

**Supported Decision-
Making:
Where We've Been
Where We Are
Where We Can Go**

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SUPPORTED DECISION-MAKING

Part I
Where We've Been

SUPPORTED DECISION-MAKING: WHAT IS IT?

“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

THINK ABOUT IT

How do you make decisions?

What do you do if you're not familiar with the issue?

- Taxes?
- Medical Care?
- Auto Repairs?

What Do You Do?

SO, SUPPORTED DECISION-MAKING IS A LOT OF WORDS FOR

Getting help when its needed

Just like you and me

SUPPORTED DECISION-MAKING: WHY?

Rights=Choice

"I am my choices. I cannot not choose. If I do not choose, that is still a choice. If faced with inevitable circumstances, we still choose *how we are* in those circumstances."

- Jean Paul Sartre

RIGHTS=CHOICE CHOICE=SELF-DETERMINATION

- Life control
 - People's ability and opportunity to be "causal agents . . . actors in their lives instead of being acted upon"
- Wehmeyer, Palmer, Agran, Mithaug, & Martin, 2000.

BENEFITS OF SELF-DETERMINATION

People with greater self determination are:

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

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

SUPPORTED DECISION-MAKING: “TRADITIONAL” USE

SDM as a decision-making option other than guardianship or conservatorship

- Most common-form of guardianship is “full” or plenary”
- Used in up to 90% of cases
- “As long as the law permits plenary guardianship, courts will prefer to use it.” - Frolik, 1998

IMPACT OF GUARDIANSHIP/CONSERVATORSHIP

- Guardians have “substantial and often complete authority over the lives of vulnerable [people].” - 4 NAELA J. 1, 7 (2008).
- This includes power to make the most basic health, personal, and financial decisions. - AARP, *Guardianship Monitoring: A National Survey of Court Practices* 1-2 (2006)
- Estimated number of adults under guardianship has tripled since 1995 - Reynolds, 2002; Schmidt, 1995; Uekert & Van Duizend, 2011

WHY GUARDIANSHIP/CONSERVATORSHIP?

- State Laws differ
- In essence, though, if people lack “capacity” to make decisions or direct their lives, they may be placed under guardianship
- Some states specify that “less restrictive alternatives” should be used before guardianship

EXAMPLE: TENNESSEE

"Conservatorship" is a proceeding in which a court removes the decision-making powers and duties, in whole or in part, **in a least restrictive manner**, from a person with a disability who **lacks capacity to make decisions in one or more important areas and places** responsibility for one or more of those decisions in a conservator or co-conservators;
TN Code: 34-1-101

NOW THINK ABOUT CAPACITY:

- People may be able to make some decisions but not others.
 - Or be able to manage some life areas only with assistance.
 - Or be unable to make any decisions unless they have assistance
 - Or may be able to make decisions at some times but not others
- e.g., Salzman, 2010

Capacity to take medication is not the same as capacity to prescribe it!

SO: ASK A QUESTION

If people can only “make decisions” **with assistance or support**, are they “incapacitated”?

ARE YOU?

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AND ASK ANOTHER

If a people ARE able to “make decisions” when they have support, is conservatorship “**necessary**” or “**the least restrictive manner?**”

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WHICH MEANS

Before seeking or recommending
Guardianship or
Conservatorship:

What Else Have You Tried?

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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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PRECEDENT

In re Peery, 727 A.2d 539 (Pa. 1999).

In re Dameris L., 956 N.Y.S.2d 848 (N.Y. Sur. Ct. 2012).

Ross v. Hatch, No. CWF120000426P-03 (Va. Cir. Ct., 2013)

SUPPORTED DECISION-MAKING

Part II Where We Are

WASHINGTON DC IN RE: KING

In re: Ryan Herbert King, Case No. 2003 INT 249 (DC Sp Ct (Probate), 2016).

- Ryan and his parents always worked together so he could make his own decisions
- Ryan's parents told he had to get guardianship when he turned 18
- Court refused to terminate guardianship in 2007

IN RE: KING

- In 2016, presented new evidence to the court including new functional evaluation
- Submitted affidavits showing use of SDM
- Submitted draft Power of Attorney if guardianship terminated
- Held: because Ryan uses SDM to make his own decisions he is not "incapacitated."
- Guardianship terminated

VERMONT: IN RE: CB

In re: CB, Docket No. 4-9-16 OsGS, Sp Ct
(Family Division)

- CB was under guardianship of grandmother
- Grandmother moved to resign as guardian, public guardian was to be appointed
- Public guardian raised possibility of using SDM instead of guardianship for CB
- Court ordered public guardian to meet with CB's support team to explore possibility

IN RE: CB

- Supporters met to develop SDM plan
- Submitted SDM plan to the Court for consideration
- Court terminated guardianship finding SDM plan was "step down" from guardianship because all parties agreed to follow SDM plan

NEW YORK: IN RE: DD

In re: DD, File No. 2014-2185, Surrogate's Court (Kings)

- DD was 29 years old with Down syndrome and full scale IQ of 54
- Two doctors certified that bc of his ID, he could not make his own decisions
- Evidence showed he worked, managed his own transportation, social life, personal hygiene

IN RE: DD

- DD said he wanted to get married
- Mother moved for guardianship
- GAL investigated, said he could make his own decisions with support, recommended alternatives to guardianship
- Held: guardianship denied. There was no evidence that he couldn't make his own decisions, with support.

IN RE: DD

- Held: alternatives to guardianship like SDM “enable individuals with disabilities to maintain as much control over their own life decisions as they are capable to make in the least restrictive setting.”
- “the standard here is not whether the petitioners can make better decisions than DD, it is whether or not DD has the capacity to make decisions for himself with the support he abundantly has.”

LEGISLATION: TEXAS

- “Supports and Services” - formal and informal resources that help people meet their needs, manage their health and finances, and make decisions – Tex. Estates Code §1002.031(2015)
- Before placing people under guardianship, Court must find by clear and convincing evidence they cannot make their own decisions using “Supports and Services” -Tex. Est. Code Ann. §1101.101(2015)

LEGISLATION: TEXAS

- Recognizes SDM Agreements where people appoint supporters to help them make decisions – Tex. Estates Code
- Provides a form to appoint supporters. In order to be legally enforceable, SDM agreement must be in substantial compliance with the form – Tex. Estates Code 1357.056
- Other model forms available including one by DD Council at:
<http://www.tcdd.texas.gov/resources/guardianship-alternatives/supported-decision-making/>

LEGISLATION: DELAWARE

- Recognizes SDM Agreements
- People can enter into legally enforceable SDM agreements that:
 - (1) Designate at least 1 supporter.
 - (2) ID the types of decisions for which the supporter is authorized to assist.
 - (3) ID the types of decisions, if any, for which the supporter may not assist.

Delaware Code, Title 16, Section 9405A

LEGISLATION: DELAWARE

- SDM Agreements must be “in a writing that contains the elements of the form developed by the Department of Health and Social Services as required under § 9410A(a) of this title.” – Delaware Code, Title 16, Section 9405A

SDM PROJECT: NATIONAL RESOURCE CENTER FOR SUPPORTED DECISION-MAKING

- www.SupportedDecisionMaking.Org
- Provide information, training, and technical assistance regarding SDM
- Model forms, research materials, educational material, SDM news
- Conduct research to determine links between SDM, self-determination, and quality of life

SDM PROJECTS: VERMONT

- Vermont Task Force “to create solutions and initiatives that transform practices in a way that brings a culture of collaboration”
- Includes consumers, families, and representatives of the Provider, Legal, Educational, Employment, Advocacy, Mental Health, Aging, and Developmental Disabilities communities

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VERMONT PROJECTS

- Pilot project between DD Provider and Public Guardian to identify people who could “take care of themselves’ with appropriate supports, plan for and provide the supports, and move to terminate guardianship
- Project between Self-Advocate Group, Schools, VR, State P&A and State DD Agency to identify students at risk of guardianship and help them receive appropriate supports and services

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VERMONT PROJECTS

- Collaboration between Public Guardian, State DD Agency, and State Evaluators to review competency evaluation guidelines to examine whether people are able to make their own decisions if they have appropriate supports
- Education of people, families, judges, attorneys, and others about alternatives to guardianship

SDM PROJECT: MY CHOICE KENTUCKY

- Identify 5-7 people under guardianship or at risk
- Help them implement SDM plans to avoid or be restored from guardianship
- Analyze impact on quality of life

SDM PROJECT: CENTER FOR PUBLIC REPRESENTATION

- Work with people with Intellectual and Developmental Disabilities who are in or at risk of guardianship
- Help them identify supporters and create SDM agreements
- Create model forms
- www.SupportedDecisions.Org

SDM PROJECT: SAKS INSTITUTE FOR MENTAL HEALTH LAW

- Work with cohort of people with mental illness
- Help them identify supporters and create SDM agreements
- Analyze impact on their quality of life

SUPPORTED DECISION-MAKING

Part III

Where Can We Go?

OPPORTUNITIES FOR SDM ARE ALL AROUND US

- “Student Led” IEPs and Transition Planning
- “Informed Choice” in Vocational Rehabilitation
- “Person Centered Planning” in Medicare/Medicaid
- Powers of Attorney/Advanced Directives

Supported Decision-Making: Special Education

“Under IDEA, schools must ensure that students in special education receive services reasonably calculated to enable the child to receive educational benefits.”

Board of Education v. Rowley, 458 U.S. 176 (1982)

What are Educational Benefits?

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).

AND YET:

- The school IEP process is usually the first “prompt” for parents to seek guardianship
- School personnel are the most frequent source of recommendations that parents seek guardianship

- Jameson, et al, 2015

Best Practices: 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

- Mason, Mcgahee-Kovac, Johnson, L., & Stillerman, S. (2002)

Doesn't That Sound Like Supported Decision-Making?

“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.”

- Blanck & Martinis, 2015

Supported Decision-Making: SpEd Transition Services

Transition services:

- “[F]acilitate the child’s movement from school to post-school activities, including post-secondary education, vocational education, integrated employment (including supported employment), continuing and adult education, adult services, independent living, or community participation;”
- **Are “based on the individual child’s needs, taking into account the child’s strengths, preferences, and interests; and**

20 USC 1401(34)

SUPPORTED DECISION-MAKING: 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)

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VR SERVICES

Some services that are available:

- Assessments
 - Counseling
 - Job search and retention services
 - Education
 - Assistive technology
 - Medical and mental health care
 - On the job training
 - Job coaches
 - Transportation
 - Services to family members (like Day Care!)
- 34 CFR 361.48

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“INFORMED CHOICE”

VR Agencies must ensure that the person 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”

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SUPPORTED DECISION-MAKING: 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.”

www.medicaid.gov/medicaid-chip-program-information/by-topics/long-term-services-and-supports/home-and-community-based-services/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 can address planning and implementation in all those areas whether as part of an HCBS Waiver or Not!

SUPPORTED DECISION-MAKING POWER OF ATTORNEY

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.**”

SUPPORTED DECISION-MAKING: MEDICAL ADVANCED DIRECTIVE

“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.”

SUPPORTED DECISION-MAKING: 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.**

SUPPORTED DECISION-MAKING: 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.**

SUPPORTED DECISION-MAKING: ABLE ACCOUNTS

Achieving a

Better

Life

Experience

WHAT IT IS

- Like 529 Accounts for Education
- Family, friends can contribute up to \$14,000 per year into an ABLE account
- ABLÉ account money can be withdrawn, tax free, to pay for housing, transportation, healthcare and other expenses
- Money in an ABLÉ account **does not** affect eligibility for Social Security or Medicaid/Medicare (if there is more than \$100,000 in account, SSI benefits will be suspended, but still receive Medicaid).

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ELIGIBILITY FOR ABLÉ

An ABLÉ 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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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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BEFORE ABLE, SPECIAL NEEDS TRUSTS

- Like ABLE, people could set aside funds for an individual with a disability.
- BUT – money in SNT is taxable.
- BUT, SNT funds could not buy anything that Medicaid paid for – so people who need more than what Medicaid pays for were out of luck.
- BUT, SNTs can be expensive. Not all states offer low cost pooled SNT option.

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THE BIG ONE

In a Special Needs Trust:

**Trustee Decides How The Money
is Spent**

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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 ABLÉ 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 ABLÉ 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).

EXAMPLE: END OF LIFE PLANNING

“The Conversation” and “Five Wishes”

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

“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.”

NEVER FORGET

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!

- We will ALL be part of the “System”
- What kind of “System” do you want to be in?

“People with disabilities will have the same opportunities for success and security as their nondisabled peers. If we change the culture, we will change the world!”

Gustin & Martinis, 2016

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