



NATIONAL CATHOLIC PARTNERSHIP ON DISABILITY  
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August 15, 2012

John R. Lake, M.D.  
President  
Board of Directors  
OPTN/UNOS  
700 N. 4th St.  
Richmond, VA. 23218

Re: OPTN Policies Plain Language Rewrite

Dr. Lake:

On behalf of the National Catholic Partnership on Disability, I offer the following comments on OPTN's "Plain Language Rewrite."

In a June 22<sup>nd</sup> email announcing the public comment period, OPTN maintained that the Rewrite did "not make any substantive changes to the content of ... [its] current policies [.]". That claim was false. The Rewrite adopted the changes to the DCD Model Elements that were the subject of a reopened comment period that ended June 15. Those changes have yet to receive specific approval from the OPTN Board and thus represent, not existing policy, but a mere proposal. To mitigate the confusion the Rewrite has caused, OPTN should immediately withdraw it from public review until the portions relating to DCD are revised to reflect current policy accurately.

After complaints last November that OPTN had not solicited comments on changes to the Model Elements from all affected groups, the OPO Committee was directed to resubmit the proposal for public comment during the spring 2012 cycle. The Committee specifically elicited comment on whether DCD candidacy should extend to patients whose non-neurological "disease" rendered them dependent on life-support.

Commenters raised serious concerns about the proposal's practical effect. For example, it could authorize local OPOs, in meeting their duty to evaluate potential DCD donors, to examine patients without their knowledge and consent. OPTN's own Ethics Committee advised that "[c]onsent is appropriate for screening tests pre-mortem[.]" concluding that, "[w]hile the patient is still alive, normal informed consent practices are still required."

Because of the obvious pressure placed on vulnerable patients and families, commenters further challenged the proposal's refusal to keep separate the decision to donate from that to withdraw life-support. Even the OPTN Ethics Committee did "not agree with the OPO approaching the family prior to decision to withdraw treatment or support."

Further, by extending DCD candidacy to patients whose “disease” is not necessarily terminal but that otherwise renders them dependent on life-support, the proposal singles out a class of persons, disabled under federal civil rights law, for adverse treatment. Comments warned this could jeopardize OPTN’s relation with HHS which is forbidden from entering into contractual arrangements with the purpose or effect of discriminating against people with disabilities.

Nevertheless, seven days after the comment period ended (clearly insufficient time to evaluate the serious concerns raised), and three days before the OPTN Board met (where the proposal to change the Model Elements was not specifically addressed), the Rewrite (a 200 page document obviously prepared well in advance) was circulated, incorporating the changes to the Model Elements, at the same time falsely claiming that nothing of substance was altered. It is hard not to conclude that the decision to change the Model Elements was made well before its comment period ended and that those who took the time to submit substantive comments were drawn into a futile gesture.

Notably, at its meeting this June, the OPTN Board adopted an OPO Committee recommendation to substitute “authorization” for “consent” in its organ donation policies, as one of several resolutions contained in a consent agenda it had approved in a single vote. The Committee’s report represented, however, that it was recommending no change to existing DCD policy. Nevertheless, the Rewrite provides that “The patient who authorizes being an organ donor candidate” is one person who can “give authorization before administering drugs or procedures for the purposes of organ donation [.]”<sup>1</sup> To the extent this suggests that only authorization and not informed consent is required for DCD donation, it would both misrepresent existing policy and evidence a distressing indifference to the vulnerability of patients on life-support.

In closing, commenters questioned whether the proposal to change the Model Elements compromised the rights of disabled patients on life-support in favor of potential transplant recipients. The Rewrite’s cavalier dismissal of those concerns leaves little doubt in that regard. By incorporating the proposed changes, the Rewrite has endorsed their assumption that certain people with disabilities are only valuable when dead. On behalf of the National Catholic Partnership on Disability and the 14 million disabled Catholics it serves, I urge OPTN to withdraw the Rewrite immediately.



Stephen L. Mikochik

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<sup>1</sup> Taken literally, Policy 2.9(c)’s rewrite would permit legal next of kin or a designated health care agent to authorize drugs and procedures for DCD donation without a conscious patient’s knowledge or consent.