Using the Tools of Supported Decision Making to Help Clients with Dementia

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Scope:

Dementia is a progressive illness resulting in a loss of memory, and cognitive skills that impacts nearly every family. Applying the person centered and person driven concepts of supported decision making (SDM) when working with persons with dementia empowers the person to play an active role in decision making for a longer period of time, and trains the advisors, agents, and surrogates in making decisions that most accurately reflect the values and goals of the person. Anytime we ask help understanding, or for advice, or a professional for guidance, we are practicing supported decision making. We all practice SDM, it is as simple as asking a trusted advisor to help us understand an issue, to make recommendations and to help us make and carry out choices. Capacity is the ability to make and communicate an informed decision. The core ethics principle of communicating matters in a manner to enable our clients to make informed decisions[1], leads lawyers to constantly assess capacity, or understanding on the part of clients. When our clients have difficulty understanding we need to break complex matters into simpler parts, enhancing our clients' ability to make informed choices. This process of breaking issues down into simpler parts, is a core skill of supported decision making.

For persons with diminished capacity, applying the principles of SDM expands the scope of issues the person can retain a degree of control on. Lawyers should explore the tools of supported decision making when working with clients experiencing a loss of memory or cognition, facilitating SDM to the extent possible, and customizing interventions to preserve client rights.

As lawyers, we need to employ the principles of SDM to help our clients, the ethical rules on communication[2] and representing clients with diminished capacity[3] direct and support using SDM in representing our clients. We need to incorporate the principles of SDM into planning for incapacity. We need to train advisors, agents and surrogates in the SDM decision making process.

The Challenge of Dementia:

One of the greatest challenges facing a person with dementia is a progressive loss of the ability to communicate. The loss of the ability to communicate complicates the attorney client relationship. We try to encourage every client to engage in basic planning for an unexpected loss of capacity, for a client experiencing changes in memory and cognition, planning takes on new urgency and importance.

Dementia is a global term for many illnesses that result in a decreased ability to make choices (executive function), decline of short or long-term memory, lessoning of the ability to acquire and understand information and decline in the ability to communicate. Changes in the brain can impact social interaction, personality, or behavior. Dementia is not a single illness such as Alzheimer's, dementia can

[1] Model Rules of Professional Conduct 1.4 (b)
[2] Model Rules of Professional Conduct 1.4(b)
[3] Model Rules of Professional Conduct 1.14

be caused by many illnesses that change the way the brain works. Different causes result in different deficits. A person with dementia may have excellent long-term memory and no short-term memory. A person with dementia may be able to make decisions, but not be unable to carry the decisions out. Persons with dementia may be unable to find the right word, or put together a coherent sentence. Just as we are all unique individuals, each person with dementia is impacted by the illness in a different way. One important principle is to focus on what the person can do, and how to maximize the use of what works.[4]

Understanding of brain aging and dementia has improved dramatically in recent years, including the ability to diagnose early stages of cognitive impairment. Early diagnosis improves options for treatment to delay the progression of dementia from some causes and expands options for legal planning. A Person can have a lot of residual capacity when diagnosed with mild cognitive impairment. As understanding of the causes of dementia expand, and treatment options emerge for some causes, there is an expanded push for early diagnosis.[5]

Understanding Capacity:

Capacity is the ability to make and communicate an informed choice.

As lawyers we are constantly assessing our clients understanding and ability to make informed choices, our core ethical obligations include communicating with clients a manner the client can understand[6], and following clients' directions regarding the objectives of representation.[7] Capacity is a spectrum of ability, from comatose to genius. Capacity is task specific, the ability to understand or perform one task, does not guarantee the ability to understand or perform a different, or even a related task. Capacity can be variable and transient, abilities can vary based on physical and mental considerations. Legal capacity is very task specific, with some legal transactions being held to a much higher standard than others.

With most clients, capacity is obvious. As long as there is nothing in your communication with a client that leads you to believe that they do not understand what you are saying, we assume the client has capacity – but we are constantly on the lookout for a lack of understanding. The level of detail needed in your explanation will vary with the issue, the client's ability and life experience.

Assessing capacity becomes a concern when we have a client with diminished capacity, or when it becomes unclear if the client understands the matter enough to make choices. When we become concerned about our clients' capacity, we take steps to assess capacity. The ABA/APA publication Assessment of Older Adults with Diminished Capacity provides an invaluable guide to understanding capacity.[8] For a client with dementia, we need to be constantly aware of the clients understanding and ability to make decisions.

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[4] https://youtu.be/Z0h2Wk6-C_I think of the scene in Apollo 13, the call to work the problem and focus on what works and what can be done, not on how things are normally done.

[5] Benefits of early dementia diagnosis,NHS online, https://www.nhs.uk/Conditions/dementia-guide/Pages/dementia-early-diagnosis-benefits.aspx; Importance of Early Diagnosis, Alz.org, https://www.alz.org/alzheimers_disease_diagnosis.asp

[6] ABA Model Rules of Professional Conduct 1.4

[7] ABA Model Rules of Professional Conduct 1.2

[8] Assessment of Older Adults with Diminished Capacity: A Handbook for Lawyers, Sabatino et al (2005), available at https://www.americanbar.org/groups/law_aging/resources/capacity_assessment.html

Signs to look for on capacity:

- Can the person make choices?
- Is the person able to explain reasoning for choices?
- Are the persons' decisions consistent with history (if not can the person explain the change?)
- Does the person repeat questions or information after a short period of time?
- Can the person list the steps that they have agreed to take?
- Does the person have unusual difficulty find the right word?
- Does the person use the wrong word?
- Ask the person to summarize what you have been discussing
- Can the person change subjects?
- Can the person do basic calculations?
- Does the person get easily disoriented?
- Is the person emotionally stressed?
- Is the persons emotional reaction inconsistent with what they are talking about?
- Does the person hold beliefs that have no rational basis?
- Is the person experiencing hallucinations (seeing, hearing, smelling or feeling things that no one else is experiencing)?
- A decline in grooming or hygiene.

Capacity can be impacted by many factors – and a decline may be short term:

- Is the person experiencing stress, grief or depression?
- Is the person ill?
- Is the person in pain?
- Is the person taking medication?
- Has the person had recent anesthesia or surgery?
- Is the person fatigued?
- What about the person's hearing and vision?

Legal Capacity Standards:

Few legal decisions have clear standards for capacity. Testamentary capacity has a clear legal standard in many states, because Wills have long been subject to challenge. The standard is often based on old English common law; – the ability to recognize the natural objects of one's bounty, the nature and extent of one's estate and the fact that one is making a plan to dispose of the estate after death."[9] Contractual capacity starts with requiring that the person be an adult, not intoxicated, mentally impaired or incompetent. A contract may be set aside with proof that the person completely lacked an understanding of the agreement, or completely lacked an understanding of the consequences of the contract.[10] Put another way, the persons "mental condition interfered with the party's understanding of the transaction, or her ability to act reasonably in relation to it."[11] To challenge a contract based on lack

[9] Black's Law Dictionary Seventh Edition, 1999, pg. 199.
[10] Legal Dictionary.net https://legaldictionary.net/contractual-capacity/
[11] Frances M. SPARROW vs. David D. DEMONICO & another, MA Supreme Ct, SJC-10868 (2012.)

of capacity you need to show that the person was unable to understand the meaning of the words making the contract.[12]

> Ed was developing dementia, he would get lost two blocks from the home he had lived in for 40 years. His kids took his car away from him. A couple of days later he took a taxi to the nearest car dealer and said, I like the red one, call Mike at Bank Zero, I have lots of money, Ed drove the Red car home (getting lost along the way.) A week later, Ed's son Fred took new Red car away, saying "call anytime you need a ride, we will take you anyplace you want to go." After a couple of days Ed got bored, took a taxi to the car dealer and said, I like the blue one, I always wanted to own a blue car, call Mike at Bank Zero, I have lots of money. The salesman asked about the Red car, and Ed said, "my kid is driving it." Ed drove home the Blue car (getting lost along the way.) Fred argued that the contact for the Blue car should be void due to lack of capacity.
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> Did Ed have capacity to contract?
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> What if Ed had said, I want to the blue one, it should be fast enough to get me to into orbit so I can go home to Mars?
>
> What if he tried to pay for it with a bag of magic beans? Or demanded that it should be free, claiming that as a space alien invading earth he claimed everything as his.

Contractual capacity is frequently the standard referred to as the capacity needed to create a power of attorney, or advance health care directive. Contractual capacity is fairly low standard to meet (meaning the burden to overcome the presumption of validity is high), of being able to understand the fundamentals of the agreement. Contractual capacity does not require a detailed understanding of all of the risks and benefits of the choice being made.

Supported Decision Making (SDM):

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

SDM is defined as:

> "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.

[12] Contractual Capacity, Study.com, https://study.com/academy/lesson/contractual-capacity-definition-cases.html

SDM is balancing point between leaving a person totally on her own, and someone taking control of that person's life. SMD utilizes advisors, agents 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 guiding choices – always in consultation with the person, and then honoring the choices of that individual.

The essence of supported decision making is that it is normal for a person to ask advisors for information and guidance when making decisions. It is a simple concept, and we all do it. When you don't feel well and you see a doctor, you are asking the doctor to help you understand what is happening, explain treatment options, make a recommendation and help you make a choice based on your values and health care goals, you are engaging in SDM. We do the same with everything from accountants and financial advisors to plumbers and trusted mechanics. The spectrum of issues we seek help with varies with our personal ability to understand the issues. There is even a hotline for seeking advice on how to cook a turkey.[13]

Supported decision making (SDM) applies the decision-making model of advisors helping the person make choices across the spectrum of capacity to empower and protect the fundamental human and Constitutional rights of persons with intellectual disabilities and dementia. SDM is based on the principle that as long as a person can make a choice or express a preference, the person should be empowered and assisted with implementing his or her own decisions. With the progressive nature of dementia, most person with dementia will eventually reach a point where it is impossible for them to express a choice. Expressing happiness or dissatisfaction will frequently last longer than the ability to describe feelings. As one caregiver described it, "I show mom her pill and explain what it is for and how it will help her and I place it in her mouth, if she swallows it, I interpret that to mean she wants to take her medication, if she spits it out, I interpret that to mean she does not want to take her medication right now." Based on her long-term relationship as a caregiver, she had a remarkable ability to read the person's likes and dislikes long after verbal communication was impossible.

A fundamental keystone of SDM is that the advisor or agent does not make the decisions, the advisor explains the issue, offers options and recommendations, but leaves the ultimate choice up to the person. Even with the most liberal impetration of likes and dislikes, many persons with dementia will become unable to express feelings in any meaningful way. If the advisors / agents / supporters have been practicing the principles of supported decision making long enough, they will be better prepared to make decisions that more closely reflect the decisions the person would make.

The range of issues a person seeks help with will vary with the individuals' capacity. Capacity is the intellectual or physical ability to do something.[14] Across the spectrum of human capacity, even persons with profound challenges, are usually able to make simple choices. Many of the issues in life can be broken down into smaller parts, with simpler choices that add up to major life decisions.

For example, we could ask the person where he or she wants to live. That is a major question that has many parts: location, alone or with whom, rent or own, house or apartment, number of bedrooms, bathrooms, city street or country lane - and hundreds more sub-decisions that add up to the ultimate answer of where the person *prefers* to live. Depending on the life experience and ability of the person,

[13] http://www.butterball.com/turkey-talk-line
[14] http://www.dictionary.com/browse/capacity

the process of answering "where do you want to live?" may be simple or it may be very complex with many little decisions to be made to get to the ultimate answer to the question.

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 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.[15] Very complex challenges can be broken down into simple understandable steps.

Let me offer an example of taking a complex decision 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.

Don't be ridiculous – SDM can't always work:

With dementia and other serious illnesses people may reach a point of being totally unable to make, or communicate, decisions, choices or preferences. When the person reaches this point someone must make decisions for the person. The goal of SDM is to make surrogate decision-making an absolute last

[15] http://www.discovery.com/tv-shows/mythbusters/mythbusters-database/person-with-no-flying-experience/

resort, only to be used after all efforts to communicate have proven fruitless. All too often surrogates take over decision making, long before the person loses the ability to make choices. *It is easier for the agent to make the decision, than it is to engage in SDM, but doing so before the person has truly lost the ability to make and express choices robs the person of fundamental human and Constitutional rights*. Further, advisors/agents who have engaged in SDM with the person will have a wealth of experience to inform decisions based on the choice the person would make, when and if the time arises later.

How Does SDM Impact Advance Care Planning?

Traditional advance care planning focusses on naming an agent to make decisions when the person is unable to do so. With Supported Decision Making we focus 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.

Selecting agents/advisors, sometimes known as supporters, or the supportive circle, is very much like selecting agents in powers of attorney, or selecting a health care surrogate. 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, offering advice and seeking input from the person. This is a departure from the traditional paternalistic view of the advisor as an agent charged with making decisions standing in 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

Health Care Planning[16]

Health care advance planning has two primary tasks: appointing a health care surrogate; and, putting into writing instructions for health care decisions.[17] Selection of the surrogate should be done with great care to assure that the person selected is willing and able to engage in SDM.[18]

The right agent is the key to success for SDM. In theory, the surrogate only makes health care decisions when the person lacks capacity. In practice, the person may defer to the surrogate before incapacity and health care providers may turn to the surrogate long before the person loses the ability to offer input into health care decisions. Selecting a surrogate who embraces the person-driven model of SDM is

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[16] State laws on health care decision making can be found at https://www.americanbar.org/content/dam/aba/administrative/law_aging/2014_default_surrogate_consent_statutes.authcheckdam.pdf

[17] State statutes on health care power of attorney laws can be found at https://www.americanbar.org/content/dam/aba/administrative/law_aging/state-health-care-power-of-attorney-statutes.authcheckdam.pdf

[18] For information on how to make health care decisions for someone else see https://www.americanbar.org/content/dam/aba/administrative/law_aging/2011_aging_bk_proxy_guide_gen.authcheckdam.pdf

essential to assuring that our clients are involved in health care decision making as long as they can express a preference.

Few decisions are more personal than what health care a person wants--or does not want--to receive. It is important to select a health care surrogate who will always start by assuring that the person understands the nature of the illness or condition, the treatment options--including the option of not treating--the possible impacts of the options, and the recommendations of the experts. A patient should always have this explained to him, in terms broken down to be understandable, and the person should be asked for choices or preferences. SDM urges doing this all of the time, even if it appears that the person is unable to understand. Doing this takes time, and effort, but is essential to preserving the human rights of the person. Research tells us that some persons who are unable to communicate, are still able to understand. Taking the time to explain improves the quality of life for some patients, so it should be done every time.

Drafting ideas for designating a surrogate:

Including language in the advance health care directive that directs the surrogate to utilize the SDM model is a good first step.

For example:

> 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. That my surrogate explain to me the treatment options available, the prognosis, risks and benefits of various treatment options, recommendations from my doctors and 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 without my input, 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.

Values and goals surveys:

The primary criticism of living will directives is that the forms give very specific directions for health care, only when death is imminent. But they offer little guidance outside of life prolonging care at the very end of life. Nearly everyone will pass through this critical end of life point, giving some value to a living will, but the bulk of health care decisions are made long before the end of life. For many persons the period of needing significant help with making health care choices extends for weeks, months or years. Generally living wills offer specific instructions on feedings tubes, mechanical interventions that replace naturally occurring bodily functions, and possible resuscitation when heart beat or respiration stops. Because of the very limited circumstances and the wide array of possible illness and situations a simple yes no answer may not be very useful.

Let me offer an example on a feeding tube.

> Would you want to be kept alive with a feeding tube?

What if it was temporary – maybe a month while you healed from surgery and then could likely be removed?

What if you were unconscious with little hope of recovery and the feeding tube was likely to keep you alive for several weeks?

What if you were comatose and the feeding tube was likely to prolong your life for years – with little or no hope of recovery?

What if after you started on a feeding tube you developed a painful and fatal illness, and the feeding tube was likely to extend the dying process from a couple of days to a couple of weeks.

Rather than try to examine the 100 variations on this question, a more useful approach is to try to understand the personal goals and health care values of the person. There are a variety of resources available to help with this process.[19]

Consumer's Tool Kit for Health Care Advance Planning, by the ABA Commission on Law and Aging is available for free download at: http://ambar.org/agingtoolkit.

The Conversation Project, an initiative begun in 2010 by noted columnist Ellen Goodman and a group of her colleagues, concerned media, clergy, and medical professionals, all dedicated to helping people talk about their wishes for end-of-life care. Resources include the Conversation Starter Kit at: www.theconversationproject.org/.

The Go Wish Game, a card game for sorting out values related to end-of-life decision-making, created by the Coda Alliance, a community organization in Santa Clara County, California. An easy, entertaining way to think and talk about what's important to you if you become seriously ill. A free online version is available and printed version for purchase at: www.codaalliance.org.

PREPARE web site. This free web site is designed to help people and their loved ones prepare for medical decision making by guiding the user through five easily understandable steps of preparation for decision-making with the help of multiple video aids. The result is a printable action plan. Available at: www.prepareforyourcare.org.

Advance Care Planning: Tips from the National Institute on Aging. This tip sheet describes advance care planning and offers some questions to get the process going. It also describes ways to share your wishes with others. Available at: http://www.nia.nih.gov/health/publication/advance-careplanning.

Tools for managing your end-of-life care: Compassion and Choices. Booklets and check lists on personal values and goals of care. Available at: https://www.compassionandchoices.org/eolc-tools/

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19 http://www.americanbar.org/content/dam/aba/administrative/law_aging/Health_Decisions_Resources.authcheckdam.pdf

The objective is to document the person's values and health care goals. Values are what is most important to the person, goals reflect the outcome the person hopes for when seeking medical treatment. Understanding the values and goals of the person helps to guide the advisor in providing options and recommending actions that create high value for the person.

For example, if family contact is a high value for the person, extra attention should be placed on assuring that family members have easy access and are encouraged to spend time with the person. Health care goals tell us what outcomes the person is hoping for when they seek medical care. It is important to know if the person's goal is a cure, or comfort, is the goal years in the life, or life in the years. It is also important to understand if there are tipping points where the person's health care goals will change. For example, if a person would want to try curative care, but if that care was showing little improvement after a specified period of time, or they were suffering debilitating side effects, would they want to change to comfort care. It is important to document how the person feels about feeding tubes. Some courts want a clear expression of the desire to not have a feeding tube, or to have one withdrawn under given circumstances. The best way to meet this is to put it in writing. Health care goals and values surveys also make it easier for family and friends to understand the reasoning behind the choices that are being made.

Integrating SDM and health care values and goals:

The person-centered planning and person-driven decision making of model of SDM makes SDM the perfect fit for advance care planning. Ideal health care decision making is person driven, based on induvial values and goals. Combining the person-centered decision-making model of SDM with documenting health care goals and values, will help to guide decision making that reflects decisions that clearly carry out the intentions of the person. While SDM will always inform the person and ask for preferences or choices, if the person becomes totally unable to communicate a preference or choice, the documented goals and values will guide choices based on what the person would most likely do.

An example, consider the two grandmothers in their early 80's. Emily was a strong believer in medicine. She went to her doctor anytime she didn't feel just right. She had a shoe box full of pills, she had something in there that would cure almost anything. Mina didn't trust doctors, she had only seen a doctor a handful of times in her life. She used traditional "folk medicine" and over the counter remedies and only saw a doctor if she thought she was going to die. When Emily didn't feel well the staff at the assisted living center called her son and said, "Emily does not feel well, she wants to go to the doctor, what should we do?" To start with, listen to her, if she says she thinks she needs to see a doctor why call her son for permission? Based on her health care goals and values, if she is showing any symptoms of not being well, get her into see a doctor. On the other hand, when the assisted living facility staff called and said "Mina has a bit of a cough and does not seem to want to get out of bed today," the answer was obvious. If she is not feeling well and is refusing to get out of bed, she is communicating to you, that she wants to stay in bed today. The staff felt that Mina was unable to decide if she needed to see a doctor, the answer was equally obvious. Based on her well-known health care values and goals (avoid doctors and treat with over the counter remedies,) let her stay in bed and treat her with over the counter drugs.

The better job we do of knowing health care values and goals, the better job we can do as advisors using SDM principles. Knowing values helps us to present information and options to help the person understand what is happening, thereby helping the person make better choices. Knowing the person's

health care goals helps the advisor/agent work with health-care providers to ensure that treatment options which carry out those goals are offered.

SDM and Financial Planning:

An important part of advance care planning is making plans to assure that income is received and accounted for, and that bills and other obligations are paid. This is done with a variety of tools. For income direct deposit into accounts that the advisor or agent can pay bills from is the most common. It is becoming more common for payment of recurring bills such as utility bills to be set up on auto-pay – so only oversight and not action is needed to assure many bills are properly paid. The advisor should monitor the account, and help the person make choices if there is not enough money to pay all of the bills that come in.

A durable power of attorney should be created to assure that the agent/advisor has legal authority to carry out the wishes of the person. Power of attorney law is state specific. A listing of power of attorney statutes in all 50 states can be found at https://www.americanbar.org/content/dam/aba/administrative/law_aging/chartpoa.authcheckdam.pdf . Some states have statutory forms, or specific clauses that must be included.

Unless a court order is entered saying an adult lacks capacity, adults are presumed to have legal capacity. But, third parties such as banks or business may question the capacity of the person to enter into transactions when illness or injury impairs the person's ability to clearly communicate. Dementia, stroke, traumatic head injury, and illnesses that make it difficult or impossible for a person to speak can all lead to the need for a legally authorized advisor/agent. The simplest way of creating agency is a durable power of attorney.

The agent named in a power of attorney stands "legally" in the shoes of the person. The agent is able to make any decision allowed by law which is within the authority granted in the document or by statute. Applying the principles of SDM to powers of attorney directs the agent to always confer with the person, ask for the preference or choice of the person, and to act in accordance with the person's directions. This is a change from the traditional view that the agent is substituted for the principal.

Drafting SDM into Powers of Attorney:

> I would like 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 honoring this document are not responsible for asking or verifying that this has taken place.

The person may be concerned about the agent on the power of attorney making sweeping changes in the person's financial affairs. This clause requires 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 _____.

Persons with dementia revoke powers of attorney in moments of frustration. The threshold of capacity to revoke a power of attorney may be lower than the capacity to create one. The result can be advisors or agents lacking legal authority to help, and at the same time the person being unable to appoint a new advisor or agent. One option is to require a cooling off period on a notice to revoke. The cooling off period allows time for the person and agent to communicate in an effort to reach understanding, allowing the power to continue in effect. During the cooling-off period authority should be suspended.

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.

Supported Decision Making Agreements.

Currently two states, Texas and Delaware, recognize by statute SDM agreements for adults.[20] An SDM agreement is a contractual agreement between the person and the advisor(s) or agent(s) outlining the issues the person needs help with and offering at least minimal guidance and the person.

Texas

In 2015 Texas passed SB 1881 (HB39) now codified as Supported Decision-Making Act Chapter 1357 of the Texas Estates Code. The Texas law was the first in the United States to recognize supported decision-making agreements. The law defines "supported decision-making" as "a process of supporting and accommodating an adult with a disability to enable the adult to make life decisions, including decisions related to where the adult wants to live, the services, supports, and medical care the adult wants to receive, whom the adult wants to live with, and where the adult wants to work, without impeding the

[20] There is a statute in the District of Columbia specific to individual education plans for persons with disabilities.

self-determination of the adult." The stated purpose of the law is to "recognize a less restrictive alternative to guardianship" for adults who need assistance but are not "incapacitated persons." The law sets the framework for persons to "voluntarily, without undue influence or coercion, enter into a supported decision-making agreement with a supporter" and sets out the scope of the agreement.

Under the Texas law the role of the supporter is to assist, "without making . . . decisions on behalf of the adult;" gather and share information, explain, and help the person understand options, including the risks and benefits and as needed communicate the person's choice to third parties.

The law talks about grounds for terminating the SDM agreement in the event that adult protective services determines that the advisor is abusing or neglecting the person, or has been found criminally liable for abuse, exploitation or neglect of the person. The law requires third parties to report suspected abuse, neglect or exploitation.

The statutory agreement includes a HIPPA waiver allowing the advisor access to confidential health care information and obligates the advisor to keep that information confidential. The statute includes a statutory form, but allows variation as long as the agreement substantially follows the statutory form.

Texas Statutory Form SDM Agreement

SUPPORTED DECISION-MAKING AGREEMENT

Appointment of Supporter

I, (insert your name), make this agreement of my own free will.

I agree and designate that: Name:

Address:

Phone Number:

E-mail Address:

is my supporter. My supporter may help me with making everyday life decisions relating to the following:

Y/N obtaining food, clothing, and shelter

Y/N taking care of my physical health

Y/N managing my financial affairs.

My supporter is not allowed to make decisions for me. To help me with my decisions, my supporter may:

1. Help me access, collect, or obtain information that is relevant to a decision, including medical, psychological, financial, educational, or treatment records;

2. Help me understand my options so I can make an informed decision; or

3. Help me communicate my decision to appropriate persons.

Y/N A release allowing my supporter to see protected health information under the Health Insurance Portability and Accountability Act of 1996 (Pub. L. No. 104-191) is attached.

Y/N A release allowing my supporter to see educational records under the Family Educational Rights and Privacy Act of 1974 (20 U.S.C. Section 1232g) is attached.

Effective Date of Supported Decision-Making Agreement

This supported decision-making agreement is effective immediately and will continue until (insert date) or until the agreement is terminated by my supporter or me or by operation of law.

Signed this _____ day of _____, 20___

Consent of Supporter

I, (name of supporter), consent to act as a supporter under this agreement.

(signature of supporter)

(printed name of supporter)

(witness 1 signature) (printed name of witness 1)

(witness 2 signature) (printed name of witness 2)

State of

County of

This document was acknowledged before me

on _____ (date)

by _____ and _____

(name of adult with a disability) (name of supporter) (signature of notarial officer)

(Seal, if any, of notary)

(printed name)

My commission expires:

WARNING: PROTECTION FOR THE ADULT WITH A DISABILITY

IF A PERSON WHO RECEIVES A COPY OF THIS AGREEMENT OR IS AWARE OF THE EXISTENCE OF THIS AGREEMENT HAS CAUSE TO BELIEVE THAT THE ADULT WITH A DISABILITY IS BEING ABUSED, NEGLECTED, OR EXPLOITED BY THE SUPPORTER, THE PERSON SHALL REPORT THE ALLEGED ABUSE, NEGLECT, OR EXPLOITATION TO THE DEPARTMENT OF FAMILY AND PROTECTIVE SERVICES BY CALLING THE ABUSE HOTLINE AT 1-800-252-5400 OR ONLINE AT WWW.TXABUSEHOTLINE.ORG.

(b) A supported decision-making agreement may be in any form not inconsistent with Subsection (a) and the other requirements of this chapter.

Added by Acts 2015, 84th Leg., R.S., Ch. 214 (H.B. 39), Sec. 23, eff. September 1, 2015. Added by Acts 2015, 84th Leg., R.S., Ch. 1224 (S.B. 1881), Sec. 1, eff. June 19, 2015.

Delaware

Delaware followed with legislation in 2016. Delaware Senate Bill 230 passed and was signed into law, becoming TITLE 16, Health and Safety Individuals with Disabilities, CHAPTER 94A. SUPPORTED DECISION-MAKING.

The goal of the Delaware law is to "provide assistance in gathering and assessing information, making informed decisions, and communicating decisions to adults who do not need a guardian or other substitute decision-maker for such activities, but who would benefit from decision-making assistance." The law defines "support services" as "a coordinated system of social and other services supplied by private, state, institutional or community providers designed to help maintain the independence of an adult." The bill provides a framework for an adult to enter into a supported decision-making agreement "voluntarily and without coercion or undue influence." The law recognized the fundamental right of all adults, "to live in the manner they wish and to accept or refuse support, assistance, or protection as long as they do not harm others and are capable of making decisions about those matters" and "to be informed about and, to the best of their ability, participate in the management of their affairs." And to live in the "least restrictive and intrusive form of support, assistance, or protection when they are unable to care for themselves or manage their affairs alone" and to have their life guided by "the values, beliefs, wishes, cultural norms, and traditions that an adult holds should be respected in managing an adult's affairs." The law requires that the Department of Health and Social Services create a standardized form for the agreement. As of June 1st, 2017 the standard agreement form has not been posted online. The contract will require to witnesses, and the advisor to accept their role in the agreement. The law allows for revocation by either party. The role of the advisor is to "assist the principal in understanding information, options, responsibilities, and consequences of the principal's life decisions, including those decisions relating to the principal's affairs or support services."

The law limits liability for third parties who rely in good faith on the supported decision making agreement, or who in good faith decline to honor the agreement on health care issues. The law obligates third parties to honor a valid agreement and allows for enforcement of the agreement.

The goal of these laws is to provide a basic framework for recognizing SDM as a person-centered planning model and a person-driven decision-making model. The statutory forms are a starting point, but other issues should also be addressed.

The SDM contract is a good place to clarify the goals and values of the person.

Areas that may be addressed include but are not limited to:

- Preferences on living arrangements.
    - My advisor/agent agrees to exhaust all possible effort to help me stay in my home for as long as possible. I understand that this may result in a lower quality of care, I believe it will result in a higher quality of life.
- Social contacts

    - I wish to maintain social contact with _____ for all of my life. I ask that my advisor/agent facilitate in person or audio/video communication with _____ for as long as possible. It is my wish to attend the annual _____ family reunion every summer in _____ and ask my advisor/agent to do everything possible to for me to attend each year.
- Furniture
    - I have always treasured the steamer trunk in my bedroom that my grandmother used when she crossed the Atlantic in 1914. I ask that it be in my room for the remainder of my life.
- Personal items of great personal value
    - I wish to be surrounded by _____. I ask that my advisors/agents help me to make this possible.
- Spending money
    - At my request, my advisor/agent shall provide to me up to $____ per week in cash as spending money and not ask for or expect an accounting for what I do with it. This amount shall not be for essential living expenses, but is my personal spending money. I have long enjoyed spending or wasting this amount, and changes in my health should not change this. This amount is affordable for me. If my agent/advisor is asked by third parties to account for this money, documenting that it was delivered to me in cash shall be considered sufficient evidence – with no additional documentation on what it was spent on required by anyone.
- Dollar amounts on financial transactions that trigger additional consultation
    - I agree not to spend or incur any debt over $_____, without first consulting with my advisors/agents. My advisors should counsel me on the wisdom of the spending I wish to engage in, and, when possible, suggest alternatives. If I fail to keep this promise, my advisors/agents are fully justified in withdrawing from helping me.
    - My advisors or agents and I agree that none of us will spend, or incur debt in excess of $_____, without discussing the proposed transaction, and allowing __ days for reconsideration before the expenditure.
- Preferences on food or diet
    - Chocolate and coffee are my favorite foods. Even if contrary to medical advice, I ask that my agent make these foods available to me for the rest of my life.
- Preferences on religious or social activities.
    - I have been a lifelong Catholic, and ask that my advisors/agents empower me to continue my practice. I ask that transportation be arranged for me to attend Mass, and if appropriate Priests from my parish be asked to call on me at home.
    - I am not an active practitioner of any religion, I ask that my advisors/agents politely ask members of the clergy and others wishing to practice their religion to leave me in peace.
- Entertainment
    - I am a lifelong CNN news fan, I ask that this station be played for me at all times.
    - Rock and roll for the 1960's and 1970's is the sound track of my life, I ask that this music be played for me to enjoy. When in doubt, look at the play list on my

computer and phone for the music that I most enjoy. I prefer music to silence, if I am awake, please have music playing for me.

- Health Care Decisions
    - I have named the advisor/agent in this document as my health care surrogate. I ask that this person accompany me for medical treatment whenever possible. I ask that my health care providers freely and openly communicate with my agent, just as they would me. I grant permission to my health care providers to share any and all medical information about me and my care with my agent. I authorize my advisor/agent to sign any needed releases for my health care information on my behalf. I ask that my agent keep me informed of all health care conditions, diagnosis, proposed treatments, including the attendant risks and benefits of any proposed treatment and the prognosis or likelihood of success. I ask my advisor/agent to always ask for my choice or preference on health care decisions, even if it appears that I may not understand.

The more detail on values and life goals included in the life care planning documents the more effective the documents will be.

Instructions for the Advisor / Agent:

The typical letter of instructions from an attorney to the agent named in a power of attorney focusses on:

- instructing the agent on how to use the document,
- how to sign as the agent,
- safe guarding the original documents,
- use of copies of the documents and important records to keep.

When adding SDM principles the attorneys' letter of instructions needs to be greatly expanded. In fact, the instructions are so much broader that the attorney really should meet with the advisors/agent to discuss SDM principles and how to use the documents that have been prepared.

A starting point for the attorney is permission from your client to discuss this information with agent/advisor. The waiver from the client should be in writing with good documentation of the potential issues. You should disclose in writing to the advisors/agents that you do not represent them or their interests, you represent the person and their best interests. If the advisors/agents have questions or concerns they may need to consult an attorney – see your states version of model rule 4.3 for guidance on working with an unrepresented person.

Training the Agent / Advisor in SDM

It is important to explain to the agent that we are engaging in person-centered planning and person-driven decision making. The role of the agent is to explain the issues, options, offer recommendations and assist the person in making choices for as long as the person is able to express a choice or preference, and then to help the person carry out those decisions. The agent should only make decisions without input from the person when the person is totally unable to communicate. Even when the person is totally unable to communicate, the agent should explain to the person what is happening, the options, the recommendation, the choice that is being made and why.

Agents/advisors that understand this process, are prepared to engage in SDM.

Reviewing the values and goals of the person with the agent/advisor will help the agent/advisor offer options and choices that honor those values and goals. So a careful review of the values surveys and goals of the person is an important step in planning. Some of the values and goals assessment tools are interactive for the person and agent/advisor/family/friend. You should encourage or even facilitate the clients working through this process.