

What to Know About Decision-Making Supports

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What We Will Cover...

- Self-determination and decision-making
- Guardianship role and responsibilities
- Guardians and HCBS
- Addressing disagreements
- How you can support decision-making



Decision-Making

- Understanding the issue
- Determining options and consequences
- Gathering information
- Evaluating options
- Making a choice
- Communicating or implementing choice
- Observing results




Decision-Making Styles

- Analytical – Pro/con lists; logic and data rule!
- Intuitive – Gut feeling, spontaneous.
- Information seeking – What do the experts say?
- Consensus seeking – Ask friends and family.
- Passive – The universe will guide you to the right decision.



Research on SDM

People with more self-determination have:

- Improved psychological health including better adjustment to increased care needs.
- O'Connor & Vallerand, 1994
 - Better quality of life, more employment and community integration. e.g. Powers et al., 2012; Shogren, Wehmeyer, Palmer, Rifenburg, & Little, 2014;
 - Increased health, welfare, and safety e.g., Khemka, Hickson, and Reynolds, 2005. 
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Research on SDM

- When denied self-determination, people experience “low self-esteem, passivity, and feelings of inadequacy and incompetency.” - Winick, 1995.
- People subjected to overbroad or undue 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



What options are available?

- Not just guardianship!
- Goal is to start with the least restrictive options possible
- Capacity as a spectrum – depends on situation, internal and external factors, skills
- Many options can be used in combination or change over time



Spectrum of Assistance



Interdependence / Technology

- Ways to help fill the gaps in someone's needs with minimal involvement
- Formal (paid services) or informal (family or friends)



Spectrum of Assistance



Less Restrictive Alternatives

- “Less Restrictive Alternatives” – an approach to meeting a person’s needs that restricts fewer rights of the person than would the appointment of a guardian.
- Includes (but not limited to):
 - Supported Decision Making Agreement
 - Appropriate technological assistance
 - Appointment of a representative payee
 - Appointment of a Health Care Representative
 - Creation of a Power of Attorney



Supported Decision-Making

- Ind. Code § 29-3-14-1

“Supported Decision-Making refers to the process of supporting and accommodating an adult in the decision-making process to make, communicate, and effectuate life decisions, without impeding the self-determination of the adult.”




SDM – Plain Language

- Accommodates the decision-making process
- Where people choose and use trusted friends, family members, and/or professionals (“supporters”) to help them through the decision-making process
- Person using SDM retains all decision-making authority
- Concept to increase empowerment and self-determination



Examples of SDM

- Understanding the issue – “explain to me in English...”
 - Determining options and consequences – “help me see the big picture.”
 - Gathering information – “help me write out what questions to ask.” “help me figure out what are good sources of information.”
 - Evaluating options – “help me make a pro/con list.” “help me express my values” 
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Examples of SDM

- Making a choice – “help me get ‘unstuck.’”
- Communicating or implementing choice – “help me express my choice”*, “help me understand what I need to do next.”
- Observing results – “support the choice I’ve made.”



Who can use SDM?

- Anyone who needs help making decisions.
- Concept can be used within other decision-making arrangements.
- Any diagnosis or disability



People without “supporters”

- Think creatively about who is involved in the person’s life.
- What community-based activities does the person enjoy that might be an opportunity for meaningful relationship development?
- Other options for building decision-making skills.



Supported Decision-Making Agreements

- States requirements for entering into a SDM Agreement.
- Describes the responsibilities and prohibitions of a supporter.
 - Expressly states that supporter is not a surrogate decision-maker for the adult.
- Describes components of a valid SDMA.
- Describes when a SDMA terminates.



Supported Decision-Making Agreements

- Provides third party protections for relying on or declining to honor a SDM Agreement.
- Provides protections from liability for supporters, except in cases of fraud, misrepresentation, recklessness, or willful or wanton misconduct.



Agency Agreements

- Person has capacity to appoint someone else to act or make decisions on their behalf.
- Don't require court oversight.
- Can be revoked by the person.
- Part of general advanced planning.



Spectrum of Assistance



What is a Guardian?

“Guardian” means a person who is a fiduciary and is appointed by a court...[to be] responsible as the court may direct for the person or the property of an incapacitated person...

Ind. Code § 29-3-1-6

- What does that mean in plain language?



What is a Guardian?

- Person of trust, stands in the legal shoes of the protected person (PP)
- Responsible for person's care and preservation of their property to the extent ordered by the court. Ind. Code § 29-3-8-1
- Guardian is NOT automatically a Representative Payee



Guardianship Types

- Temporary – 90 days with option for cause for additional 90 days.
- Limited – person retains decision-making authority for all other areas.
- Full – All decisions made by the guardian.
- Look at Letters of Guardianship – MUST be issued by a Court.



Comparing Options

LESS
LIMITING



MORE
LIMITING

SUPPORTED DECISION-MAKING



Diana



Supporter

Diana makes her own decisions with the help of another person of her choosing.

POWER OF ATTORNEY



Diana



Power of Attorney
Designee

Diana names someone else to make decisions and act on her behalf.

GUARDIANSHIP



Court



Guardian



Diana

Court appoints a person to make decisions for Diana with court oversight.



What protections are in place?

- Presumption of capacity
- Dignity of risk
- Prevention through empowerment
- No guarantee of safety under any arrangement



What MUST a Guardian do?

- Act in good faith with sound discretion
- Protect and preserve property
- Encourage self-reliance and independence
- Consider recommendations relating to the appropriate standard of support, care, education, and training for PP

Ind. Code § 29-3-8-3



What MAY a Guardian do?

- Receive, manage, dispose of property or real estate for PP's benefit.
- Take custody of PP and establish their place of residence.
- Consent to medical or other professional care and treatment
- Consent to marriage
- Delegate decision-making authority to PP

Ind. Code § 29-3-8-4



What MAY a Guardian do?

- Pay a third party for PP's care.
- Pay PP's debts from PP's assets.
- Distribute income to PP or custodian of PP.
- Get reimbursed for reasonable expenses made in good faith for the benefit of PP.
- Receive reasonable compensation.

Ind. Code § 29-3-9-3



What MAY a Guardian do?

MUST have prior Court order:

- File for divorce, legal separation, annulment
- Consent to sterilization
- Restrict voting rights (rarely granted)
- Accessing PP's electronic communications or digital assets
- Settling a claim or lawsuit for PP
- Moving PP to new county or state.



What SHOULD a Guardian do?

- Treat PP with dignity and respect, maintain privacy and confidentiality.
- Involve PP to the greatest extent possible in all decision-making.
- Select the option that places the least restrictions on PP's freedom and rights.
- Advocate for PP's goals, needs, and preferences.
- Maximize PP's self-reliance and independence.
- Avoid conflicts of interest and self-dealing.
- Comply with all laws and court orders.
- Manage all financial matters carefully. No co-mingling.

National Guardianship Association, Certified Guardian Ethics



Guardian Liability

- Immune from civil liability for performance as guardian (except for gross misconduct).
Ind. Code § 29-3-11-4
- May be removed by the court on petition if:
 - becomes incapacitated, disqualified, unsuitable, incapable of discharging duties;
 - mismanaged assets;
 - failed to perform any duty imposed by law or court order.



Guardians and HCBS

- Having a guardian does NOT mean PP loses ALL decision-making power.
 - PP should, to greatest extent possible, lead or direct their PCISP planning process and team meetings.
 - PP should have choice in activities, food preferences, personal items, friends.
- PP's perspective, wishes, and goals must be addressed and considered when identifying services and living arrangements.
- Guardian can change service providers, withdraw person from services, advocate on behalf of person.



Rights of Service Recipients

- Be treated with respect and dignity.
- To have relationships.
- To see information about themselves and to keep information private.
- To be in charge of their own meetings and services.
- To have materials available and explained to them.
- To be free from abuse, neglect, exploitation.
- To go to the doctor, dentist, hospital if needed.
- To make a complaint without fear.
- To be in charge of their belongings and money.



Rights of Service Recipients

- Have a lease or similar document with protections equal to those under Indiana's LL/T laws.
- Privacy in their sleeping or living unit.
- Units have entrance doors lockable by the person, with only them and appropriate staff having keys.
- Choice of roommates, if sharing units.
- Furnish and decorate their sleeping or living units.
- Freedom and support to control their own schedules and activities.
- Access to food at any time.
- Have visitors of their choosing at any time.



Restriction of Rights

- Guardian decisions that impair or prevent full compliance with HCBS requirements may result in an inability to use Medicaid funds.
- Any infringement on a person's rights (whether by a guardian or service provider at the guardian's direction) must be consistent with the modification requirement:
 - must be narrowly tailored and justified based on health or safety risk NOT preference, value, or convenience.
 - must be clearly documented in the PCISP, reviewed regularly, and have goals working towards ways to lessen or eliminate the need for the restriction.



Disagreements with Guardians

- Be proactive – have a policy or principles for guardian involvement.
- Determine if issue is something guardian MUST decide.
- Don't stop at "No." Is concern tied to legitimate health and safety issue? Can it be addressed in a less restrictive way?
- Be clear about potential outcomes.
- Call a team meeting, consider involving Ombudsman or IDR.
- Contact the court if guardian is jeopardizing health and safety, not acting in person's best interest, unnecessarily restricting rights.
- If person doesn't need guardian or no longer wants one, contact IDR.



Guardian Enforcement

- If a third party fails to comply with a guardian's written demand or instruction that was issued within the scope of the guardian's authority the guardian may bring an enforcement proceeding to compel compliance in the court having jurisdiction over the guardianship.
- A court may award attorney's fees and costs to the guardian if the person acted in bad faith in failing to comply with the guardian's written demand or instruction; or refused to respond within thirty (30) business days after receiving the guardian's written demand or instruction.



Sample Policy

- “We have as a principle and value to respect personal choice and support self-determination. As a Medicaid waiver provider we have an obligation to respect the rights of the people we serve.”
- “You, as guardian, agree to support the person to direct and make as many decisions about their care and treatment as possible. You, as guardian, agree that any restriction of a person’s rights must be done in compliance with HCBS rules and regulations.”



How to Help with Decision-Making

- Set the expectation for self-determination as a value/priority communicated to all staff.
- If person doesn't have a guardian, help them keep it that way.
- If you/your organization serves as guardian, consider working toward a less restrictive option.



How to Help with Decision-Making

- Help people identify how they like to make decisions.
- Help them figure out who might be good supporters.
- Talk about options for support.
- Encourage meaningful opportunities for decision-making and participation.
- Respect their dignity of risk - Include opportunities to make mistakes.
- Be a supporter!



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