SUPPLEMENTAL TESTIMONY OF WILLIAM R. STEIN
ON BEHALF OF DC APPLESEED

IN SUPPORT OF BILL 21-171,
THE HEALTH CARE DECISIONS ACT OF 2015

BEFORE THE COMMITTEE ON HEALTH AND
HUMAN SERVICES OF THE COUNCIL OF THE
DISTRICT OF COLUMBIA

July 13, 2015
I, William R. Stein, respectfully present this supplemental testimony in support of Bill No. 21-171, the Health Care Decisions Act of 2015 (the “Act”). I am a member of the DC Appleseed Board and speak on behalf of DC Appleseed.

We would like to thank the Committee on Health and Human Services of the District of Columbia Council for holding the hearing on the Act on June 29, 2015. The hearing presented a valuable opportunity for experts and other interested parties to express their support for the Medical Scope of Treatment (“MOST”) legislation, and to comment on various aspects of on the proposed program. From the witnesses’ testimony, it is clear that the bill enjoys strong support from a broad array of stakeholders, and that there is a compelling need for a MOST program to be established quickly in the District. DC Appleseed would like to first highlight a recent development regarding Medicare reimbursement for health care practitioners’ end-of-life discussions, and then address several issues that arose during the hearing’s testimony.

I. Medicare Reimbursement for End-of-Life Discussions

We would like to draw this Committee’s attention to the Centers for Medicare and Medicaid Services’ recent proposal for the Medicare program to reimburse health care professionals for end-of-life care discussions with patients.1 Widely endorsed by the American Medical Association and other medical organizations, this proposed regulation is expected to become effective January 2016.2 Further, industry analysts anticipate that private insurers will follow this Medicare policy, and more will begin reimbursing health care professionals for end-of-life discussions.3

3 Id.
This encouraging development at the federal level illustrates the growing national consensus about the value of MOST programs to improved end-of-life care. We believe this federal regulatory change will make a MOST program even more important — and widely effective — in the District. From our conversations with the medical community as part of our study on end-of-life care, one reason cited for health care providers’ reluctance to have end-of-life care discussions was the difficulty receiving compensation for those services. Reimbursement will facilitate MOST conversations, and will provide incentive to medical practitioners to initiate end-of-life care discussions with their patients. A MOST program in the District will ensure that physicians have a protocol in place to support these discussions.

II. Department of Health’s POLST Plan

We are encouraged to learn that the Department of Health (“DOH”) is supportive of the MOST program and that the department had been studying a Physician Orders for Scope of Treatment (“POST”) program for the District. We think the DOH must play a vital role in creating a successful MOST program in the District. We have concerns about several points raised in DOH Director, Dr. LaQuandra Nesbitt’s testimony.

a. Pilot Program

Dr. Nesbitt’s testimony suggested that DOH is considering implementing a pilot program before any citywide MOST program in order to gather data and solicit feedback about a MOST program. In our view, a pilot program is unnecessary and counterproductive, because it would delay considerably the implementation of the MOST program throughout the District. A pilot program is unnecessary because the MOST program is a well-established model that is fully

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4 As we mentioned in our earlier written testimony, programs that facilitate the end-of-life discussions between doctors and patients go by many names, including Physician Orders for Life-Sustaining Treatment (“POLST”), Medical Orders for Life-Sustaining Treatment (“MOLST”), Physician Orders for Scope of Treatment (“POST”), and Medical Orders for Scope of Treatment (“MOST”). In this testimony, for simplicity we refer to such programs in general as MOST programs.
developed or under development in 45 states. The MOST programs in these other jurisdictions have already generated an enormous amount of data about the effectiveness of such programs, and about which protocols are most effective. The National POLST Paradigm Task Force (“NPPTF”) collects this information and makes it available to the public. This Committee and DOH (with the assistance of a MOST commission or advisory body, as discussed later in this testimony) can easily analyze the data and incorporate any conclusions into the D.C. program. DOH has many other methods for gathering feedback on a MOST program to facilitate continuing development of a District-wide program. For example, if DOH works with a MOST commission (or advisory committee) comprised of experts, experienced practitioners and other interested stakeholders, that body would be a valuable source of feedback from the very parties that DOH presumably hopes to engage through a pilot program. While it is in the process of developing the details of the D.C. program and related regulations, DOH also might hold open public hearings (such as the one held by this Committee) about implementing the MOST legislation. As the June 29th hearing demonstrated, there are many interested stakeholders in the District who care about a MOST program and would be more than willing to share their knowledge, experience, and points of view. Leaders from programs in other states also have expressed willingness to share their experiences as the D.C. MOST program develops. In short, DOH does not need a pilot program, which would only serve to delay implementing of the MOST program.

b. Computer Software and Virtual Registry

Dr. Nesbitt also testified that DOH intends to develop an electronic registry, an on-line MOST form, and related software as part of the MOST program. DC Appleseed supports the development of such a registry because it would help achieve the purpose of the bill, and we
agree with Dr. Nesbitt’s suggestion that the language of the statute should not preclude DOH from developing regulations to implement MOST through an electronic registry and on-line form. However, while an electronic registry and an on-line MOST form are admirable goals, large amount of work remains before implementation of an electronic registry could even be attempted. We are very concerned that the amount of time and money it will take to turn these goals into a fully operational electronic registry would significantly delay implementation of the MOST program itself — and as all witnesses at the hearing agreed, a MOST program is needed now. Implementation of the MOST program should not hinge upon full scale, successful development and implementation of these on-line tools.

There is no need to wait until the registry is developed before rolling out the MOST program. Many states have well developed and effective MOST programs without an electronic registry and on-line form in place. Instead, we think it is imperative for the MOST program to be implemented while DOH (with its advisors) continues to develop electronic tools. Such tools, when ready, could integrate with the more conventional MOST system already in place.

c. The Scope of the Department’s Regulatory Authority

Dr. Nesbitt indicated that DOH prefers that parts of the MOST program be handled through the department’s regulatory process, rather than set forth in the legislation. We agree that certain features of the program — such as the exact wording and format of the MOST form — are best addressed through the regulatory process. Certain aspects, however, are so central to the program that they must be directed by the Council through the legislation.

First, it is critical to define the scope of the MOST program to make clear that it is intended for those patients who have serious, progressive life-threatening illnesses or frailty (as all the other witnesses at the hearing advocated).
Second, it is equally fundamental for this legislation to require the patient-healthcare provider conversation (better, a series of conversations) that is the core of a MOST program — although, completion of the form should always be up to the patient.

Third, it is important to set forth in the legislation, in very general terms, the topics that need to be covered: the patient’s prognosis; the expected course of the patient’s condition (what the patient can expect to happen); the likely potential life-sustaining interventions given the patient’s condition; and the consequences of each of these interventions in terms of pain, ability to communicate, mobility, level of consciousness, etc. As every study has demonstrated, this conversation is at the heart of the MOST program. Without a conversation addressing these issues, the MOST program will not achieve its objective: assuring that the patient’s well-informed preferences are honored. Experience shows that, if additional elaboration about the nature of the conversation is required, DOH (working with a MOST commission or advisory committee) can issue guidance and protocols to add specifications or fill in gaps.

Fourth, the legislation should set a deadline for DOH to issue the MOST form and to promulgate any initial regulations or guidance. Without a deadline, the MOST program might suffer from the same fate as the comfort care program; legislation authorizing that program became effective in 2001, but DOH took no action to set it up until 2006. The District needs MOST right now. Legislated deadlines for implementing the MOST program will encourage DOH to move swiftly, so that the people of the District are able to benefit from the program without significant delay.

III. Safeguards

Several witnesses at the hearing discussed the importance of certain safeguards within the MOST legislation. We would like to highlight five safeguards that we believe are essential
components of the legislation. These safeguards include: a patient signature; defining the MOST patient population in an appropriate manner; limiting the MOST program to those patients whom it is intended to benefit; keeping the MOST program voluntary; and providing adequate training for health care practitioners. The NPPTF provides support for POLST programs that meet its conditions for “endorsement.” Many of the elements we list below are required or strongly encouraged for programs seeking endorsement.

a. Patient Signature

We understand, and are sympathetic to, the position advocated by Dr. Melanie Anspacher of Children’s National Medical Center and Dr. Katalin Roth of George Washington University Medical Faculty Associates that it would be better if the legislation does not require the patient’s signature on the MOST form. From our conversations with some members of the medical community as part of our study on end-of-life care, we recognize that requiring a patient signature could make it more difficult in some situations (particularly where the patient is a minor) to obtain a signature (and therefore to complete a MOST). We also understand, however, the position of the advocates for the disabled, legal services organizations and other advocates for the elderly, and some members of the faith community, that a patient’s signature is necessary. It serves as tangible proof that the patient participated in and understood the MOST conversation, and approved the preferences expressed in the MOST. NPPTF recommends including a patient signature requirement, and most states either require a patient signature or strongly recommend it. On balance, we favor requiring a patient signature as the best way to ensure that patient’s rights are protected and that the MOST represents the patient’s wishes.

5 New York and Vermont do not require a signature but do require some indication of informed consent. Minnesota and Oregon do not require a patient signature but still strongly recommend it. In Wisconsin and Tennessee, the patient signature is optional. In each of the 6 states just mentioned, all have an optional space on the
b. Definition of Patient

In our previous written testimony, we advocated that the term “patient” in the legislation be defined as those patients whom the treating physician, in the exercise of his or her professional judgment, believes are reasonably likely to die within twelve months. From the testimony at the hearing, it appears that some witnesses were concerned about the difficulty health care practitioners might face in making such a specific prognosis. Based on our study, we believe doctors make these judgment calls every day. Of course, the patient sometimes lives longer than expected, and in such cases, no harm is done. But the twelve-month expectancy ensures that MOST is offered to and can be used by the patients who would most benefit.

Nevertheless, if the Council prefers, it could craft an alternative definition that avoids a specific time frame for the patient’s life expectancy but still captures only those patients the MOST program was designed to benefit. To this end, we suggest that the definition of “MOST” in the legislation could be revised to incorporate the underlined language:

“Medical Orders for Scope of Treatment” (“MOST”) means a set of portable medical orders for a patient with serious, progressive illness or frailty that address key medical decisions consistent with the patient’s goals of care and results from a clinical process designed to facilitate shared, informed medical decision making and communication between health care professionals and patients with serious, progressive illness or frailty.

Under this definition, the MOST program would be available to individuals who would substantially benefit from conversations with their doctors about their end-of-life treatment options. If necessary, DOH (working with a MOST commission or advisory committee) could issue guidance interpreting this definition (for example, based on NPTFF’s recommendation and the recommendations of other experts, identifying as the key question to consider is whether the

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MOST form. Only Maryland does not require a patient signature and does not provide a space on its MOST form for an optional signature.
treated doctor would answer “no” if asked the question “would it surprise you if the patient were to die within a year”).

c. Limiting MOST to Seriously Ill Patients

Related to the definition of patient or MOST (as discussed in the preceding subsection), we understand from Dr. Nesbitt’s testimony that DOH intends for the MOST program to be available to all District residents, regardless of the patient’s health condition. We strongly disagree with this position.

As explained in my written and oral testimony at the hearing, and by virtually every other witness, MOST is not meant to be another advanced directive. Instead, MOST programs are intended for those who would benefit from the detail and specificity about their course of care that is only possible in the context of a specific, diagnosed serious, progressive, life-threatening condition. The fundamental nature of a MOST is that it is the result of a conversation between a patient and the patient’s health care providers about options for life-sustaining interventions near the end of life. Without a specific condition guiding the MOST conversation, the patient and doctor will not be able to discuss a specific prognosis, course of the disease, or available intervention options. Any alternative would essentially be another version of a living will, and the District already has a strong existing legal framework for advanced directives and living wills. The MOST program is not needed as, and should not become, just a more elaborate advanced directive option.

d. Voluntary Nature of MOST

It was suggested at the hearing that patients who are transferred from a hospital to hospice or another facility be required to complete a MOST form. We disagree: a MOST must
always be voluntary. Indeed, the statue is about honoring patient preferences – including the preferences not to have a MOST.

We believe that patient must be offered a MOST (or the opportunity to revise an existing MOST) upon transfer, but we do not believe that any patient should be required to have (or modify) a MOST. The NPPTF strongly recommends that any MOST program be voluntary, and most states have so provided.

e. Training for Health Care Providers

Numerous witnesses at the hearing testified about the importance of training for health care providers, including EMS responders, to help ensure that the MOST program is effective. We strongly agree that health care providers should receive training on the procedures and requirements of MOST, and on how to conduct the sensitive and candid discussions about end-of-life care that are at the heart of a MOST program. We also agree with the views stated in oral testimony by Lindsay Baran of the National Council of Independent Living and Professor Marisa Brown of Georgetown University, that provider training on how to interact with and communicate about end-of-life care treatment options with disabled patients offers an important safeguard for such individuals. We believe that the legislation should direct DOH (or a MOST commission) to develop mandatory training programs for health care providers who would prepare or implement MOST with their patients.

IV. MOST Commission

We think that a diverse MOST commission or advisory committee should be a vital component of a MOST program. This is also the position taken by NPPTF: the first item on its required elements for endorsement is a list of names of those participating in a “single statewide
coalition that includes champions who are active in the program implementation and education.\textsuperscript{6}

Whether DOH is given full operational authority to implement and administer the program, or simply oversight responsibility, it is important to have a standing body that represents all community perspectives — including experienced healthcare providers, healthcare faculty administrators, DOH, the District’s EMS, commercial EMS companies,\textsuperscript{7} and advocates for vulnerable populations, such as patient groups, the disabled, and the frail elderly. A diverse MOST commission or advisory committee could provide to DOH immediate and essential information and perspective at the outset, as the MOST program develops. This would expedite an otherwise lengthy and inefficient process of proposed regulations, extended periods for public comment, revisions, and further periods for additional comments. As Dr. Nesbitt emphasized in her testimony, it is important for DOH to receive expert input on the front end of the regulatory process, rather than only wait for comments after regulations are proposed. We agree and urge this Committee to include language in the bill that will ensure that a MOST commission or advisory panel will provide input at the beginning and throughout the process of developing the MOST form, issuing regulations and guidance, and overseeing implementation and training.

V. Inter-jurisdictional Reciprocity

At the hearing, Dr. Nesbitt raised DOH’s concern about the bill’s reciprocity provision, which would permit District health care providers to recognize and implement out-of-state MOST forms. In particular, DOH seemed to be of the view that this provision was troublesome


\textsuperscript{7} Dr. Nesbitt testified that the Health Care Decisions Act should be amended to cover the commercial EMS companies in addition to the city’s EMS services. We agree.
because it would result in District-licensed doctors following the direction of doctors who are not licensed to practice medicine in D.C. We think this concern is not well founded.

A doctor practicing in the District who complies with an out-of-state MOST would simply be following the patient’s documented preferences within the doctor’s own practice in the District of Columbia. The doctor is following an existing, documented medical order in the patient’s chart, similar to when a patient is transferred between medical facilities within D.C. The issuing doctor would not be engaged in the practice of medicine in the District of Columbia, nor would the D.C. doctor be engaged in the practice of medicine in the state where the MOST form was first issued.

Given the close proximity of D.C. to Virginia and Maryland, and the frequent interaction between the medical systems in these and other jurisdictions, we believe that reciprocity is essential. In fact, we have consulted with providers in D.C. who frequently encounter and honor MOLST forms from Maryland and POST forms from Virginia. Our research identified many states with established or developing MOST programs that have included reciprocity provisions in their authorizing legislation. The NPPTF “strongly recommend[s]” states include reciprocity provisions in their MOST programs and includes reciprocity among the factors to be addressed in states’ application for NPPTF endorsement.

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8 Among the states with fully established MOST programs, twelve recognize valid out-of-state MOST forms: Oregon, West Virginia, Colorado, Idaho, Iowa, Maryland, Nevada, New Jersey, New York, Rhode Island, Utah, and Vermont. See http://www.polst.org/wp-content/uploads/2015/03/POLST-Leg-Chart-2-15-15.pdf. Other states with existing or developing MOST programs are largely silent on the issue of reciprocity with the exception of: (1) Illinois; whose legislation does not address reciprocity for out-of-state forms but whose own form specifically states it is not intended to be recognized outside of Illinois (http://www.polst.org/wp-content/uploads/2015/03/POLST-Leg-Chart-2-15-15.pdf), (2) Delaware; whose General Assembly removed a reciprocity provision before the legislation was submitted to the governor in May 2015 (http://legis.delaware.gov/LIS/tis148.nsf/vwLegislation/HB+64/$file/legis.html?open), and (3) Massachusetts; whose program does not recognize out-of-state MOST forms as valid medical orders but does permit such forms can be considered as evidence of a patient’s preferences (http://molst-ma.org/faqs-about-honoring-molst-forms).

9 See National POLST Paradigm Task Force’s Request for Endorsement of State POLST Program Application, p.2.
VI. Healthcare Provider Signatories

Based on our review of other jurisdictions’ laws, regulations, and experiences with MOST, we strongly endorse the bill’s provision that the District’s MOST legislation permit the order to be signed by a physician or an advanced care nurse. Most states permit nurse practitioners (and in a few cases, physician assistants), in addition to physicians, to sign a MOST. For example, 20 states with developed or developing MOST programs — Oregon, New Jersey, New Hampshire, Idaho, Wyoming, Illinois, Maine, Colorado, North Carolina, Maryland, Pennsylvania, Vermont, Massachusetts, Rhode Island, Iowa, Minnesota, Montana, Tennessee, Utah, and Washington — permit nurse practitioners to sign a MOST.10 Allowing an advanced care nurse to sign a MOST is consistent with the existing District law, which grants licensed nurse practitioners the authority to practice independently.11 By permitting advanced care nurses to sign MOST forms, the District can greatly increase the availability of this program to the patients who would benefit.

VII. Conclusion

Again, we would like to thank the Committee for its work to create a MOST program within the District. The testimony at the hearing made it clear that end-of-life treatment discussions are often complex and difficult for both patients and their health care providers, but such discussions are essential to improving end-of-life care. Establishing a MOST program is an important step toward improving end-of-life care treatment for District residents. It is consistent with steps already taken in 45 states, and endorsed by Medicare in its renewed proposal to pay providers for discussing end-of-life treatment options with patients who have a terminal,  

10 Although California currently requires a licensed physician to sign its POLST form, there is legislation pending that would amend California’s program to permit nurse practitioners and physicians’ assistants to complete the orders. See CA AB637, Bill Detail, https://www.billtrack50.com/BillDetail/599975 (last visited July 13, 2015).
11 See relevant provisions of the Nurse Practice Act, D.C. Code §§ 3-1201.02(2), 1202.04, 1206.01-04; applicable Board of Nursing regulations, D.C. Mun. Regs. §§ 17-59, et seq.
progressive illness. We look forward to working with this Committee, the District Government, the healthcare community, and other interested groups in implementing a MOST program in the District of Columbia.