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Rethinking Guardianship for Transition Age Young Adults with Disabilities: The Promise of Supported Decision Making

West Central Quality Council
November 14, 2023
Anita Raymond, LISW

1

Objectives

- Explore reasons why families are often encouraged to seek guardianship and how to address concerns
- Understand the benefits and potential downsides of guardianship
- Describe decision making options

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Introduction: Transitioning to Adulthood & Current Practices

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3

Happy Birthday! What's Next?

4

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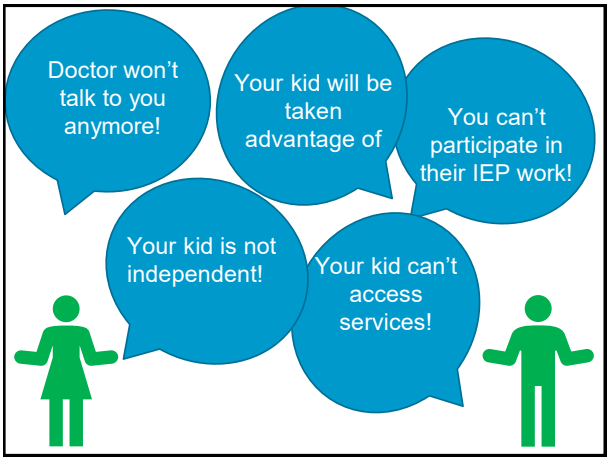

5

6

Guardianship & Conservatorship in Minnesota

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Guardianship & Conservatorship: What are these?

- Court appointed substitute or surrogate decision-maker for person lacking decisional capability, and for whom there are no other ways to address basic needs
- Voluntary or involuntary (most common)
- Guardianship/Guardian/Person Subject to Guardianship = Personal and Care Decisions
- Conservatorship/Conservator/ Person Subject to Conservatorship = Money and Assets

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Guardianship Is:

- an excellent tool….when it's necessary
- sometimes the only way to protect a person living with vulnerabilities
- sometimes the only way to meet the person's own goals
- to be utilized only in extreme circumstances when there is no other way to protect person/meet goals: last resort
- no longer the default approach

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Criteria for Legal Intervention: Guardianship

MN Stat. 524.5-102 Subd. 6: ***Incapacitated Person:***

- impaired to extent lacks sufficient understanding or capacity to make personal decisions

and

- is unable to meet personal needs for medical care, nutrition, clothing, shelter, safety even with use of appropriate technological *and supported decision making assistance and*

10

Criteria for Legal Intervention: Guardianship

…and

- Identified needs cannot be met by less restrictive means, including but not limited to use of appropriate technological assistance, supported decision making, community or residential services, or appointment of a health care agent.

Court must make specific findings particular to the respondent why less restrictive alternatives do not work.

MN Stat. 524.5-310 (a)(2)

11

Legal Intervention: Conservatorship

MN Stat. 524.5-409 Subd.1(1)(2)(3)

- Person is unable to manage property & business affairs b/c of impairment in ability to receive and evaluate information or make decisions, even with use of appropriate technological assistance;
- Has property which will be wasted or dissipated unless management is provided *or*
- Money is needed for support, care, education, health, and welfare of the person or individuals entitled to the person's support *and*

12

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Legal Intervention: Conservatorship

…and:

- Identified needs cannot be met by less restrictive means, including but not limited to use of appropriate technological assistance, supported decision making, representative payee, trusts, banking or bill paying assistance, or appt. of AIF

Court must make specific findings particular to the respondent why less restrictive alternatives do not work.

13

Less Restrictive Alternatives

Petition must state "what less restrictive means have been attempted and considered, how long…have been attempted, and…why…not sufficient to meet the respondent's identified needs

Minn. Stat. 524.5-303(b)(9)
Minn. Stat. 524.5-403 (b) 10

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Limited Guardianships for Persons Under 30

- Court may limit duration of *any* guardianship
- If the respondent is under 30 (and older than 17) the guardianship must be limited, and no longer than 72 months
- Expires automatically
- If need for long term guardianship can be filed at 29

MN Stat. 524.5-310

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15

Guardianship & Supporting People with Disabilities

Changing Perspectives

16

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Guardianship Unintended Consequences

- Adversarial, potentially traumatic process
- Even if not adversarial, process can feel traumatic (focus on deficits; going to court; lawyers, judges = believe they are viewed as criminals)
- Harms to familial relationships; ongoing burden for guardians (reports to court)
- Process focuses on deficits and problems; often no attention paid to abilities and potential opportunities for increasing capabilities

17

Harsh Realities

- Loss of sense of agency (leads to "behaviors")
- Learned helplessness
- Increased risk of abuse
- Overly protective guardian/systems
- False sense of security about safety
- Focus on medical compliance, often ignoring quality of life choices (dignity of risk)
- Transfer of rights

18

Guardianship May Promote False Sense of Security

- Belief that Guardianship will prevent person from doing "dangerous" things
- May be less (no?) emphasis on skill building, lowered expectations
- Person never learns "good" decision-making or life skills

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19

Practical Realities

- Consent power, not compliance power
- Bill of Rights
  - Right to interactions with people of the person's choosing
- Planning for the future: who will be willing to take on Guardianship when current guardian is no longer able to serve?

20

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The Good News: Preserving Rights, Meeting Needs without Court Intervention

- Supported Decision Making
- Health Care Directives
- Role of Fiduciaries / Financial Management
- Authorized Representatives for MA
- Releases of Information
- ….and limitless other approaches

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21

Balance

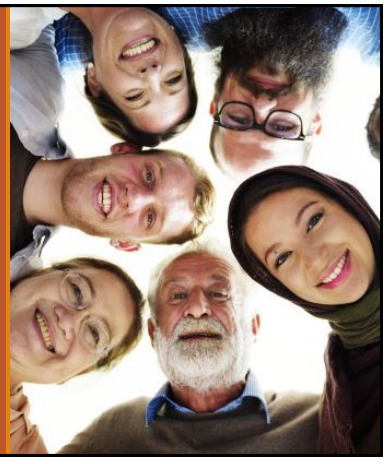
It's not an all or nothing situation

22

Safety nets, relationships, community, reducing risk, skill-building: scaffolding supports

23

Supported Decision Making: a modern approach to supporting people



24

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Supported Decision Making

Assistance from one or more persons of an individual's choosing in understanding the nature and consequences of potential personal and financial decisions which enables the individual to make the decisions and, when consistent with the individual's wishes, in communicating a decision once made.

MN Statute 524.5-102, Subd. 16a

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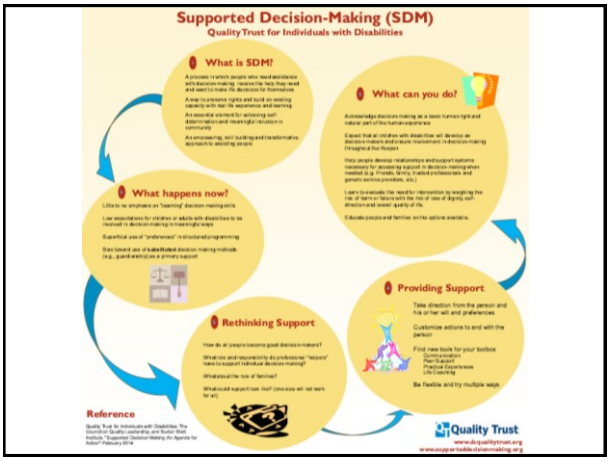
25

Principles of SDM

- No one is completely independent
- How we all make decisions:
  - what we do when we are struggling with a decision
  - turn to trusted others or experts
  - gather information to make the decision
- People who have agency (self-determination) have better outcomes

26



27

You might already be using Supported Decision Making

28

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SDM Example: Making Health Care Decisions

- person makes own decisions without talking to anyone else: not SDM
- someone else makes all medical decisions for person without discussing preferences/opinions: not SDM
- *anything else - attending medical appts. together, explains healthcare choices in plain language, shares access to medical records: is SDM*

(National Resource Center on SDM Brainstorming Guide)

29

SDM Example: Deciding Where to Live

- person makes own decisions without consulting friends, family, professionals: not SDM
- someone else makes all living decisions for person without considering preferences / opinions: not SDM
- *anything else – visiting possible residences together, making pro/con lists; discussing direct service needs: is SDM*

(National Resource Center on SDM Brainstorming Guide)

30

SDM Example: Managing Money

~ no one talks about money with the person, & person does whatever wants: not SDM

~ someone manages all the person's money, gives no choices about how it's spent: not SDM

~ *anything else - opening joint bank account, making a budget together, having a fiduciary who discusses how to spend money: is SDM*

(National Resource Center on SDM Brainstorming Guide)

31

What's Next? Supported Decision Making

What are areas of needed support/skill building?

- Money management
- Health care decisions
- Applying for MA Waiver
- Special Education participation
- Life Skills, Dating, Safety

Start thinking about in early teens!

32

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Supported Decision Making: Powerful Tools

- Representative Payee
- Banking tools
- Trusts, Power of Attorney
- Appoint Health Care Agent (Health Care Directive)
- Authorized Representative for MA / Waiver applications
- Person-Centered Planning process

33

Supported Decision Making: Powerful Tools (cont'd)

- Release of Information forms (health system, school, social services, banks)
- Coaching/on-line resources to teach good relationship decision making
- Harm-reduction interventions: as safe as necessary vs. as safe as possible
- Tech: GPS enabled on phones, Google Maps, medication reminders, etc.

Creativity = countless ways to support person's safety and well-being

34

What's Next? Guardianship

- Unmet needs that can't get met in any other way?
- Tried less restrictive alternatives?
- Benefits of Gship outweigh the harms?
- Approximately 4 months before 18th birthday, start the Guardianship Petitioning process
  - Attorney
  - Pro Se: forms and instructions at MN Judicial Branch, Help Desk

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35

Supported Decision Making Resources

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36

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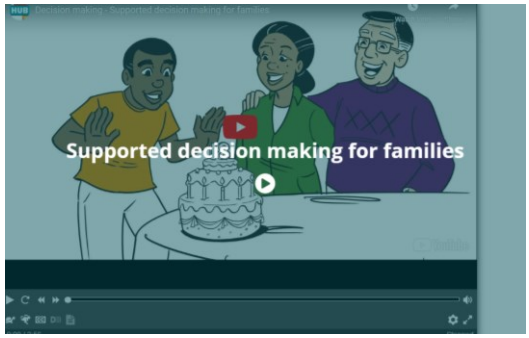
MN Disability Hub

https://youtu.be/ejeYGIf2jhA



37

SDM Brainstorming Guide

"This tool can help people brainstorm ways that they are already using supported decision-making, and think about new ways supported decision-making could help the person with a disability learn to make her own safe, informed choices."

Quality Trust, 2016

38

How to Make a Supported Decision Making Agreement

How to Make a

Supported Decision-Making Agreement

A Guide for People with Disabilities and their Families

American Civil Liberties Union

39

Table of Contents

40

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Chapter 2
Thinking about Choices

? Why do this activity?

This activity will help you think about how you make choices. You can talk about what kind of help you like and don't like. You can think about choices you have made and what you liked and didn't like when you were choosing.

This will help you think about how you want Supported Decision-Making to work.

Supported Decision-Making is different for every person! This activity will help you think about what is important to you.

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41

Chapter 3
Thinking about Support

Supported Decision-Making lets you get help or **support** in making your own choices. Everyone gets support in making choices every day.

Some kinds of support are:

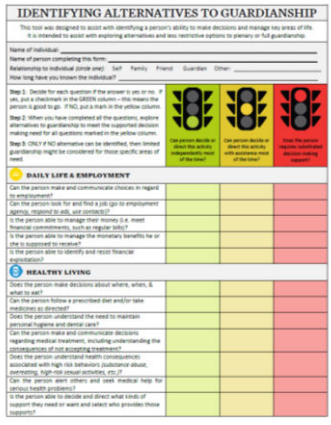
- **Plain-language information**. This means written information is provided in simple words.
-  **Information in pictures or explained**. This means getting information in pictures or by someone talking to you.
- **Research to learn more about choices.**
- **Help in knowing what choices you have.**

42

-  **Visits and trials.** This means trying out different choices, to see how you feel and which one you like.
-  **Reminders** about important dates and times
-  **Help in thinking about pros and cons.** This means making lists of the good and bad parts of different choices.
- **Having a supporter come to meetings and appointments with you.**

6

43



IDENTIFYING ALTERNATIVES TO GUARDIANSHIP

This tool was designed to assist with identifying a person's ability to make decisions and manage key areas of life. It is intended to assist with exploring alternatives and less restrictive options to plenary or full guardianship.

Name of Individual: _____
Name of person completing this form: _____
Relationship to individual (circle one): Self Family Friend Guardian Other: _____
How long have you known the individual? _____

Step 1: Decide for each question if the answer is yes or no. If yes, put a checkmark in the GREEN column – this means the person is good to go. If NO, put a mark in the yellow column.
Step 2: When you have completed all the questions, explore alternatives to guardianship to meet the supported decision making need for all questions marked in the yellow column.
Step 3: ONLY if NO alternative can be identified, then limited guardianship might be considered for those specific areas of need.

Can person decide or direct this activity independently most of the time? | Can person decide or direct this activity with assistance most of the time? | Does the person require substituted decision-making support?

DAILY LIFE & EMPLOYMENT

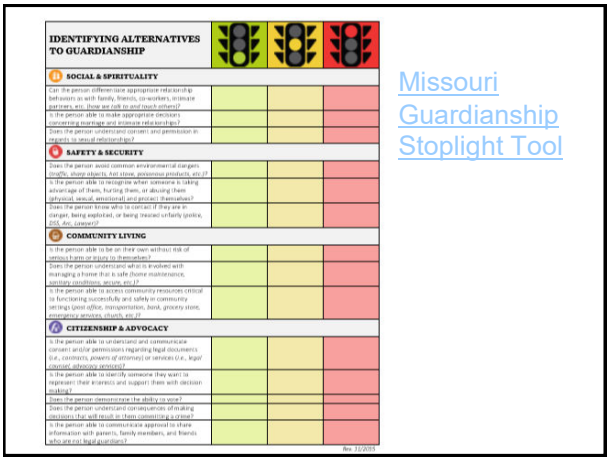
- Can the person make and communicate choices in regard to employment?
- Can the person look for and find a job (go to employment agency, respond to ads, use contacts)?
- Is the person able to manage their money (i.e. meet financial commitments, such as regular bills)?
- Is the person able to manage the monetary benefits he or she is supposed to receive?
- Is the person able to identify and resist financial exploitation?

HEALTHY LIVING

- Does the person make decisions about where, when, & what to eat?
- Can the person follow a prescribed diet and/or take medicines as directed?
- Does the person understand the need to maintain personal hygiene and dental care?
- Can the person make and communicate decisions regarding medical treatment, including understanding the consequences of not accepting treatment?
- Does the person understand health consequences associated with high risk behaviors (substance abuse, overeating, high-risk sexual activities, etc.)?
- Can the person alert others and seek medical help for serious health problems?
- Is the person able to decide and direct what kinds of support they need or want and select who provides those supports?

Missouri Guardianship Stoplight Tool

44



IDENTIFYING ALTERNATIVES TO GUARDIANSHIP

SOCIAL & SPIRITUALITY

Can the person differentiate appropriate relationship behaviors with family, friends, co-workers, intimate partners, etc. (how are still to and touch others)?

Is the person able to make appropriate decisions concerning marriage and intimate relationships?

Does the person understand consent and permission in regards to sexual relationships?

SAFETY & SECURITY

Does the person avoid common environmental dangers (traffic, sharp objects, hot stove, poisonous products, etc.)?

Is the person able to recognize when someone is taking advantage of them, hurting them, or abusing them (physical, sexual, emotional) and protect themselves?

Does the person know who to contact if they are in danger, being exploited, or being treated unfairly (police, DSS, Arc, lawyer)?

COMMUNITY LIVING

Is the person able to be on their own without risk of serious harm or injury to themselves?

Does the person understand what is involved with managing a home that is safe (home maintenance, sanitary conditions, service, etc.)?

Is the person able to access community resources critical to functioning successfully and safely in community settings (post office, transportation, bank, grocery store, emergency services, church, etc.)?

CITIZENSHIP & ADVOCACY

Is the person able to understand and communicate consent and/or permissions regarding legal documents (i.e., contracts, powers of attorney) or services (i.e., legal counsel, advocacy services)?

Is the person able to identify someone they want to represent their interests and support them with decision making?

Does the person demonstrate the ability to vote?

Does the person understand consequences of making decisions that will result in them committing a crime?

Is the person able to communicate approval to share information with parents, family members, and friends who are not legal guardians?

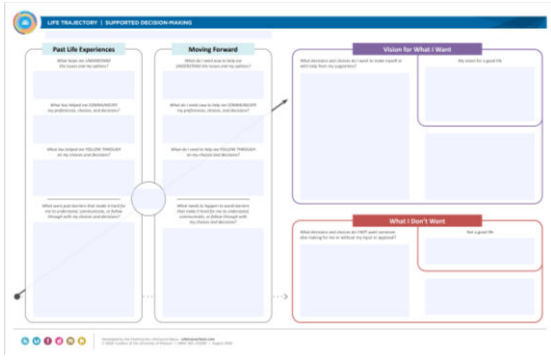
Rev. 11/2015

Missouri Guardianship Stoplight Tool

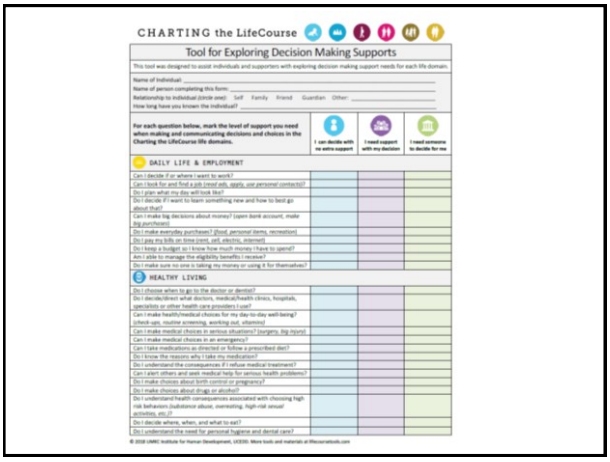
45

Life Course Nexus

www.lifecoursetools.com/lifecourse-library/exploring-the-life-domains/supported-decision-making/



46



CHARTING the LifeCourse

Tool for Exploring Decision Making Supports

This tool was designed to assist individuals and supporters with exploring decision making support needs for each life domain.

Name of Individual: _____

Name of person completing this form: _____

Relationship to individual (circle one): Self Family Friend Guardian Other: _____

How long have you known the individual? _____

For each question below, mark the level of support you need when making and communicating decisions and choices in the Charting the LifeCourse life domains.

I can decide with no extra support | I need support with my decision | I need someone to decide for me

DAILY LIFE & EMPLOYMENT

Can I decide if or where I want to work?

Can I look for and find a job (send ads, apply, use personal contacts)?

Do I plan what my day will look like?

Do I decide if I want to learn something new and how to best go about that?

Can I make big decisions about money? (open bank account, make big purchases)

Do I make everyday purchases? (food, personal items, recreation)

Do I pay my bills on time (rent, cell, electric, internet)

Do I keep a budget so I know how much money I have to spend?

Am I able to manage the eligibility benefits I receive?

Do I make sure no one is taking my money or using it for themselves?

HEALTHY LIVING

Do I choose when to go to the doctor or dentist?

Do I decide/direct what doctors, medical/health clinics, hospitals, specialists or other health care providers I use?

Can I make healthy/medical choices for my day-to-day well-being? (check-ups, routine screening, working out, vitamins)

Can I make medical choices in serious situations? (surgery, big injury)

Can I make medical choices in an emergency?

Can I take medications as directed or follow a prescribed diet?

Do I know the reasons why I take my medication?

Do I understand the consequences if I refuse medical treatment?

Can I alert others and seek medical help for serious health problems?

Do I make choices about birth control or pregnancy?

Do I make choices about drugs or alcohol?

Do I understand health consequences associated with choosing high risk behaviors (substance abuse, overeating, high-risk sexual activities, etc.)?

Do I decide where, when, and what to eat?

Do I understand the need for personal hygiene and dental care?

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47

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GUARDIANSHIP INFORMATION LINE

952-945-4174

1-844-333-1748

cesdm@voamn.org

48

In Summary…

49

"Supported Decision Making can sound like a new, foreign idea. But most families, people with disabilities, and advocates are already using [SDM] even if they don't call it that. In fact, most people without disabilities are also already using [SDM]!

[SDM] means helping a person understand, make, and communicate her own decisions. This will look different for everyone."

SDM Brainstorming Guide

50

SUMMARY: Supported Decision Making

- No court involvement
- Better chance of preserving relationship
- Less expensive
- Better outcomes for person
- Can accomplish a lot of what is accomplished in guardianship
- Required by law

51

Guardianship and SDM Considerations

- Impact (and hassle) of guardianship
- Benefits of self-determination/dignity of risk
- Safety & vulnerability concerns
- Modifying expectations of safety (is gship as protective as you think it is?)
- Guardianship is still an option

52

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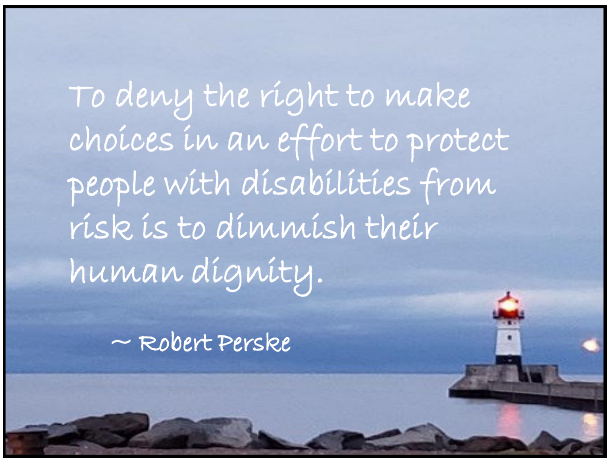

53

54

55

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cesdm@voamn.org

https://www.facebook.com/cesdmvoamn/

- *Phone Consultation, Advice, I&R*
- *Assessments*
- *Facilitation of Supported Decision Making & Surrogate Decision Making Legal Tools*
- *Petitioning for G/C, Terminations, Modifications*

56

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RESOURCES: VOA MN

- CESDM & Protective Services: links to articles, G&C FAQ and more
  voamnwi.org/cesdm

- **Guardianship & SDM Explained**
  youtube.com/playlist?list=PLKJYnxTHNgqVUVjdT6NL29vvLqSQu0l-F

57

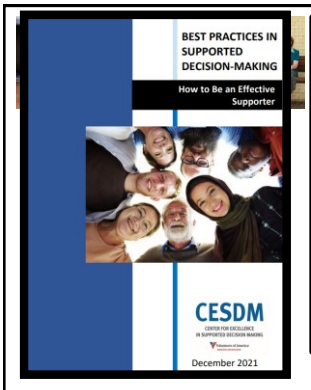
Explainer Videos

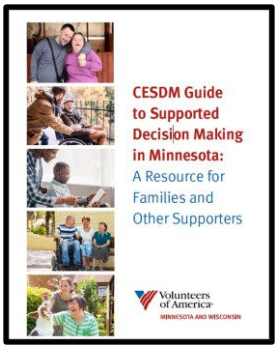
Understanding Guardianship

SDM in Practice

How to Do SDM

58





www.voamnwi.org/center-excellence-supported-decision-making

59

50

RESOURCES

National Resource Center on SDM Brainstorming Guide (and SDMA model forms)
http://www.supporteddecisionmaking.org/sites/default/files/sdm-brainstorming-guide.pdf

National Resource Center on Supported Decision Making
www.supporteddecisionmaking.org

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60

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61

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_ACLU.pdf

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

Charting the Lifecourse
https://www.lifecoursetools.com/lifecourse-library/exploring-the-life-domains/supported-decision-making/

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61

62

RESOURCES

State Courts-forms and manuals:
www.mncourts.gov/Help-Topics/Guardianship-and-Conservatorship.aspx

Bill of Rights for Persons Subject to Guardianship/Conservatorship:
www.revisor.mn.gov/statutes/?id=524.5-120

National Resource Center on Supported Decision Making
www.supporteddecisionmaking.org

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62

63

RESOURCES

MN Courts: Online Training

http://www.mncourts.gov/Help-Topics/Guardianship-and-Conservatorship.aspx

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63

64

Online Training: *Finding the Right Fit*

https://eji.courtlms.org/

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64

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65

RESOURCES

WINGS MN: www.wingsmn.org and: www.mncourts.gov/Help-Topics/Guardianship-and-Conservatorship/WINGS.aspx

Supported Decision-Making: What, Why, & How by Morgan Whitlatch http://supporteddecisionmaking.org/sites/default/files/event_files/MD-Arc-2016-Convention.pdf

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65

SUPPORTED DECISION MAKING AGREEMENT EXAMPLES

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

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66

RESOURCES

- ***American Association on Intellectual and Developmental Disabilities and The Arc Joint Position Statement***
  http://aaidd.org/news-policy/policy/position-statements/autonomy-decision-making-supports-and-guardianship#.WH_huOkiy70
- ***National Guardianship Association SDM Position Statement***
  http://guardianship.org/documents/NGA_Policy_Statement_052016.pdf

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67

RESOURCES

https://www.youtube.com/playlist?list=PLKdIRbjdmxgeDSVBZhEFyrzIli9zjO3Mc

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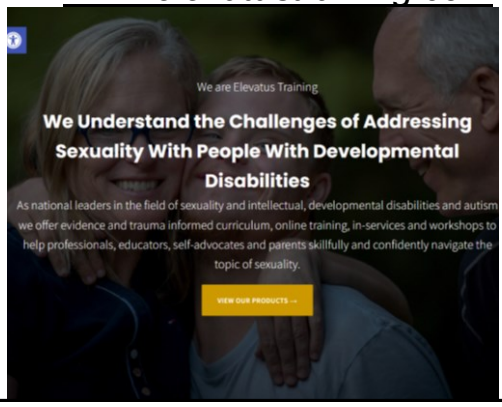
68

www.elevatustraining.com



69

MN DHS Disability Hub

disabilityhubmn.org

70

WINGS
Working Interdisciplinary Networks of Guardianship Stakeholders
MINNESOTA

- Annual Summit
- Quarterly newsletters with local and national news
- Community and Professional Education & Training: Guardianship, SDM, etc.

71

WINGS
Working Interdisciplinary Networks of Guardianship Stakeholders
MINNESOTA

Join our efforts to promote alternatives to guardianship and expand networks of people addressing maltreatment of vulnerable adults:

Become a WINGS MN community member!

cesdm@voamn.org
www.wingsmn.org

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72

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DEPARTMENT OF HUMAN SERVICES

73

Please Evaluate This Session!

https://forms.office.com/r/EFwsVBkmSK

74

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