

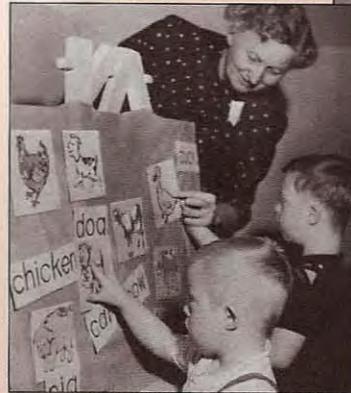
40<sup>th</sup>

ANNIVERSARY EDITION

*Reaffirming the  
Commitment...*

*Realizing  
the Vision*

HISTORY  
OF THE  
REGIONAL  
CENTERS IN  
CALIFORNIA



In the years preceding the advent of the regional center system, individuals with developmental disabilities and their families lived in a shadow world of isolation and denial, virtually invisible to the larger society – with little hope of a future.

By the early 1960s, a spirit of change was gathering momentum in California, driven in part by national events, and in part by a committed group of fearless parents, professionals and legislators who came together to challenge the state over its treatment of people with mental retardation, and to improve their quality of life.

Their actions sparked a revolution.

It has been said many times by philosophers and sages that those who neglect the lessons of history are at risk for repeating history's mistakes. We can only truly know where we're going by understanding where we've been. That is history's gift to us. And that is the purpose of this booklet.

As the passage of time increasingly separates us from the events and people that created the regional centers, we begin to lose our collective memory of our history.

The pages that follow chronicle more than four decades of our journey – of learning from experience, gaining new knowledge, taking steps forward, and constantly facing new challenges. It is a record of the human spirit – and it points the way to our future.

*Diane Anand*

Diane Anand  
Executive Director  
Frank D. Lanterman Regional Center

*"We cannot, we must not, we will not accept the situation as it is. Public concern is strong and getting stronger. We will support legislation and work for it. We will rally the communities behind us."*

*Vivian Walter, 1964*



Ann Baerwald  
1938-98

*This 40th Anniversary Edition of the History of the Regional Centers in California "Reaffirming the Commitment...Realizing the Vision" is dedicated to the memory of Ann Baerwald, a consummate professional who dedicated her life to improving the lives of people with developmental disabilities, and who many years ago provided the inspiration for this historical project, along with a working draft of the history.*



# 1955 – 1965

*“We as a Nation have long neglected the mentally ill and the mentally retarded. This neglect must end, if our nation is to live up to its own standards of compassion and dignity and achieve the maximum use of its manpower. This tradition of neglect must be replaced by forceful and far-reaching programs carried out at all levels of government, by private individuals, and by state and local agencies in every part of the Union.”*

*President John F. Kennedy,  
February 5, 1963*

## During this decade...

The United States experiences the beginnings of a period of intense social unrest and civil disobedience. The country is embroiled in the Vietnam War. A growing and increasingly vocal counterculture questions authority and decisions made both at home and abroad. There is a growing call for equality in civil rights, primarily for racial minorities, but also for people with disabilities. President John F. Kennedy, who has a sister with mental retardation, raises awareness about people with developmental disabilities through public statements and creation of the President’s Panel on Mental Retardation.

For people with developmental disabilities in California, as well as the rest of the country, the only option for government-funded services has been the state institution. The typical advice for parents of children with developmental disabilities is to place their child in an institution and “get on with” their lives. Parental

dissatisfaction causes them to band together and create their own services in the community, but also to agitate for social change through legislation. They find a sympathetic ear in Assemblyman Frank D. Lanterman.

California is also at a crossroads – the state has to build new institutions to meet the increasing demand or create services in the

community. A report to the governor and Legislature – “The Undeveloped Resource: A Plan for the Mentally Retarded of California” – calls for the state to accept responsibility for persons with mental retardation prior to state hospital admission through a network of regional community-based agencies. Acceptance of this report is followed by legislation authorizing the establishment of two pilot regional centers through which this responsibility may be realized.



## Historical highlights...

**1955** In California, five state hospitals – De Witt, Pacific (later renamed Lanterman), Modesto, Porterville and Sonoma – house approximately 8,500 people with mental retardation. Over the next 45 years there is continual change in the identity of the large state institutions serving people with developmental disabilities. At any given time there may be as few as five and as many as nine state institutions. Some of these institutions serve only people with developmental disabilities while some serve this population and people with serious mental illness.

**1959** Fairview, the sixth state hospital to serve people with developmental disabilities, opens in Orange County. This is the last state institution to be built in California.

The introduction of psychotropic medications into California's state hospitals allows large numbers of seriously mentally ill persons to leave these institutions and live in the community. Increasingly, these same drugs are used for behavioral control of people with developmental disabilities living in the community and in the state institutions. Eventually, both the community and institutional service systems become over-reliant on these drugs.

Because publicly-funded services are extremely limited and almost exclusively institutional, across the country, families of people with mental retardation create their own support and service systems. In California, parent-run organizations such as the Exceptional Children's Foundation (Los Angeles), Villa Esperanza (Pasadena), and Aid for Retarded Children (San Francisco) establish private schools, activity centers, sheltered workshops and residential services.

The Traveling Child Development Project, under the direction of Dr. Richard Koch, begins providing assessment, diagnosis and counseling for children with developmental disabilities and their parents in 15 Southern California communities. This project evolved out of an earlier activity – a Special Clinic for the Study of Mental Retardation, directed by Dr. Koch, funded by the U.S. Children's Bureau, and operated out of Childrens Hospital Los Angeles.



*“We're here to speak for justice and humanity for the legal and moral rights of half a million citizens of the state of California who through no fault nor choice of their own are mentally retarded.”*

### VIVIAN WALTER

An outspoken and active pioneer in the field of developmental disabilities, Vivian Walter joined San Francisco ARC a year after her son Ned was born with Down syndrome. As part of that group, she created a one-woman Hospital Committee and began going to the state hospitals. It was during those visits that she began to see how desperate conditions truly were – and that realization moved her to act, and set into motion a series of events that would bring about a dramatic change in both the hospitals and the treatment of individuals with mental retardation. Ultimately, these activities would culminate in the Lanterman Act.

Through her friendship with Dr. Gunnar Dybwad, she invited him to California to see the state hospitals first-hand. His reaction added impetus to the growing movement for reform.

She was a member of the board of Golden Gate Regional Center – one of the two pilot centers established in 1966. She was chair of Mental Hygiene for the California Council for Retarded Children. She also went on to be president of the board of San Francisco ARC, and vice president of the Southwest Region of the ARC National Board. In addition, she served on the State Board for the Developmentally Disabled under governors Pat Brown and Jerry Brown. Ms. Walter died in December 2002 at age 88.

The Traveling Child Development Project becomes the model for the regional center concept.

**1961** President John F. Kennedy, who himself has a sister with mental retardation, appoints a President's Panel on Mental Retardation. This group is charged with the development of a "National Plan to Combat Mental Retardation." President Kennedy announces his intention to appoint a panel of physicians, scientists and other professionals to recommend a program of action in the field of mental retardation. He notes that the nation has "for too long postponed an intensive search for solutions to the problems of the mentally retarded. That failure should be corrected..."

Robert Guthrie develops a simple, reliable newborn screening test for phenylketonuria (PKU), a metabolic disorder that, in the absence of early and lifelong dietary modification, results in mental retardation as well as other medical, behavioral and psychological problems. This test is eventually used worldwide for screening newborns for this condition.

**1962** The President's Panel submits its report on October 16, 1962. Its 95 recommendations include expansion of community-based services and a reduction of the number of persons living in large, congregate care facilities. The report endorses the concept of "normalization" to guide service delivery. This concept, first introduced by Bengt Nirje from Sweden, affirms the right of all people with developmental disabilities – regardless of the severity of those disabilities – to daily experiences and activities that are culturally normative and as close as possible to the prevailing patterns of mainstream society. Normalization shapes the conceptual framework for deinstitutionalization.



**1963** The White House Conference on Mental Retardation is convened to recommend actions based on the work of the President's Panel. A legislative package is developed, including amendments to the Social Security Act that establish the Maternal and Child Health Program. A primary goal of this program is to improve prenatal care to high-risk women from low-income families in order to reduce the incidence of children born with disabilities.

As a result of the recommendations made in 1962 by the President's Panel on Mental Retardation, Congress passes the Mental Retardation Facilities and Community Mental Health Center Construction Act (PL 88-164). This legislation provides for construction of community-based facilities for people with mental retardation and mental illness. Called University-Affiliated Facilities, these entities provide services and interdisciplinary training of clinical professionals to prepare them to work with people with mental retardation.

Assemblyman Leroy Greene of Sacramento authors a bill requiring all newborns in California to be screened for PKU.

In California, the six state hospitals – Dewitt, Pacific, Fairview, Patton, Porterville and Sonoma – serve approximately 12,700 people with mental retardation. Plans are underway to enlarge the state hospital system.

During an unscheduled visit to Fairview State Hospital, a group of people – among them Vivian Walter, then chair of Mental Hygiene for the California Council for Retarded Children, and a reporter for The Orange County Register – are stunned at the desperate conditions they find. This visit and subsequent publication of the findings prompts a series of hearings and investigations that will lead to dramatic changes in the state hospital system and in the lives of people with developmental disabilities.

**1964** California state hospitals serve more than 13,000 people with mental retardation and 3,000 people are on the waiting list for admission. People may wait as long as three years to gain admission. Dr. James Lowry, director of the Department of Mental Hygiene, asks the Legislature for an appropriation of \$47 million to construct an additional 3,000 state hospital beds. At the urging of the California Council for Retarded Children (later the Association for Retarded Citizens), the Legislature appoints a Study

Commission on Mental Retardation. The commission surveys 3,000 people who have family members on the waiting list for admission to a state hospital. The survey reveals that a large majority of families would prefer community-based alternatives to the state institution.

**1965** The report, "The Undeveloped Resource: A Plan for the Mentally Retarded of California," is submitted to the governor and Legislature by the bipartisan Subcommittee on Mental Health of the Assembly Interim Committee on Ways and Means. The members of the subcommittee are Assembly Majority Leader Jerome Waldie (D), Clair Burgener (R), Frank D. Lanterman (R), and Nicholas Petris (D). The principal consultant to the subcommittee is Art Bolton who, along with Assemblyman Lanterman, consistently solicits bipartisan support for their legislative actions. The report calls for the state to accept responsibility for persons with mental retardation prior to state hospital admission through regional community-based services that would provide "diagnosis, counseling and continuing services."

In response to the report "The Undeveloped Resource," Assembly Bill 691 (principal author Jerome Waldie; co-author Frank Lanterman) is enacted and signed by Governor Edmund G. (Pat) Brown. The bill calls for a shift of state responsibility for people with mental retardation from the point where they enter a state hospital to the point where they are diagnosed with mental retardation. The bill authorizes the establishment of two pilot regional centers for persons with mental retardation under contract with the State Department of Public Health. The centers are designed to call attention to unmet needs of people with mental retardation, facilitate the development of services, maintain records, and provide systematic diagnosis and follow-up. They are also charged with assisting state hospitals in moving their residents to the community.

In a message to the Legislature urging the passage of AB 691, Governor Brown states: "Our concern for the mentally retarded is a measure of our adherence to one of the oldest and deepest tenets of western civilization – a reverence for human life and human potential. As we prize the life of the handicapped person and seek to help him develop to the limit of his capacity, we provide for our right to be called civilized. Our major means toward this goal should be education and rehabilitation, not merely protection and custody. Society's as well as the individual's interest can be served here. If the retarded can become more self-sufficient and productive, some may become taxpayers and more active participants in our society. In any event, they will require less expensive services from society than if they were totally dependent."

The Federal Vocational Rehabilitation Act (PL 89-333) is amended to mandate that services be provided to people with severe disabilities. It allows more flexible guidelines to permit extended evaluation periods for persons with mental retardation or similar disabilities.

The Social Security Act (PL 89-98) is amended to establish the Medicaid (Medi-Cal in California) and Medicare programs, and to provide public funding for care of people with mental retardation and other serious disabilities.



# 1966 – 1975

*“In order to provide fixed points of referral in the community for the mentally retarded and their families; establish ongoing points of contact with the mentally retarded and their families so that they may have a place of entry for services and return as the need may appear; provide a link between the mentally retarded and sources in the community, including state departments, to the end that the mentally retarded and their families may have access to the facilities best suited to them throughout the life of the retarded person; and offer alternatives to state hospital placement, it is the intent of this article that a network of regional diagnostic, counseling and service centers for mentally retarded persons and their families, easily accessible to every family, be established throughout the state.”*

*Excerpt from historic bill AB 691*



## During this decade...

Nationwide, as well as in California, the horror of life in state institutions is revealed through a series of exposés published in newspapers and on television. While the federal government and individual states focus on improving the conditions within these institutions, increasing numbers of parents see them as inhumane and inappropriate alternatives to community services. At the same time, several major lawsuits in federal courts result in decisions affirming the constitutional rights of people with disabilities to treatment in the least restrictive setting and the most normal living conditions possible. Limiting a person's right to live outside of an institution is found to be a violation of the 14th amendment to the Constitution, guaranteeing all persons "equal protection of laws." At the end of this decade, the federal government passes the Education for All Handicapped Children Act (PL 94-142), guaranteeing a "free and appropriate public education" to all children, regardless of their level of disability. This same year, the federal government also passes a bill of rights for people with developmental disabilities.

As the population in California institutions peaks, the state fully embraces a bold initiative with passage of the Lanterman Mental Retardation Services Act – creation of a public-private partnership aimed at establishing a system of community-based services for people with mental retardation that will offer alternatives to state institutions. Because parents are suspicious of the capacity of the state bureaucracy to know what is best for their children, they demand that these regional centers be locally governed. The California State Employees' Association, seeing threats to its members' job security and benefits, brings an unsuccessful suit to prevent further development of these centers, arguing that, under the state constitution, such services may only be provided by state employees. During this era, the first closure of a state institution marks an initial milestone in a campaign that will continue at a maddeningly slow pace well into the next century.

## Historical highlights...

**1966** A President's Committee on Mental Retardation is established on May 11, 1966.

In California, seven state hospitals – Agnews, Dewitt, Pacific, Fairview, Patton, Porterville and Sonoma – house approximately 13,200 people with mental retardation.

The birth of the regional center system occurs with two pilot centers opening their doors in January

1966. The Department of Public Health, Bureau of Mental Retardation, negotiates contracts with two private agencies: Childrens Hospital Los Angeles which will serve Los Angeles County, and San Francisco Aid for Retarded Children which will serve Alameda, Contra Costa, Marin, San Francisco and San Mateo counties. These two organizations are charged with contacting people on waiting lists for admission to state hospitals, providing diagnostic assessments, and making recommendations for community-based care. Limited funding is available to the centers to purchase services. The initial budget for the two pilot regional centers is \$966,386. They will serve a total of 559 clients at an average cost of \$1,728 per person.

- 1967** In California, SB 499 establishes Developmental Centers for the Handicapped, segregated public schools for children with disabilities.

In the United States, the number of people with developmental disabilities living in institutions for people with intellectual disabilities peaks at 195,000. An additional 20,000 people with developmental disabilities live in institutions for people with mental illness.

Neils Bank-Mikkelsen, internationally-recognized expert in the field of mental retardation and director of the Danish National Services for the Mentally Retarded, attends a conference in San Francisco. While in California, he seeks permission to tour Sonoma State Hospital. He is stunned by the deplorable conditions he observes there. Upon completing the tour, he publicly chastises the state of California, stating: "California, with all of your vast wealth and resources, you ought to be ashamed. In Denmark, we treat our cattle better than that." He cited conditions such as an overcrowded ward with naked women lying on a cold floor in their own excrement; and a ward for men, with no bathroom doors, facing tables where people were eating. His public statements about what he sees cause a public outcry in California and result in Assemblyman Lanterman's call for an investigation into the system.

- 1968** After a yearlong legal battle, the San Francisco-based parent group, Aid for Retarded Children, wins a lawsuit requiring Governor Ronald Reagan to appoint an outside group of experts to investigate conditions at Sonoma State Hospital. A survey team, consisting of Dr. Gunnar Dybwad, a national expert on mental retardation; Dr. Richard Koch of the University of Southern California; and Dr. Ivy Mooring of the Los Angeles Coordinating Council on Mental Retardation is appointed. The survey team's report states, "Mentally retarded patients at Sonoma State Hospital, old and young alike, are



**FRANK D. LANTERMAN**

*Frank D. Lanterman represented the La Cañada area of Los Angeles County in the California Assembly for 28 years, starting in 1950. In 1963, he was appointed to the newly-formed Subcommittee on Mental Health and Developmental Disabilities, and served as its chairman from the late 1960s through the 1970s. During that time, he did more than any other legislator to improve the lives and protect the rights of persons with developmental disabilities and their families.*

*Through a number of legislative efforts, he played a key role in increasing the care and opportunities available for persons with disabilities and ensured that care would be provided closer to their homes and families. Legislation included the landmark Lanterman Mental Retardation Services Act of 1969, the Lanterman Developmental Disabilities Services Act, the Master Plan for Special Education, and the California Community Care Licensing Act. His primary goal throughout the last 15 years of service was to foster greater independence and opportunities for people with developmental disabilities.*

*Assemblyman Lanterman retired from the Legislature in 1978 and died in 1981. Others have aspired to wear his mantle, but none has achieved his stature.*

*The Memorial Resolution passed in his honor reads, in part:*

*"Whereas, he leaves behind a legacy of leadership, a history of lessons for present and future politicians; and he fashioned permanent progress for the sick in body and mind, following in his father's footsteps; Frank Lanterman was a healer on a grand scale; now, therefore, be it resolved by the Joint Rules Committee of the Senate and the Assembly...that the Legislature will pursue and preserve Frank Lanterman's vision of his beloved state and emulate his tenacity for justice for all the people of California."*

herded into huge, barn-like wards which are bereft of any niceties of home and are treated like, and consequently behave like, animals in a zoo." The report continues, "The survey found that the dignity of the individual is violated when he is stripped of his clothes, when he has no vestige of privacy, even a shoe box he can call his own."

By June of this year the two pilot regional centers are serving 770 people with developmental disabilities and their families.

The number of people with mental retardation living in state institutions in California peaks at approximately 13,400.

**1969** Neils Bank-Mikkelsen from Denmark and Bengt Nirje from Sweden introduce the concept of normalization to an American audience at a conference sponsored by the President's Committee on Mental Retardation.

"A Proposal to Reorganize California's Fragmented System of Services to the Mentally Retarded" is reported to the state Assembly. Dennis Amundson, an aide to Assemblyman Lanterman, is the principal drafter. The report concludes that the pilot regional centers are successful and the model should be expanded statewide.

Buoyed by "A Proposal to Reorganize...", Assemblyman Lanterman introduces AB 225 that extends the regional center network of services throughout California and establishes area boards for planning and monitoring of services. Within a decade, the system includes 21 regional centers. Lanterman envisioned one regional center for every one million residents of the state.

AB 225, the landmark Lanterman Mental Retardation Services Act of 1969, is signed by Governor Reagan on September 4, 1969. The governor states that this "progressive legislation provides us with a dynamic framework on which we shall build a comprehensive system to assure that the mentally retarded develop to the fullest extent to which they are capable." The act calls for the state to contract with local, community-based non-profit corporations to provide services under the act.

**1970** The Urban Mass Transportation Act (PL 91-453) is amended to require local governments to ensure that mass transportation facilities and services are accessible to people who are elderly or handicapped.

The preamble and intent sections of AB 225 provide inspiration and guidance for future generations of Californians:

- "The state of California accepts a responsibility for its mentally retarded citizens and an obligation to them which it must discharge."
- "A pattern of facilities and services should be established which is sufficiently complete to meet the needs of each mentally retarded person, regardless of age or degree of handicap, and at each stage of life's development."
- "Services should be available throughout the state to prevent the dislocation of persons from their home communities."
- "Services should be available for mentally retarded persons that approximate the pattern of everyday living available to non-disabled people of the same age."
- "Evidence must be provided that services have resulted in more independent, productive and normal lives for the persons being served."

In response to the requirement in AB 225 that the state contract with community-based non-profit corporations to establish regional centers, the California State Employees' Association (CSEA) sues to halt the further development of these agencies. CSEA argues that the state constitution requires these services to be provided by state employees. In his ruling against CSEA, Judge B. Abbott Goldberg reasons: "The fact that a particular occupational skill can be provided by civil service does not mean that the function of a program can be achieved through civil service. To use a homely metaphor, the fact that one can buy ingredients does not prove he can bake a pie."



The Developmental Disabilities Services and Facilities Construction Act (PL 91-517) is amended and includes the first legal definition of developmental disability. It integrates previous legislation addressing developmental disabilities into a comprehensive statute that includes grants for services and facilities for the rehabilitation of people with these disabilities. It also requires every state to establish a governor's council on developmental disabilities.



**1971** A suit is brought in the U.S. Court for the Eastern District of Pennsylvania. Plaintiffs in *Pennsylvania Association for Retarded Citizens v. Commonwealth of Pennsylvania* argue that children with disabilities have a right to education at public expense and due process. The suit is settled in 1972 when the state agrees it has "an obligation to place each mentally retarded child in a free program of education and training appropriate to the child's capacity."

Passage of the Intermediate Care Facility/Mental Retardation (ICF/MR) program as part of Title XIX (Medicaid) of the Social Security Act allows states to obtain federal funding for institutional services if care meets minimal federal standards for treatment and space. The availability of federal funding under these conditions adds pressure to calls for deinstitutionalization, since overcrowded facilities in many states cannot meet federal space requirements.

DeWitt State Hospital becomes the first California hospital serving people with mental retardation to close its doors. By the end of Governor Reagan's

administration, two additional institutions, Modesto and Mendocino, are ordered closed.

Assemblyman Lanterman authors legislation prohibiting restrictive zoning for licensed homes serving six or fewer "mentally disordered or otherwise handicapped" persons.

**1972** The decision in *Wyatt v. Stickney*, an Alabama class action suit filed in federal district court, sets forth the constitutional right to developmental and rehabilitation treatment in the least restrictive environment for persons committed to a state institution without a criminal trial. This decision leads to a wave of at least 70 federal lawsuits in 41 states demanding treatment in the least restrictive environment for people with disabilities.

Investigative journalist Geraldo Rivera exposes conditions endured by people with mental retardation living at the Willowbrook State School in New York. Because of underfunding of this institution, residents are living in squalid conditions, largely unsupervised. The exposé results in a 1975 lawsuit, *New York Association for Retarded Citizens v. Carey*. In its decision in this case, the U.S. District Court in Brooklyn reaffirms the constitutional right of people with developmental disabilities to treatment in the least restrictive setting and the "most normal living conditions possible."

In *Mills v. Board of Education*, the U.S. District Court for the District of Columbia rules that the District of Columbia cannot exclude children with a disability from the public schools. This decision and the previous decision in *Pennsylvania Association for Retarded Citizens v. Commonwealth of Pennsylvania* are cited by advocates during the public hearings leading to the passage of the landmark Education for All Handicapped Children Act of 1975.

Wolf Wolfensberger and colleagues publish "The Principle of Normalization in Human Services," introducing the concept that originated with Bengt Nirje to a wider audience in America. This document has a significant effect on the shape of human services in the United States in subsequent years.

Fostered by the civil rights movement and political activism of the 1960s, a group of disability activists led by Ed Roberts, found the first Center for Independent Living (CIL) in Berkeley. Over the next 40 years, nearly 500 such centers are established in the





United States. Run and controlled by persons with disabilities, these centers aim to assist people with disabilities to achieve their maximum potential within their families and communities. Though developed primarily by people with physical disabilities, CILs provide a model for empowerment and supported living for people with developmental disabilities in subsequent years.

Social Security Act Amendment PL 92-603 establishes Supplemental Security Income (SSI) to standardize assistance programs to people in need, including those with developmental disabilities.

**1973** In California, a group of people with disabilities, dissatisfied with their experience at a Canadian conference purportedly for people with mental retardation, return home and form their own self-advocacy group. They call this group "People First" to reflect the fact that their disabilities are secondary to their personhood. The idea of self-advocacy begins its spread across the United States.

The Rehabilitation Act of 1973 (PL 93-112) authorizes over \$1 billion for training and placement of persons with mental and physical handicaps into employment. Section 504 of this act prohibits discrimination based on disability and provides the legal basis for subsequent anti-discrimination lawsuits. Much to the chagrin of people with disabilities, their parents and advocates, the

government resists writing the regulations needed to implement this section of the act.

AB 846, authored by Assemblyman Lanterman, extends the regional center mandate to other developmental disabilities, including cerebral palsy, epilepsy, autism and other conditions closely related to mental retardation. The name of the act is amended to the Lanterman Developmental Disabilities Services Act.

**1974** President Richard Nixon signs Executive Order 11776 reaffirming a national goal of returning one-third of the 200,000 persons with mental retardation residing in institutions to community settings.



The U.S. Department of Justice files a class action suit, *United States v. Solomon*, on behalf of people with mental retardation living in institutions. The decision affirms their right to treatment.

In *Pennsylvania Association for Retarded Citizens v. Pennhurst School and Hospital* filed in federal court in 1974, plaintiffs charge that conditions in the state institution deny residents due process and equal protection of the law in violation of the 14th Amendment to the U.S. Constitution,

inflict on them cruel and unusual punishment in violation of the Eighth Amendment, and deny them certain rights conferred by the federal law. It also asks that Pennhurst be closed and that community living arrangements be established for its residents. The court ultimately agrees that keeping persons with mental retardation in institutions isolated from society is a violation of the 14th Amendment. The court's rationale is that the only justifiable purpose for commitment of a person with mental retardation is habilitation, and if habilitation is not provided, the nature of the commitment bears no reasonable relationship to its purpose. Thus, the person's due process rights have been violated.

**1975** Congress passes the widely heralded Education for All Handicapped Children Act (PL 94-142). This law mandates a "free and appropriate public education" in the "least restrictive environment" for all children, regardless of the severity of the child's disability. It also mandates Individualized Education Programs (IEPs) with special education and related services designed to meet the unique needs of each child.

The Developmental Disabilities Assistance and Bill of Rights Act (PL 94-103) mandates a bill of rights for persons with developmental disabilities and requires each state to establish a protection and advocacy system. Within three years, California establishes Protection and Advocacy, Inc. to ensure the rights of California residents with disabilities.

The 1975-76 budget for 20 regional centers is \$47,980,527. They serve 33,833 clients at an average cost of \$1,418 per person.

Approximately 10,200 persons with developmental disabilities reside in state hospitals in California.



*"For the parent of a retarded child, there were only two options. One you kept the child home, or two you would institutionalize the child. There was nothing in between."*

**JEROME R. WALDIE**

Jerome R. Waldie served California as an Assemblyman from 1959 through 1966. For six of those years he was the majority leader. And in 1965, along with Assemblymen Leroy Greene, Frank Lanterman, Alfred Alquist, Clair Burgener, Nicholas Petris and Charles Warren, he introduced AB 691, the landmark bill establishing regional centers.

He was subsequently elected to Congress in 1966 where he served until 1975. During that time he was a member of the House Judiciary Impeachment Committee. He later worked for the Carter Administration as executive director of the White House Conference on Aging, and as chair of the Federal Mine, Safety, and Health Review Commission.

He was also a member of the California Agricultural Labor Relations Board and president of the National Senior Citizens Law Center. He currently serves as a member of the Tahoe Regional Planning Agency, and has remained active in local Democratic politics.

In 2002, Mr. Waldie received the Community Imperative Lanterman Pioneer Award, given to leaders who helped lay the foundation for the California community service system by securing passage of the Lanterman Developmental Disabilities Services Act.



# 1976 – 1985

*“[For people with mental retardation] much has changed in recent years, but much remains the same; outdated statutes are still on the books, and irrational fears or ignorance, traceable to the prolonged social and cultural isolation of the retarded, continue to stymie recognition of the dignity and individuality of retarded people. Heightened judicial scrutiny of action appearing to impose unnecessary barriers to the retarded is required in light of increasing recognition that such barriers are inconsistent with evolving principles of equality embedded in the 14th Amendment.”*

*Justice Thurgood Marshall*

*Writing a partly concurring and partly dissenting opinion in the 1979 Supreme Court decision, Cleburne v. Cleburne Living Center, Inc.*

## During this decade...

During this era, the rights of people with developmental disabilities are repeatedly reaffirmed and expanded as a result of legal challenges to restrictions on their lives, but the challenges to social acceptance and full inclusion continue. Significant judicial decisions limit the authority of states to commit people to institutions and to confine them indefinitely. The federal government contributes to the development of community services through creation of the Home and Community-Based Waiver Program that increases financial support for community services by waiving the requirement that recipients of Medicaid funds live in institutions.

The network of regional centers is completed with the opening of the Regional Center of the East Bay, and the Lanterman Act is amended to expand coverage to people with all types of developmental disabilities, including conditions closely related to mental retardation. The state eliminates its Continuing Care Services Branch, and with this action, unifies the community service system by giving regional centers responsibility for people with developmental disabilities living in licensed facilities in the community. In addition, a light is shone on state institutions when regional centers are required to open a case for every resident of an institution and review annually the appropriateness for that person of moving to the community.

Proposition 13 is passed in California, seriously reducing local governments' ability to generate property tax revenue to support local programs. This gradually shifts control of services for people with developmental disabilities to the state. At the same time, serious state budget deficits result in the Department of Developmental Services (DDS) reducing funding for regional centers and causing some centers to implement waiting lists and categorical cuts in services. A lawsuit challenging these actions results in a state Supreme Court decision that the Lanterman Act defines an entitlement to services.



## Historical highlights...

**1976** In *O'Brien v. Superior Court*, a California court finds that individuals with mental retardation who have been committed to a state institution for being a danger to self or others have the right to a jury trial.



In the *Matter of Andre Bisagna*, the California Court of Appeals, in an unpublished decision, finds that if a person is judicially committed to a state institution for the mentally retarded because he is a danger to himself or others, that commitment order shall expire after one year. The Court further orders that regional centers be notified of all persons who are judicially committed to a state institution and that a case be opened by a regional center for each person. Regional centers are also required to conduct an annual assessment to determine each person's ability to live in the community. Within a few months of the order, Mr. Bisagna moves out of the institution into a community care facility where he still resides.

The Lanterman Developmental Disabilities Services Act is amended after extensive legislative hearings. The act affirms the right to treatment and habilitation services for persons with developmental disabilities. It changes the eligibility categories for regional center services to include "handicapping conditions found to be closely related to mental retardation or to require treatment similar to that required for mentally retarded individuals, but shall not include other handicapping conditions that are solely physical in nature." It also establishes an individualized planning process to replace the traditional medically-oriented patient record.

A decade after the establishment of the two pilot regional centers, the network is completed with the establishment of the Regional Center of the East Bay.

Nine state hospitals – Agnews, Camarillo, Pacific, Fairview, Napa, Patton, Porterville, Sonoma and Stockton – serve approximately 10,100 people with developmental disabilities.

**1977** Disabilities rights advocates in nine cities stage demonstrations and occupy offices of the federal Department of Health, Education and Welfare (HEW) demanding that the government publish implementing regulations for the Rehabilitation Act of 1973. The demonstrations are televised nationally and galvanize the disability community. For the first time, the nation sees mass demonstrations of people with disabilities attempting to ensure their civil rights. The government responds by publishing implementing regulations.

The Lanterman Act is amended (Section 4502) to give people with developmental disabilities the same legal rights and responsibilities guaranteed all other individuals by the Constitution and laws of the United States and the state of California.



**1978** Title VII of the Rehabilitation Act Amendments of 1978 establishes the first federal funding for independent living and creates the National Council of the Handicapped within the U.S. Department of Education. The Council is made independent in 1984 and is renamed the National Council on Disability (NCD). NCD's purpose is "to promote policies, programs, practices and procedures that guarantee equal opportunity for all individuals with disabilities, regardless of the nature or severity of the disability; and to empower individuals with disabilities to achieve economic self-sufficiency, independent living, and inclusion and integration into all aspects of society."



Proposition 13, capping property tax rates and increases and rolling back property values for tax purposes to the 1975-76 level, is approved by the voters of California. Its effect is to limit the ability of local governments to generate property tax revenue, thereby shifting greater responsibility and control for services to the state. Assemblyman Frank Lanterman strongly opposes Proposition 13 because he believes it will give too much power to the state while weakening local control, which he calls "home rule." At the same time, the climate for funding of state-financed health and welfare programs changes as revenue projections and the state's economy decline.

State hospitals serving people with developmental disabilities are renamed state developmental centers.

Under Governor Jerry Brown, the Department of Developmental Services (DDS) is established as an independent agency rather than a division of the Department of Public Health.

The Lanterman Act is amended to create a Program Development Fund to support the creation of additional community-based resources for people with developmental disabilities. The fund is to be supported by parental fees collected from parents whose minor children are in out-of-home placement.

Assemblyman Lanterman retires from the Legislature after 28 years.

**1979** The 21 regional centers form the Association of Regional Center Agencies (ARCA), a non-profit state association comprised of regional center board volunteers and executive directors. The purpose of this organization is to promote statewide regional center issue resolution, advocacy and coordination.

The regional center leaves Childrens Hospital Los Angeles and is reorganized as a non-profit freestanding agency, the Los Angeles County Developmental Services Foundation. The agency is dedicated to Frank D. Lanterman and he agrees to lend it his name.

**1980** A provision of the Social Security Act Amendments (PL 96-265) creates a three-year demonstration project that allows SSI recipients with developmental disabilities to continue receiving these benefits while engaged in paid employment.

The state eliminates its Continuing Care Services Branch and transfers to regional centers the responsibility for people with developmental disabilities living in board and care and other community care facilities. With this change, regional centers assume responsibility for all aspects of out-of-home living in the community for people with developmental disabilities.



The California Penal Code is amended to require regional centers to provide assessment and recommendations to the court on some defendants with developmental disabilities in criminal actions.

**1981** Section 2176 of the Omnibus Reconciliation Act (PL 97-35), "Home and Community-Based Waiver" (referred to as "Medicaid Waiver"), allows states to finance a wide array of community services through Medicaid by asking the government to waive the requirement that recipients of the benefits live in institutions. The program funds a number of services that people with disabilities need to live outside of a health facility such as a state developmental center, nursing home or intermediate care facility. It is intended to facilitate movement to the community from these institutions and to divert admissions.

Newly-elected President Ronald Reagan threatens to amend or revoke regulations implementing Section 504 of the Rehabilitation Act of 1973 and the Education for all Handicapped Children Act of 1975. Disability advocates respond with intensive lobbying and a grassroots campaign that generates more than 40,000 cards and letters. After three years, the Reagan Administration abandons the efforts to change the laws.



In the case of *In Re Hop*, the California Supreme Court rules that any adult with developmental disabilities who has been placed in a developmental center is entitled to a judicial review to determine whether he or she should remain institutionalized. The case is later extended to include judicial review prior to admission.

The California Probate Code is amended to establish a limited conservatorship specifically for adults with developmental disabilities. This conservatorship "may be utilized only as necessary to promote and protect the well-being of the individual [and] shall be designed to encourage the development of maximum self-reliance and independence of the individual."

Assemblyman Frank D. Lanterman dies. The Legislature never again has a member who so effectively champions the rights of people with developmental disabilities.

Pacific Developmental Center is renamed Lanterman Developmental Center, in honor of Mr. Lanterman. Some regard this as ironic, since he worked tirelessly in the latter part of his career in the Assembly to create community-based alternatives to state institutions.

**1982** A Social Security Act Amendment (PL 97-248, "Katie Beckett") permits states to use Medicaid funds for children with disabilities under the age

of 18 who are living at home and who would be eligible for SSI if they were residing in institutions. The impetus for this change comes in the form of a personal appeal to President Reagan from Julie Beckett, mother of Katie, a child with significant medical conditions requiring skilled nursing care. Personal intervention by the president prompts the creation of the Katie Beckett Waiver to the Medicaid law. This allows Katie and children like her to remain in the family home and still receive SSI and have medical expenses covered by Medicaid, regardless of their family income.

In *Hendrick Hudson District Board of Education v. Rowley*, the U.S. Supreme Court rules that the requirements for a "free and appropriate public education" are satisfied if a child receives personalized instruction with sufficient support services that allow him or her "to benefit" from special education.

This decision is interpreted as meaning each child with a disability is entitled to access a "basic floor of opportunity" in the public schools, in contrast to the best possible education.



Patton State Hospital closes its programs for people with developmental disabilities but continues to serve people with mental illness.

**1983** Education Amendments (PL 98-199) establish and fund services to facilitate the transition of students with disabilities from school to the community or work settings.

California is confronted with a \$1 billion budget deficit. AB 40X, authored by Assemblyman Burt Margolin, provides emergency regional center funding and gives DDS emergency authority to directly control regional center expenditures. Service reductions are authorized at 10 regional centers.

California is approved for participation in the federal Medicaid Waiver Program, three years after its authorization by Congress. This approval allows the state to receive federal funds for services to people living in the community who, without those services, would be forced into an institutional setting.

**1984** Carl Perkins Vocational Technical Education Act (PL 96-524) mandates development of quality vocational education programs and expansion of existing programs, with a 10 percent "set-aside" to support programs for people with disabilities.

In response to the decision in *United States v. University Hospital* (the "Baby Doe" decision), the federal government issues regulations that mandate reporting of medical neglect if life-prolonging treatment is withheld from infants with disabilities. The decision and the government's action mark an official end to discrimination in medical treatment against infants with disabilities. Two years later, the Supreme Court invalidates the



regulations, ruling that there was no evidence that hospitals had discriminated against handicapped infants or had refused treatment sought by parents. Thus, there was no reason for federal intervention in a sensitive area ordinarily left to state agencies.

Regional centers continue to feel the effects of significant reductions in funding for staff and purchase of services. Quality assurance standards, provider rates, prevention, development of service standards, Medicaid Waiver, and installation of a computerized uniform fiscal system are major system issues.

Serious state budget deficits cause DDS to reduce funding for regional centers, and in turn, cause some regional centers to implement cost-saving strategies such as waiting lists and categorical cuts in services. In the *Association for Retarded Citizens v. California Department of Developmental Services et al*, the California Supreme Court rules that the Lanterman Act "defines a basic right and a corresponding basic obligation... [T]he 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

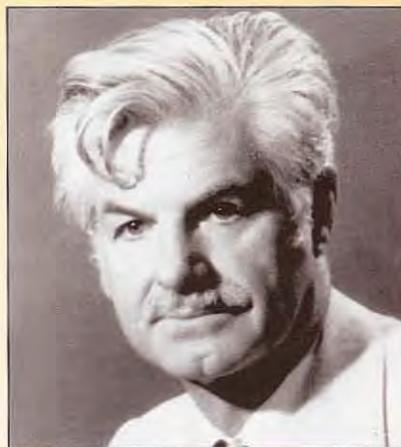


which it imposes on the state is to provide such services." These services are to be determined through the individual program planning process and provided as an entitlement. This is the first time that the Lanterman Act is explicitly defined as constituting an entitlement to services. The decision also states that regional centers, not DDS, have wide discretion in determining how to implement the Individual Program Plan, but no discretion at all in determining whether to implement it. The Court prohibits the use of cost-saving strategies such as those used by the defendant regional centers. At the same time, the Court rules that this does not give regional centers the authority to overspend their budgets. If regional center budgets are not sufficient, DDS must inform the state Legislature which must, in turn, either increase funding or statutorily change the entitlement. This decision invalidates the emergency regulations issued by DDS to reduce categories of services.

**1985** In *City of Cleburne v. Cleburne Living Center*, the U.S. Supreme Court rules that localities cannot use zoning laws to prohibit a group home for people with developmental disabilities from opening in a residential area solely because its residents have disabilities. Legislation dealing with this issue was passed in California in 1970.

The annual budget for all regional centers is \$317,803,208. They serve 78,312 people at an average cost of \$4,058 per person.

In California, eight state hospitals house approximately 7,100 residents with developmental disabilities.



*"I realized very quickly after we got into this work that it was all well and good for us to spend all this time and energy, but if the family couldn't carry out what we intended for them then it was wasted."*

#### DR. RICHARD KOCH

An internationally-recognized expert on PKU (phenylketonuria), a metabolic disorder which causes mental retardation, Dr. Richard Koch stands on more than 50 years of continuous commitment to individuals with developmental disabilities. He was an early advocate in the fight to keep people out of institutions, provide support for families to keep children at home, and ensure community living options for adults.

In the 1950s, he served as director of the Clinic for the Study of Mental Retardation and then as director of the Traveling Child Development Project which provided assessment services and advice to parents with children with developmental disabilities in 15 Southern California communities. This clinic became a model for the regional center system.

In the early 60s, he was president of the California Council for Retarded Children, which became the Association for Retarded Citizens, California and of the American Association on Mental Retardation. During that time he advocated for the establishment of the regional center system. In 1966, he became the first director of Childrens Hospital of Los Angeles Regional Center.

In 1967, he became the principal investigator for the 16-year United States Collaborative Study of Children Treated for Phenylketonuria. Results of this study led to the adoption of the "diet for life" for treatment of PKU in the United States. In 1982, he became the principal investigator of the longitudinal International Maternal Phenylketonuria Collaborative Study which documented the development of the offspring of more than 400 women with PKU over a 20-year period.

He continues to serve metabolically-involved patients with a major emphasis on PKU. He was instrumental in the development of the Koch-Vagthol's Metabolic Residential Center which serves adults who previously resided in the developmental center, and who began receiving treatment for PKU later in their lives.

In 1997, he became the first person to receive the Dr. Albert L. Anderson Health Care Professional Award from the California State Council on Developmental Disabilities, in recognition of his compassion and contributions to the lives of people with developmental disabilities and their families.

# 1986 – 1995

*“Let the shameful wall of exclusion finally come tumbling down.”*

*President George H.W. Bush*

*On signing the Americans with Disabilities Act in 1990*



## During this decade...

Protections for the rights of people with disabilities continue to expand. The federal government amends and extends the Education for All Handicapped Children Act by mandating pre-school programs for 3 to 5-year-olds with a disability and early intervention services for at-risk infants and toddlers. During this era, the federal government also passes the Americans with Disabilities Act, a groundbreaking piece of legislation establishing in statute the civil rights of people with disabilities, prohibiting discrimination in employment, and mandating accessibility in transportation and other public accommodations.

In an act that will have serious negative effects on disability services as well as many other aspects of state governance, the citizens of California vote to impose term limits on their legislators. This action begins a process whereby the institutional memory of the struggle for the rights of people with disabilities decreases and the power of the lobbyists and legislative staff to influence legislation significantly increases. The action also creates a political environment in which officials become distracted from their responsibilities to their constituents by the need to identify and prepare a campaign for their next office.

The effort to de-populate state institutions is advanced greatly as the result of an out of court settlement in *Coffelt v. DDS et al.* The settlement results in an agreement that calls for movement of 2,000 residents, approximately 40 percent of the current institutional population, into the community within five years and prevention of future inappropriate admissions.

## Historical highlights...

**1986** Amendments (PL 99-457) to the Education for All Handicapped Children Act mandate pre-school programs for 3 to 5-year-olds with disabilities and planning for early intervention programs for at-risk infants and toddlers with disabilities and their families.

In California, eight state hospitals – Agnews, Camarillo, Lanterman, Fairview, Napa, Porterville, Sonoma and Stockton – serve approximately 6,900 people with developmental disabilities.

**1987** The strength of the self-advocacy movement increases, exemplified by the creation of “Partners in Policymaking” by the Minnesota Governor’s Council on Developmental Disabilities. “Partners” is a competency-based leadership training program for adults with disabilities and parents of young children with developmental disabilities. The purpose of the program is to teach best practices in disability and the competencies needed to influence public policy. “Partners” programs are eventually implemented in 46 states and internationally. By 2006, more than 13,000 “Partners” graduates are part of a national and international network of community leaders serving on policy-making committees, commissions and boards at all levels of government.

**1988** California is approved for participation in the federal Targeted Case Management Program, providing the state with federal funds to defray some of the costs of case management. It is a milestone in DDS’s efforts to shift funding responsibility for services from the state general fund to the federal Medicaid program.

The Technology Related Assistance for Individuals with Disabilities Act (PL 100-407) provides financial assistance for persons with disabilities to purchase assistive devices.

Fair housing amendments to the Civil Rights Act of 1968 extend the principle of equal housing opportunity to persons with disabilities.

**1989** The Omnibus Budget Reconciliation Act (PL 101-239) provides a work incentive that allows Social Security Disability Insurance (SSDI) recipients with disabilities who return to work to purchase Medicare coverage after they have exhausted the trial work period and the extended period of Medicare eligibility. The act requires the Medicaid program to pay the Medicare premium for SSDI recipients earning less than 200 percent of poverty level.

A California Senate Resolution (SR 9), authored by Senator Dan McCorquodale, results in statewide hearings that gather extensive testimony concerning the Lanterman Developmental Disabilities Services Act.

Westside Regional Center creates Home Ownership Made Easy (HOME), an independent non-profit housing corporation committed to purchasing and maintaining apartments, condos and houses for low-income adults with developmental disabilities. By 2006, HOME has purchased approximately 42 properties serving 175 residents with developmental disabilities.

**1990** The Americans with Disabilities Act (PL 101-336) establishes basic civil rights for persons with disabilities, barring discrimination in employment and requiring accessibility in transportation; public accommodations; and all government facilities, services and communications. Under the act, public areas such as stores and restaurants must make “reasonable accommodations” to ensure access by people with disabilities. It also requires companies offering telephone service to the general public to provide telecommunications devices to people with hearing impairments.



The Individuals with Disabilities Education Act (PL 101-476), known thereafter as IDEA, expands eligibility categories and required services under the Education for All Handicapped Children Act. The renaming of the act reflects use of the “person first” language and national use of the term “disability.”

Nationally, the number of people with developmental disabilities living in institutions serving this population falls to 85,000 from a peak of 195,000 in 1967.

By a 52 percent majority, Californians pass Proposition 130, an initiative addressing term limits for members of the California Senate and Assembly. The proposition limits members of the Assembly to three 2-year terms and senators to two 4-year terms. The loss of many long-serving legislators is accompanied by loss of in-depth knowledge of the disability services system. Another, unanticipated,

result is increased power to shape legislation among legislative staff members and lobbyists whose tenure often exceeds legislative terms.

Thirteen state developmental center residents and their families file a class action lawsuit against DDS and four regional centers, *William Coffelt, et al v. Department of Developmental Services, et al*, with the goal of ensuring that persons with developmental disabilities have access to quality, stable, individually-tailored and integrated community living arrangements of their choice. An out-of-court settlement in 1993 results in the adoption of the Community Living Options Initiative calling for movement of 2,000 persons from developmental centers into the community over five years, reduction of the population by more than one-third, prevention of future admissions except in the most difficult circumstances, and closure of institutions in Stockton and Camarillo. The \$334 million needed to fund the initiative is to come from an expansion of the Medicaid Waiver Program.

**1991** The state of New Hampshire closes Laconia State School and becomes the first state to provide all services to people with mental retardation in the community. By 2002, eight other states follow suit.

Denny Amundson, once an aide to Assemblyman Frank Lanterman, is named director of the Department of Developmental Services.

Owing to a nationwide recession, the state budget deficit exceeds \$1.5 billion. The regional centers are required to submit "expenditure" plans outlining how they will absorb significant budget reductions.

California is one of eight states chosen to receive a federal grant under the Community Supported Living Arrangements (CSLA) program. Seven regional centers are chosen to participate in the grant. Under the CSLA program, clients own, lease, or rent homes or apartments and receive the support services necessary for them to live independently in these settings. This is the first adequately-funded, formal initiative aimed at coordinating all of the support needs of people with developmental disabilities living on their own in the community. The demonstration program continues through September 1995 and subsequently becomes part of the federal Medicaid Waiver Program.



**1992** For the first time, public expenditures for community-based services for people with developmental disabilities in the United States surpass the cost of care in large institutions.

SB 1383 (McCorquodale) makes significant changes to the Lanterman Act, updating the philosophy and expanding the range of services and supports available to clients and families. The value statements embrace the concept of "empowerment," giving clients and families more choice and more authority to make decisions about their own lives. The amendments also state explicitly that the changes do not constitute an expansion of the entitlement, although they do have such an effect in coming years.

The budget situation in California worsens, with a deficit of almost \$11 billion. In response to the continuing financial crisis in the state, SB 485 is enacted to ensure access to services within the limits imposed by the budget. This act states in part: "The Legislature finds that the state faces an unprecedented fiscal crisis...In order to ensure that services to eligible clients are available throughout the contract period, regional centers shall administer their contracts within the level of funding available within the annual Budget Act...Regional centers shall implement innovative, cost-effective methods of service delivery..."

DDS establishes an Office of Consumer Affairs and Michael Long, a person with a developmental disability, is appointed to direct the office. Mr. Long is the first person with an intellectual disability to be appointed by any governor in the United States to such a high-level post.

DDS establishes Regional Resource Development Projects, joining developmental centers with the regional centers with which they share clients in an effort to promote the movement of developmental center residents into the community. Eventually, all seven developmental centers become involved in these projects requiring coordinated resource development and service planning.

**1993** After five years of planning, California implements the Federal Part H Early Intervention Program through SB 1085, the California Early Intervention Services Act. This program, called "California Early Start," provides statewide services for eligible infants and toddlers from birth to 36 months. It also authorizes the development of family resource centers in the community to provide information

and referral to families of children receiving early intervention services. Some of these resource centers are affiliated with regional centers, while some are free-standing.

**1994** The U.S. 9th Circuit Court of Appeals issues the final ruling in the case of *Sacramento City Unified School District v. Rachel H.*, reaffirming the rights of children with disabilities to attend public school classes alongside non-disabled children. The ruling is a major victory in the ongoing effort to ensure enforcement of the Individuals with Disabilities Education Act.

DDS enters into an agreement with the Department of Housing for a \$4 million bond issue targeted at affordable housing for people with developmental disabilities. Supported living opportunities are expanded across the state.

Harbor Regional Center creates Home Ownership for Personal Empowerment (HOPE), an independent non-profit housing corporation dedicated to the creation of stable, affordable housing options for people with developmental disabilities. By 2006, HOPE has purchased 30 properties serving 86 residents with developmental disabilities.

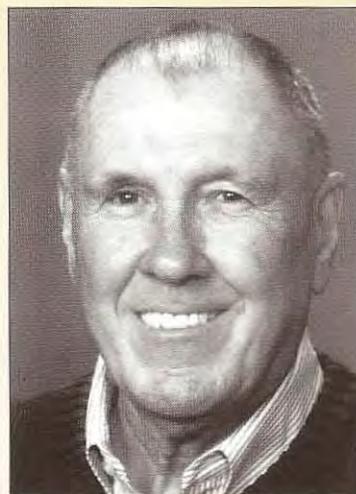


**1995** For the first time in the United States, people living in settings of six or fewer persons constitute a majority (51.8 percent) of people with developmental disabilities living in residential settings.

In California, seven state developmental centers serve approximately 5,100 persons. The decline in the developmental center population, from a high of more than 13,000 in 1966, results in several thousand empty beds across the seven existing campuses. Because of the inefficiencies and the cost of operating seven aging facilities, a plan is put in place to close some of these institutions. Stockton Developmental Center – the oldest such institution west of the Mississippi, first opened in 1851 – is set for closure. The Legislature unanimously approves the closure plan.

The annual budget for regional centers is \$941,515,000. The 21 centers serve 129,230 clients at an average cost of \$7,285 per person.

Nearly 60 percent of regional center support now comes from federal program funds.



*“People with developmental disabilities have a right to live, work and play in neighborhoods of their own choosing. It is our job to support their choices, not manage their lives.”*

#### DENNY AMUNDSON

Denny Amundson is a long-time leader and advocate in the field of developmental disabilities.

In 1968, he joined the staff of Assemblyman Frank Lanterman. As the Assemblyman's chief of staff, he helped draft the original Lanterman Act, as well as follow-up bills, including the Lanterman Developmental Disabilities Services Act, the California Master Plan for Special Education, the California Community Care Licensing Act, and the legislation prohibiting zoning discrimination against licensed homes serving six or fewer people with developmental disabilities.

In 1974, he became the first executive director of North Los Angeles County Regional Center. In the late 1970s, he returned to Sacramento to work as a management consultant in the human services arena with Arthur Bolton Associates.

In 1991, Governor Pete Wilson appointed Mr. Amundson as director of the Department of Developmental Services. He served in that position until 1997 and led the Department through a period of rapid transition. He was instrumental in the development of a person-centered planning process, performance-based contracting with regional centers, significantly increasing the amount of federal funding to expand the state's community-based system of care, and closing two state institutions.

After his departure from DDS, Mr. Amundson joined the Mentor Network, the nation's second largest human services provider. Today, he is mostly retired, but still provides occasional consulting services in the developmental disabilities field.

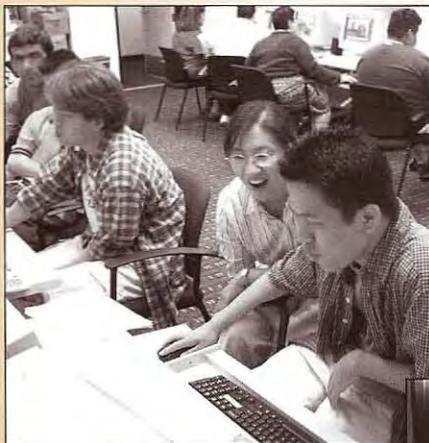
In 2002, he received the Community Imperative Pioneer Award for leaders who helped lay the foundation for California's community service system through securing passage of the Lanterman Developmental Disabilities Services Act.

# 1996 – 2005

*“Though progress has been made in the last decade, too many barriers remain. Too many Americans with disabilities remain trapped in bureaucracies of dependence and are denied the tools and access necessary for success... People with disabilities want to be employed, educated, participating, tax-paying citizens living in the community and contributing to the economic and social fabric of American life. And, in today’s global new economy, America must be able to draw on the talents and creativity of all its citizens.”*

*President George W. Bush*

*Announcing his “New Freedom Initiative”  
on February 1, 2001*



## During this decade...

The U.S. Supreme Court further advances deinstitutionalization and creation of community alternatives by holding that federal law prohibits unjustified isolation of people with disabilities in institutions. The court also supports the notion that a state can be required to fund community placements by moving resources from the institution to the community. President George W. Bush issues an executive order calling for swift implementation of this decision.

The federal government, through the Medicaid Waiver program, supports implementation of “self-directed services,” through which people with disabilities and their families are given an individual budget and responsibility to independently purchase services and supports as identified in their individual program plan. California implements pilot programs in five regional centers and signals its intent to expand this policy initiative in coming years.

For the first time ever in California, a governor is recalled. In the face of the biggest budget deficit in the state’s history, Governor Gray Davis loses his office to Arnold Schwarzenegger. The continuing fiscal crisis in the state is acutely felt by regional centers and many providers of community services. The controversy over the funding of community services becomes a major issue for regional centers, clients, families and advocates, and the state Legislature.

Twenty-five years after the first closure of a state institution, Stockton Developmental Center closes. A year later the institution in Camarillo also closes. State institutions continue to be cited for their failure to protect the health and welfare of their residents even after more than 40 years

of scrutiny, judicial orders to improve conditions, and success in moving many residents to the community. In the face of these conditions and of the clear mandate to de-populate institutions, a vocal group of parents supported by state employees within the institutions, resist further closings. While the state’s commitment to closure is

maintained, it becomes clear that the pace of moving people out of institutions and into the community will be unacceptably slow.

## Historical highlights...

**1996** Stockton Developmental Center closes. A satellite campus of California State University, Stanislaus, opens on this site the following year.

Napa State Hospital again starts serving people with developmental disabilities, after an eight-year hiatus.

Seven state hospitals – Agnews, Camarillo, Lanterman, Fairview, Napa, Porterville and Sonoma – serve a total of 4,500 people with developmental disabilities.

Two inmates with developmental disabilities incarcerated in the California prison system file a class action suit (*Clark v. State of California*) against the state, alleging that they have been discriminated against on the basis of their disability by not receiving adequate accommodations, protection and services necessary for them to adapt to prison. A settlement two years later establishes a Developmental Disability Program under which the Department of Corrections screens inmates for developmental disabilities and places identified inmates in designated institutions with staffing and programming to meet their needs.

**1997** The Individuals with Disabilities Education Act is reauthorized and includes a provision for the funding of Parent Training and Information Centers, funded by the Office of Special Education Programs of the U.S. Department of Education. The purpose of these centers is to provide technical assistance to parents of infants, children and young adults with disabilities, and professionals who work with their families. This assistance helps parents participate more effectively with professionals in meeting the educational needs of children and youth with disabilities.



Camarillo State Hospital and Developmental Center closes. The authorizing legislation passes by an overwhelming majority.

The net reduction of 2,000 persons from the state developmental centers, as specified in the Coffelt Settlement of 1993, is achieved one and one-half years ahead of schedule. This is a major achievement for regional centers.

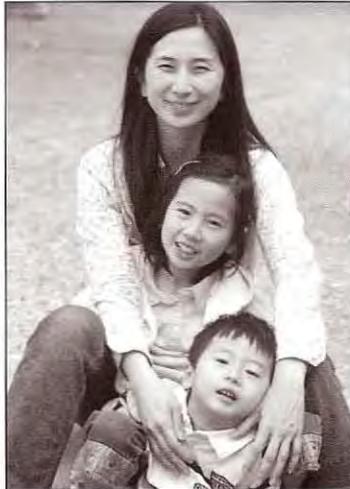
David Strauss and several colleagues release the “Strauss Report” that uses statistical analysis of a state database to argue that there is a higher rate of mortality among clients living in the community than among clients residing in developmental centers. While its methodology is questioned and its findings are never replicated, the study generates wide press coverage throughout California. The San Francisco Chronicle runs a series of articles presenting community-based services as a system in crisis because of underfunding and poorly qualified direct care staff, particularly in residential facilities. Regional centers are criticized for not ensuring the quality of services provided in the community.

Basing their argument on the “Strauss Report,” unions representing state employees and the California Association of State Hospital Parent Councils for the Retarded argue against additional closures of state developmental centers. As a result, Agnews State Developmental Center, scheduled to close, is removed from the closure list. Denny Amundson, the director of DDS, resigns in protest amid controversy.

Prompted by the “Strauss Report” and the accompanying controversy, Senator Mike Thompson conducts statewide hearings to solicit recommendations for improving community-based supports and services. Provisions in two subsequent bills, SB 1039 (Thompson) and SB 391 (Solis) are intended to ensure appropriate monitoring of people who move from state developmental centers into the community. Provisions include reinstatement of quarterly monitoring of clients living in residential care facilities; transfer of formal assessment of quality of life of people living in the community from regional centers to area boards; and movement of the position of client rights advocate from regional centers to Protection and Advocacy, Inc. (PAI).

PAI establishes the Office of Clients' Rights Advocacy, a semi-autonomous entity with an independent advisory council, to assume the advocacy function for people with developmental disabilities. Regional centers, however, retain the responsibility for advocacy as spelled out in the Lanterman Act, but are provided with no staff resources to carry out this responsibility.

The organization, Families for Early Autism Treatment (FEAT), is awarded a \$220,000 grant from DDS for Project HOPE, a program at UC Davis Medical Center to identify, treat, and ultimately find a cure for autism. In 1999, this program is renamed the M.I.N.D. (Medical Investigation of Neurodevelopmental Disorders) Institute and given additional financial support by the state of California. The mission of the institute encompasses research and clinical services designed to further understanding of the causes and development of effective diagnoses, treatments and prevention for autism, mental retardation, learning disorders, and other developmental and neurological disorders.



**1998** In yet another response to the "Strauss Report" and the subsequent publicity, the Health Care Financing Administration (HCFA) audits California's compliance with its Home and Community-Based Waiver Program, and issues a report critical of the state's community-based system of care. HCFA demands a number of reforms as a condition of California's continued participation in the waiver program, a program that brings almost \$450 million to the state annually.

An increase of \$207 million (17.7 percent) is provided for community services in the state's 1998-99 Budget Act. The budget increase includes funding for specific purposes, for example, to ensure that regional centers average a 1:62 service coordinator to client ratio, thereby enhancing their ability to protect the health and safety of clients. Nonetheless,



regional centers remain significantly underfunded in all other areas of staffing and operations.

Throughout the state, local stakeholder groups review the developmental services system and make recommendations for change. Resulting bills, SB 1038 (Thompson) and AB 2780 (Gallegos), address issues concerning structural and rate reforms for community-based services. These pieces of legislation, referred to collectively as "system reform," are aimed at developing equitable and cost-effective rates based on performance and achievement of client outcomes for residential, supported living, day program and respite services. Three principal work groups focus on personnel standards, performance accountability and quality assurance, and rates and budget. While significant changes to the Lanterman Act follow, there is no attempt to deal with the long-term inadequacies and inequities in the rate system.

One provision of SB 1038 calls for the implementation of self-determination pilot projects. Under these projects, clients and families are allotted an individual budget based on what the regional center spent on them in prior years. They are permitted to make their own decisions about how this money should be spent based on the content of the IPP. They also are asked to assume some responsibility for negotiating service arrangements and rates and for paying service providers. Self-determination pilot projects are established in three California regional centers: Redwood Coast, Tri-Counties and Eastern Los Angeles. Soon thereafter, Kern and San Diego Regional Centers join the pilot program.

Citygate Associates conducts an independent evaluation of community placement practices. It is primarily intended to allow judgments about the success of the program aimed at moving

developmental center residents into the community as required by the Coffelt Settlement. Among the findings are that people moving into the community have a better quality of life than people remaining in developmental centers, and the mortality rate for people in the community is lower than that for people remaining in institutions. This latter finding directly contradicts the main conclusion of the 1997 "Strauss Report."

A study of the buildings and infrastructure of the five remaining developmental centers by Vanir Engineering Corporation yields the conclusion that repair or replacement of the facilities would cost between \$800 million and \$1.5 billion.

Lanterman, Harbor and Golden Gate Regional Centers partner with the University of Southern California School of Cinema-Television to produce "We're Here to Speak For Justice," an hour-long documentary film telling the story of the development of the regional center system in California. The film, produced and directed by award-winning Filmmaker Theodore Braun, is shown on public television stations KCET in Los Angeles and KQED in San Francisco. The film and a companion book of the same name introduce the pioneering family members, legislators and professionals of California whose courage, commitment and vision led to the development of the community-based system of services for people with developmental disabilities.



**1999** In *Olmstead v. L.C.*, the U.S. Supreme Court holds that the Americans with Disabilities Act prohibits "unjustified isolation" in institutions. According to the Court, institutional placement is "unjustified" when the state's treating professionals have determined that community placement is appropriate for a person, when the person does not oppose community placement, and when the placement can be reasonably accommodated considering the state's resources and the needs of others with disabilities. In this decision, the Court also supports the notion that a state may be required to fund community placements by moving resources from institutions to the community

A report by the Bureau of State Audits required by the 1997-98 Budget Act concludes that the budget and allocation process used by DDS to fund regional

centers does not ensure that clients throughout the state have equal access to needed services. The audit finds that DDS is not ensuring that regional centers are properly staffed and that their clients have equal access to case managers. The report concludes that the success of the system has been undermined by insufficient state funding and more than \$106 million in budget cuts over a four-year period.

The state recognizes that the budget methodology that has been used for years to fund regional center staff and operations is outmoded. Citygate Associates is commissioned to conduct a legislatively-mandated study of the budgeting methodology for funding regional center staff and operating expenses at a level that enables the centers to meet their state and federal mandates, and be consistent with good business and professional practices. A conclusion of the report is that the regional center system is dramatically underfunded for what they are legislatively and contractually required to do. No action is ever taken on the Citygate study.

A report released by DDS shows that there are no significant differences between the type and severity of disabilities of people living in developmental centers and those living in the community.

**2000** PL 106-448 allows the U.S. Attorney General to waive the requirement that naturalization applicants take an oath of allegiance if the applicant is unable to understand or to communicate an understanding of the law's meaning because of a physical or developmental disability or a mental impairment.



In a time of unprecedented state and federal budget surplus, the regional center system is in crisis. While the

late 1990s saw an increase in regional center funding for specific purposes, such as decreasing the caseload ratio, the cuts imposed on regional centers in the early 1990s were never restored. Regional centers are overwhelmed with unfunded mandates and rising expectations of clients and their families. A November 2000 survey of regional centers finds that virtually all centers cite their inability to hire and retain an adequate number of service coordinators and other key positions as their chief operational

problem. In addition, the purchase of service budget is a closed-ended allocation intended to fund an open-ended entitlement that expands with the increasing expectations of clients and families.

Anticipating the apparent closure of state developmental centers, the FY 2001-02 Budget Act mandates that DDS prepare a report by March 1, 2001 on "a range of options to meet the future need of individuals currently served, or who will need services similar to those provided, in state developmental centers." DDS is to examine various options in conjunction with a work group of stakeholders, and evaluate options for "appropriateness in meeting clients' needs, compliance with federal and state laws, and efficient use of state and federal funds."

DDS creates an advisory committee to help determine the future of state developmental centers and clients who reside in them. This group makes five recommendations, including: 1) no capital outlays to rebuild developmental centers; 2) homes in the community no larger than four residents; 3) put developmental center resources to work in the community; 4) leverage developmental center land to create new resources; and 5) conduct individualized personal assessments and resource development for people moving to the community. The committee's recommendations are used as the basis for conducting surveys and focus groups of stakeholders.

Based on the work of the advisory group, DDS commissions a survey of stakeholder groups regarding their opinions relative to options for developmental centers. The data-gathering activities result in strong and heated reactions from stakeholders. While there is significant support for a unified service system in the community, families of developmental center residents demand guarantees that their relatives will be safe if moved to the community. They believe this can be ensured by having state-controlled community residential facilities operated by staff from the developmental centers.

In *The case of Richard S.*, a settlement agreement in a federal lawsuit brought in California mandates that third parties – parents, guardians or conservators – may not waive a developmental center resident's right to move to the community, although their objections must be heard. A permanent injunction is

issued against the DDS policy that allows family members or conservators to "veto" community placement from a developmental center, when such a move is deemed to be appropriate for the client.

DDS initiates the development of the California Developmental Disabilities Information System (CADDIS), a multi-million dollar information system intended to handle client and financial information for the entire developmental disabilities service system. It is intended to automate many key service coordination and accounting functions so that, among other things, California can more effectively and efficiently claim federal Medicaid dollars. By 2006, the system is seriously over budget and behind schedule, and is expected to require millions of additional dollars of investment before it can be made adequately functional.

DDS leases Sierra Vista and Canyon Springs, two 50 to 60 bed institutions to house people with developmental disabilities. These facilities, previously private psychiatric hospitals, are intended to serve the growing population of people with significant behavioral and forensic needs who are the most likely to be seen as requiring the level of services offered by developmental centers.

This is the last year that Napa Developmental Center serves people with developmental disabilities. Beginning in 2001, it serves only people with mental illness.

**2001** In *Sanchez v. Johnson*, seven people with developmental disabilities, their families, and six organizations file suit in federal court against the state of California on behalf of people living in developmental centers and others who are denied access to high quality, community-based services. They charge that chronic underfunding of community services and supports denies citizens with developmental disabilities their civil right to appropriate treatment in the least restrictive environment.

Two years later, the court finds for the defendants, saying that Medi-Cal recipients do not have the right to take legal action against the state to enforce equal access and quality of care provisions under the federal Medicaid laws, and that California is operating an "acceptable deinstitutionalization plan" for approximately 200,000 people being served under the state's Lanterman Developmental Disabilities Services Act.



The plaintiffs appeal the decision in 2004 and the 9th Circuit Court of Appeals upholds the decision in 2005.

Assemblywoman Dion Aroner puts forth a concept paper for legislation aimed at unifying the developmental disabilities system, rather than maintaining the current state/community division. Her legislation would unify the budget and resources of developmental services, close the five state developmental centers, apply the same personal outcome and quality standards to all programs, develop personnel standards for all workers in the system, and establish a uniform rate system. Art Bolton, who was instrumental in the original design of regional centers, comes out of retirement to assist Assemblywoman Aroner in the development of this legislation, AB 896. A year later the bill is modified and the provision calling for the closure of the developmental centers is removed. The bill dies in the Senate Appropriations Committee without a hearing.



Welfare and Institutions Code 4791 is

allowed to "sunset." This statute resulted from SB 485, passed in 1992, requiring regional centers to administer their contracts within the reduced level of funding available in the budget of that year. It also requires regional centers to "take into account... the family's responsibility for providing similar services to a child without disabilities" when identifying a minor's service needs.

President George W. Bush announces his "New Freedom Initiative," a series of proposals intended to help "ensure that all Americans with disabilities have the tools to use their skills, and make more of their own choices. [This] initiative will increase investment in and access to assistive technologies and a quality

education, and help integrate Americans with disabilities into the work force and into community life." At the same time, President Bush issues an Executive Order calling for swift implementation of the *Olmstead* decision (1999). In response, the Department of Health and Human Services (HHS) develops a comprehensive policy framework to guide and coordinate the activities of the multiple HHS components involved in supporting community living for people with disabilities. The agency also establishes an Office on Disability and Community Integration to oversee implementation of HHS-wide policy and activities concerning community supports.

The annual budget for all regional centers is \$1,877,800,000. They serve 162,970 clients at an average cost of \$11,522 per person.

Approximately 3,800 persons reside within six state developmental centers.

**2002** In September – following a two-month impasse in the Legislature – Governor Gray Davis signs a state budget that reflects an unprecedented deficit of \$23.6 billion, to be dealt with through a combined series of funding cuts, tax increases, and one-time loans, transfers and fund shifts. The projected deficit for the following year is put at \$21.1 billion, with continuing deficits of \$12 to \$16 billion expected until 2007-08.

Seventeen people become plaintiffs in *Capitol People First, et al v. the Department of Developmental Services, et al*, a class action lawsuit seeking freedom for Californians with developmental disabilities from unnecessary isolation and segregation in institutions and access to the services they

need to live in residential neighborhoods and participate as members of the community. The class represented includes both people with developmental disabilities living in large public and private institutions, and people living in the community but at risk for placement in an institution due to the lack of appropriate community



supports. In 2005, the court refuses to certify the suit as a class action.



*"It soon became apparent that the issue was not how we were going to fix the hospitals, but how we were going to create alternatives to hospitals in the community."*

#### ART BOLTON

While known as a lifelong advocate for people with developmental disabilities and as a major force behind the creation of the Lanterman Act, throughout his career Art Bolton was also involved in the development of legislation and innovative service models intended to improve the lives of people with serious mental illness.

As the first chief of the California Assembly Office of Research, he worked closely with Frank Lanterman in a bipartisan manner and drafted the original language for AB 691, the legislation that established the two pilot regional centers. He was subsequently involved in drafting AB 225, the Lanterman Mental Retardation Services Act of 1969, as well as major amendments to the Act in the 1970s and 1980s.

During the 1960s, he also directed a staff effort to restrict commitment of mentally ill individuals to state institutions. This effort culminated in passage of the Lanterman-Petris-Short Act in 1967. During these years he also worked tirelessly to establish effective community services for people with serious mental illness.

Between 1970 and 1978, as president of Arthur Bolton Associates, a public policy consulting firm, he worked with the federal and state governments on the creation of policy and systems for people with disabilities based on the concepts developed in California.

In the 1980s, as staff director of the Lieutenant Governor's Task Force on the Serious Mentally Ill, he participated in the development of a model community-based service program for people with serious mental illness. This group established integrated service agencies that could provide a comprehensive mix of treatment and rehabilitation services, as well as housing and housing support.

In the 1990s, Mr. Bolton was involved in an initiative to create better neighborhoods in low income areas. The model called for all human services to be consolidated under one roof in the neighborhood, and to be run by neighborhood residents.

In 2002, Mr. Bolton was given the first Community Imperative Lifetime Achievement Award for his original and continuous leadership in promoting community services for everyone.

DDS submits to the Legislature an evaluation of the self-determination pilot projects. The Department recommends that the pilots be extended to January 2004 without "expansion within the existing projects or to other catchment areas" and also raises questions about several aspects of self-determination as implemented in California. These questions relate to: how individual budgets are established in context of the entitlement guaranteed by the Lanterman Act, what is "reasonably related" to an IPP objective, the effect of the model on service coordinator workload, and the legality of using individual budgets to purchase services that are the responsibility of a public agency. In 2003, despite unanswered questions, the pilots in the five regional centers are made permanent.

**2003** Dissatisfaction with the economic situation in California and the administration of Governor Davis leads to a special election aimed at recalling a governor for the first time in California's history. Governor Davis is defeated in the election by actor and bodybuilder Arnold Schwarzenegger.

The state of California is in the midst of a severe recession, one of the worst in the state's history. In response to budget challenges, newly-elected Governor Schwarzenegger proposes mid-year budget cuts that include enrollment caps at regional centers, which would result in waiting lists; the elimination of "non-core" services, such as respite and non-medical therapies; and the development of statewide service standards guiding the purchase of services. Public protests by clients and advocates result in a withdrawal of the proposals.

The 2003-04 Governor's Budget directs DDS to again put forth a plan to close Agnews Developmental Center by July 2005.

The Legislature passes AB 1762, changing the eligibility criterion for regional center services to significant functional limitations in three or more areas of major life activity. The previous criterion had been limitations in at least two areas.

Frank D. Lanterman Regional Center launches the *Perspectives* International Film Festival and Forum promoting the understanding and inclusion of people with developmental disabilities. Filmmakers from the United States and overseas gather at the ArcLight Cinema in Hollywood to screen their films and talk with audiences about developmental disabilities. The first *Perspectives* Media Award is presented to Actor William H. Macy for his role in "Door to Door" and subsequent work with United Cerebral Palsy.



The regional center population rate of growth is increasing significantly faster than the rate of growth of the population in California, and the incidence of autism in the state is increasing even more rapidly. In the decade from December 1993 to December 2003, the population of the state increases by slightly more than 10 percent while the regional center population increases by 60 percent. During this same period, the number of people being served by regional centers and diagnosed with autism increases by 360 percent.

The five state developmental centers house 3,529 residents at a cost per year per person of \$205,316.

**2004** The closure of Agnews Developmental Center is delayed from July 2005 to July 2006. The following year's budget delays the closing an additional 12 months, to July 2007.

The Legislature approves a budget with a deficit of \$15 billion. Continuing substantial deficits are projected for 2005-06 (\$7 billion) and 2006-07 (\$10 billion).

The average cost of providing services to a regional center client is \$13,400, equating to a 16 percent increase in three years.

The Legislature enacts the Family Cost Participation Program, requiring families of minors living at home to share the cost of certain services purchased by regional centers. These cost-sharing requirements apply to respite, day care and camp. The law becomes effective January 1, 2005.



**2005** Congress passes a law creating a new Medicare benefit – Medicare Part D, prescription drug coverage. As a consequence, regional center clients whose medical care is covered by both Medicare and Medi-Cal, with Medi-Cal paying for medications, henceforth have their medications covered by Medicare. The implementation of Medicare Part D, beginning January 1, 2006, is disorganized and fraught with confusion, due primarily to the federal government's failure to ensure that the necessary enrollment information systems are in place and accessible to state health departments, health plans and pharmacies. As a result, many beneficiaries, particularly people covered by Medicaid, including a majority of regional center clients, are unable to obtain medications or are asked to pay substantial co-payments. Many states, including California authorize emergency funding to guarantee payment to pharmacists and health plans.

In the case of *Schaffer v. Weast*, the U.S. Supreme Court rules that parents who challenge a school district's program for their child with a disability have the burden of proving the program is not appropriate. Since IDEA does not say who bears the burden of proof when parents disagree with a school system about their child's educational program, the court reasons that the burden should lie "where it usually falls, upon the party seeking relief." Further, they reason, that party will most often – but not always – be the parents. This decision is expected to make it harder for some parents to win lawsuits that seek compensation for the cost of sending their child with a disability to a private school.

The People First organization in California grows to 85 chapters throughout the state.

The 21 Regional Centers serve more than 200,000 children and adults with developmental disabilities at an annual cost of nearly \$3 billion.

Five developmental centers serve somewhat more than 3,000 people.

An additional approximately 90 people are served in the two smaller institutions serving people with significant behavioral and forensic needs.

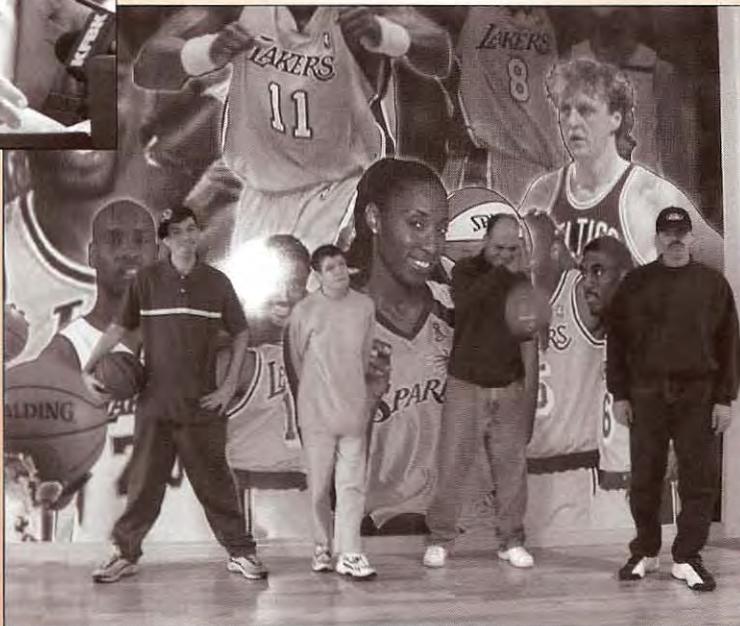
## 2006 —

*“Resolved by the Senate of the state of California, the Assembly thereof concurring, That the Legislature hereby proclaims the year of 2006 as the ‘Year of the Community’ and the beginning of a decade of renewed commitment to the vision of the Lanterman Act and investment in the community service system; and be it further*

*Resolved, That the Legislature will actively promote the rights of people with developmental disabilities and their full inclusion into community life in California.”*

*Senate Concurrent Resolution*

*No. 115 – Relative to “Year of the Community,” 2006*



As this decade begins, the California Legislature marks a renewal of its commitment to the community service system through unanimous passage of a Senate concurrent resolution. The Legislature also provides a small and long-awaited increase in rates for service providers, with additional financial incentives for day programs and workshops that agree to move to community-based day services and supported employment, respectively. Regional centers, however, face their 16th year without a cost-of-living increase. Expansion of the self-determination model brings increasing demand for services that are individualized and integrated.

The two pilot regional centers, Frank D. Lanterman Regional Center in Los Angeles and Golden Gate Regional Center in San Francisco, celebrate 40 years as partners in lifelong support for people with developmental disabilities.

The maturity of the service system is reflected in significant milestones for several major parent-run organizations that were early community partners for regional centers. Villa Esperanza in Pasadena celebrates its 45th anniversary, The ARC of San Francisco (previously San Francisco Association for Retarded Children) marks its 55th anniversary, ECF of Los Angeles (previously the Exceptional Children’s Foundation) celebrates its 60th year of service to people with developmental disabilities, as did UCP (United Cerebral Palsy) the previous year.

Progress in including people with developmental disabilities in community life is reflected in the use by clients and families of community-based organizations used by the general public. These include organizations such as typical day care programs, the YMCA/YWCA and community technology centers. To facilitate clients and families in the purchase of services from these organizations, regional centers make increased use of parent vouchers and stipends.

The state’s Community Placement Plan continues its success in providing opportunities for people with developmental disabilities to leave developmental centers and move into the community. At the same time, the California Association of State Hospital Parent Councils for the Retarded (CASH PCR) advocates for developmental centers to remain a residential option for people with developmental disabilities.

**2006** The California Legislature approves a long-awaited across-the-board increase in rates for selected service providers. While supported employment programs receive a 24 percent increase, most programs receive only a 3 percent increase. This signals an acknowledgement of the chronic underfunding of the community service system and offers some hope to families and advocates who have witnessed more than a decade of deterioration in facilities, high staff turnover, and program instability. The Legislature provides additional financial incentives for day programs that move toward community-based day activities and workshops that move toward supported employment.

The Legislature re-institutes start-up funding for new program development following a four-year period during which no such funding was available except for moving developmental center residents to the community.

The California Senate issues a concurrent resolution (SCR 115, Chesbro) reaffirming the Legislature's commitment to the system of community services for people with developmental disabilities.

DDS issues regulations signaling its intent to apply for an Independence Plus Waiver under the Federal Medicaid program. This voluntary program of "self-directed services"

would provide participating regional center clients with their own individual budgets to choose or even create many of their own services in exchange for certain limitations, including an overall cap on how much money they would receive from the state. This model of self-directed services is an evolution of a "self-determination" pilot project implemented in five regional centers beginning in 1998. Because the Independence Plus Waiver program does not allow funds to be used for the purchase of segregated services, its implementation is expected to increase significantly the demand for integrated community-based services.

Two major issues that will continue to dominate the regional center system in coming years are affordable housing and employment for people with developmental disabilities. Statewide, for the last decade, the number of adults in supported or competitive employment has been essentially flat. At the same time,

the lack of affordable housing in safe neighborhoods has made it increasingly difficult for people with developmental disabilities to live on their own in the community.

More than 210,000 people are served by 21 regional centers at an annual cost of \$3.2 billion. Fewer than 3,000 people still reside in the five state developmental centers.



# Leadership

## Community Ownership and Local Control

A foundational tenet of the Lanterman Act is local control. As the system has matured and become more complex, the locus of control has gradually shifted from the community to the state. If we continue to believe that communities are better able than a government bureaucracy to determine what services best meet the needs of their families, we must renew our commitment to an active form of community ownership of the regional center. As part of this commitment, we must not only resist the drift toward centralized control, but also reaffirm the capacity of communities to govern their regional centers in ways that are responsive to local needs and sensitive to the diverse nature of our communities.

## Social Acceptance and Full Inclusion

In the past 40 years, we have made significant progress toward integration of individuals with developmental disabilities into education, employment and community life. The circle of inclusion continues to widen, but social acceptance and full inclusion remain ideals. Employment and housing are particular challenges for adults. To the extent that people who desire real jobs and affordable homes in safe neighborhoods have no access to these, their dreams of acceptance and inclusion remain unrealized. For children, underfunding of special education combined with recent court decisions interpreting the Individuals with Disabilities Education Act raise the question of whether the promise of full inclusion of children in the public schools will be realized. We must work to ensure that full inclusion is achievable by all who want it, while also recognizing that it may not be the best or the chosen option for all people in all situations. We should, therefore, support the development of services that are individualized, meaningful and of high quality for people with disabilities, regardless of the lifestyle they choose.



## Building Strategic Alliances

Since its passage, the Lanterman Act has brought about consistent growth and improvement in the network of organizations and individuals dedicated to serving people with developmental disabilities and their families in the community. What we have been less successful at is building capacity within community organizations that will enable them to independently support people with disabilities. Such capacity building would greatly facilitate true inclusion, wherein a person with a disability becomes just like any other user of a community resource. To achieve this, regional centers must do a better job of educating the community about regional centers and the people we serve. We must also form strategic alliances with

organizations used by the community-at-large and help them develop the competence they need to support and serve people with developmental disabilities just as they do the rest of their user population.

## Funding of Regional Centers and Community Services

For nearly 20 years, regional centers and some community service providers – particularly those providing services to adults – have experienced inadequate funding, with the small increases that have been granted failing to keep pace with the real cost of doing business. Inadequate funding has prevented many service providers from hiring and keeping qualified staff, and maintaining the facilities and equipment necessary to

provide quality services and ensure continuity for clients and families. In the face of these challenges, some providers have chosen to leave the field. At the same time, rates for some specific categories of services such as therapies and behavioral interventions more accurately reflect the cost of doing business. This disparity in funding has resulted in a fundamental inequity that must be addressed if the system is to fulfill its promise to all people with developmental disabilities.



### Meeting the Needs of Special Populations

Over the next decade, the regional center system will be faced with increasing pressure to meet the needs of special populations. For example, many people with developmental disabilities are outliving their parents. Regional centers must ensure the availability of

services that are appropriate for an aging population. We must also assure families that their relatives will be safe and secure in the community. The increasing population of children diagnosed with autism is testing the capacity of the community service system to provide sufficient access to appropriate services. Further, as these children age, there will be even greater pressure on the system to create and deliver the kinds of services and supports that will meet their unique needs throughout the lifespan.

### Sustaining the Entitlement

The entitlement to services is fundamental, but with entitlement come corresponding responsibilities of stewardship of public funds and accountability – to ensure that funds are expended wisely. Regional centers, service providers, clients and families must all share in this commitment to accountability. As we move increasingly toward greater self-direction, it is particularly important that people with disabilities and their families be informed purchasers of services and supports. The regional center must help them acquire the knowledge and tools they need to evaluate quality, cost and benefit to help ensure that services and supports purchased with public funds are both cost-effective and result in desired outcomes.

### Innovation and Change

The regional center system has matured and evolved to reflect changes in what society believes is right and just for people with disabilities. Our independence, strong community base, and attention to advances in technology and information give us the ability to innovate and adapt our service models so they remain relevant to the changing needs of the people we serve. We must remain attentive to changes in social policy, societal values, and information and technology that can help us advance our mission. At the same time, we must engage in “due diligence” to



ensure that innovations and new technologies meet the test of cost-effectiveness while delivering results for people. To this end, the regional center system must develop or acquire the capabilities to validly assess new services and support strategies, and determine their value to our clients.

### Decreasing Capability of Generic Services

The public health and social programs most often utilized by people with developmental disabilities have endured chronic underfunding, often to a greater extent than regional centers. These funding shortfalls have created serious problems in both access and quality. While regional centers may step in to supplement services when public programs fail to meet the need, we too are challenged to find and maintain an adequate network of service providers who are both competent and willing to work with people with developmental disabilities.

### Continuity of Experienced Leadership

Regional centers must develop a new generation of leaders possessing the vision and commitment necessary to take us into the future. We can no longer look to the pioneers to lead us. The parents and other leaders whose efforts brought about the creation of the regional center system have retired or passed on. A great many parents currently in the system have never known a time when there was no Lanterman Act and no community service system. Consequently, they do not share the sense of urgency felt by earlier parents who had no options for their child other than a state institution. Further, term limits have resulted in a loss of institutional memory within the state Legislature and virtually eliminated the likelihood that people with developmental disabilities will ever again have a champion like Assemblyman Frank Lanterman. New leaders must rise from within the community and build on the foundation laid by the courage and persistence of those who have gone before. To achieve this end, we need to return to the volunteerism and advocacy that characterized our beginnings.



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Golden Gate Regional Center  
*-serving people with developmental disabilities since 1966*



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*We are indebted to Sharon Shueman for her thorough research and informative writing in authoring this comprehensive booklet of the History of the Regional Centers in California.*

Sharon Shueman is a principal in Shueman Troy Associates, a Pasadena, California firm providing consultation in health and disability services. She received her doctorate in psychology from the University of Maryland.

Dr. Shueman began her work in developmental services as a consultant to the Regional Center of Orange County in 1984. Since that time she has worked with many California regional centers as well as with disability services providers and the Department of Developmental Services. She continues her work in behavioral health services as a surveyor for the National Committee on Quality Assurance. She has co-authored two monographs on managed behavioral health services and published more than two dozen articles and book chapters.

### Special thanks to:

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### We wish to thank the following organizations for contributing photos:

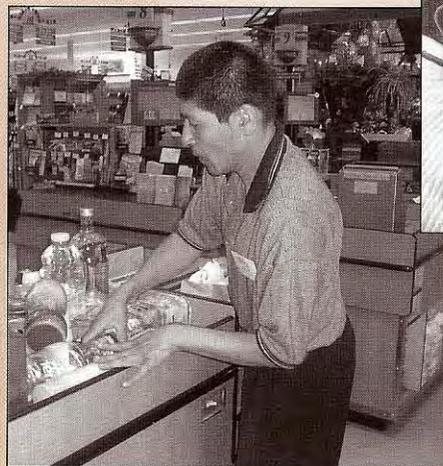
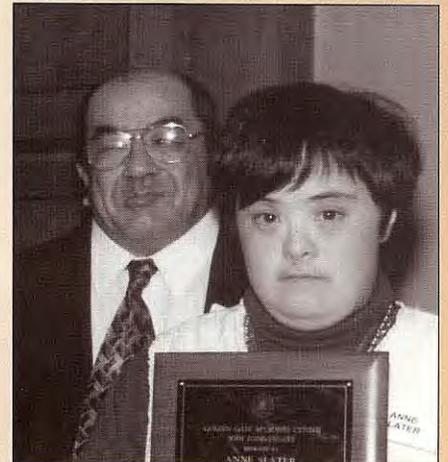
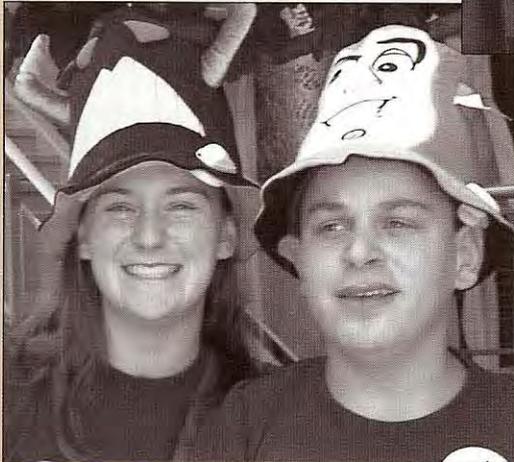
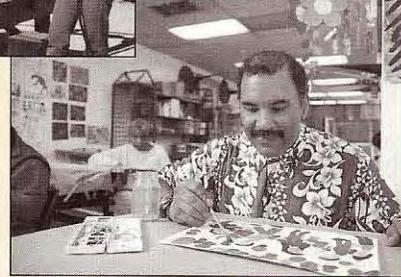
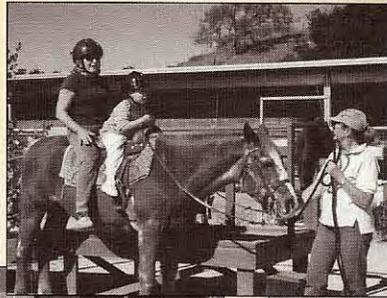
Association of Regional Center Agencies  
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Perspectives Film Festival  
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The clients, families, service providers and staff of Frank D. Lanterman Regional Center

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