

DEPARTMENT OF DEVELOPMENTAL SERVICES

1600 NINTH STREET
SACRAMENTO, CA 95814
TTY 654-2054 (For the Hearing Impaired)
(916) 654-3405



**California Department of Developmental Services
Initial Statement of Reasons**

Subject of Proposed Regulations: End of Life Option Act**Sections Affected: Title 17, Sections 51000, 51001, and 51002****Description of the Problem Addressed:**

The Lanterman Developmental Disabilities Services Act ("Lanterman Act"), Welfare & Institutions Code section 4500 *et seq.*, requires the Department of Developmental Services ("Department" or "DDS") to ensure the care and treatment of individuals with developmental disabilities. Approximately 900 individuals who require 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.* when 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, as of 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 End of Life Option Act ("Act"). (Health & Safety Code Division 1, Part 1.85, § 443 *et seq.*) Given the intellectual and behavioral challenges of persons residing in a state developmental center or a state-operated facility, the Act's requirement to provide terminal patients with aid-in-dying drugs can constitute a threat to the health and safety of the facilities' other residents and staff.

On July 25, 2016, the proposed text was approved in the form of emergency regulations, which are scheduled to expire on January 24, 2017. It is necessary for DDS to enact permanent regulations that provide clear directives to employees, facility residents, and the public regarding the Department's response to the End of Life Option Act.

Rationale for the Provisions of the Proposed Regulations:

51000:

Specific Purpose: This regulation reiterates the 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.

Necessity:

51000(a) The laws governing state developmental centers and state-operated facilities, and the policies and procedures of these facilities, require the Department to provide appropriate and necessary care and treatment for every resident. This subdivision reaffirms that notwithstanding the right to ingest aid-in-dying drugs afforded under the End of Life Option Act, the Department will continue to provide appropriate and necessary care and treatment for anyone diagnosed with a terminal illness.

51000(b) The End of Life Option Act permits an entity to opt-out of providing aid-in-dying drugs. This subdivision expresses the Department's intent to opt-out of the Act, except as otherwise specified in the regulations.

51001:

Specific Purpose: This regulation sets forth the procedures applicable 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.

Necessity:

51001(a) This subdivision is necessary to identify the individuals directly impacted by the regulations.

51001(a)(1) This subdivision ensures that employers, employees, private contractors, and consumers understand the available course of action, and proper procedures for transferring an individual who wishes to exercise his or her rights under the Act to a community facility that will allow the individual to ingest an aid-in-dying drug. It is necessary to provide the regional center with a maximum of thirty (30) days to complete the transfer. This timeline provides the regional center with adequate time to evaluate and coordinate a safe and individualized transfer and to take into account the physical and mental health needs of the individual, while balancing the need to act quickly upon an individual's request to exercise his or her rights under the Act. This subdivision also permits an individual who chooses not to exercise his or her rights under the Act after a transfer to return to the developmental center or state-operated facility.

51001(a)(2) This subdivision creates a mechanism to advise the committing court, district attorney, public defender, or other appropriate counsel of a person committed to a developmental center pursuant to Penal Code section 1370.1, and the person's regional center of the defendant's desire to exercise his or her rights under the End of Life Option Act. This is important because a criminal defendant that is committed to DDS for competency training and

evaluation remains under the jurisdiction of the court. Accordingly, it is necessary that the court and relevant parties be made promptly aware of the diagnosis of a terminal illness and the defendant's desire to exercise his or her rights under the Act. The Department has determined that seven (7) days is the necessary maximum time for service of notice after taking into account weekends, court holidays, and varied court filing requirements. It is within the discretion of the committing court to determine the appropriate next steps, and it is the regional center's responsibility under the Lanterman Act to identify a community facility that will allow the defendant to exercise his or her rights under the End of Life Option Act.

51001(a)(3) This subdivision creates a mechanism and establishes timeframes needed to promptly advise the committing court, district attorney, public defender, or other appropriate counsel of a person committed to a developmental center or transferred to a state-operated facility pursuant to Welfare and Institutions Code sections 6500 *et seq.*, and the person's regional center of the individual's desire to exercise his or her rights under the End of Life Option Act. When an individual is civilly committed to DDS by a court, he or she remains subject to the court's jurisdiction, and it is necessary that the court and relevant parties be made promptly aware of the diagnosis of a terminal illness and the person's desire to exercise his or her rights under the Act. The Department has determined that seven (7) days is the necessary maximum time for service of notice after taking into account weekends, court holidays, and varied court filing requirements. It is within the discretion of the committing court to determine the appropriate next steps, and it is the regional center's responsibility under the Lanterman Act to identify a community facility that will allow the individual to exercise his or her rights under the End of Life Option Act. It is necessary to provide the regional center with a maximum of thirty (30) days to identify an appropriate community facility. Thirty (30) days allows the regional center adequate time to identify and arrange a safe and suitable community placement, that will provide quality services and care for all of the individual's medical needs. Thirty (30) days is necessary because the Department works with a vulnerable cross-section of the population with complex care requirements. The Department has determined that once the placement is identified, seven (7) days is the necessary time required to evaluate and coordinate a safe and individualized transfer to the identified placement, while balancing the need to act quickly upon an individual's request to exercise his or her rights under the Act. This subdivision also describes the mechanism by which DDS may effect a transfer under Welfare and Institutions Code section 6509(d), which requires notice to the court and relevant parties before making a transfer to the community facility identified by the regional center.

51002:

Specific Purpose: This regulation specifies an 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.

Necessity:

51002 This section is necessary to describe an appeals process to ensure that a terminally ill individual who wishes to exercise his or her rights under the Act, but who is unable to be placed in a community facility, has a mechanism to seek to remain in the developmental center or

state-operated facility when exercising his or her rights under the Act. Based on the nature of the request to exercise one's rights under the Act, it is necessary to designate the executive director as the person charged with communicating an individual's right to appeal in order to ensure that there is continuity and clarity in policy and message. In order to adequately and effectively notify an individual of his or her right to appeal, the executive director must provide an individual with both a written and verbal explanation of his or her right to appeal. The Director has been identified as the individual to appeal to because she or he oversees all of the developmental centers and the state-operated facility. When evaluating an appeal, it is necessary for the Director to consider the totality of the circumstances, since each resident in a developmental center or state-operated facility is uniquely situated and cared for based on a variety of factors, such as the nature of his or her developmental disability, age, physical limitations, and the nature of the underlying and qualifying terminal illness. The Director may also need to consider additional factors such as the safety of other residents. The Department has determined that it is necessary for the Director to reach a decision within fourteen (14) days, in order to allow enough time for the Director to identify and address any relevant circumstances, without unduly delaying access to an individual's rights under the Act.

Economic Impact:

In accordance with Government Code section 11346.3(b), DDS has reviewed the economic impact of the regulations. 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 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. DDS has made the initial determination that the proposed regulations will not have a significant adverse economic impact on businesses because the regulations only apply to DDS' facilities.

Technical, Theoretical, and/or Empirical Study, Reports or Documents:

No technical, theoretical, or empirical studies/reports were relied upon in the proposal of these regulatory actions.

Benefits Anticipated from the Regulatory Action:

These regulations benefit consumers residing in the developmental centers and state-operated facilities by creating a clear and specific process for an individual wishing to exercise his or her rights under the Act. They also provide a clear process for notifying the court and relevant parties when a person committed to a DDS facility pursuant to a court order wishes to exercise his or her rights under the End of Life Option Act. Additionally, the regulations promote the health and safety of the residents and staff of the developmental centers and state-operated facility by ensuring that aid-in-dying drugs are generally not distributed on facility grounds.

Evaluation of Consistency/Compatibility with Existing Regulations:

DDS has evaluated existing statutes and regulations and determined that the proposed regulations are consistent with existing law.

Mandate on Local Agencies and School Districts:

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

Fiscal Impact:

DDS has determined that the 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).

Considerations of Alternatives:

The Department has determined that there are no reasonable alternatives to the regulatory proposal that would be more effective in carrying out the purpose for which the action is proposed. No proposed alternative would be as effective or less burdensome to private persons than the action proposed, nor would they be more cost-effective to private persons and equally effective in implementing the statutory policy or other provisions of law.

Outlined below are the alternatives that the Department received through the comment process in response to the emergency regulations before their adoption. DDS carefully evaluated each of these alternatives and rejected them for the following reasons:

Alternative 1: Require all terminally ill persons with a developmental disability to seek court review and approval before being transferred to a private facility for the purpose of exercising their rights under the Act.

Analysis: This proposed alternative creates a requirement of court review and approval before a person with a developmental disability may exercise his or her rights under the Act. However, prior court review and approval is not a requirement under the End of Life Option Act. DDS concludes that it would be inappropriate, and potentially unlawful, for the Department to add by regulation a procedural requirement before persons residing in state facilities may exercise the rights afforded under the Act.

Alternative 2: Allow residents of developmental centers and state-operated facilities to continue residing on the premises when exercising their rights under the Act, without transferring them to a private facility.

Analysis: The End of Life Option Act permits individuals to possess aid-in-dying drugs for a period of time before deciding to ingest the drugs. Transfer to a community facility before providing the aid-in-dying drugs ensures that such drugs do not fall into the possession of other residents or the staff of the developmental center or state-operated facility, thereby protecting staff and consumer health and safety.

Alternative 3: Create regulations that entirely opt-out of the End of Life Option Act.

Analysis: The End of Life Option Act allows an individual diagnosed with a terminal illness to exercise his or her rights under the Act. However, the Act also permits a health care provider to opt-out of the rights afforded under the Act. DDS believes it would be inappropriate for the Department to deprive the legal right afforded by the Act to the residents of a developmental center or state-operated facility. Also, the regulations delineate the Department's response when a person committed by court order seeks to exercise the rights afforded by the Act.

Alternative 4: (Pertaining to 51001) When an individual expresses a desire to exercise his or her rights under the End of Life Option Act, he or she should immediately be referred to the Clients' Rights Advocate for the developmental center or state-operated facility. This would help to ensure that the individual understands all of his or her options, including the right to change his or her mind at any point in this process.

Analysis: There is currently no prohibition against an individual seeking advice from a Clients' Rights Advocate before deciding to exercise the rights afforded under the Act. However, if DDS were to require that an individual must first be referred to a Clients' Right Advocate before the person could exercise his or her rights under the Act, it would create a procedural requirement for its residents that is not found in the Act. As indicated, DDS does not believe that it has authority to impose new procedural requirements on individuals residing in developmental centers or state-operated facilities before allowing them to exercise the rights afforded by the Act.

Alternative 5: (Pertaining to 51001) Any reference to "competency evaluation" should be changed to "competency restoration."

Analysis: The Department reviewed Penal Code sections 1368-1372, and found that when the statutes refer to "competency restoration" it is in the context of both Penal Code section 1370 and Penal Code section 1370.1. DDS has determined that the use of "competency restoration" is imprecise as it pertains to the proposed regulations because the term is primarily associated with drug treatment for an individual found incompetent due to a mental disorder and committed to the Department of State Hospitals or other psychiatric facility under Penal Code section 1370. Drug treatment is not necessarily a required clinical course for an individual with a developmental disability who is committed to DDS pursuant to Penal Code 1370.1. Therefore, "competency evaluation" is a more precise term when considering individuals with developmental disabilities committed to the Department. As a practical matter, an evaluation is undertaken before DDS will issue a certification of competency with the committing court.

Alternative 6: (Pertaining to 51001) In the event that an individual is residing in a Department owned or operated facility due to a court commitment, and the court denies the individual's request to leave the premises in order to exercise his or her rights under the End of Life Option Act, it is suggested that the individual be able to appeal that decision to the Director.

Analysis: Individuals committed to DDS pursuant to Penal Code section 1370.1 or Welfare and Institutions Code section 6500 et seq. remain under the jurisdiction of the committing court. Commitment to a DDS facility is for a limited purpose and duration. The ultimate responsibility for an individual's final placement resides with the committing court, not DDS. Accordingly, if a committing court denies a person's right to exercise his or her rights under the Act, DDS does not have the ability to circumvent the court's authority by nevertheless permitting the exercise of rights under the Act at DDS facilities.

Alternative 7: (Pertaining to 51002) Apply the appeal process to individuals who are reluctant to leave their familiar settings in order to access aid-in-dying medication, and allow them to remain in department owned or operated facilities.

Analysis: As indicated, DDS has a health and safety interest in preventing the inadvertent distribution or possession of aid-in-dying drugs to other residents or staff. The health and safety interests of staff and the other residents living in the developmental centers and state-operated facilities, who often lack safety awareness, supersedes an individual's desire to remain on the premises to ingest the aid-in-dying drugs.

Alternative 8: Instead of requiring individuals to leave the facility, DDS should assess each individual independently to determine the most comfortable location for him or her to exercise his or her rights under the Act.

Analysis: The health and safety interests of the other residents living in the developmental centers and state-operated facilities supersede an individual's desire to remain on the premises when ingesting the aid-in-dying drug. To the extent that an individual would be more comfortable in one community placement over another, those decisions are addressed through the Individual Program Plan and transition processes.