



Guardian Fact Sheet for Providers of Sex Education for Persons with Disabilities Under Guardianship

What is Guardianship? Guardianship is a legal relationship that requires a court order to establish using the statutory rules found in the Probate Act. The Probate Act 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) as well as regulating guardian's legal relationship with the ward. A close relative of the PWD may be appointed guardian but they still must act in accordance with the Probate Act.

The Order establishing guardianship is usually titled "Order of Appointment" and will specify if it is for a guardian of the person (conferring authority to arrange for services and placement) or a guardian of the estate (conferring authority to manage finances); whether it is temporary or long term; and, whether it is limited or plenary. 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.

Limited Guardianships do not result in the person being found legally incompetent and the authority granted is for a specific purpose and is not all-encompassing. The authority can be broad or narrow but is designed to meet a specific need.

Plenary Guardianships grant the full array of authority available to a guardian under the Probate Act. The document that proves that a guardian is authorized by the court to act is called "Letters of Office" and will spell out the authority granted (the clerk of court issues these) and can be relied upon by the provider; however, it is generally advisable to obtain an actual copy of the Order of Appointment as this document is the one the court has entered.

Managing disagreements about sex education. Reproduction is a Constitutional Right and a major life activity under the ADA. Sex education supports this right. The Probate Act was amended to provide a mechanism for balancing the right of procreation with the authority of a guardian. 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 at the following link: <https://www.cms.gov/Regulations-and-Guidance/Legislation/CFCsAndCoPs/Intermediate-Care-Facilities-for-Individuals-with-Intellectual-Disabilities-ICF-IID>. Information about legal guardians can be found in Sections 483.420 and 483.440)

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 effectively 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.*

General guardianship standards for decision making established by the Probate Act provide that the guardian will first use “Substituted-Judgment” and when that is not available will make decisions in the “best- interests” of the PWD. This requires that when the guardian has a PWD that has the ability to express desires that the guardian 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. This 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.

In the specific context of a PWD exercising reproductive rights, the Probate Act sterilization provisions establish that PWD’s are considered to have the ability to decide for themselves even when they have been appointed a guardian, so long as the they can understand the relationship between sexual activity and reproduction and the consequences of reproduction. From both the Medicaid regulations and the Probate Act, PWDs who have sufficient decisional capacity 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. 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.

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. (See link below)

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:

Independent Service Coordination Agencies by County:

<http://www.dhs.state.il.us/page.aspx?module=12&officetype=3&county>

Illinois Guardianship and Advocacy Commission: <https://www2.illinois.gov/sites/gac/Pages/default.aspx>

Equip for Equality: <https://www.equipforequality.org/>

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:

<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%2E+XIa&ActID=2104&ChapterID=0&SeqStart=14300000&SeqEnd=17750000>