



SUPPORTED DECISION-MAKING: NEW ALTERNATIVE TO GUARDIANSHIP

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SUPPORTED DECISION-MAKING: A NEW ALTERNATIVE TO GUARDIANSHIP

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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 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)

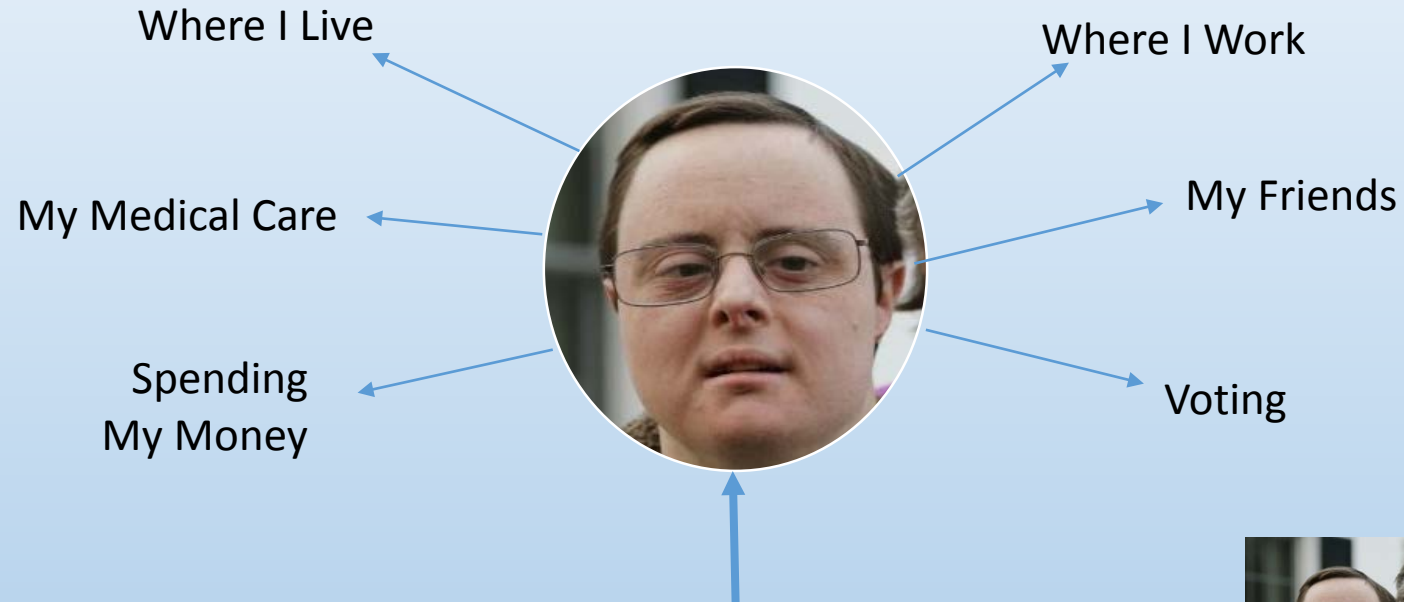
GUARDIANSHIP



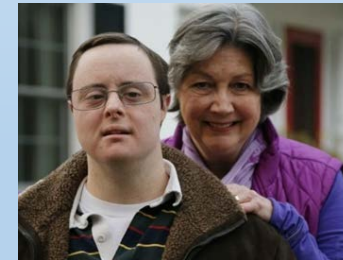
Makes The Decisions About My Life



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)*
- 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 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 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 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 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 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.

Supported Decision-Making Agreement

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.

Appointment of Supporter:

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

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

Supporter's Address: _____

Phone Number: _____

E-mail Address: _____

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: _____

My Supporter does ~~not~~ make decisions for me. To help me make decisions, my Supporter may:

1. Help me get the information I need to make medical, psychological, financial, or educational decisions;
2. Help me understand my choices so I can make the best decision for me; or
3. Help me communicate my decision to the right people.

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.

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.

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

(Signature of Adult with Disability)

(Printed Name of Adult with Disability)

CONSENT OF SUPPORTER

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

(Signature of Supporter)

(Printed Name of Supporter)

This agreement must be signed in front of two witnesses 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 Adult with a Disability) (Name of Supporter)

(Signature of Notary)

(Printed Name of Notary)

(Seal, if any, of notary)

My commission expires: _____

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.

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.

**AUTHORIZATION TO RELEASE CONFIDENTIAL INFORMATION
UNDER A SUPPORTED DECISION-MAKING AGREEMENT**

NAME OF ADULT WITH A DISABILITY

Last _____ First _____ Middle _____

DATE OF BIRTH _____

ADDRESS _____

CITY _____ **STATE** _____ **ZIP** _____

PHONE (____) _____ **ALTERNATE PHONE** (____) _____

I ALLOW THE FOLLOWING PERSON, PROVIDER OR ORGANIZATION TO RELEASE MY INFORMATION, WHICH MAY INCLUDE PROTECTED HEALTH INFORMATION:

Name _____
Address _____
City _____ State _____ Zip _____
Phone (____) _____ Fax (____) _____

**REASON FOR RELEASE
(Choose only one option below)**

- Treatment/Continuing Medical Care
- Personal Use
- Legal Purposes
- School
- Employment
- Other _____

Name of Supporter Who Can Receive the Confidential Information?

Name _____
Address _____
City _____ State _____ Zip _____
Phone (____) _____ Fax (____) _____

WHAT INFORMATION CAN BE RELEASED? Complete the following by choosing those items that you want released. Check one of the following:

1. HEALTH/MENTAL HEALTH INFORMATION

- All health/mental health information:
- Only the following health/mental health information: _____

Your initials are required to release the following information:

____ Psychotherapy Notes _____ Drug, Alcohol, or Substance Abuse Records
____ HIV/AIDS Test Results/Treatment

2. CASE-RELATED INFORMATION

- My entire case file/records
- Only the following case-related information: _____

3. EDUCATION/SPECIAL EDUCATION INFORMATION

- All education/special education records
- Only the following education/special education records: _____

4. EMPLOYMENT INFORMATION

- All employment records
- Only the following employment information: _____

5. FINANCIAL/PROPERTY INFORMATION

- All financial/property records
 - Only the following financial/property information: _____
-
-

6. HOUSING INFORMATION

- All housing records
 - Only the following housing information: _____
-
-

7. SUPPORTS AND SERVICES

- All records related to any supports and services provided to me
 - Only the following supports and services information: _____
-
-

PURPOSE OF AUTHORIZATION: I have entered a supported decision-making agreement with my supporter. I only authorize the release of my confidential information to my supporter so that my supporter can help me obtain a copy of the confidential information, help me understand the information contained in this confidential information and help me communicate my decisions based on this confidential information. My supporter shall ensure that my confidential information is kept privileged and confidential and is not subject to unauthorized access, use or disclosure. My supporter may only release my confidential information to any other person, provider or organization with my permission. I also retain the right to obtain my confidential information on my own without the help of my supporter.

EFFECTIVE TIME PERIOD. This authorization is valid until my death; the end of my supported decision-making agreement; my permission is withdrawn; or until (date): Month ____ Day ____ Year ____.

RIGHT TO REVOKE: I understand that I can withdraw my permission at any time by giving written notice stating my intent to revoke this authorization to release information to my supporter.

SIGNATURE AUTHORIZATION: I agree to the release of my confidential information to my supporter. I understand that this authorization is voluntary and I may refuse to sign this authorization. I further understand that I cannot be denied treatment based on a failure to sign this authorization form, and a refusal to sign this form will not affect the payment, enrollment, or eligibility for benefits. I have read and agree with how my confidential information may be used and shared with my supporter.

SIGNATURE _____
Signature of Adult with Disability

DATE