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## **Guardian Frequently Asked Questions Regarding Sex Education for Adults with Intellectual and Developmental Disabilities**

### **1. Where do I find the legislation that outlines sex education requirements?**

The following link will take you to Public Act 101-0506:

<https://www.ilga.gov/legislation/publicacts/fulltext.asp?Name=101-0506>

### **2. What types of facilities must comply with the law?**

CILAs, ICFDDs, including 16-bed facilities, state-operated facilities and day programs. If an individual lives in a CILA and also attends a day program, he/she can decide which entity will provide the sex education.

### **3. What resources are available on the sex education?**

- The Illinois Department of Human Services has resources to assist provider organizations comply with the law at the following link  
<https://www.dhs.state.il.us/page.aspx?item=122403>
- The Illinois Guardianship and Advocacy Commission has resources posted on the following link  
[https://www2.illinois.gov/sites/gac/Pages/Sex-Education-for-Adults-with-ID\\_DD-Public-Act-101-0506.aspx](https://www2.illinois.gov/sites/gac/Pages/Sex-Education-for-Adults-with-ID_DD-Public-Act-101-0506.aspx)
- The Illinois Self-Advocacy Alliance also has information available on its website at the following link  
<http://selfadvocacyalliance.org/resources>

### **4. What role do guardians play in deciding whether someone is assessed or has access to sex education?**

According to the Act, if an individual has a court-appointed guardian, the guardian is to be part of the treatment team that determines a person's decision-making capacity to consent to sexual activity and developmentally appropriate sex education materials and resources. Guardian decision-making shall be made in accordance with the court order of appointment and the standards of decision making established by Section 11a-17 of the Probate Act of 1972 which include substituted judgement first and then best interests second. Probate Act information about the standards of decision making can be found at the following link:

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<https://www.ilga.gov/legislation/ilcs/ilcs4.asp?DocName=075500050HArt%2E+XIa&ActID=2104&ChapterID=0&SeqStart=14300000&SeqEnd=17750000>

The Guardianship and Advocacy Commission has developed a guardian fact sheet for reference which includes information about addressing conflicts with guardians. The guardian fact sheet can be found at the Commission web page at the following link: <https://www2.illinois.gov/sites/gac/Documents/Guardian%20Fact%20Sheet.pdf>

## **5. What are my basic responsibilities as a guardian?**

Even though you may be a family member, such as a parent of an adult person with a disability:

- Your role as guardian is a special legal relationship with legal responsibilities that are different from your role as parent or other family member;
- You must comply with the Probate Act and the court order appointing you as guardian;
- Your actions as the legal guardian of a ward are accountable to the court.

## **6. What are things I should consider when making decisions for my ward?**

The Probate Act requires you to consider the following when making decisions for your ward:

- Will this decision help the person become more independent?
- Will this decision help the person with their self-reliance?
- Will this decision be the least restrictive option for the person?
- Is this decision focused on the person with the disability?

## **7. What are decision-making approaches I should use?**

**First**, check your court order regarding the type of decisions you are permitted to make. If you have a plenary guardianship order, you will be able to make all decisions that are allowed by law. If you have a limited or temporary guardianship order, the order will specify what decisions you are authorized to make.

**Second**, know the Probate Act standards for decision-making. The Probate Act requires you to make decisions in one of two ways:

- a. Primarily, decisions are to be made using *Substituted-Judgment* decision making.
- b. Alternatively, decisions can be made using *Best-Interest* decision making if you are unable to use Substituted-Judgment to make decisions for your ward.

## **8. What is meant by substituted-judgment decision making?**

You are to act as the substitute for the person with a disability, meaning, you do what your ward would do if your ward could make the decision on their own. You decide what your ward would want based on your ward's past statements, interests, religious beliefs, preferences, past behavior, etc. If the ward currently has the ability to reasonably express a preference, the guardian should also take that into consideration when making the decision for the

person. Note: the decisions you make for your ward may not to be the same decisions you would make for yourself.

Substituted-Judgment decision making must be applied whenever possible. Best Interest decision making should only be used when Substituted-Judgment is impossible.

The point: People have the freedom to make their own decisions based on their personal beliefs, thoughts and abilities. This freedom includes the right to make bad decisions, like: overeating, hanging out with questionable friends, and wearing jeans to a formal dinner. Guardians must be mindful that they cannot use their position as guardian to impose their will on an adult who has a will of their own - even if the adult ward is their child.

### **9. What is meant by Best-Interest Decision Making?**

When Substituted-Judgment decision making is impossible, you need to weigh all the risks and benefits of making the decision in question, and you choose what is in your ward's best interest.

### **10. What is meant by informed consent and how can I sure that I make decisions based on informed consent?**

- In non-emergency situations, physician and other providers must obtain **informed consent** (permission) from the guardian before treatment or services are provided for a ward under guardianship.
- The guardian is entitled to get the same information their ward would receive if their ward didn't have a disability (Think, medical records, and information about benefits and side effects of a given medication, etc.).
- HIPAA allows healthcare providers to share information with guardians.
- The guardian is entitled to have sufficient information to give informed consent for treatment or services, including:
  - a. The proposed treatment;
  - b. The risks, benefits and side effects of treatment;
  - c. The expected outcome of treatment;
  - d. Any alternatives to the treatment and the risks and benefits of those alternatives.

### **11. What are my rights as a guardian?**

You are responsible for giving informed consent to many people who will provide care and services for your ward. In order to do that you will have to exercise your rights.

#### **You have a right to:**

- participate in treatment and care planning;
- access and talk to professionals involved in your ward's care;
- look at, and obtain, a copy of your ward's records including medical records (this is allowed under HIPAA);
- access your ward's residence;
- be notified of incidents, injuries and changes in your ward's condition;

- authorize a representative payee for Social Security benefits.

## **12. Does the individual for whom I am guardian maintain rights with regard to sex, sex education and relationships?**

Persons with a disability have a right to have sex

- The ward's right to have sex includes their right to sexual education and their right to privacy.
- The person with a disability must be able to give and obtain consent from their sexual partner. The disabled person only needs a basic understanding of the risks, benefits and consequences of a sexual relationship to exercise this right .

Persons with a disability have a right to get married

- Persons with a disability have a right to get married as long as they have the ability to understand the nature of marriage.
- A guardian cannot stop a marriage of their ward without a court order.
- A guardian can pursue a divorce for their ward, but must get court approval before filing any action for divorce.

## **13. What are key things I should remember when making decisions?**

Every Decision You Make Should Start with These Three Questions

- Is this the least restrictive form of care or service available?
- Am I making a person-centered decision?
- Will this decision maximize my ward's independence?

## **14. Where can I find more information about my role as a guardian?**

<https://www2.illinois.gov/sites/gac/Pages/default.aspx>

## **15. Questions Guardians might have regarding sex education:**

- **Do faith-based organizations have to comply with the law?** Yes, faith-based providers must comply with the law; the sex education provided should take into account the individual's needs, preferences and perspectives, including any faith-based perspective.
- **Is there a licensure requirement/degree required by staff who will be providing sex education:** No, however, website resources include considerations for selecting staff for assessments and education; a train the trainer webinar series is being developed. Selected staff should be: sensitive to the topics; be aware of past trauma; possess skills and knowledge level to assess/educate; be comfortable with the topics covered; and demonstrate respect toward the individual. Gender compatibility may be a consideration.
- **Is there a specific assessment tool and curricula to be used and how frequent will assessments be done?** No specific tool is required; guidelines for assessing and pre-approved curricula are available on the DHS website. Providers can submit curricula for DHS approval. There is no mandated assessment schedule but may part of the annual planning process to confirm needs, gaps or updates.

- **What if the individual is not interested in sex education?** If an individual does not want sex education, this should be clearly documented; the provider should re-visit if the individual expresses future interest. Consideration should be given as to whether the individual would benefit from education on self-protection.
- **Who will monitor compliance?** The DHS Bureau of Quality Management will evaluate provider compliance during quality reviews.