POLST
PRACTITIONER ORDERS FOR LIFE-SUSTAINING TREATMENT

GUIDANCE ON THE USE OF POLST WITH INDIVIDUALS WITH SIGNIFICANT MENTAL HEALTH CONDITIONS AND/OR INTELLECTUAL/ DEVELOPMENTAL DISABILITIES

PURPOSE OF THE GUIDANCE

The purpose of this document is to provide guidelines and information for those physicians and advance practice nurses (APN) who may be partnering with their patients (and their guardians or family members) who have intellectual/developmental disabilities and/ or significant mental health conditions on advance care planning using the Practitioner Orders for Life Sustaining Treatment or POLST.

ROLE OF POLST

As with any other patient, a discussion about goals of care and POLST may be warranted when an individual who has a chronic mental health condition or intellectual/ developmental disability is also dealing with a chronic life-limiting condition. It is also necessary to consider each individual's ability to make these decisions as part of the discussion.

The use of a POLST document to limit or withhold treatment must be predicated on the individual's medical diagnoses and prognosis, not on the individual's disability or mental illness. Completing a POLST form is completely voluntary, and a completed POLST form does not replace an advance directive for healthcare pursuant to New Jersey's Advance Directive for Health Care Act (Appendix A) nor an Advance Directive for Mental Health Care pursuant to New Jersey's Advance Directive for Mental Health Care (as defined in P.L.2005, c.233 (N.J.S.A. 26:2H-102 et seq.), N.J.A.C. 10:32-1.1 et seq. (Appendix B).

WHEN TO CONSIDER USE OF POLST

It is most appropriate for individuals and guardians to consider formulating a POLST in situations when the individual's health care practitioners have determined that the individual may be entering the last phase of life. Questions the practitioner could ask include:

- Does the person have a progressive disease process (excluding the stable disability) that carries a prognosis of a limited life expectancy?
- Is the person experiencing a significant decline in health?
- Is the person receiving palliative care services or in a hospice program?
- Has this person's level of functioning become severely impaired as a result of a deteriorating medical condition when intervention will not significantly alter the process of decline toward death?

DEVELOPING END-OF-LIFE CARE GOALS

Once a physician/APN identifies that the patient is in the final phases of a chronic and progressive life-limiting illness, thoughtful consideration should be made about documenting preferences for care and completing a POLST form. One of the first considerations when developing the goals of care is to determine if the individual has the capacity to make decisions. There is no presumption of incapacity for a person with an intellectual/developmental disability or mental health condition. If the patient has a guardian who has been appointed for the specific purpose of mak-

ing medical decisions or has a plenary guardian, then capacity for purposes of the POLST form has already been determined and the physician/APN must consult with their patient as well as the appointed guardian. Otherwise, the patient's ability to understand the decisions at hand (capacity) must be considered and a surrogate identified if needed. As defined in New Jersey's advance psychiatric directive law, "decision making capacity means a patient's ability to understand and appreciate the nature and consequences of health care decisions, including the benefits and risks of each, and alternatives to any proposed health care, and to reach an informed decision. A patient's decision making capacity is evaluated relative to the demands of a particular health care decision." The decision of an individual's decision-making capacity may be determined by the practitioner for purposes of utilizing an advanced psychiatric directive, but for purposes of determining decision-making capacity for utilization of the POLST the decision must be made by a court of law.

INDIVIDUALS WITH LEGALLY APPOINTED DECISION MAKERS

Practitioners working with individuals who lack capacity and cannot participate in the completion of a POLST form should first determine if there is a legally appointed decision maker for the individual. Where a legally appointed surrogate for medical decisions exists, the practitioner will consult with the surrogate. Behavioral health patients may have an advance directive for mental health care pursuant to N.J.A.C. 10:32-1.5) (Appendix B). However, a surrogate designated as a "mental health care representative" is responsible only for psychiatric treatment in the event the individual is incapable of making decisions or cannot communicate them.

FACTORS TO CONSIDER WHEN COMPLETING A POLST

When completing a POLST document that will terminate or withhold care for an individual who is believed to lack decision-making capacity, the practitioner must ensure that there is "clear and convincing evidence" of the individual's wishes and the document must be reflective of those specific wishes with documentation as to the capacity of the individual at the time those wishes were expressed. Information that the individual held a firm and settled commitment to the withholding of life-sustaining treatment in the event of circumstances like the patient's current medical condition must be incorporated. The evidence may be in a written living will or advance directive or through oral statements made to others about what the individual would want in the event of a terminal illness. Consideration should be given to:

- Whether the statements were general or specific;
- Whether the statements were about specific circumstances (for example, terminal illness, persistent vegetative state) that are similar to the patient's current medical condition;
- The intensity, frequency, consistency and seriousness of such statements;
- Whether the statements tended to show that the patient held a firm and settled commitment to certain treatment decisions under circumstances like those presented;
- Whether the strength and durability of the patient's religious and moral beliefs make a more recent change of heart unlikely; and
- Whether the statements were made to one person only or to more than one person.

To determine goals of care and preferences for end-of-life care, when the individual is incapacitated (pursuant to a court decision and appointment of a legal guardian), and there is no pre-existing advance directive, practitioners should consult with the guardian. The practitioner should consult the guardian and any specific authority provided by court order before consultation with family members, friends and caregiver to provide information on what the individual would have decided or what is in the best interests of the individual based on his/her known values and preferences. For individuals who have been appointed a state guardian from the NJ Department of Human Services' Bureau of Guardianship Services (DHS-BGS), the guardian must meet the regulatory requirements set forth in N.J.A.C. 10:48B (Appendix G) when making an end-of-life decision which may require consultation with an ethics committee. Practitioners should contact the Bureau of Guardianship Services representative or the Division of Developmental Disabilities to confirm if a guardianship has been determined.

Danielle's Law (P.L.2003, Chapter 191, Appendix I) requires staff at a facility to call 911 in the event of a life-threatening emergency. The Division of De-

velopmental Disabilities does not consider that a "life-threatening emergency" within the meaning of Danielle's Law exists for an individual receiving hospice or palliative care where issues arise that relate to the person's end-of-life condition. Therefore, staff is not required to make a telephone call to 911 under these circumstances, and a violation of Danielle's Law will not have occurred. The individual would still need to be provided appropriate medical care as other issues arise, for example, a broken bone or injury with excessive bleeding. Staff may need to call 911 in such circumstances. If the individual has a Do Not Resuscitate order, or a Practitioner Order for Life-Sustaining Treatment (POLST), staff should provide these to emergency personnel. For further information or questions, go to http://www.state.nj.us/humanservices/ddd/home/.

HOW THE POLST SHOULD BE USED

The POLST form, as a portable document, will be utilized at the individual's place of residence.

CONSIDERATION ABOUT THE MEDICAL CARE NEEDED

All individuals, including people with intellectual/developmental disabilities and individuals with chronic mental health conditions, have shifting decision-making capacities. Every effort should be made to determine their understanding of their medical condition and their preferences for care, including their goals of care at the end stages of life. If an individual is unable to participate in this discussion in any way, then consultation with a surrogate decision maker, caregivers, family and friends is necessary to assure the provision of the highest quality of end-of-life care, consistent with the individual's wishes and needs. A legally authorized surrogate can assist in the completion of the POLST document.

Section E of the POLST form should not be completed in circumstances where the patient lacks decision-making capacity and a legally appointed guardian or authorized surrogate is completing the form with the practitioner. In that event, draw a line through the section and write "N/A" along with the initials of the practitioner writing the orders. As always, in the event there is dissent on this issue, practitioners should consult with family members, physicians with expertise with these populations, or the healthcare facility's ethics committee.

APPENDICES

A. N.J. 26:2H-53 (2009); *New Jersey Advance Directives for Health Care Act*.

B. N.J.A.C. 10:32 (2007): *Advance Directives for Mental Health Care*.

C. Administrative Bulletin 3:37
Advance Directives for Mental Health Care
Nov. 17, 2010

D. FAQs from the National Resource Center on Psychiatric Advance Directives
New Jersey Q and A

G. N.J.A.C. 10:48B; *Decision Making for the Terminally Ill* (2010); policy from the Department of Human Services, Division of Developmental Disabilities.

H. *Healthcare Treatment Decision-Making Guidelines for Adults with Developmental Disabilities*, published by the Midwest Bioethics Center and the University of Missouri - Kansas City Institute for Human Development Task Force on Healthcare for Adults With Developmental Disabilities.

I. P.L. 2003, Chapter 191, *Danielle's Law*.

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