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(800) 692-7443 (Voice)
(877) 375-7139 (TDD)
www.disabilityrightspa.org

CHAPTER 2: CONSENT AND CAPACITY TO MAKE DECISIONS

I. BACKGROUND OF THE DOCTRINE OF CONSENT 2

II. SIMPLE CONSENT VS. INFORMED CONSENT 2

III. CAPACITY/COMPETENCE 4

IV. BEYOND CONSENT AND CAPACITY 6

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"Consent" and "capacity" are key concepts that affect issues relating to substitute decision-making. The standard by which it is determined whether a person can make decisions for himself or herself, rather than needing a substitute decision-maker, is whether the person is able to provide consent (either "simple consent" or "informed consent" depending on the context). Whether a person can provide consent often requires an assessment of the person's capacity (capacity is sometimes called "competence").

I. BACKGROUND OF THE DOCTRINE OF CONSENT

The doctrine of consent stems from legal cases in which physicians were sued after performing a medical procedure that did not go well. The courts initially held that physicians were entitled to make decisions as to what treatment was in the best interests of the patient, regardless of whether the physician provided any information to the patient or whether the patient understood the procedure and its consequences. The law subsequently changed. Now, patients are entitled to make treatment decisions for themselves in non-emergency situations. Physicians must provide the patient with information sufficient to allow the patient to understand the proposed procedure and its benefits, risks, and consequences.

II. SIMPLE CONSENT VS. INFORMED CONSENT

Simple Consent -- Simple consent requires the individual to be informed about the matter and to make a decision. It does not require that the

individual actually have full knowledge of the issue, options, and consequences of the decision.

Simple consent generally is sufficient for a number of decisions relating to routine matters that pose no risk of harm greater than that which is normally encountered in daily living. These types of decisions include:

- choosing what to eat;
- choosing what, if any, religious activities in which to participate;
- choosing what, if any, recreational activities in which to participate;
- participating in routine physical examinations, tests, and treatment;
- choosing whether to vote and, if so, for whom to vote.

The vast majority of people with intellectual disabilities are readily able to provide simple consent for these day-to-day decisions. An individual may be able to make these decisions on his or her own or with the assistance of his or her natural support system. Even if an individual has a substitute decision-maker, such as a guardian, his or her simple consent to everyday decisions should be respected.

Informed Consent -- Decisions which have greater risks and consequences than those generally encountered during daily life require informed consent. These types of decisions include:

- whether to undergo medical treatments for complex illnesses;
- whether to undergo invasive tests;
- whether to have surgery;
- how to spend Social Security benefits or other funds.

Informed consent requires the provision of information relating to the decision. This information should identify the proposed action and explain its purpose, the possible adverse consequences, the anticipated benefits, and any alternatives.

Informed consent requires not only that the individual receive adequate information about the proposed action, but, also, that the individual have "competence" or "capacity" to consent to the action. Individuals who are not competent or lack capacity to provide informed consent will generally need some form of substitute decision-maker to make the decision.

III. CAPACITY/COMPETENCE

Competence to consent means that a person: (1) possesses an ability to understand the situation, the alternative options, and the risks and benefits;

possesses the ability to use the information in a logical and rational way to reach a decision; and (3) is able to communicate the decision (either verbally or through other effective means).

Persons age 18 and older are presumed to have capacity to make their own decisions until they are shown not to have such capacity (though Pennsylvania law provides that parents or guardians of persons in the special education system remain the educational decision-makers for persons aged 18 to 21). Minors, for the most part, are deemed to be incompetent as a matter of law, regardless of disability, and their parents are their decision-makers.

A person who has capacity is able to make his or her own decisions. It does not matter that the decisions made by a person with capacity appear **irrational or wrong to others.** A diagnosis of an intellectual or other developmental disability does not automatically mean that a person is not competent to provide informed consent for some or all of the types of decisions that require that consent.

It is vital to understand that a person may be competent to make some decisions but not others. For example, a woman with an intellectual disability may be able to consent to take aspirin for a headache, but not to heart surgery. This is because it is much easier to understand an immediate treatment to relieve a current pain than it is to understand the potential risks and complications of major surgery. Even with respect to more invasive procedures, like heart surgery, individuals with intellectual or other developmental disabilities have the capacity to consent until they are

shown not to have such capacity. Information should be offered in a form that they may understand (for example, drawings) and, if possible and if the individual consents, should be offered in the presence of people in his or her circle of natural supports. These individuals can help to relay the information to the individual and can help assess whether he or she understands it and, if so, consents.

IV. BEYOND CONSENT AND CAPACITY

Although consent and capacity are important to determine when, if at all, a substitute decision-maker should be involved, it is not the standard used in all situations. For example:

- **Medical emergencies** -- When a person is unconscious or not capable of giving consent and delay will threaten the person's life or health, a physician can perform an emergency medical procedure unless it is known that the individual had specifically refused the procedure when conscious or competent.

- **Financial management** -- When a person receives a large payment of money (for example, through a lawsuit settlement or an inheritance), it may be appropriate to place that money in a trust that is controlled by a trustee even when the person has capacity to provide consent to make financial decisions. This is because the direct receipt of money by the individual could jeopardize his or her government benefits. If the individual has capacity to make the decision, the individual decides whether to place the money in a trust.

- **Personal decisions** -- There are some decisions that are beyond the authority of a substitute decision-maker even when an adult lacks capacity to consent. These include marriage, divorce, sterilization, termination of a pregnancy, termination of parental rights, and admission to an institution. In some cases, a court may authorize a guardian to make these decisions if certain criteria are met, but others can never be made by a guardian or substitute decision-maker. For further information on the authority of a guardian, please see Chapter 10: Guardianship in Pennsylvania.

Contact Information

If you need more information or need help, please contact Disability Rights Pennsylvania (DRP) at 800-692-7443 (voice) or 877-375-7139 (TDD). The email address is: intake@disabilityrightspa.org.

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