CELEBRATING OUR Lie Contraction (Nol. 13, Nol. 3) FALL/WINTER 2006

A PUBLICATION OF FRANK D. LANTERMAN REGIONAL CENTER

FATHERS' CORNER Dad, At Home

By O. Roger Seward

y son Tim is 15 years old and is in the eighth grade in the city of Burbank. Tim has Fragile X Syndrome which he was diagnosed with in 1993 when he was $2\frac{1}{2}$ years old. He has speech delay, some autistic-like behavior, ADHD and other assorted behaviors and personality traits that make him the unique, funny, loveable soul that he is.

Life has changed incredibly in the last 15 years. In the 90s, I was working 60 to 70 hour weeks as a lighting technician at the studios. This enabled my wife Mary to work part-time and stay home with the kids, and do all the communicating with client service coordinators, school administrators, et al, reminding them of Tim's needs and why these services were important for his well-being. Me, I didn't know what IEP meant.

Four years ago, I retired from the studios because of assorted injuries and became "House Husband" and caregiver to Tim. Granted it was not cold turkey. I've always done the store shopping and cooking when I was home. And I've always



Tim Seward with a penguin character at SeaWorld San Diego, where he enjoys going several times per year.

And I've always thought of marriage as a partnership and helped my wife, the working mom. But all of a sudden, Tim became my responsibility. (Note: My wife is still the supervising employer.)

So now, I'm a 61-yearold stay at home dad. During the day, I clean the house (the kitchen gets special care); the yard (need to work on that discipline more); and I schedule activities; and taxi, teach and

support my son in his daily endeavors. Retired? I think not.

I take him to school each morning. At times I've been his sub when the aide was out sick. When I pick him up after school, I take him to: a group class in Pasadena; a music program in Burbank; Special Olympics soccer in Pasadena; speech

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A Classic Case of NIMBY Surfaces in Lanterman Community

Pasadena Family Befriends Residents of the New Beginnings Home Whose Presence is Being Challenged by a Group of Neighbors

The end of last year, Guy Robertson began looking for a house in the Pasadena area where he could open a new home for adults with developmental disabilities. After looking at a number of houses, he settled on a one-story house located on a quiet tree-lined street in the Upper Hastings Ranch area. It was the perfect location for a small group home – the house had four bedrooms, it was set back from the street, there was a large back yard, spacious common areas, and several parks and a library just down the road.

With the decision made, he set about taking all the necessary steps to open a new home – obtaining the appropriate license from Community Care Licensing, getting an inspection from the fire department, and making any necessary modifications to ensure the house was compliant with Regional Center requirements. And in March, the first residents began moving into New Beginnings. Ladi, 43; Jon, 48; and Ron, 54 all moved out of the developmental center and into the community for the first time since they were young children.

Not In My Back Yard

e've all heard the term NIMBY – meaning "Not In My Back Yard" and referring to situations where people living in a particular neighborhood wish to prevent other people with certain characteristics from moving into their neighborhood. Historically, NIMBY has been directed toward individuals or families who were members of racial or ethnic minority groups.

Racial and ethnic discrimination has become increasingly rare in the United States. NIMBY still exists, however, and it is often targeted at small group housing for special populations, including people who are homeless, people with a criminal history living in "halfway" houses, and people with a history of drug or alcohol abuse living in recovery homes. The rationale for such resistance is that residences of these types lower the property value of the neighborhood or that the residents of these homes pose a danger to the neighborhood, particularly to the children.

Perhaps surprisingly, people with developmental disabilities moving out of institutions into regular homes in regular neighborhoods, also encounter NIMBY-ism. While most of us recognize that this was true in the past, it may be difficult to believe that it still occurs. But this is just what is happening. Neighborhood resistance to the establishment of licensed homes for people with developmental disabilities has recently been reported by four different regional centers. One

Check out pages 3 to 6...

For information about the "Year of the Community," a profile on Senator Wesley Chesbro, photos and a recap of the 40th anniversary leadership symposium, a copy of the governor's letter declaring October 5 Regional Center Day, and how to get your copy of the latest edition of the regional center history and the newest video about the regional centers called "How Far We've Come." "Everything was settling down as the residents adjusted to living with each other in their new community-based environment. Two of them began attending day programs and the third started working in supported employment at The Copy House. They finally had the opportunity for the first time to make choices, get involved in meal preparation, and learn all sorts of new things that they'd never had the opportunity to do before," explains Robertson.

What Robertson didn't know at this time, was that as daily routines were being established at the home, some of his neighbors were busy

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A CNN cameraman films residents and staff enjoying an afternoon snack at the New Beginnings home in Pasadena during taping for a piece that gave all involved parties – both those for and opposed to the home's presence in the Upper Hastings Ranch area – an opportunity to present their views on the situation. The piece aired on CNN Headline News and local affiliates.

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The Director's VIEWPOINT It's Time to Defeat NIMBY-ism Once and for All

s we come to the end of our 40th anniversary year as a regional center system, we have much to celebrate. At the same time, we still face significant challenges. Among the most critical is the continued need to build a truly inclusive society.



Executive Director Diane Anand

A primary value expressed in the Lanterman Act is for children to live at home with their families and adults to be included as active members of their communities. Within our own Center, surveys of clients and families have told us repeatedly that one of the things most highly valued but regarded as most elusive is social acceptance of people with disabilities. The promotion of understanding and acceptance stands as one of our most important leadership challenges.

Throughout my years of work in the field of developmental disabilities, I have dealt with numerous issues, but among the most harmful to individuals and society is the syndrome known as NIMBY – Not In My Back Yard.

This attitude – often born of fear and intolerance – has surfaced recently in our Lanterman community. It was sparked by a few residents of the Upper Hastings Ranch area in Pasadena, who have waged a campaign of misrepresentation and distortion in an effort to close a residential care home in their community.

Regional Center staff members attended community meetings on the issue in July and September, and came away truly dismayed by the misinformation and vitriol that they observed. We were also moved by the compassion and understanding expressed by a little girl, Claire Barmann, who had the courage to address the assembly and assure those present that the residents of the home are nice, gentle men. We could all learn from that remarkable child.

Elsewhere in this edition of "Viewpoint" is an article about the situation in Pasadena and the intrepid Barmann family. A second article summarizes the federal and state laws protecting the right of people with developmental disabilities to live as active, included members of their community; and the body of empirical research that disproves virtually every concern about neighborhood safety and property values raised by people acting out of NIMBY.

Despite the existence of laws, the findings of research, and more than 40 years of effort to change the lives of individuals with developmental disabilities and their families – this syndrome appears again and again. Why does NIMBY continue to resurface, not just in our community but in other areas of California as well? What prevents people from accepting diversity and tolerating differences?

The answer lies within each individual. It is the attitudes of people we must change. We can pass laws, but we cannot legislate a change in attitudes.

The misunderstanding and misperceptions such as those exhibited by residents in this Pasadena neighborhood result from a lack of knowledge about and experience with people with developmental disabilities. While it is true that some individuals have a mind so closed or a fear so deeply rooted that their beliefs could never be changed, for most

Lanterman Helps Families Combat Oral Disease Epidemic Through Preventive Screenings and Education at Oral Health Fairs

The California Oral Health Needs Assessment of Children (1993-1994) labeled oral diseases* a neglected epidemic. And according to the Dental Health Foundation's Web site, "Oral diseases can cause significant pain, interference with eating, poor self-image, over-use of emergency rooms, and valuable time lost from school and work. In the United States in 1989, over 20 million work days and 51 million school hours were lost due to dental-related illness. In some cases, untreated oral diseases have resulted in death. Waiting until oral diseases appear and then treating them will never control the epidemic. We need to prevent the diseases from ever occurring."

The assessment concluded that oral diseases continue to be the most prevalent and also the most untreated diseases of children in California and the United States. Thirty-four percent of Americans no

longer have any of their natural teeth, but through oral health fairs, the most recent one held this October, Lanterman is educating parents of children birth to 5 on how they can help their children achieve and maintain good oral health, and keep their natural teeth throughout their lives.

Leticia Reyes, dental coordinator at Lanterman, says, "The oral health fairs help us educate as many parents as possible and debunk widely believed misconceptions about the role baby teeth play. Primary teeth don't just exist to fall out, they are important for speech development and nutrition, and to maintain space for the permanent teeth. In addition, permanent teeth that come into an unhealthy (decayed) mouth are likely to become unhealthy too."

The Dental Health Foundation Web site also says, "While the mouth is a unique part of our body, it is intimately connected to other body systems and is vital to our overall functioning and health. Teeth are live organs with blood vessels and nerves. Unlike other organs in our bodies, however, teeth have long been viewed as 'expendable.'"

We'd like to thank the following organizations and individuals for their assistance in educating families about the importance of oral health, prevention of oral diseases, and for the reminder that our teeth are not "expendable." Approximately 70 dental screenings were performed by Dr. Greg Kaplan, who also donated toothbrushes and toys, and Dr. Reza Radmand and his assistant, Gabby Castaneda.



Above: Koch+Young Resource Center staff hosted a dentalrelated story time as part of the oral health resource fair that complemented the dental screenings with hands-on demonstrations and educational information.



At left: Dr. Greg Kaplan asks a child to open wide as he performs a screening.

Three hygiene students from West Los Angeles College, Rita Gladlow, Durga Gurung and Monica Nguyen, assisted the dentists with screenings, answered questions, and also performed demonstrations for children and their parents on how to properly brush teeth.

The resource fair featured a Biotene/First Teeth station staffed by Lauren Ashtar, Smiles of Hope Health Promoters Antonia Esparza and Gina Padilla, a nutrition table staffed by *Get Fit*! Project Manager Margarita Blanco, and Xylitol products donated by Xlear Company. There was also an arts and crafts station staffed by Lanterman's Carmen Alabat and Anita Arcilla-Gutierrez, and the Koch+Young Resource Center staff hosted dental story time. "Show Me Your Smile!: A Visit to the Dentist" featuring Dora the Explorer was the most popular book with 20 readings.

A special thanks to event organizers Silvia Flores and Leticia Reyes, and to the following Lanterman staff who volunteered for event set-up, staffing the check-in table, and for filling in wherever a helping hand was needed: Claudia Ayala, Jessye Davis, Delmy Fernandez, Ameenah Francois, Hector Gravina, Gwen Jordan, Nancy Leiva, Patricia Rodriguez and Lourdes Tabullo.

If you have questions about your child's oral health, are interested in a dental screening or in finding a dentist that has experience working with children with special needs, contact your service coordinator. For more information about oral health in children birth to 5, visit www.first5oralhealth.org/.

At right: Children demonstrate the "tooth crowns" they made at the arts and crafts station.



*The term "oral" disease is used instead of "dental" disease because diseases of the mouth affect more than just the teeth; they involve the gums, palate, tongue, the inside of the cheeks, bones, and other structures that support the teeth. Oral diseases such as gingivitis (early gum disease) and dental caries (tooth decay are infections and are not self-limiting. Daily self-care, such as tooth brushing, is needed to reverse gingivitis to healthy gum tissue, and decayed teeth require professional treatment to remove the infection and restore tooth function. To view the findings of the needs assessment, visit www.dentalhealthfoundation.org/ topics/children/assessment/.

people information and dialogue do make a difference.

The fact that NIMBY-ism is still alive after 40 years of advocacy and efforts to advance social acceptance, indicates clearly that it is time for us to redouble our efforts to educate and inform the rest of the community. Like the Barmann family, we must have the courage and conviction to stand up for our values, communicate them to the community, and model them in our everyday lives.

For too long we have tolerated keeping people with disabilities segregated from the rest of society. We must ensure that young children are introduced to their peers with disabilities in preschool, before prejudices have an opportunity to develop. We need to help our segregated programs for children and adults become more engaged in the community. We need to help adults with disabilities obtain real jobs in regular work places. And, yes, we must continue to give our adults with developmental disabilities opportunities to live in and be active participants of the community.

If each one of us steps up to accept this challenge, we can – one individual and one neighborhood at a time – transform our society into one in which NIMBY is no longer a concept.

Below left: Hygiene students from West Los Angeles College demonstrated proper brushing techniques for parents and their children, and then allowed them to practice.





Dr. Reza Radmand (left) with Leticia Reyes, dental coordinator and oral health fair organizer, and Dr. Greg Kaplan. The dentists donated their time to perform screenings on approximately 70 children ages birth to 5.

Senator Wesley Chesbro and the "Year of the Community"

n 1990, by a 52 percent majority, Californians passed Proposition 140, an initiative addressing term limits for members of the California Senate and Assembly. The proposition limits members of the Assembly to three 2-year terms and senators to two 4-year terms. This resulted in the loss of many long-serving legislators accompanied by the loss of in-depth knowledge of the disability services system and the institutional memory of the struggle for rights for people with disabilities.

In the current political environment, when many officials have become distracted from their responsibilities to their constituents by the need to identify and prepare a campaign for their next office, Senator Wesley Chesbro has taken the lead in ensuring that the Legislature will actively promote the rights of people with developmental disabilities and their full inclusion into community life in California. In 2006, Chesbro, who has served as chair of the Senate Select Committee on Developmental Disabilities and Mental Health, authored senate concurrent resolution 115 which proclaimed 2006 as the "Year of the Community," and ushered in a decade of renewed commitment to the vision of

the Lanterman Act and investment in the community service system. This calendar year is the final year of Chesbro's second term in office. Following is a short bio on Senator Chesbro and his contributions to all Californians with developmental disabilities.

Who is Senator Wesley Chesbro?

Wesley Chesbro (D-Arcata) is a native Californian and 35-year resident of Humboldt County. He was elected in 1998 to represent the diverse Second Senate District, which includes California's pristine North Coast and the North Bay counties of Humboldt, Mendocino, Lake, Napa, Sonoma and Solano.

During his Senate tenure, Chesbro served as chair of the Joint Legislative Budget Committee and of the Senate Budget and Fiscal Review Committee. He also chaired the Senate Select Committee on California's Wine Industry and the Senate Select Committee on Developmental Disabilities and Mental Health. He also served on the Senate Select Committee on College and University Admissions and Outreach, and the following Senate committees: Agriculture, Environmental

Senate Issues Concurrent Resolution 115 and **Reaffirms Commitment to the Developmental Services System**

🖪 arlier this year, the California Senate issued senate concurrent resolution 115, which reaffirmed the Legislature's commitment to the system of community services for people with developmental disabilities. Introduced by Senator Wesley Chesbro, the resolution proclaims that the year of 2006 is the "Year of the Community" and the beginning of a decade of renewed commitment to the vision of the Lanterman Act and investment in the community service system.



Quality, Health, Human Services, Governmental Organization and Veterans Affairs. Chesbro also served on or chaired the Senate Budget Subcommittee No. 3 on Health. Human Services, Labor and Veteran Affairs during the last eight years. This subcommittee is



Senator Wesley Chesbro

responsible for funding and oversight of the developmental services budget.

Senator Chesbro served as a co-chair of a Joint Legislative Committee on Mental Health Reform (now disbanded); and served as the Senate representative on the Proposition 63, Mental Health Services Act, Oversight and Accountability Commission, co-chaired its Innovation Committee, and served as a member of its Executive Committee.

As Budget chair, Senator Chesbro has been a leading advocate to protect and expand funding for services that support persons with disabilities in their own homes, and has been a steadfast proponent of policies that promote client selfadvocacy and self-determination.

Senator Chesbro has authored key legislative reforms and initiatives, including:

- The statewide expansion of self-determination pilot projects, also known as self-directed services
- The merger of the area developmental disabilities boards and the State Council on **Developmental Disabilities**
- Improvements to foster more successful movement of patients from state hospitals into the community
- The establishment of the California Memorial Project, to research and commemorate persons who died while in residency at a state hospital or developmental center
- The establishment of improved criteria for the use of seclusion and restraints in a variety of residential facilities, including psychiatric hospitals, developmental centers, state hospitals, skilled nursing facilities and foster care group homes, and requirements for staff training and data collection and posting
- The development of the template for an Olmstead Advisory Council to provide advice and recommendations to the State Health and Human Services Agency for the placement of individuals in non-institutional settings (Although this bill was vetoed, the Governor subsequently administratively established an Olmstead Advisory Council.)
- Requiring the expansion of home- and community-based waivers to increase capacity and facilitate moves from nursing homes to the community
- Authorizing the California Housing Financing Agency to make loans to finance affordable housing for persons with special needs
- Establishing and funding new community residential models to serve persons moving out of Agnews Developmental Center

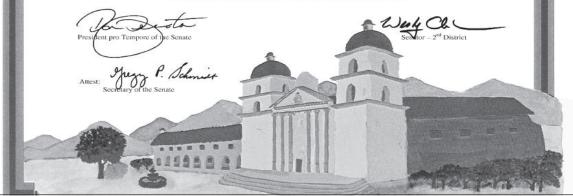
WHEREAS, During the decades following the passage of the Lanterman Act, the service system's evolution was by advances in knowledge and technology and by the increasing recognition of the right of people with disabilities to and full participation in society, including the rights of children to live at home with their families; and

WHEREAS, The 21 regional centers in California continue to expand and diversify their services while serving over persons with developmental disabilities and their families; and 200,000 pc

WHEREAS. The service system has grown increasingly complex, requirements for service providers have grown in ration, and expectations for services have become more rigorous due to advances in knowledge and technology; and

to the Lant-

sophistication, and expectations for services have become more rigorous due to advances in knowledge and technology; and WHEREAS, The 40th anniversary of the regional center system is an appropriate time to reaffirm our commitment to the Lanterman Act, and renew our investment in the community system; now, therefore, be it **Resolved by the Senate of the State of California**, the Assembly thereof concurring. That the Legislature hereby proclaims the year of 2006 as the "Year of the Community" and the beginning of a decade of renewed commitment to the vision of the Lanterman Act and investment in the community service system; and be it further **Resolved**, That the Legislature will actively promote the rights of people with developmental disabilities and their full inclusion into community life in California; and be it further **Resolved**, That the Secretary of the Senate transmit copies of this resolution to the author for appropriate distribution.



Adopted in the Senate June 26, 2006 and in the Assembly June 19, 2006.

 Establishing a workgroup to consider innovative service delivery models to meet the non-residential needs of persons with developmental disabilities

Not only has Senator Chesbro been an advocate for Californians with developmental disabilities, he has continued to be an advocate for local governments, access to health care, improved school facilities, protection of the California coastline, and California's veterans.

Prior to his election to the state Senate, Senator Chesbro served on the Humboldt County Board of Supervisors and the Arcata City Council.

Senator Chesbro was born in 1951. He attended California State University, Humboldt, and graduated from the University of San Francisco with a bachelor's degree in Organizational Behavior. He is married to Cindy Chesbro. They have two sons.

Portions of this biography and photo reprinted from the state of California Senate Democratic Caucus Web site.

40th Anniversary Leadership Symposium Addresses Current

any people believe that turning 40 is a good time in their lives to take stock and evaluate where they've been, where they are now, and where they would like to be in 40 years. As the regional center system enters its fifth decade in a journey that has shattered old paradigms and transformed the lives of hundreds of thousands of people with developmental disabilities, Lanterman and Harbor Regional Centers joined together to present "Reaffirming the Commitment...Realizing the Vision," a leadership symposium celebrating 40 years of service to individuals with developmental disabilities at the Manhattan Beach Marriott on October 5.

"The leadership symposium was a thoughtful commemoration reflecting on where we started and how far we've come, but it also offered an opportunity for us to explore the challenges that remain for people with developmental disabilities who aspire to live full, productive and satisfying lives as active members of their communities," shares Diane Anand, executive director.

The symposium featured presentations from four nationally-recognized experts in the following focus areas: education, housing, employment and technology. The morning sessions focused on education and housing and featured Judy Elliott, Ph.D., the current assistant superintendent of School Support Services at Long Beach Unified School District; and Henry Cisneros, chairman of the CityView companies and former secretary of the U.S. Department of Housing and Urban Development under President Bill Clinton. The two afternoon sessions were with Paul Wehman, Ph.D., director of the Rehabilitation Research and Training Center on Workplace Support and chairman of the Division of Rehabilitation Research at the Virginia Commonwealth University, who spoke about employment; and Jacquelyn Brand, founder and first executive director of the Center for Accessible Technology, who addressed technology.

Elliott focused her session on the promise and reality of the Individuals with Disabilities Education Act and No Child Left Behind, the successes of inclusion, as well as the continuing challenges facing educators, children and their families. She also addressed the need to realign education systems, policies and practices to include all students and promote student achievement. Cisneros' presentation included a review of national and state policy, as well as practical considerations affecting the availability of affordable housing for people with disabilities. He shared strategies on how to identify properties and funding sources, form collaboratives, and the importance of identifying appropriate residents.

The lunchtime event featured a technology and book fair showcasing the latest in assistive technology and recent publications in the four topic areas. The speakers were on hand to sign their books, which are now available for borrowing through the Koch+Young Resource Center Library.

The afternoon session on employment with Wehman shared successes in supported and competitive employment, but also focused on the remaining challenges, including support needs of people with severe disabilities, economic realities of the marketplace, social acceptance of workers, increasing demands for worker knowledge, and disincentives for employment among people with disabilities. Brand screened scenes from the movie "Freedom Machines" to help her illustrate how applications of technology can assist people with disabilities, especially people with communication limitations, to be productive citizens and full participants in society.



Above, from left: Sharon Shueman, Lanterman consultant, with Belen Vargas from the Weingart Foundation, and Warwick Troy of Shueman Troy Associates

Below: Andy Charng from San Gabriel Pomona Regional Center speaks with Henry Cisneros, chairman of the CityView companies and former secretary of the U.S. Department of Housing and Urban Development under President Bill Clinton.





Above, from left: Executive Director Diane Anand with Terri Delgadillo, director of the Department of Developmental Services, and Eileen Richey, also from DDS



Above: Ann Seisa (left) of Vagthol's Residential Care Center, Inc. and Lupe Trevizo-Reinoso of Easter Seals Southern California catch-up during the morning break between the education and housing sessions.

At right: Exhibitors from various assistive technology companies demonstrated their products and answered questions from symposium participants.

Below: Dr. Judy Elliott (right) takes questions while she signs copies of her books that were available for purchase at the book fair.



Below: Meredith Goetz (left), staff attorney at the



Below: A symposium participant has Dr. Paul Wehman, who spoke about successes and remaining challenges in employment for people with disabilities, sign a copy of his book, as Regional Manager Helane Schultz looks on.



The symposium, which was moderated by Denny Amundson, a former aide to Assemblyman Frank D. Lanterman and former director of the Department of Developmental Services, concluded with a celebratory reception and dinner, at which he presided as master of ceremonies. The evening festivities featured a screening of the rough-cut version of the sequel to "We're Here to Speak for Justice: Founding California's Regional Centers" entitled "How Far We've Come: The Journey Toward the Lanterman Vision." A final version of the film will be released by the end of 2006 and will be available for purchase, as well as for borrowing through the Koch+Young Resource Center. Whittier Law School Special Education Clinic, with Yudi Bennett, president of the Foothill Autism Alliance, Inc.

At right: Jacquelyn Brand (left), founder and first executive director of the Center for Accessible Technology, used scenes from the movie "Freedom Machines to demonstrate how technology applications can assist people with disabilities. Janet Cole (right), filmmaker, also attended the symposium.



Challenges Facing the Developmental Disability Field

At right: Symposium participants browse recent publications in the four topics of education, housing, employment and technology at the book fair presented by Special Needs Project.

Below, from left: Judith Enright of Enright and Ocheltree LLP with Associate Director Melinda Sullivan and Howard **McBroom**





Above, from left: Symposium Moderator Denny Amundson, an aide to Assemblyman Frank D. Lanterman and former director of the Department of Developmental Services, with Henry Cisneros and a symposium participant







Above, from left: Sandra Hammersmark, a longtime professional in the field of developmental disabilities, with Dr. Richard Koch, a pioneering professional who was instrumental in the creation of the regional center system, and his wife Jean

Above, from left: Lanterman's Past Board President Robert Wedemeyer with Vinita Anand, resource and information specialist; current Board President Al Marsella; and John Erdos from The Capital Group Companies



Above, from left: Lanterman Peer Support Partner Zulma Mena, Resource and Information Associate Sandy Riancho, Service Coordinator Sonia Garibay, Intake Specialist Yadira Navarro, Resource and Information Specialist Christine Mayola, and Resource Center Administrative Coordinator Ruth Zuniga enjoy the pre-dinner reception hosted by Heffernan Insurance Brokers.





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enjoyable time at the dinner and film screening.

ACKNOWLEDGING OUR SPONSORS

We wish to thank the following organizations for their support in making the 40th anniversary leadership symposium possible.

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Get Your Copy of "How Far We've Come: The Journey Toward the Lanterman Vision"

Celebrating the California Regional Center system's remarkable 40-year history, this thoughtful film continues the story begun by "We're Here to Speak for Justice." Through the voices of those who've lived the Lanterman vision, this documentary explores the regional centers' many accomplishments and their impact on the lives of individuals with developmental disabilities and their families.

The film was produced by Harbor Regional Center and Frank D. Lanterman Regional Center with support from City National Bank, 18 additional regional centers and the Association of Regional Center Agencies. The film was directed by Janas Communications.

Copies of the film are available for purchase online through the Special Needs Project at www.specialneeds.com or by calling 805.962.8087. The film is available in DVD format only and costs \$19.95. The film will also be available for loan through the Koch +Young Resource Center Library. Contact the Resource Center at 213.383.1300, x. 730 or kyrc@lanterman.org.

Governor Declares October 5, 2006 Regional Center Day

overnor Arnold Schwarzenegger declared October 5, 2006 "Regional Center Day" in recognition of the 40th anniversary leadership symposium – "Reaffirming the Commitment... Realizing the Vision" – and the accomplishments of the 21 regional centers. Department of Developmental Services Director Terri Delgadillo presented the message on behalf of the governor at the symposium, which was held in Manhattan Beach, and was a day spent reflecting on progress and looking to the future.



GOVERNOR ARNOLD SCHWARZENEGGER

October 5, 2006

Regional Center Day

I am delighted to offer my warmest greetings to all those attending the fortieth Anniversary Leadership Symposium.

California has always been at the forefront of innovation and progress, setting an example for the rest of the nation. The Lanterman Developmental Disabilities Act is a case in point. Forty years ago, our state launched a bold experiment in a public-private partnership that became the regional center system. This was a model service that dramatically improved the quality of life for people with developmental disabilities and their families.

The Act gave these individuals the right to services that enable them to live a more independent and dignified life. It also declared that they had the same legal rights and responsibilities as all other residents and gave the regional centers the task of advocating and protecting those rights. These centers are part of a community-based network that acts as a focal point to coordinate services.

Now serving more than 210,000 individuals statewide, regional centers continue to provide innovative and cost-effective programs that allow people with developmental disabilities to achieve full inclusion into their communities. Today, I join you in celebrating the forty years of this successful venture. While there are many challenges ahead, we can be proud of how far we have come in helping our fellow Californians become active members of our state.

On behalf of all Californians, please accept my best wishes for a memorable event and every future success.

Sincerely, Shoreney Arnold Schwarzenegger

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Get Your Copy of the 40th Anniversary Edition of the Regional Contor History Today

Regional Center History Today

Several years in the making, the 40th anniversary edition of the History of the Regional Centers in California, "Reaffirming the Commitment... Realizing the Vision" is now available.

The history is chock full of information about the events and people – parents, professionals and legislators – that led to the creation of the regional center system in the state of California. It chronicles more than four decades of the journey taken by individuals with developmental disabilities and their families as they worked to improve the quality of their lives.

The history is broken down into decadelong periods starting with the period from 1955 to 1965 and continuing through 2006 –

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

-Taken from the introduction to the 40th anniversary edition of the History of the Regional Centers in California

1955 to 1965 and continuing through 2006 – the year the regional center system celebrated 40 years of providing service to people with developmental disabilities and their families.

Copies of the history are available for purchase by visiting www.lanterman.org/orders.

Reaffirming the Commitment... Realizing the Vision

MEET THE PEOPLE BEHIND THE TITLES School Age/Transition Manager Bill Crosson

🖰 ince joining Lanterman in July 1999, Bill Crosson has often shared his own family's story with the families he works with. Crosson has a younger brother, Brian, who was diagnosed with autism in the 1960s, before the regional center system came into being. At the recommendation of the medical professionals, Crosson's parents placed Brian at Pacific State Hospital, which was later renamed Lanterman Developmental Center. "I don't know that anyone seriously considered that Brian could grow up living with us. I still feel the break that separation caused our family, especially around times of birthdays and holidays. My earliest memories of Brian are hazy, and one in particular is tied to an occasional visit to the state hospital," shares Crosson. "When I can, I try to remind the parents I work with how fortunate they are to have their children at home. It is a direct result of the rights and protections the Lanterman Act has afforded children and adults with developmental disabilities."

A native of California, Crosson has lived in Los Angeles for most of his life. He grew up in Eagle Rock, attended Loyola Marymount University, where he received a bachelor's degree in Humanities, and then spent a couple of years just wandering, venturing into the Pacific Northwest and Alaska trying to see if there was an alternative to Los Angeles. Family ties drew him back to the Southland. Before coming to Lanterman, he worked as an accountant and an auditor as part of a 19-year career in the criminal justice system in Los Angeles.

"I've done a number of things, but some things are qualitative rather than quantitative in the way they influence your perspective. The most important thing you bring to a job is your attitude. Regardless of your background, you have to find a way to connect with what you do. I have always been interested in justice at a fundamental level. And in this job, you also have to be motivated to help others succeed," says Crosson.

Crosson worked in the Glendale/Foothill Service Coordination unit for seven years and had been the unit's service coordinator specialist for the past year. On December 1, Crosson became manager for the new School Age/Transition Service Coordination unit. He adds, "Am I excited? Heck yes, and I look forward to continuing to serve the clients and their families with the same enthusiasm and optimism." While working as a service coordinator, most of his clients were in their 20s and 30s, while some were teenagers transitioning into adulthood and some were older. The new School Age/Transition unit serves clients from ages 3 to 22. "The school-age years are probably the most challenging, both for the children and for their families. These are the years when hope and despair may sit side-by-side in the minds of many caring parents," reflects Crosson.

"I think it takes great sensitivity to help these families understand there are options. That is why I love the transition years. This is the time when a person is coming into his or her own. They are starting to do things for themselves. It's a crucial time in a person's life to match them to the right opportunities and the right facilitators to help them become independent," he adds. "Many parents struggle with the idea that their children can be independent - that they can live in their own apartment, hold a job, or have their own things to do during the day and on the weekends. I have come to realize that if we want our children to be integrated into the community, we have to accept integration among ourselves first, before we can expect the rest of society to accept it." For Crosson, there is a spectrum of possibility for integration - and integration can't strictly be based on cognitive level. It must also be based on "emotional intelligence," a person's emotional stability and their degree of maturity.

As a service coordinator specialist, Crosson took on special projects. His all-time favorite project was interviewing potential candidates for the UCP apartments in Burbank. "We had 42 applicants for 17 units and we had to make some very tough decisions about who would get in since there were so many people capable of living there," says Crosson. "It wasn't just about who needed more or less support. It was a lot about how well they could get along with other people with developmental disabilities, and whether they could accept each other and have empathy for one another." He considers housing one of the biggest challenges facing people with developmental disabilities. "Not every person with a developmental disability may want to live in their own apartment, even with the supports that make it possible. But for those who do want their own place to live, the options are so limited they almost don't really exist," he explains.

Crosson feels that the real reward of his job is that he was frequently able to help his clients get to where they wanted to be, and to see the fruits of his efforts in his clients' successes. He shares, "Sometimes though, even what may have seemed like the best idea doesn't work out. You get knocked down but the mission requires you to pick yourself up and keep giving it your best shot. It can be hard to help other people succeed, and you just can't win all the time. You also have to see that at some point you need to get out of the way. You can help, but it is always the clients who make it happen for themselves. You also have to remember that success isn't only measured in the short term. Sometimes, something you may have done years earlier, that didn't show any results at the time, did have an impact farther down the line. You may not even be around to see it."

When asked about the one thing that he would change if he could, that would make his job easier, Crosson replied, "We have got to find better ways to take advantage of 21st century information technology to do business. It seems we move more paper around now then ever before, and this is supposed to be the age of digital documents and linked networks."

In his free time, Crosson currently enjoys reading, gardening and dabbling in electronics. He is especially fond of science and nature, and



School Age/Transition Manager Bill Crosson

enjoys reading about natural history. He also enjoys attending the Pasadena Symphony with his parents, siblings, and their families. He lives with his wife Veronica and their 11-year-old daughter Diane Montana near the Miracle Mile District of Los Angeles. He also puts his energies towards pondering some of the more complex questions of life – How to be a better citizen of a great city like Los Angeles? How to balance the needs of children and parents in households where both parents work? Whether the frenetic way of life that has become commonplace for most of us will in the end exhaust our society as a whole?

Crosson shares, "We have accomplished a lot when you think back to what people with developmental disabilities faced 40 years ago, but the distance we have come from there, is probably equal to the distance we still need to go from this present time to get to where we ought to be in the future. This is the challenge of fully integrating people with developmental disabilities and developing the right societal attitudes."

Perhaps 40 years from now, when Crosson thinks back on what he has seen and what people with developmental disabilities have accomplished, the image will be of one of the new and excited tenants at UCP's apartments in Burbank, and not that starkly haunting image of some 40 years ago when, as a child on a family visit to Pacific State Hospital, he peered through a mesh window into a dormitory where a little girl with Down syndrome cried untended and alone in a room of perhaps 20 empty beds.

Lanterman Develops New School Age/ Transition Service Coordination Unit

n light of the continued increase in the number of clients being served by Lanterman's two school-age units – Los Angeles and Foothill, the decision was made to develop a third school-age unit. The new unit, which began working with clients and their families on December 1, differs from the existing ones in that it serves children from 3 to 22 years of age, where as the other two units only serve clients through approximately 13 years of age. About one-third of the service coordinators in this unit will serve the Foothill area, while the rest will serve the Hollywood/Wilshire and Los Angeles areas. The new unit will primarily be comprised of current Lanterman school-age service coordinators who are bringing their experiences and knowledge with them. Bill Crosson, regional manager, shares, "This expanded geographical area of focus means the team will have to develop a very broad understanding of the resources available throughout much of Lanterman's service area to assist clients and their families during the periods of the most dramatic change in their lives – kindergarten, the elementary grades, middle and high school, and post high school transition services, including some first time employment."

7

Help Raise Money, Use GoodSearch

D id you know that performing your good dead of the day could be as simple as searching the Internet using GoodSearch? Simply by searching the Internet at www.goodsearch.com you can raise money for Lanterman Regional Center.

You use **www.goodsearch.com** like any other search engine – the site is powered by Yahoo! – but each time you do, money is generated for Lanterman. Here's how it works:

1. Go to www.goodsearch.com

2. Type Frank D. Lanterman Regional Center into the "I support" box and click on "verify"3. Search the Internet just like you would with any search engine

Since GoodSearch shares its advertising revenue with charities and schools, every time you search the Internet at GoodSearch, you'll be earning money for Lanterman.

GoodSearch also has a toolbar you can download from the homepage so that you can search right from the top of your browser.

You can keep track of Lanterman's estimated earnings by clicking on "amount raised" once you designate Frank D. Lanterman Regional Center as your organization of choice. The more people who use the site, the more money we'll earn, so please spread the word. All money earned through GoodSearch will be designated for Lanterman Regional Center's Help Fund, which is the fund that gives all year long by providing assistance with emergency food, clothing, shelter and other necessities for Lanterman clients and their families.

The service coordinators moving to this new team are Janett Arellano, Myrna Contreras, Jessica Ferman, Sonia Garibay, Lissette Gomez, Maribel Limon, Ana Moran, Patricia Rodriguez, Alice Vartabedian and Cecile Williams. As the service coordinators are bringing their caseloads with them, there should be no disruption on the part of the clients and families being served by them. In addition, one new service coordinator is joining the team, Celene Heman.

The Get Fit! Games: A Special Day for

hen the *Get Fit!* Program began over one year ago, the *Get Fit!* Games seemed like an awful long time away to most of the participants, and a rather intangible goal to be working towards. But as the Games approached, the excitement and anticipation of competing against Harbor Regional Center in a world-class venue like the Home Depot Center, and demonstrating their athletic abilities, became their focus and all they could talk about.

By 8 a.m. on the morning of November 4, participants began arriving by buses and vans, or via transportation provided by their parents and caregivers. The participants lined up at the registration tables to receive their official *Get Fit*! T-shirts, name tags and schedules. They donned their yellow T-shirts emblazoned with the *Get Fit*! logo and headed over to the food and beverage area where they enjoyed breakfast while anticipating the start of the opening ceremonies. After the 9 a.m. opening ceremonies, participants were chaperoned by student volunteers to the morning sporting events, which included track and field events, basketball skills, tennis skills, beach volleyball, and a soccer game.

A Family Fun Walk event featuring a climbing wall, jumpers, and a health and fitness fair was hosted by Harbor Regional Center from 10 a.m. to noon. It warmed up to be a beautiful Southern California day, and the participants returned from the morning athletic events decorated in medals and brimming with excitement, ready for lunch.

Lunch was served in the Tennis Pavilion Courtyard and featured great performances by Exbound – No Boundaries band and the AbilityFirst Drill Team; and lunchtime entertainment also featured promotions by the 102.7 KIIS FM Street Team, including music, contests and giveaways. In addition, the long-awaited Lanterman versus Harbor staff basketball game took place at lunchtime in the Velodrome. The Lanterman team came out on top with a 26-19 victory over Harbor. The afternoon events featured a participant basketball game and more soccer skills activities. By the end of the day, participants were exhausted but smiling.

"To see the joy on the participants' faces and hear the excitement in their voices, made it all worth it," says Margarita Blanco, Lanterman's *Get Fit!* project manager. "We were delighted with the level of local community involvement. Student volunteers from Narbonne High School and UCLA were a tremendous help, as were the volunteers from the Sheriff's Department Compton Station's Explorer Scouts. And, special thanks to our friends over at the Albertsons supermarket (Carson) who with short notice where able to deliver lunches to the Home Depot Center. Thanks to all of the wonderful staff, volunteers, sponsors and our program partners who made this event possible. The participants had a terrific time. The staff and volunteers did a great job and they really enjoyed making the day extra special for our participants. The event was a great success."



From left: Lanterman staff Madeline Lara, Silvia Flores, Leticia Reyes, Tammy Simmons and Zena Begin volunteer at the athlete registration booth.



The Los Angeles County Sheriff's Department Compton Station's Explorer Scouts assisted with traffic control and event parking.





The Redondo Union High School ROTC Color Guard carried the flag at the opening ceremonies of the Get Fit! Games.



Sharon Shueman, Get Fit! Program consultant, gives opening remarks.





Athletes from Goodwill anticipate the start of the Games during the opening ceremonies.



From left: Phil Duthie from the city of Torrance, along with Mr. Outrageous who inspired the crowd and posed for fan photos, and Sarah Wells who sang the national anthem during opening ceremonies.



Above: Narbonne High School students help with breakfast setup and distribution. Breakfast featured donated breakfast bars from Trader Joe's and bagels from Bagel Factory.

At left: Ruth Zuniga and Christine Mayola staffed the Lanterman booth at the health and fitness resource fair hosted by Harbor Regional Center.



Dole's Bobby Banana rallies the crowd of Get Fit! athletes during opening ceremonies.

Project managers Margarita Blanco (left) and Kerry Ryerson welcome athletes and volunteers to the Get Fit! Games.



Harbor Executive Director Pat Del Monico and Lanterman Associate Director Melinda Sullivan acknowledge the efforts and contributions of the athletes, volunteers, community partners and sponsors in making the Get Fit! Games a reality.



Athletes demonstrate their basketball skills.



At left: Randy Fortune goes in for the shot after his fast break during the participant basketball game in the Velodrome.

At right: The Lanterman staff basketball team defeats the Harbor team 26-19 during lunchtime game in the Velodrome.



Participants play a full-court basketball game with independent living skills instructors and staff.



Mark Aguilar demonstrates his free throw shot during the basketball skills session.



Athletes and Everyone Else Involved



The Home Depot Center hosted the Get Fit! Games on a sunny Saturday in November.



UCLA student volunteers assist with bagging snacks and lunches.



Above: Lanterman staff member Julio Vicente (third from left) and the KIIS FM Street Team. KIIS FM provided music and giveaways during the lunch hour.



Athletes and volunteers boogie to the sounds of Exbound

Above: Mark Nakamura and Sonia Prado enjoy a lunch that featured Subway sandwiches, Yoplait yogurt and Dole raisins.





Below: Michael Anderson (left) is congratulated on his accomplishments during the Games.







Cynthia Dresser (left) and Lucy Verdugo are presented with . medals after competing in track and field.

Joey Harris cools down with his father Steve Harris, and poses for a victory shot after his win in a track and field event.

Acknowledging Our Sponsors

We wish to thank our event sponsors without whose support the Get Fit! Games would not have been possible.

VENUE SPONSOR Home Depot Center

MUSIC SPONSOR 102.7 KIIS FM

Below: The

team shows off

their moves at

a lunchtime

pep rally.

FOOD AND BEVERAGE SPONSORS Bagel Factory (Torrance) -Francisco Sanchez, manager Dole Jamba Juice (Inglewood/Hollywood Park) Starbucks (Torrance) -Rob Lesh, manager Subway Restaurants -Bill Combs, owner (Harbor City) Rick Luthra, owner (Carson) Trader Joe's (Torrance #121) Yoplait - Community Council



OTHER SPONSORS Arroyo Developmental Services City of Glendale **City of Torrance** Corporate Express DBA Hollywood Royale Guest Home Vagthol's Residential Care Center, Inc.

Special Thanks to Lanterman's Get Fit! Games Volunteers

Ardis Adrian Anita Arcilla-Gutierrez **Ebony Beasley** Zena Begin Patrick Brown Ada Del Rio Silvia Flores Michael Greene Ashley Hooks Ali Hussain Gwen Jordan Soonthree

Madeline Lara **Christine Mayola** Monica Mauriz Jeannette Orlando Laura Parada **Patricia Pratts** Leticia Reyes Tammy Simmons Melinda Sullivan Jerry Sunada Maral Tahmizian Maria Tapia-Montes



Below: Athletes participating from Villa Esparanza refuel for their afternoon events.





Above: Athletes from AbilityFirst's Crown House anticipate the arrival of refreshing Jamba Juice fruit smoothies.



during lunch.



Athletes bend it like Beckham during a soccer game.

Below: Lanterman soccer participants and volunteers



Keaotamai **Candice Lamere**

Julio Vicente **Ruth Zuniga**

We Would Also Like to Acknowledge:

AbilityFirst Albertsons (Carson) Tracey Busbea, store director BCR Goodwill LA Works Modern Support Services

Narbonne High School Sheriff's Department **Compton Station** UCLA student volunteers Villa Esperanza



Soccer Coach Julio Vicente (top left) gives a pep talk to the Lanterman soccer team.



At left: Goodwill athletes show off their medals as the Games wind down.

At right: Lanterman Get Fit! athletes from BCR are all smiles as they get ready to head home.



Lanterman Regional Center Presents Staff with Service Awards

In a job marketplace where companies often see relatively high turnover of their employees, it becomes important to acknowledge those individuals that stay on five, 10, 15 or even 20 plus years. Years ago, the Lanterman board of directors implemented service awards to recognize the service and commitment of our own veteran employees to the Center and the Lanterman community. Service awards are presented to employees during the month in which they reach their milestone year of service – five, 10, 15, 20 and more years.

"Lanterman staff that reach these milestones do so by embodying the Center's commitment to delivering a high quality of service. Regional Center work is very challenging, and staff often find themselves working with limited resources and high expectations to achieve results. It takes a special kind of person to succeed," says Diane Anand, executive director.

During the period from July to November 2006, the following individuals received service awards for their years of service to Lanterman Regional Center and the community:

- Maral Tahmizian, quality assurance specialist, Community Services, for 15 years
- Monica Mauriz, service coordinator, Early Intervention; and Claudia Ayala, manager, Operations, for 10 years
- Abraham Estrada, service coordinator, Foothill School Age unit; Douglas Lopez, service coordinator, Los Angeles Wilshire/Transition unit; Sean Goudeau, service coordinator, Los Angeles Wilshire/Transition unit; Marc Baca, appeal and complaint coordinator, Legal Services; Ralph Bingener, resource center assistant, Koch+Young Resource Center; and Ada Del Rio, secretary, Early Intervention for five years

We asked all of the Lanterman staff that have received service awards why they stayed at Lanterman and what is their favorite memory during their time at Lanterman.



Ralph Bingener

Lanterman has provided me with the opportunity to grow and be successful. It has been a pleasure and a great experience to be a part of achieving Lanterman's mission.

- Claudia Ayala, manager, Operations

I have stayed at the Early Intervention unit at Lanterman for 10 years because I love working with families, providers and the community as a team to promote the well-being of children. My most memorable moments here at Lanterman are the celebrations held with the Spanishspeaking Early Intervention Support Group, shopping for toys for the children served by the El unit, having lunch with my co-workers to share scrapbooks and recipes, and the holiday celebration that Lanterman's leadership team hosts every year.

- Monica Mauriz, service coordinator, Early Intervention

Fathers' Corner

Continued from page 1

therapy is at home, so I have to clean the house; karate; "Friends at Play," a social skills group; dance class; and on the weekends we do the sports of the season – basketball, baseball, swimming, soccer or tennis.

Special Olympics is fun, but you can only compete in one field at the meets. So we do swimming one meet and tennis in another. We may trade one for basketball later, but we'll let Tim decide which he likes best.

We also have our weekend outings. We've been Avenger Arena Football fans for the last seven years at the Staples Center, which took some patience and hard work handling crowds and loud noises. For the last five years, I have purchased three season tickets – for myself, Tim and one of his friends. We've never missed a game and since puberty, the cheerleaders are just as important as the game. "Take cheerleaders home, Dad," says Tim. "Talk to Mom, Son."

Last month I operated the spot light for the Halloween bash for Tim's choir class. My wife was on the curtain. It was a family affair. Mary and I also do the school newsletter called "The Buzz" per year. He enjoys the whole process of driving there. We must have the television in the car – for videos – and the DVD player for restaurants. The motel must have a pool and we must see his favorite shows at SeaWorld – Shamu, the Dolphins and the 4-D Lighthouse. We all have a lot of fun, but until the dates of the activities are close, we keep quiet about what's upcoming, as Tim becomes obsessive and talks of nothing else – making all of us bonkers.

During the last four years, I've tried to work on my teaching skills and most importantly, my patience. Although we've had improvement, it's a work in progress. But Tim helps me out when I get excited by saying, "Calm down, Dad" or "Don't worry, I'm fine." I've found it's hard not to try and do everything for him, instead of letting him do for himself. And always in the back of my mind I'm wondering, "Will he ever be able to take care of himself when we're gone?"

This retirement isn't what I had planned through the years, but I wouldn't change it for anything else.

The daDA Fathers' Support Group meets on the second Monday of every month from 7 p.m. to 9 p.m. at the Denny's at 3060 San Fernando Road in Los Angeles (off Fletcher Street, exit off I-5 or near the Glendale Freeway). For more information, contact **Aaron Hinojosa** at **626.296.1556** or **Germán Barrero** at **626.840.9842**.

I have come a long way not only as a client, but as a part of the Koch• Young Resource Center. I put detailed information packets together to share as much information with our clients and families since there are moments that a family needs help with their child when they are diagnosed with a developmental disability. I participated in some of the classes here at the Center to get as much knowledge and education in this field. I'm hoping for many more years ahead.

- Ralph Bingener, resource center assistant, Koch+Young Resource Center



From left: Ada Del Rio, Claudia Ayala and Monica Mauriz

The reason why I come to work everyday is because I really love my job and also because I feel like I'm an active participant of an organization that strives to make a difference in the lives of people with developmental disabilities and their families. My favorite memory is the effort and joy that is put into the annual holiday event.

- Ada Del Rio, secretary, Early Intervention

Be the First to Know – Subscribe to Lanterman's E-mail Bulletins

t's very easy to subscribe to Lanterman's e-mail bulletins. Simply visit www.lanterman.org and click on "Subscribe" to provide us with your e-mail address. You will automatically

be signed up to receive e-mail bulletins about information related to Lanterman Regional Center's general activities and events.

You can also sign up for bulletins about a specific topic, such as legislative issues, or bulletins specific to a certain age, disability or area, by providing us with additional information. No information collected will be given to anyone outside of Lanterman; it's just for the purpose of sending targeted e-mails to the Lanterman community.

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We have Fun Cards at SeaWorld San Diego and take one of Tim's friends with us about four times



Tim Seward (left) with a quarterback from the Avengers and his friend Jeff.

Fathers' Corner is a regular "Viewpoint" feature. If you are a father and would like to write for Fathers' Corner in an upcoming "Viewpoint," contact Vinita Anand at 213.383.1300, x. 753 or vanand@lanterman.org.

There are many events, including valuable trainings and workshops, we at the Center hear about, but due to limited financial resources, we cannot mail flyers for each of these events. By subscribing to the e-mail bulletins, you too will be able to hear about them and be informed about what's going on in the Lanterman community.

Update Your E-mail Contacts – Lanterman Staff Have New E-mail Addresses

Recently, Lanterman's Information Systems department assigned new e-mail addresses to the Center's staff. The new e-mail address format for most staff is their first initial, followed by their last name, without any periods or underscores. So for example John Smith would be jsmith@lanterman.org. However, there are some staff that have the same first initial coupled with the same last name, such as Jane Smith and John Smith would, and their e-mail addresses will not follow the above address format exactly. Lanterman staff's old e-mail addresses will continue to work for several more months, but please be sure to update all of your Lanterman contacts. If you need to confirm that you have the person's correct new e-mail address, please e-mail them at the e-mail address that you have and ask them to provide you with their new e-mail address.

SAVE THE DATE

Come One, Come All to the 2007 Social Recreational Resource Fair

Join Lanterman's Foothill School Age unit for the third annual Social Recreational Resource Fair sponsored by the city of Glendale's Department of Parks, Recreation and Community Services on Friday, February 9, 2007. The fair will be held from 10 a.m. to 2 p.m. at the Pacific Community Center located at 501 South Pacific Avenue, Glendale, CA 91204. The event focuses on community resources that all families can access.

Contact Cheryl Francisco, service coordinator in the Foothill School Age unit, at **cfrancisco@lanterman.org** or **213.383.1300**, **x. 530** to RSVP and to assist you with any questions.



Lanterman Announces New Partnerships with Burbank and Glendale Public Libraries

ith the continued success of our partnership with the Pasadena Public Library, Lanterman Regional Center is pleased to announce two new partnerships that have been established with the Burbank Public Library and the Glendale Public Library.

Christine Mayola, resource and information specialist with the Koch+Young **Resource** Center says, "The partnerships were created to offer families community-based locations that integrated generic library services with our specialized collection, as well as evening and weekend hours to increase the accessibility of our library drop-off and pick-up service. In addition, we hope such collaborations with community organizations will bring about more public awareness of developmental disabilities, and strengthen community ties between the general and special needs communities.'

We would like to express our warmest thanks to the Down Syndrome Association of Los Angeles in Glendale and to BCR in Burbank for serving as dropoff/pick-up locations for the KYRC library for so many years. The new drop-off locations in Glendale are at the Montrose Crescenta Branch and the Pacific Park Branch, and the new Burbank location is at the Buena Vista Branch. Following is a list of all of the Koch+Young Resource Center Library's drop-off and pick-up locations.

Koch + Young Resource Center Library -Drop-Off/Pick-Up Locations

Important! Before you drop off items, contact the KYRC Library at **213.383.1300**, **x**. **730**, **1.800.546.3676** or **kyrc@lanterman.org** to avoid late fees. If you are picking up items at one of the following locations, please call the location first to verify the items are there.

Atwater Park Center

3370 Perlita Avenue, Los Angeles, CA 90039 Contact: Berta Rodriquez, 323.666.1377 Hours: Monday to Friday, 8 a.m. to 4 p.m.; Saturday/Sunday, Closed

Burbank Public Library - Buena Vista Branch

300 North Buena Vista Street, Burbank, CA 91505
Contact: Circulation Desk, 818.238.5625
Hours: Monday to Thursday, 10 a.m. to 9 p.m.; Friday, 10 a.m. to 6 p.m.; Saturday, 10 a.m. to 5 p.m.; Sunday, 1 p.m. to 5 p.m.

Glendale Public Library - Montrose Crescenta Branch

2465 Honolulu Avenue, Montrose, CA 91020 Contact: Circulation Desk, 818.548.2048 Hours: Monday/Thursday, 1 p.m. to 8 p.m.; Tuesday, 1 p.m. to 6 p.m.; Wednesday, 10 a.m. to 6 p.m.; Saturday, 1 p.m. to 5 p.m.; Friday/Sunday, Closed

Glendale Public Library - Pacific Park Branch

501 South Pacific Avenue, Glendale, CA 91204 Contact: Circulation Desk, 818.548.3760 Hours: Tuesday to Thursday, 1 p.m. to 8 p.m.; Saturday, 10 a.m. to 5 p.m.; Monday/Friday/Sunday, Closed

Pasadena Public Library - Hastings Branch

3325 East Orange Grove Boulevard, Pasadena, CA 91107
Contact: Circulation Desk, 626.744.7262
Hours: Monday, 11 a.m. to 9 p.m.; Tuesday to Thursday, 10 a.m. to 8 p.m.; Friday, 2 p.m. to 6 p.m.; Saturday, 10 a.m. to 6 p.m.; Sunday, 1 p.m. to 5 p.m.

Pasadena Public Library - San Rafael Branch

1240 Nithsdale Road, Pasadena, CA 91105 Contact: Circulation Desk, 626.744.7270 Hours: Monday to Thursday, 10 a.m. to 6 p.m.; Friday, 9 a.m. to 1 p.m.; Saturday, 10 a.m. to 6 p.m.; Sunday, Closed

Pasadena Public Library - Lamanda Park Branch

140 South Altadena Drive, Pasadena, CA 91107 Contact: Circulation Desk, 626.744.7266 Hours: Monday/Tuesday, 10 a.m. to 8 p.m.; Wednesday/Thursday, 10 a.m. to 6 p.m.; Saturday 10 a.m. to 6 p.m.; Friday/Sunday, Closed

Access Lists of New KYRC Library Resources Online

n response to the requests that we have had for lists of new resources available in the Koch+Young Resource Center Library, we are now publishing a list bi-weekly and posting it to our online library catalog at http://library.lanterman.org.

You can access the online catalog two different ways:

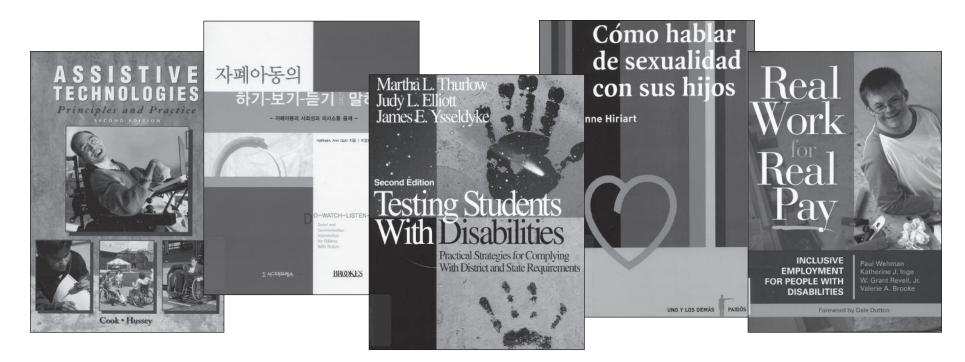
- If you want to access the online catalog from Lanterman's homepage (www.lanterman.org):
- 1. Mouse over and highlight "Information and Resources" in the navigation on the left side of the screen
- 2. Click on "KYRC Library"
- 3. Click on "http://library.lanterman.org"
- 4. Mouse over the "Lists" option at the top of the screen
- 5. Click on "New Titles"
- If you want to access the online catalog directly:
 1. Type http://library.lanterman.org into your browser's address field

2. Mouse over the "Lists" option at the top of the screen 3. Click on "New Titles"

Regardless of which option you choose to access the online catalog, by clicking on "New Titles," you will be able to browse through the bi-weekly lists of new resources recently added to our library collection. The newest list is displayed at the top.

By clicking on the name of the list, which is a range of dates (i.e., $10/16/06 \sim 10/31/06$) you will be able to see all of the titles added to our collection during that time period. You can then sort the list by title, subject, author, etc.

"We encourage you to use the online catalog and review the lists to see if there are any new titles in our collection that are of interest to you. On average we add about 40 to 50 titles to our library collection every other week. You can also view the entire library collection through this online catalog site," shares Sungkyung Kim, Lanterman's librarian.



Richard Song Studies Hard and Works Towards Realizing His Dreams

S even years ago, Richard Song, his wife Emmy and their 15-year-old daughter Jennifer immigrated to the United States from Korea. Song had a sister that was living in Los Angeles, and they settled in Koreatown to be close to her. "Because of my disability, I didn't have a chance to realize my dreams of achieving success in Korea," explains Song. "People with disabilities get virtually no social benefits, little support for education or special education, and life is pretty miserable. By moving to the States, I had the opportunity to pursue higher education."

Song spent one year taking English as a Second Language classes and then spent four years taking general education courses at Los Angeles City College. He shares, "There is a great deal of support for people with developmental disabilities in California. I was inspired and encouraged by this, and it made me realize that I can be someone – I can realize my dream of having success in life, contribute to the community and become a self-advocate."

His efforts paid off and Song finished his general education courses with a 3.9 grade point average. This fall, Song transferred to the University of California, Los Angeles, as a full-time student. He enjoys working with numbers and decided to major in Business Economy. "I like the UCLA campus, but it's so huge and can be a little bit hard to get around," adds Song. "It's also taking some getting used to attending classes on the quarter system."

Song also volunteered at the Koreatown Youth and Community Center working with others with disabilities. "While volunteering, I discovered that there were quite a few people with disabilities who were capable of working, but because of the fear of losing their benefits, didn't work," says Song. This "social dilemma" as he calls it, is the key reason he is interested in learning more about business, the economy and social welfare. While he is currently just focusing on finishing his bachelor's degree, Song's longterm goal is to pursue his graduate degree in the area of public policy and one day help enact policy changes that will make it easier for people with disabilities to work.

Song believes that his motivation is derived from his faith. He's been a Christian for more than 30 years, and was particularly inspired by the story in the bible about the blind man who asked Jesus to cure him, however, Jesus explained to him that there was a purpose in his blindness. Song shares, "If God creates, he has a purpose for each creature, whether they are disabled or not, and this has inspired me to not only dream, but work my hardest to achieve my dreams. I also know that I couldn't have accomplished what I have without the support of Emmy."



Richard Song with his wife Emmy. Song transferred to UCLA this fall to pursue a degree in Business Economy.

Song encourages all people with disabilities to challenge their disability to achieve their dreams. "Society and the community in the States are very supportive of people with disabilities, and there is a lot of opportunity in this country for education, for achieving success and for realizing dreams," he adds.

Song, who met his wife of 15 years at a church in South Korea, regularly attends church. With the limited free time that he has between studying for exams and writing papers, Song and his family like to travel. So far, his favorite place has been Yellowstone National Park.

Meet the People Behind the Titles: Karem Chacana

As director of Human Resources at Lanterman Regional Center, Karem Chacana is an integral member of our leadership team. We feel it's important for everyone in our community to have a better idea of the person behind the title and her responsibilities, so "Viewpoint" recently met with Chacana and asked about projects in the works, as well as the biggest challenges and most rewarding aspects of her job.

Then Karem Chacana was 5 years old, her family moved from Chile and settled in New York. She still remembers being a young girl of about 10 or 11 and sitting at the kitchen table late at night helping her father. "Since English was his second language, it was difficult for him to comprehend everything his teacher was saying, so my father would tape record the classes his employer would send him to, and then in the evening I would transcribe them and explain to him what the teacher was saying," shares Chacana. "I'd also help him understand the letters and forms that the company or the union would send to him, and sometime this meant calling the union representative to ask questions on his behalf."

Even at this young age, Chacana knew that she wanted to work in a profession that was about helping people, but this feeling was solidified by her experience working as a receptionist at an advertising firm when she saw how terrified the non-English-speaking cleaning crew was of the personnel office. Chacana adds, "These past experiences have inspired me to do my best to create an environment where people aren't scared to come and talk about their needs and issues and/or to ask questions."

Her first human resources position was as the human resources coordinator in a two-person department, in a union environment with 700 employees – Windows on the World, the restaurant at the top of the World Trade Center. "I worked there for three years, and it was the best schooling for me because I experienced all aspects of human resources at once – service, training, benefits, experience with the union, recruiting and terminations," says Chacana. "But most importantly, I learned that no matter the industry, for it to be successful in achieving its objective, the organization must be able to deliver personalized service, which begins with its employees."

From Windows on the World, she moved to human resources at the Four Seasons Hotel in New York and then in Los Angeles. For Chacana, regardless of whether one works in the hospitality industry or the human services arena, the human resources department exists not only to serve the organization but also to serve the employees. She says, "Human resources is not just about making sure the policies and rules are adhered to, it's about making sure the employees understand the culture of the environment which they are in. They depend on us for information and direction, in addition to us providing the proper tools they need to do their job." Chacana, who can't imagine working in any field but human resources, joined Lanterman in June of this year. Some of her responsibilities as director of Human Resources include recruiting, which is her admitted favorite aspect of her job; benefit planning; maintaining and updating the personnel policies; writing job descriptions; payroll adjustments; and workers compensation. "The bigger picture for me is to assist in defining who we are and what we do. I believe the employees of Lanterman are our biggest asset and I believe that each of us needs a sense of dignity, pride and satisfaction in what we do. Because satisfying the families served by Lanterman depends on the united efforts of many, we are most effective when we work together cooperatively, respecting each other's contribution and importance," explains Chacana. "I believe the employees of Lanterman are our biggest asset and I believe that each of us needs a sense of dignity, pride and satisfaction in what we do. Because satisfying the families served by Lanterman depends on the united efforts of many, we are most effective when we work together cooperatively, respecting each other's contribution and importance."

-Karem Chacana, director of Human Resources

Lanterman team working smoothly," says Chacana. She's also working on exploring additional choices in the health benefit area, such as bringing a Weight Watchers chapter to the Center, and creating a more user-friendly personnel policies manual.

When asked about some of the things that she'd like to change, Chacana shares, "I would like to make sure that human resources is more involved in the orientation of new staff. Lanterman is an organization that has very high expectations of its staff. I feel it's important for new employees to know what our mission and philosophy is from the very beginning. By doing this, we ensure that a new employee knows what is expected of him or her and what it is they need to deliver on."



Human Resources Director Karem Chacana

Some of the longer term projects that she's working on include introducing an information system specific to the human resources field. "This will free up human resources to focus on doing the things we need to do to keep the In the short time that Chacana has been at Lanterman, her favorite memory is of the 40th anniversary leadership symposium. She says, "It was a day of education for me, where I took in everything that was discussed. It was an opportunity to understand the challenges that continue to exist in the environment we work in, and to understand what the Center's employees are going though on a daily basis with clients so I can know better how to serve them. I am in awe of what the Center has been able to accomplish in the past 40 years and look forward to being a part of new things to come."

Chacana lives with her 13-year-old daughter Kaylene in Valencia. In her free time, she loves to read, dine out and spend time with family. A little known fact about Chacana is that she studied classical ballet for 15 years.

CAC News

Consumer Advisory Committee Members Attend Self-Advocacy Conference



While advocating on behalf of people with developmental disabilities is important to increasing their inclusion in community life, teaching them to become selfadvocates is an equally important focus. Self-advocacy for people with developmental disabilities is about giving them the tools and knowledge so they can speak out for themselves, know their rights and responsibilities, and be respected and valued members of their communities.

In pursuit of developing their own selfadvocacy skills, Lanterman's Consumer Advisory Committee Chair Armen Frundzhyan, along with Lanterman Peer Advocate Mary Flynn, and Robert Heaton, CAC member, attended the ninth annual



From left: CAC member Robert Heaton, CAC Assistant Staff Advisor Marie McGinley, CAC Chair Armen Frundzhyan, and Peer Advocate Mary Flynn attended the ninth annual self-advocacy conference.

conference put on by and for adults with developmental disabilities, "Self-Advocacy: Gate to the Future." The event was presented by the Self-Advocacy Board of Los Angeles County and held at the Sheraton Gateway Hotel near Los Angeles International Airport.

Highlights from the two-day event held on the weekend of September 30 included an exhibitor fair; a screening of the Oscar-nominated film "Autism is a World" with Sue Rubin, who was present to answer questions afterwards; and eight educational workshops that focused on living on your own, transportation, self-directed services, starting your own business, relationships, learning about your rights, getting a job and cooking.

Marie McGinley, Lanterman CAC assistant staff advisor, also attended the conference, and shares, "Mary and I attended the self-directed services workshop and it generated a lot of



From left: Armen Frundzhyan with Andrea Fay Friedman, conference keynote speaker, Robert Heaton and an unidentified conference participant during the dinner celebration.

interest from the clients as far as what it would potentially accomplish once implemented."

Protection and Advocacy, Inc. also set up a voter registration table. The dinner celebration featured keynote speaker Andrea Fay Friedman, former co-star of "Life Goes On," and was capped with a night of dancing. Frundzhyan adds his thoughts about the conference, "It was great. I liked it a lot. What I learned at the conference will help me in my role as chair of the CAC. I attended the transportation workshop since the CAC is currently focusing on transportation issues. Everything was wonderful, the food was good, and we had fun."

Which is it? – Consumer or Client

A number of years ago, the Lanterman Act was amended from "client" to "consumer," changing how the Act refers to individuals with developmental disabilities served by regional centers. While people with developmental disabilities resist labels and want to be referred to as individuals, they report not liking the term "consumer" and would rather be called "clients," so Lanterman Regional Center has made the decision to use the term "client" whenever possible in referring to the individuals with developmental disabilities that we serve.

DDS LAUNCHES "CONSUMER CORNER"

For more information about the Consumer Advisory Committee, visit the Department of Developmental Services Web site at www.dds.ca.gov and select the "Consumer Corner" option to access information that includes:

- Information about the CAC
- Materials developed by DDS and CAC committees for clients, families and professionals
- Advocacy resources to help clients ensure their rights are protected
- Links to other resources available to individuals with developmental disabilities

Visit the "Consumer Corner" section of the DDS Web site at www.dds.ca.gov/Consumer/ Consumer_Home.cfm.

Contact the Consumer Advisory Committee at Lanterman

f you are a client of Lanterman Regional Center and have an issue or idea that you think other clients would be interested in, and would like to share it with the Consumer Advisory Committee, you can write the CAC at:

Lanterman Regional Center CAC Armen Frundzhyan c/o MJ Kienast 3303 Wilshire Boulevard, Suite 700 Los Angeles, CA 90010

or call CAC Staff Advisor MJ Kienast at **213.383.1300**, **x. 606** or e-mail **mkienast@lanterman.org**.

The Consumer Advisory Committee reports to Lanterman's board of directors and is charged with providing input and advice on the policies, services and programs offered by the Regional Center for clients and their families. The CAC meets on the second Monday of the month at 4:30 p.m. at Lanterman.

Check Out "Partners in Policymaking" Program E-learning Site for Courses Created for People with Developmental Disabilities and Their Caregivers

The Minnesota Governor's Council on Developmental Disabilities has created an e-learning site for its "Partners in Policymaking" program, which is a program designed to educate participants to be active partners with those who make policy and to develop partnerships that are based on positive relationships. The e-learning site gives "Partners in Policymaking" participants the opportunity to supplement their learning; a place where program graduates can refresh their skills and stay current on

the way that people with disabilities lived, learned and worked throughout history and growth of the Disability Rights Movement. The course also introduces some of the individuals and groups whose efforts resulted in new ways of thinking about people with disabilities and their rights.



Partners in Education

best practices; and is also a site where others can increase their knowledge and understanding of best practices in the disability field, and learn how to communicate effectively with their elected officials in the continuing struggle to prevent the loss of basic rights for people with disabilities.

Five online courses are now available to anyone who would like to increase their knowledge and skills:

Partners in Living

This seven-hour, self-directed e-learning course has been created to help people with developmental disabilities, their parents, family members and friends, educators and service providers explore and understand the important concepts of self-determination, family support, community living and assistive technology. Every person has the right to a full, meaningful life. The definition of a "meaningful life" isn't the same for every person. What is meaningful to you may not be as important to your sibling, roommate, coworker or neighbor. In this course, participants decide what is a meaningful life to them and how they can achieve a life that is independent, inclusive, productive, self-determined and integrated.

Partners in Time

This eight-hour self-study was created to help people with developmental disabilities, their parents, family members and friends, educators and service providers understand the history of society's treatment of people with disabilities from ancient times through the present. The course focuses on

This three-hour self-directed course was created to help parents of children with developmental disabilities understand and maximize the special education system. The course focuses on a child's right to a free, appropriate public education; the laws that protect those rights; and offers practical ways that parents can ensure that their children benefit from an inclusive education.

Making Your Case

This three-hour self-study course is designed to help people with disabilities and their families create positive change through advocacy. The course helps participants understand the legislative process, the essential elements of good advocacy, identify and research personal issues, then advocate for systems change as individuals and as part of larger community efforts. The course includes opportunities to put what has been learned into practice through a series of interactive exercises.

Partners in Employment

This six-hour self-study course is designed to help people with developmental disabilities find meaningful jobs and plan a career. In this course, participants will create a résumé, or portfolio of their strengths, skills and interests; learn how to network and identify potential employers; prepare for an interview; and understand the hiring process.

To access the e-learning courses, visit www.partnersinpolicymaking.com/online.html.

One Mother's Story About Life, Having a Child with Special Needs and Changing Her Plans

By Lisa Schoyer

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Chief, Family Support, Children's Medical Services

ith a bachelor's degree from Yale and a master's degree in Fine Arts from CalArts, an exhibition record of 60 plus group shows and 10 solo shows, I planned to become a studio art professor. I'd been an adjunct professor at University of California, Irvine, for three years when my husband and I started a family.

Quin's Medical History

In my sixth month of pregnancy, I had too much amniotic fluid, and no one knew why. An ultrasound revealed nothing, but they were worried they didn't see Quin opening his fists. I followed the advice of my Bradley coach and walked a lot, which seemed to help – so much so that at 38 weeks in to the pregnancy, I didn't have enough amniotic fluid. By the end of that week, when Quin's heart didn't return to normal after simple Braxton-Hicks contractions, I agreed to a Cesarean.

Our son Quin was born in 1995 when I was 35. He weighed 8 pounds 5 ounces, and as far as we were concerned, he was OK, though he needed a little help – "blow-by" oxygen, unremarkable intravenous medications, and nutrition through his belly button. The first interpretation of his brain x-ray was scary – no corpus callosum and "light areas" – but the more experienced radiologist returned from a three-day weekend vacation to replace the interpretation with "Within Normal Limits," the first and best of a slew of "WNLs" we would be getting.

The doctors were pretty sure Quin had a genetic anomaly. The tests he underwent for a diagnosis grew increasingly invasive, with each biopsy sent farther away. Still, the results always returned "Within Normal Limits." At home, it grew clearer, the doctors were right.

Quin left the neonatal intensive care unit at 9 days old, just barely sucking enough breast milk. I tried everything, including going outside of the HMO for help, but Quin grew increasingly irritable, and had mysterious sugar levels in his urine that weren't found in subsequent blood tests. By 2 weeks of age, he cried 45 minutes out of every hour, around the clock, which took place for the next nine months, tapering down to crying 20 minutes out of every hour for the next year. I pumped breast milk, tried the supplemental nursing system, and tried bottle-feeding. He grew dehydrated, lost weight and spiked fevers – ending up in the hospital on prophylactic antibiotics three times in his first month.

At three weeks, Quin received a gastrostomy tube to help him get enough nutrition. This was a terribly hard decision for us, but we had no choice. Soon, it became apparent Quin was globally developmentally delayed. He developed



Quin is 3 weeks old, and already exhibiting significant signs of failure to thrive.

heart arrhythmia which turned into severe hypertrophic cardiomyopathy – for which they operated on when he was 2; orthopedic issues requiring ankle and wrist bracing, and hip tendon surgery; upper airway issues; dysphagia; and extreme myopia. When he was 5, just as we thought he was coming out of the woods, weaned from all gastrointestinal medications and starting to eat almost enough to begin considering removing the G-tube, we found a malignant

What is Costello Syndrome?

In 1987, Dr. Costello, a pediatrician in New Zealand, published a report of two children with similar physical characteristics and mild intellectual handicap in the Australian Pediatric Journal. He had published a brief description of the children in a New Zealand Medical Journal some six years before. In 199I, Dr. Der Kaloustian reported a child with similar features and suggested that this particular pattern of growth, behavioral and physical features be called Costello syndrome.

The word "syndrome" is derived from old Greek and merely means "running together." There are many thousands of syndromes in the medical literature and they often have the name of the first person to recognize that particular constellation of physical, behavioral and developmental characteristics that are related with a common, even if unknown cause.

In 1996, Dr. Costello published a follow-up of his original cases and reviewed the characteristics of 16 children in



From left: Turner, 16 months old, Lisa Schoyer, her husband Lee Johnson, and Quin who is seen at 6 years 2 months old.

tumor. At 6 years 9 months old, Quin died of relapsed cancer.

Systems of Care

After Quin was born, our HMO offered Certified Nurse Assistant (CNA) support, reviewed each month since it was not a plan benefit. Fortunately, when he was 3 months old, I changed to a PPO, which awarded us a Licensed Vocational Nurse (LVN) in the home.

Upon bringing Quin home with a G-tube, we found ourselves overwhelmed in a universe we never knew existed: Regional Center, California Children's Services, Early Intervention, CCS Medical Therapy Units, Medi-Cal...With the help of our Regional Center service coordinator, we applied for and were determined eligible for a Medicaid Waiver.

Our days were filled with early intervention and vision therapy provided through the Regional Center, physical therapy in the home provided by the insurance company, replaced, when he grew older, by center-based early intervention provided by the school district, and center-based OT and PT provided by CCS; regular monthly visits to seven specialists and the associated involved tests they prescribed. Oh yes, and I made regular calls to the insurance company, the home health agency, and collections agencies to tell them to talk to the insurance company.

I received Quin's Medi-Cal BIC card when he was 2¹/₂ years old, but didn't know how to use it. The cover letter was brief and vague. The phone number provided on the letter usually went to the voicemail of a person who hardly ever returned my calls, and when she did, she was curt and unhelpful. So, though it took me at least 30 minutes to gather all Quin's equipment and supplies together before leaving the house, between intervention, doctor and therapy appointments, I took Quin with me to the closest Medi-Cal building to learn more. Quin, equipped with his enteral pump and formula in an icepack, meds and extra diapers, and I stood in line at the Medi-Cal office for two hours before the person at the window said we were at the wrong building. It seemed I had a winning lottery ticket, but I didn't know how to cash it in.

With the last known test failing to confirm a diagnosis, the metabolic geneticist warned us we'd come to the end of the line. A college friend, now an internist, found the name of a

the literature with the diagnoses of Costello syndrome. Children with Costello syndrome typically have a birth weight in the upper normal range. The pregnancies have most often been described as normal, but there are occasional reports of decreased fetal movements with excess amniotic fluid present in approximately one-third of the pregnancies. All children with Costello syndrome have difficulty feeding and, frequently, severe failure to thrive.

Although they are normal in their dimensions at birth, children with Costello syndrome cross the growth charts downward. This failure to thrive brings most children with Costello syndrome to medical attention. Children with Costello syndrome have facial features and physical characteristics that are very similar and readily recognizable. Most children typically have darker skin or a more olive complexion than is expected for the family. Parts of the skin, particularly on the hands and feet, and even arms and legs, may become thickened with time. Many children develop warty papules on the skin, particularly around the mouth and nose. It was these skin lesions that led to the recognition of the diagnosis in most children before the condition became as well recognized as it is now. Joint abnormalities are also relatively common. There may be increased movement at the small joints of the hand and restriction of movement at the elbow. There is often tightening of the tendon at the back of the ankle and in many children this requires surgery. All the children who have been described in the literature walked, but at a variable age from 2 to 7 years. A number of children are reported to speak in simple sentences by the age of 4.

The cause of Costello syndrome remains unknown. To date, there have been about 300 cases reported worldwide. Many children have had very extensive investigations, including skin and muscle biopsies, in search of a storage disorder. In 2005, Japanese genetic researchers identified mutations of the HRAS gene to be associated with Costello syndrome. Over 80 percent of the children with clinical diagnoses have the mutation. Of the remaining children, most have tested positive for Cardio-facio-cutaneous syndrome. For more information about Costello syndrome, visit www.costellokids.co.uk/. You can also contact Lisa Schoyer at taos@earthlink.net.

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What is Children's Medical

Services?

The Children's Medical Services (CMS) Branch of the County of Los Angeles Department of Public Health provides a comprehensive system of health care for

children through preventive screening, diagnostic, treatment, rehabilitation, and follow-up services. The CMS Branch carries out this mission through a variety of programs meeting specific health care needs of targeted population, which include California Children's Services (CCS), Child Health and Disability Prevention (CHDP) Program, Medical Therapy Program (MTP) and Foster Care Program (HCPCFC). For more information about CMS, visit http://lapublichealth.org/cms/.

One Mother's Story

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dysmorphologist - a type of geneticist I'd never heard of before. We worked to get an appointment with the dysmorphologist, our gatekeeper primary care physician was very supportive, but our HMO refused. As far as they were concerned, they provided us a geneticist, so their obligation was met. I learned the dysmorphologist accepted Medi-Cal, so I tried that route, but Medi-Cal needed a denial from the HMO first. And our HMO refused to call their denial a denial. Fortunately, the dysmorphologist's administrator said he'd try to figure out what to do. I believe the dysmorphologist was never paid by Medi-Cal because of that loophole, but we finally got the diagnosis - Costello syndrome.

Change of Plans

From May 2001 to June 2002, I spent 220 days in the hospital helping Quin during his treatment for his malignant tumor. I worked hard to advocate for Quin because he simply didn't respond the way typical children do – I found myself educating the first-year residents about my son and Costello syndrome.

None of this would have been possible without the support of our Regional Center service coordinator, who worked with me to provide respite nursing in the hospital. Quin's medical history required someone knowledgeable to be by his side to ensure appropriate care for this boy who constantly responded outside the norm. Our home health nurses sacrificed their time and took a deep pay cut to provide the bedside care.

Along with meeting and talking with parents of other pediatric intensive care unit patients, I came to feel that teaching bright college students how to be critical thinkers using art as a medium was not as urgent as helping families with all the information that Quin exposed me to. I passed up a rare tenure-track art professorship opportunity.

In January 2003, six months after Quin died, I changed careers. I joined the County of Los Angeles Children's Medical Services (CMS) as a parent liaison. I was the second parent in the state hired in this capacity. I help represent the parents' viewpoints internally and work to make CMS programs easier for families to understand.

I have also become president of the national Costello Syndrome Family Network (CSFN) and Lifetime Trustee of the International Costello Syndrome Support Group (ICSSG). We estimate there have been about 300 children born with Costello syndrome since it was first identified in 1971. Through CMS and the Costello Syndrome Family Network, my personal goal is to help parents avoid the unnecessary frustrations that we went through, to participate in developing and implementing best practice care, and to give parents tools to provide the best quality of life possible for their child.

The Bresee Foundation is a Place of Opportunity in a Neighborhood that Faces Significant Daily Challenges

s part of an effort to increase the number of technology options available in the community, Lanterman used some of the grant money awarded to us from the California Consumer Protection Foundation earlier this year to contract with the Computer Access Center to help us develop relationships with community technology centers, or CTCs. One of these organizations is the Bresee Foundation. The CTCs, including the Bresee Foundation, had also received a grant from the same foundation to pilot the inclusion of people with developmental disabilities in a two-month, computer-based, autobiographical, digital storytelling project.

"As our relationship with the Bresee Foundation developed, we began to learn more about all of the different services they offered in addition to being a community technology center," says Christine Mayola, resource and information specialist in the Koch+Young Resource Center. "The first time we took a tour of the Bresee Foundation and learned from staff about the various other services they offer, we couldn't believe how fortunate our community is that they have this wonderful resource several blocks from our office."

Seth Eklund, director of Education and Career Development at Bresee shared, "We believe in the ultimate worth and dignity of each individual, and this is an important stepping stone for how we approach working with people with developmental disabilities and their families." Up until the grant project, the Bresee Foundation had no formal program in place to work with people with developmental disabilities. If someone with a developmental disability walked through Bresee's doors to use their services, whether recreation or technology or anything else, they would do their best to help that person.

"We've never done any specific outreach to this particular population, but we definitely agree with the philosophy of trying not to train people with developmental disabilities in isolation," adds Eklund. "One of the Lanterman clients that



Students are hard at work in the Bresee Foundation's CyberHood computer lab.



As part of its outreach and recreation program, the Bresee Foundation organized a bike trip from San Francisco to Los Angeles.

participated in our film class, was a member of Bresee prior to ever taking the class. Not only does Bresee afford all people the ability to access technology they might not have at home, coming to Bresee gives members a sense of belonging and makes them feel like they are part of something bigger, part of a community."

While the initial pilot storytelling project was considered a success, the Bresee Foundation is evaluating how the curriculum and programming can be adapted to make it even better. As part of the grant the Bresee Foundation received, they were to include five individuals and only two have been through the digital storytelling program so far. Jerold Kress, multimedia coordinator and digital storytelling instructor, explains, "It was challenging to adapt my standard storytelling curriculum. I couldn't loan out equipment or leave the facility, so we were very much locked into simply telling stories into the camera. I'm really into making films about social justice issues, and many of the stories that they would tell about their daily experiences were more interesting than what came out in the actual filming of their digital stories, such as stories about being discriminated against, and realizing this was happening, but at the same time being powerless to do anything about it. If they could film in their own way, in their own environment, and we could see the world through their eyes as they shared their stories, it would have made for a better project."

"We are looking forward to continuing our collaboration with Lanterman and reaching out to a new segment of our community," says Eklund. "This new collaboration is one more step on the path to achieving full inclusion and acceptance for all people with developmental disabilities throughout our community," adds Mayola.

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About the Bresee Foundation

The Bresee Foundation is a non-profit organization named after Dr. Phineas Franklin Bresee, a Methodist minister who founded the Church of the Nazarene in Los Angeles in 1895. Bresee believed that faith was demonstrated and transformation achieved through serving others, and the Bresee Foundation was established in 1982 by the Los Angeles First Church of the Nazarene to honor his example and carry out his mission. The Bresee Foundation works hand-in-hand with community members to address these issues and remedy difficult problems. Bresee Foundation programs provide community members with access to health care, education, technology and job preparation, recreational activities and other crucial supports. The organization's work is focused in four key areas:

It is a source of faith, hope and service to one of the poorest and most densely populated communities in Los Angeles County, serving the neighborhoods of Koreatown, Pico Union, Westlake and South Central Los Angeles. The organization is working to build a stronger, healthier, safer community for area residents by providing them with access to important resources and services, and empowering them with the knowledge and skills to improve their lives. The Bresee Foundation serves more than 3,000 people on an annual basis in an area that has the highest crime rate in the city of Los Angeles. Most residents live below the poverty level and have no access to health care.

- **Health Services** which provides access to preventive and basic health services, health screenings and health education. The program also provides medical referrals and assists community members in registering for Healthy Families, a state medical insurance program for children.
- Literacy and Academic Enrichment supports the educational development of area youth and their families. The program helps students develop essential reading, writing, language arts and math skills, provides mentors, promotes literacy and encourages and prepares youth for college attendance.
- **Technology and Employment Services** operates a community computing center and job training program that offers low income community members access to computers and the training to use them, as well as access to the Internet and other technological resources. The program also provides career preparation and employment opportunities.
- **Outreach and Recreation** offers positive recreational, cultural and community activities for neighborhood youth. The program connects young people with caring adults in a positive environment and helps them to develop the strength and skills to cope with difficult issues.

The Bresee Foundation is located in Central Los Angeles near the intersection of Vermont Avenue and Third Street. For more information, visit **www.bresee.org**, e-mail **info@bresee.org** or call **213.387.2822**. Memberships cost \$5 annually.

A Classic Case of NIMBY

Continued from page 1

filing complaints with Community Care Licensing, the Pasadena police, Pasadena Building and Safety, and ultimately the Regional Center and the Department of Developmental Services. The anonymous residents of Upper Hastings Ranch, who claimed to be speaking for other Upper Hastings Ranch and Pasadena residents, further incited many of the home's neighbors by suggesting that the residents of this facility were dangerous people; had been inmates and criminals that posed a risk to the community; and that the residents had severe maladaptive behaviors, which caused senior citizens, children and parents to live in fear.

"The first I ever even heard about this matter was when Lanterman called to follow-up on the complaint they'd received," adds Robertson. "I came to find out that neighbors had called the police on us, suspecting that drugs were being dealt from the home. The home always has someone on duty, 24/7, but during the day there are more support staff around to assist each of the clients with basic daily skills, at their day program or work, and in the afternoon with recreational activities. They even referred to many of us as thugs."

At the request of interested parties, Pasadena City Councilmember Steve Ĥaderlein held a community meeting in July to give all sides an opportunity to voice and respond to questions and concerns. "The attitude at the community meeting could at best be described as hostile. The residents had a lot of concerns and questions that stemmed from the misinformation and unsubstantiated claims that were made in the anonymous memorandum about the adults with developmental disabilities living in the home," says Diane Anand, executive director. "It quickly became evident that this situation is a clear cut case of NIMBY (Not In My Backyard) syndrome that was based on irrational fear and ignorance. While the anonymous authors claimed that this was not the case, they were requesting that the city relocate the home to a neighborhood that could better accommodate it."

As the meeting concluded, Robertson invited all of the neighbors to come and meet Ladi, Jon and Ron, and get to know them and the support staff. Another community meeting was also scheduled for September. "After reading the memo, I did my own research about the situation. There was a lot of erroneous information included in the memo, little of it having to do with actual facts. I went to the community meeting with some of our own questions, but it became clear after the meeting, that most of the arguments in the memorandum were based on irrational fear," shares Noelle Barmann, a 15-year resident of Upper Hastings Ranch who lives up the street from the home. "After my mom attended the first community meeting, we decided to visit the home and see for ourselves just what was going on," shares 10-year-old Claire Barmann. "You can't read a book and just learn, you have to be hands-on and experience it for yourself."

"In the 14 years that I've been in the

After their first visit, the Barmanns became regular visitors at New Beginnings, stopping by to hang out with the guys on average a couple of times per week. "So far, the Barmanns have been our only neighbors to stop by to meet everyone and see the home," says Robertson. "It's fun here and we enjoy it," adds Claire. Eventually, Claire's two older brothers also started visiting as their schedules permitted. They do everything from reading stories and hanging out to watching television and spending time outside playing catch or even basketball.

ball around when Claire visits.

After returning home from school, on the afternoon prior to the second community meeting, Claire prepared a little speech about her experiences at the home. She adds, "I wasn't sure when I wrote it if I was going to get up and read it. I wanted to see what direction the meeting was going to take and whether it would make a difference if I said anything." Claire did get the opportunity to read what she wrote. "The people who were smart and wanted to know more about it listened. Some people were very convinced about their beliefs and wouldn't

listen. The neighbors are upset because the guys are different than them. Many of them are older, and they are less accepting. They complain about this, but not the retirement home in our neighborhood," explains Claire.

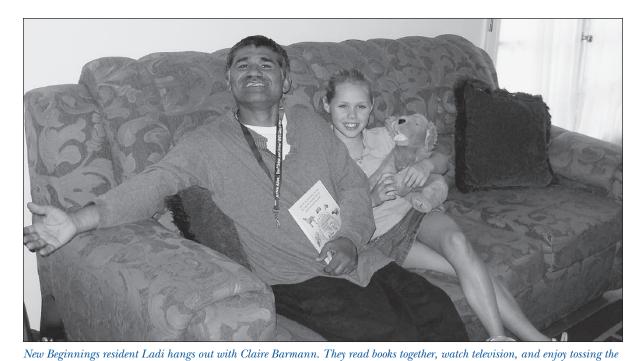
Anderson Crenshaw, who works at New Beginnings, shares, "It seems like things have been improving since the last community meeting where Claire gave her speech. It's hard to know how the neighbors feel about the guys and that they won't give them a real honest chance and get to know them. I tip my hat to the Barmann family for making the effort to get to know the guys. They don't have outside family,

Hello -

I am Claire. I live up the street just a few houses away from New Beginnings. After the meeting in July, my family and I wanted to know more about our new neighbors. We went down to the house and met the residents that live there. One of the residents loves dogs. I decided to donate some of my stuffed animal dogs and books and I think they really appreciate it. I personally think it is a good experience for the residents to not be kept in facilities and be allowed to live in a safe neighborhood. My family and I had nothing but a good experience there at the house. We now go there quite often and all the residents have been very kind toward us. I know that they like the privilege to live there, have their own belongings, and to have visitors.

– Thank you

After the response paper was distributed, the Barmanns received very positive feedback from most of the neighbors on their street and surrounding ones. "My husband brought some facts to the situation, and as time has gone by with no extraordinary event, the hostility has also calmed down," adds Noelle. "There's definitely a division in the neighborhood and a loss of some friendliness between neighbors. What I don't understand is the families with young children who are not taking advantage of this prime opportunity to teach their children about tolerance and differences. What message are they sending?"

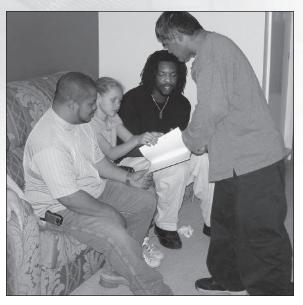


field, this experience took the spirit out of me for a while. I've had to deal with adverse situations in the past, but the degree of hostility here has been unbelievable to me. It's made me more determined than ever. These guys didn't do anything to warrant this backlash and they deserve to be treated with the utmost dignity and respect and to live in the least restrictive environment, and in this case, it's living in a home in Upper Hastings Ranch."

-Guy Robertson, New Beginnings director

relax and interact with the family."

Bernard Barmann, who had not attended the first meeting, decided to attend the second meeting to hear for himself what the complaints of the residents really were. In reaction to what he heard, he wrote an eight-page response to the memorandum from the anonymous residents of the Pasadena and Upper Hastings Ranch and to the Upper Hastings Ranch Association (UHRA) Web site discussion forums. In his response, he states, "I felt compelled to write this because I know many of the assertions in the memorandum and the UHRA Web posting to be factually baseless and find both the author(s)' views and twisting of facts to fit their agendas to be morally repugnant. I felt I had to let Hastings Ranch residents and our elected representatives know that not everyone living near [the home] agrees with those views. I am also writing this because the ARF (adult residential facility) residents, solely because of their disabilities, are incapable of responding themselves. If I do not speak up, then who among my neighbors will?"



Ladi (standing) points to various pictures in the new book he just received from Claire Barmann. Ladi also brought Guy Robertson, New Beginnings director (left) and Anderson Crenshaw over to share with them his newest book.

A Classic Case of NIMBY

Continued from page 16

"My husband brought some facts to the situation, and as time has gone by with no extraordinary event, the hostility has also calmed down. There's definitely a division in the neighborhood and a loss of some friendliness between neighbors. What I don't understand is the families with young children who are not taking advantage of this prime opportunity to teach their children about tolerance and differences. What message are they sending?"

-Noelle Barmann, neighbor

For the last couple of years, Claire and her siblings have all attended schools that have inclusion programs. Claire says, "People at my school have the same disabilities that Ladi, Jon and Ron have. I spend time with them on the playground, the ones that are high functioning enough are in my same classes. I don't feel at all uncomfortable around people with developmental disabilities and others shouldn't either. It's a good experience for them to be out in the community." "It's been very interesting to watch the growth that's taken place in the guys since we met them. I don't know what I'm looking for, but just from being around on a regular basis you can see a clear difference in their vocabulary, in their ability to do things for themselves, and many fewer behaviors," adds Noelle.

In the end, the most neighborly of all of the neighbors have been the guys living at New Beginnings. They have readily watched the Barmanns' house when the family vacations – watering the plants and bringing the mail in. They have even been known to bring the Barmanns' trash cans in off the street on trash day. "Let's face it, these guys are more vulnerable to the neighbors than the neighbors are to them, and of all of the people we are worried about coming into our neighborhood, the least of our worries should be the staff at New Beginnings, who have all been thoroughly screened from fingerprinting to drug testing," notes Noelle.

Robertson shares, "In the 14 years that I've been in the field, this experience took the spirit out of me for a while. I've had to deal with adverse situations in the past, but the degree of hostility here has been unbelievable to me. It's made me more determined than ever. These guys didn't do anything to warrant this backlash and they deserve to be treated with the utmost dignity and respect and to live in the least restrictive environment, and in this case, it's living in a home in Upper Hastings Ranch."

Not In My Back Yard

Continued from page 1

of these is Lanterman Regional Center. Yes, this kind of NIMBY-ism is happening in Lanterman's own "back yard."

Starting on the front page and continuing on pages 16 and 17, you will find an article about residents of a neighborhood in Northeast Pasadena who have mounted a campaign against a licensed home that houses three people with developmental disabilities who have moved out of the state developmental center. Multiple laws, both federal and state, protect the right of these three individuals to live without restriction in this, or any other, residential neighborhood. But, as we are seeing, laws can't change attitudes, and a small group of residents are apparently determined to drive these three people out of their home.

We are very concerned about this situation. We are certain, also, that our concern is shared by a majority of citizens of California who respect the rights of people with developmental disabilities to live – in the words of the Lanterman Act – "independent, productive, and normal lives as active members of their community." For this reason, we are taking this opportunity to review the legal protections accorded to people with development disabilities who want to be included in their neighborhoods and their communities. The information we offer may help readers respond to people who don't want individuals with developmental disabilities in their "back yards."

The Laws Protecting the Rights of People with Disabilities

California was a leader among states in regulating local zoning to protect the rights of people with disabilities. In fact, it was Frank Lanterman himself who, in 1971, authored legislation that prohibited restrictive zoning for licensed homes serving six or fewer "mentally disordered or otherwise handicapped" persons. Fifteen years later this protection was endorsed at the national level by the U.S. Supreme Court. In City of Cleburne v. Cleburne Living Center, the Court ruled 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.

Subsequent federal legislation provided additional protections for people with disabilities who wished to live in the community. The Fair Housing Act (FHA), enacted in 1968 but expanded in 1988 to include people with disabilities, prohibits housing discrimination on the basis of disability and other factors. This law applies to private housing, housing that receives federal assistance, and state and local government housing. Specifically, the FHA makes it illegal to discriminate in "the sale or rental of a dwelling to any buyer or renter because of a handicap of (A) the buyer or renter, (B) a person residing in or intending to reside in that dwelling after it is so sold, rented or made available, or (C) any person associated with that buyer or renter."

The Fair Housing Act specifically prohibits states or local governments from establishing zoning requirements that would prevent a group home (usually with fewer than six residents) from being developed in a neighborhood zoned for single family residences. disability wants to live in the community, the state has no right to prevent that from happening.

Most recently (2001), President George W. Bush issued an executive order calling for swift implementation of the Olmstead decision. In that same year, he also proposed the New Freedom Initiative containing a series of orders intended to "help integrate Americans with disabilities into the work force and into community life."

Clearly, legislation, judicial opinion and public opinion have increasingly supported the rights of people with developmental disabilities to live in homes and neighborhoods of their choice. Further, social research has demonstrated that many, if not all, of the arguments used by NIMBY proponents have no basis in fact.

What Research Tells Us About the NIMBY Arguments

The rationale proposed by people who wish to control who moves into their neighborhoods is typically that want to protect property values or that they want to protect the community from people who might harm them. Two decades of research in both the United States and Canada has shown, however, that property values are not negatively affected when people with disabilities



CNN Reporter Chuck Conder interviews New Beginnings Director Guy Robertson for a piece that gave all involved parties – both those for and opposed to the home's presence in the Upper Hastings Ranch area – an opportunity to present their views on the situation and share their stories. The piece aired on CNN Headline News and local affiliates.

move into a neighborhood. Further, a recently published review of 58 studies of the effects of small, homelike residential facilities on property values revealed no evidence to support neighbors' fears that presence of such a facility would decrease property values, increase crime, or change the character of the neighborhood. They found, to the contrary, that the most reliable and consistent predictor of property values is the neighborhood itself – its schools, its economy, its crime rate, and its infrastructure.

Some people claim to fear an increase in crime with the development of group homes. Research has addressed this issue also, demonstrating that crimes against property or persons do not increase in neighborhoods where people with developmental disabilities live in group homes. In fact, there is evidence that the crime rate for people living in group homes is actually significantly lower than that for the general public.

Sometimes people object to group homes in single family neighborhoods because they consider them to be "businesses." In general, a group home is regarded as what it is – a home, not a business, regardless of who owns the property.

Read Bernard Barmann's Detailed Response

The response written by Bernard Barmann, "A Medford Resident's Thoughts About 'New Beginnings' in Glenda's House," can be read in it's entirety at www.geocities.com/ uhrgrouphomeinfo/response.pdf. It's a thoroughly researched, comprehensive response to the questions and concerns posed by the anonymous residents about New Beginnings. Finally, the Americans with Disabilities Act (ADA) of 1990 barred discrimination and established basic civil rights for persons with disabilities. Importantly for this discussion, it also provided the basis for the U.S. Supreme Court to strongly support the right of people with disabilities to live in the community. In Olmstead v. L.C. (1999), the Court held that unnecessary institutionalization of people with disabilities is a form of discrimination prohibited by the ADA. The essence of the Court's position was that, if a person with a developmental

Conclusion

State and federal laws and increasing social acceptance strongly support the rights of people with disabilities to live in appropriate housing in traditional residential neighborhoods. An unwillingness to accept and honor these rights is a violation of the law. More importantly, it unfairly punishes people with disabilities while, at the same time, depriving residents of these neighborhoods of the opportunity to get to know people with developmental disabilities as individuals, neighbors and friends.

"A recently published review of 58 studies of the effects of small, homelike residential facilities on property values revealed no evidence to support neighbors' fears that presence of such a facility would decrease property values, increase crime, or change the character of the neighborhood."

More Lanterman Families in Need of Assistance from Holidays are for Sharing Program than Ever Before

Traditionally, as part of most holiday celebrations, families and friends will share in the joy of a dinner celebration, exchange gifts, and take a few moments to enjoy the sights, smells and sounds of the holidays. But what happens when a family doesn't have the resources to participate in their holiday traditions?

This year, the sustained increased cost of living, in part due to high oil prices, has resulted in a larger number of families than ever before requesting assistance from Lanterman through our



Holidays are for Sharing program. At the same time, the ability of donors to meet this need has also been impacted by the higher cost of living.

Not only are monetary donations predicted to be lower this year, the continued long-term deployment of Marine Corps Reservists is hampering their ability to collect enough toys through their Toys for Tots program to fill all the requests they've received for toys.

"We are reaching out to our Lanterman community to ask them to help us make this *Holidays are for Sharing* campaign as successful as possible for the Lanterman families who would otherwise not be able to have even a simple holiday celebration this year," shares Karem Chacana, director of Human Resources and coordinator of the *Holidays are for Sharing* program.

Please Help Us Share the Spirit of the Holidays

For over 25 years, friends and families of Lanterman Regional Center have stepped up to meet the critical needs of members of our community who require a little extra help not only during the holidays, but throughout the year as well. The *Holidays are for Sharing* campaign has two objectives, one to help make holiday celebrations possible through



donations of food and gifts, and also to raise money for the Help Fund – the fund that gives all year long by providing assistance with emergency food, clothing, shelter and other necessities.

Throughout the years, *Holidays are for Sharing* has made a significant difference in the lives of members of our community and there are several ways that you can help:

- Donate online with your credit card at www.lanterman.org/donate/onlinedonations.asp
- · Send a tax-deductible contribution in the form of cash, check or money order
- Donate a new gift, art supplies, personal care items, baby products or a food/gift certificate
- Adopt-a-Family and provide them with food and gifts for the holidays
- Give through your company's United Way program
- Participate in "Matching Dollars" if your company has a matching fund program
- Publicize the program through your business, club, church or service organization

Checks should be made payable to "FDLRC *Holidays are for Sharing*" and mailed to *Holidays are for Sharing*; c/o Frank D. Lanterman Regional Center, 3303 Wilshire Boulevard, Suite 700; Los Angeles, CA 90010. Gifts should be delivered unwrapped to Lanterman Regional Center.

For more information about *Holidays are for Sharing*, e-mail **hafs@lanterman.org** or call **213.383.1300**, **x**. **684**. One hundred percent of all donations go directly to the recipients.

From All of Us at Lanterman Regional Center ~ All the Best Wishes for a Happy, Healthy and Meaningful New Year!



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