NCPD
NATIONAL CATHOLIC PARTNERSHIP ON DISABILITY
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November 9, 2011

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

Re: Proposed changes to the DCD Model Elements

Dear Dr. Lake:

I chair the National Catholic Partnership on Disability. NCPD was established thirty years ago to implement the U.S. Catholic Bishops' *Pastoral Statement on People with Disabilities*. On behalf of the fourteen million disabled Catholics NCPD serves, I urge the OPTN/UNOS Board of Directors to delay amending the DCD Model Elements. The proposed changes raise grave concerns under federal nondiscrimination law that, if left unresolved, could jeopardize UNOS' contractual relations with HHS.

One goal of the proposed changes is to clarify the elements OPOs and transplant centers must include in their DCD policies.[1] Donor eligibility, however, remains distressingly obscure. Though patients with permanent, irreversible, but not necessarily terminal, conditions or diseases are eligible candidates, it is unclear whether the examples the proposal then gives are meant as exhaustive or mere illustrations.[2] The proposal next repeats these examples, apparently as optional criteria, without reference to permanence, irreversibility, or even reliance on life-support, and without clearly indicating whether "end-

[1] *See* Proposal to Update and Clarify Language in the DCD Model Elements, available at http://optn.transplant.hrsa.gov/PublicComment/pubcommentPropSub_283.pdf (accessed Nov. 8, 2011).

[2] *See id.* at (c)(1)("A patient … with a permanent and irreversible neurological injury (i.e. upper spinal cord injury), or permanent and irreversible disease (i.e. end-stage musculoskeletal or pulmonary disease) that results in necessary life-sustaining medical treatment or ventilated support but who does not fulfill the neurologic criteria for death, may be a suitable candidate for DCD.").

stage" qualifies all the examples or only the first.[3] Conceivably, this could authorize local OPOs to treat some patients with transitory conditions as eligible DCD candidates.

One thing is clear, however: by identifying patients with upper spinal cord injuries as DCD candidates, requiring solicitation of their organs for transplant, necessarily entailing withdrawal of life-support and their deaths, the proposal singles out a class of persons, disabled under federal civil rights law,[4] for adverse treatment. This constitutes discrimination.

Another goal of the proposed changes is "to maximize the number of donors and transplants by identifying the currently unrealized donor potential through the clarification and updating of language." To that end, the changes eliminate the requirement that evaluation of patients' candidacy for DCD occur only after the decision to remove life-support is made. The potential for undue influence this creates is obvious. Those suffering from upper spinal cord injuries often adjust to their condition over time and, despite their impairment, can lead meaningful lives. Not surprisingly, they and their families are most vulnerable at the onset of the injury and most open to the suggestion of those required to identify "unrealized donor potential" that they can salvage some good through ending their lives and giving their organs to others.

There are no safeguards to ensure that such patients, when conscious, are competent to make donation decisions. There are no safeguards to ensure that such patients are not clinically depressed. There are no safeguards to ensure that members of the local OPO or primary health care team are trained to identify such depression. In fact, there are virtually no safeguards at all to ensure that the donation decision is voluntary.[5] It is difficult to avoid the conclusion that such safeguards were thought unnecessary because such patients were considered more valuable when dead.

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[3] *See id.* at (c)(2)("A patient with end-stage musculoskeletal disease, pulmonary disease or upper spinal cord injury may also be a suitable DCD candidate.").

[4] *See* 45 C.F.R. § 85.3.

[5] The only safeguards in that regard prohibit any "member of the Transplant Center surgical team ... [from being] present for the withdrawal of life-sustaining medical treatment or ventilated support" or "member of the Organ Recovery team or OPO staff ... [from] guid[ing] or administer[ing] palliative care or declar[ing] death." Proposal, *supra* note 1, at (E)(4).

Under regulations implementing the 1978 Amendments to the Rehabilitation Act, HHS "may not, directly or through contractual or other arrangements, utilize criteria or methods of administration the purpose or effect of which would [s]ubject qualified individuals with handicaps to discrimination on the basis of handicap[.]"[6] It is hard to imagine a criterion more discriminatory on its face or as applied than one that values persons only as body parts because of the disabling conditions they possess. For HHS to approve the proposed changes would violate its duty not to utilize, "through contractual or other arrangements," criteria that discriminate on the basis of disability. For the OPTN/UNOS Board to adopt such criteria would cause many within and outside the disability community to question UNOS' continued oversight role under its contractual arrangements with HHS.

Accordingly, I urge the OPTN/UNOS Board to delay adopting the proposed changes, to allow sufficient time to cure their grave deficiencies.

Respectfully submitted,

Stephen L Mikochik/JLB

Stephen L. Mikochik
Chair
National Catholic Partnership on Disability

Professor of Law
Temple University School of Law
1719 N. Broad St.
Philadelphia, PA 19122

(610) 930-3550
Stephen.mikochik@temple.edu

[6] 45 C.F.R. § 85.21(b) (1) (i). The regulations establish procedures to resolve individual and class-based complaints of non-compliance with this and other provisions. *See id.* at § 85.61.