



STATE OF DELAWARE  
**STATE COUNCIL FOR PERSONS WITH DISABILITIES**  
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**MEMORANDUM**

DATE: April 29, 2015

TO: All Members of the Delaware State Senate

FROM: Ms. Daniese McMullin-Powell, Chairperson  
State Council for Persons with Disabilities

RE: H.B. 64 (DMOST)

The State Council for Persons with Disabilities (SCPD) has reviewed H.B. 64 regarding Delaware Medical Orders for Scope of Treatment (DMOST). It is a revised version of H.B. 400 from the previous legislative session. SCPD endorses the proposed legislation. The bill seeks to address a serious shortcoming in the current way that our legal documents (ACHDs) address real medical situations faced by Delawareans every day. The DMOST empowers people with serious advanced illness or frailty, whose health care provider believes may die within the year to make their goals and preferences clearly understood and translated into a medical order that will be followed. HB 64 also allows authorized representatives to participate in this process when the patient lacks the capacity to do so. This process will benefit when a person takes the time to make their preferences known, but this has always been the case. Finally, numerous safeguards are in place to prevent treatment decisions for people with disabilities from being driven by prejudices about disability. SCPD also has the following observations.

The DMOST bill creates a new Title 25A which outlines the context and the mechanics for creating a DMOST by patients, their representatives, and health care providers. DMOST is a clinical process in which patients, with serious, advanced illness or frailty, or their authorized representatives if they lack decision-making capacity, discuss and have reduced to a medical order their goals of care and treatment choices. The DMOST order must be signed by the patient or their representative, and a health care practitioner, in order to be valid. The DMOST is not meant to supplant advance health care directives ("AHCD"); rather it is meant to address a more immediate need for a medical order reflecting current goals and treatment choices that can be followed by emergency medical personnel and treatment providers in multiple settings. AHCDs are of limited utility in emergency situations, situations where people are transferring frequently between locations (home, nursing home, hospital) or situations where the AHCD doesn't address a specific medical decision that has to be made.

The DMOST is a voluntary process. If a patient lacks decision-making capacity, authorized representatives can execute a DMOST on their behalf. Representatives must follow the patient's express directions or wishes, if known. If wishes are not known, a representative is to act as closely as possible to what a patient would have done. A representative cannot revoke or modify a DMOST if a patient has expressly withheld that power. The law provides guidance for dealing with conflicting directives and clearly allows a patient with capacity to void a DMOST at will.

There are penalties in the statute to address several potential areas of abuse. First, any person can petition the Court of Chancery for appointment of a guardian of an incapacitated person where there is good cause to believe that a decision to treat or withhold treatment is contrary to the most recently expressed wishes of the patient, that a person is not in fact lacking in capacity, if a DMOST has been improperly obtained or been revoked, or if the decision is based on a person's status as a person with disabilities or a person who is poor. Second, there are a number of protections related to treatment of DMOST by insurance companies. Finally, there are penalties associated with failing to follow a properly executed DMOST form or concealing, defacing or withholding a DMOST form that is known to exist.

#### CHANGES FROM H.B. 400

HB 64 varies from HB 400 in the following ways:

1. DHSS has been given the responsibility of creating or approving a DMOST form by regulation. §2503A(e)
  - a. *DHSS has regulatory responsibility for other aspects of DMOST, so it makes sense for it to promulgate a standard form.*
2. Someone with a "[s]erious illness or frailty," which is the state in which the DMOST is considered to be appropriate, is further defined as one "whose health practitioner would not be surprised if they died within the next year." §2503A(e)(1)
  - a. *This is very inartful language, but it is attempting to limit the use of DMOST to individuals who are in the final stages of a serious illness or condition. It does capture a number of conditions that do not fit neatly into the terminal illness/persistent vegetative state limitations for advance health care directives<sup>1</sup>*
3. The word "revoked" has been substituted for "voided" or "void" almost throughout.
  - a. *We are not sure why the drafters have chosen "void" over "revoke"*
4. Health care practitioner who can sign DMOST is expanded to include anyone who is licensed or authorized to write medical orders under Title 24. §2503A(h)

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<sup>1</sup> The bill later proposes to expand Qualifying Conditions under the Advance Health Care statute to include serious illness and frailty

- a. We are assuming that this language would allow for any future expansion of who can sign a medical order in the code*
5. Removes language that required health care providers to receive training on DMOST. §2503A(i)
  - a. We do not why they removed the training requirement for health care providers, though it may be because training would be difficult to monitor.*
6. Expands the definition of “patient’s authorized representative”, which is fleshed out to cover the order of priority of representatives; the health care practitioner must affirmatively decide which decision maker has priority by reviewing documentation and following future regulations that will explicate priority amongst potential authorized representatives. §2503A(l)
  - a. This change places a responsibility on the health care practitioner to ascertain who has authority in a more formal way, and is a response to concerns raised about the earlier draft not providing enough clarity.*
7. Added language regarding authorized representatives’ authority being limited by documents that empowered representative. §2504A(a)
8. Adds a requirement that the DMOST form must contain a statement that the form is being signed after discussion with either the patient or the authorized representative. §2509A(3)
  - a. This is not objectionable; it is an affirmation that there has been a discussion of the form and its contents prior to signing.*
9. Adds a requirement that if the DMOST form is not signed by the patient in the presence of the signing health care practitioner, it must be witnessed by another individual. §2509A(5)
  - a. This is an additional safeguard.*
10. Adds a requirement that the DMOST form has to have a statement that the patient or authorized representative if patient is incapacitated has been given a plain language statement explaining a DMOST and its consequences. (meaning that this plain language statement must be given to the patient or representative). §2509A(6)
  - a. This is not particularly objectionable but one wonders if it isn’t overkill to require it to be given each time a person signs a DMOST.*
11. A DMOST may only be modified in accordance with future promulgated regulations. (bill eliminates existing language regarding modifications). §2511A(d)
  - a. Because this is a medical order, it is not something that can be*

*unilaterally modified by a patient. The patient can always void a DMOST, but to change the terms requires the participation of the health care practitioner.*

12. Clarifies that a DMOST cannot be construed to amend or alter any type of insurance policy. §2516A(b)
13. Clarifies that a physician must make a determination of decision -making capacity if an authorized representative is going to sign a DMOST
14. Adds “Serious illness or frailty” to the list of Qualifying Conditions in Title 25.
  - a. *It was felt that an amendment to Title 25 was necessary in order to empower health agents and surrogates operating under this Title to sign DMOST forms as authorized representatives. This will have the effect of broadening the authority of agents to make end of life decisions under Advance Health Care Directives, which is currently limited to terminal illness and persistent vegetative state. This expansion reflects the reality that many people die from extended illnesses or declining health issues that are not encompassed under the current law.*

From the outset, it is important to remember that an adult with capacity directs their own care. Concerns have been expressed regarding whether authorized representatives would follow a person’s preferences regarding treatment. HB 64 creates a number of potent safeguards that address concerns individuals may have regarding potential abuse. First, a DMOST must be signed by a patient or their representative. Second, a patient can restrict a representative from voiding or altering a DMOST in the future by making that election. Third, a representative cannot use a person’s status as a person with disabilities as a factor in making a decision regarding scope of treatment. Fourth, if anyone suspects that a treatment decision is being made based on a person’s status as a person with disabilities, rather than based on specific medical criteria in consultation with a physician, they can petition for guardianship.

Thank you for your consideration and please contact SCPD if you have any questions regarding our position or observations on the proposed legislation.

cc: Mr. Brian Hartman, Esq.  
Governor’s Advisory Council for Exceptional Citizens  
Developmental Disabilities Council

P&I/HB 64 DMOST 4-29-15