

## **Article 17A of the Surrogate's Court Procedure Act**

Article 17A of the Surrogate's Court Procedure Act, which only applies to the appointment of Guardians for individuals with mental retardation or other developmental disabilities, was significantly amended in 2003 to give such guardians the authority to make end of life care decisions. Since individuals who have mental retardation, and in many cases other developmental disabilities, never had the capacity to leave a previously expressed opinion through the execution of a healthcare proxy, the argument in support of its passage was made that to not provide some mechanism for dignity at the end of life for such individuals would be discriminatory.

The Healthcare Decisions Act for Persons with Mental Retardation, later amended to include other persons with developmental disabilities, provides that guardians appointed, unless specifically excluded in the order, are presumed to have the authority to make healthcare decisions. Those guardians are to be guided by a decision-making standard as to what is in the "best interest" of the individual. The legal basis of that decision, as discussed in the statute, should be the dignity and uniqueness of each individual, the preservation, improvement, or restoration of the individual's health, the relief of suffering or pain, and the unique nature of artificial nutrition and hydration. When the withdrawal or withholding of life sustaining treatment is being considered, in addition to the above considerations, the individual must have a terminal condition or be permanently unconscious, or have a condition that is irreversible and life sustaining treatment would impose an extraordinary burden in light of the medical condition and expected outcome. In the case of the withdrawal or withholding of nutrition or hydration, in addition to the above, there must be no hope of maintaining life or such treatment would impose an extraordinary burden on the individual. The statute provides a variety of notices and safeguards relating to such a decision.

The statute was further amended in the spring of 2007 to extend the authority to withhold or withdraw life sustaining treatment to involved family members in circumstances where such persons have not become guardians. As of the writing of this paper, the Office of Mental Retardation and Developmental Disabilities had not completed regulations formally identifying such surrogate decision makers. Seldom are law and ethics so closely related as when concerning medical care decision making in general and end of life care in particular. The Healthcare Decisions Act for Individuals with Mental Retardation and Developmental Disabilities, in emphasizing consideration for the "uniqueness and dignity" of each individual, and the relief of suffering and pain is clearly attempting to provide an ethical framework for the decision maker.

When engaged in end of life care decisions that framework is enhanced by asking the surrogate decision maker to consider whether or not continued treatment would impose an extraordinary burden upon the individual. In reviewing the parameters, both legal and ethical, of providing or declining aggressive end-of-life treatment, including artificial nutrition and hydration, and enrolling an individual who lacks capacity to make healthcare decisions for themselves in hospice care, the legal and ethical parameters become blurred. It would appear that wherever the law has attempted to confront these issues, it has made its determinations based upon "ethical" considerations. Whether or not those considerations are universally accepted is another issue.