



Guardian Fact Sheet for Home and Community Based (HCBS) Settings Requirements and 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 the guardian's legal relationship with the ward. A close relative of the PWD may be appointed guardian but that does not change that they are in a legal relationship that is controlled by the requirements of 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 HCBS services will be dealing with long term plenary guardians of the person. It is important to review the guardianship order 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. With a limited guardianship the order states the authority granted to the guardian and in all other areas the PWD retains full decision-making capacity.

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. With regard to placement, the Probate Act states that "No guardian appointed under this Article, except for duly appointed Public Guardians and the Office of State Guardian, shall have the power, unless specified by court order, to place his ward in a residential facility. The guardianship order may specify the conditions on which the guardian may admit the ward to a residential facility without further court order." (755 ILCS 5/11a-14.1)

Managing disagreements about Home and Community Based (HCBS) Settings Requirements. The Probate Act requires that the guardian "maximize the independence and self-reliance" of the PWD and this is consistent with the HCBS settings rules that require increased opportunities for individuals to access community living, community employment and choices related to daily living, living arrangements, schedules, relationships, visitors and how to spend money. Federal law protects an individual's right to choice and the Probate Act provides mechanisms for balancing individual rights 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 preferences that the guardian act in conformity with those preferences unless it is clear that substantial harm would result to the ward. When the PWD lacks such ability, the guardian should act in 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. The standards for guardianship decision apply to PWDs receiving HCBS services, namely that a guardian is to act in accordance with the preferences of the PWD unless those preferences would place the PWD at substantial risk of harm. There will be times when a guardian, ward or service provider do not agree on a decision to be made for the PWD, with the guardian refusing to consent to a proposed action. Below are potential avenues to address individual conflicts with guardians.

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>