

Using Decision Supports to Engage and Empower Persons with Dementia

David Godfrey

Senior Attorney

ABA Commission on Law
and Aging

January 20, 2021



AMERICAN **BAR** ASSOCIATION

Commission on
Law and Aging

SPONSORED BY



CATHOLIC CHARITIES
HAWAII
CIRCLE OF CARE FOR DEMENTIA



Supported in part by grant No. 90ADPI0011-01-00 from the U.S. Administration for Community Living, Department of Health and Human Services, Washington, D.C. 20201. Grantees undertaking projects with government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official ACL policy. The grant was awarded to Catholic Charities Hawaii for the Alzheimer's Disease Program Initiative.



Supporting Decision Making Across the Age Spectrum

https://www.americanbar.org/content/dam/aba/administrative/law_aging/2020-supporting-decision-making-final-report.pdf

Supported by a subcontract with the National Center on Law and Elder Rights, pursuant to contract number HHSP233201650076A, from the U.S. Administration on Community Living, Department of Health and Human Services, Washington, D.C. 20201. Grantees carrying out projects under government sponsorship are encouraged to express freely their findings and conclusions. Therefore, points of view or opinions do not necessarily represent official Administration for Community Living or DHHS policy. In addition, the views expressed in this report have not been approved by the ABA House of Delegates or the Board of Governors and should not be construed as representing the policy of the American Bar Association.





Dementia

- ▶ Illness or disease that results in a decline cognitive ability including memory
- ▶ Not normal age-related changes in memory and cognition
- ▶ Has many causes – Alzheimer's is just one
- ▶ Differing causes impact memory and reasoning in different ways
- ▶ Progressive, from mild to severe
- ▶ Currently no cure, the best treatments slow the progression for some people (research is rapidly moving forward)
- ▶ For recorded programs with details please see <https://www.catholiccharitieshawaii.org/dementia/dementia-trainings-workshops/>

Engaging the Person

- Every adult has the right to
- To be informed
- To be a part of the process
- To make choices
- To express preferences
- To be engaged



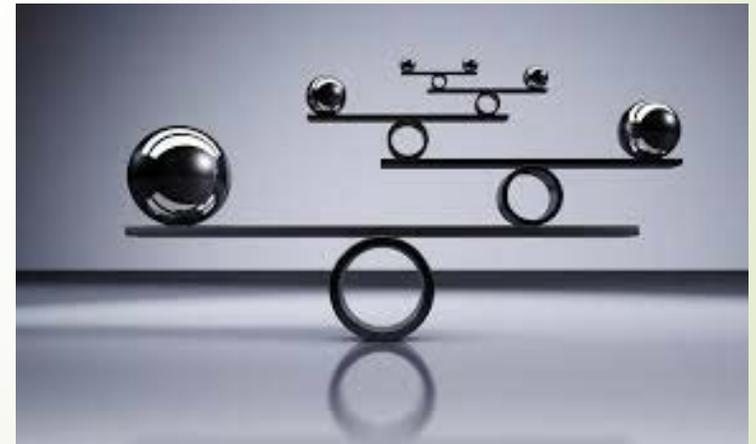
Impact of diagnosis

- ▶ Early diagnosis
 - ▶ Offers greater opportunities for treatment
 - ▶ Allows time for conversations
 - ▶ Creates an opportunity for the Person to select and empower caregivers
 - ▶ Allows time for legal planning
- ▶ Diagnosis does not modify, terminate, or end a person's legal rights.



Leveraging Ability

- ▶ Until the very latest stages of the illness
- ▶ Most persons with dementia will have the ability to
- ▶ To listen, to think, to worry, be concerned, to have emotions, to feel
- ▶ Communicate
- ▶ Express Preferences
- ▶ Make many choices



Protecting the Rights of a Person with Dementia is:

- A human rights issue
- A legal issue
- A social service issue
- A health care issue
- A community services issue
- An issue of respect



“Supported Decision-Making”:

- **Supports and/or services** that help people make their **own decisions**, by using friends, family members, professionals, and other **people they trust**:
 - To help **understand** the issues and choices;
 - Ask **questions**;
 - Receive **explanations** in language they understand; and
 - **Communicate** their own decisions to others.

(e.g, Blanck & Martinis 2014, Dinerstein 2012, Salzman 2011)



What Is Supported Decision Making?

- ▶ Concept and process
- ▶ With widespread acceptance with advocates for persons with disabilities,
- ▶ The person selects supporters and asks them to help
- ▶ The supporters help by carefully communicating with the person
- ▶ In ways that the person can understand
- ▶ Offering options
- ▶ Explaining risks and benefits
- ▶ Making a recommendation
- ▶ Asking the person to make choices
- ▶ Helping as asked or needed, to implement the choices



We All Do It Across The Spectrum Of Experience And Abilities





Decision Support Model

- Explain the issue, question or concern
- Confirm that the person understands the question
- Explain options
- Explain risks and benefits of the options
- Confirm that the person understands
- Break complex issues into smaller easier to understand questions as appropriate
- Ask the person for a choice, or preference
- Express and explain concerns but honor the choice or preference as long as there is not an unreasonable risk.
- Advocate and assist with implementation as asked or needed

Supported Decision Making Decision Supports

States are passing SDM statutes

- Urging exploration of decision supports before pursuing guardianship/conservatorship (as described in latest uniform law)
- Some states include provisions for SDM contracts or agreements
 - Agreements between the person and the supporter outlining what help will be provided and how
 - Concern that the focus goes to the agreement and not the process
 - Concerns about understanding of agreements when the agreement is signed

Decision Supports

- The core Person Centered and Person Driven decision-making model in SDM
- Services and technological supports that enhance decision-making or reduce the need for making routine decisions
 - Direct deposit, automatic payment, electronic medication dispensers, housekeeping services, home delivered meals, GPS
- Plus, asking fiduciaries, agents, and guardians to the extent possible, to apply the decision-making model
- Drafting decision supports into letters of instruction and advance care planning documents

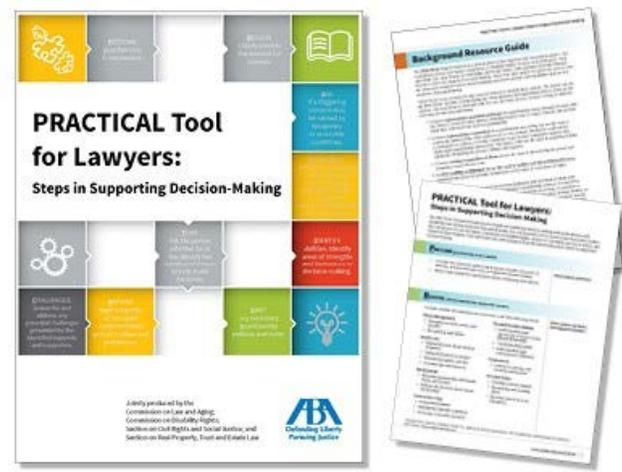
https://www.americanbar.org/content/dam/aba/administrative/law_aging/2020-supporting-decision-making-final-report.pdf

Technology Redefines Ability



Practical Guide to SDM

9 Issues to
Explore
Or Consider



Presume

- ▶ Presume that guardianship is not needed.
- ▶ For years the assumption was that if a person needed help, the person needed a guardian without first examining less restrictive alternatives.
- ▶ By changing this default presumption, we start with examining what the person can do, what the person needs help with, and what kinds of help are possible to meet the needs of the person.



Reason

- ▶ **R**eadon. Clearly identify the reasons for concern.
- ▶ This step explores the strengths of the person and what the person needs help with, in a clear checklist format covering money, health care, relationships, community living, personal decision-making, employment and personal safety.
- ▶ The goal is to identify the issues that the person needs help with.



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

- ▶ **Ask** if a triggering concern may be caused by temporary or reversible conditions.
 - ▶ **Guardianship is permanent solution**
 - ▶ **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 – language**





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.
- Community programs such as in-home care, day programs, and meals on wheels can be used to fill many gaps.
- Family and friends often help with medications and at home health care, transportation, and communications.
- Assistive technologies and modifications to the home expand the ability to live independently.
- A supervised or supportive living environment helps many people retain independence.





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

- ▶ **T**eam: Ask the person whether he or she already has developed a team to help make decisions.
- ▶ Team, always start by asking the person who they turn to for help, who they trust to help them.
- ▶ Does the person have family members, friends, or professionals available to help?
- ▶ Has the person appointed a surrogate to help make decisions?
- ▶ Help develop a team.



Identify

- Identify abilities. Identify areas of strengths and limitations in decision-making.
- What decisions can the person make? Are decisions consistent across time?
- Does the person understand the consequences of decisions?
- Help should focus on supporting abilities and filling gaps with additional supports as needed.



Challenges

➤ **Challenges.** Screen for and address any potential challenges presented by the identified supports and supporters.

- Are the supports available and accessible to the person?
- Are supports and services reliable?
- Will the people wanting to help, be available and reliable?
- Are all on board and willing to cooperate or collaborate?
- Back up plans for essential supports?





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

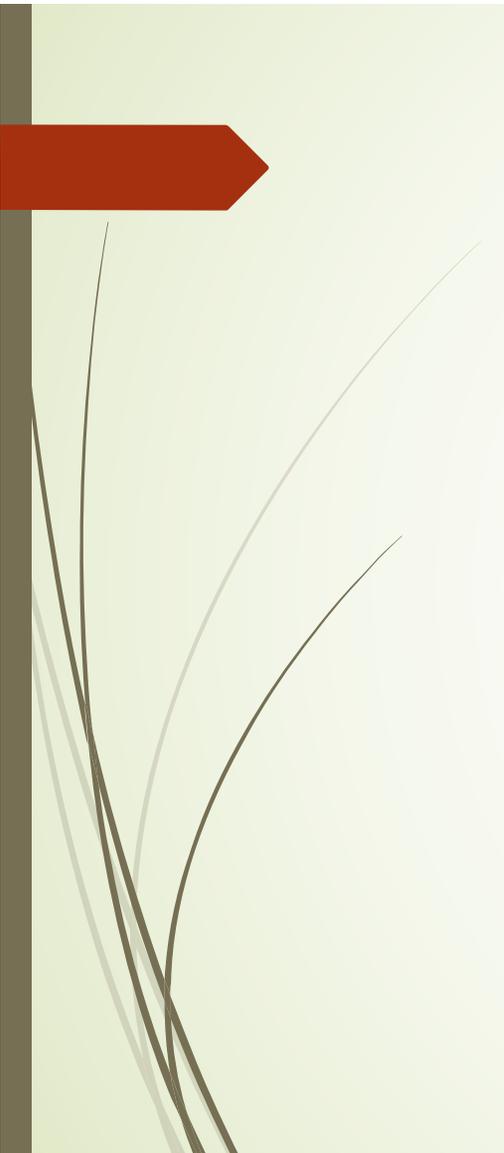
Observations and Notes:



Appoint

- ▶ Appoint a legal supporter or surrogate consistent with person's values and preferences:
 - ▶ Select the best people
 - ▶ Train them in SDM/person-driven decision-making
 - ▶ Empower them to carry out choices of the person
 - ▶ The person must have capacity to legally empower supporters (agents)





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

- ▶ LIMIT any necessary guardianship petition and order:
 - ▶ If it becomes necessary to seek appointment of guardian or conservator, ask the Court to limit the order to what the person needs help with, leaving as many rights un-effected as possible.
 - ▶ Ask guardians to practice the person-centered and person-driven principles of supported decision-making by always informing the person, offering options, recommendations, and asking the person a preference.





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:

Balancing Empowerment and the Progressive Nature of Dementia

- Persons who are actively involved in choices - Retain ability longer
- Dementia will progress to the point of being unable to express choice
- Those closest – will be able to understand the Person longer than others
- Decision Supporters should know values and decision-making process of the person



Always keep the Person
At the Center



“No tubes, take me home”

Values

- Values = Strongly held personal beliefs
- Stable over time
- In practicing SDM, the supporters come to understand the values of the person
- By understanding values we can better guide
- When needed, values should guide choices made for a person





Review of Questions

1. A person with Alzheimer's is always unable to make informed choices T / F
2. Early diagnosis allows opportunities for treatment, planning, and important conversations T/F
3. Protecting the rights of a person with dementia is just a legal issue T/F
4. A person with dementia will always be overwhelmed by being offered choices T/F
5. Every Person uses Supported Decision Making in their life T/F
6. Supported Decision Making is both person centered and person driven T/F

The Role of Decision Supporters On Money

- Difficulty with managing money is often



- Role of the supporter
- Keep the Person informed
- Provide oversight
- Help assure income is received and bills are paid
- Help the person make decisions on discretionary spending
- Provide the person with spending money, cards
- Keep meticulous records
- Keep other family members informed
- Watchdog on exploitation

The Role of the Supporter in Health Care

- Help make appointments
- Help them attend
- Accompany as asked or needed
- Help the person understand the medical condition
- Explain treatment options, risks, benefits,
- Ask for a choice, or preference
- Advocate for what the person wants
- If the person is unable to make a choice, let the persons values and goals guide decision making



The Role of the Supporter on Personal Choices

- Explain, offer options, explain risks, benefits, ask / allow the person to make choices or express preferences
- Advocate for what the person wants
- Focus on how can we make this happen,
- Delay or divert only if risks are unreasonable
- Learn the persons values, goals, what they enjoy
- When absolutely necessary, base choices on the persons values, goals and enjoyment



Concerns You Will Hear About SDM

- Abuse, and exploitation
- The choices are not “in her best interest”
- He asks the same question, over and over
- She forgets the choice that she made
- It is so hard to communicate
- Sooner or later SDM won't work





AMERICAN **BAR** ASSOCIATION

Commission on
Law and Aging