



# HISTORY OF DEVELOPMENTAL SERVICES



**FORTY YEARS AGO**, the regional center system was created through the efforts of a dedicated and determined group of parents, advocates, and elected officials, most notably visionary California Assemblyman Frank D. Lanterman. In this booklet we take the opportunity to look back on the significant events occurring in California, as well as nationally, that preceded the development of regional centers and nurtured their growth. We focus on the achievements that have resulted in ever-expanding opportunities for people with developmental disabilities and their families to live full, productive and satisfying lives as active members of their communities. And finally, we reflect on the challenges that still must be addressed if we are to ensure that the vision of Frank D. Lanterman is realized.



*“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

# OUR VISION

*Children with developmental disabilities live with families in typical communities. They attend neighborhood schools and play with neighborhood friends. Adults with developmental disabilities live in the residence of their choice – with their families, with friends, or on their own.*

*They engage in a variety of activities of their choice – work, volunteering, education, or socializing. They have meaningful relationships with friends and co-workers. They are seen as valuable, contributing members of their communities.*

*Families are respected and supported, and are in control of their lives with respect to parenting their child with special needs. They are seen as capable, competent decision-makers and as major sources of support for their children.*

*Harbor Regional Center assures that families receive early, consistent, culturally sensitive support to assist in promoting family stability and security.*

*The Center has a major role in providing information, explanation, education, and training which allows families to increase their knowledge base, to make competent choices, to exercise increased responsibility, and to emerge more in control of their lives.*

*Harbor Regional Center builds and maintains strong partnerships with clients and families to ensure a service delivery system that is flexible, accessible, responsive, and community-based.*

*Clients and family members take a leadership role in the governance of the service delivery and demonstrate responsibility in ensuring its success.*

Harbor Regional Center

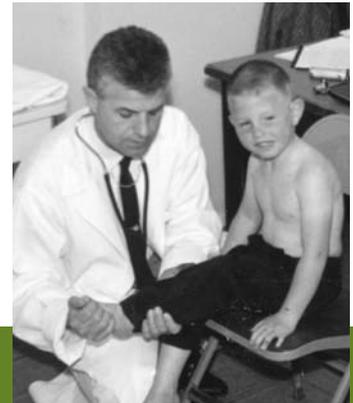
# 1955

**1955** In 1955, California had five state hospitals that served 8,500 people with mental retardation. Some of these institutions also served people with serious mental illness.

Over the next 45 years the number of these institutions changed frequently, with the number reaching as high as nine.

At this time, the state supported virtually no community-based services for the vast majority of people with mental retardation – those living with their families. A few services existed in some communities under the auspices of parent-run organizations such as the Association for Retarded Citizens, but these services came nowhere near meeting the need.

**1959** Fairview State Hospital opened in Orange County to serve people with developmental disabilities. Fairview was the last state institution to be built in California.



**1961** President John Kennedy took a special interest in people with mental retardation because he had a sister with this disability. He appointed a President's Panel on Mental Retardation and charged them with the

development of a National Plan to Combat Mental Retardation. He made a public commitment to implement a plan to improve services to people with mental retardation, stating 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...."



**1962** The President's Panel submitted its report calling for an expansion of community-based services for people with mental retardation and a reduction in the number of persons living in large institutions.

**1963** The number of Californians with mental retardation being served in six state hospitals reached 12,700 and many more people were on the waiting list to enter one of these hospitals.

*"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



Vivian Walter, the mother of a child with mental retardation and Chair of Mental Hygiene for the California Council for Retarded Children, paid a surprise visit to a state hospital, taking with her a reporter for the Orange County Register. They found terrible conditions there and the reporter published an article about what he saw. The public outrage that followed led to a series of legislative hearings and investigations that resulted in efforts to improve the conditions in these hospitals and eventually to provide more services to people with mental retardation in the community.

**1964** Despite the publicity about the terrible conditions in the state hospitals, many families were unable to support their disabled sons and daughters at home and had no alternative to the state hospital. Consequently,

the number of people with mental retardation in these institutions increased to 13,000 and an additional 3,000 people remained on the waiting list for admission. The Director of the Department of Mental Hygiene (the department that managed these hospitals) asked the state legislature for \$47 million to build additional hospitals to accommodate the people on the waiting list.



**1965** The controversy and outrage surrounding the state hospitals caused the Subcommittee on Mental Health of the Assembly Interim Committee on Ways and Means to hold additional hearings. This bipartisan



subcommittee was chaired by Assembly Majority Leader Jerome Waldie (D) and also included Clair Burgener (R), Frank D. Lanterman (R), and Nicholas Petris (D). The subcommittee report, *Undeveloped Resource: A Plan for the Mentally Retarded of California*, called for the state to accept responsibility for persons with mental retardation prior to state hospital admission through regional community-based centers that provided “diagnosis, counseling, and continuing services.”

In response to the report *Undeveloped Resource*, Jerome Waldie and Frank Lanterman co-authored Assembly Bill 691 that called 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. It was signed into law by Governor Pat Brown. The bill established two pilot “regional centers,” designed to call attention to the unmet needs of people with mental retardation, facilitate the development of services for these people in the community, maintain records, and provide diagnosis and follow-up. They were also given the responsibility of helping people who live in state hospitals move into the community.

Also in 1965, the U.S. Congress amended the Social Security Act (PL 89-98) to establish the Medicare and Medicaid (Medi-Cal) programs and to provide public funding for care of people with mental retardation and other serious disabilities.

**1966** A President’s Committee on Mental Retardation was established on May 11, 1966 by an Executive Order of Lyndon Johnson. The Committee was charged with advising the President and the Secretary of The Department of Health, Education, and Welfare on issues concerning citizens with mental retardation, coordinating activities across federal agencies, and evaluating the impact of government policies on the lives of people with mental retardation and their families.



In the same year in California the two pilot regional centers opened their doors in January. The State Department of Public Health negotiated contracts with Childrens Hospital of Los Angeles (serving Los Angeles County) and San Francisco Aid for Retarded Children (serving Alameda, Contra Costa, Marin, San Francisco, and San Mateo counties) to establish these centers. The two organizations were responsible for contacting people on the waiting list for admission to state hospitals, providing diagnostic assessments, and making recommendations for services that could be provided in the community. Most of the \$966,386 budget was intended to support operations, but a small amount was available to purchase services. During the first year, the two centers served a total of 559 clients at an average cost of \$1,728 per person.



**1967** Neils Bank-Mikkelsen, an international expert in the field of mental retardation and Director of the Danish National Services for the Mentally Retarded, attended a conference in San Francisco. While in California he

*“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.”*

visited Sonoma State Hospital where he found its residents living in deplorable conditions, such as overcrowded wards with naked men and women lying on the floor in their own excrement. He publicly chastised the state, saying, among other things, “In Denmark, we treat our cattle better than that.” His statements caused a public outcry in California and resulted in Assemblyman Lanterman’s call for yet another investigation into the state hospital system.

**1968** The San Francisco Aid for Retarded Children won a legal judgment against the state that required Governor Reagan to appoint an outside group of experts to investigate conditions at Sonoma State Hospital. The team included Gunnar Dybwad, a Professor at Brandeis University and national expert on mental retardation; Richard Koch, a physician from the University of California and a national expert on metabolic disorders; and Ivy Mooring of the Los Angeles Coordinating Council on Mental Retardation. Consistent with previous reports, the team found deplorable



living conditions for the residents of these institutions. They found that patients, “old and young alike, are herded into huge, barn-like wards... bereft of any niceties of home and are treated like, and consequently behave like, animals in a zoo.” The report continued, “...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.”

In this year, the number of people with mental retardation living in state institutions in California peaked at approximately 13,400. Nationally, 195,000 people with developmental disabilities were living in state institutions.

**1969** A report to the state Assembly, *A Proposal to Reorganize California's Fragmented System of Services to the Mentally Retarded*, concluded that the pilot regional centers had been successful and recommended that the model be expanded statewide.



Dennis Amundson, an aide to Assemblyman Frank Lanterman, was the principal drafter of the report. In response, Lanterman introduced AB 225, calling for the expansion of the regional center system throughout California and the establishment of area boards for planning and monitoring of services. Within a decade, the system included 21 regional centers, one for every one million residents of the state.

Governor Ronald Reagan signed the landmark Lanterman Mental Retardation Services Act of 1969 on September 4, 1969. The governor described the bill as “progressive legislation [that] 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 bill called for the state to contract with local, community-based non-profit corporations to carry out its provisions.





**BRYAN**

**NEARLY 40 YEARS AGO**, Bryan was a toddler with severe cerebral palsy, unable to walk or to speak. Neither of his parents was able to care for him. Luckily, a foster parent took him into her home, and cared for him into his young adult years. Like other children of his time with severe disabilities, he attended special schools, segregated far away from regular education students. Few at that time may have foreseen the impressive accomplishments that lay ahead for him.

Fast forward to the present day: Bryan lives in his own apartment with the help of supported living services he receives from Harbor Regional Center, and a personal attendant he employs with funding from In-Home Supportive Services (IHSS). He uses his motorized wheelchair to visit friends, go to church, and attend Long Beach City College, where he is very close to completing an Associate degree.

And he now communicates quite articulately, with the help of his computer, e-mail, and his augmentative communication device. He recently took on the challenge of cross-country travel to attend a national conference of Augmentative and Alternative Communication (AAC) Users. He is an inspiration to his peers.



**1971** The Pennsylvania ARC sued the Commonwealth of Pennsylvania (*PARC v. Commonwealth of PA*) in federal court to force the state to provide children with disabilities an education at public expense and give their families access to due process to ensure this right. The suit was settled the following year when the state agreed it had “an obligation to place each mentally retarded child in a free program of education and training appropriate to the child’s capacity.” This lawsuit sparked numerous other right-to-education lawsuits and also inspired advocates to bring legal actions in Federal courts to obtain additional rights for people with disabilities.

Frank Lanterman authored legislation prohibiting local governments in California from passing zoning laws to prevent licensed homes serving six or fewer “mentally disordered or otherwise handicapped” persons from opening in residential neighborhoods.



**1972** Federal Judge Frank Johnson issued a decision in an Alabama class action lawsuit (*Wyatt v. Stickney*) establishing standards for treatment of persons with mental illness and mental retardation. The suit, filed two years earlier on behalf of Ricky Wyatt, a resident at Bryce Hospital in Tuscaloosa, alleged that a layoff of staff at the facility denied treatment to court-committed patients in violation of their civil rights. The judge ruled that people in state institutions have a constitutional right to individualized treatment that gives them “a realistic opportunity to be cured or to improve [their] mental condition.” This decision was a crucial victory in the struggle for deinstitutionalization, and it led to at least 70 federal lawsuits in 41 states demanding treatment in the least restrictive environment for people with disabilities.



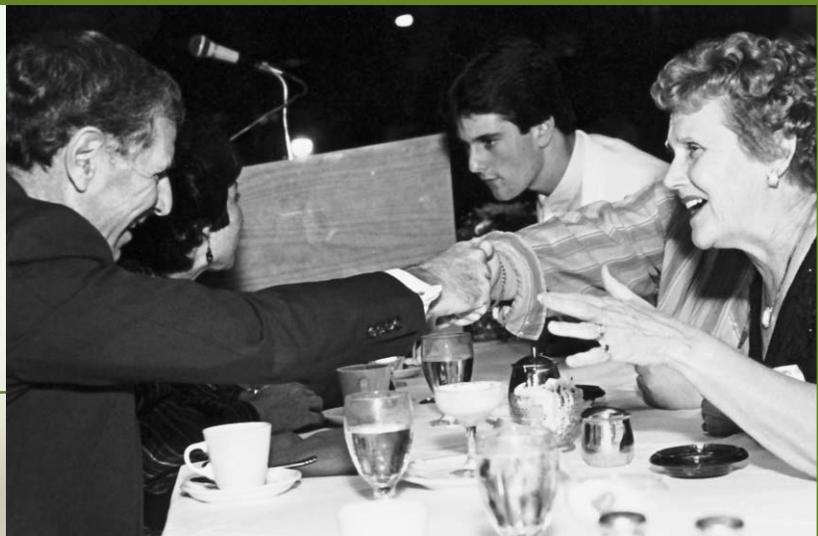
Using a stolen key to gain entrance, investigative journalist Geraldo Rivera and a camera crew from WABC-TV infiltrated Willowbrook State School on Staten Island New York, and recorded the brutal and horrific



living conditions that existed there. The exposé resulted in an immediate government inquiry and a 1975 lawsuit, *New York State ARC v. Carey*. In its decision in this case, the U.S. District Court in Brooklyn reaffirmed 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 ruled that D.C. could not exclude children with a disability from

the public schools. This decision and the decision in the 1971 case, *PARC v. Commonwealth of Pennsylvania*, were subsequently cited by advocates during the public hearings leading to the passage of the Education for All Handicapped Children Act of 1975.



Congress passed the Social Security Act Amendment (PL 92-603), creating the Supplemental Security Income (SSI) program. SSI was intended to provide a monthly stipend to cover the costs of basic needs (food, shelter and clothing) for people who are blind, disabled, or over age 65 and have limited income. This legislation consolidated existing federal programs for people who were disabled but not eligible for Social Security Disability Insurance. It relieved families of the financial responsibility of caring for their adult children with disabilities.

DeWitt State Hospital became the first California hospital serving people with mental retardation to close its doors. Two additional institutions, Modesto and Mendocino, were ordered closed before Governor Reagan left office in 1975.

**1973** In California, a group of people with disabilities, dissatisfied with their experience at a Canadian conference being held for people with mental retardation, returned home and formed their own self-advocacy group. They called their new



group “People First” to reflect the fact that their disabilities were secondary to their personhood. The idea of self-advocacy began to spread across the U.S.

The Rehabilitation Act of 1973 (PL 93-112) authorized over \$1 billion for training and other services aimed at helping people with mental and physical handicaps gain employment. Section 504 of this act prohibited discrimination based on disability and provided a legal basis for many anti-discrimination lawsuits that would follow.

Assemblyman Frank Lanterman authored Assembly Bill 846, extending the regional center mandate to cerebral palsy, epilepsy, autism, and other neurological handicapping conditions “closely related” to mental retardation. The name of the Act was amended to the Lanterman Developmental Disabilities Services Act.

**1974** In *Pennsylvania ARC v. Pennhurst School and Hospital* filed in Federal Court, plaintiffs charged that conditions in that state institution denied residents due process and equal protection of the law in violation of the 14th Amendment to the U.S. Constitution, inflicted on them cruel and

*“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



unusual punishment in violation of the 8th Amendment, and denied them certain rights conferred by federal law. The plaintiffs asked that Pennhurst be closed and that community living arrangements be established for all residents. The court ultimately agreed that keeping persons with mental



retardation in institutions isolated from society was a violation of the 14th Amendment. The court's rationale was that the only justifiable purpose for committing a person to an institution was habilitation, and if habilitation was not provided, the nature of the commitment bore no reasonable relationship to its purpose. Thus, the person's due process rights were violated.

**THERE WAS A TIME** – not so long ago – when doctors strongly advised parents of children born with Down syndrome and other developmental disabilities to never take their child home or become attached, because their children would never be able to develop at all. The wisdom of the day was that parents should immediately turn to the institution. With no resources available to help them, parents often felt they had no alternatives.

*Cristina's parents find such a scenario quite hard to imagine.*

*Soon after she was born, her parents were referred straight from the hospital to Harbor Regional Center, and were given encouragement about the services they could receive there to promote their daughter's development.*

*Today, Cristina is one of the many young people with Down syndrome who would amaze those doctors of the past. From the beginning, with early intervention at home, support through her school years and at every phase of her development, she has blossomed. This beautiful, poised and confident young lady now attends high school, where she is active in her classes and extra-curricular activities. She has danced in her community's ballet performances, and marched as a member of the high school drill team. As she becomes increasingly independent, she looks forward to a job, sharing an apartment – and enjoying a full life like everyone else.*





**CRISTINA**

# 1975

**1975** Congress passed the Education for All Handicapped Children Act (PL 94-142). This law required all children to be given a “free and appropriate public education” in the “least restrictive environment,” regardless of the severity of the child’s disability. It also mandated Individualized Educational 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) mandated a bill of rights for persons with developmental disabilities and required each state to establish a protection and advocacy system. Within three years, California established Protection and Advocacy, Inc. to ensure the rights of California residents with disabilities.

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

**1976** *In the Matter of Andre Bisagna*, the California Supreme Court ordered that, if a person with mental retardation is judicially committed to a state institution because he



is a danger to himself or others, that commitment order shall expire after one year. The Court further ordered that regional centers must be notified when such a person is judicially committed to a state



institution, must open a case for that person, and must conduct an annual review to assess that person's ability to live in the community. Within a few months of the order, Mr. Bisagna moved out of the institution into a group home in the community where he was still residing in 2006.

A decade after the establishment of the two pilot regional centers, the network was completed with the establishment of the 21st regional center, the Regional Center of the East Bay.

The number of people being served by state hospitals declined significantly from the peak of 13,400 reached in 1968. In 1976 nine

*"[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, *City of Cleburne v. Cleburne Living Center, Inc.*

hospitals - Agnews, Camarillo, Pacific, Fairview, Napa, Patton, Porterville, Sonoma, and Stockton - served approximately 10,100 people with developmental disabilities.

**1977** The Lanterman Act was amended 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.

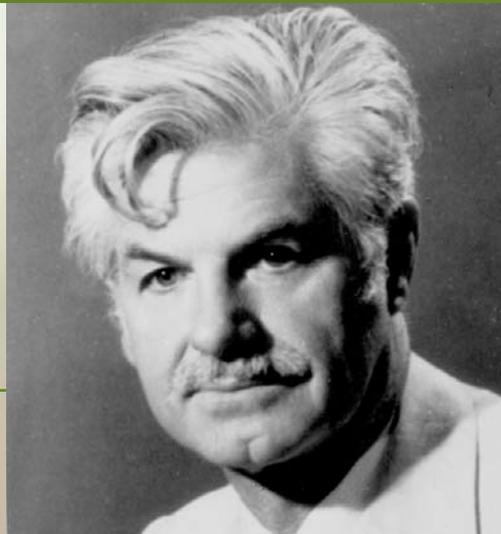


**1981** In the case of *In Re Hop*, the California Supreme Court ruled that any adult with developmental disabilities who is unable to provide informed consent for his placement in a developmental center is entitled to a judicial review to determine whether such a placement is necessary and appropriate. The ruling was later extended to include judicial review prior to admission.

In this year Assemblyman Frank Lanterman died. The legislature has never again had a member who so effectively championed the rights of people 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



**1982** Patton State Hospital closed its programs for people with developmental disabilities but continued to serve people with mental illness.

**1983** The U.S. Supreme Court ruled, in *City of Cleburne v. Cleburne Living Center, Inc.*, 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 consistent with this decision had been in effect in California for more than two decades.

Serious state budget deficits caused DDS to reduce funding for regional centers, and in turn, caused some regional centers to implement cost-saving strategies such as waiting lists and categorical cuts in services.

In a challenge to these actions, the California Supreme Court (in *Association for Retarded Citizens v. California Department of Developmental Services et al.*) ruled 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.” The court further noted that these services were to be determined through the individual program planning process and provided as an entitlement. This was the first time that the Lanterman Act was explicitly defined as constituting an entitlement to services.

By 1983 the 21 regional centers were serving 78,312 people and their annual budget was \$317,803,208.



In California, eight state developmental centers housed approximately 7,100 residents with developmental disabilities.

**1984** The U.S. Congress amended the Education for All Handicapped Children Act to require free pre-school programs for three- to five-year-olds with disabilities. The new law also required states to develop a plan to

*“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

implement early intervention programs for at-risk infants and toddlers (age birth to 3) by the 1991-92 school year.

**1988** The Americans with Disabilities Act established basic civil rights for people with disabilities. It prohibited discrimination in employment and required that people with disabilities be given equal access to transportation, public accommodations, and all government facilities, services, and communications. Public areas such as stores and restaurants were required to make “reasonable accommodations” to ensure that people with disabilities could access these facilities.



The Individuals with Disabilities Education Act superseded the Education for all Handicapped Children Act. Known thereafter as IDEA, this law expanded eligibility for special education to include children with autism and traumatic brain injury, and mandated transition services for students with disabilities, beginning no later than the student’s sixteenth birthday.



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

In California, 13 state developmental center residents and their families filed a class action lawsuit against DDS and four regional centers, 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 (*William Coffelt, et al. v. Department of Developmental Services, et al.*). An out-of-court settlement in 1993 resulted 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 developmental center population by about one-third, prevention of future admissions except



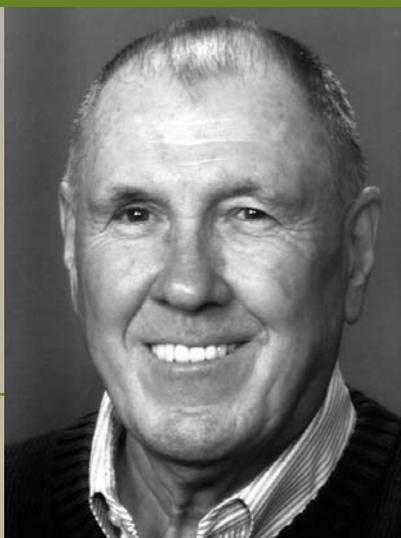
in the most difficult circumstances, and closure of Stockton and Camarillo Developmental Centers.

**1989** The state of New Hampshire closed Laconia State School and became the first state in the U.S. to provide all services to people with mental retardation in the community. By 2002, eight other states had followed suit.

**1990** For the first time in U.S. history, public expenditures for community-based services for people with developmental disabilities surpassed the cost of care in large institutions.

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

**1993** After five years of planning, California implemented “California Early Start” (the California Early Intervention Services Act). This program, authorized under Part H of IDEA, provided statewide services for infants



*“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

and toddlers from birth to 36 months who have or are at risk for a developmental delay.

**1995** For the first time in the U.S., people living in settings of six or fewer persons made up a majority (51.8%) of people with developmental disabilities living in residential settings.

In California, seven state developmental centers were serving approximately 5,100 persons.

The annual budget for the 21 regional centers had reached \$941,515,000. The centers were serving 129,230 persons.

**1996** Stockton Developmental Center - the oldest such institution west of the Mississippi, first opened in 1851 - closed its doors.

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





**1997** The California state developmental center in Camarillo closed.

**1999** In *Olmstead v. L.C.*, the U.S. Supreme Court held that the Americans with Disabilities Act prohibits “unjustified isolation” of people with disabilities in institutions. According to the court, institutional placement is “unjustified” when a 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.

**2000** DDS created an advisory committee to help determine the future of developmental centers and their residents. This committee made five recommendations: 1) there should be no capital outlays to rebuild developmental centers; 2) resources previously devoted to developmental centers should be put to work in the community; 3) valuable developmental center land should be “leveraged” to create new resources in the community; 4) homes for developmental center residents moving to the community should house no



more than four people with disabilities; and  
5) people moving into the community should receive individualized personal assessments and individualized resource development.

In the case of *Richard S.*, a federal court in California found that parents, guardians or conservators may not waive a developmental center resident's right to move to the community. The court issued a permanent injunction on the DDS policy that allowed third parties to "veto" community placement from a developmental center when such a move was found to be appropriate for the consumer.

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



**2001** The annual regional center budget had grown to \$1,877,800,000.  
The 21 centers were serving 173,233 people.

Approximately 3,691 persons resided in five state developmental centers.

**2003** In response to a directive contained in the 2003-04 Governor's Budget, DDS put forth a plan to close Agnews Developmental Center by July 2005.

The five state developmental centers were serving 3,467 residents.

**2004** The closure of Agnews Developmental Center was delayed from July 2005 to July 2006.

The following year's budget delayed the closing an additional 12 months, to July 2007.

**2005** The People First organization in California grew to 85 chapters throughout the state.

**2006** The 21 Regional Centers now served more than 210,000 children and adults with developmental disabilities at an annual cost of \$3.2 billion. Five developmental centers now serve only 2,845 people.



*"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



JUDITH

**WE FIRST MET JUDITH** when she was in a Neonatal Intensive Care Unit (NICU), where she had spent the first three months of her life. She had been born at only 26 weeks gestation and weighed well under 2 lbs. She had many serious respiratory problems, including recurrent collapsing of her lungs. A tracheostomy tube placed into her neck allowed Judith to be weaned from the ventilator, and her parents took their little daughter home with a suction machine, oxygen, apnea monitor, and multiple medications. Over the next year they would face more hospitalizations, and Judith would need to use a ventilator and have many hours of nursing care each day.

If Judith had been born in earlier times – if she had survived – she would not have been so lucky. She would have had no alternative but to live in a hospital. It wasn't so long ago that there were no home ventilators, and no programs to support children and families with such serious health needs. Her developmental needs would have been neglected.

But Judith was an alert, social and curious child, and with the help of her in-home nursing care and early childhood developmental services, she never let her dependence on a ventilator get in her way. She met all of her developmental milestones at appropriate times, and sometimes sooner.

Today, at the age of almost five, Judith attends an inclusive preschool class. She is bubbly and outgoing, and will explain what her trach is to anyone who asks. She is learning how to read and spell words, and has been computer savvy for two years. Her artwork adorns her walls at home, and she is proud to demonstrate how well she can ride her bike.



# CHALLENGES

**CHALLENGES FOR THE FUTURE...**In the past 40 years, we have seen great successes in expanding opportunities for children and adults with developmental disabilities to be included in the life of their communities. Increasingly, children are included in classrooms and neighborhoods with their non-disabled peers. More and more adults are living on their own with support in the community and finding real jobs in typical work settings. Many of these children and adults do these things with support from the regional center, and many more receive natural support from family members, friends, neighbors, classmates, and co-workers. For people with developmental disabilities, the world is very different from that of 40 years ago when Frank Lanterman's vision was taking shape.

Despite the progress, challenges remain. For every success there is a person whose opportunities are limited by lack of knowledge of options, lack of resources, or lack of support. Continued expansion of opportunities depends upon our ability to effectively address challenges such as these:

**Community ownership.** The regional center system was born of the passion, commitment and determination of parents whose children with developmental disabilities had few options and few opportunities. It was the stark contrast between the reality of their world and the dreams they had for their children that motivated them to be agents of change. These parents not only created



the system, but also nurtured it by continued vigilance and continued involvement in the community service organizations that they helped create. In this sense, they “owned” the system. Virtually all of these early pioneers have passed on, leaving behind as their legacy an established network of services and supports for children and adults with developmental disabilities and their families. Will the young parents now involved with the regional center system be able to maintain the passion, commitment and sense of ownership that is necessary to ensure the future of a locally-controlled, community-based system of services and supports for their children?

**Real jobs and a living wage.** It is not enough for people to be in the community; they should be a genuine part of the community. For adults, this requires that they have access to meaningful jobs which pay a living wage. Opportunities for people



with developmental disabilities to be employed in real jobs increased markedly in the 1980s and 1990s in California, and their presence in the workforce has expanded. Yet, the rate of increase in jobs has slowed significantly in the last decade and the jobs that are typically available



to people with developmental disabilities rarely pay more than minimum wage. Much work remains to be done to educate potential employers about the contributions that can be made by qualified employees with disabilities.

**Decent homes in safe neighborhoods.** As is true in employment, opportunities for people with developmental disabilities to live in their own homes in safe neighborhoods are increasing more slowly than the demand. While we have made much progress in our ability to support people in the community, we are increasingly challenged by the lack of affordable housing across the state. Affordable housing initiatives must be fashioned that place priority on the urgent housing needs of our most vulnerable citizens.

**Inclusion in the classroom.** The Individuals with Disabilities Education Act has given millions of children with disabilities opportunities to learn in schools and classrooms alongside their non-disabled peers. At the same time, the promise of the Act has been limited by a lack of adequate funding for services necessary to support these children in the classroom.

**Social isolation.** While society increasingly offers people with disabilities opportunities to live, work and socialize alongside their non-disabled peers, these inclusion opportunities sometimes result in people





being isolated from their natural social networks. For example, the normal social interactions available in a group home or a segregated day program are less available to a person who lives and works with supports in the community. Opportunities to be included must not isolate people with disabilities from the social networks that are important determiners of their quality of life.

**Access to appropriate medical care.** While access to adequate quality medical care is a challenge for many low- to middle-income people, it is especially so for people with disabilities. While most regional center clients have the benefit of Medi-Cal coverage, they are challenged to find health care providers who are able and willing to serve them. The lack of available providers is due to both inadequate funding of Medi-Cal and lack of knowledge about the health care needs of people with developmental disabilities among physicians and other health care providers.

**Service for populations with more complex needs.** While we have improved our ability to support people who wish to live, work and socialize in the community, we are faced with an increasing number of clients with complex service needs. This



includes people with significant medical challenges, and people with coexisting developmental disabilities and mental or emotional disorders. These complex needs challenge our ability to integrate these people into society in meaningful ways.



**Stability of the workforce.** A challenge transcending all disability services is the stability of the community workforce. The failure of reimbursement rates to keep up with service providers' cost of doing business has resulted in a decreasing ability among them to recruit and maintain the qualified staff needed to provide effective day-to-day support in residential, employment, and day activity settings.

**The promise and challenge of self-direction.** In the unrelenting search for resources to support the regional center system, we must avoid falling prey to what appear to be easy solutions. The most recent solution, self-directed services, is regarded as a vehicle to increase California's access to federal dollars. The Lanterman Act supports the principle of self-direction, but we will need to keep a watchful eye on this initiative lest an unintended result leave the person with developmental disabilities with fewer resources and fewer supports.

*Despite these challenges, we look back with great pride and satisfaction on forty years of progress in service to people with developmental disabilities and their families. And we look to the future with optimism and with the expectation that opportunities for people with developmental disabilities will continue to expand, and our vision of a society of true equality will be realized.*

*We wish to acknowledge the contribution of Frank D. Lanterman  
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HARBOR DEVELOPMENTAL DISABILITIES FOUNDATION, INC.  
21231 Hawthorne Boulevard, Torrance, CA 90503  
(310) 540-1711  
[www.harborrc.org](http://www.harborrc.org)