



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

Charting the Cs
Conference 2025:
*To Literacy and
Beyond*

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Cooperation
Communication
Collaboration

Objectives

- Explore reasons why families are often encouraged to seek guardianship when their child with disabilities turns eighteen and how to address concerns regarding safety, access, and vulnerability
- Understand the benefits and potential downsides of guardianship
- Describe decision making options for those with impaired decisional capacity, including supported decision making

Historically...

Happy 18th Birthday! Let's talk about guardianship!

- At diagnosis
- Young teens or pre-teens
- Other families
- Benign, necessary step
- Required by IDEA

Changing Perspectives About Guardianship

- No longer the default
- Policy, law and best practices emphasize self-determination and person-centered approaches
- Removal of civil rights, transferred to guardian
- Good intentions may lead to bad outcomes
 - Overly protective decisions
 - False sense of security
 - Increased risk of abuse
 - Person never learns how to be a good decision maker

Harsh Realities of Guardianship (potential)

- Decreased or no sense of agency / self-determination
- Perpetual childhood
- Resulting feelings: frustration, anger, defeat
- Reactions
 - Increased resistance, decreased cooperation
 - Communicating their emotions by “acting out” or “behaviors”
 - Depression, isolation
 - Learned helplessness

Practical Realities of Guardianship

- Consent power, not compliance power
- Bill of Rights:
 - right to due consideration of preferences
 - right to interact with people of their choosing
- Future considerations
 - what skills/supports are needed when guardianship ends in 72 months?
 - successor guardian when current is not longer able to serve?

Legal Realities of Guardianship

MN Law Requires Trying Alternatives First

- Impaired, lacking capacity to make decisions †
- Unable to meet personal needs, even with help †
- Identified needs can't be met by less restrictive means, including
 - Technological assistance
 - Supported decision making
 - Community or residential services
 - Appointment of health care agent

Key Questions

- Incapacitated to do what?
- What has been tried, for how long, and why didn't it work?

Is Guardianship All Bad? Should We Abolish It?

- No! Guardianship is a valuable, effective, and necessary tool. When it's needed.
- Guardianship is the best tool when:
 - need for protection and substitute decision making outweighs possible harms and unintended consequences
 - powers of guardianship will effectively address the problem
 - act of removing rights for the person's own good won't worsen the situation
 - situation is so dire and there is no other way to address the person's unmet needs or maltreatment or safety concerns
 - all less restrictive options have been eliminated

Contemplating Parental Authority

- Parents/legal guardians of minors: legal decision makers for all decisions
 - Legal decision making authority? yes
 - Child obeying/abiding parental decisions? Maybe
 - “I want” “I won’t” “You can’t make me”
 - Navigating and gaining compliance and cooperation
- Planning for child’s age of majority:
 - “goodbye and good luck”?
 - Ready for adulting: college, student loans, residence, prescriptions, banking preparations, car insurance, broken hearts, job choices

Transitioning to Adulthood

- Legal decision-making rights transferred to young adult
 - Exceptions: alcohol consumption, car rentals
- Cognitively ready?
- Emotionally ready?
- Practically ready?
- Young adults: ready for complete independence?
 - Without disabilities: very, very few are totally independent
 - With disabilities: very, very few are totally independent

Conversations with Students and Parents

- “Your legal decision-making rights transferred to child when they turn 18...”
“...unless you get guardianship”
vs.
“....so let’s start planning”
- Planning for adulthood
 - What areas still need more skills and knowledge development?
 - What areas need someone to do for them?
 - Learning how to be good decision makers

Changing Drivers

- Parent was the driver, child was passenger
- Now, young adult is in the driver's seat
- Parent in passenger seat for some trips
- Parent in back seat for some trips
- Parent doesn't need to be in the car for every trip
- Parent and young adult prepare for reasonably safe trips together



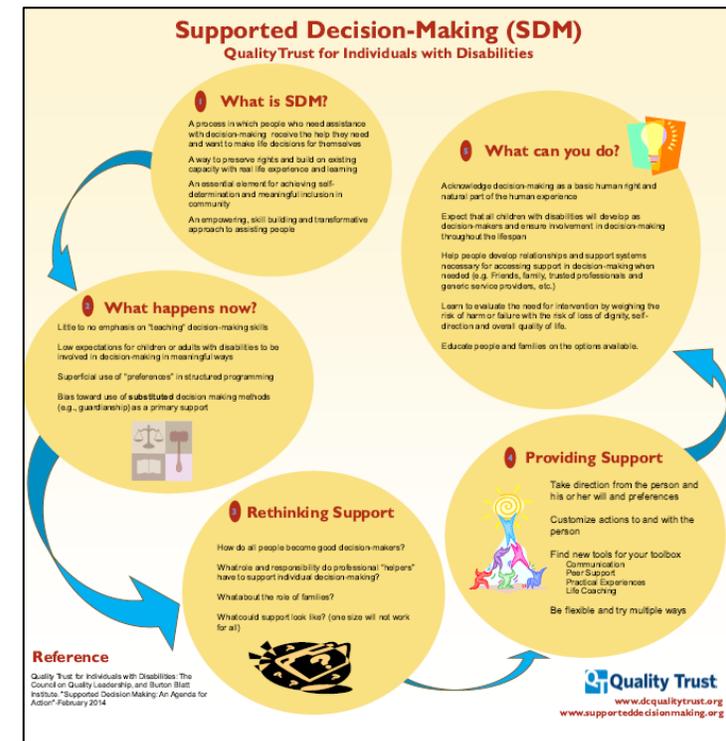
Supported Decision Making: It's the Law

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

Supported Decision Making Highlights

- People who need help with decision making receive the help they need and want
- Preserves rights and builds on existing capacity with real life experience and learning
- Essential element for achieving self-determination & meaningful inclusion
- An empowering, skill-building, transformative approach to assisting people



Principles of Supported Decision Making

- No one is completely independent
- How we all make challenging decisions:
 - Turn to trusted others or experts
 - Gather information needed to make decision
- People who have agency / self-determination have better outcomes

Identifying Areas of Needed Support / Skill-Building

- Money management
- Health care decisions / managing health conditions
- Applying for MA Waiver, accessing Home & Community Based Supports
- Special Education participation
- Life Skills, Dating, Community Safety, Jobs

Powerful Tools: Supported Decision Making

- Coaching/on-line resources to teach good decision making in relationships
- Tech:
 - Smart Phones: GPS, Maps, medication reminders, etc.
 - Apps: Let Me Do It; Can Plan; Monefy
- Creativity required: countless ways to support person's safety and well-being

SDM Planning Tools and SDMAs

- [Charting the Life Course Framework](#)
- [SDM Brainstorming Guide](#)
- [How to Make a Supported Decision-Making Agreement](#)
- [National Resource Center on Supported Decision Making](#)

Remember: Written Supported Decision Making Agreements are ***NOT*** required!

More Powerful Tools

- Representative Payee
- Banking tools
- Trusts, Power of Attorney
- Appoint Health Care Agent (Health Care Directive)
- Authorized Representative for MA / Waiver applications
- Releases of Information (education, health, social service systems)
- Person-Centered Planning process

But What About Bad Choices, Safety, and Vulnerability?

Building Scaffolds of Supports

- Relationships
- Community
- Skill-building
- Safety Nets
- Risk/harm reduction
- Goal: as safe as necessary (vs. as safe as possible)

Bad Choices or Human Choices?

- Alcohol and other substances
- Online dating
- Dating and intimacy
- Giving money to others
- Medication choices
- Food choices
- Friend choices
- Residential and care choices

Helping Families and Student Navigate “Bad Choices”

What is the Issue? Listen with non-judgmental true curiosity

- Why is the choice important to the person?
- Why do they want to...? Why don't they want to...?
- Is the choice really about something else?
 - Trying to claim a sense of control in their life
 - Expressing frustration or anger or fear
 - Want to do what their peers are doing
- Person is just dreaming out loud?

Navigating Choice & Safety

- Help student understand how it will impact desired outcome, goals, and desires
- Person-centered approaches
 - Inquire to understand what is important *to* the student (personal choices)
 - Help student understand what is important *for* the student (health and safety)
 - Find ways to leverage important *to* so you can achieve important *for*.
- Use leverage, negotiation, trials to find balance between safety and choice (happiness, quality of life)

Navigating Choice & Safety (cont'd)

- Creative way to meet both? (temporary tattoo, GPS in phone)
- Set them up for best chances of success instead of setting them up to fail?
 - What will they accept? What are they willing to try?
 - What can we live with?
 - Trials, skill-building, coaching, partnering
- Revisit later
- Trusted relationship with supporter
 - Is there someone else to have this conversation with them
 - If they feel we'll blame, restrict, they will never come to us if struggling

Summary: Supported Decision Making Key Principles

- Philosophical, transformative approach
 - helps people receive the help they need and want
 - preserves rights and builds on capacity with experience and learning
 - Essential element for achieving self-determination & meaningful inclusion
- Viable, legal less restrictive alternative to guardianship
- Umbrella term encompassing several (countless?) options
- Everything we do to help person make decisions to get their needs met
- Balances choice/quality of life with safety
- How we all make decisions

Summary: Supported Decision Making Takeaways

- No court involvement
- Better chance of preserving relationship(s)
- Less expensive
- Better outcomes for the person
- Along with additional tools, can accomplish a lot of what is sought in guardianship and/or conservatorship
- Required by law to try before seeking guardianship/conservatorship

Summary: Guardianship Might Be Needed

- Person can't or won't cooperate with others to get their needs met or help them make decisions (and we can't overcome this resistance)
- Person can't appoint someone to help with decision making (Health Care Agent)
- Person can't sign a Release of Information to allow others to gather information and talk to providers
- Rep Payee and Authorized Rep insufficient to meet needs

Education Professionals Play a Critical Role!

- *I don't need a guardian. I just need a little help.* ~ Jenny Hatch
- *To deny the right to make choices in an effort to protect people with disabilities from risk is to diminish their human dignity.* ~ Robert Perske



Center for Excellence in Supported Decision Making



- Assessments
- In-depth, personalized consultations for individuals, families, communities, professionals
- Technical Assistance, trainings, education sessions

Guardianship Information Line

- 952-945-4174 1-844-333-1748 (toll free)
- cesdm@voamn.org

For More Information

- CESDM: links to articles, G&C FAQ and more
www.voamnwi.org/center-excellence-supported-decision-making
- SDM / Gship Information Videos
youtube.com/playlist?list=PLKJYnxTHNgqVUVjdT6NL29vvLqSQu0l-F

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Thank you!

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