

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

Jonathan Martinis
Senior Director for
Law and Policy
*The Burton Blatt
Institute at
Syracuse University*
Co-Project Director,
*National Resource
Center for
Supported
Decision-Making*

ARTICLE OF FAITH

“[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

RIGHTS=CHOICES

CHOICES=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

WHY SELF-DETERMINATION?

People with more self-determination have:

- Improved psychological health including better adjustment to increased care needs.

- O'Connor & Vallerand, 1994

- Better quality of life, more employment and community integration.

e.g. Powers et al., 2012; Shogren, Wehmeyer, Palmer, Rifenburg, & Little, 2014;

- Increased health, welfare, and safety

e.g., Khemka, Hickson, and Reynolds, 2005

AND YET: 1,500 YEARS AND COUNTING

- **Ancient Rome:** “Curators” appointed for older adults and people with disabilities.
- **5th Century Visigothic Code:** “people insane from infancy or in need from any age . . . cannot testify or enter into a contract”
- **Feudal Britain:** divided people with decision-making challenges into “idiots” and “lunatics” and appointed “committees” to make their decisions

GUARDIANSHIP IN THE U.S.

“Plenary” or “Full” Guardianship

- Gives the Guardian power to make ALL decisions for the person.
- Used in the **VAST** Majority of cases
- “As long as the law permits plenary guardianship, **courts will prefer to use it.**”

- Frolik, 1998

WHEN PEOPLE ARE DENIED LIFE CONTROL

Study after Study shows:

- “[F]eel helpless, hopeless, and self-critical”
- Deci, 1975
- Experience “low self-esteem, passivity, and feelings of inadequacy and incompetency,”
decreasing their ability to function
- Winick, 1995

RESEARCH

People under guardianship can experience a “**significant negative impact** on their physical and mental health, longevity, ability to function, and reports of subjective well-being”

- Wright, 2010

ON THE OTHER HAND

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

- Powers et al., 2012; Shogren, Wehmeyer, Palmer, Rifenburg, & Little, 2014; Wehmeyer and Schwartz, 1997; Wehmeyer & Palmer, 2003; Khemka, Hickson, and Reynolds, 2005

AND

People with Intellectual and Developmental Disabilities who do **NOT** have a guardian are more likely to:

- Have a paid job
- Live independently
- Have friends other than staff or family
- Go on dates and socialize in the community
- Practice the Religion of their choice

2013-2014

2017-2018



SO, WHERE DO WE GO FROM HERE?

If:

- We **KNOW** that some people need more support as they age or due to disability
- We **KNOW** that guardianship can result in decreased quality of life and
- We **KNOW** that increased self-determination leads to improved quality of life

Then we need a means of **INCREASING** self-determination while **STILL** providing support

A WAY FORWARD: 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

WHY SUPPORTED DECISION-MAKING?

Endorsed by:

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

AND YET

People with Disabilities have more medical conditions, yet are more often poorly diagnosed [and] over/under treated

- Office of the Surgeon General "The surgeon general's call to action to improve the health and wellness of persons with disabilities." (2005)

MAYBE THAT'S BECAUSE...

In a recent survey, 10% of people under guardianship or who sought guardianship for someone identified a medical professional as the person who first recommended it.

- Jameson, et al 2015

THE SITUATION OUT THERE

- In DC....
 - 70% of people served by Department on Disability Services have a guardian or substitute decision-maker.

- Nationally....
 - According to the CQL database, only one-half or fewer of the over 8,100 people reviewed were exercising choices about home, work, goals or services in a way that was meaningful to them.

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 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

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?

People working with friends, family members, and professionals to help them understand the situations and choices they face so they can make their own decisions

- Blanck & Martinis, 2015

“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”

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

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.”**

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.”

“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?

ACCESSING SUPPORTED DECISION-MAKING THROUGH MEDICAID: EPSDT

Early and

Periodic

Screening

Diagnosis

Treatment

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

IN PRACTICE: WHAT IT COVERS

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

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).

COORDINATION OPPORTUNITY: SPECIAL EDUCATION AND EPSDT

If a school is a Medicaid Provider, any medical services and supports in an IEP are covered by Medicaid.

<https://www.cms.gov/research-statistics-data-and-systems/computer-data-and-systems/medicaidbudgetexpendsystem/downloads/schoolhealthsvcs.pdf>

PLANNING THROUGHOUT THE LIFE COURSE

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

EXAMPLE: 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.**

EXAMPLE: 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.**

WHAT DOES THAT ALL ADD UP TO?

“[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

WHEN 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.

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 Collaborative, Inc., Consortium for Citizens with Disabilities Housing Task Force.”

ENTER ABLE

Achieving a

Better

Life

Experience

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 \$102,000 in account, SSI benefits will be suspended, but still receive Medicaid).

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.

ESTABLISHING ELIGIBILITY

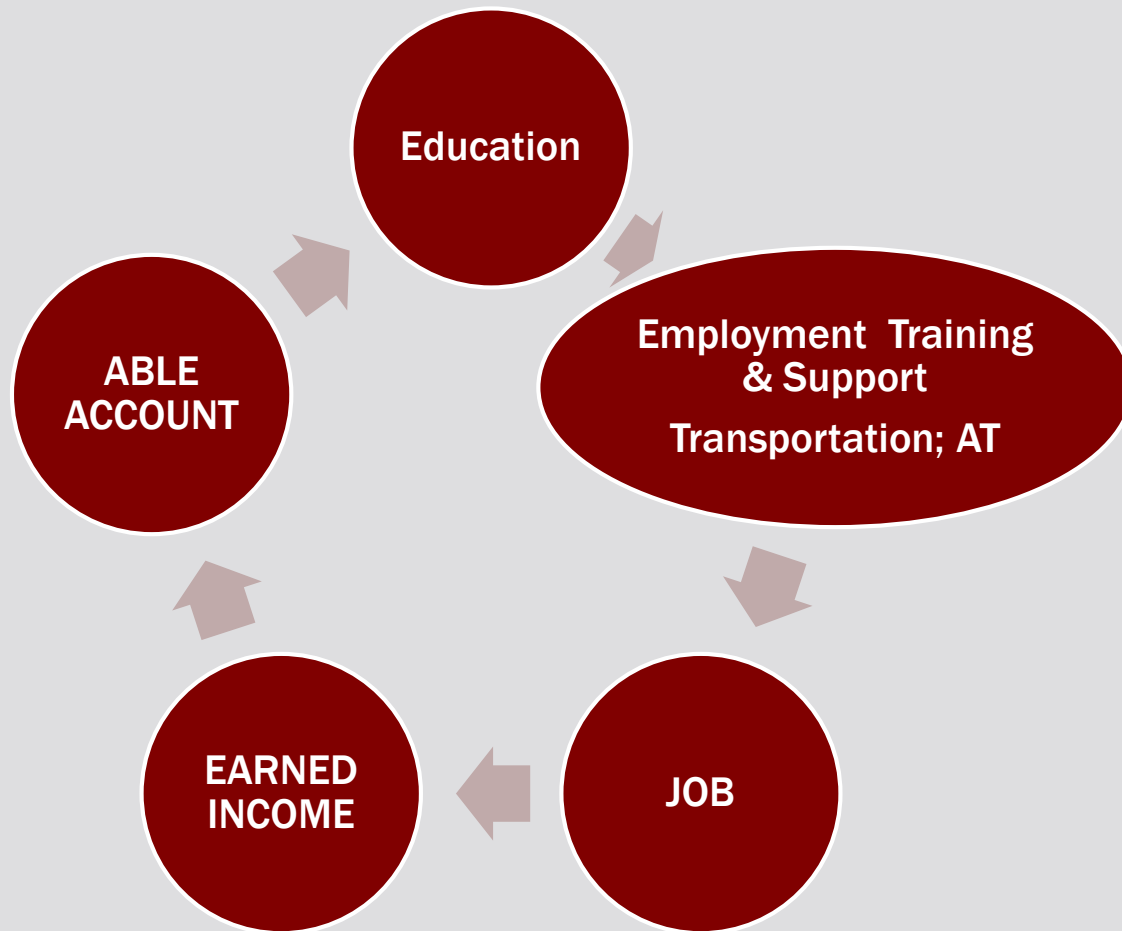
- Is designed to be done by filling out a tax form with a Dr certification saying the person has a disability that would make him or her eligible for SSI or SSDI
- States can set up their own ABLE accounts but you don't have to live in the state to open an account
- In Virginia go to: www.able-now.com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

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.

A PATH OUT OF POVERTY



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.

THE BIG ONE

In a Special Needs Trust:

**Trustee Decides How The Money
is Spent**

ABLE ACCOUNTS AND SELF- DETERMINATION

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

THE WHOLE POINT

Purpose of the ABLE Act is:

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

MAKING IT ACHIEVE-ABLE

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

**Shouldn't ABLE Accounts
Increase Self-Determination?**

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.”

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).

SIGNS AND SIGNALS -ABUSE

- Injuries
- Unusual bruising or abrasions
- Fear or nervousness
- Withdrawal

SIGNS AND SIGNALS - EXPLOITATION

- Basic needs not being met
- Bills not being paid
- Living below means
- Things are missing
- Unexplained ATM or Credit Card
- Unexplained cash withdrawals
- Unexplained changes in lifestyle
- Retitling assets
- Changes in power of attorney

SIGNS AND SIGNALS – CAREGIVER NEGLECT

- Dependence on another, isolation
- Basic needs not being met
- Inappropriate living environment
- Caregiver not seeking resources or help
- Caregiver not assisting with needs
- Caregiver dismissive of wants and needs
- Changes in dress, hygiene, or housekeeping
- Diet – weight gain or loss
- Medications not available

SIGNS AND SIGNALS- SELF NEGLECT

- Failure to meet basic needs despite ability
- Poor or unsafe hygiene
- Lack of needed health care
- Unsafe living conditions

PROTECTION IS AVAILABLE

If you see Abuse, Neglect or Exploitation:

Neglect

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

BUT REMEMBER: ADULTS ARE ALLOWED TO MAKE BAD DECISIONS

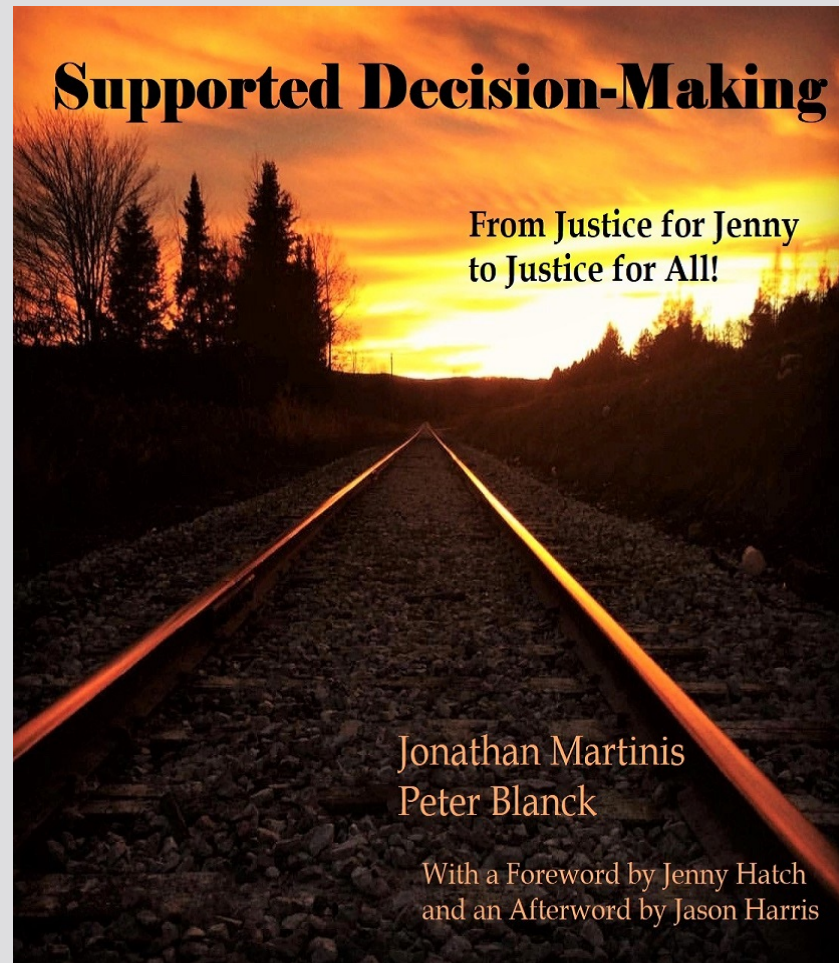
- Health
- Money
- Love
- Living Conditions

CHANGE THE CULTURE, CHANGE THE WORLD!

“Long after the schools, Vocational Rehabilitation, early interventionist, behavioral consultants, and para-educators have gone. the students will be adults. . . We [are] ethically, morally, and fiscally responsible for supporting their lives of success and meaning. . . . We have the tools, we have the means . . . we have the vision.”

Gustin, 2015

RESOURCE: SDM GUIDEBOOK



JOIN THE CONVERSATION

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

The Burton Blatt Institute at Syracuse University: www.bbi.syr.edu

Jonathan Martinis: JGMart@Law.Syr.Edu

“Supported Decision-Making: From Justice for Jenny to Justice for All”: https://www.amazon.com/Supported-Decision-Making-Justice-Jenny/dp/1693400251/ref=sr_1_1?keywords=supported+decision+making+martinis+jenny&qid=1573662603&sr=8-1