Supported Decision-Making From Theory to Practice: Health Care and Life Planning

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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

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Article of Faith: Self Determination

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

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

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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

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So, Supported Decision-Making Is A Lot of Words For

Getting help when its needed

Just like you and me

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Supported Decision-Making and Self Determination

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

- Blanck & Martinis, 2015

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Research

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

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Why Supported Decision-Making?

Endorsed by:

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

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And Yet

- People with Disabilities have more medical conditions, yet are more often poorly diagnosed [and] over/under treated – Office of the Surgeon General, 2005
- I0% of people who sought guardianship for someone identified a medical professional as the person who first recommended it. - Jameson, et al 2015

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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

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As With EVERY Decision

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

  "Explain that to me in English"

- 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

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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

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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"

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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.

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Forms

- Easy as adding language "and for decision-making purposes" in HIPAA release
- Or make up your own form.
- Or use models, like those found at www.SupportedDecisionMaking.Org

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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

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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*.

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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.

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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."

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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. "

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POA with Supported Decision-Making

Power of Attorney giving agent decision-making authority:

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

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Medical POA

"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."**

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Medical Advanced Directive with Supported Decision-Making

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

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"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

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Person Centered Planning Focuses On

What is:
- Important TO the Person
- Important FOR the Person

The Plan should:

- Be focused on the person's strengths and interests;
- Identify what the person likes to do and doesn't like to do; and
- Describes activities and programs the person would like to take part in

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Doesn't That Sound Like…

Supported Decision-Making?

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Accessing Supported Decision-Making Through Medicaid:EPSDT

Early and
Periodic
Screening
Diagnosis
Treatment

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The Basics

- EPSDT is designed to identify and treat problems EARLY before they worsen.
- Available to ANYONE receiving Medicaid (through "State Plan Option," HMO, or Waiver) who is under 21
- You do not have to enroll - it is NOT a separate Medicaid program

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In Practice: What it Covers

ANYTHING that can conceivably be covered by Medicaid, whether or not Illinois covers it. If some state COULD cover it to fix a medical problem, help it, or keep it from getting worse, your state MUST cover it under EPSDT.

- Example: Virginia does not cover most dental care under Medicaid but other states do. So, Virginia MUST cover dental care for children receiving EPSDT.

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Self-Determination

So, if child's disability causes him or her to have difficulty making decisions, EPSDT must cover supports and services to help the child overcome this.

This is especially true if the disabilities are likely to result in him or her being unable to "take care of [him or herself] in a manner that society believes is appropriate"
Kapp, M. (1999).

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Special Education and EPSDT

For students who receive Medicaid, if the school is a Medicaid Provider, any medical services and supports in an IEP are covered by Medicaid.

https://www.medicaid.gov/medicaid/hcbs/downloads/1915c-fact-sheet.pdf

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SDM and Financial Planning

- Supported Decision-Making can work in a number of contexts – if it requires a decisions, Supported Decision-Making can help the person exercise the Right to Make Choices
- Financial Planning and Money Management is something we ALL have to make decisions about all through our lives

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SDM, Power of Attorney, And Financial Authority

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**.

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SDM, Power of Attorney And Banking

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.**

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What is this Leading To? TRUE Inclusion

What Do You Think Of When I Say:

- "Independence"
- "Community Integration"

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Think About It

- What REALLY integrates us into our communities?
- How do we REALLY interact with our friends, neighbors, and neighborhoods?

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REALLY THINK ABOUT IT

True community integration means being integrated into all facets of the community, INCLUDING the financial sphere.

It's NOT just where you live

It's HOW you live

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HOW CAN THAT HAPPEN WHEN…

"[P]eople with disabilities cannot have a decent quality of life with limited financial resources and modest government support."

- Forbes Magazine, "Are Tax-Free ABLE Accounts The Right Financial Solution for People with Disabilities," 12/4/14

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THINK ABOUT IT

Programs encouraging Americans to save:

- **Individual Retirement Accounts (IRAs)**: Traditional and Roth
- **Education Savings Accounts**: Section 529 Qualified Tuition Plans, Coverdell Education Savings Accounts
- **Medical Savings Accounts**: Archer Medical Savings Accounts, Health Savings Accounts
- **Employer Savings Accounts**: 401(k) plans, SIMPLE 401(k) plans, Thrift plans, charitable 403(b) plans, governmental 457 plans

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Unless You Receive Public Benefits

- To live independently, many people rely on public benefits like Medicaid, SSI, and SSDI
- To qualify for Medicaid/SSI, you generally may not have more than $2,000 of countable assets. Earnings of more than the substantial gainful activity (SGA) level can also affect eligibility for these programs.
- If families provide financial or "in-kind" support, the person may be disqualified or have benefits reduced.

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How Can People With Disabilities Save Money For Their Needs Or Retirement?

Because of the "means test"

- People with disabilities fear working because if they make too much, they can lose their benefits
- Families are discouraged from supporting for fear of causing the person to lose benefits
- People with disabilities must "spend down" assets they receive or they can lose benefits.
- As a result, people with disabilities often cannot afford housing or must live in dangerous or substandard conditions - "Priced Out in 2008: The Housing Crisis for People with Disabilities," by Technical Assistance Collaboraive, Inc., Consortium for Citizens with Disabilities Housing Task Force."

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Enter ABLE

Achieving a

Better

Life

Experience

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What It Is

- Like 529 Accounts for Education
- Family, friends can contribute up to $15,000 per year into an ABLE account
- ABLE account money can be withdrawn, tax free, to pay for housing, transportation, healthcare and other expenses
- Money in an ABLE account **does not** affect eligibility for Social Security or Medicaid/Medicare (if there is more than $101,999 in account, SSI benefits will be suspended, but still receive Medicaid).
- Find the ABLE program in your state at www.ABLENRC.Org

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Eligibility for ABLE

An ABLE Account can be established for or by any individual with a disability, including:

- An individual eligible for SSI or SSDI due to blindness or disability.
- An individual who WOULD be eligible under disability criteria for SSI/SSDI, even if
  - S/he has not been found eligible
  - S/he WOULD NOT be found eligible due to income.

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Establishing Eligibility

- Is designed to be done by filling out a tax form with a Dr certification saying the person has a disability that would make him or her eligible for SSI or SSDI
- States can set up their own ABLE accounts but you don't have to live in the state to open an account
- For more information, see www.ABLENRC.Org

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SPECIFICALLY

ABLE Account funds can be used for:

- **Education**—including tuition for preschool thru post-secondary education, books, supplies, and educational materials related to such education, tutors, and special education services.
- **Housing**—including rent, mortgage payments, home improvements and modifications, maintenance and repairs, real property taxes, and utility charges.
- **Employment Support**—including expenses related to obtaining and maintaining employment, including job-related training, assistive technology, and personal assistance supports.
- **Health**—including premiums for health insurance, medical, vision, and dental expenses, habilitation and rehabilitation services, durable medical equipment, therapy, respite care, long term services and supports, and nutritional management.
- **Transportation**—including the use of mass transit, the purchase or modification of vehicles, and moving expenses.
- **Other Life Necessities**—including clothing, activities which are religious, cultural, or recreational, supplies and equipment for personal care, community-based supports, communication services and devices, adaptive equipment, assistive technology, personal assistance supports, financial management and administrative services, expenses for oversight, monitoring, or advocacy, funeral and burial expenses.

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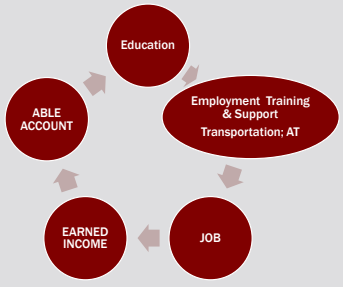
A PATHWAY



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ABLE ACCOUNTS AND SELF-DETERMINATION

In ABLE Accounts, the person with disabilities decides how the money is spent

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The Whole Point

Purpose of the ABLE Act is:

"supporting individuals with disabilities to maintain health, independence, and quality of life."

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Making it Achieve-ABLE

If Increased Self-Determination=Improved Health, Increased Independence, and Better Quality of Life . . .

Shouldn't ABLE Accounts Increase Self-Determination?

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Doesn't That Sound Like a Job For

Supported Decision-Making:

"[P]eople 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

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SDM Through Life
The "Growth Clause"

"My agent and I will review this [Power of Attorney/Advanced Directive/Plan] to see if it **should be changed or cancelled at least every _____**. However, unless my agent and I change the power of attorney, I cancel it, my agent resigns, or either I or my agent dies, the [ ] will continue."

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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.

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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).

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Signs and Signals –Abuse, Neglect, and Exploitation

- Injuries
- Unusual bruising or abrasions
- Fear or nervousness
- Withdrawal
- Unexplained changes in lifestyle
- Retitling assets
- Changes in power of attorney

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Protection Is Available

If you see Abuse, Neglect or Exploitation: Neglect

- Police
- APS
- CPS
- Attorney General's Fraud Unit
- Protection and Advocacy System

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BUT REMEMBER: Adults Are Allowed to make bad Decisions

- Health
- Money
- Love
- Living Conditions

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Remember The Goal

EVERY person with self-determination, the "causal agent" in his or her life.

- We all need help making decisions
- People with Disabilities may need more or different help but have the **SAME** rights
- People with Disabilities having "the same opportunities for success and security as their nondisabled peers" – Gustin & Martinis, 2016

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Join the Conversation

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

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

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

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