

The Lanterman Act: Promises and Challenges

**Senate Human Services Committee
Senator Jim Beall, Chair**

October 9, 2014

1:30 to 3:30 p.m.

**Edward R. Roybal Board of Public Works Session Room
Room 350 City Hall
200 North Spring Street, Los Angeles**

Background

The Lanterman Developmental Disabilities Services Act, passed in 1974, established an entitlement to services and supports for Californians with developmental disabilities and set up an extensive system to care for individuals who living in their communities. Although a number of lawsuits and policy decisions have helped reinforce the state's practice of delivering services to individuals in their communities, at the time, the Lanterman Act's entitlement to services was a landmark.

Today, more than 270,000 children and adults are served in community-based programs and supported by state- and federally funded services that are coordinated by the state's 21 nonprofit regional centers. The regional centers vary considerably in size and organization, from tiny Redwood Coast Regional Center, which serves approximately 3,300 consumers to Inland Regional Center, with a caseload of nearly 29,000.¹ The statewide mean is around 12,000 consumers. Slightly more than half of the regional center population is between age 18 and 61 years old; about two-thirds of all consumers have an intellectual disability, 3 in 10 are diagnosed with autism or a related disorder, and 18 percent are identified as having severe behaviors, according to data reported by the Department of Developmental Services (DDS). About 74 percent of consumers live in the home of a parent or guardian, according to DDS statewide data from June 2014.

In addition to the consumers who live in their communities, another 1,205 individuals live in four state-run institutions and one small community facility intended to provide care for individuals with more acute health and behavioral needs. The institutional population in California has decreased dramatically since the 1960s, from a high of 13,400 people in eight institutions in 1968 to the current population. Closure of Lanterman Developmental Center is expected by the end of 2014, and the population as of October 1, 2014 was 20 residents. The population at the remaining facilities, which originally were designed to serve between 2,500 and

¹ Department of Developmental Services, Quarterly Consumer Characteristics Report Index, July 2014

3,500 clients each is now below 450, with Sonoma at 430, Fairview with 309 residents and Porterville at 393, as of October 1, 2014. Canyon Springs, the smaller state-run facility, had 53 residents.

The focus of this hearing is to discuss the sustainability of California's developmental services system in the wake of more than a decade of budget reductions and rate freezes totaling more than \$1 billion, as well as new federal and state mandates that appear to require changes to multiple developmental services program structures. First, the state must consider whether reforms need to be made to preserve existing programs that are necessary to continue critical services and supports. Second, the state and its developmental services stakeholders must prioritize those programs that are most in need of support, and third these groups must collaboratively plan a clear path to enact necessary program changes that will be required to fulfill the promise of the Lanterman Act in the years to come.

Community infrastructure

The state's 21 regional centers are nonprofit organizations established through the Lanterman Act to provide diagnosis and assessment of consumers' eligibility for services. Regional center case managers help to plan, access and coordinate consumers' services and supports, and to monitor outcomes. Regional centers also have a role in overseeing the care of individuals residing in the state's developmental centers and play a pivotal role in moving a consumer from a DC to community settings.

Services for consumers are determined through an Individual Program Plan (IPP) process, and coordinated by regional center case managers. The planning team includes the consumer, a parent, guardian or conservator, professionals who evaluate and/or assist the consumer and representatives from the regional center or developmental center, as appropriate. Regional center supports and services are delivered through a network of local providers, which are authorized to receive state and federal funding by becoming vendors of the local regional center. Statewide, there are approximately 45,000 agencies, which provide services in more than 150 service category types including residential care, day programs, behavioral therapies, independent and supported living, supported employment, respite, transportation and many others. Regional centers estimate that \$3.9 billion will be spent on these services in 2014-15, or more than 87 percent of the regional center system's budget.²

Integrated community settings

With passage of the Lanterman Act, California began shifting its model of care from one of institutional placement to community-based services. That move was reinforced by a number of

² "Inadequate Rates for Service Provision in California," the Association of Regional Center Agencies, January 2014, page 10.

federal and state legal decisions, as well as numerous administrative and legislative moves. Notably, in 1993, a settlement was negotiated in the class-action lawsuit *Coffelt v DDS* to develop 300 additional community placement options and to reduce the institutional population by 2,000 individuals within five years. Following that, the U.S. Supreme Court 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 a move from an institution into a community setting if they could benefit from community placement. Such a denial, the court ruled, was discrimination under the Americans with Disabilities Act and a violation of individual civil rights. In California, the *Olmstead* decision was followed in 2009 by a settlement in the case *Capitol People First et al v Department of Developmental Services et al*. Under the settlement agreement, DDS and the regional centers agreed to develop additional community placement options, in addition to a variety of other new practices.

Recent state and federal policies have directed DDS to create new models of care to better integrate regional center consumers into their communities, as well. These include:

- Self-determination (*SB 468 (Emmerson) Chapter 683, Statutes of 2013*) which provides consumers with the option of being provided an individual budget with which to purchase services they choose, with the approval of a financial manager and providing they fit into the consumers IPP plan. Implementation is contingent upon approval a federal waiver. DDS, in collaboration with a stakeholder advisory group is currently writing the waiver application.
- The Employment First policy (*AB 1041, (Chesbro) Chapter 677, Statutes of 2013*) which requires the state to prioritize integrated, competitive employment when planning activities for working age adults with developmental disabilities.
- Creation of a Statewide Specialized Resource Service (SSRS) registry for services designed to treat individuals who are deemed difficult to serve. The registry allows DDS and the regional centers to track the availability of specialized treatment services, per the 2012 budget trailer bill (*AB 1472, Chapter 25, Statutes of 2012*).
- Creation of Adult Residential Facilities for Persons with Special Health Care Needs (ARFPHSN) homes, per *SB 962 (Chesbro, Chapter 558, Statutes of 2005)* and expanded by the 2010 budget trailer bill (*SB 853, Chapter 717, Statutes of 2010*) to provide care to residents with intensive health and other needs who generally require 24-hour nursing care. The homes were created initially to accommodate individuals with high health needs who moved into the community during the closure of the Agnews Developmental Center. Up to five individuals can live together in an ARFPHSN home.
- In 2012, the Legislature authorized certain facilities with fewer than 15 beds to use “delayed egress devices” in combination with “secured perimeters” (*AB 1472*,

Chapter 25, Statutes of 2012). A home with delayed egress involves a device that temporarily delays someone from leaving the facility without warning. A secured perimeter is a fence. This change was intended to provide more options for community living for individuals who currently live in institutions.

- In 2014, the budget trailer bill (*SB 856, Chapter 30, Statutes of 2014*) included a pilot project to develop up to six enhanced behavioral homes per year to provide intensive services and supports to adults and children with developmental disabilities who would otherwise be at risk of institutionalization or other high intensity placement. Additionally, it authorized development of two community crisis homes to provide intensive crisis treatment for no more than eight consumers at a time in order to avoid institutionalization in a crisis unit at a developmental center or psychiatric hospital or other similar institution.

Additional Federal Changes

Recently, the federal government has signaled that efforts to integrate consumers into their communities have fallen short in many states. Implications of a federal Justice Department lawsuit and new federal Medicaid waiver rules will have significant impact on California programs.

HCBS waivers

In March, the federal Centers for Medicaid and Medicare Services (CMS) put into place new regulations for federal reimbursement of home and community based services.³ Among the changes are requirements for consumers to live in and receive services in the most integrated setting possible, with CMS stepping away from defining allowable services by location and instead requiring an outcome-based evaluation of whether services comply.

The regulations affect federal waivers used by DDS to pay for consumer services, the 1915 (c) HCBS waiver and 1915(i) HCBS state plan amendment. California and other states are now required to submit a state transition plan to comply with the new requirements within 120 days of submission of any waiver amendment or renewal. Various stakeholder processes are scheduled to allow DDS to receive input, and all waivers are required to be in full compliance with the federal rules by March 16, 2019.

³ "Changes to the HCBS Waiver Program," Centers for Medicare and Medicaid Services, January 10, 2014.

Sheltered workshops

In April 2014, the U.S. Justice Department announced that it had entered into an agreement with the state of Rhode Island to redirect consumers who were working in segregated sheltered workshops and facility-based day programs into integrated settings.⁴ While the ruling directly affects approximately 3,250 Rhode Island residents with intellectual and developmental disabilities, the Justice Department called the ruling a landmark agreement to address the rights of people with disabilities to receive state fund employment services in their communities and noted that the ruling had implications for 450,000 people nationwide.

Cost reductions

In the current budget year, funding for DDS is \$5.2 billion. Since 2009, the state has reduced costs to developmental services programs by more than \$1 billion (GF) including restrictions on payments for specific services, across-the-board reductions, mandated holidays, suspension of services and other cuts. Prior to that, the state had frozen rates to providers in order to contain costs. A report by the Legislative Analyst's Office prepared for this hearing, which is attached, will provide greater detail about these recent cuts.

In 1999, even before the substantial reductions and freezes prompted by the Great Recession, the Bureau of State Audits released a report concluding that community services were “undermined by insufficient state funding and budget cuts.”⁵ The report noted that insufficient state funding was a major obstacle in delivering quality services to consumers and that most direct care staff remained in their jobs for no more than two years. Frequent vacancies created service disruptions and impeded continuity of care for consumers. The auditor noted that regional centers also had similar delays in replacing their case managers who leave, causing consumers to lose contact with the person who is key to ensuring that they get their services. “Until the State commits to ensuring that sufficient funding is available for this program, it will never be able to realize the spirit of the Lanterman Act,” the auditor concluded. (pg 3)

The auditor additionally recommended the state take interim steps to align funding with program costs while DDS pursued a plan to restructure provider and regional center rates. By 2000, the state was able to restore some of the cuts made in the early 1990s, however an economic slow-down in 2001 kept the state from fully restoring those cuts. In 2008 and 2009, as the nation's economy went into free-fall and the state faced a massive budgetary shortfall, DDS convened a

⁴ “Department of Justice Reaches Landmark Americans with Disabilities Act Settlement Agreement with Rhode Island,” U.S. Department of Justice Announcement, April 8, 2014

⁵ “Insufficient Funding Undermines Optimal Service Delivery to the State's Developmentally Disabled Population,” California Bureau of State Audits, October 1999.

series of stakeholder meetings in an effort to make judicious cuts and other cost-saving measures rather than forfeiting the entitlement to services. The resulting reductions were substantial.

Service providers have protested that they are unable to create the new programs demanded by the passage of legislation without rate adjustments. Various legislative efforts have tried to secure rate increases, with some success, but providers still say they are operating too close to the margin function effectively. As an example, in mid-August one provider, Futures Explored, gave notice to two regional centers that it was discontinuing services for Supported Employment – Individual Placement after recent efforts to secure a rate increase failed.

Rate Restructuring

In 2001, DDS and its stakeholders completed a four-year review of the community based service delivery system and released a 67-page document with that year's May budget revision.⁶ The report, prompted by *SB 1038 (Chapter 1043, Statutes of 1998)*, underscored the need to shift the current system to one of quality-based outcomes. Inherent in this process was a restructuring of rates, also mandated by the Legislature, to reflect accurately the cost of providing services. A recession in late 2001, initiated by the terrorist attacks of Sept. 11, forced the state to shelve this plan, although DDS said it would continue with smaller workgroups focused on this effort.

In 2014, the Legislature again tried to establish a rate reform process in its budget bill, however the Governor vetoed the language noting that the issue would be taken up by a task force convened.

Agency task force

In July 2014, state Health and Human Services Secretary Diana Dooley convened a task force to study the community service delivery system and to recommend reforms. The Developmental Services task force has met twice, tasked with considering the appropriateness of services for consumers within the current system, regardless of setting, community rates, regional center staffing levels and the impact of new state and federal laws. It is intended to follow up on the initial work of a similar task force convened to consider the future of Developmental Centers in California, and is asked to “develop recommendations to strengthen the community system in the context of a growing and aging population, resource constraints and availability of community resources to meet the specialized needs of clients and past reductions to the community system.”⁷

Association of Regional Center Agencies

In January 2014, the Association of Regional Center Agencies issued a report on the status of the developmental services system in the wake of deep and sustained cuts.⁸ The report concluded

⁶ “Draft Report to the Service Delivery Reform Committee,” Department of Developmental Services, May 15, 2001

⁷ Press Release issued by Secretary Dooley, September 30, 2014

⁸ “Inadequate Rates for Services Provision in California,” Association of Regional Center Agencies, January 2014.

that “longstanding underfunding of the service system not only undermines this potential forward progress, but also the adequacy of the community-based provider network.” It noted that for decades, concerns have been expressed about the erosion of rates and quality services, but that current freezes and reductions have brought the system to the place where quality services are “unachievable within the limitations of current rates.”

Without question, the system today is poorly poised to make federally required changes to foundational programs. The purpose of this hearing is to focus on some of the critical issues facing the state as it continues to provide services and supports to a growing number of consumers with increasingly complex needs.