



Empowering Adults Through Supported Decision Making--The Role of Families, Guardians, Caregivers, and Others in Supporting Individuals Receiving HCBS

2020 HCBS Technical Assistance Series
March 19, 2020 3:00-4:30 p.m. ET



Agenda

- **Welcome (ACL)**
- **Opening Remarks (CMS)**
- **Introductions of Guest Presenters and Presentations**
- **Q&A/Interactive Discussion**

WELCOME & OPENING REMARKS

Vicki Gottlich

**Director, Center for Policy & Evaluation
Administration for Community Living**

Michele MacKenzie

**Division of Long Term Services and Supports
Disabled and Elderly Health Programs Group
Center for Medicaid and CHIP Services
Centers for Medicare & Medicaid Services**

Decision Supports at all Stages

March 19, 2020

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https://www.americanbar.org/groups/law_aging/



AMERICAN **BAR** ASSOCIATION

Commission on
Law and Aging

The Commission on Law and Aging is a collaborative and interdisciplinary entity that works to strengthen the legal rights, autonomy, quality of life, and quality of care of aging persons.

The Commission accomplishes its work through research, policy development, advocacy, education, training, and through assistance to lawyers, bar associations, and other groups working on issues of aging.



Who May Need Decision Supports?

- People with intellectual/developmental disabilities
- Older adults experiencing cognitive decline, dementia
- Individuals with traumatic brain injuries
- People with psychiatric disabilities

Decision Supports Across the Age Spectrum

Young people with intellectual disabilities entering adulthood

- Live in the community
- Develop decision-making skills
- Lifetime of decision-making
- Network of family and friends to provide support (?)
- Aging parents

Older adults with age-related cognitive decline, dementia

- Experienced lifetime of decision-making
- Concerns about physical health and wellbeing
- Network diminishes due to advancing age
- Adult children

Decision Supports Principles

- Person centered and person directed – values, priorities and wishes of the individual drive the decision-making process.
- Supporter's role: communicate, explain risks and benefits of a decision, respect person's choices and preferences, assist as needed.
- Individualized: circumstances, preferences, abilities, resources, life experiences, culture, and stage of life.
- Autonomy and self-determination.
- Substitute decision-maker: learn of and honor the person's values, goals, priorities, and wishes to the greatest extent feasible.

Decision Supports for Financial Matters

- Representative Payees
- Daily or regular money management
- Financial power of attorney
- Trusts
- Joint ownerships
- Protective Arrangements

Decision Supports for Healthcare Matters

- Shared decision making with physician and medical treatment team
- Advance directive/living will
- Using technology to manage healthcare: e.g. diabetes, remote access to health information, diet choices
- Healthcare power of attorney
- Substitute decisionmaker laws

Supported Decision Making

Supports and services that help an adult with a disability make his or her own decisions, by using friends, family members, professionals, and other people he or she trusts: to help understand the issues and choices; ask questions; receive explanations in language he or she understands, and communicate his or her own decisions to others (Dinerstein, 2012; Blanck and Martinis, 2015).

Supported Decision-Making in State Law

Supported Decision-Making Agreement Laws

2015: Texas

2016: Delaware (2016)

2018: Alaska, District of Columbia, Wisconsin

2019: Indiana, North Dakota, Nevada, Rhode Island

2020: Massachusetts, Kentucky (submitted for adoption in state legislature)

Supported Decision-Making as an Alternative to Guardianship

- UGCOPAA, Maine, Washington, Missouri, New Mexico

Guardianship

- Individual (or agency) appointed by **court** (probate, general jurisdiction) with power and duty to make personal and/or financial decisions **on behalf of another person** whom court determines cannot make some or all decisions.
- Pathways to guardianships: school, nursing facility, hospital, family dispute, abuse, neglect, exploitation.

Guardianship and Self-Determination

Guardian shall (when possible) support and encourage the person to exercise individual rights, maximize self reliance and independence, participate in decision-making, lead the planning process.

NGA Standard of Practice #9 and Uniform Guardianship, Conservatorship, and Other Protective Arrangements Act Sec. 313(b).

Guardian's Authority

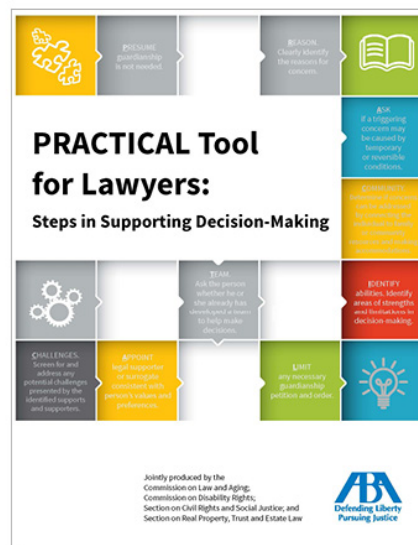
- Makes most decisions on behalf of the person (standards vary by state as to substituted judgment, best interests, and involving the person in decision-making).
- Typical guardian decisions include: financial, healthcare, living arrangements, relationships, visitation, education, legal representation.

Best Practices for Guardian Decision-Making

- A. Ask the person what she or he wants.
- B. If person has difficulty expressing what he or she wants, do everything possible to help the person express goals, needs, and preferences.
- C. Only when the person, with assistance, cannot express his or her goals and preferences, shall the guardian seek input from others familiar with the person to determine what the individual should have wanted.
- D. Best interests (last resort).

NGA Standard of Practice #7

See also: Uniform Guardianship, Conservatorship, and other Protective Arrangements Act (UGCOPAA); National Probate Court Standards, state guardianship laws.



Resources

Empowering Adults Through Supported Decision-Making March 19, 2020

**Molly Burgdorf, Director of Rights Policy
The Arc of the United States**

The Arc

- 600+ State and Local Chapters
- Our Mission: promote and protect the rights of people with intellectual and developmental disabilities and actively support their full inclusion and participation in the community throughout their lifetimes.

Developmental Disabilities and Bill of Rights Act

“Disability is a natural part of the human experience that does not diminish the right of individuals with developmental disabilities to live independently [and] to exert control and choice over their own lives...”

Autonomy, Decision-Making Supports, and Guardianship (1 of 4)

- All people with I/DD have the right to recognition as persons before the law and to enjoy legal capacity on an equal basis with individuals who do not have disabilities in all aspects of life.
- The personal autonomy, liberty, freedom, and dignity of each individual with I/DD must be respected and supported.
- Each individual with I/DD should receive the preparation, opportunities, and decision-making supports to develop as a decision-maker over the course of his or her lifetime.

Autonomy, Decision-Making Supports, and Guardianship (2 of 4)

- Less restrictive means of decision-making supports (e.g., health-care proxies, advance directives, supported decision-making, powers of attorney, notarized statements, representation agreements, etc.) should be tried and found to be ineffective in ensuring the individual's decision-making capacity before use of guardianship as an option is considered.

Autonomy, Decision-Making Supports, and Guardianship (3 of 4)

- The primary goals in assisting individuals with I/DD should be to assure and provide supports for their personal autonomy and ensure equality of opportunity, full participation, independent living, and economic self-sufficiency.
- All people with I/DD can participate in their own affairs with supports, assistance, and guidance from others, such as family and friends. People with I/DD should be aware of and have access to decision-making supports for their preferred alternatives.
- Information and training about less restrictive alternatives to guardianship should be available to people with I/DD, their family members, attorneys, judges, and other professionals.

Autonomy, Decision-Making Supports, and Guardianship (4 of 4)

- If the use of a guardianship becomes necessary, it should be limited to the fewest restrictions necessary for the shortest amount of time and tailored to the individual's specific capacities and needs.
- Strict monitoring must be in place to promote and protect the autonomy, liberty, freedom, dignity, and preferences of each individual even when placed under guardianship.
- Regardless of their guardianship status, all individuals with I/DD should be afforded opportunities to participate to the maximum extent possible in making and executing decisions about themselves. Guardians should engage individuals in the decision-making process, ensuring that their preferences and desires are known, considered, and achieved to the fullest extent possible.

Self-Determination

- People with I/DD have the same right to self-determination as all people and are entitled to the freedom, authority, and supports to exercise control over their lives. People with I/DD must understand that they can direct and influence circumstances that are important to them.
- Families, friends, and other allies should understand, recognize, and promote the rights and responsibilities of self-determination **and respect the limitations on their own authority.**
- To this end, people with I/DD must be able to lead in decision-making and problem-solving about all aspects of their lives and have the supports they want to make decisions; advocate for themselves with the assurance that their desires, interests, and preferences will be respected and honored; and take risks to achieve the lives they desire.

Housing

- People with I/DD must have freedom, authority, and support to exercise control over their housing, including choice of where and with whom they live, privacy within their homes, access to flexible supports and services when and where they choose, choice in their daily routines and activities, freedom to come and go as they please, and housing that reflects their personal preferences and styles.
- To ensure that people with I/DD can make informed decisions about where and with whom they live, they and their families must be given understandable information about the benefits of living in the community, have the chance to visit or have other experiences in community settings, have opportunities to meet other people with disabilities who are living in the community, and have any questions or concerns addressed.

Housing, cont.

- Adults with I/DD should receive the supports they need to transition out of the family home when they wish to do so.
- Public policy should promote small, typical living situations for people with I/DD. Information about innovative housing models that promote independence should be widely disseminated.
- Housing for people with disabilities should be scattered within typical neighborhoods and communities, and should reflect the natural proportion of people with disabilities in the general population.

Public Policy Agenda

Recognize and respect supported decision-making agreements and state legislation fostering and respecting the use of supported decision-making and other protective proceedings as less restrictive alternatives to full guardianship and/or conservatorship.

Center for Future Planning

Resources tailored to Self-Advocates and Families

- A Letter for My Doctors - to help more people with disabilities make their own decisions about their health.
- Plain language document: “Decision-making”
 - Everybody makes big and little decisions about their life. We sometimes need or want help to make these decisions.
 - Many people get advice from people to make decisions. Some people may receive other help or support to make a decision.
 - We find people to give us the help we need to make these decisions. We call this supported decision-making.

Center for Future Planning, cont.

['There's No Place Like Home: A National Study on IDD Housing,'](#)

The Arc and The Council on Quality and Leadership (CQL)

The research found that:

- Most people with I/DD and their families said that they had very little choice in where they live because there were not many home options that would accept a person with I/DD.
- Family members often decided where the person with I/DD would live, but people with I/DD wanted to be involved in this decision.
- People with I/DD want to contribute to the choices that impact their lives, such as where they live, who they live with, and how they spend their time.
- People with I/DD want opportunities to learn new skills, participate in tasks such as cleaning, cooking, and administering their own medication, and the chance to interact with friends and romantic partners.

Chapters (1 of 3)

The Arc of California
**Supported Decision-Making Bootcamp
Training Videos and Materials**

<https://thearcca.org/info-resources/supported-decision-making/>

The Arc of Indiana
Supported Decision-Making

<https://www.arcind.org/future-planning/supported-decision-making/>

Guardianship & Alternatives to Guardianship

<https://www.arcind.org/future-planning/guardianship/>

Chapters (2 of 3)

The Arc of Mississippi

Supported Decision-Making

<https://www.arcms.org/supported-decision-making>

The Arc of Texas

Alternatives to Guardianship

<https://www.thearcoftexas.org/alternatives-to-guardianship/>

The Arc Wisconsin

Learn about Supported Decision-Making in Wisconsin

<https://arcwi.org/2018/04/13/supported-decision-making/>

Chapters (3 of 3)

The Arc of the Capital Area (Austin, Texas)

Supporting Independence

<https://www.arcaustin.org/supported-decision-making/>

The Arc Westchester (New York)

Guardianship and Supported Decision Making

<https://arcwestchester.org/services/guardianship-supported/>

Resources

Center for Future Planning

<https://futureplanning.thearc.org/>

A Letter for My Doctors

<https://thearc.org/wp-content/uploads/forchapters/Making-My-Own-Health-Care-Decisions--A-Letter-for-to-My-Doctors.pdf>

Decision-making

<https://thearc.org/resource/decision-making/>

Resources, cont.

There's No Place Like Home 2019 Housing Study

<https://futureplanning.thearc.org/pages/learn/where-to-start/deciding-where-to-live/housing>

The Arc's **Position Statements**

<https://thearc.org/position-statements/>

The Arc's **Public Policy Agenda** for the 116th Congress

https://thearc.org/wp-content/uploads/2019/08/18-122-Public-Policy-Agenda-booklet_DIGITAL-002-1.pdf

Questions?

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Center for Public Representation

Supported Decision-Making and the HCBS Settings Rule

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HCBS Settings Rule

- In March 2014, the Centers for Medicare & Medicaid Services (CMS) issued the Medicaid Home and Community Based Services (HCBS) Settings Rule.
- The HCBS Settings Rule ensures that all people receiving community services have the benefits of community living, including:
 - access to the broader community,
 - control over their daily lives, and
 - choices about services and who provides them.
- Visit <https://hcbsadvocacy.org> for more resources on the Rule

Supported Decision-Making can be used to realize the goals of the HCBS Settings Rule

- Focus of the HCBS Settings Rule is on the individual's experience. The rule requires that HCBS settings must support an individual's self-determination and independence in making life choices.
- Supported Decision-Making (SDM) can be an essential tool to help translate the Settings Rule into a reality for people:
 - SDM is itself a way for people to identify their wishes and make decisions for themselves.
- SDM is also critical to Person-Centered Planning (PCP), an essential part of the HCBS Settings Rule

Person-Centered Planning in HCBS Settings Rule

- HCBS Settings Rule contains requirements on person centered planning.
 - planning services around the person's preferences, interests and goals.
- SDM is key to making this a reality because:
 - SDM can be used to determine what an individual's preferences and goals are.
 - SDM empowers people to make their own choices.
- Note that SDM is not the same as PCP

SDM: how does it work?

- SDM is structured and there is a process to it, yet it is also flexible. It takes many different forms.
- **Generally SDM works as follows:**
 - Introduction of SDM concept to decision-maker
 - Decision-maker selects supporters
 - Trust and commitment
 - Formal SDM agreement developed
 - Identify areas of support for each supporter
 - Supporters certify commitment to process
 - Decisions made using SDM model
 - Information provided in a way that is personalized to the individual to allow decision-maker to make own choices
 - Assistance with communicating decisions

Exercising self-determination and making choices: role of staff

- Support staff is in a unique position to recognize the skills, talents, and values of the individuals with disabilities they serve
- Direct care staff may have insight and inside knowledge about key issues: particularly the person's likes, dislikes, will, preferences – the things that are important to decision making and the interpretation of will and preference.
- **For someone using formal SDM**
 - Support staff may be a formal SDM supporter.
 - Support staff may assist with setting up SDM agreement but not serve as a supporter.
- **Even where more formal constructs of SDM are not adopted**, the tools and methods that make SDM work are available in every day interactions between support staff and the people with disabilities who they work with.

Tools for direct care staff to promote SDM principles

To lay the groundwork for SDM, staff should:

- Always include the individual in the conversation; ask for his/her opinion, even if you are talking about routine day-to-day matters, such as clothing (what shirt do you want to wear today? the green one? the striped one?); breakfast selections (oatmeal or eggs?); choice of activities (watch the news, converse with colleagues, etc.).
- Encourage and support people to make their own decisions.
- **Respect those decisions.**

How to incorporate training about decision-making in care plans

- Training in decision making should be incorporated in treatment and services plans like Individual Service Plans (ISPs)
- The plan could include language and provisions that all staff will, for example:
 - Always interact with individuals with the belief that all people with necessary supports can make their own decisions, regardless of the extent of disability.
 - Reject that paradigm only when there is conclusive proof that even with support, it is impossible.
 - When there is such proof, design a plan to teach decision-making.

How to help design a decision-making plan

- Helping to identify the person's preferences, health status, strengths, values, developmental needs, strengths, interests, talents, service needs, including his or her:
 - **Interests:** like hobbies and activities that energize people mentally, physically, emotionally
 - **Talents:** like natural abilities/gifts (music, skills, writing, reading)
 - **Values:** those core beliefs that are important to people
 - **Environmental preferences:** where person feels comfortable, motivated
 - **Dreams, goals:** can be reflected in activities such as employment, where a person lives and with whom, relationships

Person-Centered Planning and SDM

- The decision-making plan should advance self-advocacy and self-determination through person-centered planning.
 - *Encouraging self-advocacy*: speaking up for oneself
 - *Encourage self-determination*: the right to be provided opportunities, supports and authority to make choices and decisions about one's life
 - Identify and focus on preferences, interests and goals
 - Identify and explore opportunities to make meaningful choices to realize goals
 - Teach individuals to assume responsibility for their choices

How does SDM facilitate choices envisioned by the Settings Rule?

- Example: Decision-maker used SDM process to consider whether he wanted to live independently. Decided on trial basis, and then moved back home. Later, in consult with supporters, he decided he needed a different set of supports and chose to live in a different setting. Now has selected a roommate and plans to move in together.

How does SDM facilitate choices envisioned by the Settings Rule? (cont.)

- Example: Decision-maker changed shared living homes and providers. She asked that former shared living provider be removed as a decision supporter and replaced with current provider.

Conflicts of Interest

- Medicaid includes requirements to prevent and mitigate conflicts of interest under 1915(c), 1915(i), and 1915(k) HCBS authorities.
 - An entity independent of the provider must be the one to facilitate the service planning and PCP so the person can have a real choice about what services they want and who provides them.
- Similarly, conflicts arise with SDM when direct care providers are involved with SDM (helping create SDM agreements/arrangements or acting as supporters)

Tools for addressing potential/actual conflicts with SDM and direct care providers

- For providers acting as supporters:
 - Neutral third party (family member, friend, attorney) should discuss decision to have provider as a supporter with the decision-maker and describe potential conflicts so decision-maker has necessary information
 - Agreement can carve out support around certain decisions (i.e. paid staff does not assist with decisions about where to live or where to get services)
 - Best practice is that there is at least one supporter who is not paid staff (not always possible)

**For more information SDM
and CPR's SDM pilots:**

www.supporteddecisions.org



Questions?

Feedback

Please complete a brief survey to help ACL monitor the quality and effectiveness of our presentations.

Please use the survey link: <https://www.surveymonkey.com/r/RVL3BCX>

WE WELCOME YOUR FEEDBACK!