

The Ethics of Supported Decision Making

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Webinar Agenda

Week One

1. Define Supported Decision-Making and the basic underlying values.
2. Provide an understanding of the difference between supported decision-making and legal guardianship.

Week Two

3. Ethical consideration about the use of the supported decision-making agreement and how to interact with others who may be providing this support.

Webinar Agenda

Week One

1. Guardianship
2. Capacity and Competence
3. Supported Decision-Making
4. Self-Determination
5. Supported Decision-Making Agreements
6. Decision Making Continuum

Legal Concepts

- Guardianship
- Capacity
- Competency
- Supported Decision-Making

What Is Guardianship?

Guardianship is a legal mechanism whereby a substitute decision-maker (a person, family member, institution, or agency) is appointed by the Probate Court to make decisions for and act on behalf of a person who has been judicially determined to lack the mental capacity to manage their person, estate, or both.

Capacity & Competence

- CAPACITY

Ability to understand the nature and consequences of a decision and to reach and communicate an informed decision on the matter.

- COMPETENCE

Mental ability to understand problems and make decisions.

Capacity

Texas law presumes that adults have decision-making capacity – this applies to everyone, including people with disabilities.

A person can only be “adjudicated” to lack capacity by a court.

RELATED CONCEPTS THAT ARE *NOT THE SAME*

- Involuntary commitment.
- Lack of competence to proceed to trial.
- Determination by a physician that the person lacks capacity for informed consent to medical treatment.

THESE MAY LIMIT A PERSON’S LEGAL DECISION-MAKING AUTHORITY BUT ONLY IN DISCREET AREAS.

Remember

- Capacity and Competence are not “Black and White.”
- A person may be able to make some decisions and not others.
- A person may make decisions at some times, and not others.

Legal Determination

In a Guardianship proceeding the Court determines if a person is “incapacitated.”

A court decides if, due to a physical or mental condition, an individual is substantially unable to:

- manage their financial affairs,
- care for their physical health, or
- provide food, clothing, or shelter for themselves.

Under a guardianship, someone is appointed to make decisions on behalf of the incapacitated person, referred to as the “ward.”

The Guardianship Process

- Guardianship is a legal process and decisions are made by a judge.
- An individual seeking to become guardian is called an “applicant,” and must be represented by an attorney to obtain guardianship.
- The applicant files an application for guardianship, including a physician’s certificate of medical examination (CME).
- An attorney ad litem will be appointed to represent the person with a disability’s desires.
- A guardian ad litem may also be appointed to advocate for the best interest of the person with a disability.
- The judge has the ultimate authority to decide whether or not someone needs a guardian, and if the guardianship should be full or limited.
- The judge also has the final say in who is appointed to be guardian.

What Is Supported Decision Making?

A process of **supporting and accommodating** an adult with a disability to enable the adult to make life decisions, including decisions related to where the adult wants to live, the services, supports, and medical care the adult wants to receive, whom the adult wants to live with, and where the adult wants to work, **without impeding the self-determination of the adult.**

Tex. Est. Code § 1357.002(3)

What Is Supported Decision Making?

4 Primary Characteristics (Salzman, 2010):

1. Individual retains legal decision making authority;
2. Relationship is freely entered into & can be terminated at will;
3. Individuals actively participates in decision making; and
4. Decisions made with support are generally legally enforceable.

Three Core Elements of Supported Decision-Making

1. It recognizes the person's right to make decision on an equal basis with others;
2. It recognizes that people can create a decision-making process that does not result in the removal of decision-making rights;
3. It recognizes that people will often need assistance in decision-making through various means.

(Dinerstein, 2012)

What is Self-Determination?

- Self-determination means making your own choices, learning to effectively solve problems, and taking control of and responsibility for one's life.
- Practicing self-determination also means that one experiences the consequences of making choices.

(National Parent Center on Transition and Employment)

The Benefits of Self-Determination

People with greater self-determination have a higher quality of life:

- Participate and contribute to community individual lives in
- Independent living within the community
- Financial independence
- More ownership in service plan and goal setting
- Healthier
- Better able to recognize and resist abuse
- “Making choices based on one’s preferences has been identified as one of the essential aspects of independent functioning in society”.

(Khemka, Hickson and Reynolds, 2005; O’Connor and Vallerand, 1994; Wehmeyer and Schwartz, 1998).

Why is Self-Determination Important?

When denied self-determination, people:

- “[F]eel helpless, hopeless, and self-critical” (Deci, 1975).
- Experience “low self-esteem, passivity, and feelings of inadequacy and incompetency,” decreasing their ability to function (Winick, 1995).
- When a person experiences the above mentioned emotions and mental states, there is a strong likelihood of a person’s physical (and mental) health to be projected into a state of decline.

Who Can Enter into a Supported Decision-Making Agreement?

- Any individual over 18 who has a physical or mental impairment that substantially limits one or more major life activity. *Tex. Est. Code § 1357.002(1) & (2)*
- A level of capacity a person must have in order to enter a supported decision-making agreement is not defined, but a person must have sufficient capacity to agree to the supporter assisting him or her in making particular decisions.

Who Can Be the Supporter? Any Adult

- The law does not place any restrictions on who may become a supporter.
- The person who needs the support decides on someone they trust.
- Typically, the supporter may be a family member, relative or friend.

Tex. Est. Code § 1357.002(5)

Is it Voluntary or Court Ordered?

- An adult with a disability decides they need supports with decisions.
- The person with a disability and supporter enter into the agreement voluntarily, just like a power of attorney.
- It is informal and does not require going to court.

Tex. Est. Code § 1357.001

How is it Different from Power of Attorney?

- A supported decision-making agreement is distinct from a power of attorney because it does not allow a person to make the decisions for a person.
- In a supported decision-making agreement, **the person with a disability retains the right to make decisions.**
- Chief Justice Hecht described supported decision-making agreements as “Power of Attorney Lite.”

Tex. Est. Code § 1357.054

What Can a Supporter Do?

A supporter may do any or all of the following:

1. Assist adult with a disability in understanding options, responsibilities and consequences of life decisions;
2. Assist adult with a disability in accessing, collecting and obtaining medical, psychological, financial, educational and treatment records;
3. Assist adult with a disability in understanding information in (2); and
4. Assist adult with a disability in communicating his or her decision to appropriate persons.

Tex. Est. Code § 1357.051

When Does a Supported Decision-Making Agreement End?

A supported decision-making agreement ends:

1. When terminated by the adult with a disability or the supporter;
2. By the terms of the agreement;
3. If DFPS finds that adult with a disability has been abused, neglected or exploited by the supporter; or
4. The supporter is found criminally liable for the abuse, neglect, or exploitation of the adult with a disability.

Tex. Est. Code § 1357.053

What About Confidential Information?

- A supporter is only authorized to assist adult with a disability to access, collect, or obtain information.
- This includes protected health information under HIPAA and education records under FERPA.
- A supporter shall ensure that information is kept privileged and confidential and is not subject to unauthorized access, use, or disclosure.
- A supported decision-making agreement does not prevent an adult with a disability from seeking personal information on his or her own without the assistance of the supporter.

Tex. Est. Code § 1357.054

What are the Requirements for the Supported Decision-Making Agreement Form?

- The adult with a disability and the supporter must sign the agreement voluntarily in the presence of two witnesses over 14 *or* a notary public.
- There is a sample agreement in Texas Estates Code § 1357.056.
- A supported decision-making agreement may be in any form as long as it substantially complies with §1357.056(a).

Reliance Upon a Supported Decision-Making Agreement

- A person shall rely upon the original or a copy of the supported decision-making agreement.
- A person is not subject to criminal or civil liability or professional misconduct for an act or omission done in good faith and in reliance upon the supported decision-making agreement.

Tex. Est. Code § 1357.101

What If Someone Suspects Abuse or Exploitation?

If a person who receives or is aware of the supported decision-making agreement has cause to believe that an adult with a disability is being abused, neglected, or exploited by the supporter, the person shall report the allegation to DFPS.

Tex. Est. Code § 1357.102

Is a Supported Decision-Making Agreement Binding on a Third Party?

- That is unclear. There is disagreement over whether a supported decision-making agreement is binding on a third party.
- Regardless, the supporter is authorized to assist the person with a disability to understand and communicate what is needed to provide informed consent.

Can a Supported Decision-Making Agreement Be Used Along With Other Alternatives to Guardianships?

- Yes. A supported decision-making agreement can be used in conjunction with other alternatives to guardianships, such as a medical power of attorney or representative payee.
- This is consistent with the goal of supported decision-making as a way to promote the self-determination of persons with disabilities and avoid guardianships.

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“Judgment-Insight-Reasoning”

Varies across life-areas and is dependent upon:

- Types of decisions that need to be made.
- Type of disability.
- Past life experiences and history of the person making decisions.
- Person’s pattern of rational/irrational behavior and thinking.
- Socio-cultural differences in decision-making.
- Other relevant or additional factors.

Balancing Advocacy and Protection

- Guardianship and advocacy are both grounded in the doctrine of “least restrictive alternative” balancing client decision-making capacity with the professional advocate.
- Many rehabilitation and human service professionals are natural advocates.
- Providing services requires a balance of the ethical principles to facilitate services in a competent and ethical manner.
- Most rehabilitation and human service professionals truly believe that they are working in the best interests of their client - even those who lack the decision-making capacity.

Decision-Making Continuum

- **Best Interest**

- Focus on well-being, health and welfare
- Cost/benefit analysis
- “Reasonable person”

- **Substituted Judgment**

- Acting on a determination of what the individual would choose if they were able to make a choice.
- *Required* when an individual used to have capacity

- **Supported Decision-Making**

- Empowers individuals with disabilities by ensuring that they are the ultimate decision-makers but are provided support from one or more others, giving them the assistance they need to make decisions for themselves.

Potential of Supported Decision Making to Enhance Fundamental Freedoms

- Due process - Access to the courts
- To assign rights to others
- Right to an attorney
- Right to a proper education
- Free from abuse, neglect, and exploitation
- Right to remain as independent as possible in the least restrictive environment
- Be treated humanely, with dignity and respect.

Resources

Practice Guides for Promoting Self Determination:

Horner, R., Loman, S., Strickland-Cohen, K., Walker, H., & Vatland, C. (2010). *Promoting Self-Determination: A Practice Guide*. A National Gateway to Self-Determination.

Doren, B., Horner, R., Loman, S., Strickland-Cohen, K., Walker, H., & Vatland, C. (2011). *Promoting Self-Determination for Adults: A Practice Guide*. A National Gateway to Self-Determination.

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THANK YOU