

DECISION-MAKING FOR ADULTS

The law assumes that all people 18 and older, including people with disabilities, have the capacity to make decisions for themselves. This assumption can be overcome, however, when circumstances suggest otherwise. One way to do so is after a hearing in court, where a judge decides, based on expert testimony, that the ability of a particular individual to make decisions is so diminished that he or she is unable to properly manage personal finances and/or properly protect personal health and safety. Such a decision can also be made by a government agency or by a treating physician. When such a determination has been made, we say that the person is **incapacitated** or **incompetent**. In these situations, another individual (the **substitute decision maker** or **guardian**) is usually given the power to make decisions about property management and/or personal health and safety on behalf of the incapacitated person. This **substitute decision maker** can be chosen either by the incapacitated individual, by the court, or by a government agency.

The standard for competency varies depending on the subject matter. An individual who is not competent to manage financial affairs, for example, may still be competent to make his or her own healthcare or other personal life decisions.

Decision-Making Power Given by the Person

A **power of attorney (POA)** is a document in which a person, called the **principal**, gives another person or organization, called the **agent** or **attorney-in-fact**, the power to act on his or her behalf. For example, the principal might want an agent to handle his or her banking account. Traditionally, a POA only stays in effect as long as the principal is still competent. However, a special kind of POA, called a **durable POA**, includes language which makes it clear that the POA remains in effect even after the principal becomes incompetent. The durable POA can also be written so that it takes effect *only* when the principal becomes incompetent. In this way, the individual can choose his/her own substitute decision maker and not leave it up to the courts.

An **advance directive** is a document written by a person which directs the kind of healthcare that the person should receive if he or she becomes unconscious or otherwise mentally incapacitated. Examples of advance directives include **living wills**, which give instructions on the kinds of treatment a person wants to receive in particular situations (terminal illness, persistent vegetative state, need for respirator, dialysis or other life-saving treatment, etc.), and **powers of attorney for health care**, which appoint another person to make healthcare decisions when the original person becomes incompetent. Special forms of these documents are also used by individuals with mental illness – they are called **mental health advance directives** and **mental**

health powers of attorney. Pennsylvania law includes directions and suggested forms for creating these various kinds of advance directives.

Individuals who may not be competent to handle their own financial affairs may still be competent to create an advanced directive or a durable power of attorney. Before creating any such document for a person with potential competency issues, however, an attorney who specializes in these kinds of matters should be consulted.

Decision-Making Power Given by the Courts or Government Agencies

Guardianship results from a legal proceeding in which a court finds that a person is unable to make independent decisions for him or herself; the court then appoints a **guardian** to make those decisions for the person. A **guardian of the estate** has the power to make decisions about a person's property or **estate**, which means anything that the person owns. A **guardian of the person** has the power to make decisions about the person's health, safety, housing arrangements, etc. The law in Pennsylvania allows for either a **limited or plenary guardianship**. Under a **limited guardianship**, the court determines that the person, or **ward**, is unable to do some, but not all, of the things necessary to take care of his or her person or property. In such a case, the guardian can only exercise the legal powers specifically listed by the court order. However, in almost all cases, the courts find that the person, or **ward**, is totally incapable of caring for him or herself or property. In these cases, the court appoints a **plenary guardian**, who is given the power to exercise almost all of the person's legal rights and powers. There are a few powers – things like consenting to admission to a mental institution, giving up parental rights, or consenting to sterilization – which the guardian cannot exercise on behalf of the ward. Guardianship is the most restrictive kind of substitute decision making; it often leaves the person being represented with almost no control over his or her own life.

A **representative payee** is an individual or organization named by a government agency, such as the Social Security Administration or the Veterans Administration, to manage governmental payments for the benefit of the **beneficiary**, who is the person entitled to receive the benefits. When someone wants to become a representative payee, he or she must file a petition with the relevant agency to demonstrate the need. In general, it is a simpler process to be named a representative payee than it is to be named a guardian. It also requires less ongoing paperwork. Becoming a representative payee does not give a person any power over other assets of the beneficiary or of his or her person. However, for many people with disabilities, their main source of income is governmental benefits (such as supplemental security income or social security disability insurance), so having a representative payee for those benefits may make other substitute decision-making, such as guardianship, unnecessary.

For individuals who do not have a court-appointed guardian, a doctor may, in the course of treatment, determine that the patient is not competent to make healthcare

decisions (because he/she doesn't understand the consequences of the medical choices and/or because he/she can't communicate a consistent medical choice to the doctor). In that situation – assuming that the patient hasn't already created a living will or healthcare power of attorney that would provide the necessary guidance – Pennsylvania law allows certain family members of the patient (the **health care representative**) to make medical decisions on the patient's behalf. Under the statute, priority in decision-making authority goes first to the patient's spouse, then adult children, then parents, then adult siblings, and then adult grandchildren.

Designating Others to Receive Medical Information – HIPAA Rights

Under a federal law known as the **Health Insurance Portability and Accountability Act of 1996 (HIPAA)**, hospitals and doctors are required to protect the privacy of their patients' medical information. This even includes not discussing medical information with a patient's family. HIPAA rights can, however, be waived by the patient. Such a waiver can be provided formally – by a written document – or informally, as when a patient brings family members with him or her to a doctor's appointment and doesn't object when a family member asks for information about the patient. If a patient is incompetent, however, doctors will disclose medical information to the patient's **guardian, health care agent, or health care representative** without seeking the patient's prior approval.

For More Information

Disability Rights Pennsylvania (formerly the Disability Rights Network of Pennsylvania), with support from the Pennsylvania Developmental Disabilities Council, has developed a guide entitled "Consent, Capacity, and Substitute Decision-Making." The purpose of the guide is "to help people with disabilities, their family members, service providers, and others to be better informed about the important issues related to decision-making and thus assure that this right is protected for all." The guide is available at <https://disabilityrightspa.org/page/decision-making/>. It includes chapters on consent and capacity to make decisions, health care decision-making, powers of attorney, guardianships, and trusts. It also lists other available resources.