Using Supported Decision-Making to Avoid Guardianship: Screening with the PRACTICAL Tool and Beyond



CHAPTER SUMMARY • September 2018

David Godfrey, American Bar Association Commission on Law and Aging

American Bar Association Commission on Law and Aging

The mission of the American Bar Association Commission on Law and Aging (ABA Commission) is to serve as the collaborative, interdisciplinary leader of the Association's work to strengthen and secure the legal rights, dignity, autonomy, quality of life, and quality of care of aging persons, particularly low-income and vulnerable elders. Since 1979, the ABA Commission has carried out this mission through research, policy development, technical assistance, advocacy, education, and training.

Key Lessons

- 1. Guardianship should always be the last option considered. Guardianship should only be considered when all alternatives have failed to meet the essential needs of a person in need of protection.
- 2. Supported Decision-Making is a person-centered, person-driven decision-making model that leverages the person's ability to make choices.
- 3. The PRACTICAL Guide walks through the alternatives to be considered before filing for guardianship.
- 4. Understanding the values and goals of a person are essential to helping with decisionmaking.
- 5. All persons who help with decisionmaking should practice the principles of Supported Decision-Making.

Guardianship Should Always Be the Last Option Considered

Guardianship or Conservatorship Should Only Be Pursued When:

The person is unable to participate in decision-making in a meaningful way.

AND

Urgent decisions must be made to protect the person or property.

OR

When the person is unable to protect themselves from harm, and all alternatives have failed to end ongoing abuse, neglect, or exploitation of the person.

AND

No one has legal authority to make those decisions.

Guardian or Conservator?

Traditionally, a guardian was responsible for the person, and a conservator was responsible for money and property. The answer is now state specific and the terms are used somewhat interchangeably. For simplicity, we will refer to all such persons as guardians.

Guardianship should not be pursued just because a person lacks the ability to participate in decisionmaking in a meaningful way. If the person's essential needs are otherwise being met, there is no need to pursue guardianship. Alternatives such as a durable power of attorney, default health care surrogate, or representative payee meet the needs of many persons. Many decisions, such as scheduling caregivers or transportation, do not require "legal authority" for action. Not all decisions that require legal authority need to be made immediately. If the decision can be delayed, there is no reason to file for guardianship now.

If the person is being abused, neglected, or exploited and all other options have failed to end the abuse, guardianship can be an essential tool. For example, if the person has named an agent in a power of attorney, and the agent is abusing or exploiting the person, and the person lacks the ability to revoke the power of attorney, an order from a guardianship court may be the only option for terminating the legal authority of the agent. It is essential that the guardian practice the principles of Supported Decision-Making to avoid the guardianship becoming abusive.

Supported Decision-Making

Supported Decision-Making (SDM) is a person-centered, and person-driven decision-making model. SDM assumes that every person uses support to make decisions. It assumes that every person has a fundamental right to make decisions, and all persons who can communicate can make decisions. The supporter's role is to skillfully communicate with the person, explain issues in a way the person can understand, break complex choices into simpler choices, make recommendations, ask the person to make choices, honor those choices, and assist with implementing the choices as needed.

We all practice SDM. For example, when you call a plumber, you trust the plumber will explain what is wrong in terms you can understand. You trust the plumber to offer options, to make recommendations, to ask you to make choices, and to help you implement that choice. We all practice SDM. The thing that varies is the scope of choices that people need help with based on life experiences and abilities.

Capacity and Supported Decision-Making

Capacity is the ability to make an informed choice. An informed choice assumes that the person is able to make a choice. This means the person understands, in at least general terms, the question, the options, and the risks and benefits of the options. SDM urges supporters to break complex issues into smaller component parts that are easier to understand.

CASE EXAMPLE

Tabatha asked her mother Samantha, "are you going to sell your house and move to assisted living?" Samantha answers "no!" Frustrated, Tabatha asked her great-uncle Arthur to try to help. Arthur, skilled in SDM, asked Samantha questions to help her make an informed choice. He asked Samantha, what do you like most about your home? What do you always want to have nearby? What do you find that you don't use around your house any longer? How much housekeeping do you feel comfortable doing? Would it be good

to have someone clean the bathroom and vacuum the floors? Would it help you if someone was able to bring you meals when you are not feeling up to cooking? What things do you want to live near? Would you be happy with one or two bedrooms? If we could find a two-bedroom apartment and someone to help with cleaning and meals would that be better? Let's go look at this nice apartment, shall we?

Selling a home and moving is a major life-changing question. By breaking the issue down into smaller parts, it is easier for Samantha to articulate what she wants or needs, and easier for her to decide what she wants to do. Samantha may still decide she wants to stay where she is at, while at the same time, understanding other options that would make her life easier or better.

PRACTICAL Tool

The American Bar Association Commission on Law and Aging's <u>PRACTICAL Tool</u> walks advocates through SDM-based alternatives to guardianship. It is designed to help lawyers carefully identify and implement decision-making options, and assure that if guardianship is needed, it is tailored to the needs of the person: the PRACTICAL tool was developed by an interdisciplinary group of aging and disability advocates. While the tool was field tested by lawyers, it has proven useful for other advocates.

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.

R eason asks us to clearly identify the reasons for concern. This option 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, decisionmaking, employment, and personal safety. The goal is to identify the issues that the person needs help with.

sk if a triggering concern may be caused by a temporary or reversible condition. We want to avoid guardianship being a permanent solution to a temporary challenge. Illnesses, pain, medication, and mental health can all impact ability. If the underlying challenges can be treated, the person can regain the ability to be self-sufficient. Stereotypes and cultural assumptions can overshadow personal choices, and should be carefully avoided.

Community can help determine if concerns can be addressed by connecting the person with 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 additional independence.

T eam. Always start by asking the person who they turn to for help, and who they trust to help them. Many times, the person already has a support team in place, or the core of one.

Identify the persons' abilities. 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.

C hallenges. It is important to look at challenges to the supports and services that are considered. Are the supports available and accessible to the person? Will the people wanting to help be available and reliable? Are all family members on board and willing to cooperate or collaborate?

A ppoint and legally empower agents to help carry out the choices of the person. Supporters without legal authority will sooner or later find that they cannot implement the wishes of the person. The person must have capacity to appoint legally empowered agents.

L imit any guardianship petition and order to only what is needed. 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 intact 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 for a preference.

CASE EXAMPLE

A new caseworker visited an 87-year-old man named Charlie in a rural, mountainous area. Charlie lived alone in a two-room house at the end of a one-lane dirt road that hadn't been painted in 50 years. The house didn't have electricity or running water. Charlie had a big garden and staples, but, in the eyes of the caseworker, little "food" in the house. When she asked Charlie about it he said, "I'm fine, I could really use some firewood; it is hard for me to split wood anymore." She reported to her supervisor that Charlie needed a guardian. The supervisor accompanied the case worker on a home visit the next day. She talked with Charlie and found that he had lived alone in that house for nearly 40 years. He had never lived in a home with running water or electricity. He grew a big garden, hunted, and his nephews delivered staples such as flour and salt. He liked living this way. He just needed help with splitting wood.

The risks and areas Charlie needed help with were firewood, monitoring his health, assuring he was checked on a little more often, and a steady water supply. Arrangements were made for firewood and bottled water to be delivered. Charlie agreed to a visiting nurse stopping by a couple of times a month. The nephew arranged to check in every couple of days, and Charlie lived out his days in the house at the end of the one lane dirt road.

SDM Beyond The PRACTICAL Tool

The decision-making model of SDM empowers a person to play an active role in decisionmaking. When SDM is used for a person with dementia, the person should remain actively involved in making choices that impact their life for as long as possible. The progressive nature of dementia results in a decline in the person's ability to understand, make choices, or express preferences. This challenges one of the basic principles of SDM, that all people have the right and ability to make choices. As dementia progresses, the person will need greater levels of support and will make fewer choices, and the supporter, surrogates, and agents will make more choices. As this happens, we want to make choices based on the values of the person.

Values are strongly held personal beliefs. Values are slow to change, and guide the choices that we make in our daily lives. A person's values are a great predictor of the choices the person will make. In SDM, understanding the values of the person will help the supporter or agent explain questions and options to the person. Offering options that reflect the values of the person will ease the decision-making process.

If we begin practicing SDM early in the life of a person with dementia, we can learn the person's values by understanding the choices that they make. By understanding the person's values, we can make better decisions when it becomes necessary to do so.

Conclusion

It is critical to exhaust all alternatives before considering guardianship. Supported Decision-Making is a person-centered and person-driven decision model that leverages the abilities of the person to make decisions with the help of trained supporters or agents. The PRACTICAL Tool offers a step-by-step review of alternatives and a review of SDM to help advocates find the least restrictive options. Practicing SDM helps the supporters, surrogates, or agents develop a deep understanding of the values of the person. Knowledge of those values will help the supporters make better choices that reflect the values of the person if it ever becomes impossible for the person to make their own choices.

Additional Resources

- Administration for Community Living Supported Decision-Making Resources
- American Bar Association Commission on Law and Aging
- Burton Blatt Institute at Syracuse University
- National Center on Law & Elder Rights
- National Resource Center on Supported Decision-Making
- Quality Trust for Individuals with Disabilities
- <u>David Godfrey</u>, Senior Attorney, American Bar Association Commission on Law and Aging

Case consultation assistance is available for attorneys and professionals seeking more information to help older adults. Contact NCLER at ConsultNCLER@acl.hhs.gov.

This Chapter Summary was supported by a contract with the National Center on Law & Elder Rights, contract number HHSP233201650076A, from the U.S. Administration for Community Living, Department of Health and Human Services, Washington, D.C. 20201.