

**DEPARTMENT OF DEVELOPMENTAL SERVICES**

**California Code of Regulations**

**Title 17, Division 2**

**Chapter 1- General Provisions**

**SubChapter 10: End of Life Option Act**

**Article 1- General**

**Sections 51000, 51001, 51002**

**FINDING OF EMERGENCY**

The regulations are required in order for the State Department of Developmental Services (DDS or Department) to immediately institute protocols and procedures necessitated by the enactment of the End of Life Option Act (Act), commencing with Section 443 *et seq.*, of the Health and Safety Code, which became effective on June 9, 2016. The proposed regulations must be adopted on an emergency basis in accordance with Government Code sections 11346.1 and 11349.6, in order to avoid serious harm to the public peace, health, safety, and general welfare.

The regulations are required to protect health and safety because the Act requires that an individual with a terminal illness, as defined by the Act, residing in a state developmental center or state-operated facility be provided aid-in-dying drugs if he or she invokes the rights afforded by the Act. The state developmental centers and state facility operated by DDS house individuals with significant intellectual disabilities who often lack safety awareness and may not be able to properly manage, control or prevent the unauthorized dissemination of aid-in-dying drugs dispensed pursuant to the Act. Providing aid-in-dying drugs to such individuals presents a risk to the health, safety, and security of the facilities' patients and staff. A terminal patient could inadvertently lose possession of the aid-in-dying drugs and such drugs could improperly be obtained by residents without a terminal condition or by the facility's staff.

The proposed regulations are also necessary to protect the general welfare because individuals in a state developmental center and state-operated facility are often committed to the facility by court order, or their placement at the facility is subject to judicial review. For individuals committed to a DDS facility by court order, the regulations are necessary to ensure that a patient's wish to exercise the end-of-life rights under the Act is promptly brought before the committing court for appropriate disposition of the patient's request to end his or her life due to the terminal condition.

The Welfare and Institutions Code authorizes DDS to promulgate regulations. Specifically, the Legislature designated the Department with the administration of developmental centers and state-operated facilities, entities that care for persons with significant developmental

disabilities. (Cal. Welf. & Inst. Code, §§ 4440, 4441, 4449, and 4484.) The statutes governing DDS also permit the Department to promulgate regulations governing the operation and training of DDS employees and others working at a developmental center. (See Cal. Welf. & Inst. Code, §§ 4449, 4485.) There is not sufficient time to promulgate these regulations through the nonemergency regulation process because the End of Life Option Act has already become effective.

### **INFORMATIVE DIGEST/POLICY STATEMENT OVERVIEW**

The Lanterman Developmental Disabilities Services Act (Lanterman Act), commencing with Welfare & Institutions Code section 4500 *et seq.*, requires the Department to ensure the care and treatment of individuals with developmental disabilities. The individuals who require the most critical care and services under the Lanterman Act reside in developmental centers and state-operated facilities, which are under the jurisdiction of the Department. Individuals with developmental disabilities can be committed to a DDS facility under Penal Code section 1370.1 for competency training and restoration, or civilly committed pursuant to Welfare and Institutions Code section 6500 *et seq.* where the person is dangerous to himself or others.

Presently, individuals residing in the developmental centers and suffering from a terminal illness receive appropriate and necessary medical care for their condition, including counseling, hospice, and palliative care. However, effective June 9, 2016, qualified terminally ill individuals residing in a DDS facility have the ability to seek to participate in the end-of-life activities permitted under the Act. Given the intellectual challenges of persons residing in a state developmental center or a state-operated facility, the Act's requirement to provide patients with aid-in-dying drugs can constitute a threat to the health and safety of the facilities' other residents and staff. Accordingly, it is necessary for DDS to enact regulations that provide clear directives to employees and facility residents regarding the Department's response to the End of Life Option Act.

51000: Reiterates entitlement to treatment for terminally ill individuals residing in a developmental center or state-operated facility, and precludes DDS' employees and others acting on the Department's behalf from providing end-of-life options on DDS premises.

51001: Sets forth the procedures governing when a terminally ill individual residing in a developmental center or state-operated facility requests to exercise his or her rights under the End of Life Option Act.

51002: Identifies the appeal process for terminally ill individuals seeking to participate in end-of-life options under the Act on the premises of a developmental center when no community option is available.

## **OBJECTIVE AND ANTICIPATED BENEFITS OF THE PROPOSED REGULATIONS**

With the enactment of the End of Life Option Act, DDS employees and others acting on the Department's behalf are confronted with novel legislation permitting qualified terminally ill persons to participate in end-of-life options under the Act. The objectives of the proposed regulations are to create clear directives issued by DDS relating to the Department's response for those wishing to exercise their rights under the Act. These regulations articulate the procedures necessary to ensure the health, safety, and ethical treatment of the vulnerable persons residing in or committed to developmental centers and state-operated facilities. The regulations prohibit the participation in end-of-life options under the Act on premises owned or operated by DDS. They also preclude employees, independent contractors, and other persons from participation in end-of-life activities while acting within the scope of their employment or contract with DDS.

The regulations set forth protocols that articulate the authorized actions that an employee or other person may take when an individual residing at or committed to a developmental center or state-operated facility requests to exercise rights specified in the Act. The regulations provide an appeals process where the Director of DDS may authorize a person to exercise his or her rights under the Act when no community facility is available.

### **Benefits:**

Adoption of these regulations is necessitated by the enactment of the Act. These regulations create a mechanism to ensure the continued safe and ethical care provided to persons residing in developmental centers and state-operated facilities, while also establishing a structure to permit individuals to exercise the rights afforded under the Act. The regulations ensure that as a matter of course, the aid-in-dying drugs will not be stored or accessible on DDS premises, eliminating the safety risks associated with the housing and distribution of such drugs. The regulations are protective measures that guarantee the continued health and safety of the developmental centers' residents and provide appropriate notices to the courts and interested parties regarding individuals judicially committed to the Department who wish to exercise the rights afforded by the Act.

### **Determination of Inconsistency/Incompatibility with Existing State Regulations:**

DDS has determined the proposed regulations are not inconsistent or incompatible with existing state regulations.

**Mandate on Local Agencies and School Districts:**

DDS has determined that the proposed emergency regulations do not impose a mandate on local agencies or school districts.

**Fiscal Impact:**

DDS has determined that the emergency regulations do not impose any additional costs or savings requiring reimbursement under Government Code section 17500, *et seq.*, any non-discretionary cost or savings to local agencies or school districts, or any cost or savings in federal funding to the state. DDS has determined there will be no cost or savings to any state agency pursuant to Government Code section 11346.1(b) or 11346.5(a)(6).

**Economic Impact:**

DDS is not aware of any cost impacts that a representative, private person, or business would necessarily incur in reasonable compliance with the proposed action. DDS has made a determination that the emergency regulations would not affect the creation or elimination of jobs, the creation of new businesses, the elimination of existing businesses, or the expansion of businesses currently doing business within the State of California.