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MEMORANDUM

TO: Committee on Scope and Program

FROM: Nora Winkelman
Chair, Study Committee on Amending or Revising
the Uniform Health-Care Decisions Act

DATE: December 18, 2020

SUBJECT: Final Report of Study Committee

The Study Committee on Amending or Revising the Uniform Health-Care Decisions Act (the “Act”) recommends the appointment of a drafting committee to consider amending the Act in the specific ways that are set forth in this memorandum.

We were fortunate to have ULC Commissioners on the committee with backgrounds in, and familiarization with, the issues raised in the initial proposal for this study committee to the Committee on Scope and Program. Those included David English, who was the Reporter for the Act, and Suzanne Walsh, who chaired a study committee in 2008 that considered whether to recommend a drafting committee on mental health advance directives.

Nina Kohn, who was the Reporter for the recently-approved Guardianship, Conservatorship, and Other Protective Arrangements Act, acted as the Reporter for this committee. With Nina’s help, we were able to attract observers to the work of the committee from a variety of different perspectives, all of which are described on the attached Study Committee Stakeholder Outreach Form. We had excellent participation from most of the observers on the committee during the course of the three Zoom meetings that we held. Nina had prepared an initial issues memorandum for consideration by the committee which formed the bases for our initial discussion, and follow-up memoranda to guide each of the subsequent meetings. Once we thoroughly discussed those issues with the full committee and had a strong sense of areas of agreement, we held a Commissioners-only Zoom meeting to determine the thoughts of the Commissioner members and to answer any specific questions they may have had – especially for Nina – given that not all of the Commissioners on the committee were health



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care decision experts. The recommendations in this memorandum were unanimous among the Commissioners on the committee and supported by the observers.

A key priority during the Commissioners-only call was to understand a concern expressed by some Commissioners – a concern I also had when I was first appointed as Chair of this committee - that only seven states have enacted the Act since it was promulgated by the ULC in 1993 (Alaska, Delaware, Hawaii, Maine, Mississippi, New Mexico and Wyoming).¹ Commissioner English, who as noted above was the Reporter for the Act, explained that the drafting committee was appointed in the wake of the US Supreme Court’s decision in *Cruzan v. Commissioner, Missouri Department of Health*, 497 U.S. 261 (1990). That decision upheld Missouri’s requirement that an incompetent patient’s wish to withdraw life-sustaining treatment, to be effective, must be shown by clear and convincing evidence. Many states rushed to adopt advance directive legislation in response. As a result, by the time the ULC’s very deliberative process was completed, most states already had enacted their own statutes on the subject. Moreover, there is ample evidence that, as our observers noted, the Act nevertheless had a positive impact on the development of state law and served as the basis for many of the statutes that were enacted notwithstanding that they are not on the ULC list of enactments. Attached in Appendix A is an example from California. Attached in Appendix B is an example from Tennessee.²

The foregoing led us to discuss at some length how we might convince states to enact a new and improved Act if the Executive Committee ultimately approves the appointment of a drafting committee. The suggestions included drafting a new standalone act, drafting new

¹ It should also be noted that Alabama was on the ULC enactment list in 2002 but is not on the current list. Alabama appears to have substantially revised its Natural Death Act in 2016 which may have changed the original act so much that it no longer could be counted as an enactment. The Chicago office staff is researching this further for us but as of this writing has not come up with anything definitive as, working remotely, they do not currently have access to their paper files that are stored in the office. Alabama’s substantial revision of the Act may be indicative of the fact that even states that had originally enacted the Act, or at least a close version of it, have felt the need to update it since then.

² In addition, in volume 3 of the four-volume treatise “Advising the Elderly Client,” A. Kimberly Dayton and others discuss the Act in a manner that suggests many states have based their legislation on it – or at least parts of it. See 3 Advising the Elderly Client, Ch. 33. In an earlier (2007) version of the section on “Planning Tools for Health Care Decision-Making,” they stated that “the Act has affected the development of state law concerning advanced medical directives in both direct and subtle ways...The overview of this uniform law serves as well as an overview of the general characteristics and contents of advance health care directives drafted pursuant to state law even in jurisdictions that have not adopted the uniform Act.”



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articles that could be dropped into existing state legislation, and of course, preparing line-by-line amendments to the Act for the states that have already enacted it. The exact form amendments to the Act might take should be left up to the drafting committee. The consensus of the Commissioners on this committee, however, was that the topics we discussed with the very experienced observers who participated were important enough – and moved the law in this area forward sufficiently – to warrant the expenditure of ULC resources on a drafting committee.

What, then, should be the scope of the charge to a drafting committee? Following are the topics that are recommended by this committee for consideration by a drafting committee.

1. Scope of the Act.

- (a) Decisions covered. The Act should include authority for psychiatric advance directives (also known as “mental health advance directives”) which can provide treatment preferences for mental health care or appoint a surrogate to make decisions regarding mental health care in the event that an individual has an acute mental illness event.

While the Act currently authorizes the inclusion of mental health treatment preferences in either a health care power of attorney or an advance directive, the National Alliance on Mental Illness (NAMI) supports the use of a separate psychiatric advance directive, or PAD, because of the unique issues of mental health care and treatment. As of 2019, approximately ½ of the states have statutes that authorize and govern PADs. But they are not uniform in their breadth, effectiveness or approach. The NAMI website has a wealth of state-by-state information on this topic that can be found at <https://www.nrc-pad.org/states/>. It would be a helpful tool for a drafting committee to understand the current lay of the land in the several states.

As mentioned above, Commissioner Walsh chaired a ULC study committee appointed in 2008 to consider whether the ULC should draft a Mental Health Advance Directives Act. Commissioner Walsh reports that there were contentious discussions among mental health advocates on the one hand and those representing families of mental health patients on the other. The committee was discharged by the Committee on Scope and Program prior to the completion of its work and the production of its final recommendations – although it is unclear why that happened.



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Even given the prior history mentioned above, there was strong consensus among the observers for the inclusion of provisions in the Act specific to mental health advance directives. It's been more than 10 years since that issue was reviewed by the ULC and much has happened in this landscape since – including a trend toward a more person-centered philosophy regarding guardianship and other protective proceedings that could impact how organizations that represent persons with mental illness and their families now approach these issues. Such provisions could help individuals with mental illness not only direct their own care, but potentially avoid guardianship.

However, it is important to stress that if the Act is revised to include authority for psychiatric advance directives, organizations representing both patients and patients' families should be included as observers for the drafting committee. We currently have at least one observer on this committee on the patient side of the equation – a representative from the Bazelon Center for Mental Health Law. But a commitment from someone representing families' concerns – such as NAMI – to participate in a drafting committee would be essential to the success of including this issue in a revised Act.

(b) Capacity trigger. Although titled as a health-care “decisions” act, one observer pointed out to us early in our discussions that the Act is really more about the execution of advance directives and the appointment of surrogates than about decision-making and the capacity for doing the same. That is, the Act does not wade too deeply into how and who makes the determination that a patient lacks capacity, thus triggering the terms of a health care POA or advance directive or requiring the health care provider to turn to the state's surrogate priority list.

However, it was widely acknowledged that the flexibility regarding this issue in the Act has its benefits, and that these issues are volatile and could unnecessarily bog down a drafting committee or an enactment process. As a result, this committee recommends that a drafting committee consider whether additional direction should be provided in the Act as to how a capacity determination is to be made (e.g., with what level of confidence) and whether there should be provisions included about what happens when a patient objects to the determination of incapacity. In addition, a drafting committee should incorporate into the Act an acknowledgment that the fact that a patient uses support (i.e., technical assistance or help from another person), in other areas of the patient's life or in making health-care decisions, does not mean the patient lacks capacity. This would be consistent with the growing embrace of



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supported decision-making, including recognition of supported decision-making in the ULC's recent Act on guardianship.

(c) Persons Covered. The Act only covers decisions made by adults and emancipated minors. The proposal to the Committee on Scope and Program for this study committee specifically included the suggestion that the Act cover decisions made by “mature” minors – that is, individuals under the age of majority in a state who, because of their maturity, should have the ability to direct their own health care treatment and appoint their own surrogates, even if their desires are contrary to the wishes of their parents or guardians. This study committee decided against recommending including mature minors in the Act and I thought it was important for you to know why.

The committee had a robust discussion about this issue. There were a myriad of issues identified by the observers that a drafting committee tasked with including mature minors in the Act might find difficult to wrestle with. For instance, who determines whether a minor is “mature,” when is that decision made, and what are the criteria for making it? We know that some states have provisions for mature minors in other aspects of life. Can/should a drafting committee come up with a universal standard? If it does, what effect might that have on other mature minor provisions in a state? Should an unemancipated (but “mature”) minor be permitted to override the decision of a parent or guardian? As an aside, if the minor is at odds with his or her parent or guardian over an important issue such as this, most if not all states have an avenue for that minor to become emancipated prior to reaching the age of majority so that his or her health-care or surrogacy decisions would be respected. One of our observers, who is the Director of the ABA Commission on Law and Aging, advised us that while 17 states include emancipated minors in their advance directive laws, only a handful include mature minors. As a result of all of the foregoing, the committee decided that including mature minors in the Act is not something a ULC drafting committee should take on. However, if the Executive Committee ultimately decides to include the consideration by a drafting committee of this issue, additional observers with experience specifically representing the rights and needs of minors should be included on the committee.

2. Default Surrogates.

(a) Expanding the List. Observers on this committee indicated that the list of priority surrogates in the Act for patients who do not (or cannot) name one of their own does not



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currently reflect the reality of what patients, their medical providers and their families contend with on a day-to-day basis. The July 9, 2018 memo from Christopher Robertson, Research Reporter for the ULC Health Monitoring Committee, accompanying the proposal to the Committee on Scope and Program that led to this study committee, advises that 22 states have added grandparents and/or grandchildren to the list, others refer to “nearest adult relative” or “next of kin” while others provide lists of “interested persons.” The study committee believes that the Act would benefit from an updating of the priority surrogate list to, among other things, include additional individuals such as grandparents, domestic partners, long-term cohabitants, etc.

(b) “Un-befriended Patients.” The lack of provisions in the Act that effectively address individuals who lack a trusted other person willing and able to make decisions on their behalf may disproportionately adversely affect certain groups of people (e.g., LGBT+, individuals with intellectual disabilities). Section 5(c) of the Act provides that if none of the individuals on the priority list is “reasonably available,” “an adult who has exhibited special care and concern for the patient, who is familiar with the patient’s values, and who is reasonably available may act as surrogate.” However, Professor Robertson in his memo suggested that patients frequently come to hospitals without the ability to assist the hospital in identifying and/or finding such individuals. Our observers concurred with that assessment. Some states, according to Professor Robertson, have added some combination of attending physician, independent physicians and/or hospital ethics committees for these patients. The comments in the Act suggest that a health care provider faced with this dilemma can always turn to a court for help. As you can imagine, both of these approaches have their own critics and practical problems. In addition, observers described substantial variation from facility to facility in how decisions are made for this vulnerable population and, without guidance, facilities will continue to implement ad hoc mechanisms for dealing with it. Thus, the study committee believes that the states (and uniformity) would benefit from modifications to this provision that take these issues into account.

(c) Disagreement Among Surrogates. The Act directs a health care provider to comply with a decision articulated by the majority of the class of surrogates authorized by the Act when an individual unable to make decisions has not appointed an agent or surrogate. If the class of surrogates is divided, then no one is authorized to make the decision without a court order – obviously a cumbersome and expensive proposition. The study committee believes that a drafting committee could be instrumental in moving this issue forward by amending the Act to



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include best practices for making decisions when there is disagreement among a class of default surrogates.

3. Barriers to Use and Execution. The study committee discussed three specific barriers to the use and execution of health care advance directives and powers of attorney described below and recommends that a drafting committee consider addressing them in its work.

(a) Electronic Documents. The Act does not address the effectiveness of, or include rules governing the use of, electronic documents and signatures. The Act was adopted by the ULC in 1993, 6 years before promulgation of the Uniform Electronic Transactions Act (as of September, 2019, adopted in 48 states, the District of Columbia, and the US Virgin Islands) and 7 years before Congressional adoption of similar electronic transactions legislation on the federal level. Thus, there is no reason to assume that the original drafters of the Act omitted provisions for the use of electronic documents and signatures on purpose (and in fact Commissioner English confirmed that). The electronic world we live in now – especially in light of the challenges faced during the recent pandemic – suggests that the Act is ripe for amendments to address this issue. In fact, during the pandemic, there has been a flurry of temporary laws and executive orders that allow for remote witnessing and notarization. The observers on this study committee felt modifications to the Act that would address these issues would add real value to the Act and thus were very enthusiastic in their support for including this topic in any amendments to the Act that might be drafted. Given the interest among the states in this topic generally, including it could help in the enactment process. The recently promulgated Uniform Electronic Wills Act could be a useful aid to a drafting committee in this respect.

(b) Statutory Form. The statutory form included in the Act should remain, but it could be improved upon. Suggestions from the observers on this committee ranged from making it shorter (and thus simpler) to making it more lay person friendly by putting it in plain language. We would caution a drafting committee against including mandatory disclosures in the form since those can be a barrier to usage, especially by low-literacy individuals, making it a mandatory form and requiring the written acceptance by any named agent in the form. Other relatively minor changes, such as eliminating the need for witnesses, were also discussed. As a result, this committee believes the form should be reviewed in its entirety with a view to amending it to reflect changes in the law and in practice throughout the country since the Act was first promulgated by the ULC..



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(c) Oral Designations. The recent pandemic has highlighted the need to rethink the ability for patients to make oral designations of agents and surrogates and under what conditions. While there were mixed opinions among the observers on the desirability of allowing oral designations, the study committee recommends that a drafting committee revisit this issue.

4. Physician Orders for Life-Sustaining Treatment (POLST). Since the adoption of the Act in 1993, medical orders known as POLST have become widely used in many states. They are typically created by a medical provider in consultation with a significantly frail or ill patient for end-of-life planning and are meant to supplement, rather than supplant, a health care advance directive or power of attorney. They are typically short documents intended to document patient preferences and to accompany a patient through different care settings (home, hospital, nursing home, etc.). They are seen as especially important guidance for emergency responders. However, some confusion has arisen as to the relationship between a health care advance directive and a POLST when both are available for a particular patient. The committee does not believe that the ULC should tackle what could be a daunting task of regulating POLST, but it is recommended that a drafting committee determine and include in amendments to the Act the relationship between and among the instructions that may be included in a health care advance directive or power of attorney and those found in a POLST.

5. Miscellaneous. Lastly, but by no means less importantly, this committee recommends that a drafting committee include consideration of the following:

- (i) authorizing an agent or surrogate named under a health care power of attorney to apply for government health-care benefits for the principal;
- (ii) revisiting grounds for disqualifying agents and default surrogates beyond what is already included in the Act;
- (iii) revisiting whether additional qualifications should be placed on an agent's or surrogate's ability to consent to mental health treatment for individuals who may not be in the category of patients who have or need a psychiatric advance directive; and



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- (iv) updating the language in the Act for gender neutrality and substituting words and phrases now considered stigmatizing.

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The ULC Statement of Policy Establishing Criteria and Procedures for Designation and Consideration of Acts includes the following guidelines for considering proposals to revise or amend existing acts:

- (1) Whether the act advances the law on a subject that the ULC has already addressed.
- (2) Whether the act addresses matters that have been the subject of successful enactments in the past.
- (3) Whether the act concerns an area of the law where the ULC has significant presence.

As applied to the recommendations of this study committee, the first criterion appears to have already been met by the fact that the committee is recommending amendments to an existing ULC act. While the second criterion on its face would appear to thwart the committee's recommendations given that the Act has so far only enjoyed seven enactments, as discussed above, it is believed that that fact may be more the result of timing than substantive resistance to the Act itself. We also believe that the Act had an impact on the development of the law in the states on this issue and served as a starting point for many of them. Moreover, the recent pandemic has provided an opportunity for modifications – especially as they may relate to electronic documents and signatures – that states might find particularly useful. Finally, given the ULC's substantial presence in the family law, elder law and trusts and estates law areas, the committee believes its recommendation to appoint a drafting committee meets the third criterion.

Thank you for your consideration of the committee's recommendations. Please feel free to contact me if you have any questions or need any additional information.



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Scope and Program Committee Study Committee Stakeholder Outreach Form

For each study committee, the chair and Scope liaison are jointly responsible for filling out this form, with input from the division chair as needed.

A preliminary list of key stakeholders must be submitted to the chair of Scope and Program within two months of the appointment of the study committee chair. Updated lists should be submitted for each quarterly meeting of Scope and Program. Feel free to add rows as needed.

A list of key stakeholders—noting which of them have been successfully contacted and a description of their substantive views—must be submitted with the study committee’s final report.

Study Committee	Chair	Scope Liaison	Division Chair
Amending the Health Care-Decisions Act	Nora Winkelman	Diane Boyer-Vine	John McGarvey

Government stakeholders, if any (e.g., NAAG, NASS, federal agencies):

Stakeholder	Response?	Views

Private sector stakeholders, if any (e.g., US Chamber, trade associations, specific companies):

Stakeholder	Response?	Views
Geoff Drucker – ABA Advisor, Section of Dispute Resolution	Yes	
Linda Fentiman – ABA Advisor, Senior Lawyers Division	Yes	Health care decision-making; health law; bioethics; mental disability law



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John Way – ABA Advisor, Real Property, Trust and Estate Law Section	Yes	
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Non-profit stakeholders, if any (e.g., consumer groups, advocacy groups, think tanks):

Stakeholder	Response?	Views
Glen Fewkes - AARP	Yes	Older adults
Diana Noel - AARP	Yes	Older adults
Marty Ford – The Arc	Yes	Individuals with intellectual and developmental disabilities
Jennifer Mathis – Bazelon Center for Mental Health Law	Yes	Individuals with mental disabilities

Other experts who have written about or are otherwise interested in the subject (academics, etc.):

Stakeholder	Response?	Views
Loren Wissner Greene	Yes	Physician; bioethics
Sarah Hooper – UC Hastings College of the Law	Yes	Medical-legal collaboration; advance planning
Mei Ching Lee – University of Maryland	Yes	Palliative and end-of-life care and advance care planning, including specifically with Asian American older adults
Frances Nedjat-Haiem – San Diego State University	Yes	Health care disparities, end-of-life care, and advance planning, including with Latino older adults.



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David Orentlicher – University of Las Vegas	Yes	Health care law; constitutional law
Brendan Parent – NYU Langone Heath	Yes	Organ donation, procurement, and transplantation ethics and policy
Thaddeus Pope – Mitchell Hamline School of Law	Yes	Health care law; clinical ethics; end-of-life decision-making
Charles Sabatino – ABA Commission on Law and Aging staff member	Yes	Law and aging; health-care decision making
Thomas Simmons – University of South Dakota	Yes	Trusts and estates
Rebecca Sudore – University of California	Yes	Advance care planning and medical decision making for diverse, vulnerable older adults; POLST
Deborah Tedford – private practice attorney	Yes	Trusts and estates; member of ACTEC
Susan Tolle – Oregon Health & Science University	Yes	POLST; end-of-life and compassionate healthcare; ethics
Susan Wolf – University of Minnesota	Yes	Health law; bioethics; end-of-life decision making
Stu Zimring – private practice attorney	Yes	Elder law; Past President of the National Academy of Elder Law Attorneys