Let’s Learn About Supported Decision-Making in Illinois

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Meet the Presenters

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• 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

Non-School Support Release of Information

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.
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.
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 “N/A” 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.
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.
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
Supported Decision-Making

Supported Decision-Making Brochure

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

Supported 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
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. 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.
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.
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.
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.
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.
• 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.
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.
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