

Supported Decision- Making: Protecting Rights, Ensuring Choices

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FIRST PRINCIPLES

What's Your Favorite
Right?

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

Older Adults and People with Disabilities who have 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

FOR EXAMPLE

- Older adults who exercise more control over their lives have a **better quality of life.** - Mallery, 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

BUT...

Are Your Rights Worth
ANYTHING If You're Not
Allowed to Use Them?

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 US

“Plenary” or “Full” Guardianship

- Gives the Guardian power to make ALL decisions for the person.
- Used in the **vast** majority of cases
 - Teaster, Wood, Lawrence, & Schmidt, 2007.
- “As long as the law permits plenary guardianship, **courts will prefer to use it.**”
 - Frolik, 1998

AS A RESULT

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).

AS WE'VE KNOWN FOR FORTY YEARS

When denied self-determination, people:

- “[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

THE PROBLEM

“The typical ward has fewer rights than the typical convicted felon By appointing a guardian, the court entrusts to someone else the power to choose where they will live, what medical treatment they will get and, in rare cases, when they will die. It is, in one short sentence, the most punitive civil penalty that can be levied against an American citizen.”

- House Select Committee on Aging, H.R. Rpt. 100-641 (opening statement of Chairman Claude Pepper)

DINO AND LILLIAN

“To Collect Debts, Seizing Control Over Patients” New York Times, 1/25/15



DINO AND LILLIAN

- Married over 45 years
- Worked together to develop Powers of Attorney and Advanced Directives
- When Lillian developed dementia, chose a nursing home for her

DINO AND LILLIAN

After Dino asked questions about a bill and Lillian's care

- Nursing Home petitioned for a **plenary** guardianship - giving **ALL** decision-making rights to a stranger
- Nursing Home's attorney: "[G]uardianship is a legitimate means to get the nursing home paid."

IN VIRGINIA

- “Unguarded” Investigative report from Richmond Times Dispatch
- Explored the use of private guardianships by Virginia Commonwealth University Health System
 - Found that VCU triggered guardianships to remove poor patients from hospital beds, and sought to have patients under the guardianship of a lawyer whose firm worked for the health system.
 - A review of more than 250 cases found instances of inadequate care for people under the lawyer’s care, and life-ending decisions that went against family’s wishes — or locked them out altogether.

https://richmond.com/news/state-and-regional/after-a-times-dispatch-investigation-state-watchdog-recommends-changes-to-woefully-inadequate-guardianship-system/article_94721492-03a5-5716-aa0e-b3e28e9b2606.html

WHERE DO WE GO FROM HERE?

Guardianship **MAY** be Needed:

- In emergency situations when
 - The person is incapacitated and cannot give consent
 - The person did not previously identify how decisions should be made in that situation
 - There is no one else available in the person's life to provide consent through a Power of Attorney, Advanced Directive, or other means

- To support People:
 - Who face critical decisions and have no interest in or ability to make decisions
 - Who need immediate protection from exploitation or abuse

GUARDIANSHIP IS NEVER NEEDED

JUST

- “Because you have ____”
- “Because you’re ___ years old”
- “Because you need help”
- “Because that’s the way its always been”
- “For your own good”

BUT WE MEANT WELL

“Experience should teach us to be most on our guard to protect liberty when the Government’s purposes are beneficent. . . . The greatest dangers to liberty lurk in insidious encroachment by men of zeal, well-meaning but without understanding.”

Olmstead v. U.S., 277 U.S. 438 (1928)

WE MUST'VE MEANT REALLY WELL

Estimated number of adults under guardianship has **tripled** since 1995

- Reynolds, 2002; Schmidt, 1995;
Uekert & Van Duizend, 2011;
National Council on Disability, 2019

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

- Older adults who exercise more control over their lives have a **better quality of life**.
 - Mallery, et al., 2014
- Providing support to people with dementia can lead to them being able to provide informed consent.
 - Haberstroh, et al. 2014

AND

- 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, Rifenburg, & Little, 2014; Wehmeyer and Schwartz, 1997; Wehmeyer & Palmer, 2003

AND

Women with intellectual disabilities exercising more self-determination are **less likely to be abused**

- 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

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

AN SDM STORY

Abigail Avery

Twenty-Five year old woman
with Intellectual Disabilities

- High School graduate
- Married for 6 years, 2 children
- Husband also has developmental disabilities
- Has two children
- She and her husband, Austin live with her parents
- Her parents love Austin and refer to him as their son



BRIEF FACTS

- Tennessee APS receives anonymous complaint that Abby is being sexually abused by her husband because she is allegedly unable to consent to sex due to her disability
- APS investigator initially says case should be closed because Abby is legally married and has the right to consent to sex with her Austin
- Former medical provider said she doubts Abby has capacity to consent to sex because she once came in complaining that it hurt to have sex and had a yeast infection
- APS referred to police who investigated and said that there was no abuse and they would not arrest

BRIEF FACTS, CONTINUED

- APS continues to investigate, and pulls Abby out of the house on the grounds that she does not have capacity to consent to sex and is, therefore, being abused by Austin every time they have sex
- An APS doctor “evaluated” Abby on the day she was pulled out of the house and opines that she is in need of support and cannot make decisions for herself
- APS states that one of the reasons she should be pulled out of the house is that her parents consented to the marriage only because they wanted Abby to have grandchildren for them

SDM EVALUATION

- I was retained to evaluate whether, in my opinion, Abby was using Supported Decision-Making to consent to marriage and sex with her husband
- I reviewed all case records and interviewed Abby, Austin, and Abby's parents and grandmother

INTERVIEW HIGHLIGHTS

- Parents taught Abby about sex from a young age, telling her about “no touch zones” on her body when she turned 5
- At 10, they told her about sex and how babies are born.
- Advised her to not have sex unless she is in love, ““Don’t just put yourself out there . . . It takes a special person”
- They also taught her about safe sex practices and that she can and should say “No” if someone want to have sex with her and she does not want to

INTERVIEW HIGHLIGHTS

- A boy liked Abby when she was in HS, Rocky.
- Rocky said he wanted to be her boyfriend
- Abby went to her stepfather and asked for advice, saying “How do you know if you’re in love”
- Father explained “what love is — a good feeling inside and always wanting to be with that person and no one else and you’ll probably want to have sex with them. I explained the different types of love like the love I had for her as my daughter. I told her that if she likes someone, that’s ok. That’s a different type of love, like a friend.”
- He then asked her “if she would want to go out with” Rocky and she said no “but liked him as a friend.”

INTERVIEW HIGHLIGHTS

- Abby (interviewed separately) remembered Rocky, saying
- She said talking with her parents helped her realize that Rocky was a friend and no more. She said, “I love Austin. I didn’t want to marry Rocky.”
- She said that being with Austin is different than being with Rocky because “I love Austin always” and “I didn’t love Rocky like Austin.”
- She said she asked Mike how she would know if she was in love and he said “It’s when you’re happy around the person.”
- She said because she talked with her parents about sex and “I know when it’s wrong and I know when it’s right.”
- “I know when a guy does it and I don’t want it that’s wrong” and “Love” is when it is right.

INTERVIEW HIGHLIGHTS

- Abby's parents, Austin, and Abby all (separately) said that while she likes sex with Austin and frequently initiates it, she has declined it
- Abby said "I say no sex" when she does not want to have sex with him.
- When I asked her to give examples of when she would say that, she said "Because it might hurt" and "When I'm tired."
- She said that when she says "No sex," Austin does not force her and accepts it. She stated, "Austin knows when I don't want to" and she tells him so.

INTERVIEW HIGHLIGHTS

- Abby's parents, Austin, and Abby all (separately) stated that Abby decided not to have more children after talking with her parents
- Father stated Abby said she was thinking of having more children and asked their opinion
- Father said he told her "We don't want no more grandbabies. We don't have space or money. It wasn't because we don't want them, it's that we want to concentrate on the two we have."
- Abby said she talked to her parents about having another baby and they helped her realize "I am done" having babies and she decided not to have another child.

MY OPINION

Based on the “Cognition Plus” test – Boni-Sanez, 2015 – I opined that Abby had the capacity to and did consent to sex using SDM

- Abby could and did express “volition” for sex.
 - All agreed she liked sex and frequently initiated it.
 - All also agreed that she declined sex when she did not want it
- Even assuming, for the sake of argument, that Abby didn’t have the intellectual capacity to understand the consequences of deciding to have sex, she had a supportive network – her parents and grandparents – in place to help her understand and make that decision

WITH SUPPORT FROM HER NETWORK

With support from her parents and grandmother, Abby:

- Understood what sex is, that children are born through sex and that she has the right to refuse sex when she does not want it
- Decided not to have a romantic and sexual relationship with someone she does not love — her friend, Rocky;
- Decided to have a romantic and sexual relationship with someone she does love — her Husband, Austin; and
- Decided to have and initiate sex when she wants it and to decline it when she does not
- Decided not to have more children

CASE RESULT

- I submitted my report to the parties and Court
- At deposition, APS' doctor – who previously evaluated Abby – opined that she could consent to sex through SDM
- Shortly thereafter, APS entered into a settlement that resulted in Abby moving back home and the charge being dropped
- Abby is home today

WHAT COULD APS HAVE DONE BETTER?

- APS could have used SDM to interview and evaluate Abby was put under guardianship even though she already had a POA
- That way, APS could have asked and learned about Abby's sexual understanding and history of consenting and refusing sex
- APS could also have interviewed Abby's parents in a nonthreatening way, to determine their role in supporting Abby to, among other things, decide to have sex and marry Austin
- APS could have reviewed its own records, which indicated (based on its own assessment scale) her living situation was never worse than "stable."
- APS could have consulted further with the police, who advised them against taking action

ALL OF THIS WAS CONSISTENT WITH APS LAW AND POLICY

- An “adult” in need of protection is one who is “unable to . . . Protect [themselves] from neglect, hazardous or abusive situations without assistance from others and who has no available, willing, and responsibly able person for assistance and who may be in need of protective services - TN Code § 71-6-102(2)

Why didn't APS fully interview or consider Abby's parents as “responsibly able” people who could help Abby use SDM to decide whether to have sex. Instead, they assumed her parents were part of the problem

ALL OF THIS WAS CONSISTENT WITH APS LAW AND POLICY

- APS policy stated:
 - Clients, regardless of their age or condition, have a right and responsibility to direct their own lives to the extent that it is possible for them to do so. This means that each client will:
 - Be given every opportunity to make plans for himself/herself to the degree possible;
 - Be given full and honest information about the alternatives and options that are available to assist in making an informed decision;
 - Be given the opportunity to direct the degree and order in which services are provided.

Why didn't APS use SDM with Abby to help her understand her options and give her the opportunity to explain how she decides to consent to sex? Instead, they assumed she couldn't

WHERE DO WE GO FROM HERE WHEN IS GUARDIANSHIP APPROPRIATE?

If, after considering the evidence presented at the hearing, the court or jury determines on the basis of **clear and convincing evidence that the respondent is incapacitated and in need of a guardian** or conservator, the court shall appoint a suitable person, who may be the spouse of the respondent, to be the guardian or the conservator or both

Va Code Ann. 64.2-2007(D)

TWO STEPS

(1) Is the person “incapacitated”

If so,

(2) Is guardianship “necessary”

Supported Decision-Making should be part of the analysis for each!

WHEN IS A PERSON “INCAPACITATED”

"Incapacitated person" means an adult who has been found by a court to be **incapable** of receiving and evaluating information effectively or responding to people, events, or environments to such an extent that **the individual lacks the capacity** to (i) **meet the essential requirements for his health, care, safety, or therapeutic needs** without the assistance or protection of a guardian or (ii) **manage property** or financial affairs or provide for his support or for the support of his legal dependents without the assistance or protection of a conservator. **A finding that the individual displays poor judgment alone shall not be considered sufficient evidence that the individual is an incapacitated person within the meaning of this definition.**

- VA Code Ann. 64.2-2000

WHEN IS GUARDIANSHIP “NECESSARY”

In determining the need for a guardian or a conservator and the powers and duties of any guardian or conservator, if needed, consideration shall be given to the following factors: (i) the limitations of the respondent; (ii) the development of the respondent's maximum self-reliance and independence; (iii) **the availability of less restrictive alternatives, including advance directives, supported decision-making agreements, and durable powers of attorney**; (iv) the extent to which it is necessary to protect the respondent from neglect, exploitation, or abuse; (v) the actions needed to be taken by the guardian or conservator; (vi) the suitability of the proposed guardian or conservator; and (vii) the best interests of the respondent.

Va Code Ann 64.2-2007(c)

“INCAPABLE” AND “NECESSARY”

- How do you know?
- In the VAST majority of cases, the court should not assume that, just because a person has a particular diagnosis, s/he is “incapable.”
- Unless there is evidence that something was tried to make the person “capable,” how can you know, but clear and convincing evidence, that the person isn’t?

THINK ABOUT “CAPACITY”

- People may have “capacity” to make some decisions but not others.
- Or be able to make decisions some times but not others.
- Or be unable to make decisions unless they get help understanding the decision to be made.
- Salzman, 2010

Capacity to consent to surgery is not the same as capacity to perform it!

So...

If people only have the “capacity” to “meet” their needs or “manage” their finances **with assistance or support**, are they incapacitated?

ARE YOU?

WHICH MEANS: ASK A QUESTION

Before seeking or
recommending Guardianship:

**What Else Have You
Tried?**

OR, AS THE NATIONAL GUARDIANSHIP ASSOCIATION SAYS

“Alternatives to guardianship, **including supported decision making**, should always be identified and considered whenever possible **prior to the commencement of guardianship proceedings.**”

- National Guardianship Association Position Statement on Guardianship, Surrogate Decision Making and Supported Decision Making, 2015

SUPPORTED DECISION-MAKING CAN HELP PEOPLE “MANAGE” MONEY AND “MEET” THEIR NEEDS

- Supported Decision-Making can help people:
- Understand information, issues, and choices;
 - Focus attention in decision-making;
 - Weigh options;
 - Ensure that decisions are based on their own preferences
 - Interpret and/or communicate decisions to other parties.
- Salzman, 2011

IT'S A PARADIGM, NOT A PROCESS

There is no “one size fits all” method of Supported Decision-Making.

Can include, as appropriate

- Informal support
 - Written agreements, like Powers of Attorney, identifying the support needed and who will give it
 - Formal Micro-Boards and Circles of Support
- Martinis, Blanck, and Gonzalez, 2015

IN COMMON

ALL Forms of Supported Decision-Making recognize:

- That EVERYONE has The Right to Make Choices to the maximum of their capabilities;
 - That people can get help exercising their Right to Make Choices without giving up that right; and
 - There are as many ways to give and get help as there are people
- e.g., Dinerstein, 2012

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

RESEARCH

- Older adults (Brown, 2017) and people with disabilities (Jayes, et al, 2021, 2022) provided with support were better able to understand, consent to, and take part in medical care and procedures including capacity evaluations
- People provided support were better able to make everyday decisions and manage their lives (Harding and Tascioglu, 2018; Browning, et al, 2020)

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>

EVEN AFTER GUARDIANSHIP

A guardian shall, to the extent feasible, encourage the incapacitated person to participate in decisions, to act on his own behalf, and to develop or regain the capacity to manage personal affairs. A guardian, in making decisions, shall consider the expressed desires and personal values of the incapacitated person to the extent known and shall otherwise act in the incapacitated person's best interest and exercise reasonable care, diligence, and prudence.

Va. Code Ann. 64.2-2019

WHAT ARE YOU TRYING?

KEEP TRYING

Self-Determination is directly correlated with quality of life, including their “care, education, health, and welfare.”

- Khemka, Hickson, & Reynolds, 2005;
O'Connor & Vallerand, 1994; Wehmeyer & Schwartz, 1998

WHEN WHAT YOU TRIED WORKS

- Upon petition by the incapacitated person, the guardian or conservator, or any other person or upon motion of the court, the court may (i) declare the incapacitated person restored to capacity; (ii) modify the type of appointment or the areas of protection, management, or assistance previously granted or require a new bond; (iii) terminate the guardianship or conservatorship; (iv) order removal of the guardian or conservator as provided in § [64.2-1410](#); or (v) order other appropriate relief.

Va Code Ann. 64.2-2012

DOESN'T THAT MEAN...

A Guardian's job is to work with the person:

- To help the person learn to make his or her own decisions, with support
- To build self-determination
- To “take care of” their person and property
- And then ask the Court to terminate the guardianship?

Guardianship as a Way-Station, Not a Final Destination

IT HAPPENS



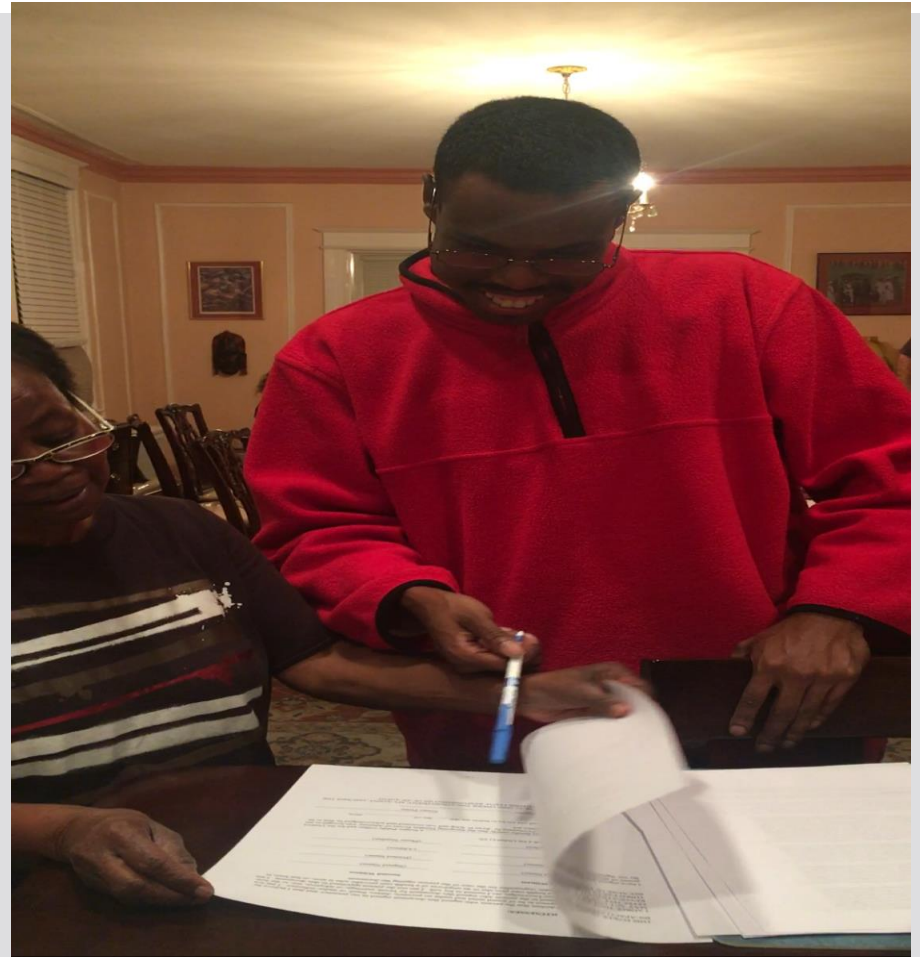
Jenny Hatch and her attorney celebrate after the court victory. (TWP)

‘I’m so happy to go home today’

Theresa Vargas

Jenny Hatch, a 29-year-old-woman with Down syndrome, can live the life she wants after a judge rules she can reside with friends.

IT IS HAPPENING



IT CAN HAPPEN



IT DOES HAPPEN



IT'S STILL HAPPENING





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IT WILL KEEP HAPPENING



**BUT IT WILL ONLY HAPPEN
IF WE REMEMBER THAT**

Supported Decision-Making
ONLY works if we Recognize,
Respect, and Honor
EVERYONE's Right to Make
Choices

AND 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

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

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

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