

**APS TARC**

Adult Protective Services Technical Assistance Resource Center

enhancing  
effectiveness of  
**APS** programs

**Supported Decision-Making:  
Maximizing Self-Determination, Safety, and  
Opportunity**  
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# About the APS TARC

The mission of the APS TARC is to support federal, state, and local partners' use of data and analytics, research and evaluation, and innovative practice and innovative strategies to enhance the effectiveness of APS programs.

# Supported Decision- Making: Maximizing Self- Determination, Safety, and Opportunity

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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

# ANOTHER STUPID QUESTION

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



# AND YET: 2,000 YEARS AND COUNTING

- **Ancient Rome:** “Curators” appointed for older adults and people with disabilities.
- **5<sup>th</sup> 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."



# 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

# 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

# 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**

# PROBLEMS FOR LILLIAN

- She was put under guardianship even though she already had a POA
- The guardianship didn't do anything "protective" for her that the POA didn't already do
- The guardianship didn't respect her choice, including her choice of a decision-maker

# THINK ABOUT IT: “UNJUSTIFIED ISOLATION”

“diminish[es] ... everyday life activities ... including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment”

- *Olmstead vs. L.C.*, 527 U.S. at 600-01

**Isn't that what happened to Lillian?**

## THINK ABOUT “CAPACITY” OR “INABILITY”

- People may be “able” or “capable” to make some decisions but not others.
- Or be “able” to meet some personal needs some times, but not others unless they get help
- Or be “incapable” of managing their property unless they get help understanding important issues (taxes, etc)
- Salzman, 2010

**Capacity to Take Medication is Not the Same as Capacity to Prescribe It!**

So...

If people are only “able” or “capable” to meet their needs or manage their property if they get **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 ADDRESS LIMITATIONS IN DECISION-MAKING

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

# OPPORTUNITIES FOR SDM ARE ALL AROUND US

- “Informed consent”
- “Informed choice”
- “Person Centered Planning”

Are ALL forms of SDM!

# JOIN THE CONVERSATION

**National Resource Center for Supported Decision-Making:**  
[SupportedDecisionMaking.Org](http://SupportedDecisionMaking.Org)

**The Burton Blatt Institute at Syracuse University:** [BBI.Syr.Edu](http://BBI.Syr.Edu)

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# About this Project

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# **From Theory to Practice**

**Supported Decision Making,  
Guardianship, and APS: What's  
Choice Got to Do With It?**



*About NAPSA*

*WWW.NAPSA-NOW.ORG/ABOUT-NAPSA/CODE-OF-ETHICS*

## **NAPSA (OR APS) CODE OF ETHICS**

Adult Protective Services...promote safety, independence, & quality-of-life for older persons & persons with disabilities...being mistreated or in danger of being mistreated, and who are unable to protect themselves.



*About NAPSA*

## NAPSA (OR APS) CODE OF ETHICS

**Guiding Value:** Every [APS] action...must balance duty to protect the safety of the VA with the adult's right to self-determination.



*About NAPSA*

## *Principles*

Adults have the right to be safe.

Adults retain all their civil and constitutional rights i.e., the right to live their lives as they wish, manage their own finances, enter into contracts, marry, etc. unless a court adjudicates otherwise.

## *Principles*

- Adults have the right to make decisions that do not conform with societal norms as long as these decisions do not harm others.
- Adults have the right to accept or refuse services.



*About NAPSA*

## *Practice Guidelines: APS Responsibilities*

- Recognize: interests of the adult are first concern of any intervention.
- Avoid imposing personal values on others.



*About NAPSA*

## *Practice Guidelines: APS Responsibilities*

- Recognize *individual differences* such as cultural, historical and personal values.
- Honor right of adults to *receive information* about choices & options in *form or manner that they can understand*.

## *Practice Guidelines: APS Responsibilities*

- Focus on case planning that *maximizes the vulnerable adult's independence and choice* to the extent possible based on the adult's capacity.
- Use the *least restrictive services* first whenever possible—community-based services rather than institutionally-based services.



## *Practice Guidelines: APS Responsibilities*

- Use *family and informal support systems first* as long as this is in the best interest of the adult.
- In the absence of an adult's expressed wishes, support casework actions that are in the adult's *best interest*.

## *Practice Guidelines: APS Responsibilities*

- Use substituted judgement in case planning when historical knowledge of VA's values is available
- Do no harm. Inadequate or inappropriate intervention may be worse than no intervention.

# DO NO HARM

*“...our most cruel failure in how we treat the sick and the aged is the failure to recognize that they have priorities beyond merely being safe and living longer; that the chance to shape one’s story is essential to sustaining meaning in life ... we have the opportunity to refashion our institutions, our culture, and our conversations in ways that transform the possibilities for the last chapters of everyone’s lives.”*

— Atul Gawande, *Being Mortal: Medicine and What Matters in the End*

# DO NO HARM

**Time for culture change, to move away from guardianship by default to systems that value avoiding *unnecessary* guardianship**

Benefits of Self-Determination vs.  
Potential Harm Associated with  
Guardianship

# HOW DO WE DO THIS?

- Understand we all have the right to make choices.
- Needing help  $\neq$  needing guardianship
- Confront own and other professionals' lack of comfort with ambiguity

# HOW DO WE DO THIS?

- Confront own assumptions about:
  - Capacity & diagnosis
  - Need for legal decision maker
  - Ability of family (however imperfect) to play significant and positive role
- Recognize risk factors re: family, but sort out reality vs. perception

# SW SKILLS (& WILLINGNESS) REQUIRED

- Confront your own risk tolerance
- May need to confront other professionals
- Build trust; joining with person
- Advocate for decisions person can make
- Accommodate for disabilities
- Give information about rights

# SW SKILLS (& WILLINGNESS) REQUIRED

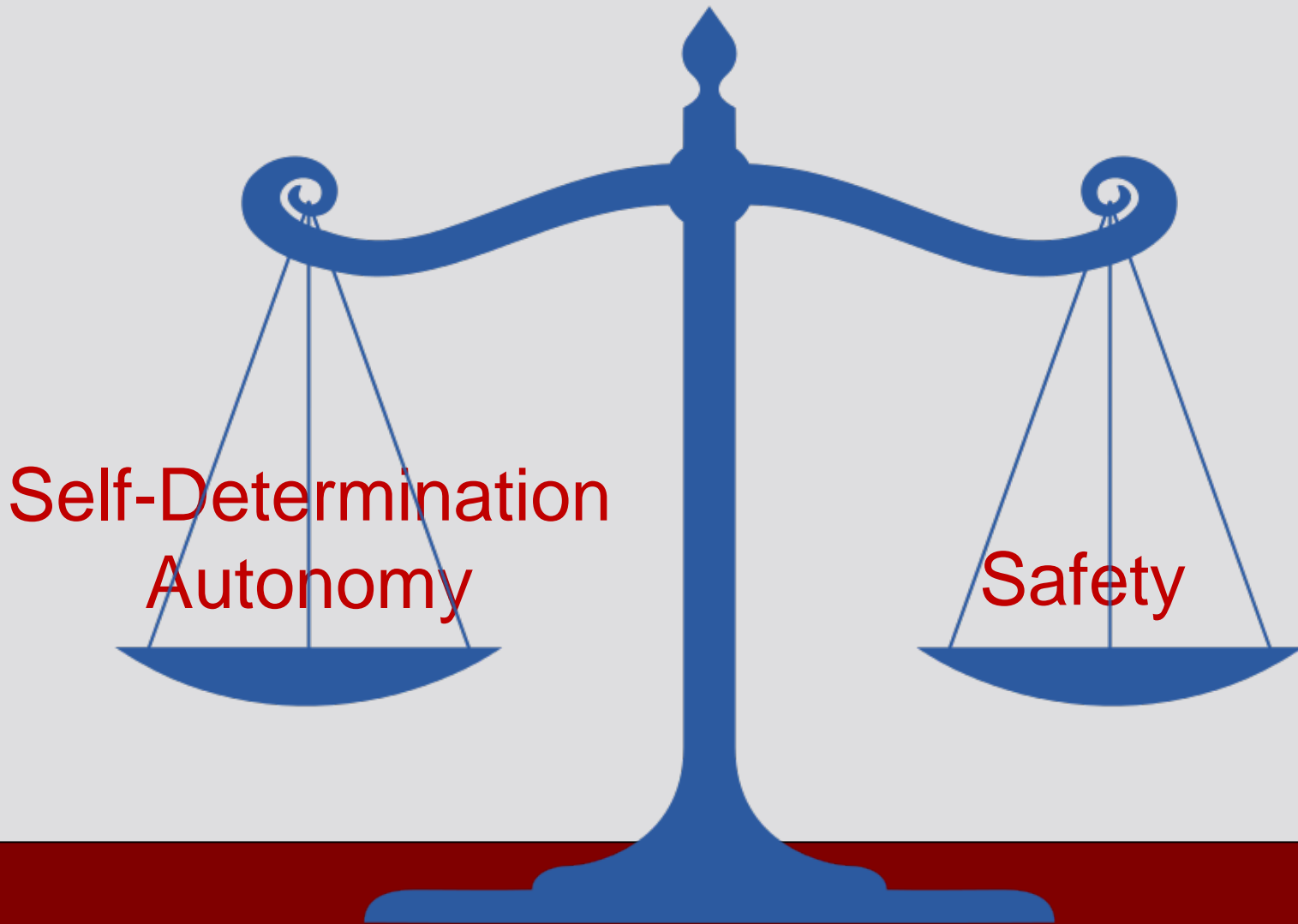
- Help person identify needs and resources
- Facilitate realistic goal setting (Insight Proxy)
- Identify and link to formal and informal resources and supporters
- Weigh risk of harm with impacts of protection that means loss of self-determination



# HOW IS APS WORK INFORMED BY SDM?

- Changing our approach and assumptions about vulnerability and disability
- From “telling” to “coaching”
- Is neither abandoning person to their choices nor is it singular focus on total risk elimination.

# FINDING THE BALANCE: PERSON CENTERED PRACTICES



# PERSON CENTERED SERVICE PROVISION

Important **TO**  
the Person:

- Relationships
- Hobbies
- Residential choices
- How to spend day
- Providers
- Personal expression: clothing, makeup
- Etc.



Important **FOR**  
the Person:

- Health
- Safety
- Basic needs
- Policy/law compliance
- Etc.

# SDM TOOLS & APPROACHES

## Health Care Decision Making

- Health Care Directive
- Consent for Release of Information
- Professional Standards & Ethics
- Family or Other Supporters
- Supported Decision Making Agreement

# SDM TOOLS & APPROACHES

## Care and Residential Decision Making

- Care Management (private pay or county)
- Community & Residential Services
- Fiduciary

# SDM TOOLS & APPROACHES

## Financial Decision Making

- Skill Building
- Banking Tools
- Power Of Attorney
- Representative Payee

# BUT WHAT ABOUT....?

Person may make a bad decision?

- What happens when people without disabilities make bad decisions?
- Can we learn from our mistakes?

# BUT WHAT ABOUT?

- Does not recognize need for help/refuses
- Resistiveness cannot be overcome
- Person sabotages others' efforts (and this can't be overcome)
- No trusted supporters
- Supporters not able to act per wishes/best interests (and can't be "trained")



# PROTECTIONS STILL AVAILABLE

- Emergency Guardianship
- Conservatorship (Guardianship of Estate)
- Limited Guardianship (duration, scope)
- Orders for Protection and other legal tools
- Plenary Guardianship

# RESOURCES

- ***National Resource Center On Supported Decision Making***

[www.supporteddecisionmaking.org](http://www.supporteddecisionmaking.org)

- ***Supported Decision-Making: Theory, Research, and Practice to Enhance Self-Determination and Quality of Life*** Book

[www.amazon.com/Supported-Decision-Making-Self-Determination-Cambridge-Disability/dp/1108475647](http://www.amazon.com/Supported-Decision-Making-Self-Determination-Cambridge-Disability/dp/1108475647)

# RESOURCES

- ***American Bar Association: The PRACTICAL TOOL***  
[www.americanbar.org/groups/law\\_aging/resources/guardianship\\_law\\_practice/practical\\_tool.html](http://www.americanbar.org/groups/law_aging/resources/guardianship_law_practice/practical_tool.html)
- ***SDM Brainstorming Guide***  
<http://www.supporteddecisionmaking.org/sites/default/files/sdm-brainstorming-guide.pdf>

# RESOURCES

- ***How to Make an SDMA***

<http://www.ucdmc.ucdavis.edu/mindinstitute/centers/cedd/pdf/How%20to%20make%20a%20SDM%20agreement%20for%20people%20with%20disabilities%20and%20their%20families%20ACLU.pdf>

- ***Missouri Stoplight Tool***

<http://moguardianship.com/Alternatives%20to%20Guardianship%20Tool%20Revised%2011-2015.pdf>

# RESOURCES

# RESOURCES

## *SDM Agreement Examples*

<http://www.supporteddecisionmaking.org/sites/default/files/sample-supported-decision-making-model-agreements.pdf>

# RESOURCES

- ***What Guardianship Means to Me***  
<https://youtu.be/u6FTL7bYUAW>
- ***Missouri Tool***  
[https://youtu.be/D\\_XnGrCi8L4](https://youtu.be/D_XnGrCi8L4)
- ***Last Week Tonight with John Oliver***  
<https://www.youtube.com/watch?v=nG2pEffLEJo>

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*Thank  
You*





## Contact Us

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