

SUPPORTED DECISION-MAKING: A NEW ALTERNATIVE TO GUARDIANSHIP

WHY NOT GUARDIANSHIP?

What Does Guardianship Do?

- Requires a court order to establish and ongoing court oversight.
- Removes the person's freedom of choice, self-determination and independence.
- Removes some or all of a person's decision-making rights.
- Assigns decision-making to a third party (the guardian).

What Does Guardianship Do?

- Expensive – attorney fees and court costs; bond
- May be difficult to terminate or modify.
- Annual accounting and reports on the condition of the ward.

Why Families May Seek Guardianship

- Child reaches 18 years of age
- School or physician tells them it is necessary.
- Think it is necessary for school, health care or other decisions after age 18.
- Help their child handle money.
- Connect their child with adult services.
- May believe this is the only legal solution.

Important Things to Remember

- The law presumes all adults have the capacity for decision-making – this applies to everyone, including people with disabilities.
- Decision-making is a learned skill – people with disabilities need opportunity, experience and support to learn to make well informed decisions.
- There are other legal ways to assist people with decision-making that do not restrict, limit or remove individual rights.

SELF-DETERMINATION

What is Self-Determination?

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

(National Parent Center on Transition and Employment)

What Are The Benefits of Self-Determination

People with greater self determination are:

- Healthier
- More independent
- More well-adjusted
- Better able to recognize and resist abuse

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

Does the Research Support Self-Determination?

When denied self-determination, people:

- “[F]eel helpless, hopeless, and self-critical” (Deci, 1975, p. 208).
- Experience “low self-esteem, passivity, and feelings of inadequacy and incompetency,” decreasing their ability to function (Winick, 1995, p. 21).

WHAT IS SUPPORTED DECISION-MAKING?

Supported Decision-Making Pilot Project

Texas was the first state with a pilot program designed to try supported decision-making as an alternative to guardianship. Under a bill passed by the legislature in 2009, a pilot run by the Arc of San Angelo and created by DADS demonstrated how volunteers can support individuals with intellectual, developmental and other cognitive disabilities in making decisions about their own lives.

The three year pilot trained volunteers to assist in decision-making based on the principles of self-determination and matched them with individuals with disabilities with shared interests. It also successfully helped avoid several court-initiated guardianships.

“Justice for Jenny”

- The “Justice for Jenny” case was the first to order the use of supported decision-making instead of a full guardianship for a person with a disability.

“Justice for Jenny”

- Jenny Hatch, a 29 year-old woman with Down Syndrome, won the right to live and work where she wants instead of having all her decisions made for her by a guardian.
- Jenny’s parents filed for guardianship to take away her right to make decisions about where to live, what to do and whom to see.
- Her parents placed her in a group home, took away her cell phone and laptop and wouldn’t let her see her friends.
- Quality Trust for Individuals with Disabilities represented Jenny and showed the court that Jenny did not need a guardian because she had a history of making good decisions when given appropriate support.

“Justice for Jenny”

- That support, known as “supported decision-making” uses trusted friends, family members and professionals to help Jenny understand her situation and choices so she can make her own well informed decisions.
- Jenny won the right to make her own decisions using supported decision-making. She now lives and works where she wants and has the friends she chooses.

Underlying Principles Behind Supported Decision-Making

- While there is no “one-size-fits-all” model for supported decision-making, it generally occurs when people receive assistance from one or more trusted friends, family members, professionals or advocates to help them understand the situations they face and choices and options they have so they can make their own decisions.

Underlying Principles Behind Supported Decision-Making

- The right to make decisions through supported decision-making is based on the constitutional right of a person to make his or her own decisions.
- That right should not be dependent on the quality of any decision made.

Americans With Disabilities Act (ADA)

- This generation of people with disabilities is the first to grow up with rights and opportunities protected and promoted by the ADA.
- Over-reliance on guardianship can hinder or prevent inclusion, self-determination and community integration in violation of the ADA.

How Can Supported Decision-Making Help Persons with Disabilities?

- Understand information, issues, and choices;
- Focus attention in decision-making;
- Weigh options;
- Ensure that decisions are based on their own preferences; and
- Interpret and/or communicate decisions to other parties.

(Salzman, 2011)

THE LAW

Reforming Guardianship in Texas

As part of the Guardianship Reforms enacted in 2015, the 84th Legislature passed two bills establishing supported decision-making:

- 1) HB 39 – Alternatives to Guardianship; and
- 2) SB 1881 – Supported Decision-Making.

[Note: All references are to the Estates Code and not the Bill provisions.]

Significant Changes

- For the first time, the Texas legislature mandated that probate courts consider **alternatives to guardianships and supports and services** before a guardianship is created.

Supports and Services: Now Defined in Estates Code

“Supports and Services” –means available formal and informal resources and assistance that enable an individual to:

- 1) Meet the individual’s needs for food, clothing, or shelter;
- 2) Care for the individual’s physical or mental health;
- 3) Manage the individual’s financial affairs; or
- 4) Make personal decisions regarding residence, voting, operating a motor vehicle, and marriage.

Tex. Est. Code § 1002.031

Common Supports and Services

- 1) Supportive and Trusted Individuals, Family Members and Friends** – Support and assist with explaining potential benefits and risks when making decisions about everyday issues like money management, cooking, hygiene, health care, safety, and relationships.
- 2) Community-Based Medicaid Waiver Programs** – Assist with supports to ensure that medical and personal needs are addressed.
- 3) Case Management Services** – Coordinate services with goal of individual with disability being as self-sufficient as possible.
- 4) Person Centered Planning** – Process of planning with and supporting an individual that honors the individual's preferences, choices and abilities.
- 5) Free or Reduced Price Meals, Foods and Prescription Delivery**

Alternatives to Guardianship: Texas Estates Code

Alternatives to guardianship include:

- 1) Medical Power of Attorney;
- 2) Durable Power of Attorney;
- 3) Declaration for Mental Health Treatment;
- 4) Representative Payee;
- 5) Joint Bank Account;

Alternatives to Guardianship

- 6) Management Trust;
- 7) Special Needs Trust;
- 8) Designation of Guardian Before the Need Arises;
- 9) Alternate Forms of Decision-Making Based on Person-Centered Planning; and
- 10) Supported Decision Making Agreement.

Tex. Est. Code §§ 1002.0015 & 1357.001 et seq.

Supported Decision-Making as an Alternative to Guardianship

- Supported Decision Making Agreement was specifically identified as an alternative to guardianship by the Legislature.

Tex. Est. Code § 1002.0015(10)

The Supported Decision-Making Agreement Act – We're Number One!

Texas is the first state to authorize supported decision-making as a substitute for guardianship.

Tex. Est. Code § 1357.001 et seq.

What is Supported Decision-Making?

It is defined in statute as:

“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); 1357.003

Who Can Enter 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 decision.

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 selected by the person with a disability.

Tex. Est. Code § 1357.002(5)

Is this 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 a Power of Attorney?

- A supported decision-making agreement is distinct from a power of attorney because it does not allow someone else to make the decisions for a person.
- In a supported decision-making agreement, the person with a disability retains the right to make decisions.

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

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

Fiduciary Duty?

- A fiduciary relationship is when a person acts on behalf of another person by agreement to conduct business or manage their affairs.
- A fiduciary duty generally includes the duty to act in good faith and with loyalty and to avoid conflicts of interest.
- By law, a fiduciary duty exists between a guardian and a ward in a guardianship and between a principal and an agent under a power of attorney.

Does A Supporter Have a Fiduciary Duty?

- A supported decision-making agreement does not create a statutory fiduciary relationship.
- However, a supported decision-making agreement creates a confidential relationship between the supporter and a person with a disability because the person with a disability trusts and relies upon the supporter. Therefore, a supporter could be held liable for the breach of the confidential relationship.

Enax v. Noack, 12 S.W.3d 609 (Tex. App.—Houston [1st Dist.] 2000, no writ)

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 the Department of Family and Protective Services 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 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).
- A simplified supported decision-making agreement form will be available on DRTx's website at www.dr.tx.org.

What Are Liability Risks?

- A person may 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 abuse, neglect or exploitation to Department of Family and Protective Services.

Tex. Est. Code § 1357.102

Does a Supported Decision-Making Agreement Guarantee Informed Consent?

- No, a person with a disability must still demonstrate that he or she has the capacity to make a particular decision.
- The supporter can assist the person with a disability to understand and communicate what is needed to provide informed consent.
- The supporter may be able to help the person with a disability overcome the paternalist bias that people with disabilities lack the capacity to make their own decision.

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 to promote the self-determination of persons with disabilities and to avoid guardianships.

Supported Decision-Making is Hard Work

- Supporter is not the decider with no contact with person with a disability.
- Requires building and maintaining a trusting relationship between person with a disability and the supporter.
- This requires time, commitment and open communication.

Resources

- National Resource Center for Supported Decision-Making:
www.supporteddecisionmaking.org
- Disability Rights Texas: www.DRTx.org

Need Assistance in Getting a Supported Decision-Making Agreement

- Contact Disability Rights Texas at 512-454-4816 or online intake at www.dr.tx.org.

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THANK YOU