

Let's Learn About Supported Decision- Making in Illinois

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Meet the Presenters



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Illinois Guardianship and Advocacy Commission (GAC)

- GAC is an Illinois state agency that helped pass the law on supported decision-making.
- GAC has offices in Chicago, Springfield, and across Illinois.
- GAC has programs for persons with disabilities.



GAC Programs for People with Disabilities

1. Office of State Guardian - guardian of last resort for adults with disabilities
2. Legal Advocacy Service - provides legal advice/representation for children and adults, often mental health related
3. Human Rights Authority - investigates complaints of disability rights violations involving service providers
4. Special Education Advocacy Division - provides Illinois families assistance with special education questions/issues

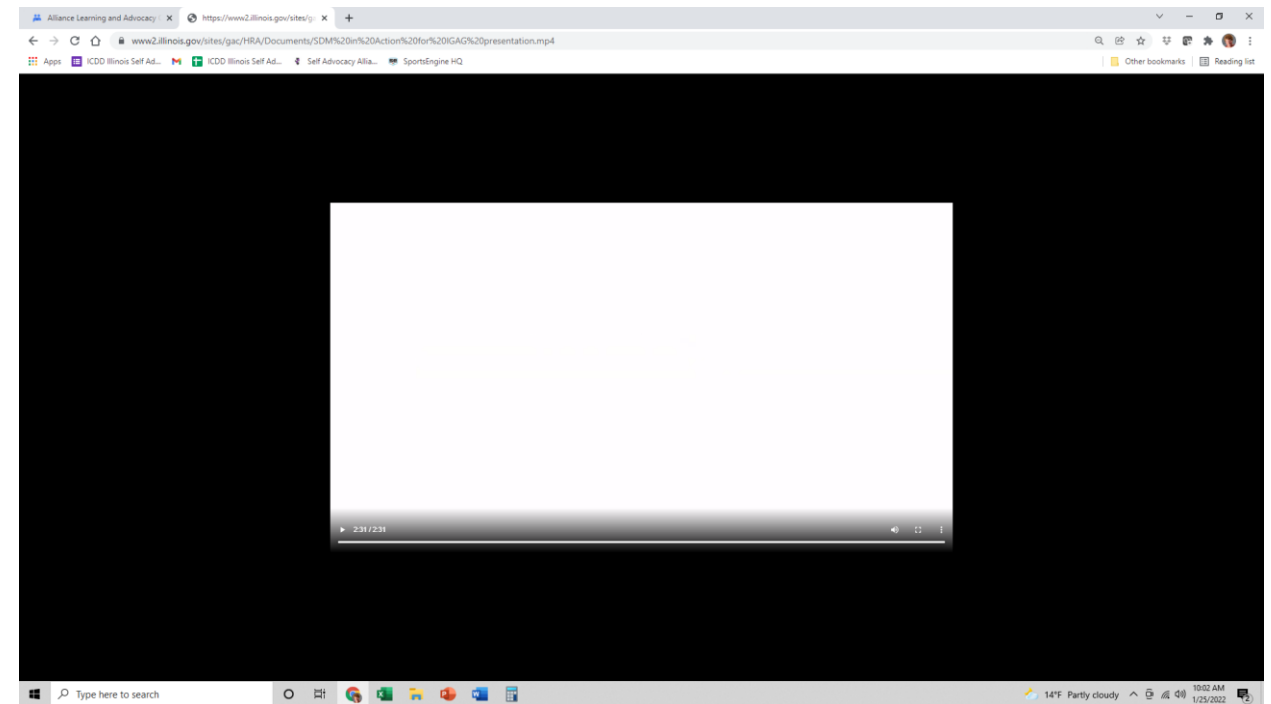
GAC's Legislative Role

- GAC can recommend legislation
- Legislative proposals come from GAC's work
- Supported Decision-Making Proposal
 - Based on Guardianship experiences
 - Based on referrals from families
 - Based on research of other state statutes

Learn more more about Supported Decision-Making by watching a video.

To start the video, click [here](#). The video will start playing.

After watching the video, click the back arrow on the upper left-hand side of the computer screen to go back to the presentation.



Overall Purpose of Supported Decision-Making

“To recognize a less-restrictive alternative for adults with intellectual or developmental disabilities (ID/DD) who need assistance with decisions regarding daily living.”

Supported Decision-Making provides an alternative to guardianship for adults with intellectual or developmental disabilities who need help in making decisions.

The Supported Decision-Making Act Covers...

- guiding principles and a presumption of capacity
- Supporter duties
- Supporter prohibitions
- a model Supported Decision-Making Agreement
- Releases of Information
- methods to end an agreement
- abuse/neglect/exploitation resources

General Description of Supported Decision-Making - 1

- An adult with an ID/DD (called a Principal) identifies a trusted Supporter (relative, friend) to assist in certain areas of life (medical, financial, living arrangements, work, etc.).
- The Supporter arrangements are put into a written Supported Decision-Making Agreement which both the Supporter and the Principal sign in front of 2 witnesses.

General Description of Supported Decision-Making - 2

- The Supporter helps the Principal with decisions in the identified areas of support.
- The Principal still makes the final decision.
- A Principal can act independent of a Supported Decision-Making Agreement if they so choose.

Guiding Principles of the Supported Decision-Making Act

- All adults should be able to live in a manner of one's own choosing.
- All adults should be able to participate in decisions regarding their own lives.
- Adults who need assistance should receive the most effective and least intrusive assistance.
- When providing assistance to another, the person's values, beliefs, cultural traditions should be respected.

Presumption of Capacity Statement

- The Supported Decision-Making Act emphasizes that all adults are presumed to have the capacity to make their own decisions unless otherwise determined by a court.
- Capacity is not voided simply because of:
 - A person's disability.
 - The manner in which a person communicates.

Supporter Duties



- Assist with understanding information about a decision
- Help access information about a decision
- Assist with appointments
- Track services
- Determine the Principal's decisions, assist with communicating the Principal's decisions, and advocating for the Principal's wishes and decisions

Supporter Access to Information

- A Supporter can only access information with the Principal's consent and as approved under the Agreement.
- The Supporter must keep information confidential.
- The Principal can still access information without the Supporter.
- Releases of Information may be needed for a Supporter to access information.

Release of Information - 1

Service agencies may require a Release of Information to allow the Supporter to obtain information related to the Principal.

A Release of Information must list the specific types of information the Supporter can have such as medical, financial or school records.

A Release of Information must be signed by the Principal and witnessed by a person who observes the Principal signing it. It is recommended that someone other than the Supporter be a witness.

Release of Information - 2

Release of Information for Supporter Involvement (Non-School Related Supporter)

This disclosure of information is necessary to accomplish the statutory purposes of the Supported Decision-Making Act.

I, _____
(Name of Principal in a Supported Decision- Making Agreement which should accompany this release),
Authorize: _____
(Name of Entity to release information) _____
To Release Information To: _____
(Name of Supporter in a Supported Decision-Making Agreement) _____

For the purpose of carrying out Supporter duties under a Supported Decision-Making Agreement. Specific information to be released (list types of information to be released to the Supporter such as financial, medical or psychological information): _____

I understand that I may revoke this consent in writing at any time and that no revocation of this authorization shall be effective to prevent disclosure of records and communications until it is received by the person/agency otherwise authorized to disclose records and communications. I understand that the above-named person authorized to receive this information has the right to inspect and copy information to be disclosed. I further understand that if the entity receiving this information is not a healthcare provider/plan covered by HIPAA privacy regulations, the information described above may be re-disclosed and no longer protected by the HIPAA regulations (45 CFR 160; 164). I understand that the records and communications to be disclosed may include sensitive information such as evaluations, habilitation/treatment information for mental health, developmental disabilities, alcohol or substance use/abuse, sickle cell anemia and sexually transmitted diseases or HIV/AIDS unless specifically designated for exclusion: _____

It has been explained to me and I understand that my refusal to consent to this release of information will prevent information from being released and reviewed by my Supporter in a Supported Decision-Making Agreement. I understand that entities may not condition treatment, payment, enrollment or eligibility for benefits on whether I sign this authorization. This authorization is valid for 12 months following the date of signature.

(Witness Signature) (Signature of Principal)

(Date) (Date)

Standards for Privacy of Personally Identifiable Information under 45 CFR 160 and 164 state that information used or disclosed by this authorization may be subject to redisclosure by the recipient of the information. Federal Confidentiality Rules under 42 CFR 2 prohibit further disclosure of drug or alcohol information unless further disclosure is permitted by written consent of the person it pertains to or as otherwise permitted under 42 CFR 1.

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Non-School Support

Release of Information

Release of Information for Supporter Involvement (School Related Support)

This disclosure of information is necessary to accomplish the statutory purposes of the Supported Decision-Making Act. The Principal under a Supported Decision-Making Agreement is requesting the disclosure of educational information pursuant to 740 ILCS 110/5, 105 ILCS 10/5 and 10/6 and 34 C.F.R 99.30.

I, _____
(Name of Principal in a Supported Decision- Making Agreement which should accompany this release),

Authorize: _____
(Name of School District or Special Education Program to release information)

To Release Information To: _____
(Name of Supporter in a Supported Decision-Making Agreement)

For the purpose of carrying out Supporter duties under a Supported Decision-Making Agreement. List the types of information to be released to the Supporter (such as academic records, evaluations, psychological testing, IEPs): _____

I understand that I may revoke this consent at any time and that the above-named person authorized to receive this information has the right to limit, consent, inspect, copy and challenge information in the records to be disclosed. It has been explained to me that if I refuse to consent to this release of information, the supporter will not receive information about my education.

(Witness Signature)

(Signature of Principal/Student age 18 or over)

(Date)

(Date)

NOTICE TO RECEIVING AGENCY/PERSON: Under the provisions of the Illinois Mental Health and Developmental Disabilities Act, you may not redisclose any information unless the person who consented to this disclosure specifically consents to such redisclosure.

Under the Federal Act of July 1, 1975, Confidentiality of Alcohol and Drug Abuse Patient Records, no such records, nor information from such records may be further disclosed without specific authorization for such redisclosure.

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Illinois Gateway to Adult Guardianship

School Support

Release of Information

Supporters Cannot...

- exert undue influence or force a certain decision.
- make a decision for the Principal.
- access information about the Principal unless authorized to by the Principal or the Agreement.
- access information unrelated to an identified area of support.
- be paid for being a Supporter.
- work for the Principal unless they are family.



Supporters Cannot Be... - 1



- a current teacher involved in the Principal's education.
- a person who is an employee or an employer of the Principal, unless an immediate family member.
- a person providing paid support services, unless immediate family member.
- a person who works for an agency financially responsible for the care of the Principal.
- a person who is listed on the Healthcare Registry (a person who has a finding of abuse, neglect, financial exploitation)

Supporters Cannot Be... - 2



- a person who has a court order prohibiting contact with the Principal.
- a person who has been convicted of certain crimes:
 - Sex offense
 - Aggravated assault
 - Fraud
 - Theft
 - Forgery
 - Extortion

Questions a Supporter Might Ask a Principal

Specific questions a Supporter might ask a Principal when developing a SDM Agreement may include:

- What are your strengths?
- What are your needs?
- What help would benefit you the most?
- What role do you want me to play in decisions?
- What things do you want me to do on your behalf?
- What things do you NOT want me to do?

Ways a Supporter Involves the Principal

- Making sure that the Principal understands what is currently happening or has happened.
- Reviewing any information obtained regarding a decision directly with the Principal.
- Informing any service providers about Supporter duties and limitations, and that decisions are always made by the Principal.
- As much as possible, having the Principal present when information is gathered.

Supported Decision-Making Agreement

You can find the Supported Decision-Making Agreement by clicking [here](#).

Agencies that support a Principal **must** follow the Agreement unless the Principal tells them not to.



Supported Decision-Making Agreement

Under the Supported Decision-Making Act:

A **Supporter** is an adult who has entered into an agreement with a Principal.

A **Principal** is an adult with ID/DD who seeks to enter or has entered into an agreement with a Supporter.

Important Information for the Supporter: Duties

If you agree to provide support to the Principal, you have a duty to:

- 1) act in good faith;
- 2) act within the authority granted in this agreement;
- 3) act loyally and without self-interest; and
- 4) avoid conflicts of interest.

Appointment of a Supporter

I, _____ (insert Principal's name), make this agreement of my own free will. I agree and designate that the following individual as my Supporter:

Name: _____

Address: _____

Phone Number: _____

Email Address: _____

Parts of a Supported Decision-Making Agreement - 1

- The Agreement states that the Supporter must help the Principal based on what the Principal wants.
- The Supporter must list an address and phone number.

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Supported Decision-Making Agreement

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Address: _____

Phone Number: _____

Email Address: _____

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Parts of a Supported Decision-Making Agreement - 2

- The Principal puts initials on the areas where they want help and N/A on the places they don't want help:
 - Food, clothing, a place to live
 - Medical or Counseling
 - Money
 - Public benefits
 - Work
 - School
- The Principal can initial as many or as few areas as they want or need help.

My Supporter is to help me make decisions for myself and may help with making everyday life decisions relating to the following (items initialed by Principal). All other items should be marked as "NA" for "Not Applicable."

- _____ Obtaining food, clothing, and shelter.
- _____ Taking care of my physical and emotional health.
- _____ Managing my financial affairs.
- _____ Applying for public benefits.
- _____ Helping me find work.
- _____ Assisting with residential services.
- _____ Helping me with school.
- _____ Helping me advocate for myself.
- _____ Other, describe: _____

My Supporter is not allowed to make decisions for me. To help me with my decisions, my Supporter may:

- 1) help me access, collect, or obtain information that is relevant to a decision, including medical, psychological, financial, educational, housing and treatment records;
- 2) help me understand my options so that I can make an informed decision; and
- 3) help me communicate my decision to appropriate persons.

I want my Supporter to have (only items initialed by principal)

- _____ A release allowing my supporter to see protected health information under the Health Insurance Portability and Accountability Act of 1996, and/or confidential information under the Mental Health and Developmental Disabilities Confidentiality Act, and/or to see substance abuse records under Confidentiality of Alcohol and Drug Abuse Patient Records regulations is attached.
- _____ A release allowing my supporter to see educational records under the Family Educational Rights and Privacy Act of 1974 and the Illinois School Records Act is attached.

Parts of a Supported Decision-Making Agreement - 3

- The Agreement includes a part about records the Principal may want to share with the Supporter.
- A Release of Information can be for school support or non-school support.

My Supporter is to help me make decisions for myself and may help with making everyday life decisions relating to the following (items initiated by Principal):

- _____ Obtaining food, clothing, and shelter.
- _____ Taking care of my physical and emotional health.
- _____ Managing my financial affairs.
- _____ Applying for public benefits.
- _____ Helping me find work.
- _____ Assisting with residential services.
- _____ Helping me with school.
- _____ Helping me advocate for myself.
- _____ Other, describe: _____

My Supporter is not allowed to make decisions for me. To help me with my decisions, my Supporter may:

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- 2) help me understand my options so that I can make an informed decision; and
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- _____ A release allowing my supporter to see educational records under the Family Educational Rights and Privacy Act of 1974 and the Illinois School Records Act is attached.

Parts of a Supported Decision-Making Agreement - 4

- The Principal and the Supporter must sign and date the Agreement.
- Two (2) other people called Witnesses must sign and date the Agreement.

This supported decision-making agreement is effective immediately and will continue until _____ (insert date) or until the agreement is terminated by my supporter or me or by operation of law.

Signed this _____ day of _____, 20____

(Signature of Principal) (Printed Name of Principal)

Consent of Supporter

I, _____ (name of supporter), consent to act as a supporter under this agreement.

(Signature of Supporter) (Printed Name of Supporter)

(Witness 1 Signature) (Printed Name of Witness 1)

(Witness 2 Signature) (Printed Name of Witness 2)

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 ADULT PROTECTIVE SERVICES HOTLINE:

1-866-800-1409 OR 1-888-206-1327 (TTY)

This form is not intended to exclude other forms or agreements that identify the principal, supporter, and types of support.

GAC/07-21

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SDM Safeguards - 1

Safeguards ensure the protection of the Principal's interests, choices and preferences against potential abusive situations.

- The legislation emphasizes that Principal makes all decisions.
- The written, signed and witnessed Agreement documents what a Support can and cannot do.
- The legislation clearly defines the Supporter duties to help gather information, help weigh options, help determine risks and benefits and perhaps help communicate the Principal's final decision.

SDM Safeguards - 2

- The legislation addresses Supporter disqualifications and includes abuse reporting should a Supporter overstep identified areas of assistance.
- The Principal can end the Agreement at any time.

Ending the Supported Decision-Making Agreement - 1

A Principal or a Supporter can end the Agreement at any time:

- Tearing up the Agreement.
- Asking someone to tear up the Agreement in front of the Principal.
- The Principal can sign and date a statement that they are ending the Agreement.
- The Principal can say they want to end the Agreement in front of two (2) people (witnesses).

Ending the Supported Decision-Making Agreement - 2

- There is a finding of abuse, neglect or exploitation by the Supporter.
- There is a restraining order against the Supporter by the Principal.

The Supporter can end the Agreement by:

- Giving notice to the Principal (a two (2) week notice is recommended)

GAC's Resources on Supported Decision-Making

- Brochure
- Training for Persons with Disabilities
- Supporter Training (certificate at end)
- Fact Sheets about Supported Decision-Making
- A Model Agreement
- Releases of Information
- Frequently Asked Questions

Click [here](#) to visit IGAC's SDM webpage

Click [here](#) to visit the National Center for Supported Decision-Making

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[GAC](#)

Supported Decision-Making

[Supported Decision-Making Brochure](#)

[SPED](#)

[SPED Form](#)

[Supported Decision-Making training for Persons with Disabilities - PDF](#)

[Supported Decision-Making Fact Sheet August 2022](#)

[Supported Decision-Making FAQ December 2021](#)

[Supported Decision-Making - Easier to Understand - Updated September 2021](#)

[Supported Decision-Making Agreement Revised July 2022](#)

[Supported Decision-Making Agreement Non-School Release Revised November 2021](#)

[Supported Decision-Making Agreement School Release Revised November 2021](#)

[Supporter Training - Supported Decision Making in Illinois: Your Role in Supporting a Person with Intellectual and Developmental Disabilities under a Supported Decision-Making Agreement](#)

[Link to the Supported Decision-Making Act](#)

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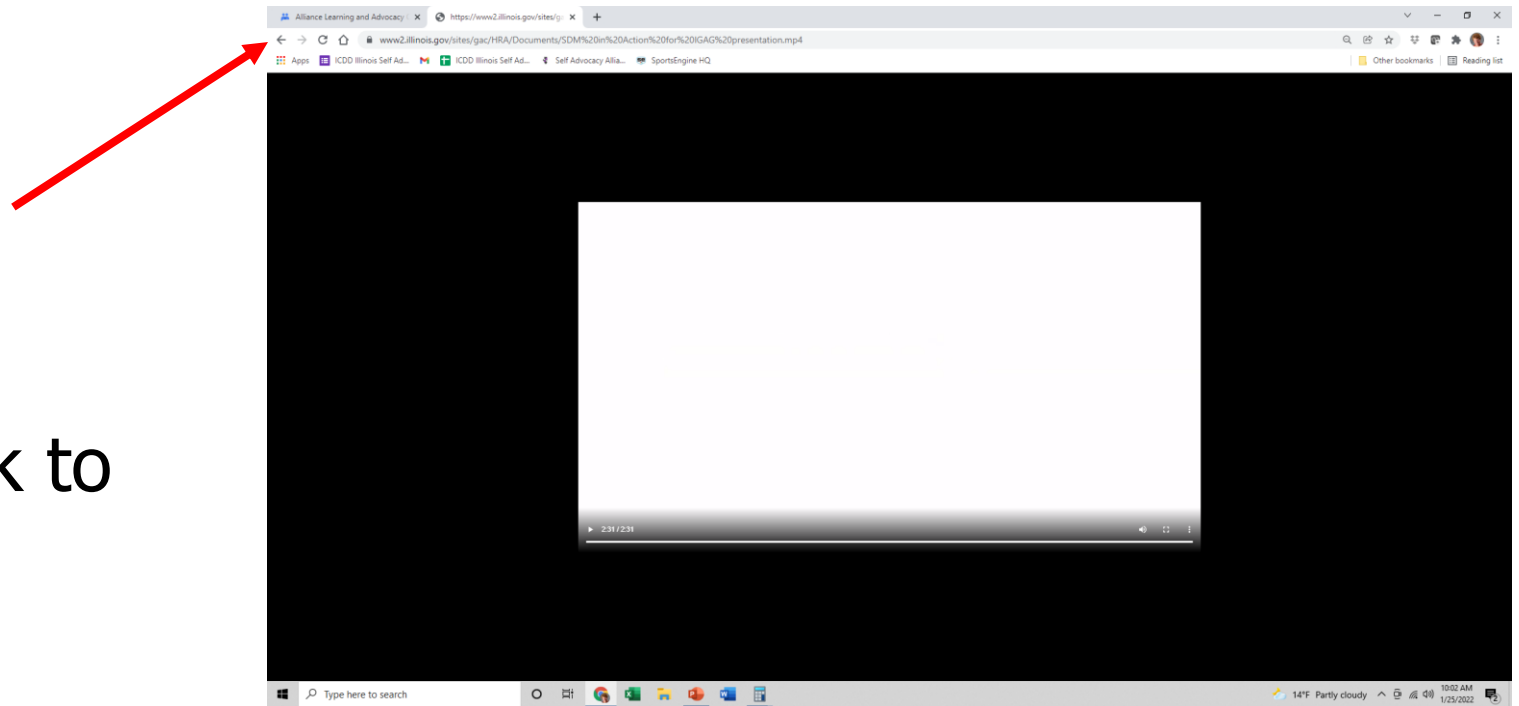
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Supported Decision-Making In Action

Watch a video about self-advocate Will McMillan sharing his experience with Supported Decision-Making.

To start the video, click [here](#). The video will start playing.

After watching the video, click the back arrow on the upper left-hand side of the computer screen to go back to the presentation.



Dignity of Risk

- Respecting a person's autonomy and self-determination to make choices for themselves.
- Giving people place/space to take risks that go along with ordinary life, which are necessary for personal growth and development.
- Providing support based on a person's interests, abilities, and needs.

Mistakes = Experience

10 Tips for Supported Decision-Making - 1

1. Give people time to think about what a question means to them and say things in their own words.
2. Give people the chance to ask about something that they don't understand before you explain it to them.
3. Make sure all facilitators know their roles and give each other time to do their parts.
4. Be prepared to do role play to help explain things on the agreement form.

10 Tips for Supported Decision-Making - 2

5. Keep track of time and don't spend too much time on one thing.
6. Focus on support for deciding things, not for doing things.
7. Spend more time talking about who could be good supporters and what supporters look like.
8. Make sure people talk about the support that they want in the future, not just the support that they are getting now.

10 Tips for Supported Decision-Making - 3

9. Talk about how the person will use the agreement in their lives and try to educate them about other ways they could use it, too.
10. Share examples from your own life about the hard decisions you made with support.

Supported Decision-Making in Action - 1

Tony wants a Supporter to help him with medical decisions and paying bills.

Tony has an older sister named Mary. Tony really trusts Mary and talks with her about being his Supporter. Mary hasn't been convicted of any crimes that would prevent her from being a Supporter. Mary agrees to be Tony's Supporter.



Photo by [cottonbro](#) from [Pexels](#)

Supported Decision-Making in Action - 2

Tony fills out the Supported Decision-Making Agreement. He initials medical and financial assistance for his areas of support.

Tony and Mary sign the Agreement, and their mom and dad signs the Agreement as the witnesses.



Photo by [RODNAE Productions](#) from [Pexels](#)

Supported Decision-Making in Action - 3

Tony has a doctor's appointment. The doctor wants Tony to change medicine. Tony tells the doctor he wants to talk to his Supporter first.

Tony signs a Release of Information so that Mary can look at his medical records to help him get information.

Mary helps Tony learn about the new medication. Mary also helps Tony write a list of questions to ask the doctor. Tony will decide if he wants to take the new medication.

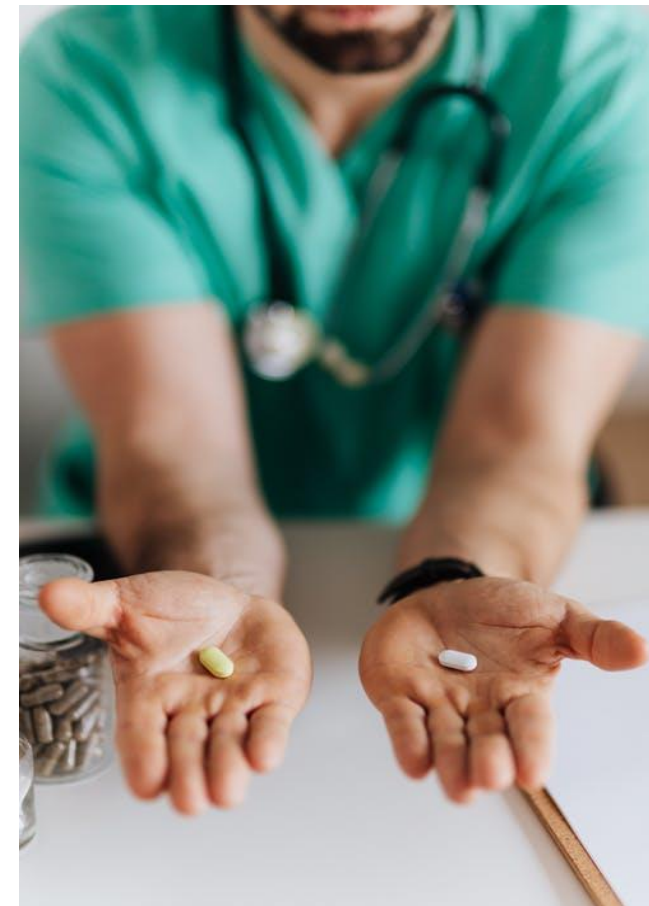


Photo by [Karolina Grabowska](#) from [Pexels](#)

Supported Decision-Making in Action - 4

After a few years, Tony learns how to take care of his medications and pay his bills without Mary's help. Tony decides he wants to end the Agreement.

Tony thanks his sister Mary for helping him learn about his medical and financial needs. Tony tears up the Agreement.

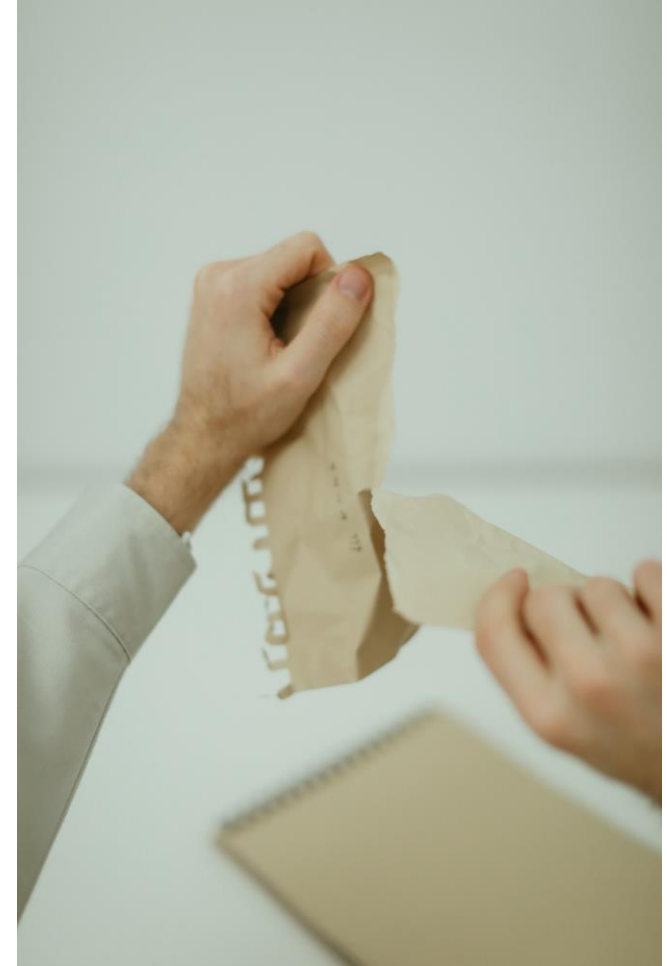


Photo by [Cup of Couple](#) from [Pexels](#)



- The goal of SDM is to recognize a less-restrictive alternative for adults with intellectual or developmental disabilities (ID/DD) who need assistance with decisions regarding daily living.
- The SDM Act emphasizes that all adults are presumed to have the capacity to make their own decisions unless otherwise determined by a court.
- Capacity is not voided simply because of:
 - A person's disability.
 - The manner in which a person communicates.

Frequently Asked Questions - 1

Does the Supported Decision-Making Agreement found in the legislation have to be used?

- The legislation does not specifically require the use of the exact form, only that any agreement substantially follow the legislated form
- This is similar language used in sample forms for Advanced Directives such as a Power of Attorney.
- Most other states with supported decision-making statutes in place incorporate a sample form.

Frequently Asked Questions - 2

Does the Supported Decision-Making form have to be notarized?

- No. The Supported Decision-Making form does not have to be notarized.
- Two (2) However, two witnesses must observe the signing of the agreement.
- The Supporter cannot serve as one of the witnesses.

Frequently Asked Questions - 3

Is a physician's statement required for a Supported Decision-Making agreement?

- No. A physician's statement is not required.

Frequently Asked Questions - 4

Can the adult with an intellectual/developmental disability have more than one Supported Decision-Making agreement?

- Yes, if that is what the person wants.
- More than one Supporter can help gather information to make informed decisions, weigh options, determine risks and benefits and help communicate final decisions made by the person.
- To help avoid conflicts between supporters, any such arrangements should be documented in the Agreement.

Frequently Asked Questions - 5

Within the Agreement, is there a way for the Principal to designate a back-up Supporter in case the Supporter is suddenly not able to function due to illness or death?

- There is nothing in the Act that would prohibit a Principal from adding an addendum to the Agreement that would identify a back-up Supporter.

Contacting Illinois Guardianship and Advocacy Commission



Questions regarding guardianship or disability rights
1-866-274-8023



Resource information on guardianship and disability rights
<https://www2.illinois.gov/sites/gac>

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Questions

Comments

Considerations