THE SCAN FOUNDATION
Long-Term Care Fundamentals
www.TheSCANFoundation.org
June 2013 • No. 12

California's Developmental Disabilities Service System

The LTC Fundamentals series is produced by The SCAN Foundation to highlight and describe the organization and financing of long-term care (LTC) in California. This LTC Fundamentals Brief provides a background on California's developmental disabilities service system, the role of Regional Centers, the Home-and Community-Based Services Waiver for Individuals with Developmental Disabilities, and system-wide deinstitutionalization efforts.

Introduction

California is considered a model across the nation for its developmental disabilities (DD) service system. California's DD service system uses a coordinated service delivery model that provides consumer choice and prioritizes home- and community-based services (HCBS) as an alternative to institutionalization. Much can be learned from the successes of the DD system, although it also confronts challenges. This *LTC Fundamentals* brief describes the history of the system, the characteristics of individuals who are eligible for services, its underlying principles and organizational structure, and system challenges, including increasing costs and oversight of a complex rate-setting system.

Background

State law defines a developmental disability as one that originates before an individual reaches 18 years of age, continues or can be expected to continue indefinitely, and constitutes a substantial impairment in three or more areas of major life activity including self-care, receptive and expressive language, learning, and mobility.[1] These types of disabilities include intellectual disability, cerebral palsy, epilepsy, autism, and conditions closely related to or requiring treatment similar to intellectual disability.

Governed by the *Lanterman Developmental Disabilities Act* (the Lanterman Act) and the *Early Intervention Services Act*, California's developmental disabilities service system consists of both regional centers and state-operated facilities. Regional centers provide or coordinate services that include diagnosis and assessment, care monitoring, advocacy for the protection of legal, civil and service rights, as well as training and education for individuals and their families.[2] The state-operated facilities consist of four developmental centers and one community facility that provide 24-hour habilitation and treatment services for residents with developmental disabilities.[3] Approximately 228,000 individuals diagnosed with developmental disabilities of all ages and approximately 28,000 infants and toddlers with a developmental delay or an established risk condition that has a high probability of leading to a developmental delay receive services through this system.[4]

The Lanterman Act

The Lanterman Act, originally enacted in 1969, defines the structure and principles of California's service system for individuals with developmental disabilities. The Lanterman Act establishes the right of qualified individuals to receive treatment, habilitation services, and supports in the least restrictive environment as well as to be involved in the planning of how those services are delivered and by whom. The Lanterman Act lays out the following principles.[5,6]

Access: Every individual with a developmental disability (consumer) should have access to an array of services and supports that meets "the needs and choices of each person…regardless of age or degree of disability, or stage of life and to support their integration into the mainstream life of the community."[5]

Integration: Consumers should not be excluded from typical life activities; services and supports should be available to enable inclusion in community life.

Consumer choice and empowerment: Consumers should be able to choose where and with whom they live, and should be given choice regarding their education, employment, and leisure, the pursuit of their personal future, as well as program planning and implementation.

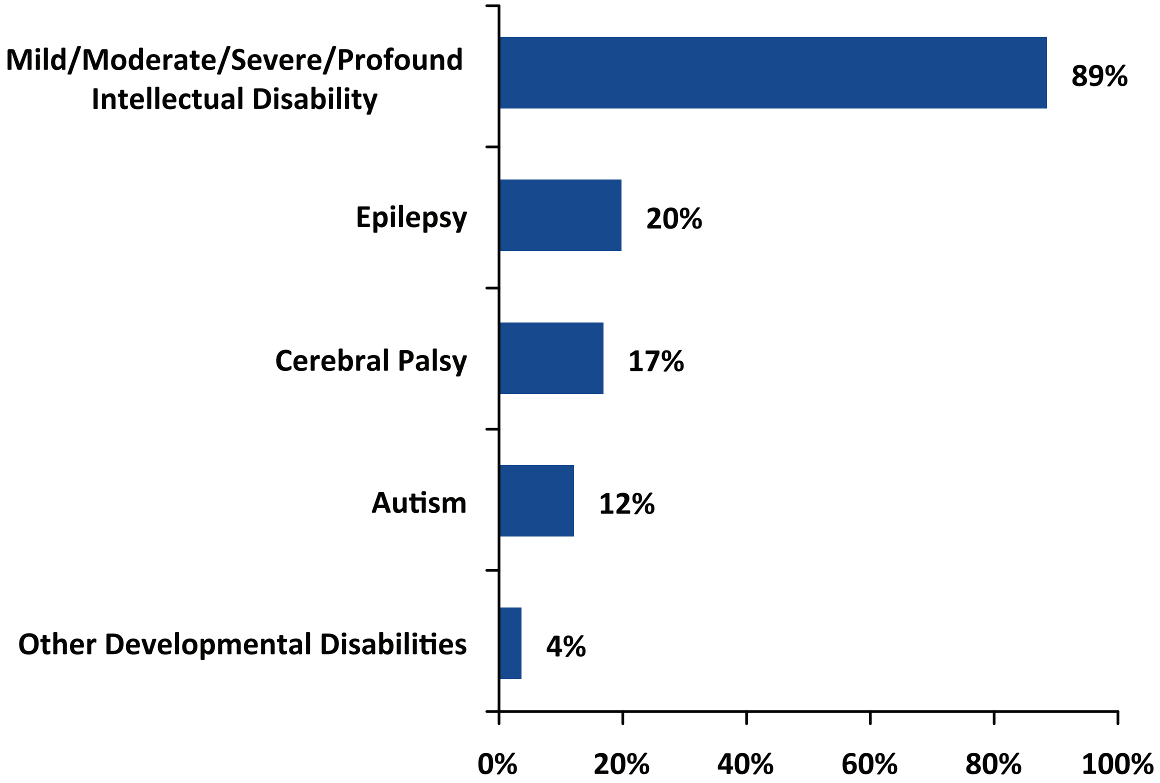
Early Intervention Services Act

The Early Intervention Services Act offers a coordinated statewide system of comprehensive, person- and family-centered, multidisciplinary, interagency programs that provide services and support to all eligible infants and toddlers from birth to 36 months of age, and their families.[7] Early intervention services are coordinated through the regional centers. To be eligible for services, infants or toddlers under the age of 36 months must be assessed as meeting one of the following criteria: 1) infants or toddlers showing developmental delay in one or more of five defined areas, or 2) infants and toddlers with established risk conditions "of known etiology or conditions with established harmful developmental consequences."[8]

Demographics of Individuals Served

As of December 2012, approximately 73 percent of developmental services consumers lived in the home of a parent or guardian, 11 percent resided in community care settings, 4 percent in a skilled nursing facility/intermediate care facility, 10 percent in a supported living or independent living setting, less than one percent in developmental centers, and less than one percent in other settings.[9] The data show that the majority (63 percent) of individuals served by the developmental disabilities services system were male and a little over 50 percent of the population were under 22 years of age. Considering the population by race and ethnicity, 37 percent of individuals were White, 34 percent were Hispanic, 10 percent were Black, 6 percent were Asian, and 2 percent were Filipino. Figure 1 below shows the proportions of the developmental services population affected by the four major categories of developmental disabilities.

FIGURE 1 Composition of Population Served by the Developmental Disabilities System, by Type of Disability, December 2012



Source: Department of Developmental Services. Statewide Quarterly Report. December 2012.
Note: No information related to primary disability is available; therefore, there are overlaps in diagnoses as individuals may have more than one qualifying disability.

Organization of the Developmental Disabilities System in California

The developmental disabilities system in California is administered by the state Department of Developmental Services (DDS). Located administratively within the California Health and Human Services Agency, DDS is responsible for managing and overseeing the programs that serve individuals with developmental disabilities. Specifically, DDS administers the Lanterman Act and the Early Intervention Services Act through the 21 regional centers located throughout the state, providing access to a range of services as outlined below. DDS also maintains responsibility for certain out-of-home placements in state-operated facilities that include four developmental centers and one community facility.[10]

Regional Centers

Before passage of the Lanterman Act, services in the home or community-based settings were not available for individuals with developmental disabilities. The only service option was institutionalization through one of the four overcrowded state-operated developmental centers (previously referred to as “state hospitals”), which had a total census of over

13,000 with a wait list of 3,000 individuals.[11,12] In 1965, the first regional centers were established in San Francisco and Los Angeles in a pilot project to provide local community-based services for individuals with developmental disabilities who would otherwise require services in an institutional setting. The legislation establishing this pilot program responded to the findings of both a study commission and legislative committee charged with studying the care of and reviewing the services available to individuals with developmental disabilities (who at the time were referred to as individuals with "mental retardation").[11-13]

In 1969, the Lanterman Act was enacted, providing for statewide expansion of regional center services as the dominant model for supporting those with developmental disabilities through the establishment of the current statewide network of 21 regional centers by 1976. The Legislature intended for the network of regional centers to "be accessible to every family in need of regional center services"[14] and because the services are "special and unique in nature... (they) cannot be satisfactorily provided by state agencies."[15] Therefore, the statute requires the state to contract with these community agencies to respond to local needs. Regional centers operate with a governing board that includes individuals with particular specialty skills, consumers, family members, and other individuals that reflect the geographic and ethnic characteristics of the area.[16]

As provided under the Lanterman Act, DDS contracts with 21 regional centers across California that serve as the "single entry point" into the developmental disabilities service system, providing or funding a range of services that assist individuals and their families in accessing services and developing individualized plans.[2]

Regional centers coordinate a range of home- and community-based services provided to consumers (see Table 1).

The Home- and Community-Based Services Waiver for Individuals with Developmental Disabilities

Since 1983, California has administered a Medicaid 1915(c) Home- and Community-Based Services waiver for individuals with developmental disabilities (HCBS-DD). Overseen by DDS, the waiver provides a federal funding match for services that are necessary for achieving individual goals. Regional centers assist eligible individuals with accessing waiver services. With the exception of IHSS program services and education services provided by local education agencies, the HCBS-DD waiver covers a wide array of services (see Table 1). Additionally, the HCBS-DD waiver covers many other regional center-funded services including home health aide services, habilitation, and adult residential care provided to regional center consumers. To be eligible for the HCBS-DD waiver, individuals must be eligible for full-scope Medi-Cal, have a formal diagnosis of a developmental disability that originates before the age of 18, and meet the clinical qualifications for admission to an intermediate care facility for the mentally retarded (ICF/MR) (see CA Code of Regulations, CCR, Section 51343).[24] In 2009, 78,527 individuals were served by the HCBS-DD waiver, with an enrollment cap of 95,000 for fiscal year 2010-2011.[25]

1915(i) State Plan Amendment

DDS recently received federal approval for a Medi-Cal 1915(i) State Plan Amendment that will provide community-based services to individuals with developmental disabilities. Section 1915(i)

TABLE 1 Home- and Community-Based Services Coordinated by Regional Centers

Service	Description
Day Program Services	These programs provide services related to developing and maintaining self-help and self-care skills; self-advocacy and employment skills; behavior management; and community integration skills.[17]
Education Services	Local education agencies provide special education and related services to children with disabilities in environments including the home, school, public or private preschools or child care settings. Regional centers provide some services for children who are eligible under the Lanterman Act that are otherwise not provided as special education and related services.[18]
Work Services Program (formerly Habilitation)	This program provides work and community integration opportunities through Supported Employment Programs (SEPs) and Work Activity Programs (WAPs).
Supported Living Services	These services assist the individual in establishing and maintaining a safe, stable, and independent life in his or her own home. Services include assistance with selecting and moving into a home; choosing personal attendants and housemates; acquiring household furnishing; community integration; managing personal financial affairs, and other supports.[19]
Independent Living	These services provide functional skills training for adults aimed at increasing self-sufficiency in the individual's home and community.[20]
In-Home Supportive Services (IHSS)	The IHSS program provides personal care and domestic services to persons who are aged, blind or disabled, including individuals with developmental disabilities and enrolled in Medi-Cal. IHSS is administered locally by each county, with oversight from the California Department of Social Services.[21]
Respite services	Respite services provide in-home non-medical care and/or supervision and assist family caregivers by attending to needs and other activities that would ordinarily be performed by the family member in order to provide the family member time away from caregiving responsibilities.[22]
Transportation	Transportation services enable the consumer to participate in programs and/or other activities identified in the IPP, including public transit and other providers; specialized transportation companies; day programs; and family members, friends, and others.[23]

of the Social Security Act gives states the option to provide HCBS without a waiver. Eligibility criteria for these services must be less stringent than the institutional level of care criteria required under other Medicaid waivers. Therefore, approval of the 1915(i) State Plan Amendment allows DDS to access federal funding for community services provided to specified individuals who do not meet the eligibility criteria of the current HCBS-DD waiver.[26,27]

Out-Of-Home Placements

For individuals who cannot live independently and for whom living in the family home is not the preferred option, regional centers assist in arranging out-of-home placements, including the following:

Community Care Facilities: Community Care Facilities (CCFs) provide 24-hour non-medical residential care to children and adults with developmental disabilities who are in need of personal services, supervision, and/or assistance essential for self-protection or sustaining the activities of daily living. These entities are licensed by the Community Care Licensing Division of the California Department of Social Services. CCFs are designated to provide services in one of various service levels depending upon the level of support provided.[28]

Supported Living Services: For individuals not living in his or her family home, but who still want to live independently, supported living services provide a broad range of services to enable the individual to function in the community (see Table 1).

Family Home Agency: A Family Home Agency (FHA) permits up to two adult individuals with developmental disabilities to reside with a family and share in the interaction and responsibilities of being part of that family. The individual with developmental disabilities receives the necessary service and supports from the family, the FHA and the community to enable the individual to be a participating member of the family and the community.[29]

Intermediate Care Facilities: Licensed by the California Department of Public Health, Intermediate Care Facilities (ICF) are health facilities that provide 24-hour-per-day services for individuals with developmental disabilities.[30] These facilities range in size and setting (4 to 15 beds in a house within the community or an institution).

Developmental Centers: DDS operates four state developmental centers that are licensed and certified as skilled nursing facilities, Intermediate Care Facilities/Developmentally Disabled (ICF/DD), and general acute care hospitals. As of May 2013, approximately 1,503 individuals of all ages resided in the state-operated developmental centers.[31] Additionally, DDS operates a community facility, Canyon Springs, a licensed ICF/DD that provides residential services, treatment, and training for adults with developmental disabilities and challenging behavioral issues. The population of Canyon Springs, as of May 2013, was 53 residents.[31]

To identify and meet service and treatment needs of the residents, these state-operated facilities use a person-centered planning process that involves the resident, their parents or other appropriate family members or legal representatives, as well as facility and regional center staff.[32] In a recent briefing report by the Senate Budget Committee, DDS indicates that "care in Developmental Centers 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" (p. 5-6).[33]

Moratorium on Developmental Center Admissions: The 2012-13 budget revised the admissions policy for developmental center placement. Only Porterville Developmental Center and Fairview Developmental Center can admit new residents, under specified circumstances. An individual can only be placed by referral of the court into Porterville Developmental Center for secure treatment if s/he is involved with the criminal justice system, and the court has determined the person is mentally incompetent to stand trial. Individuals can be placed in Fairview Developmental Center by court order and only for short-term admissions and crisis stabilization.[32]

Task Force on the Future of Developmental Centers

On May 22, 2013, the California Health and Human Services Agency announced the establishment of a Task Force on the Future of Developmental Centers. This task force will focus on developing a "Master Plan" that addresses a number of issues including the needs of developmental center residents, availability of community resources to meet these needs, a timeline for future closures of developmental centers and related program and fiscal issues.[34,35] The Secretary of the California Health and Human Services Agency appointed members to the task force including consumers, family members, regional centers, advocates, community service providers, organized labor, and DDS representatives. The task force had its first meeting in June 2013.

Person-Centered Planning: The Individual Program Plan

The DD service system provides for a person-centered planning process to establish an Individual Program Plan (IPP), or, for a child under the age of three, an Individualized Family Service Plan (IFSP). Through this planning process, consumers engage with a planning team consisting of his or her family or legal guardian/designated representative (when appropriate), regional center staff, and others as identified by the consumer. Through a series of discussions with the planning team, the consumer identifies his or her goals, building off his/her strengths, capabilities, preferences, lifestyle and cultural background. A planning team develops the IPP to outline the services and supports necessary to achieve individual goals. IPPs are prepared for every consumer served by a regional center, regardless of whether the individual resides in the community or in an institution.[36]

Before using regional center funds to purchase services and supports to meet consumers' and families' needs, regional centers must first seek and access all other available resources, including services provided or funded by "generic" resources.[37] A generic resource is a service provided by an agency that has a legal responsibility to serve all members of the general public and that receives public funds for providing such services.[38] Examples of generic agencies or services include Medi-Cal, Social Security, county mental health services, and In-Home Supportive Services.[11,12]

Entitlement to Regional Center Services

When first enacted, the Lanterman Act had intended for regional center services to be accessible for all in need. Eventually, some individuals questioned whether the Lanterman Act intended for individuals with developmental disabilities to have an *entitlement* to the services and supports identified in the individual program plans.[11,12] In 1982, with California facing a $1 billion budget deficit, DDS issued a directive to regional centers that outlined priorities for expenditures in an effort to achieve cost savings and limit regional center funded services to those that were "basic and essential."[7] The state budget deficit led DDS to reduce funding for regional centers, with some regional centers implementing waiting lists and categorical cuts in services.[11] In response to this action, the Association of Retarded Citizens (now known as The Arc) filed a lawsuit challenging the state spending guidelines as illegal under the Lanterman Act.[39] The trial court issued a preliminary injunction on the implementation of the spending directive and priorities for expenditures. In 1985, the Supreme Court ruled in favor of the Plaintiffs, finding the following:

> *"… the Act defines a basic right and a corresponding basic obligation: the right which it grants to the developmentally disabled person is to be provided with services that enable him to live a more independent and productive life in the community; the obligation which it imposes on the state is to provide such services. . . By requiring the regional centers in effect to cut back on services by category without regard to the individual client's IPP, the (spending) Priorities would have vitiated the IPP procedure, and with it the rights and obligations the Act defines. Because they would have radically altered the Lanterman Act and greatly impaired its scope, the (spending) Priorities are void" (sec 5B).*[39]

The Supreme Court's decision clarified that individuals with developmental disabilities are entitled under the Lanterman Act to receive all necessary services and supports outlined in the IPP.

Deinstitutionalization Efforts

Resulting from a national trend underlining an individual's right to receive services in the least restrictive setting, California's developmental center population has decreased over time – from a high of 13,355 individuals in 1968 to 1,591 persons as of January 2013.[31,40] The U.S. Supreme Court's decision in *Olmstead v. L.C.* formalized this right for all individuals with disabilities.[41] At the state level, several major events helped to spur this trend:

Coffelt et al., v. DDS, et al.: In January 1994, the Department of Developmental Services entered into an agreement to settle the *Coffelt* lawsuit, which alleged that DDS and several regional centers had not sufficiently developed community-based services, thereby denying developmental center residents the opportunity to live in the community and instead restricting them to institutional settings.[42] The settlement included an order to reduce the developmental center population by 2,000 people over a five-year period (1993-1998). Through this time, the Stockton and Camarillo Developmental Centers closed, and the statewide developmental center population decreased by more than 2,320 individuals.

Agnews Developmental Center Closure, San Jose, CA: The 2003-04 Governor's Budget directed the Department to develop a plan to close Agnews Developmental Center. The closure of the Agnews Developmental Center marked the first significant deinstitutionalization initiative in California since the 1994 *Coffelt* settlement agreement. The Agnews closure plan centered on developing sufficient community capacity to support the transition of residents into the community, consistent with the requirements governing the developmental center closure process outlined in statute.[43] The Agnews closure process included stakeholder outreach and planning, with broad participation from a range of stakeholders. Between July 1, 2004, and March 27, 2009, a total of 327 Agnews residents transitioned to living arrangements in the community (including five who returned to their family homes), and 20 residents transferred to other developmental centers. As of March 27, 2009, all Agnews residents had been successfully transitioned to placements outside of the Agnews Developmental Center.[40]

Lanterman Developmental Center Closure, Pomona, CA: In January 2010, DDS recommended closure of the Lanterman Developmental Center. The closure plan incorporated stakeholder input as well as best practices and policy initiatives from the closure of Agnews. The plan was submitted to the Legislature on April 1, 2010, and closure activities were initiated upon enactment of the Budget Act of 2010. When developed, the Lanterman Developmental Center closure plan did not abide by an arbitrary timeline, but rather, focused efforts on lining up all necessary services in the community to meet the needs of all transitioning individuals, as follows:

> *"The core principle of the Plan is to achieve a safe and successful transition of individuals with developmental disabilities from Lanterman Developmental Center (LDC) to other appropriate living arrangements as determined through the individualized planning process… transition will only occur after the necessary services and supports identified in the IPP are available in another appropriate setting" (p. 3).*[44]

In addition, DDS posted for public comment the "*Draft Milestones for the Closure of Lanterman Developmental Center*" which focused on identifying the estimated completion dates for specified components of the closure process. The milestones were finalized and made public on January 22, 2013.[45,46] DDS notes that of December 1, 2012, 146 residents had moved to other living arrangements. DDS estimates that the transition plans will be developed for all residents by July 2014.[46]

Community Placement Plan

The Lanterman Act provides for a Community Placement Plan (CPP) process that allows individuals whose needs can be met outside of a developmental center or other restrictive setting the opportunity to return to the community with the necessary services and supports. The process also focuses on ensuring that individuals who are at high-risk of institutional placement are deflected from institutional placement.[47] The CPP provides dedicated funding for comprehensive assessments of selected individuals, transition to the community, and deflection of individuals residing in the community who are at-risk of placement in a restrictive setting. Each year, regional centers prepare a CPP that is submitted to DDS, which includes requests for resources necessary to implement the CPP. The CPP includes requests for funds for regional center operations, assessments, resource development, and ongoing placement expenses. Funding for the acquisition and development of permanent affordable and accessible housing may also be requested, consistent with the CPP resource development requirements and DDS Housing Guidelines.[48,49] To this end, CPP funds may be used to develop homes for individuals with developmental disabilities as alternatives to institutional settings. One such example includes the "Buy It Once" model, through which a non-profit ownership entity owns property for restricted use by regional center consumers.[49]

As part of the CPP, the regional centers complete comprehensive assessments for developmental center residents, and work cooperatively with staff in the existing placement to develop transition plans that outline the necessary services and supports needed upon transition to a community-based setting. Upon transition to the community, these individuals are visited by the service coordinator at least quarterly, with at least two unscheduled visits per year to licensed community settings.[24]

System Challenges

The developmental disabilities service system faces challenges stemming from a variety of factors, including an increase in the number of individuals needing services, increases in the cost for services, as well as resource limitations, rate freezes, and issues related to transparency of resource allocation.[50-52]

<u>Increased Number of Individuals Served</u>: The UCLA Center for Health Policy Research reported that between 2000 and 2011, the number of consumers in the system increased 57 percent, while, in comparison, California's general population grew by 14 percent. Specifically, the population of children under the age of three receiving early start services in the community increased by 62 percent, and the population of individuals over age three who are served in the community increased by 53 percent.[52] Much of the growth in the population of individuals served in the community system can be attributed both to growth in the number of new individuals served in the community, as well as the closure of state developmental centers and a corresponding increase in consumers residing in the community.[52]

The increase in the number of new individuals served can be attributed in part to a growth in the prevalence of individuals diagnosed with Autism Spectrum Disorders. In California, the number of individuals with autism who are served by the developmental disabilities service system has grown 283 percent since 2000.[52] The incidence of other major developmental disabilities has also increased, among them: mental retardation (34 percent), epilepsy (21 percent), cerebral palsy (19 percent), and the "fifth category," representing conditions resembling mental retardation or requiring similar treatment (122 percent).[52] Furthermore, average annual per-person expenditures for individuals with autism are higher than the average per-person annual expenditures for individuals with other types of developmental disabilities.[52] Finally, advances in medical care have successfully increased the life-span of individuals with developmental disabilities, which means that these individuals remain in the system for longer periods of time.

<u>Resource Challenges</u>: The developmental disabilities service system has faced significant pressure in light of the state's budgetary challenges, which has led to a need for cuts to the statewide budget for developmental services, including rate freezes for vendors serving the population.[52] The 2012-2013 budget included a decrease of $200 million General Fund to DDS, which has been implemented through new cost-saving measures. These cost-saving measures include the redesign of options for consumers who have been hard to serve in the community, which among other provisions entails restricting new admissions to state developmental centers. Other new policies include, but are not limited to, maximizing the use of federal funds, increasing insurance billing for certain autism-related services, and implementing a 1.25 percent provider payment reduction for one year.[53]

<u>Complex and Fragmented Rate Setting Process</u>: The rate setting process for vendors is complex.[50-52] The California Code of Regulations (Title 17 CCR) establishes different rate setting methodologies for different types of services, which translates into a complicated rate setting processes.[52] Under state law, DDS sets certain rates, including rates for in-home respite care and community-based day programs. For other types of services, when an established rate is not applicable, the regional center must determine if the vendor has a defined "usual and customary"

rate. If there is no "usual and customary rate," then the regional center negotiates the rate with the vendor. The transparency and accountability of the rate-setting process is in question, with recommendations focused on adopting more equitable and transparent vendor payment systems. In a 2010 report, the California State Auditor found that, among other issues, "regional centers set rates using different methodologies, often do not keep documentation demonstrating how rates were set, and in certain instances (give) the appearance of favoritism or fiscal irresponsibility" (p. 4).[50]

<u>Health and Safety Concerns at Sonoma Developmental Center</u>: An October 2012 hearing of the Senate Budget Committee highlighted issues regarding resident safety at Sonoma Developmental Center.[33] In its July 2012 annual survey, the Department of Public Health found numerous violations at Sonoma Developmental Center, including "failure [by management] to take actions that identified and resolved problems of a systemic nature, to ensure adequate facility staffing, to provide active treatment, to provide appropriate health care services" and several other issues (p. 6).[33] In response to these findings, the Senate Budget Committee reported that DDS has removed two top executives, contracted with an internal monitor for ongoing evaluation of the plans of correction, required unannounced checks by facility managers and other DDS headquarter staff, and implemented new policies designed to provide closer supervision and better staff training.

Conclusion

Despite its challenges, California's system of supports and services for people with developmental disabilities provides a critical network of services, while reflecting a commitment to serving individuals throughout their lifetime. Emphasizing the importance of individual empowerment, independence, and integration in community life, the Lanterman Act establishes the right for individuals to receive all necessary services and supports through the regional center network. The system's commitment to deinstitutionalization has enabled many individuals who previously resided in state-operated facilities to relocate to the community. Through its efforts to guarantee access to home- and community-based services, the developmental disabilities service system serves as a model for how to maximize independence, dignity, and choice for the broader population of seniors and persons with disabilities who seek to remain in the community and avoid institutionalization.

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