SUPPORTED DECISION-MAKING FOR OLDER ADULTS

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Fundamental Human and Constitutional Rights

"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
What If....

- Your **life decisions** were called into question by people close to you?
- Your **personal choices** were used as “evidence” that your decision-making capacity was not adequate or in decline?
- Concerns about your **health or safety** were determined to be more important than your personal history, beliefs, heritage, and preferences?
- You were **not included** in discussions about where you live, what medical treatment you receive, and how your money is spent?
Supported Decision Making: What?

- Empowering persons with disabilities (including changes in memory and cognition)
- To make choices
- With the help from supporters, who assist them to:
  - To understand and explore the options
  - To know the risks and benefits of those options
  - To get guidance and recommendations
  - To make and communicate a choice
  - To carry out that choice, if help is needed to do so.
- SDM mirrors how everyone makes decisions.
- SDM is an emerging nationally and internationally recognized alternative to adult guardianship.
Why is SDM a particularly important alternative to guardianship for older persons?

Best guess is 1.3 million people total under guardianship in the U.S.

Case file reviews have suggested that a majority of persons under guardianship are over 65
Why are older persons at risk for guardianship?

Rates of disability increase with age.
- 35 percent of persons ≥65 and over report some type of disability (including hearing, vision, cognition, ambulation, self-care, or independent living difficulty)
- Rates of Alzheimer’s dementia
  - 10 percent of persons age 65 and older
  - Prevalence increases with age
    - 3 percent of people age 65-74,
    - 17 percent of people age 75-84
    - 32 percent of people age 85 and over
But...

Ageism

- Negative stereotypes often presume more severe impairments than older persons actually experience
Pathways to guardianship

Third party demands

Health care, social services entity, financial institution or government agency determines person lacks capacity and requires guardianship in order to provide service or benefit

- Sometimes a family member files the petition because it is the only way to help the individual
  - Home being foreclosed upon and older person deemed unable to renegotiate mortgage
- Sometimes the institutional actor files the petition
  - Nursing home, hospital petitions
Pathways to guardianship

Intervention when decisions thought to be risky and/or irrational
✓ Adult protective services/hoarding/eviction
✓ Intra-family disputes
  ✓ Adult custody battles
  ✓ Inheritance
✓ Hospital discharge planning
✓ Elder abuse
  ✓ Under undue influence of another
  ✓ Older person subjected to financial exploitation
Supported Decision-Making: Why?

- SDM has “strong potential for promoting favorable outcomes in the lives of people with disabilities and older adults”

- SDM and Human Dignity:
  - Recognizing the inherent value and worth of a person as a human being
  - Honoring that person’s unique identity
  - Preserving any existing capacity
  - Ensuring access to accommodations as needed.

Self-Determination

- **Life Control**
  - People’s ability and opportunity to be causal agents in their own lives.
  - Studies have shown people with disabilities and **greater self-determination** are:
    - More *independent*
    - More *integrated* into their communities
    - Healthier
    - Better able to **recognize and resist abuse**
  - **Older adults with more self-determination** have **improved psychological health**, including better adjustment to increased care needs.
Without Self-Determination . . .

When denied self-determination, people can:


Experience “low self-esteem, passivity, and feelings of inadequacy and incompetency,” decreasing their ability to function (Winick 1995, p. 21).

Decreased Life Outcomes

Overbroad or undue guardianship can cause a “significant negative impact on . . . physical and mental health, longevity, ability to function, and reports of subjective well-being” (Wright, 2010, p. 354)
Supported Decision-Making: How?

- There is no “one size fits all” method.
  - SDM is a **paradigm**, not a process of program
  - It means working with the person to **identify where help is needed and how it can be provided.**
  - The key question is: “**What will it take?**”

- It can include, as needed and appropriate:
  - Informal support
  - Formal Micro-Boards and Circles of Support
  - Technology
Supported Decision-Making: How?

**Written Documents**
- Release of Information forms – “HIPAA” or “FERPA”
- Other Written Plans
- Supported Decision-Making Agreements

**Supported Decision-Making Guides**
- www.supporteddecisionmaking.org

**U.S. Law, Regulations, and Policy**
- Americans with Disabilities Act
- Older Americans Act
- Individuals with Disabilities Education Act
- Medicaid HCBS Settings Rule
Rethink “Capacity”

Capacity is **not**
- “all or nothing”
- Based solely on IQ or diagnosis.

People **may have** “capacity” to:
- Make **some decisions** but not others.
- Make **decisions some times** but not others.
- Make decisions if they get help understanding the decision to be made.

A lack of opportunity to make decisions can prevent people from developing capacity or further decrease capacity (Salzman, 2010)
Case Study #1: Dolores

“It makes you feel powerful to be in charge of your own life. You can have a lot of help everywhere, but you are your own boss.”

— “Dolores”

For more on Dolores’s story, visit http://www.supporteddecisionmaking.org/state-review/district-columbia
Case Study #1: Dolores

Key Take-Aways:
- First case in DC to terminate the guardianship of a senior in favor of Supported Decision-Making (June 2018)
- Demographics are relevant to how SDM arrangements look
- Help people bolster their SDM network
- Ageism and ableism impact people
- Advance planning is important, particularly in the context of older adults and diminishing capacity.

See: http://www.supporteddecisionmaking.org/state-review/district-columbia
Case Study #2: Ms. N.

- Consented to a guardianship in order to get help with pending eviction from her long-time apartment.
- Thought guardianship would save her apartment or provide help to relocate
- Ended up finding supportive services outside of guardianship
- Ultimately, with support from care coordinator, supportive housing agency and peers, was able to transition to new housing arrangement.
- After supports put in place, successfully terminated guardianship
SDM IN CONJUNCTION WITH OTHER ALTERNATIVES TO GUARDIANSHIP

• Advance directives
• Friends, family and peer support
• Mediation among family members
• Adult day care and multipurpose senior citizen centers
• Case management/geriatric care management
• Supported housing
• Assisted living
• Visiting nurses, home health aides, home attendants
• Housekeeping assistance
Guardianship Alternatives (continued)

- Special needs trusts
- Guardian ad litem
- “One-Shot” approval of transaction
- Representative Payee Programs
- Other pensions may exercise discretion to designate “pension representative” under terms of particular plan
- Assistance with benefit program eligibility and appeals
- Bill-paying assistance
- Alerts on bank, credit card accounts, listing trusted contact
- Withdrawal limits
- Telling pensions, reverse mortgage companies, annuities et al. to stop payments.
- Do not call registry
- Real property alerts
SDM and Dementia

Decline in Memory and Cognition
- Not all dementia affects each person the same way

Early Diagnosis:
- Improved treatment options (no “cure”)
- Improved opportunities for ADVANCE PLANNING and building a support network

SDM = Person-Centered and Driven
- Always ask the person what they want.
- As long as a person can communicate in any meaningful way, they have the ability to make choices

As dementia progresses:
- Look at history of decisions and preferences
- A history of practicing SDM will prepare supporters
The Biggest Challenges

- **Training** family, friends, caregivers, advisors, agents and guardians

- In the **principles** of person-driven decision-making
SDM: Where in the U.S.?

**NRC-SDM State Grant Program**
- 18 projects so far
- DC, DE, FL, GA, IN, ME, MN, MS, NC, NV, NY, OR, SC, TN, WI

**Court Orders and Decisions**
- Examples: DC, FL, IN, KY, MA, ME, MN, NV, NY, PA, VA, VT

**State Laws**
- At least **33 states and DC have introduced legislation or resolutions** referring to SDM (as of 2/1/2020)
  - AL, AK, AR, CA, CT, DC, DE, IL, IN, KS, KY, LA, ME, MD, MA, MN, MO, MT, NV, NM, NY, NC, ND, OH, OR, OK, RI, TN, TX, UT, VA, WA, WI, WV
- Of these, **17 have enacted legislation or resolutions** referring to SDM.
  - AK, DC, DE, IN, KS, LA, ME, MD, MO, NV, ND, OH, RI, TX, VA, WA, WI
- SDM has been codified in **various ways**
  - SDM Agreements, UGCOPAA or Less-Restrictive Alternative, Education, Organ Transplantation, SDM Studies, and more!
Looking Nationally for Older Adults...

- U.S. Administration for Community Living
- National Guardianship Association (2016)
- Social Security Advisory Board (2016)
- Uniform Guardianship, Conservatorship, & Other Protective Arrangements Act (2017)
- National Council on Disability Reports (2018)
- U.S. Senate Special Committee on Aging (2018)
Questions?
Contact Information

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