



“Fact Sheet on Sex Education for People with Disabilities who have Legal Guardians” For Consumers

What is Guardianship?

- A legal relationship that is created when a judge names a guardian to help a person with a disability.

What is The Probate Act?

- It is the law that allows a court/judge to name a guardian. It imposes duties and court oversight upon the guardian with respect to how the guardian can act on behalf of the person with a disability (PWD) (also referred to as the ward)
- It regulates the guardian’s legal relationship with the ward
 - A close relative (parent, sibling, aunt/uncle) of the PWD may be appointed guardian and must act in accordance with the Probate Act

Types of Guardianship

- Limited Guardianship
 - Does not result in the person being found legally incompetent
 - Authority is granted is for a specific purpose and is not all-encompassing
 - Authority can be broad or narrow and is designed to meet a specific need
- Plenary Guardianship
 - Grants the guardian full authority under the Probate Act
 - “Letters of Office” is the document that proves that a person has been named a guardian by the court.
 - “Letters of Office” are issued by the clerk of courts

“Order of Appointment”

- Also called “Order”
- Establishes guardianship
- Outlines if it is for a guardian of the person (giving the guardian authority to arrange for services and placement) or a guardian of the estate (giving authority to manage finances)
- Says if guardianship is temporary or long term
- Says if guardianship is Limited or Plenary

NOTE: It is important for service providers to determine if guardianship is Limited or Plenary. While the “Letters of Office” can be relied upon, it is recommended that the provider obtain a physical copy of the Order of Appointment as this document is the one the court has entered.

General Guardianship Standards

- The guardian will first use “Substituted-Judgment” and when that is not available will make decisions in the “best- interests” of the PWD
- “Substituted judgment” means that for a PWD who has the ability to express desires, the guardian must act in conformity with those desires unless it is clear that harm would result to the ward. When the PWD lacks such ability, the guardian may act in what is considered the PWDs’ best interests
- The “Substituted-Judgement” approach to decision making has been adopted as the accepted practice by the National Guardianship Association that provides guidance to professional guardians across the country
- Medicaid rules require the legal guardian’s participation unless it is unobtainable or inappropriate

Medicaid rules require the legal guardian's participation unless it is unobtainable or inappropriate. Surveyor guidance on inappropriate states:

"Inappropriate", for the purposes of this guideline, means that

- the parent or legal guardian's behavior is so disruptive or uncooperative that others cannot meaningfully participate, the client does not wish his or her parent to participate, and the client is competent to make this decision; or
- there is strong and documented evidence that the parent or legal guardian is not acting on the client's behalf or in the client's best interest. In the case of the latter, determine what the facility has done to bring effective resolution to the problem

People with Disabilities Exercising Reproductive Rights

- The part of the Probate Act dealing with sterilization establishes that PWD's are considered to have the ability to decide for themselves even when they have been appointed a guardian, so long as they can understand the relationship between sexual activity and reproduction and the consequences of reproduction (pregnancy).
- From both the Medicaid regulations and the Probate Act, PWD's who have sufficient ability to decide whether they want sex education should be allowed to do so
- The issue then becomes what can be done when the guardian still refuses to consent.

People with Disabilities who have Legal Guardians Have the Right to Access Counseling

Effective July 12, 2019, Public Act 101-0059 revised the Mental Health and Developmental Disabilities Code ([405 ILCS 5/2-101.1](#)) to allow any adult with a guardian to receive counseling or psychotherapy, including counseling related to sexual assaults, without guardian consent or notice for twelve 60-minute sessions.

Managing Disagreements About Sex Education

- Reproduction is a Constitutional Right and a major life activity
- under the ADA (Americans with Disabilities Act)
- Sex education supports the constitutional right to reproduction
- The Probate Act was amended to provide a mechanism for balancing the right of the PWD to have a child with the authority of a guardian to prevent that.
- Medicaid regulations and guidance to surveyors provides general guidance on how to manage disagreements between the interdisciplinary team, PWD and guardian

Centers for Medicare and Medicaid regulations and guidance to surveyors can be found [here](#). Information about legal guardians can be found in Sections 483.420 and 483.440)

NOTE: Generally, a service provider that is providing sex education will be dealing with long term plenary guardians of the person. It is important to determine if the guardianship is limited or plenary because under limited guardianship the person is not considered legally incompetent and can make decisions in all areas where the court has not given authority to the guardian.

Conflict resolution for managing disagreements related to guardianship and exercising reproductive rights is available:

- [Independent Service Coordination \(ISC\)](#) agencies are contracted by DHS to provide advocacy support and conflict resolution to persons served under the waiver
- [Equip for Equality](#) is the Illinois protection and advocacy agency for persons with disabilities. It has funding to provide advocacy and litigation support for persons with developmental disabilities
- Contact the Judge: The Probate Act provides that a request by the ward or any person acting on behalf of the ward may be communicated to the judge by any means including letter, telephone call or visit. In response the court may appoint guardian ad litem to investigate the request

Helpful Links

Illinois Guardianship and Advocacy Commission

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

Illinois Guardianship Association

<http://illinoisguardianship.org>

National Guardianship Association

<https://www.guardianship.org/>

Public Act 101-0506 regarding sex education for adults with ID/DD
(Intellectual and Developmental Disabilities)

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

Illinois Probate Act Section on Adult Guardianship

[http://www.ilga.gov/legislation/ilcs/ilcs4.asp?DocName=075500050HArt
%](http://www.ilga.gov/legislation/ilcs/ilcs4.asp?DocName=075500050HArt%20)

NOTE: The “Fact Sheet on Sex Education for People with Disabilities who have Legal Guardians” for Providers can be found [here](#).



Thank you to the self-advocates who helped put this “Fact Sheet for Providers of Sex Education for People with Disabilities who have Legal Guardians” into easier-to-understand language. The Illinois Self-Advocacy Alliance, Inc. (The Alliance) is proud to be an initiative of the Illinois Council on Developmental Disabilities. In partnership with the Illinois Council on Developmental Disabilities. This project was supported, in part by grant numbers 19/2001ILSCDD-02, from the U.S. Administration for Community Living, Department of Health and Human Services, Washington, D.C. 20201. Grantees undertaking projects with government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official ACL policy.