



*For people with intellectual
and developmental disabilities*

The Arc

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July 11, 2013

Dear Uniform Law Commissioners:

The undersigned organizations are vitally interested in the current work of the Committee working on drafting an update to the Uniform Determination of Death Act. This letter responds to the language available for discussion for the informal Zoom session on Friday, June 9 from 2-4 pm, EDT. This session was an opportunity for Commissioners to ask questions about the current draft before the ULC annual meeting in July. The draft under discussion on June 9 included two alternative approaches: the first, Option 1, was the current (1980) definition with changes made by the Committee on Style and the second approach, Option 2, was a recent draft developed by the Reporter and included in the draft at the last scheduled meeting of drafting Committee.

We believe that Option 2 is so problematic that it will prove too controversial for enactment by most states and that it should not become law.

- The physician, hospital, and organ donor interests which seem to have dominated the draft to date do not address the many concerns that we have.
- Our constituency has rights and concerns beyond what can be captured by the medical terminology, including:
 - The basic human right to sustenance and health care.
 - The right to trust caregivers and medical professionals to have the individual's best interests as a top priority, and to understand that "best interest" does not mean "better dead than disabled".
 - The need for the medical community to understand that, despite severe disability or medical frailty, a patient is far more than a complex system of biological functions, but rather a complex individual with a past, present, a desire for a future, with thoughts, desires, loves, fears, and the wide range of human emotions, personal relationships, and personal spiritual or religious beliefs who has a right to live until natural death.
- The medical community must accept with humility that which they do not fully know, including the capacity of the human brain.
- The definition in Option 2 does not include the cessation of function of the whole brain. It is a step back from the current definition to include only "loss of brainstem reflexes".
- Moving from "irreversible" to "permanent" in Option 2 appears to remove the responsibility of medical professionals to determine whether improvement is possible.

During the discussion on June 9, one Commissioner described Option 2, part (2) in a way that aptly captured some of the discomfort with the newly proposed approach. He described the new section as allowing a determination of death where an individual is essentially "deemed" dead because the three factors required to satisfy this new section (permanent coma, permanent

cessation of spontaneous respiratory functions, and permanent loss of brainstem reflexes) do not necessarily or actually cause biological death. The new section equates those circumstances to death, therefore allowing death to be deemed. The disability community is quite familiar with deeming in large benefits programs; deeming can result in positive or negative consequences for the individual in those cases where it is used, often for administrative purposes. But here, the result is death and, therefore, deeming is unacceptable. If the person is not, in fact, biologically dead, then allowing deeming of such a result must be removed from this approach.

We appreciate the opportunity to comment on this draft. If you have any questions, please contact me at ford@thearc.org.

Sincerely,

Marty Ford

Marty Ford
Senior Advisor, Public Policy

ON BEHALF OF:

American Association of People with Disabilities
Autistic Self Advocacy Network
Autistic Women & Nonbinary Network
Caring Across Generations
Not Dead Yet
Paralyzed Veterans of America
The Arc of the United States
United Spinal Association