

Date: December 16, 2019

To: Scope and Program Committee

From: Barbara Atwood, Chair, JEB Uniform Family Laws

Re: Proposal for Study Committee to Revise Uniform Health-Care Decisions Act

At the December 2019 meeting of the JEB for Uniform Family Laws, the JEB voted to recommend that a study committee be appointed to consider revising the Uniform Health-Care Decisions Act. The Health Law Monitoring Committee has been considering this topic for the past year. Chair Abby Gluck referred the question of revising the UHCDA to the JEB for input, since medical decision-making often implicates family law concerns. The JEB for Trust and Estate Law has also been in the loop.

At our December meeting, Professor Chris Robertson, ULC Health Law Monitoring Committee Research Reporter, spoke with us via telephone about the need to revise the Uniform Health-Care Decisions Act. JEB materials included his 2018 memorandum on the UHCDA (copy attached). The Act was drafted in reaction to *Cruzan v. Director, Mo. Dept of Health*, 497 U.S. 261 (1990) (upholding Missouri's requirement that an incompetent patient's wish to withdraw life-sustaining treatment be shown by clear and convincing evidence and rejecting a constitutional challenge under the Due Process Clause). In response to *Cruzan*, most states enacted durable health care POA acts. At present, only 7 states have enacted the UHCDA. The key issues in the UHCDA warranting possible revision (identified by Professor Robertson) are the priority list of those who can act as surrogates; identification of residual surrogates; the provision for oral appointment; the lack of domestic partnerships, civil unions, or cohabitants in the surrogate list; disqualification of surrogates; and scope of surrogate decisions. The JEB discussed some of the more salient needs in revising the UHCDA.

The list of decision-making surrogates should be updated in various ways. The UHCDA does not expressly include domestic partners or long-term cohabitants in its default list of surrogates. While prioritizing spouses may have made sense in 1993, the proportion of the population that is unmarried has grown significantly since that time. Also, states vary widely on the validity of an oral designation of a surrogate, a method recognized by the UHCDA but not carefully defined. Disqualification of a surrogate is another area needing attention. An individual whose physical violence resulted in a spouse's hospitalization, for example, should probably not have decision-making authority as a surrogate. In addition, where a surrogate is not available, a more streamlined in-house system should be established. Under the current UHCDA, a provider must go to court in the absence of a listed surrogate. Judicial action is cumbersome, expensive, and impractical in situations where time is of the essence. Importantly, the UHCDA does not provide standards for such judicial intervention.

Professor Robertson noted that shared or team decision-making is the current widely-accepted model for medical decision-making for seriously ill and incompetent patients. The concept of collective decision-making is missing from the UHCDA. There is also a need to integrate the use of popular forms, such as the Five Wishes and POLST forms, in a nationwide collaboration.

Scope of care is another issue that should be revisited under the UHCDA. At present, the Act encompasses a broad range of medical treatment, including withdrawal of life support and the imposition of mental health treatment, areas in which states differ widely. Some states require certification by two doctors for withdrawal of life support, and others have stopped short of authorizing mental health treatment over the objection of an incompetent but conscious patient. Greater attention in the UHCDA to the liberty interests of such patients would be an improvement. Similarly, UHCDA does not directly address treatment of terminally ill newborns, a topic about which hospital ethics committees may be at odds with parents.

The JEB was particularly interested in the lack of provisions for decision-making by mature minors. The Act applies to adults and “emancipated minors,” but the statutory and common law has evolved since the Act was enacted to address decision-making rights of the “mature minor.” Mature minors have been recognized as having medical decision-making authority in a range of contexts, including the right to refuse life-sustaining treatment in cases of terminal illness as well as the right of access to reproductive health care, treatment for STD’s, and treatment for drug addiction. The recent revision of the guardianship act lowered the age for a child to express a preference from 14 to 12 years of age and provided complementary notice provisions. *See generally* Uniform Guardianship, Conservatorship, and Other Protective Arrangements Act (Article 2). This is consistent with a trend in the law toward a greater deference to a minor’s views. The JEB believes that a separate article in a revised UHCDA should be devoted to decision-making by mature minors, including careful standards for assessing maturity and informed consent and clear provisions on the scope of decision-making by mature minors. The current Tentative Draft of the Restatement of Children and the Law includes a section on medical decision-making by mature minors, with extensive commentary and citation of authority. The Tentative Draft of that section is attached.

The JEBUFL recommends that the UHCDA be amended to address the areas discussed above and, in particular, to add provisions for decision-making by mature minors. Lacking expertise in health care law, the JEB members voted to send its recommendation to the JEB on Trust and Estate Law and to the Health Care Monitoring Committee, in order for those two groups to consider the proposal. After the meeting, however, David English and Chris Robertson both recommended that we send the recommendation directly to Scope, since the JEB on Trust and Estate Law and the Health Law Monitoring Committee have already indicated agreement on the need to revise the UHCDA.