

“End the UNEthics Committees” **or “Nothing About Us Without Us!” Campaign**

Ethics committees are a prevalent means of giving the illusion of due process in health care decision-making by hospitals and other facilities. Yet there are virtually no accepted standards for ethics committee composition, procedures or decision-making guidelines. In some states, these committees have the authority to determine whether life-sustaining treatment can be withdrawn against the will of the person or their surrogate decision maker, often making determinations based on the degree of disability and perceived quality of life.

History of Hospital Ethics Committees:

- *In re Quinlan*, 355 A.2d 647 (N.J. 1976) was the first case to state that a health care facility could establish an ethics committee to act instead of probate court for health care decisions.
- 1983 report of the President’s Commission for the Study of Ethical Problems in Biomedical and Behavioral Research entitled *Deciding to Forgo Life-Sustaining Treatment*, encouraged creation of ethics committees to assist decision makers facing questions on the use of life-sustaining interventions.
- American Society of Bioethics and Humanities, the American Medical Association, and the American Nurses Association endorsed the idea.
- 1992: The Joint Commission for the Accreditation of Healthcare Organizations (JCAHO) mandated establishment of ethics committees.
- Current Joint Commission standards require that hospitals adhere to twenty-four guides on ethics implementation found in Sections RI.1 through RI.3.1

The American Hospital Association published a *Handbook for Hospital Ethics Committees* in 1986 that identified three primary functions for ethics committees.

- educating medical staff, hospital staff, and patients
- developing institutional policies and guidelines
- consulting and reviewing cases.

2007 article in ABA Human Rights Magazine –
Health Care Facility Ethics Committees: New Issues in the Age of Transparency

- By the year 2000 over 95 percent of community hospitals had established a clinical ethics committee.
- Forty-five percent of the participants in such committees, however, had no formal ethics training to support their role.
- No consistent standards for the methods or outcomes of ethics committee consultations.

A few states have statutes, including requirements for the composition of ethics committees:

Typical Examples of Required Members:

- Physicians, nurses and social workers
- Hospital administrator

Optional Members:

- Attorney, ethicist, clergy
- Community representative

Ethics Committee Process Models:

- Case conference – no recommendation
- Consultation with recommendation
- Mediation to achieve consensus
- Quasi-judicial with process and determination (appeal requires going to court, do any states prohibit that?)

Not Dead Yet of Texas Proposal for Accountability

- Composition: At least one quarter non-hospital staff
- Must include members of both disability and aging advocacy organizations
- An independent oversight committee to adjudicate when individuals or families are in conflict with decision of ethics committee
- Slogan: “End the UNethics Committees”

What We Can Do Next?

- Push for disability membership on ethics committees back home
- Develop model legislation to introduce at the state level

If you are a disability rights advocate who would like to work on the (UN)Ethics Committee project, please email Diane Coleman at dcoleman@notdeadyet.org.