

# Need Help Making Decisions?

# Let's Learn About Supported Decision-Making

Stepping Stones of Transition  
17th Annual Illinois Statewide Transition Conference  
Peoria, Illinois  
November 4, 2022



# Speak Up and Speak Out!



What kind of decisions do adults make?

# Speak Up and Speak Out!



Do adults ever need help making decisions?

# Legal Help to Make Decisions in Illinois

- Guardianship
- Supported Decision-Making

# The Supported Decision-Making Act

The purpose of the Supported Decision-Making Act is to provide an alternative to guardianship for adults (age 18 and older) with intellectual or developmental disabilities who need help in making decisions.

The adult who has the Supported Decision-Making Agreement is called the Principal.

# 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 way a person communicates.
- The Principal can choose to act independent of a Supported Decision-Making Agreement.

# Supported Decision-Making is About - 1

- Being involved in your own decisions, regardless of disability or how you communicate.
- Making your own decisions, unless you have a legal guardian.
- Getting help in the way that you want and works best for you.

# Supported Decision-Making is About - 2

- Your beliefs and values being respected.
- Living as you choose if you are not not hurting yourself or anyone else.



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



# Speak Up and Speak Out!



When do we make our best decisions?

# A Supporter is...

an adult who supports the person with intellectual or developmental disabilities with a supported decision-making agreement.

A Supporter is

- someone you trust.
- someone who will listen to you.
- someone who will act on your behalf.
- someone who will keep your record private.



# A Supporter Can Be

- a parent or step-parent.
- a brother or sister.
- a relative such as a cousin, aunt, or uncle.
- a close family friend.
- a person who used to be your teacher at school.

A Supporter will learn what they can and cannot do.



# A Supporter is NOT...

- a boss or employer, unless it is an immediate family member
- an agency that provides services unless it is an immediate family member
- an agency that helps with money.
- a person who has committed abuse and certain crimes.

A Supporter is not someone who does not want to be a Supporter.





**Let's Get Ready for  
Audience Participation!**

# Bianca's Story

Bianca has heard about the Supported Decision Making and is sure that is the option for her. Bianca has worked for the same boss since she was in high school and not only respects her but likes her, too.

Bianca would like her boss to be her Supporter to help her make decisions about money.

What choices does Bianca have?

# Betty's Story

Betty has learned about Supported Decision-Making and is ready to fill out the Supported Decision-Making Agreement. Betty has asked her sister Laura to be her Supporter. Laura tells Betty, "No. I do not want to be your Supporter".

What choices does Betty have?

# Antonio's Story

Antonio wants go to an "R" rated movie at the local movie theater. He can't decide which "R" rated movie to pay for, and he doesn't want to ask his parents. Antonio also doesn't want to waste his money.

Antonio thinks he should ask his Supporter to help him decide which "R" rated movie to pay for.

What are Antonio's choices?



# Ways a Supporter Can Help

- Helping advocate.
- Helping get food, clothes and a place to live.
- Helping with money.
- Helping with medical or counseling appointments.
- Helping apply for benefits
- Helping find work.
- Helping with school.

# George's Story

George is 18 years old and attends high school. He has an IEP (Individualized Education Program) meeting coming up next week.

George is nervous about making decisions about his education by himself and wants his older sister to come to the meeting. George's guidance counselor says she can help him make his decisions. George's mom wants to come to the IEP meeting and continue to make decisions for him.

What choices does George have?

# Supported Decision-Making at School

- If a student is in school and has an Individualized Education Program (IEP) at school, Transition Planning for the future as an adult will begin at age 14½.
- A Transition Plan should include opportunities to practice Supported Decision-Making with the help of the IEP team consisting of parents and school staff.

# Common Transition Goals in an IEP (Individualized Education Program)

Transition goals to include in a plan:

- Classes to take to graduate from high school
- How to make decisions
- Life skills training (money/finances, cooking, cleaning, self-care, etc.)
- Job skills or finding a job
- Education after high school such as college

# Transfer of Parental Rights for Education After Age 18

- A parent's right to make school decisions ends unless a legal guardian has been appointed.
- A student will be able to make all decisions on their own unless they want a parent or someone else to help them.
- A student can think about having a Supported Decision-Making Agreement.
- Parents can continue to be involved only if the student signs a [Delegation of Rights Form](#)

# Remember...

It is important for a student to attend their IEP meetings and speak up and speak out about what they want.

It doesn't matter if a student does or doesn't have a legal guardian or a Supported Decision-Making Agreement.

A student's voice counts!



# Supported Decision-Making Agreement

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

Agencies that help you **must** follow the Agreement unless you tell 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 you based on what you want.
- The Supporter must list an address and phone number.

**IGAG**  
INDEPENDENT GROWTH AND AGING SERVICES

Supported Decision-Making Agreement

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Name: \_\_\_\_\_  
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 initialed 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:**

- 1) help me access, collect, or obtain information that is relevant to a decision, including medical, psychological, financial, educational, housing and treatment records;
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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)
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_____ (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.  
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# 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 Support)**

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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## School Support Release of Information

# Frank's Story

Frank would like to sign a Supported Decision-Making Agreement. Frank has only found one Witness to sign the Agreement, and there is space for two Witnesses.

What choices does Frank have?

# Ending the Supported Decision-Making Agreement

A Principal 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).

# Brian's Story

Brian has a signed Supported Decision-Making Agreement with Luke as his Supporter. Brian wants to cancel the Agreement, while Luke wants to continue his role as Supporter.

What choices does Brian have?



# The Supported Decision-Making Agreement Can Also End If...

The Supporter is found to be abusive or neglectful.

**OR**

There is a court order that the Supporter can't contact the Principal.

# Mabel's Story

Mabel has a Supported Decision-Making Agreement and a Supporter that is supposed to help Mabel do her banking. Mabel has learned that her Supporter is stealing money from Mabel's bank account.

What choices does Mabel have?

# Reporting of Suspected Abuse, Neglect or Exploitation

- You have a right to be free of abuse, neglect and financial exploitation.
- If you or someone else believes that you are being abused, neglected or taken advantage of financially by your Supporter, you or anyone can report this to the Adult Protective Services Hotline:  
1-886-800-1409  
1-888-206-1327 (TTY)

# Terry's Story

Terry is 48 years old and has learned about about Supported Decision-Making. He would like to have a Supported Decision-Making Agreement. Terry's mother does not think that Terry should use Supported Decision-Making.

What choices does Terry have?

# Hank's Story

Hank has a Supported Decision-Making Agreement and has chosen Peter to be his Supporter. Peter has taken control over all of Hank's choices. Peter says that Hank should be grateful for all the help he is giving. Hank does not like Peter taking over his choices.

What choices does Hank have?

# Larry's Story

Larry has a Supported Decision-Making Agreement with Jay as his Supporter to help him with medical decisions. Larry tells Jay he wants to get the COVID-19 vaccine. Jay tells Larry that he should ***not*** get the vaccine.

What choices does Larry have?

# Rachel's Story

Rachel has a Supported Decision-Making Agreement that lists Sally as her Supporter. Sally recently made a decision for Rachel without giving her information or waiting to hear from her.

What choices does Rachel have?

# Dignity of Risk & the Right of Failure

**Dignity of Risk** is the idea that self-determination and the right to take **reasonable risks** are essential for **dignity** and **self esteem** for **everyone**.

Mistakes are teachable moments and provide opportunities for growth, insight and personal transformation.

**Mistakes = Experience**



# Speak Up and Speak Out!



Final questions, comments, considerations?