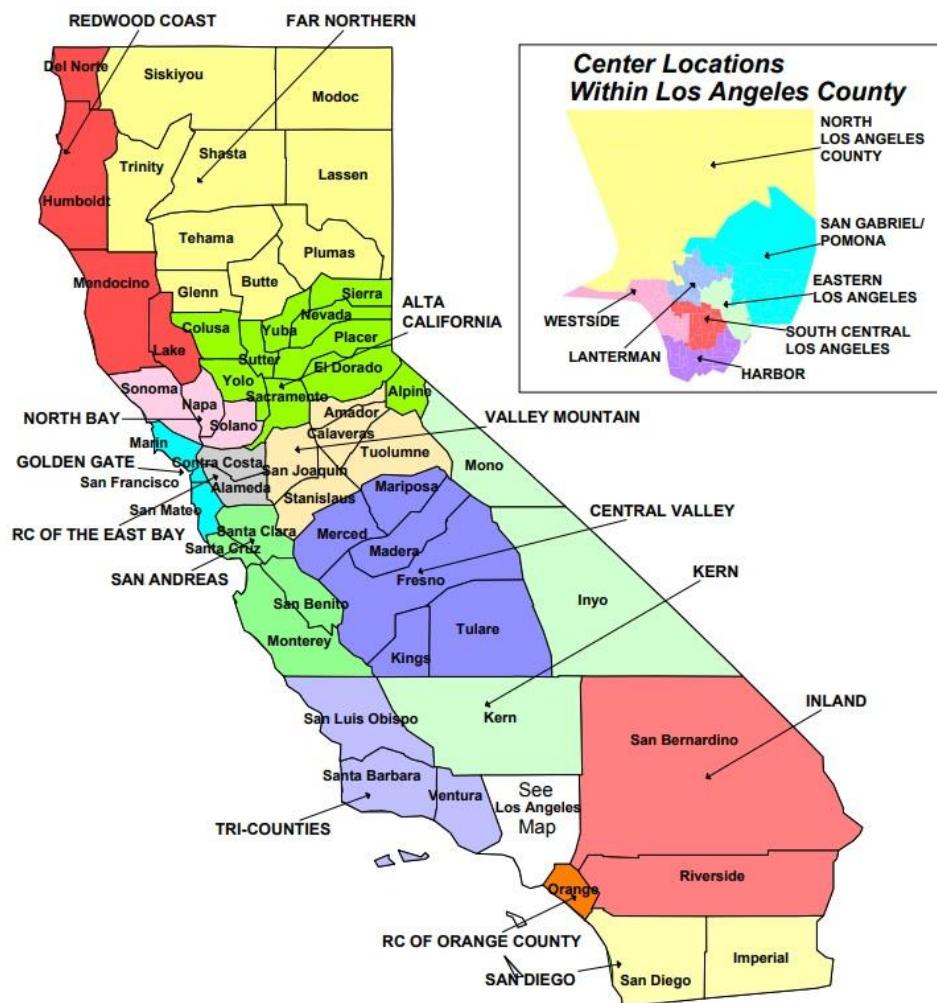


Over 300,000 Californians with developmental disabilities live, study, work, and engage in community life, supported by a partnership between independent non-profit “regional centers” and the local businesses that serve them.

The state is divided into 21 “catchment areas,” or regions, in which a single regional center is responsible for coordinating services. The day-to-day services, including housing, transportation, day programs, and therapeutic work, are provided by the over 40,000 businesses across the state dedicated to meeting those needs. The number of individuals served by each center varies significantly, as does the nature of that population, the geography, and the types of challenges facing each community.

Map of regional center catchment areas



The Core Of The System

The over 40,000 businesses responsible for the day-to-day service needs of people with developmental disabilities are called “service providers” or “vendors.” They contract with regional centers to provide services and supports needed through an individual’s life. This enables them to lead full, integrated lives in communities of their choosing. Each person’s needs, goals, and services are described in an Individual Program Plan (IPP) or Individualized Family Service Plan (IFSP). This process is driven by person-centered planning, to make sure that each plan is uniquely tailored to each individual’s needs.

Regional centers’ most visible role is to identify, coordinate, and monitor those services, but they also provide:

- Assessment, diagnosis, and referrals
- Lifelong individualized planning and case management
- Payment for services included in the IPP/IFSP for which other funds are not available
- Advocacy for the protection of legal, civil, and service rights
- Community education about developmental disabilities
- Development of new services to better meet individual needs

But What Is A Developmental Disability?

The term developmental disability refers to a disability caused by a mental or physical impairment, begins before the 18th birthday, is expected to continue indefinitely, and presents a substantial disability in three life areas. It must be due to one of the following conditions:

- Intellectual Disability
- Autism
- Cerebral Palsy
- Epilepsy
- Disabling condition closely related to intellectual disability or requiring similar treatment.

Infants and toddlers (age 0 to 36 months) who are at risk of becoming developmentally disabled or who have a developmental delay may also qualify for intensive intervention services through the state’s Early Start Program. The program is aimed at helping eligible children catch up developmentally with their peers. By age three, approximately 75% of participants have advanced to a point that they will not need regional center services.

System Origins

Historically, for people with developmental disabilities the only option for services was placement in a large, state-run facility. The typical advice for parents was to place their child in an institution, minimizing and even negating the importance of a family and community life. This was codified through various states' laws.

In California in the 1950s, parental dissatisfaction led them to band together and to create their own services in the community, and to also agitate for social change through legislation. They found a sympathetic ear in Assemblyman Frank D. Lanterman. Significantly, the state was at a crossroads – increasing demand meant that either new institutions or new models of care needed to be built.

At the national level, the tenure of President John F. Kennedy – whose sister, Rose, had an intellectual disability – saw additional progress. Kennedy convened the President's Panel on Mental Retardation in 1961, which published a report the next year recommending “community-based care and a reduction of the number of people living in large, congregate facilities.” In 1963, the Mental Retardation Facilities and Construction Act was passed, providing funds for construction of community living facilities and marking the beginning of the (federal) turn away from institutional care.

Advocacy by Californian parents, meanwhile, prompted the 1964 creation of A Study Commission on Mental Retardation. Their findings showed over 13,000 people living in overcrowded state hospitals, with 3,000 more on waiting lists. In 1965, a report to the Governor and Legislature – “The Undeveloped Resource: A Plan for the Mentally Retarded of California” – called for the State to accept responsibility for persons with mental retardation prior to state hospital admission through a network of regional community-based agencies.

As a result, AB 691 (Waldie) was signed by Gov. Edmund G. (Pat) Brown, creating two pilot “regional centers,” contracted with the State Department of Public Health. The centers were tasked with calling attention to unmet needs of people with intellectual disabilities, facilitating service development, record maintenance, and both diagnosis and follow-up. They were also charged with assisting state hospitals, now called “developmental centers,” in moving their residents to the community.

The New Approach

The first two regional centers, Childrens Hospital of Los Angeles Regional Center and Golden Gate Regional Center, served 559 clients in 1965. Their success led to the passage in 1969 of AB 225 (Lanterman), signed by Governor Ronald Reagan. Formally titled the “Lanterman Mental Retardation Services Act,” the bill expanded the pilot program statewide. The Governor’s signing statement described to goal of the bill as being to meet each person’s needs, “regardless of age or degree of handicap, and at each stage of his life’s development.”

This marked both the blossoming of the community care model in California and, shortly thereafter, the beginning of the long end of institutional care. In 1971, DeWitt State Hospital became the first state institution (serving people with intellectual disabilities) to close.

In 1973, AB 846 (Lanterman) was passed, expanded the services of his eponymous Act and renaming it the Lanterman Developmental Disabilities Services Act. The new version added cerebral palsy, epilepsy, autism, and conditions similar to intellectual disabilities to the qualifying conditions. Two years later, the 21st and final regional center was established.

In 1978, the State reorganized the administration of the service system, and moved the (state-level) responsibility from the Department of Health. A newly-created, stand-alone department (of Developmental Services) took over the role of acting as the connection between the regional center system and the State.

Budget cuts in the early 1980s were challenged in state courts. The lawsuit, ARC-California v. DDS, went all the way to the State Supreme Court. In its ruling, the court stated that while “regional centers have wide discretion in determining how to implement the Individual Program Plan (IPP); they have no discretion at all in determining whether to implement it: they must do so.” This ruling enshrined the intent of the Act by guaranteeing the right to services.

In 1993, the Coffelt v. DDS lawsuit was settled. The net effect of the suit was to increase the long history of pressure to close state-run institutions. Over the next three-and-a-half years, further closures and consolidations moved 2,000 people into community living.

Throughout the 2000s, a wave of challenges confronted the service system. Notably, the proportion of people served whose primary diagnosis of autism began to rise sharply. And in 2008-9, the Recession prompts significant cuts to a range of programs. Approximately one billion dollars of funds were cut within the community-based developmental disabilities service system.

Modern Challenges

Since the 1990s, services benefiting people with developmental disabilities have evolved, as have oversight and recordkeeping requirements. But state budget crises led to a range of cuts, including provider rate freezes, inadequate median rates, limited start-up funding, and the end of the historic practice of basing regional center staff salaries on comparable state salaries. The quality and effectiveness of those services and supports has suffered, harming individuals and families. Multiple state-authorized studies have borne this out.

Nationally, there are models available that demonstrate how best to provide individualized services in each person's community. And there are a range of services cut during the recent recession that should be restored, bringing back the tremendously positive benefits provided. California's community service providers have the drive and skills to re-offer cut services, and to make innovative services informed by other models available here. What the system lacks are the resources to make that vision a reality for the majority of people it serves.

In 2015, Governor Brown called a special session of the Legislature to focus on funding various programs. The session ended in 2016, and in exchange for reforming managed care organization taxes (MCOs, or health insurance companies), an extra \$500M (Total Fund) was added to the community-based developmental disabilities services system. This solution received bipartisan support, and was endorsed by advocates and managed care organizations alike.

This extra funding is helping people with developmental disabilities and their families by:

- Providing much-needed raises for direct service professionals;
- Allowing regional centers to raise staff wages to reduce turnover;
- Strengthening culturally and linguistically appropriate services and staff skills to benefit the changing needs of families;
- Supporting locally-tailored regional center projects to better serve diverse communities;
- Advancing a study of service provider rates to help create a sustainable system; and
- Creating a competitive integrated employment internship program;

But there is still work to be done. The payment rates providers receive and regional center funding formulas are still outdated. And both are subject to an ever-increasing number of unfunded federal, state, and local mandates. Fortunately, the Department of Developmental Services is doing a new rate study, meant to bring critical hard data to the question of sustainability. But whether the study's recommendations are implemented, and a sustainable service system is built for the next 50 years, depends entirely on the will of our elected officials.