

SUPPORTED DECISION-MAKING: A NEW ALTERNATIVE TO GUARDIANSHIP

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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 in 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 on decision-making;
- Weigh options;
- Ensure that decisions are based on their own preferences; and
- Interpret and/or communicate decisions to other parties.

(Salzman, 2011)

GUARDIANSHIP

Decides Where I Live

Decides if I Work and Where I Work

Makes My Medical Decisions

Decides If I Can Visit Family and Friends



Guardian

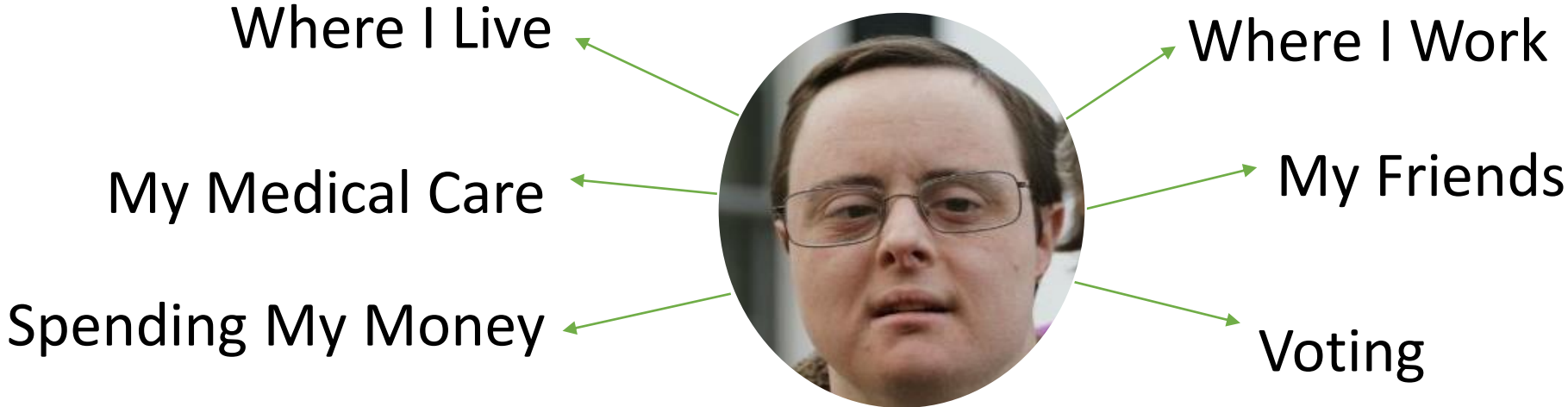
Controls My Money

May Mean I Never Get to Vote

Makes The Decisions About My Life



SUPPORTED DECISION-MAKING



**I Make My Own
Decisions with Help of
My Supporter**



THE LAW

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)*
- The level of capacity a person must have in order to enter a supported decision-making agreement is not defined. However, the person must understand the nature and consequences of his or her entering a supported decision-making agreement when the supported decision-making agreement is signed. *In the Estate of Vackar*, 345 S.W.3d 588, 597-598 (Tex. App.-San Antonio 2011, no pet.)

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 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.

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 supporter has a fiduciary duty to the adult with a disability.
- A supported decision making-agreement creates a relationship of trust and confidence between the adult with a disability and the supporter and does not undermine the decision-making authority of the adult with a disability.

Tex. Est. Code § 1357.052(b) & (c)

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.

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 abuse, neglect or exploitation to the Department of Family and Protective Services.

Tex. Est. Code § 1357.102

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

- Not sure, there is disagreement over whether a supported decision-making agreement is binding on a third party.
- Regardless 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 bias that people with disabilities lack the capacity to make their own decisions.

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 durable 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.

ETHICAL CONSIDERATIONS

Does a Person with a Disability Have the Capacity to Enter Into a Supported Decision-Making Agreement?

- Tex. Disciplinary R. Prof. Conduct 1.02(a) assumes that the lawyer is legally authorized to represent the client.
- Comment 12 of Tex. Disciplinary R. Prof. Conduct 1.02 provides:
 - “...The usual attorney-client relationship is established and maintained by consenting adults who possess the legal capacity to agree to the relationship. ...Unless the lawyer is legally authorized to act for a person under a disability, an attorney-client relationship does not exist for the purpose of this rule.”
- Tex. Disciplinary R. Prof. Conduct 1.02(g) provides:
 - “A lawyer shall take reasonable action to secure the appointment of a guardian or other legal representative, or seek other protective orders with respect to client whenever the lawyer reasonably believes that the client lacks legal competence and that such action should be taken to protect the client.”

WHO IS THE CLIENT?

The Person with a Disability

Or

The Supporter

Can an Attorney Represent Both the Person with a Disability and the Supporter?

- Loyalty is an essential element in the lawyer's relationship to a client. Tex. Disciplinary R. Prof. Conduct 1.06 cmt. 1.
- Even though there are no ethics opinions on this issue, Tex. Disciplinary R. Prof. Conduct 1.06 cmt. 15 warns that conflicts of interest in non-litigation situations may sometimes be difficult to assess. Conflicts may arise in estate planning and estate administration even in matters as simple as preparing a will for spouses.

Joint Representation?

- If an attorney decides to represent the person with a disability and the supporter in entering a supported decision-making agreement, the attorney must comply with Tex. Disciplinary R. Prof. Conduct 1.06(b) & (c).
- Joint representation is only permissible if:
 1. The lawyer reasonably believes the representation of each client will not be materially affected; and
 2. Each affected or potentially affected client consents to such representation after full disclosure of the existence, nature, implications, and possible adverse consequences of the common representation and the advantages involved, if any. Tex. Disciplinary R. Prof. Conduct 1.06(c).

Joint Representation?

- Comment 8 of Tex. Disciplinary R. Prof. Conduct 1.06 warns that:
 - “Disclosure and consent are not formalities. Disclosure sufficient for sophisticated clients may not be sufficient to permit less sophisticated clients to provide fully informed consent.”
- If a lawyer has represented the person with a disability and the supporter in entering a supported decision-making agreement, the lawyer shall not represent the person with a disability or the supporter in a dispute between them arising out of the supported decision-making agreement unless prior consent is obtained from both the person with a disability and the supporter. Tex. Disciplinary R. Prof. Conduct 1.06(d).

Duty to Communicate with Person with a Disability

- Tex. Disciplinary R. Prof. Conduct 1.03(b) provides that “A lawyer shall explain a matter to the extent reasonably necessary to permit the client to make informed decisions regarding the representation.”
- When communicating with a client under a disability, Comment 5 provides:
 - “In addition to communicating with any legal representative, a lawyer should seek to maintain reasonable communication with a client under a disability, insofar as possible. When a lawyer reasonably believes a client suffers a mental disability or is not legally competent, it may not be possible to maintain the usual attorney-client relationship. **Nevertheless, the client may have the ability to understand, deliberate upon, and reach conclusions about some matters affecting the client’s own well-being. Furthermore, to an increasing extent the law recognizes intermediate degrees of competence.** The fact that a client suffers a disability does not diminish the desirability of treating the client with attention and respect.” (Emphasis added)

Resources

- National Resource Center for Supported Decision-Making

www.supporteddecisionmaking.org

- Disability Rights Texas

www.dr.tx.org

HOW TO FILL OUT A SUPPORTED DECISION-MAKING AGREEMENT

Step 1: What is Supported Decision-Making Agreement?

The first paragraph in the agreement explains what supported decision-making is. You should explain this paragraph to your client.

"This agreement is governed by the Supported Decision-Making Act, Chapter 1357 of the Texas Estates Code. This supported decision-making agreement is to support and accommodate an individual with a disability to make life decisions, including decisions related to where and with whom the individual wants to live, the services, supports, and medical care the individual wants to receive, and where the individual wants to work, without impeding the self-determination of the individual with a disability. This agreement may be revoked by the individual with a disability or his or her supporter at any time. If either the individual with a disability or his or her supporter has any questions about the agreement, he or she should speak with a lawyer before signing this supported decision-making agreement."

Step 2: Who is Making the Agreement?

It says “Appointment of Supporter.” Under “Appointment of Supporter,” you should explain to your client that he or she is choosing someone to help him or her make decisions. Write your client’s name on the first line.

I (Name of Adult with Disability), _____ am entering into this agreement voluntarily.

On the next lines, write the name and contact information for the Supporter.

I choose (Name of Supporter) _____ to be my Supporter.

Supporter’s Address: _____

Phone Number: _____

E-mail Address: _____

Step 3: What Decisions Does Your Client Want Help With?

Put an X in the boxes for the types of decisions your client wants the supporter to help with. You can check yes or no for each type of decision. You can also write other kinds of decisions on the last line.

My Supporter may help me with life decisions about:

Yes ___ No ___ *obtaining food, clothing and a place to live*

Yes ___ No ___ *my physical health*

Yes ___ No ___ *my mental health*

Yes ___ No ___ *managing my money or property*

Yes ___ No ___ *getting an education or other training*

Yes ___ No ___ *choosing and maintaining my services and supports*

Yes ___ No ___ *finding a job*

Yes ___ No ___ *Other: _____*

Step 4: What Private Information Does Your Client Want to Share With the Supporter?

Put an X in the boxes as to whether your client wants the supporter to have access to private health information or educational records.

Yes ___ No ___ *My Supporter may see my private health information under the Health Insurance Portability and Accountability Act of 1996. I will provide a signed release.*

Yes ___ No ___ *My Supporter may see my educational records under the Family Educational Rights and Privacy Act of 1974 (20 U.S.C. Section 1232g). I will provide a signed release.*

Step 5: When Does the Agreement End?

State when your client and the supporter want the agreement to end.

This agreement starts when signed and will continue until _____ (date) or until my Supporter or I end the agreement or the agreement ends by law.

Step 6: Your Client Signs the Agreement.

At the bottom of the first page, your client signs and dates the agreement.

Signed this _____ (day) of _____ (month), _____ (year)

(Signature of Adult with Disability)

(Printed Name of Adult with Disability)

Step 7: Fiduciary Duty

Explain to your client and the supporter that the agreement creates a fiduciary duty:

IMPORTANT INFORMATION FOR SUPPORTERS:

When you agree to provide support to an adult with a disability under this supported decision-making agreement, you have a duty to:

- 1. Act in good faith*
- 2. Act loyally and without self-interest; and*
- 3. Avoid conflicts of interest.*

Step 8: Supporter Signs the Agreement

At the top of the second page, the supporter signs the agreement.

CONSENT OF SUPPORTER

I (Name of Supporter), _____ consent to act as a Supporter under this agreement.

(Signature of Supporter)

(Printed Name of Supporter)

Step 9: Witnesses Sign the Agreement.

In the middle of page 2, two witnesses over 14 years old may sign the agreement or the agreement may be notarized.

This agreement must be signed in front of two witness or a Notary Public.

(Witness 1 Signature)

(Printed Name of Witness 1)

(Witness 2 Signature)

(Printed Name of Witness 2)

OR

Notary Public

State of _____

County of _____

This document was acknowledged before me on _____ *(date)*

By _____ *and* _____

(Name of Person with Disability)

(Name of Supporter)

(Signature of Notary)

(Printed Name of Notary)

(Seal (if any) of Notary)

My commission expires: _____

Step 10: Protection From Harm.

Explain to your client that anyone receiving the agreement has the duty to report abuse, neglect or exploitation of your client by the supporter to Adult Protective Services.

WARNING: PROTECTION FOR THE ADULT WITH A DISABILITY

If a person who receives a copy of this agreement or is aware of the existence of this agreement has cause to believe that the adult with a disability is being abused, neglected, or exploited by the supporter, the person shall report the alleged abuse, neglect, or exploitation to the Department of Family and Protective Services by calling the Abuse Hotline at 1-800-252-5400 or online at www.txabusehotline.org.

Step 11: Relying on the Agreement.

Explain to your client that any professional or person receiving the agreement should accept the agreement.

DUTY OF CERTAIN PERSONS WITH RESPECT TO AGREEMENT

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

THANK YOU
