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.

o 35 percent of persons ≥65 and over report some type of disability (including hearing, vision, cognition, ambulation, self-care, or independent living difficulty)

o 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

<u>Third party demands</u>

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.

From "Supported Decision-Making Basics," Morgan K. Whitlatch & David Godfrey, 2017 National Aging and the Law Conference presentation

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:

"[F]eel **helpless, hopeless, and self-critical**" (Deci, 1975, p. 208).

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 **principle**s 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!
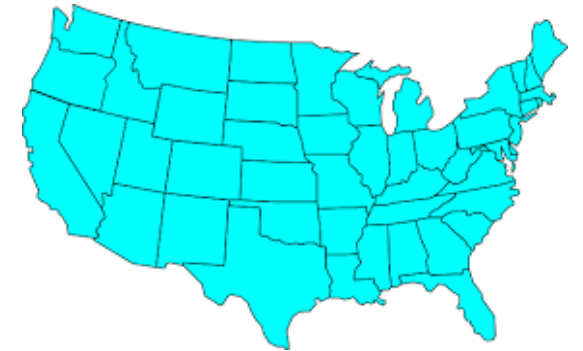
Looking Nationally for Older Adults…

- U.S. Administration for Community Living

- National Guardianship Association (2016)

- Social Security Advisory Board (2016)

- American Bar Association (2016 & 2017)

- Uniform Guardianship, Conservatorship, & Other Protective Arrangements Act (2017)

- National Council on Disability Reports (2018)

- U.S. Senate Special Committee on Aging (2018)

Questions?

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