



# Supporter Training

Supported Decision Making in Illinois: Your Role in Supporting a Person with Intellectual and Developmental Disabilities under a Supported Decision-Making Agreement

*Training Developed by the Illinois Guardianship and Advocacy Commission*

# Illinois Guardianship and Advocacy Commission

This training is being provided by the Illinois Guardianship and Advocacy Commission in consultation with various disability and advocacy organizations and consistent with provisions under the Supported Decision-Making Act, Public Act 102-0614.

# Welcome to Supported Decision-Making in Illinois

- You are taking this training because a Person with Intellectual and Developmental Disabilities (ID/DD) has asked you to enter into a Supported Decision-Making Agreement to provide assistance in identified areas of support.
- Training is not required but highly recommended to ensure that a Supporter understands the role as well as limitations.
- This training will provide you with basic information about fulfilling your role as a Supporter.
- The training will also provide you with additional informational resources to assist you with your role.

# Let's get started with some background information:

- Persons with Intellectual and Developmental Disabilities have faced a history of unnecessary and restrictive guardianships, often when they reach the age of 18, simply because of a disability diagnosis.
- Sometimes Persons with Intellectual and Developmental Disabilities(ID/DD) simply need limited assistance or support with decisions rather than the more restrictive option of guardianship.
- Supported decision-making is a mechanism for persons with ID/DD to identify a supporter to help interpret information, weigh options and communicate the person's decisions in identified areas of support.
- Supported decision-making is an alternative to guardianship. However, guardianship is still an option for an individual who cannot make or participate in decisions and a court determines the individual needs a guardian.

# A Solid and Tested Concept

- Supported Decision Making is not a new concept.
- Several States already have Supported Decision Making Statutes in place and multiple other states have related pilot projects and task forces.
- Foreign Countries as diverse as Israel, Canada, Australia and Croatia have adopted the model and it is recognized by the United Nations.
- A National Center for Supported Decision Making is in place and serves as an ongoing resource at the following link:

[Supported Decision-Making News | Supported Decision Making](#)

# Legislative Journey

- The Guardianship and Advocacy Commission initiated this legislation based on its guardianship work as well as advocacy, including advocacy for persons with ID/DD.
- Several organizations were consulted in the legislation's development including the Illinois Council on Developmental Disabilities, the Arc of Illinois, Adult Protective Services, the National Association of Elder Lawyers and the Illinois Department of Human Services.
- Representative Lindsey LaPointe sponsored the bill in the House and Senator Sara Feigenholtz sponsored the bill in the Senate.
- The Legislation had bipartisan co-sponsorship and support.

# More about the Illinois Guardianship and Advocacy Commission (GAC)

- GAC is a state agency governed by a board of 11 Commissioners appointed by the Governor. Commissioners have disability and human service experience and include legislators from both sides of the aisle.
- GAC has 2 administrative offices; one in Chicago and one in Springfield and it has 7 regional offices.
- GAC has primary programs:
  - Office of State Guardian
  - Legal Advocacy Services
  - Human Rights Authority
  - Special Education Division

# GAC's Primary Programs

Office of State Guardian – Serves as Guardian of last resort for adults with disabilities as appointed by the courts.

Legal Advocacy Services – Provides Legal advice and representation to both children and adults with disabilities most often representing persons facing involuntary mental health commitment or court-ordered treatment.

Human Rights Authority – Investigates complaints of disability rights violations committed against persons with disabilities by disability service providers.

Special Education Division – provides Illinois families with a resource for special education questions and issues.

# Other GAC Services

- Toll-Free Intake Line – For questions regarding guardianship or disability rights:
  - 1-866-274-8023
  - 1-866-333-3362 (TTY)
- Website – Provides resource information on guardianship and disability rights:
  - <https://www2.Illinois.gov/sites/gac/>

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# Legal Advice Disclaimer

- This training is for educational purposes only and is not intended to provide legal advice. When legal advice is required, an attorney who practices in the area of adult guardianships should be consulted.
- [Click Here to Find a Lawyer](#)



# **Module 1: Who Can Serve as a Supporter**

# Supported Decision Making Act

- Supported Decision-Making and the role of the Supporter is governed by the Supported Decision Act which can be found at the following Legislation Link:
- [Illinois General Assembly - Bill Status for HB3849 \(ilga.gov\)](http://ilga.gov)

# What the Act says and doesn't say about Supporters

- While the Act does not specify who CAN serve as a Supporter, it does specify who CANNOT serve as a Supporter.
- The next two slides identify who CANNOT serve as a Supporter.

# Persons who cannot serve as a Supporter (#1)

- An employer or employee of the Principal unless the person is an immediate family member of a Principal;
- A person directly providing paid support services to the Principal unless the person is an immediate family member of the Principal;
- A person who works for an agency that is financially responsible for the care of the principal;
- A person who is listed on the Health Care Worker Registry maintained by the Illinois Department of Public Health as ineligible to work.

# Persons who cannot be Supporters (#2)

- A person who is the subject of a civil or criminal order prohibiting contact with the principal.
- A person who has been convicted of:
  - A sex offense
  - Aggravated assault
  - Fraud
  - Theft
  - Forgery, or
  - Extortion

# Before Agreeing to be a Supporter

- Ensure that you are not disqualified as a Supporter based on the Act requirements.
- Examples of individuals who might serve as a Supporter (as long as not disqualified) might include:
  - A Parent or Step-Parent
  - A Sibling
  - Another Relative such as a Cousin, Aunt or Uncle
  - A Close Family Friend
- An identified Supporter should be knowledgeable of the Person with ID/DD.

# Quiz

- ***Which of the following individuals cannot serve as a Supporter?***
  - A Personal Assistant to the Person with ID/DD who is not a family member
  - A person who works at a group home where the Person with ID/DD lives
  - A Person who has been convicted of theft
  - All of the Above

# Correct Answer

- All of the Above. The Act states disqualifies an individual from being a Supporter if they are providing any care or services to the Person with ID/DD if not a family member, and if they have a conviction of theft as well as other crimes.



## Module 2

# Your Role as a Supporter

- In understanding your role as a Supporter, it is important that you have an understanding of:
  - Underlying principles of the Supported Decision-Making Act
  - Key Definitions
  - Next Steps upon being designated as a Supporter
- The next few slides will share information on these topic areas related to your role as a Supporter

# The Purpose of the Supported Decision-Making Act

*The Act begins with an overall purpose*

“...To recognize a less-restrictive alternative to guardianship for adults with ID/DD who need assistance with decisions regarding daily living.”

# Key Definitions in the Act

- **Adult** – a person who is 18 years of age or older.
- **Everyday life decisions** – decisions that support one's existence, including but not limited to, decisions regarding medical care and treatment, residence, work, finances and social life.
- **Principal** – an adult with ID/DD who seeks to enter, or has entered into a supported decision-making agreement with a supporter under this Act.
- **Supported decision-making agreement** – an agreement between a principal and a supporter under this Act.
- **Supporter** – an adult who has entered into an agreement with a principal under this Act.

# The Act's Guiding Principles (#1)

*The Act also lists specific guiding principles that Supporters must recognize to fulfill their role, including the following:*

- **All adults should be able to live in the manner they choose and can accept or refuse assistance as long as they do no harm and are capable of making decisions.**  
Example: A person with ID/DD may decide that they want to live in their own apartment versus living with parents. A Supporter might be asked to assist with finding an apartment.
- **All adults be informed about and participate in decisions regarding daily living to the best of their ability.**  
Example: A person decides how to plan their day such as when to eat meals or go to bed. A Supporter might help the person set up a daily schedule based on the person's choices.

# The Act's Guiding Principles (#2)

- **That all adults receive the most effective yet least restrictive and intrusive forms of support.**

Example: An individual might only want assistance with scheduling medical appointments and not having anyone present during those appointments. A Supporter would only assist the individual as requested by the individual.
- **That an individual's values, beliefs, wishes, cultural norms and traditions should be respected.**

Example: A person might have different religious beliefs than a Supporter; the Supporter should respect the person's religious beliefs.

# The Act's presumption of capability statement

- Section 15 of the Act stresses that **all adults are presumed to be able to make decisions regarding daily living and to have capacity unless determined otherwise by a court.**
- A presumption of capacity ***is not voided*** simply because of:
  - A person's ID/DD diagnosis
  - The manner in which the person communicates.
- In addition, a Supported Decision Making (SDM) Agreement can't be used as evidence of capacity or incapacity in a civil or criminal proceeding.
- And a **Principal can act independently of an agreement if they choose to do so.**

# Quiz

***A “Principal” defined under the Supported Decision-Making Act is:***

- A. The Person who agrees to be the Supporter.
- B. A Guiding Statement of the Act.
- C. The Adult with ID/DD.

# Answer

- C. The Principal is the Adult with ID/DD who has a Supporter to assist with identified areas of support

# Quiz

***Which of the following Do NOT represent a guiding Principle under the Supported Decision-Making Act.***

- A. A Supporter directs a person with ID/DD to take a certain medication.
- B. A Supporter speaks on behalf of the Principal over home care services without including the Principal.
- C. A Supporter continues to be involved in a decision regarding living arrangements based on the agreement even though the Principal requests that the Supporter no longer assist with the arrangements.
- D. A Supporter communicates a decision to a service provider that is different than what the Principal wants.
- E. All of the Above.

# Quiz Answer

- E. All of the Above. The Guiding Principles of the Act emphasize the choice, participation, preferences, and respect of the Principal. None of the statements in the quiz were representative of the guiding principles.



# **Module 3**

## **Your Duties as a Supporter**

# Supporter's Authority

## *According to the Act:*

“A supporter may exercise the authority granted to the supporter in the supported decision-making agreement.”

This means that the supported decision-making agreement guides the duties of the Supporter.

# What the Act says a Supporter can do (#1):

- *Except as otherwise provided by a Supported Decision-Making agreement, a Supporter may:*
  - **Assist the Principal with understanding information, options, responsibilities and consequences of the Principal's decision, including support services**

Example: A Supporter might help a Principal review options regarding a living arrangement and needed supports within those arrangements.
  - **Help the Principal access, obtain and understand any information regarding a life decision, including medical, psychological, financial, educational decisions or treatment records or other records regarding support services.**

Example: A Supporter might help a Principal review information about a needed surgery, including the risks and benefits.

# What the Act says a Supporter can do (#2):

- **Assist the Principal in finding, obtaining, making appointments for support services.**  
Example: A supporter helps the principal set up and schedule home health services.
- **Help the Principal monitor and track information about services.**  
Example: A supporter helps track the hours that a home care worker provides.
- **Ascertain the wishes and decisions of the Principal, assist in communicating those wishes and decisions to other persons and advocate to ensure that the wishes and decisions of the Principal are implemented.**  
Example: A Supporter shares with a vocational program the Principal's desire to seek community employment.

# Other Supporter Duties and Responsibilities

- A Supporter is also required to do what's right by the person by acting with care, competence and diligence.
- An example would be to carry out duties in a timely manner to the best of the supporter's abilities in the identified areas of support, seeking assistance with questions when needed.

# A Supporter's access to personal information

- A Supporter is only authorized to assist the Principal in accessing, collecting or obtaining information that is relevant to a decision authorized under the SDM agreement.
- If a Supporter assists with accessing information, including protected Health Insurance Portability and Accountability Act (HIPAA) information or educational records under the Family Education Rights and Privacy Act of 1974, the supporter shall protect the confidentiality of those records.
- A Principal can still access records without the assistance of the Supporter.

# Releases of Information

- A Principal will be asked to sign releases allowing a Supporter access to information according to the Supported Decision-Making agreement provisions in the Act.
- The Guardianship and Advocacy Commission has developed releases that can be used and are available on the agency's website.

<https://www2.illinois.gov/sites/gac/>



# **Module 4**

## **Supporter Prohibitions**

# Supporter Prohibitions (#1)

*The Act also specifies what a Supporter cannot do:*

- **Exert undue influence upon or make decisions on behalf of the principal.**  
Example: A Supporter cannot force a Principal to use spending money a certain way or tell a service provider a Principal's decision without involving the Principal.
- **Obtain, without the Principal's consent, information that is not reasonably related to the matters with which the supporter is authorized to assist under the SDM agreement.**  
Example: A Supporter cannot access a Principal's educational information if the Principal has not designated in the Agreement that the Supporter is authorized to assist with education.

# Supporter Prohibitions (#2)

- **Use, without the Principal's consent, information acquired for a purpose other than to assist the principal to make a decision under the Supported Decision-Making agreement.**

Example: A Supporter cannot access a psychological evaluation on the Principal just out of curiosity and not related to any areas of support.

- **Receive compensation for acting as a Supporter except as otherwise provided by this Act.**

Example: A Supporter cannot be paid by the Principal for providing support under an Agreement. A Supporter who is a family member and paid to provide personal care can still be paid for that personal care. However, paid personal care workers other than family members cannot be Supporters.

# QUIZ

***Which of the following can a Supporter do under the Act:***

- A. Provide Support as Designated in the Supported Decision-Making Agreement.
- B. Receive payment for being a Supporter.
- C. Access any and all available information about a Principal.
- D. Pressure the Principal into choosing a particular living arrangement.

# Answer

- A. is the Correct Answer; the Supporter should follow the Supported Decision-Making Agreement, not receive pay for being a Supporter, not access information other than what is needed to assist the Principal, and not pressure the Principal in any decisions.



## **Module 5**

# **Areas of Support (#1)**

Supported Decision-Making can occur in a variety of areas depending on the designated areas identified by the Principal.

The following areas are listed in the Act's Supported Decision-Making Agreement form. The Principal indicates by circling or underlining – and/or initialing the areas in which the Supporter is to assist.

# Areas of Support (#2)

*The Supported Decision-Making Agreement form identifies the following potential areas of support:*

## **Obtaining Food, Clothing and Shelter**

Example: The Supporter might assist with arrangements for purchasing food and clothing. The Supporter might also help the Principal find an apartment and review a rental agreement.

# Areas of Support (#3)

## **Taking care of physical and emotional health**

Example: The Supporter might help the Principal set up medical or counseling appointments, review options for medical treatment, review risks and benefits of medication, and/or participate in a care or treatment plan. If requested by the Principal, the Supporter might accompany the Principal to appointments.

## **Managing financial affairs**

Example: The Supporter might assist the Principal with balancing a checkbook, paying bills or budgeting for expenses.

# Areas of Support (#4)

## Applying for public benefits

Example: The Supporter might assist with gathering documents and applying for Social Security, Medicare, or Medicaid. The Supporter might attend appointments with the Principal to assist with sharing needed information.

## Helping find work

Example: The Supporter works with the Principal to review employment opportunities, complete an application, and practice for an interview.

# Areas of Support (#5)

## **Assisting with Residential Services**

Example: The Supporter might help the Principal to report concerns at a group home. The Supporter might also assist with reviewing group home options and submitting an application.

## **Helping with School**

Example: The Supporter might attend and provide support at an IEP meeting or, the Supporter might help with setting up accommodations for the Principal at a college.

# Areas of Support (#6)

## Helping to advocate

Example: The Supporter, at the request of the Principal, might assist the Principal in filing a complaint involving a service provider or help the Principal prepare for a treatment planning meeting.

# Supported Decision-Making at School

- If the Principal/student has an Individualized Education Program (IEP) at school, Transition Planning will begin at age 14 ½.
- The Transition Plan should include opportunities for the student to practice supported decision-making with the help of the IEP team consisting of parents and school staff.
- Common Transition Plan Goals a student can make with team support:
  - Graduation goals
  - Life Skills Trainings (financial planning, cooking, cleaning, etc.)
  - Vocational Counseling
  - Vocational Training
  - Post secondary education
  - Supported Employment Services
  - Career Development/Job Placement

# Transfer of Parental Rights for Education

- At age 18, unless a guardian has been appointed, parental rights transfer to the student. This should be discussed with the IEP team the year prior to the student's 18<sup>th</sup> birthday.
- This transfer allows the student to make legal and financial decisions, including special education services.
- Schools should discuss the student's right to a Supported Decision-Making Agreement with the student.
- Parent(s) can continue to be involved IF the student signs a Delegation of Rights Form.
  - [https://www.isbe.net/Documents/nc\\_deleg\\_34-57k.pdf](https://www.isbe.net/Documents/nc_deleg_34-57k.pdf)

# Supporter as IEP Team Member

- Students should attend IEP meetings
- A Supporter can attend the meeting with the student and assist with:
  - advocating for their rights and preferences
  - identifying strengths and interests
  - understanding information, issues, and choices so that they may weigh their options
  - selecting educational, employment, and independent living goals
  - accessing educational records when needed

# Remember!!!!

- The Supporter assists the Principal in areas the ***Principal designates***.
- Within those designated areas, the ***Principal decides*** what type of assistance the Supporter provides.
- The ***Principal still makes the final decision*** in all areas of life.



**Module 6**  
**The Supported Decision-Making**  
**Agreement**

# Supported Decision Making (SDM) Agreement

- An SDM is authorized when a **Principal** and a **Supporter sign and date** the agreement in the presence of **2 or more witnesses** who are at least 18 years of age.
- The Principal's Supporter **CANNOT** serve as a witness to the SDM agreement.
- An agreement is valid if it substantially follows the form included in the legislation. A link to the form can be found at the following link on the GAC website: <https://www2.illinois.gov/sites/gac/>

# Components of a SDM Agreement #1

- ***The Agreement begins with the Supporter's acknowledgement of duties to:***
  - Act in good faith
  - Act within the authority of the agreement
  - Act loyally and without self-interest
  - Avoid conflicts of interest

# SDM Agreement Components (#2)

- The Principal designates the Supporter and lists the Supporter's
  - Name
  - Address
  - Phone number
  - E-mail address

# SDM Agreement Components (#3)

- The Principal identifies by initialing the areas in which the Supporter is to assist. The areas of support may include one, a combination of areas or all of the following:
  - Obtaining food, clothing, shelter
  - Taking care of physical and emotional health
  - Managing financial affairs
  - Applying for public benefits
  - Helping to find work
  - Assisting with residential services
  - Helping with school
  - Helping to advocate.

# SDM Agreement (#4)

- ***The agreement specifically states that the Supporter is NOT to make decisions for the Principal but may:***
  - Help access, collect, or obtain information regarding a decision,
  - Help the principal understand options to make a decision
  - Help communicate a principal's decision to appropriate persons.

# SDM Agreement (#5)

- ***The agreement includes a section that allows the principal to identify by initialing the types of releases for information the Supporter may need to carry out the Supporter role such as:***
  - Access to protected health information under HIPAA ([link to release](#))
  - Access to confidential mental health or developmental disabilities information under the Mental Health and Developmental Disabilities Confidentiality Act ([link to release](#))
  - Access to educational records under the Family Educational Rights and Privacy Act of 1974 and the Illinois School Records Act ([link to release](#))
  - Access to substance abuse records under the Confidentiality of Alcohol and Drug Abuse Patient Records regulations ([link to release](#))

# SDM Agreement (#6)

- The agreement
  - Allows for the principal to identify an **effective date and signature date**
  - Requires the **Principal's signature** and printed name
  - Requires the **Supporter's signature** and printed name
  - Requires the **signatures and printed names of two witnesses**

The agreement concludes with a **warning regarding abuse, neglect or exploitation** of a Principal by a Supporter and includes contact information for Adult Protective Services for anyone who is concerned about the Supporter's behavior toward the Principal.

# Reliance on an Agreement

- The Supported Decision-Making Act also states that;
  - **A person who receives the original or a copy of a supported decision-making agreement shall rely on the agreement.**
    - Example: A residential service provider who receives a copy of an agreement that a sibling of a resident is a Supporter under the area of residential services can include the Supporter in communications along with the resident.
  - **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.**
    - Example: A residential service provider cannot be accused of a confidentiality breach for including a Supporter in communications if the supported decision-making agreement includes the area of residential services and there is a signed release.

# Supporter Recognition

- ***The Act also states that:***

**“A decision or request made or communicated with the assistance of a supporter in conformity with this Act shall be recognized for the purposes of any provision of law as the decision or request of the principal and may be enforced by the principal or supporter in law or on the same basis as a decision or request of a principal.”**

Example: A Supporter and Principal together communicate a Principal’s decision to consent to psychotropic medication; the physician prescribing the medication can rely on that consent in the same way as if the consent was given directly by the Principal.

# Things to Remember About Supported Decision Making Agreements

- The agreements clarify the **areas in which the Supporter can provide assistance**. A copy can be provided at the time of assistance or copies can be given to relevant service providers.
- They should typically include **releases of information** which any related service providers may require copies of or a service provider may require the Principal to sign one of its releases.
- Service providers can **rely on the agreements** and include Supporters as indicated in the agreements.
- The agreements should be **completed** in their entirety.
- Another agreement can be used but it should include all the same elements as required in the Act.

# QUIZ

- ***Which of the following are NOT true regarding a supported decision-making agreement?***
  - A) The agreement allows the Supporter to access, collect or obtain information regarding a decision.
  - B) The agreement allows the Supporter to understand options to make a decision.
  - C) The agreement allows the Supporter to make decisions for the Principal.
  - D) The agreement allows the Supporter to help communicate a Principal's decision to appropriate persons.

# Answer

- C is the incorrect answer. An agreement does not allow a Supporter to make a decision on behalf of the Principal.

# Quiz

- ***What are the components of a Supported Decision-Making Agreement?***
  - A) The identified areas of support.
  - B) Contact information of the Supporter.
  - C) Signatures of both the Supporter and Principal.
  - D) Two witness signatures.
  - E) All of the above.

# Answer

- E. All of the listed items are to be included in a supported decision-making agreement.



# **Module 7**

## **Terminating A Supported Decision-Making Agreement**

# Terms of a Supported Decision-Making Agreement

- The Act says that a supported decision-making agreement extends until terminated by either party or by the terms of the agreement.
- It is also important to note that the last signed agreement holds.

# Ways in which a Supported Decision-Making Agreement can be Terminated:

- 1) The Office of Inspector General or Adult Protective Services **substantiates an allegation of abuse or neglect** by a supporter.
- 2) There is a **restraining order** against the Supporter by the Principal.

# Ways in which a Principal can Revoke and Agreement:

*A Principal can revoke and invalidate the agreement at any time by doing one of the following:*

- 1) **Canceling or destroying the agreement** or directing another in the presence of the principal to destroy the agreement.
- 2) **Executing a statement, in writing**, that is signed and dated by the principal, expressing his or her intent to revoke the agreement.
- 3) **Verbally expressing** the intent of the Principal to revoke the agreement in the presence of 2 witnesses.

# How can a Supporter resign?

- Unless the supported decision-making agreement provides a different method for the resignation of the Supporter, a Supporter may resign by giving notice to the Principal.
- The Supporter should provide ample notice of a resignation, such as two weeks, so that the Principal is not left in a difficult situation.

# Quiz

## True or False?

To invalidate a supported decision-making agreement, a Principal must revoke the agreement in writing.

# Answer

- **False**

- A Principal can revoke by destroying the document, asking someone else to destroy the agreement in the presence of the principal, making a written statement of revocation, or verbally expressing revocation in the presence of 2 witnesses.



# **Module 8**

## **Abuse, Neglect and Exploitation**

# Reporting of Suspected Abuse, Neglect or Exploitation

- 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 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:
  - 1-886-800-1409
  - 1-888-206-1327 (TTY)

# Case Study #1

Kathy, a person with Down Syndrome, asks her Aunt Judy to be her supporter for medical decisions as she is facing gall bladder surgery and is unsure of how to approach it.

- a. How would the Supported Decision-Making agreement be set up?
- b. What kinds of information would Judy help Kathy access?
- c. What else might Judy help with?
- d. Who would sign the consent for surgery?

# Case Study #1 Responses

- a. Kathy would complete the Supported Decision-Making Agreement stating that Judy would be her Supporter and she would initial the area of support pertaining to medical decisions. Two individuals would witness the signatures of both Kathy and Judy – perhaps staff at a facility where Kathy receives services, other family members or staff at a doctor’s office. Kathy would also sign a release allowing Judy to access her medical records.
- b. Judy would help Kathy gather information about pros/cons of surgery, appointment information and instructions, and follow-up instructions.
- c. Judy might attend appointments or surgery with Kathy if Kathy requests this, review information with Kathy, help Kathy identify and ask questions, and keep in touch with Kathy after the surgery.
- d. Kathy would still give the final consent and sign the consent form.

# Case Study #2

Ben is 18 years old, has a diagnosis of an intellectual disability and attends school where he receives special education services. He asks his cousin Max to be his Supporter and help him with school services as well as transitioning to adult services including residential and vocational services.

- a. What areas of support should be indicated on the agreement?
- b. Would releases be needed for all areas?
- c. How might Max support Ben?

# Case Study #2 Responses

- a. Ben might initial the areas of support pertaining to school, employment, residential services and perhaps even public benefits.
- b. A release would be needed for school. Releases may eventually be needed for employment and residential services if a service provider is identified. A release might also be needed for public benefits. Ben would also need to sign a Delegation of Rights Form allowing Max to be involved in school decisions.
- c. Max might attend IEP meetings with Ben, help Ben gather information about different adult service providers, help Ben visit different providers and help Ben complete applications for public benefits. Ben would make the final decisions regarding IEP goals, adult service providers and sign off on public benefit applications and then receive those public benefits.

# Case Study #3

Ellen, who has Cerebral Palsy, and her mother, Joyce, mutually agreed to a supported decision-making agreement in all areas of support when Ellen turned 18. However, Ellen is now 23, lives in her own apartment with services and has a community job. Ellen doesn't think she needs the agreement for anything other than to assist with money management.

- a. How can Ellen change the agreement to be just for money management?
- b. What kinds of things can Joyce assist Ellen with in an agreement concerning money management?

# Case Study #3 Responses

- a. Ellen can simply destroy the existing agreement, let Joyce know and then ask Joyce if she would be a Supporter for money management only. If Joyce agrees to be a Supporter for money management only then both Ellen and Joyce can institute a new agreement for money management only and complete any needed releases if Ellen wants Joyce to have access to her bank records.
- b. Joyce might help Ellen develop a budget, review bills, pay bills and balance her bank account. Joyce might help Ellen set up direct deposits of income and automatic withdrawals for bills. Joyce would not necessarily have access to Ellen's bank accounts or bank account information.



# **Module 9**

## **Resource Information**

# Abuse, Neglect, Exploitation Reporting

<b>Dept. of Human Services Licensed Facilities</b> (e.g. community integrated living arrangements (CILAs), day/vocational programs, state-operated centers)	<b>Office of Inspector General, 24-hour hotline</b> 1-800-368-1463 Voice/TTY
<b>Abuse/Neglect of a person with a disability, age 18+, in a domestic setting</b>	<b>Adult Protective Services</b> 1-866-800-1409 1-888-206-1327 (TTY)
<b>Abuse/Neglect in hospitals, nursing homes or group homes licensed by the Dept. of Public Health</b>	<b>Illinois Department of Public Health</b> 1-800-252-4343
<b>Sexual Assault of a Person with Disabilities</b>	<b>Any local Rape Crisis Center</b>  <b>Illinois Coalition Against Sexual Assault</b> 217-753-4117
<b>Domestic Violence</b>	<b>Domestic Violence Help Line</b> 1-877-863-6338 (voice) 1-877-863-6339 (TTY)
<b>Human Trafficking</b>	<b>National Human Trafficking Resource Center</b> 1-888-373-7888

# Advocacy Resources #1

**Legal advice and assistance for persons with disabilities, including assistance with involuntary mental health admission, court-ordered medication, mental health declarations**

**Legal Advocacy Service  
II. Guardianship and Advocacy  
Commission**

1-866-274-8023

1-708-338-7500 (out of state callers)

1-866-333-3362 (TTY)

<http://gac.state.il.us>

**Disability Rights Violations**

**Human Rights Authority  
II. Guardianship and Advocacy  
Commission**

1-866-274-8023

1-708-338-7500 (out of state callers)

1-866-333-3362 (TTY)

<http://gac.state.il.us>

**Federally Mandated Protection & Advocacy System for Illinois**

**Equip for Equality**

1-800-537-2632 (voice)

1-800-610-2779 (TTY)

# Advocacy Resources #2

The Client Assistance Program (CAP) helps people with disabilities receive quality services by advocating for their interests and helping them identify resources, understand procedures, resolve problems, and protect their rights in the rehabilitation process.

**Client Assistance Program**  
100 S. Grand Ave. E, Basement  
PO box 19429  
Springfield, IL 62794-9429  
Phone: 1-800-641-3929  
TTY: 1-888-460-5111  
Email: [dhs.cap@illinois.gov](mailto:dhs.cap@illinois.gov)

Website: <http://www.dhs.state.il.us/page.aspx?item=37637>

The Illinois Long-Term Care Ombudsman Program (LTCOP) is a resident-directed advocacy program which protects and improves the quality of life for residents in a variety of long-term care settings.

**Senior HelpLine**  
Monday - Friday, 8:30 a.m. - 5:00 p.m. CST  
Toll-free: 1-800-252-8966,  
1-888-206-1327 (TTY)  
Phone: 217-524-6911  
FAX: 217-524-6968  
E-mail: [aging.ilsenior@illinois.gov](mailto:aging.ilsenior@illinois.gov)

Discrimination complaints with respect to employment, financial credit, public accommodations and real estate transactions.

**Illinois Department of Human Rights**  
100 West Randolph Street  
10th Floor  
Intake Unit  
Chicago, IL 60601  
(312) 814-6200  
(866) 740-3953 (TTY)

# Adult Disability Services Resources

**Adult developmental disability and mental health services**

**Department of Human Services**

1-888-337-5267 (voice)

1-866-376-8446 (TTY)

<http://www.dhs.state.il.us>

**Centers for Independent Living**

**Illinois Network of Centers  
for Independent Living**

217-525-1308

1-800-587-1227

**Employment and Vocational Resources**

**II. Department of Human Services**

1-888-337-5267 (voice)

1-866-376-8446 (TTY)

<http://www.dhs.state.il.us>

**Illinois Department of Rehabilitation Services**

1-877-761-9780 Voice

1-866-264-2149 TTY

(312) 957-4881 VP

[DHS.DRS@illinois.gov](mailto:DHS.DRS@illinois.gov)

# Americans with Disabilities Act Resources

<b>Information and Education about the ADA</b>	<b>Great Lakes ADA Center</b> 1640 W. Roosevelt Road · Room 405 Chicago, IL 60608 (312) 413-1407 (V/TTY) or (800) 949-4232 (V/TTY) (312) 767-0377 (Video Phone) (312) 413-1856 (Fax)
<b>To file an ADA complaint</b>	<b>US Department of Justice</b> 950 Pennsylvania Avenue, NW Civil Rights Division Disability Rights Section – 1425 NYAV Washington D.C. 20530 To file by fax: (202) 307-1197 <a href="https://www.ada.gov/complaint/">https://www.ada.gov/complaint/</a>
<b><i>Protects rights of persons with disabilities with regard to equal access to buildings, housing and services, including Environmental Barriers Act.</i></b>	<b>Illinois Attorney General</b> 312-814-5684 (Chicago) 1-800-964-3013 (TTY) <a href="http://www.illinoisattorneygeneral.gov/rights/drb_complaintform.pdf">http://www.illinoisattorneygeneral.gov/rights/drb_complaintform.pdf</a>

# Legal Resources

**Assistance with legal problems that including the following:**

- Housing
- Family
- Consumer
- Homeownership
- Public Benefits and Health
- Services for Senior Citizens and Disabled Persons
- Education

**Land of Lincoln  
Legal Assistance Foundation, Inc.**

Legal Advice and Referral Center  
Mon. – Thurs.: 9 a.m. to 4 p.m.  
Friday: 9 a.m. to 1:30 p.m.  
Toll Free: (877) 342-7891

***Free legal services for low income persons and those age 60 and over who have serious civil legal problems and need legal help to solve.e them.***

**Prairie State Legal Aid  
Administrative Office**

303 N. Main, Suite 600  
Rockford, IL. 61101  
(815) 965-2134  
Fax: (815) 965-1081  
<https://www.pslegal.org/psls-locations-detail.asp?locID=17>

# School Resources #1 – Special Education Questions and Concerns

## **Illinois State Board of Education**

217-782-5589

312-814-5560

<https://isbe.net>

## **Office of Civil Rights**

**Chicago Office**

**Office for Civil Rights**

**U.S. Department of Education**

Citigroup Center

500 W. Madison Street, Suite 1475

Chicago, IL 60661-4544

Telephone: 312-730-1560

FAX: 312-730-1576; TDD: 800-877-8339

Email: [OCR.Chicago@ed.gov](mailto:OCR.Chicago@ed.gov)

## ***Illinois Guardianship and Advocacy Commission – Special Education Division***

401 Main St., Suite 620, Peoria, IL. 61602

Contact: Laura Hart (309-673-3030)

# **School Resources #2**

**Parent and Family Information/Special Education Information  
(For Cook County Only)**

**Family Resource Center on Disabilities**

1-312-939-3513

<https://frcd.org>

**Parent and Family Information/Special Education Information  
(For All Counties outside Cook County)**

**Family Matters Parent  
Training and Information Center**

1-866-436-7842

<http://www.fmptic.org>

# Supported Decision Making Resources

- **Illinois Guardianship and Advocacy Commission:**

<https://www2.illinois.gov/sites/gac>

- **National Center for Supported Decision-Making:**

[www.supporteddecisionmaking.org](http://www.supporteddecisionmaking.org)

# Frequently Asked Questions #1

## ***What other states have this statute?***

Ten states and the District of Columbia have supported decision-making statutes in place including, Wisconsin, Missouri, Texas and Delaware; multiple other states have related pilot projects and task forces.

## ***Why a prescribed form?***

The form was inserted into the legislation to be used at face value or as a guiding document. Other states use a prescribed form. Prescribed forms are used in advanced directives such as Powers of Attorneys.

# Frequently Asked Questions #2

## *What might be a way to establish a supported decision-making agreement?*

A person with a disability may seek assistance from a family member or friend on a routine basis in specific areas. Such an arrangement can then be formalized into a written agreement and presented to involved service providers, medical providers, etc. The Principal and Supporter should go through the items and discuss needs, questions, parameters and concerns before finalizing. And, both the supporter and principle should take the training offered at the GAC website: <https://www2.Illinois.gov/sites/gac/>

# Frequently Asked Questions #3

***What are specific questions a Supporter might ask a Principal in the development of an agreement?***

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?

# Frequently Asked Questions #4

## *What are ways in which a Supporter involves a Principal?*

- Ensure that the Principal understands what you are doing or have done for the Principal.
- Review any information obtained regarding a decision directly with the Principal.
- Ensure that any service providers are aware of your duties, limitations and that the decision is still in the hands of the Principal.
- As much as possible, ensure that the Principal is present when information is gathered or decisions are made.

# Frequently Asked Questions #6

## ***Is a notary required to finalize a supported decision-making agreement?***

To ensure adequate accessibility for persons with disabilities, a notary is NOT required to formalize an agreement. However, two witness signatures are required and the proposed Supporter CANNOT be one of the witnesses.

## ***Is a physician's statement required for an agreement?***

NO

# Frequently Asked Questions #7

## ***What are some examples of how an agreement might work?***

A Supporter would help an individual weigh options about living situations, work, medical choices and relationships. A Supporter might marshal resources for the individual to consider, help focus a treatment team, communicate information and assist with questions.

## ***Is Guardianship still an option?***

Guardianship would still be an option for persons who truly lack decisional capacity as determined by the courts.

# Frequently Asked Questions #8

## *Can an individual have more than one Supporter?*

There is nothing in the Act that would prevent an individual from having more than one Supporter, however, there should be a clear understanding of the role and areas of support for each Supporter.

# Frequently Asked Question #9 (slide 1 of 3)

***How does a potential Supporter determine that the principal is someone with an intellectual/developmental disability?***

Under the Mental Health and Developmental Disabilities Code (405 ILCS 5/1-116) an ***intellectual disability*** means significantly subaverage general intellectual functioning which exists concurrently with impairment in adaptive behavior and which originates ***before the age of 18 year***.

The same Code in Section 5/106 defines a developmental disability.

# Question #9 Continued (slide 2 of 3)

Under the Code, a ***developmental disability*** means a disability which is attributable to : (a) an intellectual disability, cerebral palsy, epilepsy or autism; or (b) any other condition which results in impairment similar to that caused by an intellectual disability and which requires services similar to those required by persons with an intellectual disability. Such disabilities must ***originate before the age of 18 years***, be expected to continue indefinitely, and constitute a substantial disability.

# Question #9 (slide 3 of 3)

Most often individuals with an intellectual or developmental disabilities have a related **diagnosis** such as intellectual disability, Down Syndrome, autism, cerebral palsy, spina bifida, fetal alcohol syndrome or fragile X syndrome.

Frequently individuals with an intellectual or developmental disability will have received **services** associated with early intervention, physical/speech/occupational therapy, special education, or Department of Human Services licensed residential or vocational services.

If in doubt, a Supporter can always ask for confirmation of an intellectual or developmental disability such as a physician's statement, psychological or other type of evaluation, school record, etc.

# Frequently Asked Question #10

***How does a Supporter determine that the Principle is not already subject to a court-appointed guardian?***

Certainly, the Supporter can ask the Principal if there is an existing guardianship. Otherwise, guardianships for adults are public records and the Supporter can check for the Principal's name in court records of any county of residence maintained by the Principal. Most courts have an on-line system for checking court records or a Supporter can call the circuit clerk's office in the county of residence to inquire about accessing adult guardianship records.

# Final Points

- Supported Decision-Making is just that – SUPPORT – the individual with the disability still maintains decision-making authority and makes all final decisions. There is a difference between making a decision and supporting the decisions of the individual.
- A Supporter and the Principal should have a clear understanding of the Supporter's role and it should be documented into a Supporter agreement.
- The Agreement should be presented to any involved service providers when a Supporter is providing assistance.
- The Agreement should be completed in its entirety.
- There are resources for investigating abuse, neglect and exploitation should there be such issues with Supporters.

# More Final Points

- It is possible that Parents may serve as Supporters. Even when Parents serve as Supporters, the Principal's decision is the final decision even when there are disagreements.
- Supporters and Principals may need to educate doctors, hospitals, dentists and other providers about supported decision-making and refer such professionals to training materials.

# Certificate of Completion

By signing this statement, I attest that I have taken Supporter Training offered by the Illinois Guardianship and Advocacy Commission as to my duties under the Supported Decision-Making Act (Public Act 102-0614).

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Signature of Supporter

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Date