STATE OF DELAWARE
STATE COUNCIL FOR PERSONS WITH DISABILITIES
MARGARET M. O'NEILL BUILDING
410 FEDERAL STREET, SUITE 1
DOVER, DE 19901

VOICE: (302) 739-3620
TTY/TDD: (302) 739-3699
FAX: (302) 739-6704

MEMORANDUM

DATE: June 23, 2014

TO: All Members of the Delaware State Senate
and House of Representatives

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

RE: H.B. 400 [Delaware Medical Orders for Scope of Treatment (DMOST)]

The State Council for Persons with Disabilities (SCPD) has reviewed H.B. 400 regarding Delaware Medical Orders for Scope of Treatment (DMOST). The proposed legislation amends Title 16 of the Delaware Code to create a new Chapter 25A which outlines the context and the mechanics for creating a DMOST by patients, their representatives, and health care providers. H.B. 400 also amends 16 Del.C §2501(h) to expand the definition of a health care decision to include the execution of a DMOST form and 16 Del.C §9706 to remove "prehospital advance directives," the predecessor to a DMOST, from that section of the Code. SCPD endorses the proposed legislation and has the following observations.

As the bill suggests, a DMOST is a clinical process in which a patient with a serious and advanced illness or frailty (or an authorized representative if the patient lacks decision-making capacity) discusses and has reduced to a medical order his/her goals of care and treatment choices. The DMOST order must be signed by the patient or representative, and a health care practitioner, in order to be valid.

The DMOST is not meant to supplant advance health care directives (AHCD). 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 (e.g. 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, an authorized representative can execute a DMOST on the patient's behalf. A representative is either an agent appointed with an ACHD, a surrogate under Title 16 Chapter 25 of the Delaware Code, or a person otherwise authorized by law to make decisions. 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 decided regarding treatment. 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 revoke or otherwise modify 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) a decision to treat or withhold treatment is contrary to the most recently expressed wishes of the patient; b) a person is not in fact lacking in capacity; c) the DMOST has been improperly obtained or been revoked; or d) 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.

There are some people in the disability community that may have concerns about DMOST. One concern is that the DMOST process may influence people with disabilities or their representatives to accept less treatment because of misconceptions and prejudices about quality of life. Another is the concern that family members or other representatives will make decisions that are inconsistent with the patient's values and wishes. From the outset, it is important to remember that adults with capacity direct their own care. Bearing that in mind, H.B. 400 creates a number of potent safeguards that address these concerns. First, a DMOST must be signed by a patient or authorized representative. Second, a patient can restrict a representative from modifying or revoking 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, anyone suspecting 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, can petition for guardianship.

In summary, SCPD endorses the proposed legislation since it intends 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, or with a life expectancy of less than a year, to make their goals and preferences clearly understood and translated into a medical order that will be followed. H.B. 400 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 treatment preferences known. Finally, numerous safeguards are in place to prevent treatment decisions for people with disabilities from being driven by prejudices about disability.

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

cc: Mr. Brian Hartman, Esq.
Governor's Advisory Council for Exceptional Citizens
Developmental Disabilities Council
P&I/HB 400 DMOST 6-23-14