

Supported Decision Making

A NEW ALTERNATIVE TO INTERDICTION



What is Supported Decision Making?

- **GETTING HELP WHEN IT'S NEEDED!!!**
- Supported decision-making (SDM) allows individuals with disabilities to make choices about their own lives with support from a team of people they choose. Individuals with disabilities choose people they know and trust to be part of a support network to help with decision-making.
- Supported decision-making is an alternative to tutorship and interdiction.
- If you think about it, that's just a fancy way to describe the way we all make decisions.

Do you use Supported Decision Making?

- Seek help with your taxes?
- Ask questions about your health issues?
- Talk to your friends or family members about life choices?

Bottom Line: We **ALL** use Supported Decision Making **EVERYDAY**, and we **ALL** still make bad choices!!



What we know!!

- When individuals with I/DD are denied control they feel
 - Helpless
 - Hopeless
 - Self-Critical
- Cultures over the last 1500 years have instilled this mentality of “it’s for your own good” which has lead to the number of 18 year old’s with I/DD being Interdicted since 1995 tripling.

Facts of Supported Decision Making

- Improves health outcomes for individuals with I/DD
- Individuals are more independent
- Well – Adjusted
- Maintain gainful employment
- Feel safer and more secure



What happens with those Bad Choices?

It doesn't matter how many mistakes you
have made or how slow your progress is.

We learn from our mistakes and
all good things take time.

So keep going because you're still way ahead
of those who don't even bother trying.

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Principles behind Supported Decision Making (SDM)

- There is no “one size fits all” model for 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



Facts about Adult Legal Status

Capacity

vs.

Competency:
Not the same!

Capacity

Not a legal status on its own:

Instead, capacity is a factor in determining competency, which is a legal status.

An individual's ability to make an informed decision.

“Informed” not the same as “Good”

- Capacity ranges and is fluid.
- Capacity may be better at some times than others.
- Capacity is not easily measures.

Designation usually made by a clinician

It is Diagnosis-based, and may be biased.

Frequently seen in a psychological report

“Competent Major”

Per La. Code of Civil Proc. art. 27:

Once an individual reaches the age of 18, that person is presumed competent to handle **all** of his/her affairs regardless of his/her capacity to make informed decisions.

In non-lawyer:

All adults are competent majors until a court says that they are not!

Competent or Incompetent

Unlike capacity, competency is a *Legal Status*

- Decision as to competency made **only** by a judge.
 - If a judge has not found someone incompetent, they are considered competent under the law.
- Requires a decision by the court as to whether an individual has capacity or not.
 - Evidence based.
 - Functional rather than medical.
 - Issue-specific.

Competency

A person may be found competent or incompetent as to specific areas, not necessarily across the board.

Examples:

- Person
 - Medical
 - Living arrangements
- Property
 - Money management
 - Real property
 - Sale of house
 - Acceptance of an inheritance

Competency, Informed Decision-making, Capacity

Presumption of competency does not always equate to informed decision-making.

- **Non-lawyer translation:** As adults, we get to make bad decisions! AND WE ALL DO!

A person can be legally competent but lack capacity.

- **Example:** If a person has no way to communicate his or her wants or needs, he or she may lack capacity. But until a court says otherwise, he or she is legally still a competent major.

Due to competency/capacity issues, it may sometimes be appropriate to change someone's legal status.

Louisiana Options

- Continuing Tutorship
- Power of Attorney
- Interdiction
- Supported Decision Making





Continuing Tutorship or Permanent Tutorship for Persons with Intellectual Disabilities

La. Code of Civil Procedure: Art. 355

For a person over the age of fifteen but under eighteen who:

Possesses less than “two-thirds of the average mental ability” of “a normal person of the same age.”

- Requires evidence “by standard testing procedures administered by competent persons.”

Continuing Tutorship

Continuing tutorship is a legal status for persons

-with an *intellectual disability*;

-who are between the ages of 15 and 18;

Continuing Tutorship

Parents may:

With the concurrence of the Coroner of the parish of the person's domicile;

petition the court;

to place such person under a continuing tutorship.

Lasts until revoked by the court of domicile, but effects change when tutee turns 18.

Continuing Tutorships

No Need for Continuing Tutorships

Individuals Subject to Continuing Tutorships Minors, between the ages of 15 and 18.

- Incompetent in the eyes of the law.
- Cannot make decisions for themselves legally anyway.

So why do continuing tutorships exist?

- Ease the process of changing the legal status of an individual with a profound intellectual disability. (less procedure)
- Lessens the cost of a later interdiction.

Why are continuing tutorships unnecessary?

The tools that parents needs already exist:

- Medical Decisions – Medical Consent Law
- Financial Decisions – Representative Payee
 - ABLE Accounts
 - Special Needs Trusts

These options already exist in the law and do not have the financial burden that a continuing tutorship has.

How do these work?

Medical Consent Law

Hierarchy of Consent for Surgical/Medical

- Adult, for himself.
 - Judicially appointed curator/tutor.
 - Spouse.
 - Adult child of patient.
 - Parent.
 - Sibling.
 - Other relatives.
-
- La. R.S. 40:1299.53

Representative Payee

Used for Social Security Administration purposes only.

Rep Payee designated when SSA receives info that the beneficiary is either beneficiary legally incompetent, or mentally/physically incapable of managing payments.

Beneficiary may object to appointment.

Payments are to be used *only for the use and benefit of the beneficiary.*

- Current maintenance.
- No co-mingling of funds.

ABLE Account

What is it?

- A tax-advantaged savings account for individuals with disabilities and their families
- Legislation describes it as: “secure funding for disability-related expenses on behalf of designated beneficiaries with disabilities that will supplement, but not supplant, benefits provided through private insurance, Medicaid, SSI, the beneficiary’s employment and other sources”

Want more information?

- Please visit the ABLE National Resource Center: <https://www.ablenrc.org/>

Special Needs Trust

What is it?

- It is a trust tailor to a person with a disability that is designed to manage assets for that person's benefit while not compromising access to important government benefits.

What's the difference between ABLE and SNT?

- An Able account is a savings account that only money may be deposited into. A SNT is a trust that may contain any type of asset imaginable (e.g., house, stocks, bonds, money from inheritance or legal settlement, etc.)

Must be created by an attorney so there is a cost

Continuing Tutorship

So what can a person under a tutorship do?

The rights of a child?

- Voting
- Medical decisions
- Own property
- Acts of free will

What about the power of administration?

- Constitutionally questionable because of retroactivity

Continuing Tutorship

“Interdiction of the Young” is a Misnomer

Not a full interdiction.

La. C.C. art. 356 is clear that interdiction and continuing tutorship are not the same.

Power of Attorney: Financial and/or Medical

What is a power of attorney?

- It is a legal document allowing someone else to act on your behalf
- Gives broad or limit legal authority to make decisions regarding property, finances, or medical care

In Louisiana, a Power of Attorney is also called a **Mandate**

It is advisable to consult a Louisiana attorney if the primary resides in Louisiana because the rules for POA are different

Power of Attorney: What's the purpose?

Confers authority on an individual to act on another person's behalf.

Does NOT take away the individual's right to make their own decisions.

A competent major can grant power of attorney allowing the representative to act on their behalf in any way specified in the document: in financial matters, medical decisions, property-related decisions, etc.

Representative and mandate can be revoked at ANY TIME.

If the competent major changes his/her mind, the representative no longer has authority to make decisions for them.

Power of Attorney: What's the purpose?

All persons have the “**fundamental right**” to control decisions relating to their medical care.

- Grants right to make a declaration to withdraw or withhold life-sustaining procedures.
- Irreversible and terminal condition.
- Palliative care not withdrawn.

Power of Attorney: Durable vs Springing

What is a durable power of attorney?

- Effective immediately
- No requirement for grantor to become incapacitated
- In Louisiana, all POA/Mandates survive incapacity, so they are by law durable

What is a springing power of attorney?

- Effective only when the grantor becomes incapacitated
- Creates a backup plan for possible future incapacity

INTERDICTION

Full/Limited

Full Interdiction

“A court *may* order the full interdiction of a natural person of the age of majority, or an emancipated minor, who due to an infirmity, is *unable consistently to make reasoned decisions* regarding the care of his person and property, **or** *to communicate those decisions*, and whose *interests cannot be protected by less restrictive means.*”

La. C.C. art. 389

Let's break that down

- 18+ or emancipated minor;
 - Unable to *consistently* make reasoned decisions regarding the care of his person and/or property;
- or**
- Unable to *communicate* those decisions in a manner understandable by others;
- and**
- Unable to care for person and/or property/estate due to “*infirmity*.”
 - Condition must be serious enough to cause significant impairment on the exercise of judgment.
 - Chronic substance abuse may qualify, but advanced age alone does not.

La. C.C. art. 389 and 390

Full Interdiction

Full Interdiction is the Most Restrictive Remedy

Described by the Supreme Court as a “civil death.”

Most intrusive remedy.

Often more sweeping in its effect than necessary.

All legal rights are transferred to another person. Does not deprive the interdict of free will!

Full Interdiction

Rights Lost

- Right to contract;
- Right to marry;
- Right to accept or renounce succession;
- Right to sue or be sued;
- Right to vote;
- Other rights (e.g. drive; consent to medical treatment; leave the State w/o permission).

Interdiction

Termination/Modification of Interdiction

Only right that an interdict retains

Court may modify or terminate a judgment of interdiction when it finds by a **preponderance of the evidence** that the terms are excessive or insufficient or that the ability of the interdict to care for his person or property has changed. La.C.C.P. art 4554

Interdiction terminates at death of the interdict or by judgment of the court. La. C.C. art. 397

Limited Interdiction

“A court may order the limited interdiction of a natural person of the age of majority, or an emancipated minor, who due to an infirmity, is unable consistently to make reasoned decisions regarding the care of his person or property, *or any aspect of either*, or to communicate those decisions, and whose interests cannot be protected by less restrictive means.”

La. C.C. art. 390

Limited Interdiction

Less intrusive than full interdiction.

Limited interdict retains all rights except those *specifically granted to another in the judgment.* La. C.C.P. art. 4551(B)

Court confers only those powers required to *protect the interests* of the interdict. La. C.C. art. 392

Interdiction: Important to Note

“Reasoned Decisions”

Risky/poor decisions are not sufficient reasons for interdiction.

- Everyone has the right to make mistakes.
- Everyone has the right to make bad decisions

“Unable to Communicate Reasoned Decisions”

If the person can communicate in *any* form - verbal or nonverbal – they are not a proper candidate for interdiction.

What's the least restrictive option?

Supported Decision Making

The Law: The Dustin Gary Act



Who made it Possible?



The Arc of Louisiana would like to sincerely thank Representative Paula Davis for authoring HB 361, now Act 258 The Dustin Gary Act, and Representatives Richard Nelson, Charles Owen, and Senators Patrick McMath, Franklin Foil, and Heather Cloud for co-authoring this monumental piece of legislation.

Also, thank you to the following organizations for their assistance during the Legislative process and work on drafting the bill: People First of Louisiana, The Office of Citizens for Developmental Disabilities, Disability Rights Louisiana, and The Louisiana Department of Health.

Reforming Interdiction in Louisiana

In 2020, the Louisiana Legislature passed HB 361 authored by Representative Davis establishing Supported Decision Making.

Supported Decision Making was specifically identified as an alternative to Interdiction by the Louisiana Legislature!!

<https://legis.la.gov/legis/ViewDocument.aspx?d=1178579>



Significant Changes

A petitioner for Interdiction will have to prove to the courts that a less restrictive means was tried, and if not tried, a reason why!

Including all of the following:

- (a) The less restrictive means for meeting the defendant's needs that were considered or implemented
- (b) If a less restrictive means was not considered or implemented, the reason that the less restrictive means was not considered or implemented
- (c) The reason a less restrictive means is insufficient to meet the needs of the defendant

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 preference
- Communicate decisions to other individuals



Who can enter into a Supported Decision Making Agreement?

"Adult" means an individual with a disability as defined by the Americans with Disabilities Act of 1990 (42 U.S.C. 12102) who has attained eighteen years of age or who is an emancipated minor



How do I know???

You never know until you try. We should presume that everyone – including people with intellectual disabilities - has the right to make choices and everyone needs support until proven otherwise.

The advice the National Guardianship Association – an organization made up of guardians and conservators – gives: try SDM before seeking Interdiction.



My Choices!



Who should the Supporter be??

1. Someone the person trusts and who is willing to go on the journey implementing SDM.
2. Someone who accepts and supports the individual/family.
3. Someone who has knowledge in a particular area we are seeking to include in the SDM agreement.
4. Someone that can be available long term (although changes to the Team should be anticipated over time).
5. Someone who is open to novel ideas, flexible and can make the individual “the agenda”.

Talking to Potential Supporters

Once a person chooses whom he trusts to help him make decisions, he will need to find out if the potential supporter is able and willing to help.

It is important that the potential supporter understand what is involved, and be able and willing to fulfill the role of supporter.

The Decision-Maker might:

Share what areas in which he would like support

Share how he would like to get support

Share a sample Supported Decision-Making Agreement

What can a Supporter do?

A supporter may do any or all of the following:

- Provide supported decision making, including assistance in understanding the options, responsibilities, and consequences of the adult's life decisions, without making those decisions on behalf of the adult
- Assist the adult in accessing, collecting, and obtaining information that is relevant to a given life decision, including medical, psychological, financial, educational, or treatment records
- Assist the adult in understanding the information described
- Assist the adult in communicating the adult's decisions to the appropriate parties

What CAN'T a Supporter do?

- Exerting undue influence upon the adult
- Obtaining, without the consent of the adult, information relating to the adult acquired for a purpose other than assisting the adult in making a specific decision authorized by the supported decision making agreement
- Acting outside the scope of authority provided in the supported decision making agreement
- Obtaining, without the consent of the adult, nonpublic personal information relating to the adult

Being an Effective Supporter

Have clear boundaries

Ground action in respect

Focus on what can be done

Seek common ground

Manage the role of emotion



Healthy Adult Relationships

Talk about respect and boundaries

Expect differences of opinion and world view

Make room for change

Focus on the present and future (not the past)

Think about how to disagree



Filling out an Agreement

1. The Decision-Maker should meet with her supporters, either one at a time, or all at once, depending on what works best.
2. They should go over the Agreement page-by-page and make sure that everyone understands and agrees upon what is in the Agreement.
3. It is as important for supporters to understand what kind of help the Decision-Maker does *not* want as it is for them to understand what kind of help is wanted.

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.
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)

What Should the Agreement Contain?

A supported decision making agreement shall contain all of the following information:

The name, address, and phone number of at least one supporter

A description of the decision making assistance that a supporter shall provide to the adult and, if multiple supporters, how they shall work together

Signatures of both the adult and the supporter(s)

Authorize a supporter to share information with any other supporter or others named in the agreement

Voluntary or Court Ordered?

- An adult with a disability decides they need supports when making decisions
- The person with a disability and a supporter enter into the agreement voluntarily
- It is informal and does NOT require going to court
- Agreement MUST be notarized

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** ever allow someone else to make the decisions for a person
- In a supported decision making agreement, the person with a disability retain their rights to make **ALL** decisions

CONFIDENTIAL

Confidential Information

- A supporter can also be authorized to assist an adult with a disability to access, collect or obtain information
- This includes protected health information under HIPPA 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 seeing personal information on his or her own without the assistance of the supporter

When Does an Agreement End?

A supported decision making agreement ends when:

- The adult subject of the supported decision making agreement passes away
- The adult subject of the supported decision making agreement revokes the agreement under R.S. 13:4261.206
- The named supporter revokes his participation in writing without naming successor supporters



When Does an Agreement End?

- A court of competent jurisdiction determines that a supporter has used the supported decision making agreement to commit financial exploitation, abuse, or neglect of the adult

ZERØ
TOLERANCE

ENDING THE ABUSE, NEGLECT, AND
EXPLOITATION OF PEOPLE WITH
DISABILITIES

Revocation

An adult with a disability, or a Supporter may revoke a supported decision making agreement at any time.

A revocation shall be in the form of an authentic act, dated, and signed by the adult or the adult's guardian if the adult lacks capacity under Civil Code Article 1918, and a copy of the revocation shall be provided to each supporter

What if Someone Suspects Abuse?

- If a person who receives a copy of a supported decision making agreement or is aware of the existence of a supported decision making agreement and has cause to believe that the adult is being abused, neglected, or exploited by a supporter, the person shall report the alleged abuse, neglect, or exploitation to any adult protection agency or any local or state law enforcement agency

Adult Protective Services

Adult Protective Services (APS) is responsible for investigating reports and arranging for services to protect vulnerable adults ages 18-59 and emancipated minors who are at risk of abuse, neglect, exploitation or extortion. Reports of adult abuse may be made 24 hours a day, seven days a week, to **1.800.898.4910**(toll-free)



Does an Agreement Guarantee Informed Consent?

NO!

- 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 SDM be used along with other alternatives to Interdiction?

YES!

- A supported decision making agreement can be used in conjunction with other alternatives to Interdiction such as Power of Attorney
- This is consistent with the goal of supported decision making to promote the self determination of persons with disabilities and to avoid interdictions

Incorporate SDM everywhere...

- SDM can/should be written into:
 - IEP's
 - IPE's
 - CPOC's
 - Any other plan for programs the individual is in



Supported Decision Making is Hard Work

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



Important Things to Remember

- The law presumes that **ALL** adults have the capacity for decision making
 - 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

Important Things to Remember

A Supported Decision-Making Agreement is a “living document.” This means that it can be changed as needed.

A Decision-Maker may want to change a supporter, or have a different type of help in making a certain kind of decision.

A supporter may decide to drop out. Or, a new supporter may be identified.

What Supported Decision-Making agreements do NOT do.

They do not restrict a Person's rights to make any decisions.

- Having a supported decision-making agreement does not preclude the Person from acting independently of the agreement or making decisions that the Supporter does not agree with.
- The Person is always in control of their own decisions.

It does not give Supporters any new rights

- The Supporter has no authority to make the person's decisions. The Person makes all their own decisions.
- Supporters cannot sign legal documents for the Person or bind a Person to a legal agreement
- Supporters have only the authority/role granted by the Person under the terms of the supported decision-making agreement.

Don't Forget!!

The Decision-Maker and the supporters should each have a copy of the Agreement. It's also a good idea to share the SDMA with doctors, banks, or others who will be expected to acknowledge and honor the Agreement.

Resources

- National Resource Center for Supported Decision Making:
 - www.supporteddecisionmaking.org
- The Arc US
 - <https://thearc.org/?s=supported+decision+making>

Need Assistance?

Contact The Arc of Louisiana at 225-383-1033

Contact Disability Rights Louisiana at 800-960-7705 or 504-522-2337

Thank You

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