

Supported Decision- Making: From Theory to Practice

Jonathan
Martinis
Jonathan
Gerald
Martinis, LLC

ARTICLE OF FAITH: EQUAL RIGHTS

“[P]hysical or mental disabilities in no way diminish a person's right to fully participate in all aspects of society”

The Americans with Disabilities Act,
42 U.S.C. 12101

ARTICLE OF FAITH

Older adults and people with disabilities who have more self determination are:

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

SPECIFICALLY

- Older adults who exercise more control over their lives have a **better quality of life**. - Mallers, et al., 2014
- Older adults provided with support to make decisions regarding treatment for kidney disease showed increased knowledge of the risk, benefits, and symptoms of dialysis, allowing them to make more informed decisions consistent with their personal values. - Brown, 2017
- Providing support to people with dementia can lead to them being able to provide informed consent. - Haberstroh, et al. 2014

GETTING TO SELF-DETERMINATION: 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

SUPPORTED DECISION-MAKING IS A LOT OF WORDS FOR

Getting help when its needed

Just like you and me

SDM HELPS 1

“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

SDM HELPS 2

In a study, young adults who used Supported Decision-Making showed:

- Increased independence, confidence, and decision-making abilities
 - Made better decisions
 - Had enhanced quality of life
- Martinis & Beadnell, 2021

<http://supporteddecisionmaking.org/node/488>

THAT'S WHY SUPPORTED DECISION-MAKING HAS BEEN ENDORSED BY

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

EXPLORING SUPPORTED DECISION-MAKING: THE PRACTICAL METHOD

BY THE AMERICAN BAR ASSOCIATION

PRESUME that guardianship/conservatorship is not needed.

REASONS for concern – “What’s the problem?”

ASK if the problem is temporary or easily addressable- “What’s the root cause?”

COMMUNITY Connect with resources – “What would it take to solve the problem?” and “Who can provide that?”

TEAM Has the person already identified people s/he wants to work with?

IDENTIFY If the person does not have a team, examine abilities, limitations, wants, needs, and contacts to see if a team can be made or supports provided

CHALLENGES Are there potential problems with team members or resources?

APPOINT If the person wants to give someone else the power to support or make decisions, help the person do it consistent with his or her wishes

LIMIT As a last resort, seek a guardianship/conservatorship limited to **ONLY** those areas the person **cannot** make decisions with or without support

MAKING IT HAPPEN

STEPS IN SUPPORTED DECISION-MAKING

Listen and Think

- Supported Decision-Making should always be based on the person's strengths, needs, and interests.
- Start by encouraging the person to think about decisions he or she makes now and those the person needs help to make.
- RESOURCE: The Missouri Stoplight Tool:
<https://www.moddcouncil.org/uploaded/Guardianship%20Manual%20Appendix%201.pdf>

MAKING IT HAPPEN

STEPS IN SUPPORTED DECISION-MAKING

Identify Opportunities and Challenges

- Explore the types of support the person wants to use.
- Talk about the support he or she uses now. If one way of supporting the person works well, think about trying it for other life areas.
- If you're not sure what to try, brainstorm about ways to give and get support
- RESOURCE: The "Supported Decision-Making Brainstorming Guide:"
<http://supporteddecisionmaking.org/sites/default/files/sdm-brainstorming-guide.pdf>

MAKING IT HAPPEN: STEPS IN SUPPORTED DECISION-MAKING

Find Supporters

- Connect with the people, professionals, agencies, and organizations that can provide the support the person wants.
- Consider support from programs like Aging and Disability Resource Center, Area Agency on Aging, Medicaid Waiver, Centers for Independent Living.

MAKING IT HAPPEN

STEPS IN SUPPORTED DECISION-MAKING

Coordinate Support

- Work with the person, supporters, professionals, and agencies to develop a Supported Decision-Making plan laying out who will support the person and how the person will use that support.
- RESOURCE: “Setting the Wheels in Motion”:
<http://supporteddecisionmaking.org/sites/default/files/Supported-Decision-Making-Teams-Setting-the-Wheels-in-Motion.pdf>

MAKING IT HAPPEN: STEPS IN SUPPORTED DECISION-MAKING

Put it in Writing

- Create written plans saying who will give support, when, and how
- This can be as easy as creating a Supported Decision-Making Team “Roster” listing who will do what, how, and when
- Include SDM language in existing plans (Power of Attorney/ISP/IEP/IPE)
- Examples of agreements are at www.SupportedDecisionMaking.Org

SDM OPPORTUNITY: HEALTH CARE

Key Concept: “Informed Consent”

- The Heart of the Dr/Patient relationship
- Three Key Parts:
 - Information from Dr to person
 - Understanding by the person
 - Choice by the person and communication to Dr
- American Medical Association

AS WITH EVERY DECISION

- Assistance can be provided to help individual make medical decisions:

“Explain that to me in plain language”

- Ability to make decisions is a continuum. A person may be able to make some but not others

Capacity to Consent to Surgery is NOT the Same as Capacity to Perform Surgery

THEREFORE

There is a need to empower and enable Informed Consent in ways that are

- Flexible
- Immediate
- Improve Dr-Patient communication and collaboration
- Increase the role of family, friends, and people close to the patient

DOESN'T THAT SOUND LIKE SUPPORTED DECISION-MAKING?

“The solutions also are different for each person. Some people need one-on-one support and discussion about the issue at hand. For others, a team approach works best. Some people may benefit from situations being explained pictorially. With Supported decision-making the possibilities are endless.”

- Administration for Community Living,
“Preserving the Right to Self-determination:
Supported Decision-Making”

BY USING SDM

- People who might not otherwise be able to provide informed consent work with supporters to understand their choices, make informed health care decisions, and manage their health care;
- Doctors who might otherwise recommend that their patients be ordered into guardianship communicate more effectively with them, treat them, and have better outcomes; and
- Family members, friends, and other supporters help people with disabilities and doctors form an effective, working relationship that respects people's rights and preferences.

WHAT ABOUT HIPAA?

- Drs may say that they can't use SDM because of HIPAA
- HIPAA is a law that says health care providers cannot share a person's health care information or records
- So, doctors may say that if a person has a supporter, the doctor can't talk to them because that would violate HIPAA

REALLY, WHAT ABOUT HIPAA

- HIPAA DOES protect a person's right to privacy
- BUT, HIPAA protects *the person's* right to privacy and *that person's* right to keep his or her medical records and information private.
- However, that also means that people may give their doctors *permission* to share their health information and records.
- A person's right to privacy under HIPAA belongs to *the person*. That means the person *may waive* that right and authorize someone else to see his or her records.
- Therefore, doctors can't claim that HIPAA *always* prevents them from using SDM. They may only say that HIPAA stops them from using SDM *without the person's permission*.

AFTER ALL, SDM IS ABOUT SHARING INFORMATION

- The person shares information with his or her supporter to help the person communicate more effectively with the doctor;
- The doctor shares information about the person with the supporter to help the person understand the doctor's diagnoses and recommendations;
- The supporter and person share information to help the person understand the situation and the decisions he or she must make; and
- Once the person makes his or her decision, the supporter may help the person communicate it to the doctor.

SO, GIVE PERMISSION TO SHARE

- When we go to the doctor, we sign a HIPAA release or HIPAA Statement.
- So, you can add language to it giving the doctor permission to share your information with your supporter:

“I also authorize you to share my information and records with [person’s name] to help me understand and make medical decisions. I also authorize [person’s name] to attend my medical appointments to help me understand and make medical decisions.”

ANOTHER WAY: CREATE AN AUTHORIZATION

- You can also write a formal authorization giving the doctor permission to share your information and records.
- This may be easier than writing on the HIPAA release every time you go to an appointment

“I authorize [person’s name] to work with me to help me understand, make, and communicate my own medical decisions.

I intend for [person] to be treated as I would be with respect to my rights regarding the use and disclosure of my individually identifiable health information or other medical records. This release authority applies to any information governed by the Health Insurance Portability and Accountability Act of 1996 (aka HIPAA), 42 USC 1320d and 45 CFR 160-164 XII, and to other applicable federal and state laws regarding my medical care and records. “

SAMPLE LANGUAGE: MEDICAL DECISION-MAKING POWER OF ATTORNEY

“[M]y 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.”

MEDICAL POWER OF ATTORNEY PART 2

“If I am found to be incapable of making my own health care decisions as described above, my attorney-in-fact shall make decisions and take actions on my behalf as directed below or (if not directed below) in accordance with **preferences I made known to her prior to my incapacity. If I had not previously made my preferences known, then, in making any decisions or taking any actions under the terms of this instrument, my attorney-in-fact will first discuss the situation and the decision to be made/action to be taken with me and give primary consideration to my express wishes before making the decision or taking action. If I am not capable of discussing the situation with my attorney-in-fact and I have not previously made my preferences known, my attorney-in-fact must use her best judgement to **make the decision I would have made/take the action I would have taken in that situation, even if it is different from what she would have done in that situation.**”**

SDM OPPORTUNITY: CENTERS FOR INDEPENDENT LIVING

Centers for Independent Living (CILs) provide services and supports that help people live independently in the community, avoid institutionalization, and “promote equal opportunities, self-determination, and respect

Find your local CIL at
<https://www.incil.org/locate>

CIL SERVICES AND SUPPORTS

- Independent Living skills training,
- Peer counseling,
- Psychological counseling,
- Housing services,
- Personal assistance services, and
- “Other services necessary to improve the ability of individuals with significant disabilities to function independently in the family or community and/or to continue in employment.

CILs AND SDM

- CILs can also help people learn about and use SDM.
- A majority of CIL employees must be people with disabilities
- So, they can provide peer support to help others learn from their life experiences.
- As a result, people may learn SDM and ways to direct their lives from people who direct their own lives and use SDM.

SDM OPPORTUNITY: FINANCIAL POWER OF ATTORNEY

I will not buy, sell, manage, or otherwise take or exercise any interest in any tangible property or item costing or worth more than \$X without my agent's agreement. For example, if I want to buy or sell a car for \$20,000, I would need my agent to agree or the sale could not go through.

In making decisions whether or not to buy, sell, manage, or otherwise take or exercise any interest in any tangible property or item costing or worth more than X, **my agent and I will discuss the situation and give consideration to my express wishes before my agent decides whether or not to agree.**

SAMPLE LANGUAGE

FINANCIAL POWER OF ATTORNEY 2

I agree that my agent will be listed as a joint account holder on all bank or other financial institution accounts – including checking and savings accounts, as well as credit and debit cards – that I have or open while this power of attorney is in effect.

I agree that I will not withdraw more than \$X from any account, write a check for more than \$X, or otherwise cause more than \$X to be withdrawn from or charged to any account unless my agent agrees.

In making decisions whether or not to agree to write checks, withdraw money from my accounts or charge money to my accounts, my agent and I will discuss the situation and **give consideration to my express wishes before my agent decides whether or not to agree.**

SDM 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).

Creating and Reaching Goals: 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

DOESN'T THAT SOUND LIKE

SUPPORTED DECISION-MAKING

THE STUDENT LED IEP IS CONSISTENT WITH RESEARCH

- Students who led their IEP meetings “gained increased self-confidence and were able to advocate for themselves, interacted more positively with adults, assumed more responsibility for themselves, [and] were more aware of their limitations and the resources available to them.” - Mason, C. Y., McGahee-Kovac, M., & Johnson, L., 2004

SDM OPPORTUNITY: VOCATIONAL REHABILITATION

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 CAN PROVIDE A LOT

Some services that are available:

- Assessments
- Counseling
- Job search and retention services
- Assistive technology
- Medical and mental health care
- Education and training (including college)
- On the job training
- Job coaches
- Transportation
- “Maintenance” payments
- Services to family members (like Day Care!)

34 CFR 361.48

“INFORMED CHOICE” IN VR

VR must ensure that the you 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”

34 CFR 361.52

DOESN'T THAT SOUND LIKE

SUPPORTED DECISION-MAKING

COORDINATION OPPORTUNITY: 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.”
- <https://www.medicaid.gov/medicaid/hcbs/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?

SDM THROUGH LIFE

END OF LIFE PLANNING

“The Conversation” and “Five Wishes”

A facilitated process where the Person makes decisions about hospice, palliative care, and services.

THE ELEPHANT IN THE ROOM: SAFETY

NOTHING: Not Guardianship, Not Supported Decision-Making is 100% "Safe."

HOWEVER: Supported Decision-Making Increases Self-Determination (Blanck & Martinis, 2015), which is correlated with increased Safety (Khemka, Hickson, & Reynolds, 2005).

BUT REMEMBER: ADULTS ARE ALLOWED TO MAKE BAD DECISIONS

- Health
- Money
- Love
- Living Conditions

BUT REMEMBER: THE SAME PROTECTIONS ARE AVAILABLE

Whether you are in guardianship/conservatorship or not

- Police
- APS
- Medicaid Fraud Unit
- Protection and Advocacy
- Adult Disability Resource Center

REMEMBER

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

Remember the Goals

- **EVERYONE** “the causal agent” in his or her life
- **EVERYONE** giving and getting the help we ALL need to make decisions to the maximum of our abilities
- Older adults and people with disabilities with “the same opportunities for success and security as their nondisabled peers.” - Gustin & Martinis, 2016

JOIN THE CONVERSATION

The Connecticut Supported Decision-Making Coalition: www.CTsilc.org/supported-decision-making/

National Resource Center for Supported Decision-Making:
SupportedDecisionMaking.Org

Jonathan Martinis, JGMartinisLLC@Gmail.com