



# Supported Decision-Making



**COLORADO**  
Department of Health Care  
Policy & Financing



# Our Mission:

Improving health care equity, access and outcomes for the people we serve while saving Coloradans money on health care and driving value for Colorado.



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Policy & Financing

# About Us

The Department of Health Care Policy and Financing administers Health First Colorado (Colorado's Medicaid program), Child Health Plan *Plus* (CHP+) and other health care programs for Coloradans who qualify.



# Supported Decision-Making (SDM)

- A model to support people with disabilities in making and communicating their own decisions about their lives
- Retains the individual as the primary decision maker
- Recognizes that the individual may need some assistance
- Emphasizes the importance of all people deciding what their lives should look like
- Based on self-determination practices



# Supported Decision-Making Principles

## The individual

- Directs the plan for their own life
- Decides what is most important to them
- Sets goals
- Works to achieve those goals so they can live the most fulfilling life possible
- Acknowledges need for support while preserving autonomy and legal decision-making authority

# Decision-Making is a learned skill

- Manages and avoids risks
- Preserves dignity of risk
- We all use supported decision-making

“Physical or mental disabilities in no way diminish a person's right to fully participate in all aspects of society.”

The Americans with Disabilities Act, 42



**2006 - 2008: Convention on the Rights of Persons with Disabilities, Article 12 sets out that people with disabilities:**  
**“Have the right to recognition everywhere as persons before the law”**  
**and**  
**“Enjoy legal capacity on an equal basis with others in all aspects of life.”**

# Self-Determination Enhances Individual Control

- Improves health
- Promotes employment
- Expands community integration
- Increases capacity to identify and resist abuse

(Khemka, Hickson, & Reynolds, 2005; Wehmeyer, Kelchner, & Reynolds, 1996; Wehmeyer & Schwartz, 1998. Deci. “Intrinsic Motivation,” 208, 1975)



# Outcomes of Self-Determination Being Denied



- Helplessness
- Hopelessness
- Self-criticism
- Low self-esteem
- Passivity
- Feelings of inadequacy and incompetency
- Decreased functioning

# What Does Self-Determination Mean to Me?

- Having more say about my life
- Having people listen to me and what my needs are
- Learning by acting on my choices
- Being able to do something when I am frustrated
- Making changes in my life when I want to

*Consumer-Direction at a Glance, Access to Independence, 1999*

# SDM in Service Planning

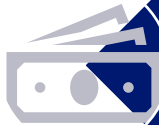
- SDM is an integral component of person-centered planning
- Informed choice guides decisions
- Outcomes based on individual wishes
- Support can be provided by supportive team



# Using SDM in Personal Life



Housing



Finances



Health Care

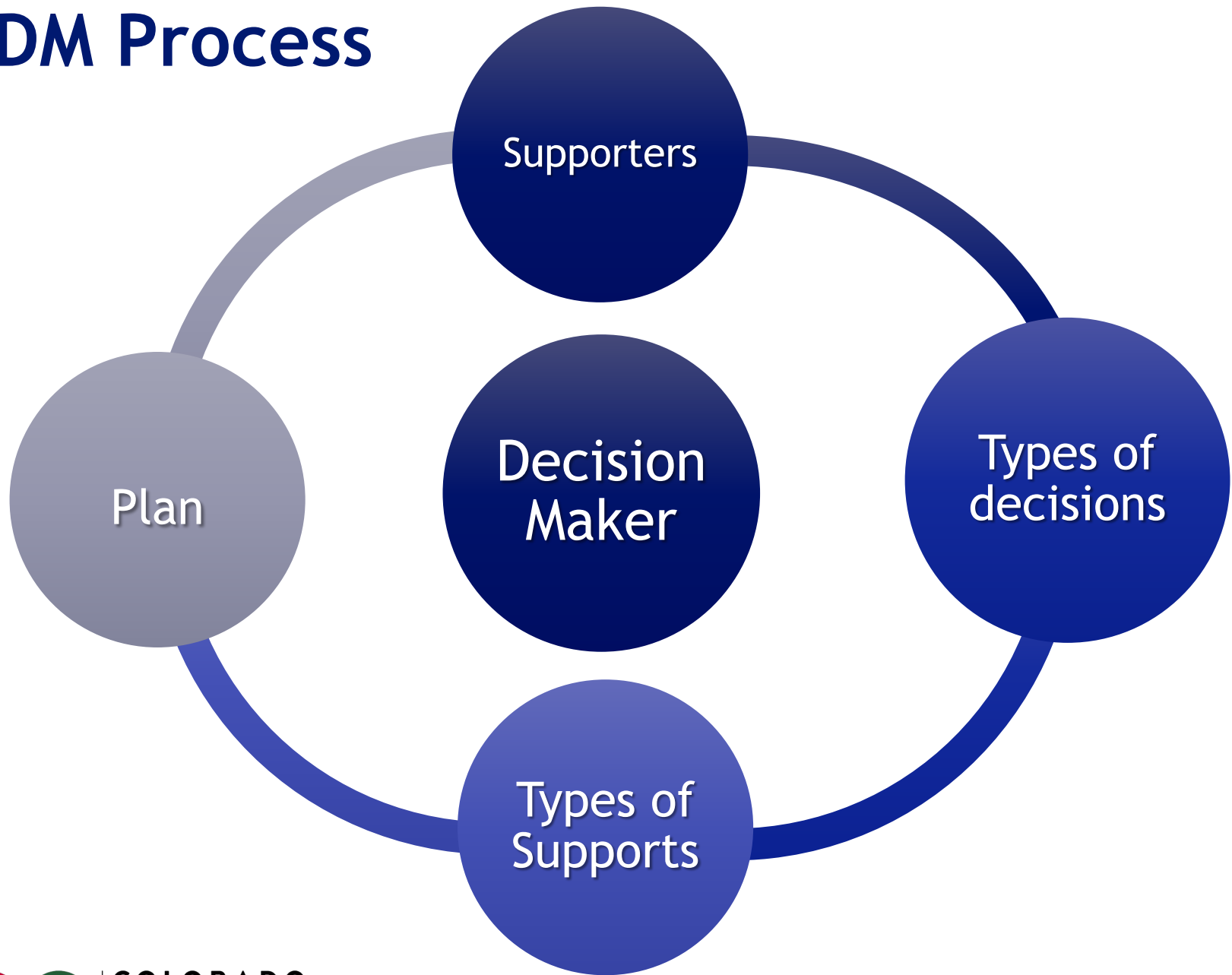


Leisure Time



Education, Employment

# SDM Process



# Types of SDM Supports

- Assistance to gather and understand information
- Discussing the consequences of different decisions
- Communicating decisions to others
- Ensuring decisions are carried out
- Promoting increased independence for making decisions

# SDM Strengthens Personal Capacities

- Decision-making skills
- Understanding rights and responsibilities
- Facilitating planning meetings
- Communication and advocacy skills
- Acquiring technology skills
- Asking for help
- Creating opportunities to be in community
- Problem-solving
- Setting and meeting goals



# Quote

**A lack of opportunity to make decisions can prevent people from developing capacity or further decrease capacity  
(Salzman, 2010)**

# The Role of Supporters

Supporters should be individuals the person knows and trusts to provide the type of support they want for the types of decisions they want to make.

## Individuals:

- Assign certain supporters to certain types of decisions and not others
- Have as many supporters as they want
- Fire their supporters at any time; supporters have the option of quitting



# Building a Supportive Relationship

- Individual's wishes are paramount
- Least restrictive form of support is provided
- Growth and maturity opportunities are provided
- Respect and boundaries are discussed
- Differences of opinion and world view are acknowledged
- Change is expected and supported
- The present and future are the focus
- Discussion about how to disagree occurs



# Initial Assessment to Determine Level of Support

- Identify areas of strengths and limitations in decision-making
- Discuss each area of the individual's life
- Determine how supported decision-making is currently being used
- Identify any areas of concern
- Determine if concerns are the result of or related to temporary or reversible conditions

# Initial Assessment to Determine Level of Support

- Determine which areas the person may need support in
- Ask, “What would it take?” to enable the person to make the needed decision(s) or address the presenting concern
- Screen for and address any potential challenges presented by the identified support
- Determine next steps to helping the person gain capacity or a support network



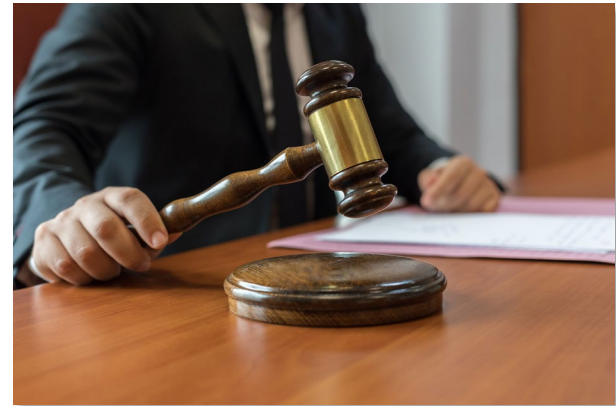
# Continuum of Decision-Making Supports

- Least restrictive supports
- Assistive technology
- Release of information
- Representative payee program
- Trust
- Power of attorney
- Guardianship



# Guardianship

- Approved and appointed by the court
- Has legal authority to make decisions on behalf of the individual
- Supervised by the court



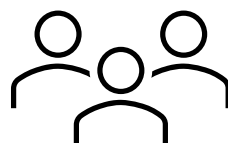
# Guardian Guidelines

- Required to provide an annual report on the status of the protected person
- Responsible for monitoring the care of the person with disabilities
- Must attempt to ensure that the person is receiving proper care, housing, and supervision
- Responsible for decisions regarding most medical care, education, vocational planning, and end-of-life decisions

# Guardianship Decision

Often, guardianship is the family's first choice rather than the last resort. However, guardianship, by definition, decreases self-determination and can lead to a “significant negative impact on. . . physical and mental health, longevity, ability to function, and reports of subjective well-being.”

(Wright, 2010)



# Guardianship Decision

“Supported decision-making should be considered for the person before guardianship, and the supported decision-making process should be incorporated as a part of the guardianship if guardianship is necessary.”

National Guardianship Association. "Position Statement on Guardianship, Surrogate Decision-Making, and Supported Decision-Making " (2015)



# Professional Level SDM Barriers

- Perception that SDM may create challenges for providers
- Response methods to crisis situations viewed as inadequate
- Lack of system support
- Additional time required for shared decision-making
- Assumption that people with disabilities are unable to make decisions
- Need for some support is interpreted as lack of ability to make any decisions

# Consequences of “Presuming Incompetence”

- Inadequate focus on building skills that the person already has
- Doctors may speak directly to support persons instead of including persons in conversations about their own health care
- Doctors may refuse treatment to persons who don't have a guardian
- Belief that people with disabilities can't provide “informed consent” to own care
- Outcomes of treatment don't meet person's goals



# Challenges at the Individual Level - Why Is Self-Determination So Hard?

- Trying to make good choices
- Realizing what funds you have and what things cost
- Being afraid of how others will react to your decisions
- Having the courage to say what you want
- Knowing when to ask for help
- Finding people to help you

From *Self-Determination at a Glance*, Access to Independence, Inc., 1999.





# Questions?



# Contact Information

**Nora Brahe**

Transitions Administrator

[Nora.Brahe@state.co.us](mailto:Nora.Brahe@state.co.us)



# Thank you!

