



## **MOLST for Minor Patients with Developmental Disabilities**

### **Frequently Asked Questions (FAQs)**

**April 2014**

#### **What is MOLST (Medical Orders for Life-Sustaining Treatment)?**

Honoring patient preferences is a critical element in providing quality end-of-life care. Medical Orders for Life-Sustaining Treatment (MOLST) is a program designed to improve the quality of care patients receive at the end of life by translating patient goals for care and preferences into medical orders. MOLST is based on communication between the patient, his or her health care agent or other designated surrogate decision-maker, and health care professionals that ensures shared, informed medical decision-making.

#### **What is the DOH-5003 MOLST form?**

To help physicians and other health care providers discuss and convey a patient's wishes regarding cardiopulmonary resuscitation (CPR) and other life-sustaining treatment (LST), the Department of Health has approved a physician order form DOH-5003 MOLST, which can be used statewide by health care practitioners and facilities.

The MOLST form is a bright pink medical order form signed by a New York State licensed physician or a border state physician that tells others the patient's medical orders for life-sustaining treatment. All health care professionals must follow these medical orders as the patient moves from one location to another, unless a physician examines the patient, reviews the orders, and changes them.

The MOLST serves as a single document that contains a patient's goals and preferences regarding:

- Resuscitation instructions when the patient has no pulse and/or is not breathing
- Instructions for intubation and mechanical ventilation when the patient has a pulse and the patient is breathing
- Treatment guidelines
- Future hospitalization and transfer
- Artificially administered fluids and nutrition
- Antibiotics
- Other instructions about treatments not listed

Under State law, the MOLST form is the only authorized form in New York State for documenting both nonhospital Do Not Resuscitate (DNR) and Do Not Intubate (DNI) orders. In addition, the form is beneficial to patients and providers as it provides specific medical orders and is recognized and used in a variety of health care settings.

### **Has the DOH-5003 MOLST been approved for use for children with developmental disabilities?**

Effective January 21, 2011, the DOH-5003 MOLST form has been approved by the Office for People with Developmental Disabilities (OPWDD) for use as a nonhospital DNR/DNI form for persons with developmental disabilities, including persons who are incapable of making their own health care decisions or who have a guardian of the person appointed pursuant to Article 81 of the Mental Hygiene Law or Article 17-A of the Surrogate's Court Procedure Act.

The most significant change resulting from approval of the MOLST form by the OPWDD is with respect to non-hospital Do Not Resuscitate (DNR) orders. Previously, such DNR orders were required to be on the DOH-3474 form <http://www.nyhealth.gov/forms/doh-3474.pdf>. Now a non-hospital DNR order can be written on either the DOH-3474 form or the MOLST form (DOH-5003).

The advantage of the MOLST form is that it is transferable to other settings across care transitions. Accordingly, a DNR or DNI issued on a MOLST form is effective in hospitals, nursing homes and community settings. In addition, MOLST is the only approved medical order form that EMS can follow for both DNR and Do Not Intubate (DNI) order.

### **How can providers adhere to all legal requirements for completing the MOLST form for a child with developmental disabilities who lacks medical decision-making capacity?**

The Office for People with Developmental Disabilities has developed its own checklist for individuals with developmental disabilities who lack medical decision-making capacity.

The DOH-5003 MOLST must be completed with the OPWDD approved checklist, and *the checklist **MUST** be attached to the MOLST form*, when the form is used for a child with a developmental disability who is incapable of making his/her own health care decisions or who has a guardian of the person appointed pursuant to Article 81 of the Mental Hygiene Law or Article 17-A of the Surrogate's Court Procedure Act.

The OPWDD checklist can be found at:

[http://www.opwdd.ny.gov/opwdd\\_resources/information\\_for\\_clinicians/MOLST](http://www.opwdd.ny.gov/opwdd_resources/information_for_clinicians/MOLST)

### **How is a MOLST form completed for a child with developmental disabilities who lacks medical decision-making capacity?**

Completion of the MOLST begins with a conversation introducing the MOLST process between the 1750-b Surrogate and a qualified, trained health care professional. A conversation or series of conversations between and the treating physician defines the minor patient's goals for care and reviews possible treatment options on the MOLST form, using a shared, informed medical decision-making process. The conversation should be documented in the medical record.

Following these discussions, the 1750-b surrogate makes a decision to withhold or withdraw LST, either orally or in writing.

The MOLST form may only be completed after the Surrogate's Court Procedure Act § 1750-b process has been completed for a minor patient with developmental disabilities who lacks decision-making capacity. Use of the [MOLST Legal Requirements Checklist for Individuals with Developmental Disabilities](#) developed by OPWDD ensures that the appropriate statutory standards have been met.

The MOLST form must be accompanied by the OPWDD Checklist as the child travels to different clinical settings.

### **Who makes the request to withdraw or withhold life-sustaining treatment?**

The 1750-b surrogate makes the request either orally or in writing.

### **How does the provider identify and notify the appropriate Surrogate's Court Procedure Act § 1750-b Surrogate?**

The attending physician identifies and names the appropriate §1750-b Surrogate from the prioritized list. In order of highest priority, the appropriate §1750-b surrogate is:

- 17-A guardian
- actively involved spouse
- actively involved parent
- actively involved adult child
- actively involved adult sibling
- actively involved family member
- Willowbrook CAB (full representation)
- Surrogate Decision Making Committee (MHL Article 80)

If a minor patient with developmental disabilities who lacks medical decision-making capacity has a guardian of the person appointed pursuant to Article 81 of the Mental Hygiene Law or Article 17-A of the Surrogate's Court Procedure Act, guardianship is established by the court. Consult with legal counsel regarding whether the guardian has the authority to make MOLST decisions.

### **Who determines capacity for the child with developmental disabilities?**

The attending physician determines the child's lack of capacity to make health care decisions and a second determination must be made by a concurring physician or licensed psychologist.

Either the attending physician or the concurring physician or licensed psychologist must:

- (a) be employed by a DDSO; or
- (b) have been employed for at least 2 years in a facility or program operated, licensed or authorized by OPWDD; or
- (c) have been approved by the commissioner of OPWDD as either possessing specialized training or have 3 years experience in providing services to individuals with developmental disabilities.

### **Who determines necessary medical criteria?**

The attending physician determines the necessary medical criteria for the life-sustaining treatment that is requested to be withdrawn or withheld by the 1750-b surrogate.

The determination of necessary medical criteria needs to be made for **each** specific life-sustaining treatment that the 1750-b surrogate makes a decision to withhold or withdraw.

Specifically, the attending physician and a concurring physician must determine, to a reasonable degree of medical certainty, necessary medical criteria for withholding or withdrawing a life-sustaining treatment, including **BOTH**:

1. the child's medical condition warrants use of the MOLST, **AND**
2. the life-sustaining treatment would impose an extraordinary burden on the child.

The physician must determine the child has one of the following medical conditions and briefly describe the condition:

1. a terminal condition; or
2. permanent unconsciousness; or
3. a medical condition other than DD which requires life-sustaining treatment, is irreversible and which will continue indefinitely.

The physician must determine and briefly describe how the life-sustaining treatment would impose an extraordinary burden on the child in light of:

1. the person's medical condition other than DD
2. the expected outcome of the life-sustaining treatment, notwithstanding the person's DD

### **Who must be notified BEFORE the MOLST can be completed?**

Notifications must occur at least 48 hours prior to the implementation of a decision to withdraw life-sustaining treatment, or at the earliest possible time prior to a decision to withhold life-sustaining treatment. Notifications are required WITH or WITHOUT a MOLST.

The attending physician must notify the child with developmental disabilities who retains the ability to decide, unless therapeutic exception applies.

If the [child is in a group home](#), (described in Step #5 on the OPWDD Checklist as "if the person is in or was transferred from an OPWDD residential facility") the attending physician must notify the Facility Director and Mental Hygiene Legal Services (MHLS) and document the date of notification. **Consultation with MHLS regarding the clinical case and necessary medical criteria for decision to withhold or withdraw life-sustaining treatment is helpful.**

If a [child is at home and receiving OPWDD services](#), (described in Step #5 on the OPWDD Checklist as "if the person is **not** in and was not transferred from an OPWDD residential facility") the attending physician must notify the director of the local DDSO and document the date of notification.

The MOLST form may ONLY be completed with the §1750-b surrogate after all 6 steps on the MOLST OPWDD checklist have been completed. (Note Step 6 - I certify that the §1750-b process has been complied with, the appropriate parties have been notified and no objection to the surrogate's decision remains unresolved.)

Other parties **not** entitled to notice have the right to object and suspend the life-sustaining treatment decision/MOLST orders. Such parties include parents or adult siblings who have maintained substantial and continuous contact with the patient.

### **If a child with developmental disabilities has a properly completed MOLST form, when must the physician repeat the §1750-b process outlined on the OPWDD Checklist?**

If a child with developmental disabilities and a properly completed MOLST form is readmitted to the hospital, the physician must ascertain the child's goals for care. If the child experiences progressive deterioration during the hospitalization, the physician must reassess the child's goals for care and MOLST orders. In either situation, the physician should proceed as follows:

1. If there is **NO** change in the child's goals for care and **NO** request to change the MOLST orders by the §1750-b surrogate, the §1750-b process as outlined on the OPWDD Checklist is **NOT** required to be repeated.

2. If there is a **change** in the goals for care and a **new order to withhold or withdraw a new LST** on the MOLST orders, the §1750-b process as outlined on the OPWDD Checklist is required to be repeated. This includes appropriate notification based on whether the child is at home or in a group home.

The child's health status, goals for care and MOLST orders should be reviewed at the time of discharge from the hospital to ensure MOLST orders remain appropriate and align with the child's health status and goals for care.

### **How often must the MOLST orders be reviewed and renewed?**

The MOLST form must be reviewed and renewed for persons with developmental disabilities every 60 days. A medical order to withhold or withdraw life-sustaining treatment (e.g. DNR/DNI) for persons with developmental disabilities must be reviewed and renewed every 60 days WITH or WITHOUT a MOLST.

### **Can a person with developmental disabilities complete a health care proxy when they turn 18 years of age?**

Capacity is task specific. A person may lack the capacity to make complex medical decisions to withhold or withdraw life-sustaining treatment, but may have the ability to choose a health care agent. A person  $\geq$  18 years of age has the right to choose a health care agent and should be encouraged to do so.

### **What is OPWDD?**

The New York State Office for People With Developmental Disabilities (OPWDD) is responsible for coordinating services for New Yorkers with developmental disabilities, including intellectual disabilities, cerebral palsy, Down syndrome, autism spectrum disorders, and other neurological impairments. OPWDD provides services directly and through a network of approximately 700 nonprofit service providing agencies, with about 80 percent of services provided by the private nonprofits and 20 percent provided by state-run services.

OPWDD was created in 1978 as the Office of Mental Retardation and Developmental Disabilities, an independent cabinet-level state agency. In 2010, the agency and its stakeholder partners marked an historic milestone for the people they support when New York State changed the agency's official name, eliminating the term "mental retardation" from its new title.

### **What is DDSO?**

Developmental Disabilities Service Office (DDSO) refers to the local district office of the Office for People With Developmental Disabilities (OPWDD).

In order to strengthen the service delivery system and structure, and provide a consistent approach and culture for persons receiving services, the OPWDD has recently undergone a reorganization of local district offices with the goal of improving oversight and promoting quality services. As a result of the restructuring efforts, the *DDSO* no longer exists as a local contact, rather, the service system has been reconfigured into five (5) Developmental Disabilities Regional Offices and six (6) State Operations Offices.

Developmental Disabilities Regional Offices (DDROs) work with voluntary provider agencies to improve access to and coordinate services within a region, in order to assist individuals and families to make informed choices about supports and services best suited to their needs. [Learn more about the functions of DDROs.](#)

Developmental Disabilities State Operations Offices (DDSOOs) administer and oversee state operations for OPWDD. This includes, but is not limited to, statewide systems improvements, fire safety initiatives and specialized supports/services in the areas of clinical and food services, volunteers/senior companions, and the direct delivery of supports and services by OPWDD staff. [Learn more about the functions of DDSOOs.](#)

### **What is MHLS?**

The Mental Hygiene Legal Service (MHLS) provides legal services, advice and assistance to persons receiving care or alleged to be in need of care at inpatient and community based facilities for individuals with mental disabilities. Created in 1964 and organized under Mental Hygiene Law article 47, the Service represents individuals in judicial and administrative proceedings concerning admission, retention, transfer, treatment and guardianship.

In addition to handling judicial proceedings, the Service provides advice and representation regarding standards of care and other matters affecting the civil liberties of persons receiving care at facilities for individuals with mental disabilities.

For assistance, contact MHLS through a Departmental Office:  
<http://www.justicecenter.ny.gov/mental-hygiene-legal-service-mhls>