Today’s Topics

Guardianship & Supported Decision-Making Facts and Comparisons

Identifying SDM Candidates

How to Build a Team of Supporters

Using SDM Through Challenges and Changes

For more information, please contact transition@perkins.org or heather@guardianshipcenter.org.
SUPPORTED DECISION-MAKING for Independence & Growth

Meet Angie & Alexis

ANGIE
• 20-year-old recent high school graduate
• Loves video games, music concerts, scary movies, fashion, the environment, soccer and football (players)
• Muscular Dystrophy diagnosis age 6
• Strengths include honesty, reliability, fairness, kindness, self-motivation, emotional intelligence, recipe creation, art
• Challenges with reading, math, memory, planning and organization, controlling legs

ALEXIS
• 38-year-old mother
• Skilled advocate for daughter’s needs & wants
• Advised by high school administrators to petition for guardianship of Angie to avoid losing legal rights to make medical decisions for Angie, manage Angie’s finances, etc.

What is Guardianship?
Advocacy + Decision-Making Tool for Adults

Effective guardians make decisions that include what is important FOR the individual and what is important TO the individual.

1 Court-appointed adult
Guardian decree dictates powers and limitations including tenure
Specified decision-making powers have assigned to Guardian by a judge
Guardian meets with the adult 1+ times per month to observe, assess and take action to help (some states but not all states require visits)
State oversight includes care plan report submitted yearly (varies by state)

For more information, please contact transition@perkins.org or heather@guardianshipcenter.org.
The Process for Becoming Guardian of an Adult Includes Proof of Incapacity

Family, Friends + Professional Guardians use the same process

Petition may include:
  a. Petition form
  b. Proof of Incapacity
  c. Bond
  d. Advance Directive (if exists)

Definitions: Capacity & Incapacity

Capacity
• The ability to receive & evaluate information or make or communicate decisions.
• Adults are assumed to have capacity and full legal rights until a court decides otherwise.

Incapacity
• A legal ruling based on evidence provided to the court and presented at a hearing after the adult respondent has been notified, given the opportunity to contest, and given the chance to attend the hearing.
• This ruling means the adult has been determined to lack the ability to understand, evaluate, or communicate information well enough to give consent or make (some or all) informed decisions.

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Then, Alexis told Angie what she had learned about guardianship

“My whole life my mom has included me in decisions. She taught me I can do anything and be anything. Now my school thinks she should get evidence that I am “decisionally incapacitated” and present that in court to a judge? No way!”

SDM was developed & introduced to support people with ID/DD

“Supported Decision-Making Initiative” developed to explore alternative to guardianship for individuals with intellectual or developmental disabilities

Support without losing the power to choose:
- living arrangements
- health care
- lifestyles
- financial matters

Supporters can be family members, co-workers, friends, or service providers
People who respect the person’s preferences; are committed to honoring individual’s choices & decisions

Endorsed in 2006 by the United Nations’ Convention on the Rights of Persons with Disabilities

Trusted group of “supporters” to help discuss options as process for making one’s own decisions

Proven in Canada, Sweden, Australia and Ireland, and gaining foothold in US

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What is Supported Decision-Making?
Self-Efficacy Tool for Adults

“Our belief in our own ability to succeed plays a role in how we think, how we act, and how we feel about our place in the world.”
Albert Bandura, PhD
“Self-Efficacy,” 1977

Selected group of adults who agree to be available to advise an adult during a decision-making process (called supporters)

4-6 supporters, typically, with varied life experiences or expertise; may include parents, friends, teachers, caregivers, caseworkers, etc.

Supporters are chosen by the adult whose decisions they are contributing to because they are trusted + respected by the adult

Adult calls on 1 or more team members, as needed, to discuss and help decide on a simple or complex decision

Team has no legal authority or power to choose or enforce decisions

Can you envision SDM being used during a guardianship?

Let’s look at the definition of “self-efficacy” to decide if SDM has value to an adult who already has a guardian.

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Definition: Self Efficacy

Self-Efficacy

• An individual’s belief in their capacity to act in the ways necessary to reach small or large new or existing goals.

• A strong sense of self-efficacy promotes human accomplishment and personal well-being. It is a foundation for joy.

• People with high self-efficacy view challenges as things to be mastered rather than threats to avoid. They have less fear.

Americans with Disability Act & The Covid-19 Pandemic

• During pandemic, most patients were alone

• ADA requires reasonable accommodations for persons with disabilities

• SDM is considered a reasonable accommodation
  • Hospitals provided entry to supporters so that patients could use the SDM process to give “informed consent”

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Identify Good Candidates for SDM

Look for ANOD

Articulates

Articulates enough to discuss issues and opinions with supporters verbally or using communication tools

Networks

Has network of trusted people who actively use effective decision-making skills or tools; and who treat person with respect

Overcomes

Overcoming of small or large challenges through effort and time has been observed; demonstrates ability to handle consequences and rewards of decisions

Desires

Desires control over some or all decisions

Who Looks for ANOD?

Family members

Guardians

Friends

Caregivers

Case Workers

Medical Professionals

Group Home Staff

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From ANOD to A CONVERSATION

When a good candidate has been identified, these same caring people can bring up the subject and begin to educate the candidate about SDM.

“You heard guardianship was recommended by your school and were not a fan of the idea. I found an alternative called SDM and I want to talk it through with you.”

“I just learned about a procedure called ‘Supportive Decision-Making’ that I think you might want to consider. Can I tell you more about it?”

“You participate in every decision that is made for you. I can see how much control you already have and want. I have learned about a program called SDM. What do you think about taking a look at SDM and learning how it works?”

“I am happy to continue being your guardian. Part of my role is to help you reach the highest level of independence that you want. I would like to introduce a new process for making good decisions. It is called ‘supported decision-making.’

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How to Build a Team of Supporters

1. **Identify aspects of adult life where decision-making is required.**
   - Make a list

2. **Identify who adult already knows/trusts to ask for advice about 1 or more of the decisions listed**
   - Match the person to the subject

3. **Decide how adult ask each person to become a supporter for a specific subject (or subjects)**
   - Prepare explanation of SDM [written, verbal, graphical, or a blend]
   - Schedule individual or group request for support discussions
   - Conduct discussions and gain agreement

4. **Copy or design a written supporter agreement and get signatures from each supporter.**
   - Create documents for signatures that can be shared with service providers

5. **Train supporters using a test topic, so supporters understand what is expected of them.**
   - Process for discussion follow this model: “the topic,” “the facts,” “my feelings”
   - Respect for everyone’s input
   - Respect for adult as decision-maker

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1. Identify aspects of adult life where decision-making is required.

**Resources**  
**ACLU Sample**

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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.

**What to do:**

Think about a choice you made. It could be a choice about:

- where you live
- what you will do in school
- what you work
- what you spend time with
- if you want to go to the doctor
- if you want to go on a date
- or anything else!

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1. List of adult living decisions on Angie’s mind right now:
   a) Spending money/saving money
   b) Group vacation with church
   c) Change dentist
   d) Stay friends with Bonnie or not
   e) Is mom right about makeup?
   f) Job
   g) Is mom right about sports bars?
   h) Sports, boys, athletes, getting strong

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**Alexis helped Angie complete Step 1**

**Easiest approach to Step 1.**

- What’s on Angie’s mind right now and recently?
- Expect list to change with time

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Before Angie could ask anyone to be a supporter, she had to decide who.

With Alexis’ help. She created a line-item map.

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2. My first-choice supporter list of trusted people:
   a) Cousin Casey in college studying accounting and business
   b) Mrs. Dawson neighbor who goes to my church
   c) Mom is my most trusted person for medical advice
   d) Dr. Everly, therapist I have been talking to for years
   e) Farrah Friend, student counselor We talk about personal things
   f) Cousin Casey
   g) Farrah Friend
   h) Dad is my go-to person for watching sports, talking about boys, and strengthening my body, even though he lives far

Angie’s SDM Vision Board & Presentation

For more information, please contact transition@perkins.org or heather@guardianshipcenter.org.
4. Copy or design a written supporter agreement and get signatures from each supporter.

- SDM becomes a formal decision-making program when an adult shares its existence with service providers using an SDM contract.

- There is no widely accepted formal contract so people are adapting them to include their own preferences.

- Signed, notarized agreements may be required.

- Release of information form may be useful (medical release form, for example).
4. Copy or design a written supporter agreement and get signatures from each supporter.

**ACLU/QUALITY TRUST SAMPLE SUPPORTED DECISION-MAKING AGREEMENT**

**Supported Decision-Making Agreement**

This agreement must be read out loud or otherwise communicated to all parties to the agreement in the presence of a notary. The form of communication shall be appropriate to the needs and preferences of the person with a disability.

My name is: _____________________________.

Today’s date is: _______________________

I want to have people I trust help me make decisions. The people who will help me are called **supporters**. I can say what kind of help my supporters will give me. If I want supporters to help me make choices about money, I will sign a different agreement, called “Supported Decision-Making Agreement for Finances.”

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**Supporters**

My supporter(s) are:

**Supporter #1**

Name: ____________________________

Address: ____________________________

Phone Number: _______________________

Email address: _______________________

I want this person to help me with:

(***check as many boxes as you want**)

- [ ] Making choices about food, clothing, and where I live
- [ ] Making choices about my health
- [ ] Making choices about how I spend my time
- [ ] Making choices about where I work

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Medical Release Forms

- May be requested by some providers before they will share private medical information with a supporter
- See what your state offers and consider keeping copies with your supporter agreement

Test Topic 1 & Supporter Training

Decision Discussion Template

**TOPIC:** I would like help deciding if I should change dentists.

**FACTS:** I have been seeing Dr. Gould for 3 years (7 visits). She filled my front teeth and left rough white gunk that I had to go back to get removed. She looks away when I talk. She is weird. I hate going to all dentists.

**FEELINGS:** She makes me uncomfortable. I don’t think I trust her.

What would you advise in this scenario? If I did just the opposite, what would you say to me afterward?
SUPPORTED DECISION-MAKING for Independence & Growth

• Not always logical, more often includes emotions and desires
• Not always permanent, minds change, and circumstances change

Decision-Making Is Complicated

• Mistakes can have consequences that create emotional and physical setbacks, yet they are part of the human experience, part of growing
• Expect mistakes because we all make them
• Adults using SDM must be forgiven for mistakes and given help to recover, if needed

Common SDM Challenges

Supporters fail to support and need to be changed
How will you know when a supporter needs to be changed?

Providers refuse to include supporters in conversations
What can you do or say to change a provider’s behavior?

Providers focus on supporters not adult
What can you do or say to change a provider’s behavior?

Complex medical decisions may require planning or more experienced support
Where can you find experts to help educate supporters?

Parents overrule SDM process due to fear of risks
What can parents do to avoid destroying an adult child’s self-efficacy?

Family patterns of authority overrule SDM process
How can you stand up for the SDM process and break a family pattern?

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Final Thoughts about SDM

1. Become conversant in SDM. Understand it well enough to explain it to your family members, providers, etc.
2. Look for ANOD and encourage others to look too. Candidates for SDM deserve the chance to grow in confidence and power. Use one of our downloadable job aids or your knowledge to help someone decide to get started with SDM.
3. Realize that the topics and supporters an adult chooses today are only for today. Changes are expected as part of growth.
4. Keep copies of supporter agreements in case a provider needs written proof.
5. Train supporters using “the topic,” “the facts,” and “my feelings” discussion template. Then use the template for future decision-support conversations.

Heather Connors, PhD
Executive Director
The Center for Guardianship Excellence
heather@guardianshipcenter.org

The Center is a non-profit organization focused on protecting the rights of adults by educating and supporting caregivers and guardians.

✓ Research on Guardianship + Alternatives
✓ Training on Ethical Guardianship
✓ Downloadable Job Aids
✓ Tools for Assessment + Person-Centered Decision-Making
✓ Events for Learning + Networking

Please feel free to join our community.

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