surrogate. You start by asking people trusted by the Person if they are willing and able to help. Because the goal of SDM is person-driven decision making, the best advisors are persons who are willing to commit to always consulting with the person, while offering advice and seeking input from the person. This is a departure from the traditional paternalistic view of the advisor as an agent charged responsibility and authority to make decision as if standing the shoes of, or in the best interest of the Person. The advisors need to commit to:

- Always provide information to the Person,
- Communicate by breaking the information into smaller parts
- Always offering choices
- Always addressing all questions or concerns
- Offering advice, without undue influence
- Always asking the Person to make a choice or express a preference
- Assisting the Person as needed with carrying out choices while not making them.

The changes in drafting documents to incorporate SDM principles can be simple. In addition to appointing a legal agent to act for the Person under certain circumstances (e.g., in cases of incapacity), the document can offer a supported decision-making framework for the agent to follow before and after those circumstances should arise. We want to instruct the agent in “how” to go about making and supporting a Person's decisions in a person-centered and person-driven manner. For a document, such as a power of attorney of health care, that appoints health care agents to make health care decisions for the Person if he or she is incapable of doing so, or a form naming a health care surrogate, incorporating SDM can be done by including language such as:

I ask that my that my health care surrogate named in this document or otherwise empowered by law explain to me the nature of any illness, condition, or diagnosis. I ask that my surrogate explain to me the treatment options available, the prognosis, the risks and benefits of various treatment options, and the recommendations from my doctors, and then ask for my choice or preference. I ask that my surrogate continue to do this, even if it appears that I may not be able to understand what is being explained. I ask that any decisions that are made by my surrogate be based on what my surrogate

thinks I would do if I were able to make the choice. When in doubt, please consult the attached documents for guidance. These documents reflect my instructions, my health care goals, and my personal values in making health care decisions.

To make good health care choices, the agent needs to understand the health care values and goals of the Person. There are many effective tools for reviewing health care values and goals. Part of the planning process needs to include facilitating discussions and exercises aimed at developing understanding of the Person's health care wishes. One legal practitioner calls this process "gradual counseling," whereby he can help a Person build and use a trusted network of support to help clarify goals, values, and lifetime.¹⁰

Care needs to be taken in incorporating SDM language into a Power of Attorney so that third parties remain comfortable relying on the authority of the document. Some clauses to consider including are:

I ask that my agent named in this document, before taking any actions using this document, always discuss with me what is being considered, what the options are, make a recommendation and seek my input. Even if it appears that I am unable to understand, I ask that my agent continue to explain to me what is happening and the choice you are making and why. Third parties can rely on my agent's representation that they have followed this request. A failure to follow this request shall not invalidate any transaction entered into by agent using this document.

The Person may be concerned about the agent using the power of attorney to make sweeping changes in the Person's financial affairs. Here is a sample clause that would require a second signature on transactions above a stated dollar amount.

Financial transactions in excess of \$_____ require the signature of my agent, and either myself or _____.

For many low to middle income adults, real estate is the most valuable asset that they own.

My agent shall not have authority to sell, gift or otherwise transfer any interest in any real estate that I own.

Or

My agent shall only sell, transfer or gift my home, after consultation with and agreement by _____.

There is a concern that a Person engaged in SDM will try to revoke a power of attorney, and then may be unable to appoint a replacement agent. This can lead to guardianship that the parties were seeking to avoid. One way in which this may be avoided is by drafting into the power of attorney document a "cooling off period" on any revocation. The cooling off period gives the parties time to resolve conflicts or questions. For example:

Any notice of termination, revocation or suspension of this power of attorney by me must be in writing and will start a five-day cooling-off period from the date of the notice until it is effective. During the five-day cooling-off period, the authority of my agent is suspended. During the cooling-off period, I ask that my agent communicate with me, including bringing in a neutral third party to discuss the revocation, the implications of it, and any alternatives.

By using the document, my agent is certifying, subject to penalties for perjury, that we are not in a cooling off period and I have not revoked this document.

A concern is abuse or exploitation by the agent during the cooling-off period. This clause allows police or adult protective services to immediately terminate or revoke the power of attorney based on a reasonable belief that the person is being abused by the agent.

This document may be terminated immediately by written notice from law enforcement or adult protective services to my agent, based on reasonable belief that I am being neglected, abused or exploited by my agent as defined by state law.

The core advance care planning documents deal with money and health care. But there is so much more that the Person may want or need help with over their lifetime. Most of these additional issues can be addressed in a Supported Decision Making Agreement. SDM agreements will be covered in a later section.

Supported Decision-Making: Update on Trends in the United States

Supported Decision-Making (“SDM”) is an emerging nationally and internationally recognized alternative to adult guardianship that is currently used both within the United States and abroad.¹¹ It has been recognized by scholars as having the strong potential for promoting favorable outcomes in the lives of people with disabilities and older adults, and studies are underway to further verify such outcomes.¹²

Many see the United Nations Convention on the Rights of Persons with Disabilities (“CRPD”) as the impetus of current reform efforts advancing SDM. Its Article 12 requires signatory nations to “recognize that persons with disabilities enjoy legal capacity on an equal basis to others in all aspects of life” and “take appropriate measure to provide access by a person with disabilities to the support they require in exercising their legal capacity.”¹³ As the CRPD Committee explained, the term “supported decision-making” describes one of the ways a person can be assisted in exercising legal capacity.¹⁴

While the United States is not among the many countries that have ratified the CRPD,¹⁵ SDM has been linked to the overarching aims of U.S. laws and federal policy impacting older adults, including the Americans with Disabilities Act, the Older Americans Act, and the Medicaid and Home and Community Based Services regulations.¹⁶ It has been recognized and endorsed by the Administration for Community Living (ACL) of the U.S. Department of Health and Human Services, which has funded the National Resource Center for Supported Decision-Making (NRC-SDM) since 2014.¹⁷

As such, Supported Decision-Making is taking hold within this country’s disability and aging advocacy discourse¹⁸ and legal literature,¹⁹ as well as by state legislatures, policymakers, and courts. For example:

- Since 2012, there have been court decisions recognizing SDM over permanent guardianship in New York, Virginia, Massachusetts, the District of Columbia, Florida, and Vermont.²⁰
- State legislatures are recognizing SDM in legal agreements (Texas²¹ and Delaware²²) and areas of medical decision-making (Maryland²³) and are ordering SDM-related studies (Virginia,²⁴ Maine,²⁵ and Indiana²⁶). At least half a dozen states currently have pending SDM-related bills in their legislatures.²⁷
- SDM pilot projects have occurred or are underway in states including Massachusetts,²⁸ Maine,²⁹ New York,³⁰ North Carolina,³¹ South Carolina,³² Texas,³³ and Vermont,³⁴ among others.
- Since 2015, The NRC-SDM has administered grants for state-based projects committed to advancing an innovative approach to increasing knowledge of and access to SDM by older adults and people with intellectual and developmental disabilities across the life course. Thus far, grantees have included collaborations in Delaware, Florida, Georgia, Indiana, Maine, North Carolina, Nevada, New York, Tennessee, and Wisconsin.³⁵
- The American Bar Association Commission on Law and Aging, along with other partners, developed a tool to help lawyers identify and implement less-restrictive decision-making options for people with disabilities and older adults.³⁶ NRC-SDM has compiled SDM tools and guides on its web portal. Some are already being used in cases in D.C. and California.³⁷ The Maine and North Carolina NRC-SDM grantees have developed and used SDM forms in their states,³⁸ as has the Massachusetts SDM pilot.³⁹

On the broader scale:

- On July 19, 2017, the National Conference of Commissioners on Uniform State Laws approved revisions to what will be known as the Uniform Guardianship, Conservatorship & Protective Arrangements Act

(UGCPAA). This model law would, among other things, formally recognize SDM and require its consideration as a less-restrictive alternative to guardianship.⁴⁰

- The House of Delegates of the American Bar Association approved a resolution urging the amendment of guardianship statutes to require that SDM “be identified and fully considered as a less restrictive alternative before guardianship is imposed” and be considered a “grounds for termination of a guardianship and restoration of rights.”⁴¹
- In addition to ACL, other federal agencies⁴² and federal advisory bodies⁴³ are specifically recognizing SDM as an important alternative to guardianship and substitute decision-making arrangements.
- The National Guardianship Association has recognized the role of SDM both before and within guardianship.⁴⁴
- SDM has been the topic of national stakeholder summits, including those convened by the American Bar Association,⁴⁵ Quality Trust for Individuals with Disabilities, the Burton Blatt Institute, the Council on Quality and Leadership,⁴⁶ and the NRC-SDM, among others.

More work needs to be done to ensure SDM becomes firmly entrenched within the ethos of supporting older adults with cognitive decline in a way that will address critics concerns regarding the risks of undue influence and exploitation -- the latter of which must be acknowledged occurs in all decision-making arrangements, including guardianship. Initiatives should include supporting demographically and geographically diverse SDM pilots that specifically focus on older adults; continuing to provide widespread education on SDM to the public, legal practitioners and the judiciary systems; and exploring ways in which to provide supports for people who have no one suitable to act as a supporter. Expanding the use of the practical strategies identified in this Pre-Conference that promote the use of SDM will go a long way towards reaching the goal of advancing everyone’s right to make choices.

Endnotes

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² Supported Decision Making: Protecting Rights, Ensuring Choices, Jonathan G. Martinis, BIFOCAL, Vol. 36, No. 5, May – June 2015, pages 107-110.

³ <http://supporteddecisionmaking.org/>

⁴ Brainstorming Guide: How Are We Already Using Supported Decision-Making?
<http://supporteddecisionmaking.org/sites/default/files/sdm-brainstorming-guide.pdf>

⁵ Supported Decision-Making: What, Why, & How, Morgan K. Whitlatch,
http://supporteddecisionmaking.org/sites/default/files/event_files/MD-Arc-2016-Convention.pdf

⁶ See, e.g., Melanie H. Maller et al., *Perceived Control in the Lives of Older Adults: The Influence of Langer and Rodin’s work on Gerontological Theory, Policy, and Practice*, 54 *Gerontologist* 67, 67 (2014); Brian P. O’Connor and Robert J. Vallerand, *The Relative Effects of Actual and Experienced Autonomy on Motivation in Nursing Home Residents*, 13 *Canadian Journal on Aging*, 528-38 (1994).

⁷ <http://www.discovery.com/tv-shows/mythbusters/mythbusters-database/person-with-no-flying-experience/>

⁸ Early Diagnosis of Dementia, Karen S. Santacruz, Daniel Swagerty, American Academy of Family Physicians, 2001, viewed online http://www.drplace.com/Early_Diagnosis_of_Dementia.16.26479.htm (7/22/2016)

⁹ See, e.g., Gaines B. Brake, "Supported Decision-Making in the Elder Law Practice: Promoting the Aging Client’s Right to Legal Capacity," 290 *Elder Law Advisory* NL 1-9 (May 1, 2015).

¹⁰ *Id.*

- ¹¹ Anna Arstein-Kerslake, Joanne Watson, Michelle Browning, Jonathan Martinis, and Peter Blank, “Future Directions in Supported Decision-Making,” *Disability Studies Quarterly*, Vol. 37, no. 1 (2017),
- ¹² Peter Blanck and Jonathan Martinis, “The Right to Make Choices: The National Resource Center for Supported Decision-Making,” *Inclusion* 3, no. 1 (2015): 26-7 and 29.
- ¹³ United Nations Convention on the Rights of Persons with Disabilities art. 12, Dec. 13, 2006, 2515 U.N.T.C. 3; Piers Gooding, “Supported Decision-Making: A Rights-Based Disability Concept and its Implications for Mental Health Law,” *Psychiatry, Psychology and The Law* 20, no. 3 (2013): 431-51, doi: 10.1080/13218719.2012.711683 (quoting Article 12 of the CRPD, 2006).
- ¹⁴ Cliona de Bhailis and Eilionoir Flynn, “Recognising legal capacity: Commentary and analysis of Article 12 CRPD,” *International Journal of Law in Context* 12 no. 1, (2017): 6021.
- ¹⁵ See Robert Dinerstein, Esme Grant Grewal, and Jonathan Martinis. “Emerging International Trends and Practices in Guardianship Law for People with Disabilities.” *ILSA Journal International and Comparative Law* 22, no. 2 (2016): 452.
- ¹⁶ See Margaret “Jenny” Hatch, Samantha A. Crane, and Jonathan G. Martinis, *Unjustified Isolation Is Discrimination: The Olmstead Case Against Overbroad and Undue Organizational and Public Guardianship*, *Inclusion* 3, no. 2, 65-74 (2015); see also Salzman, “Rethinking Guardianship (Again): Substituted Decision Making As a Violation of the Integration Mandate of Title II of the Americans with Disabilities Act,” 81 *Univ. of Colo. L.R.* 221-31 (2010); Mary Jane Ciccarello and Maureen Henry, “WINGS: Person-Centered Planning and Supported Decision-Making” *Utah Bar Journal* 27, no. 3, at 48 (2014).
- ¹⁷ See ACL, Webpage on Supported Decision-Making Program, available at <https://www.acl.gov/programs/consumer-control/supported-decision-making-program> (last visited June 14, 2017).
- ¹⁸ See, e.g., Quality Trust for Individuals with Disabilities, The Council of Quality & Leadership, and Burton Blatt Institute, *Supported Decision-Making: An Agenda for Action* (February 2014), available at: <http://jennyhatchjusticeproject.org/node/264> (last visited June 14, 2017),
- ¹⁹ See, e.g., Martinis supra note 2; Peter Blanck & Jonathan G. Martinis, “‘The Right to Make Choices’: The National Resource Center for Supported Decision-Making,” *Inclusion*, Vol. 3, No. 1, 44-33 (2015), available at <http://www.supporteddecisionmaking.org/node/323> (last visited June 14, 2017); Robert D. Dinerstein, “Implementing Legal Capacity Under Article 12 of the UN Convention on the Rights of Persons with Disabilities: The Difficult Road from Guardianship to Supported Decision-Making,” 19 *Hum. Rts. Brief* 8, 10 (Winter 2012), available at: <http://digitalcommons.wcl.american.edu/cgi/viewcontent.cgi?article=1816&context=hrbrief> (last visited June 14, 2017).
- ²⁰ See, e.g., *In re Ryan King*, 2003 INT 249, PIN CITE (D.C. Super. Ct. 2016); *Matter of Michelle M.*, 2016 N.Y. Misc. LEXIS 2719, at *PIN CITE (Kings Cty Sur. Ct., 2016); *Matter of Hytham M.G.*, 2016 N.Y. Misc. LEXIS 2722, at *PIN CITE (Kings Cty. Sur. Ct. 2016); *In re CC*, Berkshire County Probate Court; Pittsfield, MA (November 11, 2015, <http://supporteddecisions.org/cory/>); *Ross v. Hatch*, No. CWF120000426P-03, slip op. at 17 (Newport News, Va. Cir. Ct. Aug. 2, 2013)); *In re Guardianship of Dameris L.*, 956 N.Y.S.2d 848, PIN CITE (N.Y. Cty. Sur. Ct. 2012); *In re SCPA Article 17-A Guardianship Proceeding for Mark C.H., Ward*, 906 N.Y.S.2d 419, PIN CITE (N.Y. Cty. Sur. Ct. 2010); *In re Peery*, 727 A.2d 539, 540 (Pa. 1999). See also Consent Order for M.M. (Florida, 10/13/16, described at http://www.disabilityrightsflorida.org/podcast/story/episode_5_supported_decision_making); *In re C.B.*, Stipulation to Dismiss Guardianship (Superior Court, Orleans Unit, Vermont, April 11, 2017).
- ²¹ Tex. Est. Code Ann. § 1357.056 (West 2017).
- ²² Del. Code Ann. tit. 16, §§ 9401a-9410a (2017).
- ²³ Md. Code Ann. Health--Gen. § 20-1601 (incorporating SDM in the medical context concerning non-discrimination in access to organ transplantation).
- ²⁴ H.J. Res. 190, 2014 Leg., Reg. Sess. (Va. 2014) (ordered study of SDM, which, when complete, recommended SDM be implemented in all service systems).

²⁵ H.B. 900, 127th Leg., 2nd Reg. Sess. (Me. 2016) (resolving that the Probate and Trust Law Advisory Commission will examine SDM and make recommendations about inclusion within Probate Code, with report due January 15, 2017).

²⁶ S. Res. 44, 120th Gen. Assemb., 1st Reg. Sess. (In. 2017)

²⁷ See, e.g., S.B. 264, 110th Gen. Assemb., 1st Reg. Sess. (Tenn. 2017); H.B. 941, 110th Gen. Assemb., 1st Reg. Sess. (Tenn. 2017) (proposing recognition of SDM agreements); H.B. 713, 2017 Gen. Assemb., Reg. Sess. (N.C. 2017) (proposing direction of legislative research commission to study supported decision-making as an alternative to guardianship); S.B. 748, 85th Leg. (Tex. 2017) (proposing an SDM requirement in special education transition planning, and was sent to the Governor May 28, 2017); H.B. 2343, 87th Leg., Reg. Sess. (Kan. 2017) (proposing recognition of SDM in the context of organ transplantation); H.B. 21, 149th Gen. Assemb., 1st Reg. Sess. (Del. 2017) (similar to the aforementioned Kansas legislation); S.B. 5447, 65th Leg., Reg. Sess. (Wash. 2017); H.B. 1139, 65th Leg., Reg. Sess. (Wash.) 2017 (proposing a requirement that the public guardian administrator establish an SDM assistance program); and Assemb. B. 437, Reg. Sess. (Cal. 2017) (proposing to define SDM within the context of a Voluntary Online At-Risk Community Network).

²⁸ Human Services Research Institute, *Supported Decision-Making Pilot: A Collaborative Approach, Pilot Evaluation Year 1 Report*, 1-47, November 30, 2015, accessed July 18, 2017, http://supporteddecisions.org/wp-content/uploads/2015/04/SDM-Evaluation-Report-Year-1_HSRI-2015.pdf (accessed October 13, 2016).

²⁹ Disability Rights Maine, SupportMyDecision.org, accessed July 18, 2017, <http://supportmydecision.org/coalition>.

³⁰ Kristen Booth Glen, "Supported Decision-Making and the Human Right of Legal Capacity," 3 Inclusion 8 (2015); Developmental Disabilities Planning Council, "Supported Decision-Making," New York State, accessed July 18, 2017, <http://ddpc.ny.gov/supported-decision-making-0> (describing the New York SDM pilot program)).

³¹ First in Families of North Carolina, "Lifetime Connections," accessed July 18, 2017, <http://www.fifnc.org/programs/connections.html> (describing the work of North Carolina's SDM coalition).

³² <http://www.scdcd.state.sc.us/documents/06--2016-2017%20Grant%20Narratives.pdf>

³³ Texas Department of Aging and Disability Services, *Volunteer-Supported Decision-making for People with Cognitive Impairments: A Report on the San Angelo Alternatives to Guardianship Project*, 1-9, December 2012, accessed July 18, 2017, http://www.tcdd.texas.gov/wp-content/uploads/2013/01/2013_Feb_handout_05_Guard.pdf; Texas Law INCLUDE Project, "Texas Law INCLUDE Project," Texas Law, accessed July 18, 2017, <https://law.utexas.edu/probono/opportunities/texas-law-include-project/>.

³⁴ Jessalyn Gustin and Jonathan Martinis, "Vermont to Change Culture of Disabilities," *Apostrophe*, September 27, 2016, accessed July 19, 2017, <http://apostrophemagazine.com/vermont-change-culture-disabilities/>.

³⁵ See National Resource Center for Supported Decision-Making web portal at www.SupportedDecisionMaking.org,

³⁶ See ABA Commission on Law and Aging, *PRACTICAL Tool for Lawyers: Steps in Supporting Decision-Making and Resource Guide* (2016), 1, 6, accessed July 18, 2017, http://www.americanbar.org/content/dam/aba/administrative/law_aging/PRACTICALTool.authcheckdam.pdf.

³⁷ The National Resource Center for Supported Decision-Making, "Supported Decision-Making Model Agreements," 2016, <http://www.supporteddecisionmaking.org/node/390> (accessed October 13, 2016).

³⁸ Maine's SDM coalition at <http://supportmydecision.org/coalition> (accessed October 13, 2016) and North Carolina's SDM coalition at <http://www.fifnc.org/programs/connections.html> (accessed October 13, 2016).

³⁹ See Center for Public Representation and Nonotuck Resource Associates, Inc., Supported Decision-Making Pilot Project web site, www.supporteddecisions.org.

⁴⁰ Uniform Law Commission, “Guardianship, Conservatorship, and Other Protective Arrangements Act Committee,” accessed July 18, 2017, <http://www.uniformlaws.org/Committee.aspx?title=Guardianship,%20Conservatorship,%20and%20Other%20Protective%20Arrangements%20Act>.

⁴¹ http://www.americanbar.org/content/dam/aba/directories/policy/2017_am_113.docx

⁴² See, e.g., U.S. Department of Education, Office of Special Education Rehabilitation Services, *A Transition Guide to Postsecondary Education and Employment for Students with Youth and Disabilities*, 1-40, January 2017, accessed July 18, 2017, <https://www2.ed.gov/about/offices/list/osep/transition/products/postsecondary-transition-guide-2017.pdf> (includes section on “Parental Consent, Age of Majority, Supported Decision-Making and Guardianship”).

⁴³ Social Security Advisory Board, *Representative Payees: A Call to Action*, March 2016, accessed July 18, 2017, http://ssab.gov/Portals/0/OUR_WORK/REPORTS/Rep_Payees_Call_to_Action_Brief_2016.pdf (recognizing SDM as an alternative to SSA appointment of representative payee); Advisory Committee on Increasing Competitive Integrated Employment for People with Disabilities, *Final Report*, 53-4, September 15, 2016, accessed July 18, 2017, https://www.dol.gov/odep/topics/pdf/ACICIEID_Final_Report_9-8-16.pdf (endorsing supported decision-making as a method of equipping people with disabilities “with the knowledge, skills, abilities, and tools they need to succeed. . .”).

⁴⁴ See National Guardianship Association, “Position Statement on Guardianship, Surrogate Decision Making, and Supported Decision Making,” 2015, accessed July 19, 2017, http://www.guardianship.org/documents/NGA_Policy_Statement_052016.pdf (“Supported decision making should be considered for the person before guardianship, and the supported decision-making process should be incorporated as a part of the guardianship if guardianship is necessary.”).

⁴⁵ American Bar Association Commission on Disability Rights and American Bar Association Commission on Law and Aging, *Beyond Guardianship: Supported Decision-Making by Individuals with Intellectual Disabilities* (2012), accessed July 18, 2017 http://www.americanbar.org/content/dam/aba/administrative/mental_physical_disability/SDMRoundtable_Summary.authcheckdam.pdf (providing a short summary of the roundtable discussion).

⁴⁶ Blanck and Martinis, *supra* note 13

Supported Decision Making and Legal Ethics

Supported Decision Making and Legal Ethics

David Godfrey

ABA Commission on Law and Aging
Washington, D.C.

Lawyers practice supported decision making all the time. Lawyers communicate complex issues in a manner that can be understood by the client, allow the client to set the objectives of the representation, and help clients carry out the decisions that are made. This is the core of supported decision making.

The preamble to the Model Rules of Professional Conduct lists being a zealous advocate for the client's position, as one of the core duties of a lawyer.¹ The position the lawyer takes must be based on the wishes of the client.² It is the duty of the lawyer to "provide(s) a client with an informed understanding of the client's legal rights and obligations and explains their practical implications."³ If after consultation a client with diminished capacity wishes to retain control over decision making, it is the lawyers obligation to pursue strategies aimed at this outcome.

ABA MRPC

PREAMBLE: A LAWYER'S RESPONSIBILITIES

[1] A lawyer, as a member of the legal profession, is a representative of clients, an officer of the legal system and a public citizen having special responsibility for the quality of justice.

[2] As a representative of clients, a lawyer performs various functions. As advisor, a lawyer provides a client with an informed understanding of the client's legal rights and obligations and explains their practical implications. As advocate, a lawyer zealously asserts the client's position under the rules of the adversary system. As negotiator, a lawyer seeks a result advantageous to the client but consistent with requirements of honest dealings with others. As an evaluator, a lawyer acts by examining a client's legal affairs and reporting about them to the client or to others.

Supported Decision Making (SDM) is person centered and person driven decision making. SDM balances supporting the wishes of the client to remain in control, with protections aimed at providing understandable information, recommendations, guidance in making good choices and help with carrying out those decisions. This balancing point of support, addresses the moral question of wanting to protect the client from unintentional risk or harm – that may lead some lawyers to wish to withdraw or not represent a client with diminished capacity wishing to retain control.⁴ SDM leaves a client with diminished capacity in a better place, than leaving the same client to face the world alone.

MRPC 1.16 Declining or Terminating Representation

(b) Except as stated in paragraph (c), a lawyer may withdraw from representing a client if:

(4) the client insists upon taking action that the lawyer considers repugnant or with which the lawyer has a fundamental disagreement;

One of the core duties of a lawyer is to communicate with a client in a manner that the client can understand,⁵ and this same principle is at the core of Supported Decision Making. For a client to make choices, to make decisions, the client issue must be explained so that the client can understand it. The extent of the explanation will vary with the complexity of the issue, the clients' experience, and the clients' abilities. Just as great care would be taken by a lawyer to explain a complex business transaction to a client with no experience in business, great care must be taken to assure that a client with diminished capacity understands the issues, options, and recommendations of the lawyer. To advocate for SDM for a client with diminished capacity a lawyer must utilize the principles of SDM in communicating with the client.

MRPC 1.4

(a) A lawyer shall:

- (1) promptly inform the client of any decision or circumstance with respect to which the client's informed consent, as defined in Rule 1.0(e), is required by these Rules;
- (2) reasonably consult with the client about the means by which the client's objectives are to be accomplished;
- (3) keep the client reasonably informed about the status of the matter;
- (4) promptly comply with reasonable requests for information; and
- (5) consult with the client about any relevant limitation on the lawyer's conduct when the lawyer knows that the client expects assistance not permitted by the Rules of Professional Conduct or other law.

(b) A lawyer shall explain a matter to the extent reasonably necessary to permit the client to make informed decisions regarding the representation.

If the client tells the lawyer, that the client wants to retain control and avoid, modify or terminate a guardianship, the lawyer should follow the clients' instructions as to the objective of the representation.⁶ The model rules of professional conduct require attorneys to follow the direction of the client regarding the objective of the representation.⁷ The comments to rule 1.2 say:

[1] Paragraph (a) confers upon the client the ultimate authority to determine the purposes to be served by legal representation, within the limits imposed by law and the lawyer's professional obligations.

The limitation on the client setting the goals of the representation are the limits of the law and not violating the ethics rules. While SDM is an emerging concept, and only two states have adapted laws specifically recognizing it,⁸ the underlying principles of health care decision making and power of attorney law are well established law.⁹

Client-Lawyer Relationship

Rule 1.2 Scope Of Representation And Allocation Of Authority Between Client And Lawyer

(a) Subject to paragraphs (c) and (d), a lawyer shall abide by a client's decisions concerning the objectives of representation and, as required by Rule 1.4, shall consult with the client as to the means by which they are to be pursued. A lawyer may take such action on behalf of the client as is impliedly authorized to carry out the representation. A lawyer shall abide by a client's decision whether to settle a matter. In a criminal case, the lawyer shall abide by the client's decision, after consultation with the lawyer, as to a plea to be entered, whether to waive jury trial and whether the client will testify.

A client with diminished capacity, is just another client, and should be treated the same as any other client,¹⁰ with an effort made to communicate in a manner the client can understand¹¹, and following the objectives of the client.¹²

Client-Lawyer Relationship

Rule 1.14 Client With Diminished Capacity

(a) When a client's capacity to make adequately considered decisions in connection with a representation is diminished, whether because of minority, mental impairment or for some other reason, the lawyer shall, as far as reasonably possible, maintain a normal client-lawyer relationship with the client

Abuse, neglect and exploitation take place across the spectrum of legal settings, from persons entirely on their own, to persons with legally appointed agents, to persons subject to guardianship. The legal setting is

not the source of the abuse, neglect or exploitation – abuse, and exploitation occur when people decide to do bad things to other people. Steps should be taken in setting up SDM plans to provide oversight and accountability by the persons agreeing to help the client. The same should be done when planning with powers of attorney and health care surrogates, and even in guardianship. Oversight is a powerful tool in preventing and catching abuse, neglect and exploitation and lawyers should find ways to incorporate oversight in all settings.

When a lawyer has a client who is being abused, neglected or exploited and the lawyer reasonably believes that the client is unable to take steps to protect themselves, the lawyer may take steps to protect the client.¹³

Rule 1.14 Client With Diminished Capacity

(b) When the lawyer reasonably believes that the client has diminished capacity, is at risk of substantial physical, financial or other harm unless action is taken and cannot adequately act in the client's own interest, the lawyer may take reasonably necessary protective action, including consulting with individuals or entities that have the ability to take action to protect the client and, in appropriate cases, seeking the appointment of a guardian ad litem, conservator or guardian.

Comments 5,6, and 7 to model rule 1.14 offer some guidance as to the actions that might be taken. The comments urge consulting with other professionals on the best course of action. Talking with trusted family members about potential protections. It also talks about the issue of clients who are truly unable to communicate in a meaningful way. Comment 6 offers some guidance on understanding capacity and additional information is available in the "Assessment of Older Adults with Diminished Capacity: A Handbook for Lawyers."¹⁴ Paragraph 7 of the comments to rule 1.14, talk about seeking conservatorship or guardianship, but additionally remind the lawyer to look at laws about the least restrictive alternative. The least restrictive alternative that removes the risk of abuse, neglect and exploitation should be the goal. Using the principles of SDM, will help the lawyer seek the least restrictive option.

Client-Lawyer Relationship

Rule 1.14 Client With Diminished Capacity - Comment

[1] The normal client-lawyer relationship is based on the assumption that the client, when properly advised and assisted, is capable of making decisions about important matters. When the client is a minor or suffers from a diminished mental capacity, however, maintaining the ordinary client-lawyer relationship may not be possible in all respects. In particular, a severely incapacitated person may have no power to make legally binding decisions. Nevertheless, a client with diminished capacity often has the ability to understand, deliberate upon, and reach conclusions about matters affecting the client's own well-being. For example, children as young as five or six years of age, and certainly those of ten or twelve, are regarded as having opinions that are entitled to weight in legal proceedings concerning their custody. So also, it is recognized that some persons of advanced age can be quite capable of handling routine financial matters while needing special legal protection concerning major transactions.

[2] The fact that a client suffers a disability does not diminish the lawyer's obligation to treat the client with attention and respect. Even if the person has a legal representative, the lawyer should as far as possible accord the represented person the status of client, particularly in maintaining communication.

[3] The client may wish to have family members or other persons participate in discussions with the lawyer. When necessary to assist in the representation, the presence of such persons generally does not affect the applicability of the attorney-client evidentiary privilege. Nevertheless, the lawyer must keep the client's interests foremost and, except for protective action authorized under paragraph (b), must look to the client, and not family members, to make decisions on the client's behalf.

[4] If a legal representative has already been appointed for the client, the lawyer should ordinarily look to the representative for decisions on behalf of the client. In matters involving a minor, whether the lawyer should look to the parents as natural guardians may depend on the type of proceeding or

matter in which the lawyer is representing the minor. If the lawyer represents the guardian as distinct from the ward, and is aware that the guardian is acting adversely to the ward's interest, the lawyer may have an obligation to prevent or rectify the guardian's misconduct. See Rule 1.2(d).

Taking Protective Action

[5] If a lawyer reasonably believes that a client is at risk of substantial physical, financial or other harm unless action is taken, and that a normal client-lawyer relationship cannot be maintained as provided in paragraph (a) because the client lacks sufficient capacity to communicate or to make adequately considered decisions in connection with the representation, then paragraph (b) permits the lawyer to take protective measures deemed necessary. Such measures could include: consulting with family members, using a reconsideration period to permit clarification or improvement of circumstances, using voluntary surrogate decision-making tools such as durable powers of attorney or consulting with support groups, professional services, adult-protective agencies or other individuals or entities that have the ability to protect the client. In taking any protective action, the lawyer should be guided by such factors as the wishes and values of the client to the extent known, the client's best interests and the goals of intruding into the client's decision-making autonomy to the least extent feasible, maximizing client capacities and respecting the client's family and social connections.

[6] In determining the extent of the client's diminished capacity, the lawyer should consider and balance such factors as: the client's ability to articulate reasoning leading to a decision, variability of state of mind and ability to appreciate consequences of a decision; the substantive fairness of a decision; and the consistency of a decision with the known long-term commitments and values of the client. In appropriate circumstances, the lawyer may seek guidance from an appropriate diagnostician.

[7] If a legal representative has not been appointed, the lawyer should consider whether appointment of a guardian ad litem, conservator or guardian is necessary to protect the client's interests. Thus, if a client with diminished capacity has substantial property that should be sold for the client's benefit, effective completion of the transaction may require appointment of a legal representative. In addition, rules of procedure in litigation sometimes provide that minors or persons with diminished capacity must be represented by a guardian or next friend if they do not have a general guardian. In many circumstances, however, appointment of a legal representative may be more expensive or traumatic for the client than circumstances in fact require. Evaluation of such circumstances is a matter entrusted to the professional judgment of the lawyer. In considering alternatives, however, the lawyer should be aware of any law that requires the lawyer to advocate the least restrictive action on behalf of the client.

Conclusion

SMD is written into the backbone of the Model Rules of Professional Conduct. Lawyers practice SDM with nearly every client, breaking complex issues down into elements that can be reasonably understood by clients. Lawyers offer the client options, and let the client determine the goals and objectives of the representation. We meet every client in the place that the client is. A client with diminished capacity may need help understanding a broader spectrum of issues, but as long as the client can make and communicate rational choices, the lawyer represents the client and what the client wants.

Endnotes

¹ ABA MRPC, Preamble [2]

² ABA MRPC 1.2

³ ABA MRPC, Preamble [2]

⁴ ABA MRPC, 1.16 (b) (4)

⁵ ABA MRPC 1.4 (b)

⁶ ABA MRPC 1.2 (a)

⁷ Id

⁸ The Texas Supported Decision Making Agreement Act, Tex. Estates Code § 1357.001 et seq.;

Delaware Supported Decision-Making 80 Del. Laws, c. 427, § 1.

⁹ https://www.americanbar.org/content/dam/aba/administrative/law_aging/chartpoa.authcheckdam.pdf;
https://www.americanbar.org/content/dam/aba/administrative/law_aging/state-health-care-power-of-attorney-statutes.authcheckdam.pdf;
https://www.americanbar.org/content/dam/aba/administrative/law_aging/2014_default_surrogate_consent_statutes.authcheckdam.pdf;

¹⁰ ABA MRPC 1.14 (a)

¹¹ ABA MRPC 1.4

¹² ABA MRPC 1.2

¹³ NRPC 1.14 (b)

¹⁴ https://www.americanbar.org/groups/law_aging/resources/capacity_assessment.html#forlawyers

Durable Power of Attorney -- Adults With Disabilities

DURABLE POWER OF ATTORNEY
FOR HEALTH CARE DECISIONS

My name is..... (insert your name) and my address is..... (insert your address). I would like to designate..... (insert the name of the person you wish to designate as your agent for health care decisions for you) as my agent for health care decisions for me if I am sick or hurt and need to see a doctor or go to the hospital. I understand what this means.

If I am sick or hurt, my agent should take me to the doctor. If my agent is not with me when I become sick or hurt, please contact my agent and ask him or her to come to the doctor's office. I would like the doctor to speak with my agent and me about my sickness or injury and whether I need any medicine or other treatment. After we speak with the doctor, I would like my agent to speak with me about the care or treatment. When we have made decisions about the care or treatment, my agent will tell the doctor about our decisions and sign any necessary papers.

If I am very sick or hurt, I may need to go to the hospital. I would like my agent to help me decide if I need to go to the hospital. If I go to the hospital, I would like the people who work at the hospital to try very hard to care for me. If I am able to communicate, I would like the doctor at the hospital to speak with me and my agent about what care or treatment I should receive, even if I am unable to understand what is being said about me. After we speak with the doctor, I would like my agent to help me decide what care or treatment I should receive. Once we decide, my agent will sign any necessary paperwork. If I am unable to communicate because of my illness or injury, I would like my agent to make decisions about my care or treatment based on what he or she thinks I would do and what is best for me.

I would like my agent to help me decide if I need to see a dentist and help me make decisions about what care or treatment I should receive from the dentist. Once we decide, my agent will sign any necessary paperwork.

I would also like my agent to be able to see and have copies of all my medical records. If my agent requests to see or have copies of my medical records, please allow him or her to see or have copies of the records.

I understand that my agent cannot make me receive any care or treatment that I do not want. I also understand that I can take away this power from my agent at any time, either by telling my agent that he or she is no longer my agent or by putting it in writing.

If my agent is unable to make health care decisions for me, then I designate..... (insert the name of another person you wish to designate as your

alternative agent to make health care decisions for you) as my agent to make health care decisions for me as authorized in this document.

(YOU MUST DATE AND SIGN THIS POWER OF ATTORNEY)

I sign my name to this Durable Power of Attorney for Health Care on
(date) at (city), (state)

.....

(Signature)

AGENT SIGNATURE

As agent for..... (insert name of principal), I agree that a physician, health care facility or other provider of health care, acting in good faith, may rely on this power of attorney for health care and the signatures herein, and I understand that pursuant to [NRS 162A.815](#), a physician, health care facility or other provider of health care that in good faith accepts an acknowledged power of attorney for health care is not subject to civil or criminal liability or discipline for unprofessional conduct for giving effect to a declaration contained within the power of attorney for health care or for following the direction of an agent named in the power of attorney for health care.

I also agree that:

1. I have a duty to act in a manner consistent with the desires of..... (insert name of principal) as stated in this document or otherwise made known by..... (insert name of principal), or if his or her desires are unknown, to act in his or her best interest.

2. If..... (insert name of principal) revokes this power of attorney at any time, either verbally or in writing, I have a duty to inform any persons who may rely on this document, including, without limitation, treating physicians, hospital staff or other providers of health care, that I no longer have the authorities described in this document.

3. The provisions of [NRS 162A.840](#) prohibit me from being named as an agent to make health care decisions in this document if I am a provider of health care, an employee of the principal's provider of health care or an operator or employee of a health care facility caring for the principal, unless I am the spouse, legal guardian or next of kin of the principal.

4. The provisions of [NRS 162A.850](#) prohibit me from consenting to the following types of care or treatments on behalf of the principal, including, without limitation:

(a) Commitment or placement of the principal in a facility for treatment of mental illness;

(b) Convulsive treatment;

(c) Psychosurgery;

(d) Sterilization;

(e) Abortion;

(f) Aversive intervention, as it is defined in [NRS 449.766](#);

(g) Experimental medical, biomedical or behavioral treatment, or participation in any medical, biomedical or behavioral research program; or

(h) Any other care or treatment to which the principal prohibits the agent from consenting in this document.

5. End-of-life decisions must be made according to the wishes of..... (insert name of principal), as designated in the attached addendum. If his or her wishes are not known, such decisions must be made in consultation with the principal's treating physicians.

Signature: Residence Address:

Print Name:

Date:

Relationship to principal:

Length of relationship to principal:

(THIS POWER OF ATTORNEY WILL NOT BE VALID FOR MAKING HEALTH CARE DECISIONS UNLESS IT IS EITHER (1) SIGNED BY AT LEAST TWO QUALIFIED WITNESSES WHO YOU KNOW AND WHO ARE PRESENT WHEN YOU SIGN OR ACKNOWLEDGE YOUR SIGNATURE OR (2) ACKNOWLEDGED BEFORE A NOTARY PUBLIC.)

CERTIFICATE OF ACKNOWLEDGMENT
OF NOTARY PUBLIC

(You may use acknowledgment before a notary public instead of the statement of witnesses.)

State of Nevada }
 } ss.
County of..... }

On this..... day of....., in the year...., before me,..... (here insert name of notary public) personally appeared..... (here insert name of principal) personally known to me (or proved to me on the basis of satisfactory evidence) to be the person whose name is subscribed to this instrument, and acknowledged that he or she executed it. I declare under penalty of perjury that the person whose name is ascribed to this instrument appears to be of sound mind and under no duress, fraud or undue influence.

NOTARY SEAL

.....

(Signature)

STATEMENT OF WITNESSES

(If you choose to use witnesses instead of having this document notarized, you must use two qualified adult witnesses. The following people cannot be used as a witness: (1) a person you designate as the agent; (2) a provider of health care; (3) an employee of a provider of health care; (4) the operator of a health care facility; or (5) an employee of an operator of a health care facility. At least one of the witnesses must make the additional declaration set out following the place where the witnesses sign.)

I declare under penalty of perjury that the principal is personally known to me, that the principal signed or acknowledged this durable power of attorney in my presence, that the principal appears to be of sound mind and under no duress, fraud or undue influence,

that I am not the person appointed as agent by this document and that I am not a provider of health care, an employee of a provider of health care, the operator of a health care facility or an employee of an operator of a health care facility.

Signature: Residence Address:

Print Name:

Date:

Signature: Residence Address:

Print Name:

Date:

(AT LEAST ONE OF THE ABOVE WITNESSES MUST ALSO SIGN THE FOLLOWING DECLARATION.)

I declare under penalty of perjury that I am not related to the principal by blood, marriage or adoption and that to the best of my knowledge, I am not entitled to any part of the estate of the principal upon the death of the principal under a will now existing or by operation of law.

Signature:

Signature:

Names: Address:

Print Name:

Date:

COPIES: You should retain an executed copy of this document and give one to your agent. The power of attorney should be available so a copy may be given to your providers of health care.

2. The form for end-of-life decisions of a power of attorney for health care for an adult with an intellectual disability may be substantially in the following form, and must be witnessed or executed in the same manner as the following form:

END-OF-LIFE DECISIONS ADDENDUM

STATEMENT OF DESIRES

(You can, but are not required to, state what you want to happen if you get very sick and are not likely to get well. You do not have to complete this form, but if you do, your agent must do as you ask if you cannot speak for yourself.)

..... (Insert name of agent) might have to decide, if you get very sick, whether to continue with your medicine or to stop your medicine, even if it means you might not live..... (Insert name of agent) will talk to you to find out what you want to do, and will follow your wishes.

If you are not able to talk to..... (insert name of agent), you can help him or her make these decisions for you by letting your agent know what you want.

Here are your choices. Please circle yes or no to each of the following statements and sign your name below:

1. I want to take all the medicine and receive any treatment I can to keep me alive regardless of how the medicine or treatment makes me feel. YES NO

2. I do not want to take medicine or receive treatment if my doctors think that the medicine or treatment will not help me. YES NO

3. I do not want to take medicine or receive treatment if I am very sick and suffering and the medicine or treatment will not help me get better. YES NO

4. I want to get food and water even if I do not want to take medicine or receive treatment. YES NO

(YOU MUST DATE AND SIGN THIS END-OF-LIFE DECISIONS ADDENDUM)

I sign my name to this End-of-Life Decisions Addendum on (date) at (city), (state)

.....

(Signature)

(THIS END-OF-LIFE DECISIONS ADDENDUM WILL NOT BE VALID UNLESS IT IS EITHER (1) SIGNED BY AT LEAST TWO QUALIFIED WITNESSES WHO YOU KNOW AND WHO ARE PRESENT WHEN YOU SIGN OR ACKNOWLEDGE YOUR SIGNATURE OR (2) ACKNOWLEDGED BEFORE A NOTARY PUBLIC.)

CERTIFICATE OF ACKNOWLEDGMENT
OF NOTARY PUBLIC

(You may use acknowledgment before a notary public instead of the statement of witnesses.)

State of Nevada }
 }ss.
County of..... }

On this..... day of....., in the year...., before me,..... (here insert name of notary public) personally appeared..... (here insert name of principal) personally known to me (or proved to me on the basis of satisfactory evidence) to be the person whose name is subscribed to this instrument, and acknowledged that he or she executed it. I declare under penalty of perjury that the person whose name is ascribed to this instrument appears to be of sound mind and under no duress, fraud or undue influence.

NOTARY SEAL

.....

(Signature)

STATEMENT OF WITNESSES

(If you choose to use witnesses instead of having this document notarized, you must use two qualified adult witnesses. The following people cannot be used as a witness: (1) a person you designate as the agent; (2) a provider of health care; (3) an employee of a provider of health care; (4) the operator of a health care facility; or (5) an employee of an operator of a health care facility. At least one of the witnesses must make the additional declaration set out following the place where the witnesses sign.)

I declare under penalty of perjury that the principal is personally known to me, that the principal signed or acknowledged this End-of-Life Decisions Addendum in my presence, that the principal appears to be of sound mind and under no duress, fraud or undue influence, that I am not the person appointed as agent by the power of attorney for health care and that I am not a provider of health care, an employee of a provider of health care, the operator of a health care facility or an employee of an operator of a health care facility.

Signature: Residence Address:

Print Name:

Date:

Signature: Residence Address:

Print Name:

Date:

(AT LEAST ONE OF THE ABOVE WITNESSES MUST ALSO SIGN THE FOLLOWING DECLARATION.)

I declare under penalty of perjury that I am not related to the principal by blood, marriage or adoption and that to the best of my knowledge, I am not entitled to any part of the estate of the principal upon the death of the principal under a will now existing or by operation of law.

Signature:

Signature:

Names: Address:

Print Name:

Date:

COPIES: You should retain an executed copy of this document and give one to your agent. The End-of-Life Decisions Addendum should be available so a copy may be given to your providers of health care.

How to Make a Supported Decision Making Agreement

How to Make a Supported Decision-Making Agreement



A Guide for People with Disabilities
and their Families



This guide was created by Zoe Brennan-Krohn, while on a Ford Foundation Fellowship with the Disability Rights Project of the American Civil Liberties Union Foundation.

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For questions, please contact Susan Mizner at the ACLU’s Disability Rights Program, smizner@aclu.org.



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Chapter 1

What is Supported Decision-Making?

Supported Decision-Making, or “SDM,” is a way to get help making choices. Supported Decision-Making means that **you** make **your own** choices. You can choose family, friends, or staff who you want to help you make your choices.



The people who will help you understand and make your choices are called **“supporters”**.

Supporters are there to help you. You are the one who makes the final decision. You are called the **“decider”**.

This book will help you start using Supported Decision-Making.

You should read and talk about this book with people you trust. This book has questions and activities that will help you think about how you want to use Supported Decision-Making.

It will take a while to read through this book and do all of the activities. You might spend a month or more working on it. That’s ok! Doing Supported Decision-Making takes time.

Chapter 2 Thinking about Choices



Why do this activity?

This activity will help you think about how you make choices. You can talk about what kind of help you like and don't like. You can think about choices you have made and what you liked and didn't like when you were choosing.

This will help you think about how you want Supported Decision-Making to work.

Supported Decision-Making is different for every person! This activity will help you think about what is important to you.

What to do:



Think about a choice you made. It could be a choice about:

- where you live
- what you will do in school
- where you work
- who you spend time with
- if you want to go to the doctor
- if you want to go on a date
- or anything else!



Write down the choice that you want to think about and talk about: _____
_____.



Who made the choice? *Check one box.*

- ☐ I made the choice alone.
- ☐ I made the choice, but someone helped me. The people who helped me were: _____.
- ☐ Someone else made the choice for me. The person who made the choice for me is named: _____.



Think about **how** did you make the choice? Did you:

- talk about it? Who did you talk with?
- write down your possible options?
- write down the good and bad things about each choice (pros and cons)?
- visit places (like a home, office, or school)?
- do research?
- talk to people who had made the same choice before?



What I did to help me make my choice: _____



What did you **like and dislike** about making this choice?

- Did you understand your choice?
- Did you understand all of your options (different choices you could make)?
- Could you communicate your choice? Did anyone help you?
- Did you have enough time to make sure you were happy with your choice?
- Did you know what to do if you had questions?
- Did you feel like you could say “no” if you didn’t want help?
- Are you happy now with the choice you made?
- Could you change your mind if you wanted to make another choice?

Chapter 2
Thinking About Choices



<p><i>What I <u>liked</u> about making this choice:</i></p> <hr/> <hr/> <hr/> <hr/> <hr/>	<p><i>What I <u>didn't like</u> about making this choice:</i></p> <hr/> <hr/> <hr/> <hr/> <hr/>
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Chapter 3 Thinking about Support

Supported Decision-Making lets you get help or **support** in making your own choices. Everyone gets support in making choices every day.

Some kinds of support are:

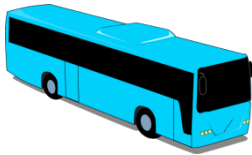
- **Plain-language information.** This means written information is provided in simple words.



- **Information in pictures or explained.** This means getting information in pictures or by someone talking to you.

- **Research to learn more about choices.**

- **Help in knowing what choices you have.**



- **Visits and trials.** This means trying out different choices, to see how you feel and which one you like.



- **Reminders** about important dates and times



- **Help in thinking about pros and cons.** This means making lists of the good and bad parts of different choices.

- **Having a supporter come to meetings and appointments with you.**



- **Talking to experts who know a lot about my choice.**



- **Extra time to think about choices.**
- **Reminding you of about your values.** Supporters can help you remember what is most important to you. They can remind you how these things might affect your choice.



- **Classes to learn about healthy choices.**



- **Technological support.** This means using a phone or computer to help with choices.
- **Advice from supporters.** Even if you get advice, you are still the decider.



- **Help communicating a choice.** After you have made a choice, someone might make sure that everyone understands and respects your choice.

Here is an example of how a person might use supports in making a choice:

Mary lives with her mother and father. Now she wants to move away from home. Mary has a bank account, but the letters she gets from the bank are confusing. So her mother explains to Mary how much money she gets every month, and how much she can spend each month on rent. Mary's mother is giving her **plain language information**.

Once she knows how much money she can spend, Mary's case worker helps her find apartments that she can afford. She makes a **list of her choices**. The case worker takes Mary to **visit each apartment**, so she can see what they look like. The case worker also helps Mary write lists of **pros and cons** of each apartment. One apartment is very big but it is far from the subway. Another apartment is smaller, but is very close to the subway. In the smaller apartment, Mary can get to work and to see her friends quickly. In the big apartment, Mary will have more room for her things, but she will need help going to see her friends.

Mary shows her list of pros and cons to her parents. Mary's father reminds Mary of how much she likes taking the subway, and how important it is for her to be able to visit her friends and travel alone. Her father is **reminding Mary of her values**. It is very important to Mary to be independent. Mary decides to move to the smaller apartment, so she can get to work on her own and see her friends.

Mary made **her own choice** but her parents and her case worker helped her understand, think about, and make her choice. Mary used supported decision-making.



Questions to Think About:

- Did you use any support in making the choice from Chapter 2?
- Can you think of support that would have helped you make that choice better?
- Have you used supports in other choices?

Chapter 4 When Do I Want Support?



Why do this activity?

You can make lots of choices on their own. But you might need or want support making some kinds of choices, especially difficult or important choices.

This activity will help you think about all the choices you have to make in your life. You will think about whether you want to make those choices alone, or with support, or if you want someone else to make those choices for you. This will help you decide how you want to use supported decision-making.

What to do:

The list below describes different areas of your life.



Think and talk about whether you can do each thing by yourself, if you want support to do it, or if you want someone else to do it for you. Think about how you make these choices now, and whether you want to change anything.

You don't have to check a box for all of these areas now. Some of them might not be important to you. You might want to think more about some of them before you decide.

If you want support, write down what kinds of support you want. There are many, many kinds of support a decider can get! Look at the list of supports in Chapter 3 to help you think of ideas.

When Do I Want Support? Worksheet






Check the boxes to say if you want support in each area.






If you check the box that says “I want support to do this,” you can write what kind of support you want.




You do not have to check a box for every category.

	I can do this <u>alone</u> . 	I can do this <u>with support</u> . 	I need <u>someone else</u> to do this for me. 
COMMUNICATION			
Telling people what I want and don't want			
Telling people how I make choices			
Making sure people understand what I am saying			
PERSONAL CARE			
Choosing what I wear			
Getting dressed			
Choosing what to eat, and when to eat			




Chapter 4
When Do I Want Support?

	<p>I can do this <u>alone</u>.</p> 	<p>I can do this <u>with support</u>.</p> 	<p>I need <u>someone else</u> to do this for me.</p> 
Taking care of my personal hygiene (for example, showering, bathing, brushing teeth)			
Remembering to take medicine			
STAYING SAFE			
Making safe choices around the house (for example, turning off the stove, having fire alarms)			
Understanding and getting help if I am being treated badly (abuse or neglect)			
Making choices about alcohol and drugs			
HOME AND FRIENDS			
Choosing where I live			
Choosing who I live with			
Choosing what to do and who to see in my free time			
Keeping my room or home clean			
Finding support services and hiring and firing support staff			
HEALTH CHOICES			
Choosing when to go to the doctor or the dentist			

Chapter 4
When Do I Want Support?

	<p>I can do this <u>alone</u>.</p> 	<p>I can do this <u>with support</u>.</p> 	<p>I need <u>someone else</u> to do this for me.</p> 
Making medical choices in everyday situations (for example, check-up, medicine from the drug store)			
Making medical choices in serious situations (for example, surgery, big injury)			
Making medical choices in an emergency			
PARTNERS			
Choosing if I want to date, and who I want to date			
Making choices about sex			
Making choices about marriage			
Making choices about birth control and pregnancy			
TRAVEL			
Traveling to places I go often (for example, getting to work, stores, friends' homes)			
Traveling to places I do not go often (for example, doctors' appointments, special events)			
JOBS			
Choosing if I want to work			
Understanding my work choices			

Chapter 4
When Do I Want Support?

	<p>I can do this <u>alone</u>.</p> 	<p>I can do this <u>with support</u>.</p> 	<p>I need <u>someone else</u> to do this for me.</p> 
Choosing classes or training I need to get a job I want, and taking these classes			
Applying for a job			
Going to my job every work day			
MONEY			
Paying the rent and bills on time			
Keeping a budget so I know how much money I can spend			
Making big decisions about money (for example, opening a bank account, signing a lease)			
Making sure no one is taking my money or using it for themselves			
BEING A CITIZEN			
Signing contracts and formal agreements			
Choosing who to vote for and voting			
OTHER (write any other choices or activities here)			

Chapter 5 Who are my Supporters?



Why do this activity:

This will help you think about who you want to support you.

What to do:

Supported Decision-Making has both **supporters** and a **decider**.

You are the decider.

You can choose who will be your supporters. You can have many supporters. You might want some supporters to help you with some things but not others. For some things, you might want two or three people to support you. For other things, you might just want one supporter.

You can always change your mind and change your supporters.

Every supporter should be:

- ✓ Someone you trust
- ✓ Someone who agrees to be a supporter



The people I might want to be my supporters are (*write as many people as you want*):

- _____
- _____
- _____

Chapter 6 **Talking to My Supporters**

Everyone has to agree to do supported decision-making. You have to ask your supporters if they can help you. They might say no. They can still be your friends even if they don't feel like they can be your supporter.



Why do this activity:

You will talk to the people who might be your supporters. You will find out if they can support you, and you will talk about how they will support you.

What to do:



Make a time to meet with each person you listed on page 20. You can have meetings with each person separately, or with many people together.

Give them a copy of the paper What is Supported Decision-Making and What Does a Supporter Do? (at the end of this book) to help them understand what you want to talk to them about. Many people don't know about supported decision-making, so you might have to explain it.

When you meet with your supporters, you should talk about:

- ✓ What kind of support or help you want from this person
- ✓ Whether this person agrees to be a supporter
- ✓ How you want to get support
- ✓ Whether your supporters can talk to each other when you are not there



Fill out this worksheet with each person who might support you. There are extra copies at the end of this book.

Worksheet: Meeting with Possible Supporter

Decider's name: _____

Supporter's name: _____

I want support from this person in these parts of my life:

(look at Chapter 4 for more information about these areas)

Personal Care

- | | |
|---|---|
| <input type="checkbox"/> Clothing choices | <input type="checkbox"/> What I eat and when I eat |
| <input type="checkbox"/> Personal hygiene | <input type="checkbox"/> Remembering to take medicine |

Living and Working

- | | |
|--|--|
| <input type="checkbox"/> Choosing work or day programs | <input type="checkbox"/> Getting to work or programs |
| <input type="checkbox"/> Choosing where to live | <input type="checkbox"/> Keeping my home clean |
| <input type="checkbox"/> Finding, hiring, firing staff | |

Staying Safe

- | | |
|---|--|
| <input type="checkbox"/> Safe choices at home | <input type="checkbox"/> Choices about sex |
| <input type="checkbox"/> Help if I am being treated badly | <input type="checkbox"/> Choices about alcohol and drugs |

Money

- | | |
|--|------------------------------------|
| <input type="checkbox"/> Paying rent and bills | <input type="checkbox"/> Budgeting |
| <input type="checkbox"/> Protecting myself from exploitation | |

Friends and Partners

- | | |
|------------------------------------|---|
| <input type="checkbox"/> Free time | <input type="checkbox"/> Dating and sex |
| <input type="checkbox"/> Marriage | <input type="checkbox"/> Birth control |

Health Choices

- | | |
|---|--|
| <input type="checkbox"/> When to go to the doctor | <input type="checkbox"/> Over the counter medication |
|---|--|

☐ Non-emergency care

☐ Emergency care

Communication

☐ Expressing likes and dislikes

☐ Expressing choices

Other

☐ Write any other areas where you want support: _____
_____.

The kind of support I want from this person is:

(look at Chapter 3 for ideas about different kinds of supports)

_____.

I want to communicate this supporter in these ways: *(check as many boxes as you want)*

☐ Talking on the phone

☐ Texting

☐ Meeting in person

☐ Other: _____

I want to get support from this supporter at these times: *(check as many boxes as you want)*

☐ On a regular schedule. *Write down how often you will meet with this person, like “every week” or “every month”.* We will meet every _____.

☐ Every time I am making a certain kind of choice. *Write down what kind of choice you want to get support from this person for, like “every time I have to go to the doctor” or “every time I get a check”.*

_____.

☐ Only when I have a question or want advice.

Chapter 7

Filling out a Supported Decision-Making Agreement



Why do this activity:

Now you have thought about when you want support. You have also thought about what kind of support you want. And you have talked to people who can support you.

You are ready to put together your supported decision-making agreement!

This activity will help you fill out your agreement. It will also make sure all your supporters know each other and agree to support you.

What to do:

1. Look at the “Supported Decision-Making Agreement” form on page 22.
2. Look back at Chapter 5 to remind yourself who will be your supporters and what kind of support they will give you.
3. Fill out the Supported Decision-Making Agreement, but do not sign it yet. Write down who your supporters are and what help you want from them.
4. Plan a time that all of your supporters can meet with you. They should all be together at the same time.
5. Plan to have all your supporters meet you at the office of a **notary public**. A notary public is a person who promises that he or she saw you sign important documents.
6. When everyone is together, someone will read the Supported Decision-Making Agreement out loud. This is important to make sure everyone understands the agreement.

7. Sign the agreement. You sign to say that you want to do supported decision-making.
8. Have your supporters sign the agreement. They sign to say that they will help you make your own choices. They also sign to say that they know that you are the decider.
9. The notary public signs and stamps the agreement. The notary public signs to say that he or she saw you and the supporters sign the agreement.
10. You are ready to start using supported decision-making! Some people like to celebrate!

Chapter 8

Where Can I Learn More about Supported Decision-Making?

If you have questions, or if you want to talk to someone about supported decision-making, you can contact:

- Susan Mizner, ACLU Disability Rights Program
smizner@aclu.org
415-343-0781
- Jonathan Martinis, Burton Blatt Institute at Syracuse University
jmartin@law.syr.edu

If you want to read more about Supported Decision-Making, here are some websites you can visit:

- American Civil Liberties Union Disability Rights Program:
www.aclu.org/supported-decision-making-resource-library
- National Resource Center for Supported Decision-Making
www.supporteddecisionmaking.org
- Center for Public Representation Supported Decision-Making Pilot Project
www.supporteddecisions.org
- Autistic Self-Advocacy Network (ASAN)

[The Right To Make Choices](#), a series of very detailed, Easy Read documents ASAN put together to provide self-advocates with an overview of SDM and some of the many different options available.

Extra Documents

Supported Decision-Making Agreement.....	22
Worksheet: Meeting with Possible Supporters.....	31
Information Sheet: What is Supported Decision-Making and What Does a Supporter Do?.....	33
“Sharing My Medical Information” – HIPAA Authorization.....	34
“Sharing my School Information” – Educational Records Release.....	36

Supported Decision-Making Agreement

This agreement must be read out loud or otherwise communicated to all parties to the agreement in the presence of either a notary or 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 until a **notary** or **two witnesses** are there to watch you sign.*

My signature: _____

Supporters

Supporter #1

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
- ☐ 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 #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
- ☐ 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
- ☐ 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:

- ☐ My supporters can talk to each other about me only when I say it is OK
- ☐ 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:

- ☐ I want my entire support team to meet every _____.
(Write how often your whole team will meet, like “every week” or “every two months” or “before every IPP meeting”.)
- ☐ 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.

Monitor

If I want someone to help me make choices about money, I must 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: _____

Phone Number: _____

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

I, _____ 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

I, _____ 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

I, _____ 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

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

*This document must be read in front of either a notary public or two witnesses.
Witnesses may not be named in this agreement as a supporter, monitor, or decider.*

Signature of Notary

State of California County of _____.

On _____ (date), before me _____, personally appeared

_____ (names of all signers), who proved to me on the basis of satisfactory evidence of identification to be the people whose names are signed on this Supported Decision-Making agreement.

The text of this agreement was communicated to the person with a disability in my presence by:

- ☐ Reading the full agreement aloud
- ☐ Otherwise communicating the agreement to the person with a disability (*describe communication used*): _____.

Seal of notary:

My commission expires:

OR

Signature of Witnesses

I, _____, swear that this Supported Decision-Making agreement was communicated in my presence to the decider (the person with a disability).

Signature

Date

I, _____, swear that this Supported Decision-Making agreement was communicated in my presence to the decider (the person with a disability).

Signature

Date

Worksheet: Meeting with Possible Supporter

Decider's name: _____

Supporter's name: _____

I want support from this person in these parts of my life:

(look at Chapter 4 for more information about these areas)

Personal Care

- | | |
|---|---|
| <input type="checkbox"/> Clothing choices | <input type="checkbox"/> What I eat and when I eat |
| <input type="checkbox"/> Personal hygiene | <input type="checkbox"/> Remembering to take medicine |

Living and Working

- | | |
|--|--|
| <input type="checkbox"/> Choosing work or day programs | <input type="checkbox"/> Getting to work or programs |
| <input type="checkbox"/> Choosing where to live | <input type="checkbox"/> Keeping my home clean |
| <input type="checkbox"/> Finding, hiring, firing staff | |

Staying Safe

- | | |
|---|--|
| <input type="checkbox"/> Safe choices at home | <input type="checkbox"/> Choices about sex |
| <input type="checkbox"/> Help if I am being treated badly | <input type="checkbox"/> Choices about alcohol and drugs |

Money

- | | |
|--|------------------------------------|
| <input type="checkbox"/> Paying rent and bills | <input type="checkbox"/> Budgeting |
| <input type="checkbox"/> Protecting myself from exploitation | |

Friends and Partners

- | | |
|------------------------------------|---|
| <input type="checkbox"/> Free time | <input type="checkbox"/> Dating and sex |
| <input type="checkbox"/> Marriage | <input type="checkbox"/> Birth control |

Health Choices

- | | |
|---|--|
| <input type="checkbox"/> When to go to the doctor | <input type="checkbox"/> Over the counter medication |
|---|--|

☐ Non-emergency care

☐ Emergency care

Communication

☐ Expressing likes and dislikes

☐ Expressing choices

Other

☐ Write any other areas where you want support: _____
_____.

The kind of support I want from this person is:

(look at Chapter 3 for ideas about different kinds of supports)

_____.

I want to communicate this supporter in these ways: *(check as many boxes as you want)*

☐ Talking on the phone

☐ Texting

☐ Meeting in person

☐ Other: _____

I want to get support from this supporter at these times: *(check as many boxes as you want)*

☐ On a regular schedule. *Write down how often you will meet with this person, like “every week” or “every month”.* We will meet every _____.

☐ Every time I am making a certain kind of choice. *Write down what kind of choice you want to get support from this person for, like “every time I have to go to the doctor” or “every time I get a check”.*

_____.

☐ Only when I have a question or want advice.

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

Someone has asked you to be their “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, 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 try to meet the other supporters.

What do I do as supporter?

- Help, support, and advise the person with a disability. You are not making choices for them, 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.

Am I legally liable for the person's choices?

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

Do I have to be a supporter forever?

- No. You can stop at any time. However, 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?

- www.aclu.org/issues/disability-rights/supported-decision-making
- www.supporteddecisionmaking.org

Sharing My Medical Information

(Plain Language HIPAA Authorization for Disclosure of Health Information)

My name is _____.

My doctor's office or hospital is called: _____.

It is in this city: _____.

My doctors and nurses write notes about me. They also write about the tests they do. These notes are called **records**.

I want to share my medical records.

The person who can see my records is:

Name: _____

Address: _____

Phone number: _____

Email address: _____

This person can see:

Check one box.

- ☐ All of my medical records.
- ☐ Only some records. The records this person **can see** are:

Write what records you want the person to see.

This person can see my records until:

Check one box.

☐ This date: _____.

☐ When I sign a form to say that this person can no longer see my records.

I have decided to share my medical records with _____.

I know that I do not have to share these records.

I know that I can stop this agreement at any time.

My doctors and nurses have to be very careful with my medical records. They cannot usually show my records to other people. The person who I am sharing my records with cannot share them with other people unless I agree.

I trust the person I am sharing my records with.

My signature:

The date today is: _____.

Sharing School Information

(Plain Language Authorization to Disclose Educational Information)

My name is _____.

My address is _____.

I go to school at _____.

My school is in this city: _____.

I have an IEP.

I want someone to help me make choices about school.

The person I want to help me is:

_____.

This person's phone number is: _____.

I want this person to come to my IEP meetings.

I want this person to get all the information that I get from my school.

It is okay for this person to see information that my school has about me.

This agreement to share school information will continue until I say it should stop.

My signature: _____

Today's date is: _____

SDMA Quesionnaire

SDMA Questionnaire

1. What is your interest in Supported Decision Making?

- ☐ I am interested in SDMA for myself
- ☐ I am interested in SDMA for another person

2. Details about your contact:

Date of Contact:

Zipcode:

Your Personal Information:

First Name: *(optional)*

Last Name: *(optional)*

Email *(optional)*:

Date of Birth:

3. Already familiar with Supported Decision Making:

- ☐ Y ☐ N

4. Interested in Being Supporter:

- ☐ Y ☐ N ☐ Not Sure

5. Received Training on Supported Decision Making:

- ☐ Y ☐ N

6. How did you find out about SDMAs? *(select one)*:

- | | |
|---|--|
| <input type="radio"/> Healthcare Provider | <input type="radio"/> Private Guardian |
| <input type="radio"/> Teacher | <input type="radio"/> Caseworker |
| <input type="radio"/> Friend/Family | <input checked="" type="radio"/> Social Worker |
| <input type="radio"/> Attorney | <input type="radio"/> Other (please identify): _____ |
| <input type="radio"/> Hospital | |
| <input type="radio"/> School District | |
| <input type="radio"/> Care Facility | |
| <input type="radio"/> Group Home | |

7. Relationship of Contact to Supported Person *(select one):*

- ☐ Self
- ☐ Parent
- ☐ Sibling
- ☐ Spouse
- ☐ Grandparent
- ☐ Child
- ☐ Other Relative
- ☐ Friend
- ☐ Caretaker
- ☐ Agency Representative
- ☐ Other (please identify): _____

8. Living Arrangement of Supported Person at the time of Contact *(select one):*

- ☐ Lives with Family
- ☐ Lives in a Group Home
- ☐ Lives in Assisted Living
- ☐ Lives in Residential Care
- ☐ Lives in Acute Care
- ☐ Lives in Locked Facility
- ☐ Lives Independently With Assistance
- ☒ Lives Independently Without Assistance
- ☐ Other (please identify)_____

9. Is there a Current Guardianship Case:

- ☐ Y ☐ N ☐ Not Sure

10. Is Guardianship being considered:

- ☐ Y ☐ N