

**A SYSTEM IN TRANSITION:
CALIFORNIA'S DEVELOPMENTAL CENTERS**

**A JOINT HEARING OF
SUBCOMMITTEE #3 OF THE SENATE
COMMITTEE ON BUDGET AND FISCAL REVIEW
AND
THE SENATE HUMAN SERVICES COMMITTEE**

Senator Mark DeSaulnier, Chair, Subcommittee #3
Senator Carol Liu, Chair, Human Services Committee
Senator Bill Emmerson, Vice Chair, Subcommittee #3 &
Human Services Committee

**OCTOBER 23, 2012
STATE CAPITOL, ROOM 4203
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I. EXECUTIVE SUMMARY

California's Department of Developmental Services (DDS) operates four institutional Developmental Centers (DCs) and one smaller state-operated community facility that care for approximately 1,650 adults and children with developmental disabilities. These DCs are part of a larger system of developmental services overseen by DDS, which also includes services and supports for approximately 250,000 people with developmental disabilities who live in their communities. In the current budget year (2012-13), the anticipated costs associated with DCs are approximately \$559 million, including \$284 million in state General Fund (GF) resources. The budget for the larger developmental

services system, including DCs as well as community-based services, includes \$4.7 billion (\$2.7 billion GF).

The first DC opened in 1888, and residents with developmental disabilities were typically co-mingled with patients whose primary needs were related to mental illness. At their peak in 1967, the state's DCs housed more than 13,000 people. Since the late 1960s, however, California has been reducing its use of DCs as a placement for individuals with developmental disabilities. In general, this decline in the use of DCs coincides with the development of strategies to allow individuals to live at home or in other community-based living arrangements, e.g., new assessment and individual service planning procedures and appropriate services and supports.

The focus of this hearing is on some of the critical issues facing the state as it continues to decrease reliance on institutional care in DCs. First, the state must continue to ensure the health, safety, and well-being of individuals who reside in DCs. Recent, serious licensing citations related to the Sonoma DC have raised questions about whether this fundamental obligation is being fully met there and about how the protection of clients in DCs can and must be improved. Second, the state must ensure the timely, safe, and effective transition of clients who are exiting DCs in order to reside in their communities. This obligation exists on a statewide basis, and is particularly relevant with respect to the ongoing process of closing the Lanterman DC. Finally, looking forward, the state must implement new statutes enacted as part of the budget process that significantly narrow the basis for admissions into DCs and for making other restrictive placements for individuals with especially complex needs. DDS, regional centers, advocates, and other partners must assess the needs of developmental services consumers with challenging needs, including severe behavioral issues, co-occurring mental health disorders, and other complexities. Working together, stakeholders must also bolster the breadth, availability, and processes for accessing specialized resources to support these consumers.

II. BACKGROUND

A. DEVELOPMENTAL CENTER AND DEVELOPMENTAL SERVICES OVERVIEW

California's four DCs lie on large campuses with various residential units; many of them were built more than a century ago to house individuals who were unable to remain at home. Each DC has a mix of units that are licensed as skilled nursing facilities, general acute care hospitals, or intermediate care facilities. Housing within the units is based on the needs of individual residents. In addition, the state operates a smaller community facility.

The DCs are part of a larger system of care overseen by DDS that also includes services and supports (e.g., day programs, transportation, employment supports) for approximately 250,000 people with developmental disabilities who live in their communities (e.g., with parents or other relatives, in their own houses or apartments, or in group homes). Care outside the developmental centers is coordinated through 21 non-

profit regional centers, which manage individual cases and contract for appropriate services in their local communities. Regional Centers are non-profit organizations that provide diagnosis and assessment of eligibility and help plan, access, coordinate, and monitor consumers' services and supports. Regional Centers also are one of the entities responsible for oversight of the care of individuals residing within developmental centers.

A developmental disability is defined as a severe and chronic disability that is attributable to a mental or physical impairment that begins before age 18 and is expected to continue indefinitely. These disabilities include mental retardation, cerebral palsy, autism, epilepsy, and other similar conditions. Infants and toddlers (age 0 to 36 months) may also be eligible for some developmental services if they are at risk of having developmental disabilities or if they have a developmental delay.

Determination of which services an individual consumer needs is made through the process of developing an Individualized Program Plan (IPP). The IPP is prepared jointly by an interdisciplinary team that includes the consumer, parent/guardian/conservator, persons who have important roles in evaluating or assisting the consumer, and representatives from the regional center and/or DC.

Under the law that existed prior to 2012 statutory changes described later in this document, individuals with developmental disabilities could be placed in DCs through involuntary judicial commitment because of a danger to themselves or others or in order to restore their competency to stand trial on criminal charges, or with judicial review in other circumstances, including voluntary placements.

B. BUDGET FOR DEVELOPMENTAL SERVICES AND CENTERS

The 2012-13 Developmental Services budget includes approximately \$4.7 billion [\$2.7 billion General Fund (GF)]. Of this total, approximately \$550 million (\$328 million GF) is dedicated to DC expenditures. The receipt of federal funding for DCs is contingent upon satisfying requirements in eight licensing categories. The two main sources of DC costs are: 1) personnel and 2) operating expenses and equipment. There are approximately 5,150 staff positions allocated to DCs for 2012-13.

The 2011-12 budget also included uncodified trailer bill language that required DDS to reimburse the Office of Statewide Audits and Evaluations within the Department of Finance for a review of the budgeting methodology used to establish annual budget estimates for DCs. The audit, which was completed in April 2012, found that overall the DDS budget methodology for DCs was reasonable and accurately calculated. Specifically, the audit found that the methodology took into account relevant budgetary drivers, including the DC client population, evaluations of client needs, and prior expenditure levels. At the same time, the audit did find that some staffing standards and evaluation systems were outdated and made recommendations for changes. One of those systems is the Client Development Evaluation Report (CDER) program. As a result, DDS began using an updated CDER intended to better reflect the needs of the current population and established a category to better capture the needs of the dually diagnosed.

These changes were incorporated in the May Revision and final 2012-13 budget. Non-level-of-care staffing standards were also updated.

Recent Reductions to the System

Over the three years from 2009-10 to 2011-12, DDS GF spending remained relatively flat, even while the developmental services caseload grew. In general, this cost containment occurred because of: 1) increased use of federal and other funding sources; 2) a reduction in the rate of payments to service providers (ranging from three to 4.25 percent); and 3) administrative changes, cost-control measures, and some service reductions. The anticipated savings from these changes in the years they were enacted (several of which also result in ongoing savings) combined to total over \$1 billion GF.

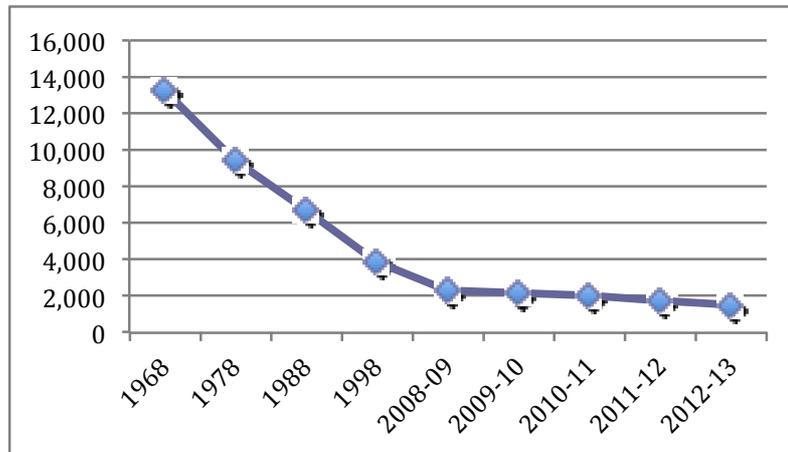
The 2012-13 budget included \$240 million GF savings: \$40 million from the anticipated receipt of California First 5 (Proposition 10) Commission funding for certain services for children with developmental disabilities and \$200 million from a variety of strategies that included increasing federal funds, implementing recent legislation regarding the use of private health insurance for certain services, changes to policies related to the use of DCs (described in greater detail toward the end of this document), and a 1.25 percent reduction to regional center and provider payment rates. The 2012-13 budget also included a “trigger” for an additional \$50 million in unspecified reductions to the budget for DDS if the voters do not approve of Proposition 30 in the November election.

C. ADDITIONAL BACKGROUND ON THE USE OF DEVELOPMENTAL CENTERS

The first DC opened originally as the Agnews Insane Asylum in 1888, and residents with developmental disabilities were typically co-mingled with patients whose primary needs were related to mental illness. Over the next 70 years, increased awareness of the unique needs of individuals with developmental disabilities prompted a change in focus, as well as the establishment of other state facilities specifically for people with developmental disabilities. At their peak in 1967, the state’s DCs housed more than 13,000 people.

Since the late 1960s, California has been reducing its use of DCs as a placement for individuals with developmental disabilities (as summarized in the table below through point-in-time data from the years reflected). In general, this decline in the use of DCs began as strategies were developed to allow people to keep their family members at home or in other community-based living arrangements, e.g., with new assessment and individual service planning procedures and appropriate services and supports. In the last five years, the population of individuals residing in California’s developmental centers has declined about 38 percent, from 2,732 on September 24, 2007, to 1,686 residents at the beginning of the 2012-13 fiscal year.

DEVELOPMENTAL CENTER POPULATION



Placements In Developmental Centers

The shift to community-based care also was given weight by the U.S. Supreme Court, which ruled in *Olmstead vs. LC* (527 U.S. 581, 1999) that a lack of community supports was not legal grounds for denying people with disabilities who could benefit from community placement by a move from an institution to a community setting. Such a denial, they said, was discrimination based on disability under the Americans with Disabilities Act and a violation of individual civil rights. Soon after the ruling, many states began shutting down their institutions and developing additional community-based services.

California's effort to de-institutionalize individuals with developmental disabilities was given another push by a lawsuit settled in 2009, known as *Capitol People First et al v. Department of Developmental Services et al*. Under the settlement agreement, the state provided additional funding to ensure regional center caseworkers would attend planning meetings in the DCs, and agreed to provide consumers with information about community living options. The state additionally agreed to identify best practices and provide training for regional centers to better identify and support individuals who are diagnosed dually with a developmental disability and mental illness. DDS and the regional centers also agreed to develop additional community placement options.

California's current efforts to close the Lanterman Developmental Center in Pomona were preceded by four other closures in the past two decades. In 1995, the state shuttered the Stockton State Hospital. In 1997, the state closed Camarillo State Hospital, which had housed clients with both mental illness and developmental disabilities. In 2009, DDS closed Agnews Developmental Center. Sierra Vista, a state-operated community facility, closed in 2010.

According to DDS, care in DCs has become more focused on serving individuals with severe behavioral issues, autism, co-occurring mental health disorders, and risk factors associated with medical conditions and sensory impairments that require additional

support. Nearly half of the residents living in DCs are aged 52 or older, including 17 percent who are 62 or older.

II. OVERSIGHT ISSUES FOR THIS HEARING

A. Recently Identified Health & Safety Concerns at Sonoma Developmental Center

Sonoma Developmental Center (SDC) is the oldest facility in California established specifically for serving the needs of individuals with developmental disabilities. The facility opened its doors to 148 residents on November 24, 1891. As of October 1, 2012, 522 individuals live on the sprawling campus in Eldridge, just south of the Sonoma County town of Glen Ellen. About 1,530 staff members work at SDC. The facility's 2012-13 budget includes \$146 million (\$76 million GF).

On July 3, 2012, licensing staff from the California Department of Public Health conducted an annual survey of SDC to assess whether the facility was in compliance with state licensing regulations, as well as to conduct, by proxy, a federal licensing review by the Centers on Medicaid and Medicare Services. Licensing requirements include eight Conditions of Participations that support the delivery of services to residents of an Intermediate Care Facilities for Individuals with an Intellectual Disability or Related Conditions (ICF/IID). These licensing requirements include:

- Appropriate oversight by the governing body, or facility management
- Client protections in areas such as freedom from harm, participation in social activities, accounting of personal funds, and others
- Facility staffing adequate to support resident functions
- Active treatment services that are purposeful and appropriate for each individual
- Client behavior and facility practices including appropriate safeguards for behavioral interventions
- Health care services appropriate to serve clients on a 24-hour basis
- Dietetic services appropriate for individual needs of consumers
- A physical environment that is safe and secure

During the July visit, licensing officials found numerous violations, outlined in a 250 page report, which included lapses in six of these eight categories. Among the findings were that SDC's management failed to take actions that identified and resolved problems of a systemic nature, failed to ensure adequate facility staffing, failed to provide active treatment, failed to provide appropriate health care services and several other key categories. According to page 3 of the report:

“Individuals have been abused, neglected and otherwise mistreated and the facility has not taken steps to protect individuals and prevent reoccurrence. Individuals were subjected to the use of drugs or restraints without justification. Individual freedoms have been denied or restricted without justification.”

On four separate occasions during the survey, the team identified conditions that posed immediate jeopardy to the health and safety of patients at the facility. Among the concerns of surveyors were:

- Thirty-five incidents in which residents ate non-edible items such as gloves, buttons, sunglasses, paper and other items. Two clients required emergency surgery to remove items from their abdomens. These consumers have pica, a disability that compels them to eat such items as clay, glass, paper and other non-edibles. In the instances documented in the Sonoma report, consumers ingested items that were documented in their files as items of concern, including the client who ate the sunglasses.
- Eleven clients who bore injuries that resembled burns from a stun gun. Facility law enforcement personnel found a loaded gun and a stun gun of another type in a staff member's car.
- The sexual assault of two residents by a staff member. Although another staff member who witnessed the alleged perpetrator expose himself to a consumer reported this incident, the facility was faulted for failure to ensure thorough and timely investigation of the incident, as well as implementation of corrective action plans for analysis of facility injury data for patterns and trends to prevent others from harm.
- Inadequate supervision of clients resulting in falls, attacks upon other consumers, clients who ran from the facility, and heightened anxiety among some clients.
- Severe and consistent understaffing patterns which resulted in employees being forced to work consecutive shifts, units being frequently short-staffed and staff members being moved into units to care for consumers they did not know. The report documents at least one incident in which a consumer's agitation was linked to frequent changes in care providers.
- The death of one client from acute peritonitis related to a misplaced gastrostomy tube. After the client's death, it was determined that physician's orders did not accurately identify the gastrostomy tubes and prescribe their care, nor did procedures at SDC adequately provide staff with information about manufacturer's specifications or best practices for gastrostomy tube care.

DDS's responses to these findings have included the removal of two top executives at the facility, contracting with an internal monitor for ongoing evaluation of the plans of correction, requiring unannounced checks by facility managers, as well as the DDS director and other executive staff from DDS headquarters in Sacramento, and implementing a number of new policies designed to provide closer supervision and better training for staff. DDS also indicates that it has informed families of the actions taken and initiated the use of a questionnaire to allow family members, visitors, and clients to provide feedback and request a response to concerns throughout the facility.

The corrective action process is ongoing, with DDS and licensing surveyors continuing to review procedures at SDC. If the issues are not resolved to the satisfaction of federal officials, the state could lose approximately \$28 million in federal financial participation in the current year (if funding were to stop on November 1st) for care provided in SDC's Intermediate Care Facilities (ICFs). After this year, if the issues are not resolved to the

satisfaction of federal officials, the state could lose approximately \$42.5 million annually in federal financial participation for care provided in those facilities.

CRITICAL QUESTIONS TO ADDRESS DURING THE HEARING:

1. For DPH/DDS: Please describe the next steps in the federal licensure review, including identifying which actions are most critical to mitigate licensing concerns and the risk of federal fund losses.
2. For DDS: The licensing report identified significant SDC staffing shortages and the use of overtime as concerns, and recent data indicates continued high vacancy rates compared with other DCs. Can you discuss how the staffing levels reached such a critical level and what steps you are taking to remedy the concerns?
 - a. Do other Developmental Centers employ mandatory overtime or have similar staffing levels? If so, are those also being addressed?
 - b. SDC also has a significantly higher proportion (39 percent as of September 2012) of unlicensed staff providing direct care than in the other DCs (which have rates of 12 and 17 percent). What accounts for this discrepancy? Do you have a plan in place to reduce it?
3. For All Panelists: What are the most critical steps that the Department, Sonoma Developmental Center leadership, and other involved stakeholders can take to better protect the health and safety of the facilities' residents? Are those steps already being taken and are sufficient communications about them taking place?
4. For All Panelists: How are oversight bodies and involved stakeholders (DDS, Regional Centers, advocates, others) able to ensure that similar care concerns do not exist at the state's other Developmental Centers?

B. The Closure Process for Lanterman Developmental Center

Lanterman Developmental Center (Lanterman) in Pomona consists of 21 client residences, one acute hospital unit, a variety of training and work sites, and recreational facilities, including a camp. The facility's 2012-13 budget includes \$96 million (\$52 million GF).

Lanterman opened in May 1927 as the Pacific Colony facility, and was later renamed to honor former Assembly Member Frank D. Lanterman for his work in creating a system of community resources, including the regional centers. At its peak, Lanterman housed more than 1,900 individuals. DDS submitted its plan to close Lanterman to the Legislature in January 2010 as part of its budget proposal for 2010-11. The plan was approved in October 2010, and the department instructed regional centers to begin developing additional residential options for consumers who would be moving to the community. At the same time, the department began collaborating with managed care

plans to provide health services for transitioning consumers and embarked on other key transitional activities.

When closure was proposed, there were approximately 400 residents and 1,300 staff at the facility. At that time the majority of the residents were between the ages of 21 and 85 years old. Twenty-three percent lived in the Nursing Facility, while the remaining 77 percent lived in the ICF/IID. As of October 1, 2012, there are 238 residents with 936 staff members who provide a wide range of services at the LDC. The majority of consumers residing at Lanterman (59 percent) have lived there for more than 30 years and 73 percent are between 40 and 65 years old. Overall service delivery needs for 27 percent fall into the Significant Health needs category with 32 percent falling within Protection and Safety. The remaining population has needs within Significant Behavioral Services (23 percent) and Extensive Personal Care needs (19 percent).

According to the department, the transition of each Lanterman resident to other appropriate living arrangements is only occurring after necessary services and supports identified in the IPP process are available elsewhere. The closure process is thus focused on assessing those needs and developing community resources to meet them. The Department and the 12 Regional Centers involved in the closure process use Community Placement Plans as one tool to help them accomplish those goals. DDS has also received recommendations from three advisory groups that include a Resident Transition Advisory Group, Quality Management Advisory Group, and Staff Support Advisory Group. The Department indicates that its staff meets regularly with parents and family members of Lanterman residents, Lanterman employees, and the involved Regional Centers.

The 132 former residents of Lanterman who have transitioned to the community so far have similar lengths of stay at Lanterman, ages, and disabilities as the overall residential population. As of June, more of the individuals who had moved have significant behavioral issues as their primary service need than the overall population of Lanterman residents (42 percent of those who have moved as compared to 19 percent of the overall residential population). Fewer of the individuals who had moved have significant health needs as their primary service need (9 percent as compared with 27 percent). The Department indicates that this is due at least in part to the pace of development of specialized homes (i.e., SB 962 homes) that are equipped to handle these particular health needs.

As part of its transition plan, the Department visits consumers who have moved into community residences at 5 days, 30 days, 90 days, and at 6 and 12 months after the move. Regional centers also visit at regular intervals and provide enhanced case management for the first two years after the move. Special incidents, including hospitalizations and other negative outcomes, are tracked by DDS, and individuals who move from Lanterman into the community are asked to participate in a National Core Indicator (NCI) study. The NCI study uses a nationally validated survey instrument that allows DDS to collect statewide and regional center-specific data on the satisfaction and personal outcomes of consumers and family members.

The Administration has declined to give a target date for closure of the facility as the development of these necessary community resources to ensure a safe and successful transition for each consumer is a continual and complex process. However, in March 2012, Subcommittee #3 of the Senate Committee on Budget and Fiscal Review requested for DDS to provide anticipated timeframes for the remaining transitions and steps in the closure process. Subcommittee #1 of the Assembly Budget Committee made a similar request. The Department's draft response to these requests, which was recently released for stakeholder feedback, is attached as an addendum to this background paper.

CRITICAL QUESTIONS TO ADDRESS DURING THE HEARING:

1. For DDS: Without identifying a specific closure deadline, please summarize the anticipated timeframes for the remaining phases of the closure process.
2. For All Panelists: What have been the significant challenges in making progress toward safely transitioning Lanterman residents to the community to date? How can those challenges be overcome in the near term (e.g., the next three months)? How do you envision progress over one year?
3. For All Panelists: How do you define and measure a successful transition?

C. Early Implementation of Recent Statutory Changes

AB 1472 (Chapter 25, Statutes of 2012), a 2012-13 budget trailer bill that was related to savings anticipated to be achieved within the DDS budget, included a series of statutory changes intended to redesign services for consumers with challenging needs. These changes, which are anticipated to result in \$20 million GF savings annually, include significant restrictions on the statutory criteria for admissions to DCs, limitations on the use of locked mental health facilities and out-of-state placements, and provisions to strengthen the capacity of the community to serve individuals with challenging needs (including expanded availability of Adult Residential Facilities for Individuals with Special Health Care Needs and the creation of a statewide Specialized Resource Service).

Restrictions on DC admissions and other specified placements

Efforts to shrink the state's reliance on DCs over the past decade have been hampered by continued admissions to the institutions, largely for consumers with complex forensic or behavioral needs. DDS data from 2011-12 indicated that approximately 100 new admissions to DCs were occurring annually in recent years. While some of these admissions were court-ordered and required by law for individuals who may not be able to understand the criminal charges filed against them, other admissions were believed to be avoidable with appropriate community resources (including some resources which may have needed to be developed). As a result, the 2012-13 budget included language restricting new admissions to DCs, except under specific conditions, including when:

- Individuals are committed for competency training under the state's Incompetent

to Stand Trial statute, which requires the state to attempt to restore individuals to competency to face criminal charges. The unit that provides this training is housed at Porterville Developmental Center.

- Individuals are in need of short-term care based on a judicial determination that they are dangerous to themselves or others due to a crisis. These individuals will be housed at the Fairview Developmental Center in a unit specifically for this purpose. In order to make a crisis placement, a regional resource development program must make a determination that admittance to a DC is necessary due to an acute crisis, as defined, and include a regional center report detailing all considered community-based options (excluding out-of-state placements and specified placements that are ineligible for federal Medicaid funding) and an explanation of why those options cannot meet the consumer's needs.

At the same time, AB 1472 created restrictions on placements in what were considered inappropriate and costly mental health institutions (mental health rehabilitation centers, MHRCs, or institutions for mental disease, IMDs) in order to encourage development in California of services for individuals with developmental disabilities who are experiencing serious mental health issues. The legislation also prohibits regional centers from purchasing out-of-state services without prior DDS authorization, places time limitations on out-of-state placements, and requires regional centers to submit a transition plan by the end of 2012 for all DDS consumers currently residing out of state.

Development of community resources for individuals with complex needs

The recent DDS budget trailer bill requires regional centers to complete comprehensive assessments of consumers residing in developmental centers by December 2015. The assessments will be provided to individual program planning (IPP) teams to help determine the least restrictive environment for each consumer. The legislation requires that this assessment be updated annually as part of the IPP process.

Finally, AB 1472 also included requirements intended to promote the development of additional community resources. Among those was the establishment of a statewide resource service to track specialty programs to serve individuals with more challenging needs, and to coordinate those services with regional centers statewide. The new statutes also require regional centers to prioritize the development of specialty resources, including regional community crisis homes. In addition, AB 1472 authorizes specified licensed community facilities to utilize delayed egress devices and secured perimeters.

CRITICAL QUESTIONS TO ADDRESS DURING THE HEARING:

1. For DDS & Regional Centers: Have there been crisis admissions to Fairview Developmental Center? If so, please provide the number of admissions and a general description of the nature of services needed.
2. For All Panelists: Please describe the types and numbers of resources that have been

developed (or are being planned) in the community as a result of the recent statutory changes for individuals with the challenging needs, including individuals who have both a developmental disability and mental illness.

3. For All Panelists: What progress has been made to begin conducting the assessments newly required for developmental center residents? What have been (and will be) the regional centers' roles, and roles of others, in planning and conducting those assessments?

IV. CONCLUSION

California's four Developmental Centers house some of the state's most uniquely challenged citizens: individuals who may have profound physical needs, social and behavioral challenges, mental illness, and in some cases, all three. The state's Department of Developmental Services has significant responsibility for their care and safety. Other organizations and individuals also play key roles in oversight and care management, including the regional centers, parents and family members, advocates, community-based organizations, outside providers, other caretakers, and consumers themselves.

At a time when California and the nation are continuing to transition from reliance on institutions to the ongoing development and refinement of community resources, it is critical to understand the role each entity plays in the transition and the collective responsibility for each individual's health, safety, and opportunity to thrive. This hearing offers an opportunity to highlight critical concerns related to the care and support of these especially vulnerable Californians, and to identify opportunities to strengthen that care and support.