



*We're Here  
to Speak for  
Justice:*

*Founding  
California's  
Regional Centers*

# *A Tradition of Neglect...*

*“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

In the years preceding the events of the documentary film *We're Here to Speak For Justice: Founding California's Regional Centers*, individuals with developmental disabilities and their families lived in a shadow world of discomfort and denial, virtually invisible to the larger society – with little hope of a future.

The paradigm in those days was that the mentally retarded were “patients.” Care was primarily institutional and custodial, with long waiting lists for admission to state hospitals. Decision-making was based on impersonal institutional standards of professional practice.

In 1963 in California, 13,500 persons with mental retardation resided in overcrowded state hospitals, with 3,000 more on waiting lists for admission, which often took two to three years. Their living conditions were marginal at best, and shocking at worst.

In the early 1960s, a small group of parents, professionals and legislators came together to challenge the state over its treatment of people with mental retardation, and to improve their quality of life.

### ***Their actions changed the paradigm.***

What follows is a chronicle of courage, marking individual actions, which alone may not have seemed significant – but taken together, created a revolution.

### ***The beginnings of change...***

Since public programs were extremely limited and focused on institutionalization, parents began developing services for their children on their own. In Fort Bragg, Lotte Moise founded and taught in a school for children with disabilities. Around the state, groups such as the Exceptional Children's Foundation in Los Angeles, San Francisco Aid to Retarded Children, and others were providing support for families and programming for persons with mental retardation by operating private schools, activity centers, sheltered workshops and residential services. In response to parent requests, church groups and other charities also began offering similar programs.

In the early 1950s, a Special Clinic for the Study of Mental Retardation, funded by the US Children's Bureau, was established at Childrens Hospital of Los Angeles. Pediatrician Dr. Richard Koch was the director.

In 1959, the Traveling Child Development Project, also under the direction of Dr. Koch, began providing assessment, diagnosis and counseling for children with developmental disabilities and their parents in 15 Southern California communities.



## *Gathering momentum...*

By the early 1960s, the spirit of change was gathering momentum in California, driven in part by national events, and in part by a committed and fearless group of parents.

The impact of Eunice Kennedy Shriver cannot be overestimated. Largely due to her influence – both personal and through the work of the Joseph P. Kennedy, Jr. Foundation which she headed – President John F. Kennedy in 1961 focused national attention on the issue, and established a President's Panel charged with preparing a national plan to combat mental retardation.

The panel submitted its report the following year, recommending community-based care and a reduction in the number of persons living in large, congregate care facilities.

That same year, Mrs. Shriver wrote an eloquent article about her family's experiences with their sister Rosemary, who had mental retardation. Published in *The Saturday Evening Post*, the article transformed public opinion, placing mental retardation squarely on the national agenda. She said, in part: "The years of indifference and neglect are drawing to a close and the years of research and experiment, faithful study and sustained advance are upon us."

In 1963, two significant pieces of legislation were passed: the Mental Retardation Facilities and Community Mental Health Centers Construction Act (PL88-164), providing financial aid to build community-based facilities for people with mental retardation and mental illness; and PL88-156, amending the Social Security Act to establish the Maternal and Child Health (MCH) program to improve prenatal care to high-risk women from low-income families.

## *At the crossroads – the episode that changed everything...*

The series of events that would culminate in the regional center system began with parents seeking alternatives to institutional placement for their children with mental retardation. Their search for options uncovered a shocking truth that would change everything.

Statewide, plans were underway to add beds to the state hospital system. But, 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, two other parents and a reporter for the Orange County Register — were stunned at the desperate conditions in which they found patients. Mrs. Walter noted that in numerous visits to institutions in seven countries, these were "the worst conditions I have ever seen."

That visit prompted a series of hearings and investigations that would lead to dramatic changes in both the state hospital system, and the lives of people with developmental disabilities and their families.

In 1964, with urging from parents through the California Council for Retarded Children (later renamed the California Association for Retarded Citizens), the Brown Administration appointed "A Study Commission on Mental Retardation."

That same year, Assembly Speaker Jesse Unruh created a new Assembly Ways and Means Subcommittee on Mental Health Services to study care for people with mental retardation in California. Assembly Majority Leader Jerome Waldie was chair, and Assemblymen Frank Lanterman and Nicholas Petris were members. The principal consultant was Art Bolton.

In powerful testimony before the subcommittee, Vivian Walter said, "We will speak about a system and a philosophy that has been perpetuated in California...It is an extravagant system and philosophy that we can no longer afford – it wastes human lives and it does not give us a dollar's worth for the dollar we spend..."

"The great majority of the population of our hospitals require non-medical services – training in self-help and social adjustments, nursery classes and schools, social services for them and their families, day care, vocational rehabilitation, recreation, sheltered gainful employment...very much the same services that are furnished without question to the rest of our society..."

"We urge this Committee to realize that California's way is the old-fashioned way...to realize that some of our Eastern and Midwestern States, and many European countries are far ahead of us in modern concepts of care, treatment and rehabilitation of the mentally retarded, so much so that what they see here horrifies them..."

"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. Our proposals must appeal to conscience and intelligence. This is 1964, and it is high time California got out of the 19th century."

In 1965, the subcommittee submitted *The Undeveloped Resource, A Plan for the Mentally Retarded of California* to the Governor and the Legislature. It called for the state to accept responsibility for persons with mental retardation prior to state hospital admission, through regional services.

In its final report on state mental health services, *A Redefinition of State Responsibility for California's Mentally Retarded*, the Assembly Interim Committee on Ways and Means Subcommittee on Mental Health Services documented overcrowded conditions at state hospitals, and the preference of many parents to have community residential care options as an alternative to institutionalization. It noted:

“The state hospitals are required to be ‘all things to all people’ and provide a wide range of services for their varied clientele. In fact, for over half the ‘patients,’ these hospitals do not really serve as hospitals at all. For some, the hospital attempts to be a school, for others a nursing home, for some a home for the aged, for others a sheltered workshop and boarding home, and for some ‘patients’ the hospital is a way station before transfer to a foster home or other community facility.”

*“The heart of the problem is that most families who are unable to care for their retarded child at home have no choice other than to place the child in a state hospital.”*

The report recommended that the state accept responsibility for persons before entering state hospitals, and that community-based medical agencies provide regional services including diagnosis, counseling and continuing services.

Assembly Bill 691 was enacted in 1965, and signed by Governor Edmund G. (Pat) Brown. The bill authorized the establishment of two pilot regional centers for persons with mental retardation under contract with the State Department of Public Health. The centers were to call attention to unmet needs, assist in service development, upgrade services, maintain records, and provide systematic assessment, diagnosis and follow-up. The centers were also to assist in state hospital placement.

In 1966, two pilot regional centers were established at Childrens Hospital of Los Angeles and Aid for Retarded Children in San Francisco. The 1965-66 budget for the two regional centers was \$966,386. They served a total of 559 individuals in the first year.

The following year, Niels Bank-Mikkelsen, an internationally recognized expert in the field of mental retardation, and Director of the Danish National Service for the Mentally Retarded, visited Sonoma State Hospital and was stunned by the conditions he observed. He says: “It was shocking... I couldn’t believe my eyes. It was worse than any institution I have seen in visits to a dozen countries...In our country we would not be allowed to treat cattle like that.”

In response to the public outcry, Assemblyman Lanterman called for a legislative investigation.

In 1968, an Assembly study reviewing the effectiveness of the pilot regional center program and the future role of the state hospitals was completed and presented a *Proposal to Reorganize California's Fragmented System of Services to the Mentally Retarded*. The report concluded that the pilot regional centers were extremely successful and should be expanded into a statewide system.

In 1969, Assemblyman Frank D. Lanterman introduced AB225 to extend the regional center network of services throughout the State of California.

In his presentation before the Assembly Health and Welfare Committee, he summed up the key aspects of the bill: “One, AB225 uses the principle of planning and funding for people rather than for agencies. In this bill, the needs of the mentally retarded will determine the kinds of services that will be given priority in each region of the state...the dollars should flow with the person to be served...this bill utilizes the principle of local initiative and a partnership between the state and the concerned people who live in the different regions of our state...this bill expands citizen participation in determining policies for the retarded on both the local and the state level...AB225 uses the regional center mechanism as the focal point for providing services and for the allocation of funds for services for the retarded in each region.”



The California State Employees' Association (CSEA) sued to halt the regional centers by challenging contracting to private agencies. A court decision by Judge B. Abbott Goldberg determined that: "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."

He further noted that "The Waldie Bill is what Justice Brandeis might have called an experiment in alleviating an unavoidable human tragedy that is weighing increasingly on the public conscience. I do not believe that the Legislature transgressed the outermost bounds of its power merely by seeking new means cutting across existing departmental lines and providing new approaches. Nothing in the Constitution says that the legislature must tailor the program to fit the bureaucracy."

On September 4, 1969, Governor Ronald Reagan signed the Lanterman Act into law. He stated, "California is currently preparing to implement the Lanterman Mental Retardation Services Act. That 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 of which they capable. The purpose of this legislation is to meet the needs of each retarded person, regardless of age or degree of handicap, and at each stage of his life's development."

One year after the Governor left office there were 21 Regional Centers, one for every million citizens – just as Frank Lanterman had envisioned.

### *Again at the Crossroads – Challenges for the Next Generation...*

After more than three decades of learning, growing and innovating, we can point to great success, and a truly changed paradigm of life for those with developmental disabilities.

Today, California's Regional Centers are serving 150,000 children and adults with developmental disabilities and their families in communities throughout California, while the five remaining developmental centers (formerly state hospitals) are serving fewer than 4,000 residents.

But the challenges continue, and we stand at a crossroads as critical as the one that led to the development of the regional centers:

**Community ownership and local control** – We must reverse the drift to centralized control of the regional centers, which has stifled autonomy and created a vast bureaucracy driven by micromanagement. We must reaffirm the capacity of communities to govern their own regional centers so that they remain responsive to local needs. Quite simply, we need to return to the volunteerism and advocacy that characterized our beginning.



**Social acceptance and full inclusion of people with developmental disabilities** – While we have made enormous strides to integrate children and adults with developmental disabilities into community life, social acceptance and full inclusion continue to elude us. We must continue to work diligently to bring down barriers.

**Community awareness** – After more than 30 years, the community continues to be largely unaware of the existence of regional centers. If we are truly a focal point for people with developmental disabilities and their families – and if we are ever to achieve acceptance and inclusion of individuals with developmental disabilities in our communities – then we must work on building greater community awareness.

**Competition for finite resources** – Competition for resources will continue to increase – improving the quality of education, providing services to the elderly and the mentally ill, rebuilding California’s infrastructure – while expectations for more and better services outpace available funding. The entitlement to services is fundamental, but it must be balanced by careful stewardship, ensuring cost-effective services that produce results.

**Innovation and change** – The ability to change the paradigm of providing services and supports to people with developmental disabilities has been a hallmark of the regional centers. We must continue to evolve to ensure that the paradigm remains relevant to the changing needs of the people we serve and our communities. To do this, regional centers must retain the ability to experiment and innovate.

**Diversity** – California will continue to become ever-more ethnically and culturally diverse, with a population that is growing increasingly older. These demographic changes carry the potential for dissonance. And while our primary focus has always been on meeting individual needs, we must also concentrate on what unites us, not on what divides us. We must recognize that people are our greatest asset, and partnerships are the way to achieve our common purpose.

**Community alternatives for developmental center residents** – We have succeeded in providing opportunities for the overwhelming majority of children and adults with developmental disabilities to live at home with their families and in the community. However, we have barely begun to meet the challenge to provide such opportunities for the 3,900 remaining developmental center residents. Our remaining state institutions are in need of massive infusions of funding to bring them to earthquake and safety standards. We must search for more innovative solutions for our most vulnerable individuals, the medically fragile and the behaviorally challenged, so that they are not left behind.

**Self-Determination** – We need to redouble our commitment to recognize the personal power and value of all people with developmental disabilities by promoting independence and initiative. We must provide an environment that supports all individuals to exercise their right to make informed decisions in all areas of their lives. We need to strive to increase access to knowledge, skills and resources that will enable every individual to choose his or her own life goals.

**Informed, experienced leadership** – The ultimate challenge is to develop a leadership capable of taking us to the edges of a future we can only begin to envision, rising from within the community and building on the foundation set by the courage and persistence of those who have gone before. We must develop a leadership committed to quality and continuous improvement in all that we do; accountability to one another, careful stewardship of our resources; and greater self-sufficiency – a leadership motivated by possibilities and united in the vision of service to individuals with developmental disabilities and their families.

In many ways, the story of the regional center is just beginning. It is time for the next generation to take up the challenges.

# *Told in their own words...*

## *We're Here to Speak for Justice: Founding California's Regional Centers*

The documentary film *We're Here to Speak for Justice: Founding California's Regional Centers* was produced and directed by award-winning filmmaker Theodore Braun, Senior Lecturer at USC's School of Cinema-Television, and is the result of a partnership between Union Bank of California, Lanterman, Golden Gate and Harbor Regional Centers, and The University of Southern California School of Cinema-Television.

The film captures for the first time, in print or moving images, the fascinating, challenging and dramatic story behind the development of the regional center system – told by the pioneers who lived it. It is a remarkable historical achievement that stands as a testament to the ability of committed individuals to effect social change.

It's the story of impassioned parents, dynamic physicians and legendary state legislators who worked together to open the doors, bring down the old system, and forge a new, more humane and responsive way to improve the quality of life for people with developmental disabilities and their families. It is a story about ordinary citizens coming together to change government for the good of their community. It is a story that celebrates partnership, idealism and compassion.

This story of a generation that transformed the lives of hundreds of thousands of Californians, reminds us all of the extraordinary obstacles we've overcome since the early 1960s, the triumphs we've enjoyed, and the spirit required to face the challenges ahead. We hope it inspires, encourages and empowers all those in the field of developmental disabilities and the broader community to "keep the vision alive."



# Those Who Spoke For Justice...

Frank D. Lanterman represented the La Cañada area of Los Angeles County in the State Assembly for 28 years, starting in 1950. He served as chairman of the Sub-Committee on Mental Health and Developmental Disabilities for many years. During that time, he did more than any other legislator to improve the lives 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.

He retired from the Legislature in 1980 and died in 1981. Others have aspired to wear his mantle, but none have 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.”*



*Frank D. Lanterman*



*Katie Nack*

*There is a way to get from  
where you are to where you want  
to go, if you just don't follow the  
rules and use your imagination.*

Katie Nack's daughter, Susan, was born in 1964 into a world where children with Down Syndrome were essentially warehoused. It was during that time that the California Legislature sanctioned two pilot programs, and Susan's age and developmental level made her exactly right for participating in new programs as the system developed.

One of the pilot programs was housed at the Childrens Hospital of Los Angeles. Frank D. Lanterman Regional Center was the direct outgrowth of that trial project.

Katie joined the support group at the hospital under the volunteer leadership of Asenath Young and became one of the incorporating officers of the Los Angeles County Developmental Foundation, doing business as the Frank D. Lanterman Regional Center.

From 1979 through 1992, she was a member of the Lanterman Regional Center Board of Directors, with one year between two board terms as advisor to the board. As Board President in 1982-84, she was also a board member of the statewide Association of Regional Center Agencies.

During the 1970s, she was on the Board of Directors of Villa Esperanza where, from age 2<sup>1/2</sup>, Susan has participated in residential, work and social programs. Katie withdrew from the board during the two decades she served as an elected member of both Pasadena's School District and City Council (part of that time as Mayor).

She returned to the Villa's board three years ago, and once again has been president. As a board member of a service provider, she knows well the impact of the regional center system on families.

Margarete Connolly has three children, two sons and a daughter, Anne, who is developmentally disabled and an artist at Creativity Explored in San Francisco.

When Anne was born, Margarete tried unsuccessfully to get the mental health community to take on the cause of mental retardation. So she began her work for people with developmental disabilities as a volunteer. She helped organize the first group of parents who formed what is now the Association for Retarded Citizens. In 1952, she helped found a state organization, then known as the California Council for Retarded Children, and from 1954 to 1956, she served on the board of the National Association for Retarded Children.

She was Executive Director of the Association for Retarded Citizens in San Francisco from 1952-1975. During a decade of that time she also administered the Golden Gate Regional Center. As Executive Director of ARC in San Francisco, she worked primarily to change the way individuals with retardation were served in California.

She participated as a member of the American delegation to the World Congress on Rehabilitation in Dublin, Ireland; was a consultant to the Mental Retardation Project of the US Department of Health, Education and Welfare; Vice-Chair of the California Advisory Council of the State Department of Rehabilitation; and a member of the Advisory Committee on the Mentally Retarded, California Department of Public Health.

After retiring from ARC, she joined the Children's Mental Health Policy Board, where she served as chair from 1990 to 1994.



*Margarete Connolly*

*The really radical thing about it was that we could sit down with people and analyze, along with their family, what it was they really needed to cope with life...Nobody had ever approached it that way.*



*Vivian Walter*

*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.*

An articulate spokesperson and advocate 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 local state hospitals. It was during those visits that she began to see how desperate conditions truly were – and that realization, along with her professional experience in public relations, 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 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 Council on Developmental Disabilities under Governors Pat Brown and Jerry Brown.

Ned, now 43, lives in a group home in Marin, and works as part of a cleaning crew.

Lotte Moise's third child, Barbara, was born with mental retardation at a time when parents were just beginning to speak up for the rights of their children with disabilities to become a part of the community. Lotte plunged into the parent movement, founding and teaching in a school for children with disabilities when the local school system refused to serve them. Whenever she found an obstacle – she overcame it.

She was a founding member of the North Coast Regional Center and charter member of the Area I Developmental Disabilities Board. She's been chair of the ARC-C Board, Area I Board, Regional Center Board, Sonoma County Citizen Advocacy, The Continuum Program and Protection & Advocacy. She's written numerous articles on mental retardation and developmental disabilities and was a presenter at the 7th World Congress of the International League of Societies for Persons with Mental Retardation.

Activist, fighter and proud, loving mother, she has chronicled her family's experiences in two books about her daughter *As Up We Grew With Barbara*, and *Barbara and Fred – Grownups Now* sharing her daughter's growth from childhood to a stable, loving relationship with a man who has Down Syndrome.

As Lotte says, "All along, Barbara has led the way and been my most important teacher."


Today, she remains active as a volunteer, advocate, planner, writer and lecturer on community living for people with special needs, with a special emphasis on residential services, advocacy, family life and sex education, and self-advocacy.

She continues to share her experience with others, such as a local parent support group in Fort Bragg, and as advisor to "People First" of the Mendocino Coast.



*Lotte Moise*

*The regional center in my mind was a place where we could get counseling, not just the children and the young people and the adults...but the parents.*

A sepia-toned portrait of an elderly woman with short, wavy hair and glasses. She is wearing a dark jacket over a light-colored top and a necklace. The background is slightly blurred, showing what appears to be a bookshelf.

*Asenath Young*

*We were clearing away  
new paths to get the work done,  
to get what we needed. They  
didn't exist, so we had to work  
on it so that they did exist.*

Mrs. Asenath Young is the parent of a son with a developmental disability and the grandparent of a young adult with cerebral palsy. Active in the Regional Center since its inception in 1966, she became the first president of the Lanterman Regional Center in 1979. A founding member of the Association of Regional Center Agencies, she also helped write the plan for Protection and Advocacy in California.

She was one of the founding directors of Pacific Oaks College in Pasadena, and successfully encouraged the Pacific Oaks Nursery School to include preschoolers with developmental disabilities as part of its regular nursery school program.

Mrs. Young had a long personal friendship with Assemblyman Frank Lanterman, and was active in encouraging and mentoring parents in the legislative advocacy process.

She has been a strong advocate for family support services. And as she says, "When you have a child with a developmental disability, you can feel very isolated and alone. Joining forces with professional people in support of families has been a cornerstone of the Regional Center from the beginning."

In recognition of her many contributions, Lanterman Regional Center honored her by naming its Koch-Young Family Resource Center after her and Dr. Richard Koch.

The Collins' son, Craig, was born in 1951. His condition was never diagnosed. Although he is non-verbal, he is able to communicate his needs and follow directions. He lives in a community home and takes public transportation to his volunteer job as a Magazine Aide at Marin General Hospital. He also works as a dishwasher at MARC.

Mrs. Collins called the first meeting of Marin Aid to Retarded Children (MARC) in 1954. Only a few people attended that first session – but it was a beginning. They next advertised in the local newspaper and drew a larger audience of interested parents. The new group modeled itself after San Francisco ARC, and using their guidelines, MARC focused on the needs of children with disabilities. The organization has since blossomed into the Marin Association for Retarded Citizens.

Her other volunteer activities have included service with organizations such as: the American Red Cross-Chair Local Chapter; Girl Scouts of America; United Way; League of Women Voters; and Marin County Mental Health – Chair Advisory Board.

A former member of the board of Golden Gate Regional Center, Dr. Daniel Collins spent many years in private dental practice in the Bay Area. He also taught at the College of Dentistry, University of California and was Co-Director of the Comprehensive Dental Health Care Project, Mt. Zion Hospital.

He was a board member and founder of the San Francisco Bay Area Urban League. He served on the board of the San Francisco branch of the NAACP, and was a trustee and vice-president of the National Urban League. He was also a member of the Governor's Committee to study Medical Aid and Health in California; a presidential appointee to the National Health Resources Advisory Committee; and a member of the San Francisco Mayor's Committee of Youth.

He has received numerous awards and honors, among them the Whitney M. Young, Jr. Award, National Urban League; and the Distinguished Alumni Award, United Negro College Fund.



*Daniel and DeReath Collins*

*The work that the regional centers do is to humanize these people – and in so doing, humanize the parents and humanize particularly the larger community.*

Daniel Collins

*I just didn't think it was fair for him not to be involved, and I wanted other people to learn that there are going to be some disabled people around, and you might as well get used to them.*

DeReath Collins



*Emmy and H. David Sokoloff*

*We did an awful lot of crying on each other's shoulders and for the very first time we were able to express our feelings to people who knew what we were talking about.*

Emmy Sokoloff

*As a consultant in this, I've seen abuses in other states that are appalling, particularly when they were happening in the richest country the world has ever seen.*

David Sokoloff

Emmy and David Sokoloff are the parents of five children, the fourth of which is Lucy, age 48. Though born brain-damaged, Lucy has lived independently since 1979. Through Lucy, both parents have been pioneers in working to improve the lives of individuals with developmental disabilities.

David is a Fellow of the American Institute of Architects; former member of the California State Advisory Hospital Council; and former Chairman of the California State Council on Developmental Disabilities, and the California Council AIA Committee on Environments for People with Special Needs.

He is a past President of the Marin Association for Retarded Citizens; and the California Association for Retarded Citizens. He was appointed to the State Advisory Hospital Council, where he chaired the Committee on Mental Health and Mental Retardation Facilities. He also served on the board of the National Association for Retarded Citizens and chaired the Committee on Residential Services and Facilities.

He has been a consultant to, among others, the President's Committee on Mental Retardation; US Department of Health Education and Welfare; California State Department of Rehabilitation; and Valley Mountain Regional Center.

Emmy is a charter member of Marin Aid to Retarded Citizens (MARC) which formed in 1954. Over the years, she has served on the MARC Board of Directors and on many committees. She was a major spearhead in establishing Marin House, a residential facility for six young women sponsored by MARC.

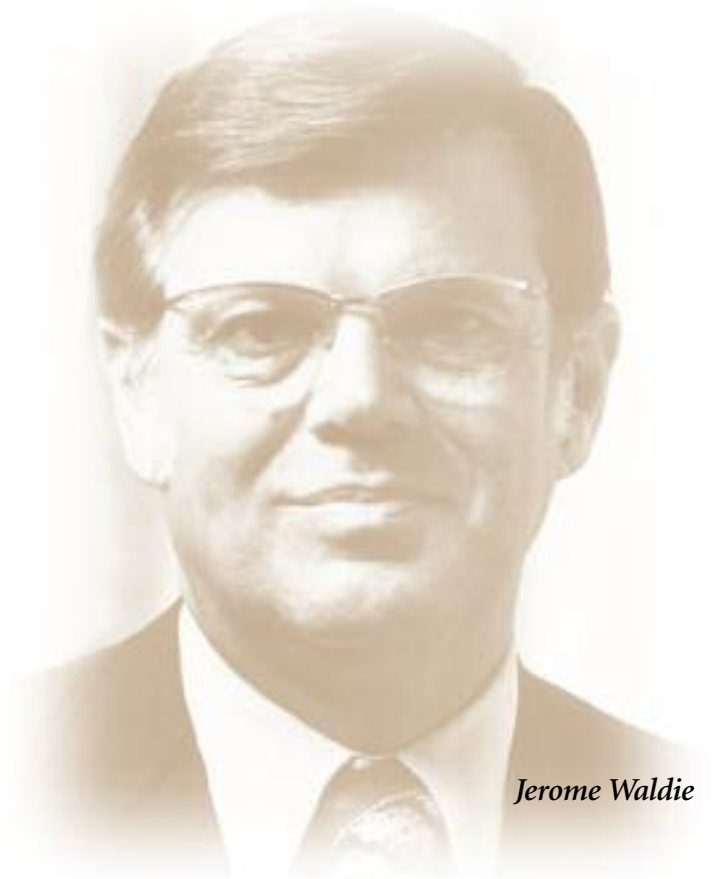
Her interest is in local and state programs, and that is where she devotes her time and energy. In addition, she supports the ongoing efforts of parents and professionals to revitalize the parent movement for a new generation.



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 Greene, Lanterman, Alquist, Burgener, Petris and Warren, and Senator McAteer on the Senate side, he introduced AB691, 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 is currently active as a member of the Tahoe Regional Planning Agency.



*Jerome Waldie*

*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.*



*Ed Pye*

In his own words, “the gist of my life activity is to develop programs for special people”– and he has accomplished just that over a long career of service.

With a Master’s Degree from the Columbia University School of Social Work, he worked for many years as a Community Organization Specialist and consultant on mental retardation for the California Department of Mental Hygiene.

Prior to his work with the regional center, Ed traveled the state raising community awareness and helping parents establish community-based services.

He was Chief Counselor, Associate Director, and Director of Golden Gate Regional Center – one of the two pilot centers established under the Lanterman Act.

He was also the Chief Social Worker at the Ambler-Wells Medical Group in Arcadia, and Chief of the Special Rehabilitation Advisement Unit of the Veterans Administration.

In retirement, Ed has applied his experience to new programs he’s developed to assist persons over 65 to access services, and has been serving on several community boards that relate to services to seniors.

*To get into the Sonoma State Hospital in the early days, it was really like getting admitted into prison. You were committed.*

Recently retired as Director of the Center for Integrated Services for Families and Neighborhoods, Art Bolton has a long and distinguished history of involvement with issues related to mental retardation and developmental disabilities, both on the state level and as a national consultant.

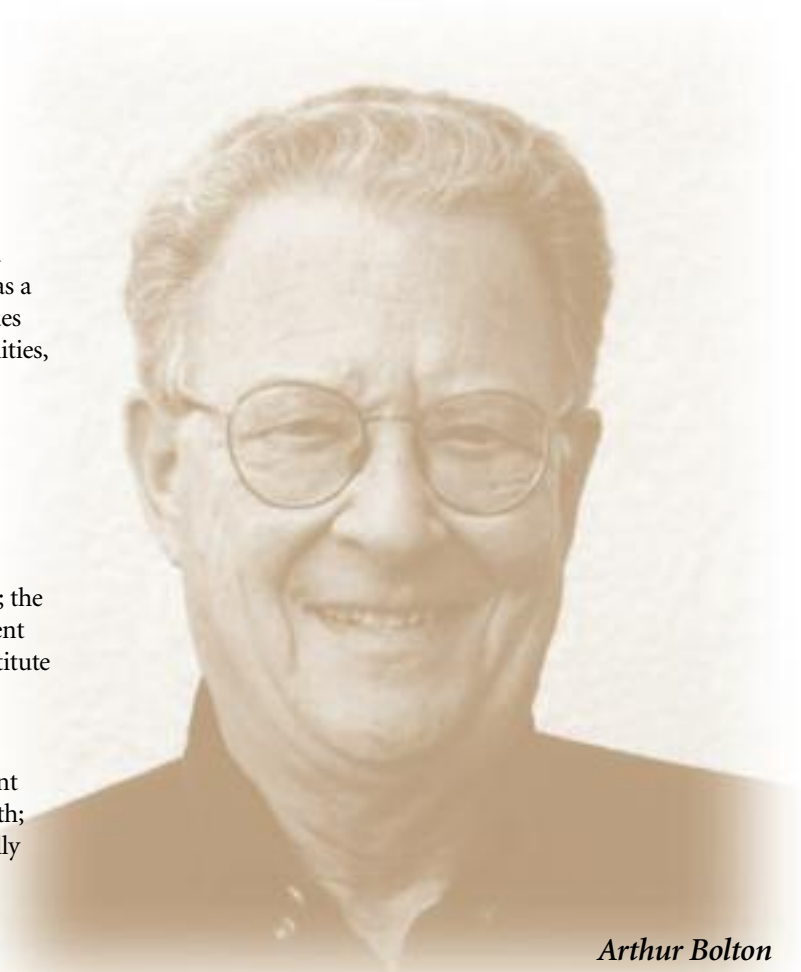
As President and Executive Director of Arthur Bolton Associates, he worked with organizations such as the California Department of Health; the California Select Committee on Mentally Ill and Handicapped Children; the State of Hawaii; the Commonwealth of Virginia; Missouri State Senate; Illinois House of Representatives; the Massachusetts Department of Education; US Department of Health, Education and Welfare; and the National Institute of Mental Health.

He has also consulted with the California Senate Committee on Health and Welfare; the State Department of Rehabilitation; the State Department of Mental Health; the Organization of Area Boards for the Developmentally Disabled; North Bay Regional Center; and the Office of Statewide Health Planning and Development.

As Director of the California State Assembly Office of Research – an office he designed – he helped develop landmark legislation in mental health, developmental disabilities and health care, including the Lanterman Mental Retardation Services Act. And as Senior Health and Welfare Consultant of the California State Assembly and Consultant to the Assembly Ways and Means Committee, he was instrumental in designing the regional center system itself.

He was also Staff Director of the California Lieutenant Governor's Task Force for the Seriously Mentally Ill; and Director of the California State Assembly Office of Research.

He presently serves as a consultant to the California Department of Mental Health, Integrated Service Systems Section, and is a Visiting Scholar at the University of California, Berkeley, School of Social Welfare.



*Arthur Bolton*

*It became apparent that the issue was not how are we going to fix the hospitals, but the central issue was how are we going to create an alternative to the hospitals?*



*Denny Amundson*

*It was the parents  
that wanted those options.  
It was the parents that wanted  
programs right in their home  
communities rather than  
being on a waiting list to get  
into state institutions.*

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

In 1968, he joined the staff of Assemblyman Frank D. Lanterman, the powerhouse legislator who authored the landmark Lanterman Mental Retardation Services Act. As his Chief of Staff, Denny drafted the original legislation as well as follow-up bills, including the updated Lanterman Developmental Services Act, the California Master Plan for Special Education, the California Community Care Licensing Act, and legislation prohibiting zoning discrimination against homes serving six or fewer people with developmental disabilities.

In 1974, he became the first Executive Director of the newly-formed 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 and Associates. He also served in the administration of Governor Jerry Brown as Chief Deputy Director of the Department of Economic and Business Development.

Governor Pete Wilson appointed him Director of the Department of Developmental Services. From 1991 through 1997, Denny headed the department during a period of rapid transition. During his tenure, he was instrumental in developing a person-centered planning process, performance-based contracts with regional centers, and capturing massive infusions of new Federal dollars to expand California's community-based system of care.

He is now Vice President of New Business Development for MENTOR Clinical Care, Inc.

As executive vice president of the Joseph P. Kennedy, Jr. Foundation and Honorary Chairman of Special Olympics International, Eunice Kennedy Shriver has been a leader in the worldwide struggle to improve and enhance the lives of individuals with mental retardation for more than three decades.

Following graduation from Stanford University, she worked for the State Department in the Special War Problems Division. In 1950, she became a social worker at the Penitentiary for Women in Alderson, West Virginia, and the following year she moved to Chicago to work with the House of the Good Shepherd and the Chicago Juvenile Court. In 1957, Mrs. Shriver took over the direction of the Joseph P. Kennedy, Jr. Foundation.

The Foundation has two major objectives: to seek the prevention of mental retardation by identifying its causes, and to improve the means by which society deals with citizens who have mental retardation.

Under Mrs. Shriver's leadership, the Foundation has helped achieve many significant advances, among them: the establishment of the President Kennedy Committee on Mental Retardation; the development of the National Institute for Child Health and Human Development; changes in Civil Service regulations that allow persons with mental retardation to be hired on the basis of ability rather than test scores; and the establishment of Special Olympics.


Recognized throughout the world for her efforts on behalf of persons with mental retardation, Mrs. Shriver has received many honors and awards, including: the Presidential Medal of Freedom, the Legion of Honor, the Priz de la Couronne Française, and the Mary Lasker Award.

In awarding Mrs. Shriver the Presidential Medal of Freedom, President Ronald Reagan said: "With enormous conviction and unrelenting effort, Eunice Kennedy Shriver has labored on behalf of America's least powerful people, those with mental retardation. Over the last two decades, she has been at the forefront of numerous initiatives on behalf of the mentally retarded, from creating day camps, to establishing research centers, to the founding of the Special Olympics program. Her decency and goodness have touched the lives of many, and Eunice Kennedy Shriver deserves America's praise, gratitude and love."



*Eunice Kennedy Shriver*

*I felt the parents had been so poorly treated in this country. I thought it was outrageous that they had these children and nothing was happening.*

A portrait of Dr. Richard Koch, an older man with white hair, wearing a white turtleneck and a light-colored jacket. He is smiling slightly and looking towards the camera. The background is a bookshelf filled with books.

An internationally recognized expert on PKU (a metabolic disorder which causes mental retardation), Dr. Richard Koch stands on more than 40 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.

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 the Childrens Hospital of Los Angeles Regional Center.

From 1975 to 1977, he served as Deputy Director of the State Department of Health. For a number of years, Dr. Koch has also provided medical consultation to the Los Angeles County Jail in assessing individuals who are suspected of having a developmental disability.

Today, he continues to see long-term patients and families in the Department of Genetics at Childrens Hospital of Los Angeles. He also serves as a member of the Lanterman Regional Center Health Care Task Force.

He was the first recipient of the Dr. Albert Anderson Health Care Professional Award from the California State Council on Developmental Disabilities.

In recognition of his many contributions, Lanterman Regional Center honored him by naming its Koch-Young Family Resource Center after him and Mrs. Asenath Young.

*Dr. Richard Koch*

*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.*

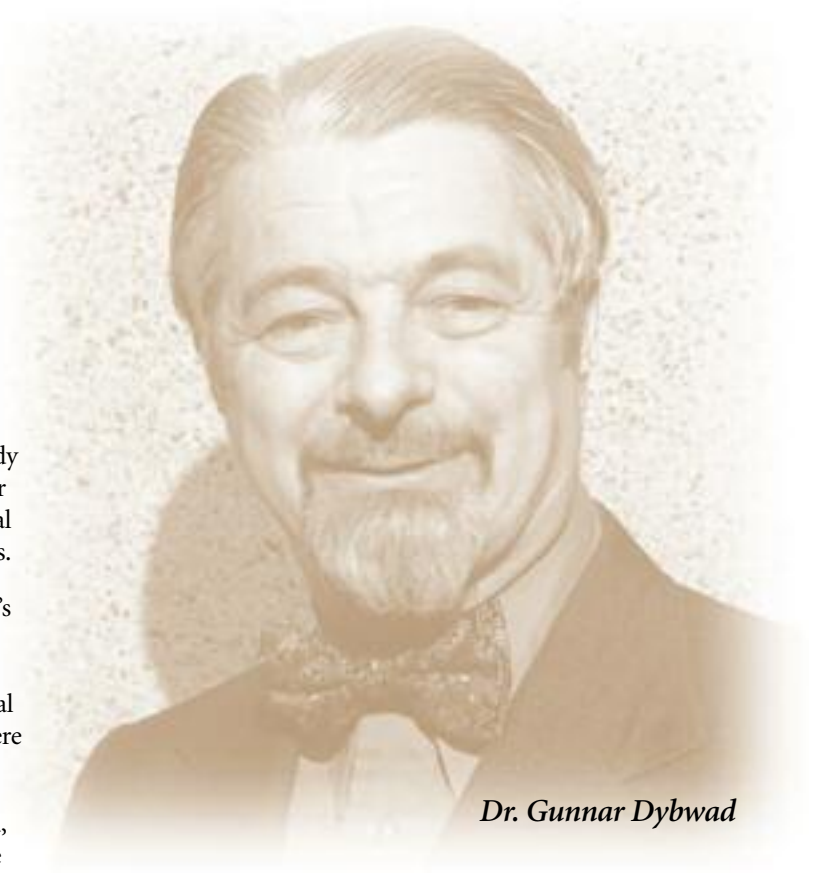
Dr. Gunnar Dybwad is Professor Emeritus of Human Development at the Heller School, Brandeis University. He received his JD from the Faculty of Laws, University of Halle, Germany, and is a graduate of the New York School of Social Work.

From 1943 to 1951, he directed the child welfare program of the Michigan State Department of Social Welfare, and subsequently served as Executive Director of the Child Study Association of America, and of the National Association for Retarded Citizens. In the latter capacity he was instrumental in energizing the parent movement across the United States.

Dr. Dybwad has served as consultant to President Kennedy's Special Assistant on Mental Retardation, the US Public Health Service, the US Office of Education, the Social and Rehabilitation Service, the President's Committee on Mental Retardation, and numerous governmental agencies both here and abroad, including the World Health Organization.

From 1964 to 1967, he and his wife, Dr. Rosemary Dybwad, were Co-Directors of the Mental Retardation Project of the International Union for Child Welfare in Geneva, working as consultants throughout Europe and in Central and South America.

He is a Fellow of the American Orthopsychiatric Association, the American Sociological Association, the American Public Health Association, and the American Association on Mental Retardation, as well as an Honorary Associate Fellow of the American Academy of Pediatrics.



*Dr. Gunnar Dybwad*

*For an outsider, particularly somebody from a Scandinavian country where we always had small facilities, always individual care, this kind of mass regime was, of course, disgusting. (Speaking of his visit with Niels Bank-Mikkelsen to Sonoma State Hospital.)*

# The Results...

Was the struggle worth it? Here are four people who would answer that question with an emphatic Yes!...

Four people who are active, productive and valued members of their community...



*Michael Pasquini*

*Everybody said to me, if you move out, you're going to get stuck. You're going to get stuck. I'm not stuck.*

Santa Rosa resident Michael Pasquini takes the bus to work, enjoys time with his co-workers and comes home to his apartment in the afternoon. Not unusual for a 52-year-old man, until you realize that until a few years ago, Michael spent his days inside the confines of the Sonoma Developmental Center, passing the time playing games and watching television – without living options or much hope for any real future.

Michael has cerebral palsy, which has left him in a wheelchair with limited arm movement and only partial control above the neck. His parents placed him in a developmental center at age 12 because they could not care for him at home. He remained there for 30 years.

He knew there must be other options, but could he make it on his own? Helping him overcome his initial concern, his involvement in People First gave him the confidence and reassurance he needed to leave Sonoma Developmental Center. He lived in a residential home for a few years, and now lives in a supported living situation in his own apartment in the community. He has a personal assistant, and is employed at Becoming Independent.

An avid opera fan, he was recently awarded a certificate for Providing A Community Service from Becoming Independent's Community Living Supports program.





*Stephanie Taylor*

*People should come to church and not be discriminated against no matter what color, handicap or white. Everybody has a right to talk to God, no matter what.*

Stephanie is a 28-year-old woman who lives at Chester House, a group home in Pasadena. She was born with Noonan's Syndrome.

Stephanie graduated from Eras School in Culver City and is very involved in the Special Olympics in which she participates in swimming, floor hockey and basketball. She has received gold, silver and bronze medals in these sports. She also likes running, and has run in 5Ks.

She is a member of the First Congregational Church of Pasadena, which she attends regularly. She also enjoys traveling to New York to visit her sister.

Stephanie has accomplished many goals that she has set – and may soon be an assistant basketball coach with her doctor's daughter's team.

Her newest project is entering a day program at Villa Esperanza called *Dimensions*, whose goal is to create a restaurant.



*Lucy Sokoloff*

*They did the best they can. Maybe they're not perfect. We're all not perfect. We all have our ups and downs.*

Lucy Sokoloff, age 48, was born brain-damaged. Despite her developmental disabilities, Lucy is a cheerful, attractive, successful woman who has lived on her own since 1979.

She attended both Marin Community College and Contra Costa Junior Colleges, taking photography and physical education classes. She has won silver and gold medals in the Special Olympics as an expert swimmer in the 50-meter freestyle.

Over the years, she has held a number of jobs, and is currently employed at the Willows Restaurant in San Rafael.

Lucy and her boyfriend of more than a decade love to dance. She also loves books, music, and animals.



*Vincent Jackson*

*This place is the most wonderful place to come to. This place is about creativity.* (Speaking of being an artist at Creativity Explored.)

Vincent Jackson lives at home in Daly City, where he enjoys a large extended family of aunts, uncles and cousins. Vincent is very active in his church, Providence Baptist Church, as a member of a Sunday School class and volunteer in the holiday gift program that provides gifts for children of incarcerated parents. He feels that program to be especially rewarding to him.

He is also an artist at Creativity Explored in San Francisco where he does printmaking and other types of artwork. He would like to go to college in the future for a degree in art.

Now 37, he says that the Lanterman Act was a great thing for helping people with disabilities to get the programs they needed.

*As a result of the Lanterman Act and the development of the regional centers, Michael, Stephanie, Lucy and Vincent – and thousands of others like them – are living in the community, working, making friends and looking forward to a future filled with possibilities... just like everyone else.*

For additional information or to place an order, contact:  
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