



KEEN LA Launches Weekend Athletic Program at Elysian Park, Now Accepting Applications for Program Expansion

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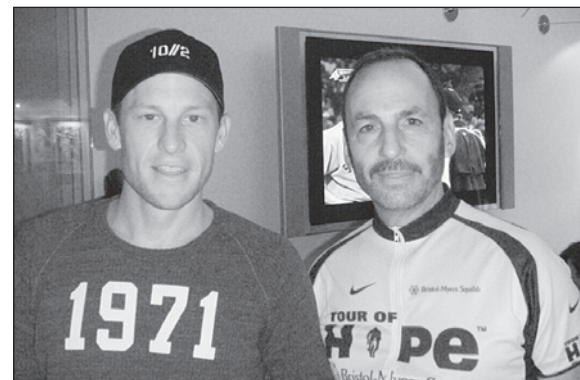
Doron Kochavi Carries Message of Hope Across the Nation in Honor of His Son

Imagine receiving the news that your 4-year-old child has an aggressive brain tumor and that he or she only has a 10 percent chance of survival. Nearly 17 years ago, Doron and Phyllis Kochavi were told that their son, Ari, who is now 21, needed imminent surgery to remove a brain tumor if he was to have any chance to live, and his parents had to quickly make a treatment decision that would impact the rest of their son's life.

"Ari beat the odds," says Doron. "We truly believe that his survival today is a result of his successful participation in a clinical trial, and that he's a living example of the importance of participating in clinical trials and supporting cancer research." Today the survival rate for children affected with the same type of cancer as Ari had is around 60 percent, thanks to better medicine – more precise surgery that causes less brain damage, more targeted radiation and chemotherapy. Phyllis shares, "Ari has a learning disability, and faces many challenges, but he has a great quality of life."

In partnership with Lance Armstrong, Bristol-Myers Squibb held the first Tour of Hope™ in October 2003. The Tour of Hope is a nine-day journey across America by a team of 24 people who have been touched by cancer – survivors, caregivers, advocates, healers and researchers – that has inspired thousands and informed the public about the importance of cancer clinical trials.

For Doron, who is an avid cyclist, the Tour of Hope presented a life-changing opportunity – the chance to ride with Lance Armstrong and spread the word about the importance of clinical trials and research. Doron took great care putting his Tour of Hope application together, and was selected as one of 56 finalists out of the 1,100 initial



Doron Kochavi (right) had the honor of riding with seven-time Tour de France winner Lance Armstrong as part of the Tour of Hope, a nine-day journey across America by a team of 24 people who have been touched by cancer, which is held annually to spread the word about the importance of clinical trials and research in developing more effective treatment options.

applications. "I don't think that any of us that were ultimately selected to be one of the 24 cyclists for the 2005 Tour of Hope could honestly say why we were chosen to carry the message across the country," adds Doron. "Every cancer story is an inspiring story, and I was very honored to have been selected the first time I applied." After being accepted, Doron participated in an individualized 16-week training regimen developed by Lance Armstrong's coach, Chris Carmichael, which involved training six days a week and riding approximately 300 miles each week.

The Tour of Hope team was organized into teams of six that rode in a relay fashion, an average of five hours every 15 hours or so for nine days, from September 29 to October 8, from San Diego to Washington, D.C., to show their

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HEALTH AND WELLNESS

Get Fit! Not Fat! Gets Going

Just in time for the holidays, Get Fit! Not Fat! gets Lanterman clients out of the house and Lanterman staff away from their desks. Clients in the Glendale area were treated to a sneak peak of what Get Fit! Not Fat! would be about when classes started November 7, 2005 at the Pacific Community Center and Park in South Glendale.

"We're so fortunate to have a partnership with the city of Glendale. They have a great location with a wonderful educational training room and gym," says Margarita Blanco, project manager of Get Fit! Not Fat!. This session of Get Fit! Not Fat! was designed to support Lanterman's adult clients that work during the day and/or live independently. It's held Monday and Wednesday evenings from 5 p.m. to 7 p.m. While the Monday session focuses on nutritional education and is classroom-based, the Wednesday session focuses on getting the heart rate going.

Pam Cook, coordinator of the Therapeutic Recreation program for the city of Glendale and co-founder of the Department's Adaptive Recreation Program, shares, "We were looking to expand our program offerings for individuals with special needs outside of social and recreational opportunities, but didn't want to change the social feel of Club Maple, when we were approached by Margarita about Get Fit! Not Fat! and decided to start a partnership to

educate adults with developmental disabilities about how to start and maintain a healthy lifestyle through exercise and nutrition. This new program is called Club Pacific." Cook adds, "This particular site in Glendale is the Department's newest facility and this was also a great opportunity for us to get the word out about the Pacific Community Center and Park."

In addition to getting the Pacific Park program off the ground, Blanco has been planning for

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After a game of kick-ball at the Pacific Community Center and Park in Glendale, Get Fit! Not Fat! participants (left to right) Douglas "Troy" Crippin, Cindy Pollie Hanks and David Binkier do some cool down stretching, which is being led by Project Manager Margarita Blanco (second from left).

"Donor Fatigue" Predicted to Significantly Impact 2005 Holidays are for Sharing Campaign

In newspapers across the country, the headlines all convey the same message, local non-profits and charities are worried that in the wake of the many natural disasters worldwide during the last year, that donors will not be able to give enough to meet local needs, especially during annual holiday fundraiser campaigns.

In the last year alone, four hurricanes pounded Florida in a period of six weeks; at least 180,000 were killed when a tsunami struck countries bordering the Indian Ocean; Hurricane Katrina submerged a city, devastated a region, displaced thousands and killed hundreds; flooding and mudslides have killed at least 2,000 in Central America; there's a famine in Niger; and over 2.5 million people are homeless and upwards of 80,000 were killed in an earthquake in South Asia.

Americans have donated to national and international charities responding to the unprecedented string of natural disasters at record levels, and these extraordinary levels of giving earmarked for disaster relief, coupled with near record high gas prices and utilities, and an overall increased cost of living, all mean less money for local food banks, shelters, after school and social/recreational programs, just to name a few. "Donor fatigue" is even apparent in the amount of money being raised for recent natural

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“The Ringer” Provides a Good Laugh While Challenging Stereotypes of People with Developmental Disabilities

Lanterman Regional Center is joining the Special Olympics and the National Down Syndrome Society in promoting “The Ringer,” an upcoming Farrelly brothers film opening December 23 in local theatres. The film uses humor to challenge destructive stereotypes of people with developmental disabilities.

When Steve Barker (Johnny Knoxville) finds himself running dead last in the corporate rat race, he sinks to an all time low... he attempts to fix the Special Olympics by pretending to be a person with intellectual disabilities. But, he is completely out-classed by his fellow Olympians, who are not only better athletes, they're just plain better people. Steve is soon spotted as a fraud, but rather than turn him in, they join forces with him to once and for all beat Jimmy, the snooty reigning champion of the annual games. Together they train Steve to become a better athlete and, more importantly, a better person.

With over 150 people with developmental disabilities in small and supporting roles, “The Ringer” provided employment opportunities to actors with disabilities who are many times overlooked for these roles. “The Ringer” uses comedy to celebrate acceptance and mutual respect, and emphasizes that individuals with disabilities are

people first, with their own interests, talents, abilities and personalities just like everyone else.

Bobby and Peter Farrelly have consistently included actors with disabilities in their films and are on the Council of Advisors for *Perspectives* 2006. They have once again provided filmgoers with and without disabilities an opportunity to laugh together and have a great time at the movies. So, regardless of whatever else you are doing this holiday season, be sure to find time to catch a showing of “The Ringer.” For more information about the movie, visit www2.foxsearchlight.com/the_ringer.

Please note that “The Ringer” has a PG-13 rating and may not be suitable for children under the age of 13.



Above: From left, John Taylor and Johnny Knoxville in “The Ringer.”

Photo credit: Deana Newcomb

Left: From left, Geoffrey Arend, John Taylor, Leonard Earl Howze, Eddie Barbanell, Bill Chott and Jed Rees, help Johnny Knoxville (third from left) prepare for the Special Olympics competition in “The Ringer.”

Photo courtesy of Twentieth Century Fox

Meet the People Behind the Titles: Helane Schultz

As regional manager of the Los Angeles/Wilshire Service Coordination unit at Lanterman Regional Center, Helane Schultz 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 people behind the titles and their responsibilities, so “Viewpoint” recently met with Schultz and asked about projects in the works, as well as the biggest challenges and most rewarding aspects of her job.

“Don’t paint anyone with broad brushstrokes.”
– HELANE SCHULTZ

The above words have guided Helane Schultz’ last six years as regional manager of Lanterman Regional Center’s Los Angeles/Wilshire Service Coordination unit. A graduate of Adelphi University in Garden City, New York, where she obtained her bachelor’s degree in speech arts, Schultz feels that it’s her life experience more than her educational experience that has prepared her for her position as regional manager.



Helane Schultz, regional manager of the Los Angeles/Wilshire Service Coordination unit

As part of her college curriculum, Schultz worked at a clinic for individuals with speech impediments. “I still remember what a thrill it was working with a young boy diagnosed with autism and getting him to verbalize,” recalls Schultz, who at that time had no idea where that would ultimately lead. Schultz, who relocated to California 22 years ago from Long Island, New York, originally settled in Orange County, eventually becoming a service provider with Regional Center of Orange County.

“After having been a service provider, I was a little apprehensive about what it would be like working directly for a regional center,” shares Schultz. “I know I have made the right decision. It may have taken me quite a few years to decide what I wanted to be doing when ‘I grew up,’ but I’ve finally found what I enjoy.”

Schultz supervises the work of 14 service coordinators who coordinate services and supports for approximately 800 clients, and who primarily serve the Los Angeles basin. The clients served by the Los Angeles/Wilshire unit are age 14 and above, and there is also a specialized aging transition team within the unit that works with people with developmental disabilities over 45 years of age.

In addition, Schultz is the facilitator of the Strategic Initiative Committee on Employment. “We work with supported employment agencies to determine the needs of the individuals we serve and to discuss what support the Regional Center can provide to improve the employment possibilities for Lanterman’s clients,” explains Schultz. She also sits on the Community Living Options Review Committee, which reviews the housing needs of the Center’s clients and makes recommendations accordingly.

When asked what drives her to get up in the morning and come to work, Schultz replied, “Seeing the successes of our clients, when they go on from high school to college or on to employment, or move from their family’s home to independent living, or from a skilled nursing facility to a residential setting – it’s these successes that make me stop and say, ‘Now I know why I do this.’” Prior to working at Lanterman, Schultz developed a program to help get clients out of workshops into supported

employment, as well as an advocacy program and a club house.

If Schultz had to pick the biggest challenge of her job, she’d say it was prioritizing. She explains, “Even though many situations are viewed as a crisis you have to learn to deal with multiple challenges at a time.” Schultz adds, “It would be great to have more people and smaller caseloads so regional centers could pay even more individualized attention to clients.”

Schultz feels that some of the biggest challenges for the regional center system lie ahead. “I really want us to make a difference. Now that regional centers are the funding sources for ongoing support for people in supported employment, I hope we are able to work towards offering better and more meaningful employment opportunities in the community. I want to see regional centers have an impact on the school districts to make sure that clients are more appropriately prepared for the adult world,” she adds.

Schultz, who recently celebrated her 38th wedding anniversary with her husband, Robert, has two grown children, 34-year-old Meredith and 31-year-old David. “They are my biggest sense of pride and accomplishment,” shares Schultz. In her spare time, she enjoys knitting, and loves reading and shopping. “I’m not a gardener, I’m not outdoorsy, I’m not athletic,” says Schultz, who also adds, “My husband says that shopping is more of a vocation than an avocation for me.”

Schultz, who will be starting her seventh year at Lanterman, would have to say that her most memorable experience at Lanterman Regional Center was being part of the planning team that helped coordinate the necessary supports so three generations of clients, from the grandfather to the infant, could live independently in the community, and then following the implementation of the plan and seeing the family’s success. Schultz adds, “I’ve really been impressed with the level of professionalism of this Regional Center. It’s been such a pleasurable experience working here and I’m pleased that even during difficult financial times, this Regional Center never loses site of individual client needs.”

THE BUDGET UPDATE

Recent Budget News Elicits Reactions of Optimism and Pessimism

You may have read recently that California has experienced robust, and unexpected, economic growth, and this has resulted in tax receipts far exceeding what had been forecast for this year. As a result, the State may end the year with as much as a \$5.2 billion budget reserve. It is natural then to ask, what effect, if any, this will have on regional center budgets in the next few years. The answer is that we do not know, but we do know that a number of factors are likely to have an influence on how our budget situation evolves.

First is the fact that Elizabeth Hill, the highly respected legislative analyst, has cautioned that this surplus situation will be short lived. The State still has a “structural deficit,” meaning the amount the State spends each year on programs exceeds the amount of taxes and other revenue it takes in. So, Hill expects the State to return to a deficit situation beginning in the 2007-2008 budget year.

At the same time, there appears to be increasing recognition of the severity of the funding crisis within the community-based system serving people with developmental disabilities. One example of this is the recent hearings within the Assembly Budget Subcommittee #1 that addressed a number of issues, including how rate freezes are affecting the delivery of community services, since residential service providers have not received a rate increase since the late 1980s. Three regional center directors addressed the Subcommittee, as did family members and clients who gave compelling testimony concerning how the under funding has a direct effect on their lives.

We are hopeful that placing the spotlight on this crisis situation will result in willingness on the part of the Legislature and Governor to begin addressing the problem. Assemblyman Hector De La Torre, chair of the Subcommittee, pledged to commit staff resources and time to finding solutions to the problems that were highlighted. So, while we may be pessimistic in light of Hill’s caution, the actions of the Legislature and increasing activism on the part of clients, families and advocates may be reasons for optimism. We will continue monitoring the budget situation and keep you informed in future issues of “Viewpoint.”

Recognize the People in Your Life that Embody Lanterman’s Core Values

As Lanterman Regional Center prepares to celebrate its 40th anniversary in 2006, it seems appropriate to reflect on and reaffirm our commitment to our core values. It is our hope that each member of the Lanterman community embraces these values.

As part of our celebration, we’d like to hear from our community about the people in your life who you feel embody these values, whether it’s an adult with a developmental disability, a family member, a service provider or professional in the community, a staff member at Lanterman or a private citizen.

A profile of each of the individuals selected from your nominations will be featured in the 2006 editions of “Viewpoint.”

Please submit your reasons for why you are nominating this candidate through e-mail to vinita.anand@lanterman.org or via mail at:

Vinita Anand
Frank D. Lanterman Regional Center
3303 Wilshire Boulevard, Suite 700
Los Angeles, CA 90010

OUR CORE VALUES ARE...

COMMUNITY OWNERSHIP

Our community is made up of the clients, families, service providers, regional center staff and the broader community in our geographic area. Lanterman Regional Center belongs to this community. This is not a passive form of ownership. One must bear an active responsibility for the Center’s welfare to be considered an owner. The obligations of community ownership are commitment, contribution and responsible stewardship.

PARTNERSHIP

We work together collaboratively, as a team, with a spirit of heightened cooperation and active participation. All members of our community – clients, families, service providers, staff and other community members – share the benefits, obligations and challenges of our joint endeavors equally.

EXCELLENCE

We pursue the very best in all that we undertake. Our members strive continuously to improve the quality of all that we do. Good intentions alone are not enough; we work hard to achieve results.

ACCOUNTABILITY

We are responsible stewards of our Center’s

resources and are accountable to one another for the decisions we make, for our actions, and the results of those decisions and actions.

LEADERSHIP

Leadership is an act of service to the community as a whole. As an organization, and as individuals, we strive to be in the forefront – pioneering new ways to enhance the lives of people with developmental disabilities, their families and the community we share. We want to inspire the Center to reach its full potential and lead the way for others.

DIVERSITY

People are our greatest asset. We value every individual and the gifts, talents and skills that he or she contributes to the benefit and enrichment of the whole community. We endeavor to create an inclusive environment so that each person knows that he or she adds value to the Lanterman community.

SPIRIT

Lanterman is marked by the special spirit of its people – a passion for caring and commitment – that gives our work its true life. A prevailing culture of willingness and a readiness to volunteer characterize the people of Lanterman.

INCLUSION

We are determined that people with developmental disabilities are brought into the full active life of our community and that barriers to their active participation are removed. We are equally determined that the members of our community recognize the benefits of the active involvement of people with developmental disabilities in their lives, and are committed to facilitating far-reaching community socialization and fundamental acceptance of people with developmental disabilities.

RESPECT

We instill all our work with an overriding consideration for the inherent quality of every person.

SELF-DETERMINATION

We are committed to recognizing the personal power and value of all individuals by providing an environment that promotes independence and initiative. We are committed to see that all people with developmental disabilities exercise their right to make informed decisions about all areas of their lives. The Lanterman community strives to increase access to the knowledge, skills and resources that enable every individual to choose his or her own destiny.

The Director’s VIEWPOINT

Valuing What We Have

Very often in communicating with our community through this column, I am focusing on the challenges we face as a system and on what we can do to further our vision of creating a truly inclusive society. It occurs to me, however, that sometimes in our effort to improve, we forget to pause and reflect on how remarkable the regional center concept truly is.

Recently, an article in “The Wall Street Journal” described the difficult choices faced around the country by parents of children – particularly adult children – with developmental disabilities.



Executive Director Diane Anand

The piece offered example after example of the lengths to which parents are forced to go to ensure that their children receive the help they need – lengths such as a father moving out of the family home so that a son with autism can have in-home care, or a parent dropping off an adult child with mental retardation at a shelter because only the homeless can get into a group home.

Nationwide, in state after state, we hear of long lists with literally thousands of people waiting for in-home assistance or a place in a group home. The numbers are staggering, and thinking of the individuals and families behind those numbers is even more distressing.

It occurs to me, however, that sometimes in our effort to improve, we forget to pause and reflect on how remarkable the regional center concept truly is.

– Diane Anand

And that certainly reminds me that the regional center system – so clearly an innovative and effective approach to supporting people with developmental disabilities and their families – is a rarity in the nation. We in California enjoy the benefits of a system that is a model for improving the lives of individuals with developmental disabilities and their families.

Despite the many challenges we face, and the need to continuously improve the service delivery system in California, the regional centers still represent the best approach to empower and enable those with developmental disabilities to live full, productive and satisfying lives as active members of their communities.

As we approach the 40th anniversary of both Lanterman and the regional center system, we indeed have much to celebrate. As we continue to evolve, we hope that the best of what we have accomplished in California will find its way into the service delivery systems of the rest of the nation.

Remembering a True Pioneer – PETER F. DRUCKER



We here at Lanterman Regional Center were saddened to hear of the passing of Peter F. Drucker. The obituaries published about him have focused on his international renown as the “Father of Modern Management,” called by BusinessWeek Magazine “the most enduring management thinker of our time.”

But few of the tributes noted his passion for the non-profit sector. It was his strongly held belief that the social sector should be the equal partner of business and government.

As he said so eloquently, “The 21st century will be the century of the social sector organization. The more economy, money and information become global, the more community will matter. And only the social sector non-profit organization performs in the community, exploits its opportunities, mobilizes its local resources, solves its problems. The leadership, competence and management of the social sector non-profit organization will thus largely determine the values, the visions, the cohesion and the performance of the 21st century society.”

“Dr. Drucker was a keynote presenter at our second Lanterman Leadership Forum, and I had the pleasure of meeting with him personally,” recalls Lanterman Executive Director Diane Anand. “I deeply appreciated his insights as applied to our work at the Regional Center, particularly his strong sense of the importance of taking the long view of events. He told me that in accomplishing major social change it’s valuable to look back to see where you started and thus realize how far you’ve come. His wisdom reminds us that our great strength is in our roots as a community-based system, and on his passing, it is fitting that we re-commit ourselves to that vision.”

Get Fit! Not Fat!

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the official launch of the project at all other program sites in January, since the end of the year is a busy time and many sites’ calendars were already booked with holiday activities and support staff would be on vacation. “All of the clients who are participating were required to undergo a health screening to rule out any reasons for why they couldn’t participate and to allow us to gather baseline data,” explains Blanco. “While the project called for us to follow the impact of the program on 50 clients, due to the inherent drop-off during studies, we’ve had to recruit considerably more.”

When it rolls out in January, Get Fit! Not Fat! will be piloted with clients who work and reside in a variety of different settings, including group-based programs, such as day programs and larger residential homes; and with those who live with a family member or independently. “We will have a number of sites throughout the Lanterman community, and in some instances, the activities will be held onsite at the workplace or group home, where as other programs will be held at community-based recreation centers,” adds Blanco. The clients’ circles of support are also encouraged to attend the educational classes and participate in the physical activity.

Get Fit! Not Fat!, a joint project between Lanterman and Harbor Regional Center, also has an employee wellness component, which prompted a friendly competition between the two centers to see which center could get the most employees to accept the challenge to get active and get healthy. The California Governor’s Council on Physical Fitness and Sports has a program called Active CA where Californians can take the Governor’s Challenge to be active 30 to 60 minutes a day, at least 3 days a week for 4 weeks. “Their Web site, www.ActiveCA.org, is really user-friendly and allows users to track their physical activity,” notes Blanco. “I recently got a call from the executive director of the Governor’s Council on Physical Fitness who noticed a large number of people signing up with the same organization name. He inquired about our success and they are interested in tracking us to see if our approach will work.” Several walking groups have started up at Lanterman including a daily beginner group, an intermediate Tuesday group, and fast-paced Thursday group.

Towards the end of the project will be the Get Fit Games, a sports competition between Lanterman and Harbor adult clients and staff that will be held at the Home Depot Center. “We just recently heard from the Governor’s Council that they will be endorsing the 2006 Get Fit Games and we are very excited about this,” adds Blanco.

While most of the Get Fit! Not Fat! sessions have controlled enrollment and will be implemented by way of existing programs, the Club Pacific program has open enrollment. If you are interested in participating in the Get Fit! Not Fat! session in Glendale at Pacific Community Center and Park, located at 501 South Pacific Avenue, contact Margarita Blanco at **213.383.1300, x. 747** or margarita.blanco@lanterman.org.



FATHERS’ CORNER

“Time” By Caesar Bates

By the time I understand a fourth of what it’s like to live in our world and have autism, my 5-year-old son will probably be able to tell me how it is. But, for now I’ll try to teach him what is right – what are appropriate behaviors, when it’s time to scream or not.

However, I must remember one important thing if I am to capture his attention, I must spend time trying to understand what it’s like to be in his shoes, and then maybe, I’ll find out what will work. I must take time to find out what ball he likes, whether it’s a football, basketball, or soccer ball; what cartoon characters catch his attention; or what facial cues he does or doesn’t respond well to.

This brings us back to time – if I spend time with him, if I give him room to grow, and don’t cut him off with a suggestion too soon – his personality will come through. At our house, we are trying the eight-second rule, which works like this: when we ask our son about making a choice, his first response is always “No,” even to his favorite items like fries, whipped cream and going to the pet store, so at this point, we wait eight seconds before asking the question again.

As I write this, I find myself in the shoes of a father that might be trying, but having a hard and frustrating time, but let me leave you with this...You may not be a rich man, but remember, your time is valuable; spend it on your children; it just might give them a wealth of memories and knowledge.



Five-year-old Timothy Bates spends time at the park exploring his environment with his family.

Caesar Bates works for the United States Postal Service’s main facility in Los Angeles as a postal tech. He lives in La Crescenta with his wife Jeanette and two sons, Timothy, age 5, and Benjamin, age 3. Caesar has a son, Solomon, age 17, who is a senior in high school and lives with his mother in Whittier. Jeanette has a daughter, Lisette, who is 18, and lives with her father in Temple City and attends Pasadena City College where she is pursuing a career in child development.

*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**.*

*Fathers’ Corner is a regular “Viewpoint” feature. If you are a father and would like to write for Fathers’ Corner in an upcoming “Viewpoint,” please contact Vinita Anand at **213.383.1300, x. 753** or vinita.anand@lanterman.org.*

Edward Perez Walks the Line as Lanterman's New Family Support Specialist

The home is the best environment to grow up in, no matter what a child's disability, and "family-centered" support services assist the family in making this a reality. These services include, but are not limited to, respite care, crisis intervention, information and referral, family training, behavior intervention and support groups.

At Lanterman Regional Center three of these key areas of family support are the responsibility of the family support specialist. "As many of you may know, our longtime family support specialist, Olivia Hinojosa, recently left her position at the Center to raise her new baby, but we are delighted to introduce Edward Perez, a former service coordinator in the Early Intervention unit at Lanterman, as the new family support specialist," shares Patricia Herrera, director of Family Support Services. "Edward is a true asset to the Koch ♦ Young Resource Center and brings with him an extensive knowledge of the developmental services delivery system, and his passion and commitment to family support."

Perez, who celebrated his fifth year of service to Lanterman in November, graduated from California State University, Los Angeles, with a bachelor's degree in social work. "As part of my educational training I learned how to develop and facilitate effective support groups, but more importantly, I learned that active listening is one of the most important tools to have in this field and this skill has been essential to me in both my career and my life," he notes.

As a service coordinator, Perez also helped facilitate the Early Intervention Spanish-speaking Parent Support Group. Perez adds, "These positions taught me the value of being organized and learning how to multi-task." An active user of the Koch ♦ Young Resource Center as a service coordinator, Perez is looking forward to continuing his work with professionals at the Center, just in a different capacity.

In his new role, Perez is responsible for recruiting and training volunteers for the Peer Support Partner Program that provides one-on-one peer support to families. He also provides technical support to the parent and professional facilitators of the 25 plus support groups offered through Lanterman. In addition, Perez coordinates education and training sessions for families and professionals, such as the Service Coordination and Advocacy Training, which teaches families how to navigate the special needs system.

Looking toward the future, Perez says, "I'd like to collaborate more with community agencies, and nurture partnerships, so we can offer additional trainings to provide enhanced educational opportunities to Lanterman families; increase the volunteer base for the support group program; and especially, train and recruit more fathers for the Peer Support Partner Program." In his three months on the job, Perez has already conducted and graduated two SCAT classes with over 50 participants, trained new Spanish-speaking peer support partners and coordinated a parenting class.



Family Support Specialist Edward Perez

"I believe in the philosophy that our Lanterman parents can learn so much from each other because they can share every day life experiences raising and living with a son or daughter with special needs, including celebrations, effective coping strategies, and how to navigate the special needs system," shares Perez. "I enjoy working with groups and training parents and clients to become better advocates for themselves, and their sons and daughters."

Perez lives in the city of Commerce with his wife and two sons. He enjoys riding the bus with his two-year-old son, Benicio, having a quiet dinner with his wife, Margie, and eating Mexican candy with Andrew while watching a movie. He has a passion for bass guitar and plays in a band called Honeybreath.

Lanterman Introduces Online Peer Support Matching Form

In order to provide the best possible match for someone who requests a peer support partner match for one-on-one support, it's essential to know as much information as possible about the person requesting the match. It's important to know the best way and time to contact someone, what their preferred spoken language is, and equally important, what are their information and support needs.

With a grant from West Ed, the Koch ♦ Young Resource Center has created peer support matching software that compares the expressed needs of the family to the areas of experience of the trained peer support partners, and suggests potential matches based on criteria, such as language and informational and support needs. As part of the project, an online informational form for families interested in being matched was developed.

So, if you are interested in being matched with a peer support partner, visit www.lanterman.org/psm, fill out your information with as much detail as possible and the peer support partner who is matched with you will be in touch with you shortly.

Don't forget that you can request to be matched with a peer support partner at any time you may need assistance. For more information about the Peer Support Partner Program, contact Edward Perez at **213.383.1300, x. 705** or edward.perez@lanterman.org.

Welcome to KYRC online Peer Support Match

Please enter your zipcode. The information will be used to verify that you are in our service area.

Zip Code:

Eighteen New Peer Support Partners Trained to Support Spanish-speaking Community



Eighteen new peer support partners were specifically trained to provide one-on-one support to the Spanish-speaking community. Along with the Lanterman staff who trained them, the new partners are: from left, Rosa Villeda, Romy Castillo, Maria Banos, Virginia Sanchez, Irma Cruz, Bertha Suazo, Magdalena Mendez, Sandy Riancho, Patricia Herrera, Randall Sancho, Vera Sancho, Agustina Mellin, Eduardo Solis, Joaquin Castillo, Gabriela Solis, Juan Barrera and Edward Perez. New partners not pictures are: Eduardo and Olivia Cholulu, Yudy Mazariagos and Sandra Davila.

The closer we get to the holidays, it seems the less hours in the day and the more things to do in that day, all in all making the holiday season more challenging than other times of the year. For families who have a family member with a developmental disability, this time of year can be even more stressful than usual, and it can help to get support from someone who has "been there."

The week before Thanksgiving, Lanterman hosted a Peer Support Partner Training over the course of two days, and successfully trained 18 new peer support partners specifically to support the Spanish-speaking community. "It had been a while since new partners were trained to support our Spanish-speaking population," shares Sandy Riancho, peer mentor coordinator.

The purpose of the training is to prepare the potential peer support partners to assist the Koch ♦ Young Resource Center with welcome calls to Lanterman families who have recently been made eligible to receive services, and who expressed an interest in a welcome call; and to provide one-on-one support to parents, guardians and other family members who request to be matched with someone who has had a similar experience with their family member. Matches can be made in a variety of areas, including similar diagnosis or subject, such as IEP, transition to adulthood, and rights and responsibilities. A key areas of the training focuses on the importance of being supportive of a family's unique situation, active listening, communication and problem solving, confidentiality, and providing effective support.

Edward Perez, family support specialist, shares, "The Peer Support Partner Program is an essential part of the Resource Center and Lanterman because the impact a trained and experienced peer support partner can have on another when sharing experiences, ideas, feelings of hope, happiness and frustration is very powerful. This program is a blueprint of support, and I admire every one of our peer support partners who remind our families that they are not alone on their journey."

If you are interested in learning more about becoming a peer support partner, contact Edward Perez at **213.383.1300, x. 705** or edward.perez@lanterman.org, or Sandy Riancho at **213.383.1300, x. 729** or sandy.riancho@lanterman.org.

Warmly Welcome Lanterman's New Board Members

The beginning of summer is a very busy time for Lanterman – the start of the new fiscal year. And with this new fiscal year comes a new budget, new challenges and new additions to our board of directors. This past summer, a number of new board members were elected to Lanterman's board, each bringing with them a wealth of experience in their respective fields. Following are bios on four of our new board members that offer a look at both the professional and personal experiences of these individuals. The Lanterman community is delighted to have Larry DeBoer, Armen Frundzhyan, Ray Lemus and Louis Mitchell as board members and looks forward to the guidance and leadership these individuals will be providing the Center during their terms on the board of directors.

Louis Mitchell's Marketing Background Will Help Lanterman Get the Word Out

Marketing your organization is one of the most important things you can do to ensure its success and is a significant aspect of any company today. In the 1970s a new discipline of marketing was born, "social marketing." Philip Kotler, the acknowledged guru of marketing, and Gerald Zaltman realized that the same marketing principles that were being used to sell products to consumers could be used to "sell" ideas, attitudes and behaviors. Kotler and Alan Andreason define social marketing as "differing from other areas of marketing only with respect to the objectives of the marketer and his or her organization. Social marketing seeks to influence social behaviors not to benefit the marketer, but to benefit the target audience and the general society."

In August, Louis Mitchell, vice president in the Marketing group at Wells Fargo, was elected to Lanterman's board of directors. He brings over 19 years of marketing experience in the banking industry, first with First Interstate Bank and now Wells Fargo.

Mitchell's marketing career began in the early 1980s when he and another person established the Commercial Marketing department at First Interstate Bank from the ground up. Mitchell shares, "It involved establishing and supporting a new brand/corporate identity, advertising, promotions, collateral development, tradeshow and special event activities, managing staff, and budgets."

In the mid-1990s, First Interstate Bank merged with Wells Fargo, followed by a merger a few years later with Norwest, and Mitchell quickly established himself in the new organization. In his new position at Wells Fargo, Mitchell is responsible for strategic marketing, tradeshows and special events.

In 1997, Mitchell's eight-month-old daughter passed away. She had experienced a SIDS attack when she was two and a half months old, spent two weeks in the hospital

under constant oxygen and was diagnosed with minor reflux. She eventually developed severe reflux for which she had surgery and as she was recovering had a brain seizure resulting in a diagnosis of damage to 10 percent of her brain. While hospitalized, she had several more seizure attacks, and was diagnosed with severe brain damage. "After my daughter was diagnosed with severe brain damage, my wife and I started thinking about the long-term effects and care options, and we had someone from Lanterman Regional Center meet with us," shares Mitchell. Complications from surgery necessitated that

Mitchell's daughter be fed using a tube. While hospitalized, she developed a respiratory infection. "It took its toll and she just couldn't fight all of it," adds Mitchell.

"In addition to my marketing and strategic planning experience, what I bring to the Lanterman board is my firsthand experience as a father who has been there, who has lost a child, and who knows the impact that having a child with special needs can have on a marriage," says Mitchell. In a testament to the importance of family support, Mitchell and his ex-wife became friends with a family who had a child with similar needs. "We vacationed with them, and because our children had similar needs, we could be supportive of them and give them a break. Even though both our children have passed on, to date we are still friends," shares Mitchell.

Mitchell is looking forward to putting his extensive background with special event planning to work and is ready to roll up his sleeves and be a part of the 40th anniversary celebrations planned for 2006.

In addition to serving on Lanterman's board of directors and strategic planning committee, Mitchell is actively involved with the Diversity Council at Wells Fargo and was instrumental in creating a mentor program. He is also a board member of the Wells Fargo Latino Resource Group known as Amigos; is a member of the Los Angeles Junior Chamber of Commerce; and is a committee member for Corazones Unidos, which was established to raise funds for American Heart Association-sponsored programs that provide health education and screenings for Latinos in their fight against heart disease and stroke. He just graduated from a 10-month program run by the Los Angeles Junior Chamber of Commerce, called the Riordan Volunteer Leadership Development Program. "The program is designed to give you a solid foundation and prepare you to serve on a non-profit board. We learned about governance, bylaws, fundraising, marketing and public relations, strategic planning, and financial management as they relate to non-profits," says Mitchell.

Mitchell, who is fully bilingual in Spanish, enjoys being busy and says that he just can't sit down and relax. In his spare time he referees basketball games and plays baseball on Sundays with a traveling team that has played at different tournaments throughout the Western United States. His two passions are playing the piano and surfing. "I was a child prodigy when it came to the piano and in the fifth and sixth grade played with a young children's orchestra at the Hollywood Bowl. My father died when I was 10, and I had to stop taking piano lessons, but continued to play until I was 18 and I left home," recalls Mitchell. Mitchell didn't play for 15 years, but in 1994 bought a piano and started the process of relearning his classical piano skills. Chopin is Mitchell's favorite composer, but on Saturday mornings, don't look for him to be tickling the ivories, he'll be out catching waves, which he's been doing for over 20 years.



Louis Mitchell

Looking for New Blood... with experience

As a multi-million dollar corporation, Lanterman is always interested in recruiting board and committee members who have backgrounds in finance, personnel and related areas. Should you or someone you know be interested in volunteering in such a capacity, contact Patrick Aulicino at [213.383.1300](tel:213.383.1300), x. 690 or patrick.aulicino@lanterman.org.

Board Welcomes Your Attendance at its Meetings

Please be aware that anyone in the community is welcome to attend Lanterman's board of directors meeting, which is conducted on the fourth Wednesday of every month at 6 p.m. Meetings are held at Lanterman Regional Center. Contact Frank Lara in advance at [213.383.1300](tel:213.383.1300), x. 665 or frank.lara@lanterman.org so you can be placed on the list of attendees. We look forward to your visit.

Lanterman Board Benefits from Armen Frundzhyan's Self-Advocacy Experience

The first line of Lanterman Regional Center's mission statement reads, "to enable people with developmental disabilities to live full, productive and satisfying lives as active members of their communities." The Center's core values of community ownership, partnership, excellence, accountability, leadership, diversity, spirit, inclusion, respect and self-determination outline how the Center will work toward achieving the first goal of our mission.

In order to ensure that the Center is meeting the needs of the clients that we serve, at any given time, at least 25 percent of the board members are adult clients served by Lanterman Regional Center.



Armen Frundzhyan

This past summer, Armen Frundzhyan was elected to Lanterman's board of directors.

For quite some time, Frundzhyan has been assuming leadership roles in the Lanterman community, first as the founder of the Mid-Wilshire Self-Advocacy group, then as a member of the Consumer Advisory Committee, and now as its chair. It was Frundzhyan's appointment as chair of the CAC that caught the attention of the Nominating Committee of Lanterman's board of directors, which is the committee that makes recommendations to the board regarding potential new board members.

Frundzhyan, who just turned 30 at the end of September, shares, "I enjoy helping people with disabilities help themselves." One of Frundzhyan's responsibilities as a board member is to report back on what issues the CAC addresses at the Committee's monthly meetings. He is currently looking to beef up membership in the Mid-Wilshire Self-Advocacy group since membership has dwindled recently, and adds, "I need more members, so please invite everyone to join the group. E-mail or call me as soon as possible." Frundzhyan is also working with Sherry Beamer, a Lanterman consultant, to establish a People First Chapter in the Lanterman area. For more information about the Mid-Wilshire Self-Advocacy group contact Frundzhyan at [323.462.7300](tel:323.462.7300) or afrundzhyan75@netzero.net.

Frundzhyan is also a graduate of the computer classes held at Lanterman in partnership with Los Angeles Unified School District's Division of Adult and Career Education's Los Angeles Community Adult School. He can adeptly surf the Internet and spends a considerable amount of his day playing word games on the computer, such as "Wheel of Fortune" and "Book Worm." Frundzhyan also helps out around his parents' house and likes going grocery shopping with his father.

When he is not promoting self-advocacy, Frundzhyan enjoys watching action-packed movies starring Chuck Norris and scary ones, such as "A Nightmare on Elm Street" and "Friday the 13th." He also enjoys watching television, primarily cartoons, and favors KCET's "Dragon Tales" and "Arthur," as well as "Full House" reruns.

Larry DeBoer's Insurance and Risk Management Experience Helps Lanterman Stay Above Par

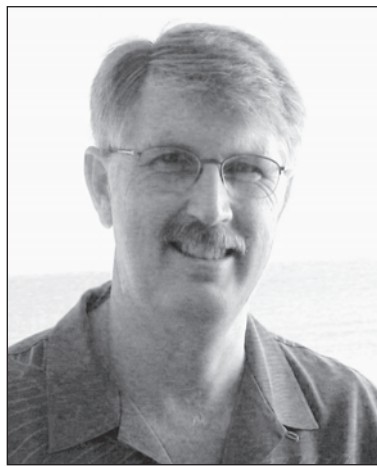
As with many human services organizations, Lanterman Regional Center is mission-driven, rather than profit-driven, but our situation is special, because even though we don't have assets as defined in the narrowest sense of the word, the Center is accountable for a \$100 million plus budget. With an operating budget of this size, insurance and risk management play a vital role.

Risk management is a discipline for dealing with uncertainty, and every non-profit faces uncertainty and risk. From uncertainty about program outcomes and the organization's ability to ensure client safety to the increasing threat of litigation and protecting staff, managing a range of risks is required for both survival and success. Risk management helps identify, assess and manage risks that may be present in operations, service delivery, staffing and governance activities.

Recently, Larry DeBoer, who has 32 years of experience in insurance and risk management, 11 years with a national insurance company and the balance with global broker Aon, joined Lanterman Regional Center's board of directors.

Aon is the second largest global insurance and risk management and insurance brokerage firm employing 44,000 people around the world. The Southern California offices are the second largest operation in Aon Risk Services' stateside operations and the largest firm of its kind in Southern California, in terms of revenue. DeBoer is the chief administrative officer for the Southern California operations.

DeBoer holds a bachelor's degree in business administration and marketing from the University of Wisconsin, Eau Claire, and a Chartered Property and Casualty Underwriting (CPCU) designation.



Larry DeBoer

He and his wife, Linda, have two grown daughters. DeBoer enjoys spending time with his family, gardening, reading and travel. He is also a member of LA 5 Rotary Club; a board member for

the California Insurance Council for The City of Hope; and is currently chairman of the board for the Insurance Educational Association, a leader in professional education since 1876.

DeBoer shares, "While I was aware of the name Frank Lanterman, I had no idea what the Regional Center did, or of the important role the Center plays for people with disabilities in the Los Angeles basin. As a member of the Los Angeles Rotary Club, I had exposure to other organizations that focused on people with disabilities and did some peripheral volunteer work. That, coupled with getting to know Marjorie Heller, a past Lanterman board member, piqued my interest and here I am. In fact, it was Marjorie who asked me to consider joining the board."

"I hope to lend my energy, intellect and experience to help the board meet the leadership challenges it faces in 2005 and beyond. I would like to play a role, however small, in expanding the diversity of our community by enhancing the opportunities for people with disabilities to enable them to contribute to the full extent of their talents and abilities," adds DeBoer.

Ray Lemus Brings Contract Management and Auditing Expertise to the Board

Every year, Lanterman Regional Center undergoes a detailed audit of everything from the Center's financial records and accounting practices all the way down to the digital camera and the furniture in the lobby. It's a time consuming and very involved process that ultimately reflects how Lanterman does business on a daily basis, as well as on the Center's policies, processes and procedures. As a member of Lanterman's board of directors, Ray Lemus brings over six years of leadership experience managing the Acquisition Planning and Compliance section, and more recently the Contract Management Office at the Jet Propulsion Laboratory in Pasadena.

"I was looking for an opportunity where I could share my business skills and make a contribution to a worthwhile organization that had a direct impact on individuals, families and our community," shares Lemus. "Karen Ingram spoke with me about the great work that Lanterman Regional Center does and informed me of an opportunity to serve on the board, which has definitely provided me the opportunities I was looking for."

Lemus leverages his expertise with contract management and his compliance background to help JPL interpret the NASA Prime Contract. This is a multi-billion dollar contract between Caltech and NASA that establishes JPL as a federally-funded research and development center. In his current role at the Contract Management Office, he represents JPL to NASA on all issues related to the Prime Contract. In addition, he manages JPL's Audit Liaison group, which is responsible for closure of all internal and external JPL audits, including Caltech's Internal Audits, the Defense Contract Audit Agency, the NASA Inspector General and Price Waterhouse Coopers.

Some of his recent accomplishments include significant change management initiatives based on 360 degree customer feedback and industry benchmarking to realign organizational

objectives. The 360 degree customer feedback resulted in the complete rewrite of the procurement procedures for JPL, creating a compliance system based on published criteria and metrics, in addition to 50 e-learning modules to accelerate the learning experience of new hires and refresh training for the existing workforce on procurement requirements.



Ray Lemus

Prior to assuming a manager role at JPL, Lemus worked for JPL as a subcontract manager specialist for the acquisition of satellite systems. He also has past experience at Techstar, Inc.; TRW, Inc.; and as an engineer for Chevron USA. Lemus' educational background includes a master's in business administration with a concentration in finance from the University of California, Los Angeles, and a bachelor of science degree in chemical engineering from the New Jersey Institute of Technology.

Lemus also has a certificate from UCLA in government contract and proposal management. He is a linguist at heart and is fluent in French, Italian and Spanish, as well as knowledgeable in German and Latin. Lemus spends his spare time maintaining his language skills through travel, conversation, literature and music. He also enjoys working out to maintain a healthy lifestyle.

Lemus adds, "I'm hoping to bring two elements to Lanterman while serving as a board member – enthusiasm and diversity of opinion and outlook."

Tour of Hope

Continued from page 1

passionate commitment to supporting cancer research and to help future generations move closer to the ultimate miracle, a cure. Riding around the clock, the team rode through California; the Arizona and New Mexico deserts; the Texas plains; the states of Louisiana, Mississippi, Alabama and Georgia; across the Appalachian mountains of South and North Carolina and Virginia; through Maryland and into Washington, D.C., sharing their personal stories, and motivating communities along the route to learn more about the benefits of cancer research.

Doron's team rode primarily in the early morning hours between 11 p.m. and 4 a.m. It was this time of day when the night was darkest and the stars the brightest that Doron says gave him time to reflect and think about what he was doing and why he was doing it. "I've been biking for many years and I'm an experienced cyclist, and for me, the more difficult the ride and the more pain the ride inflicted on me, it reminded me that this is the least we can do,



From left, Dani, Phyllis, Doron and Ari Kochavi were both delighted and honored to have been part of the 2005 Tour of Hope event.

even if it pales in comparison to what my son had to go through and what a cancer patient endures between surgery and treatment," shares Doron.

Each day, Doron wrote in his online rider's journal where he shared his feelings about the day's ride and what lay ahead for both himself and his team as they made their way across the country. "As in life, Ari gives me the opportunity to see the road from a different perspective. My son has taught my wife and me that, like cycling, the fight against cancer is truly a team effort," says Doron.

Phyllis; Dani, the couples' 19-year-old college sophomore at George Washington University; and Ari, who attends a specialized school called Riverview in Cape Cod, Massachusetts, were all waiting in Washington, D.C. to welcome the Tour of Hope team. "I rode in honor of Ari and the many children diagnosed with cancer that didn't survive," shares Doron. "The faster patients are placed in clinical trials, the faster it is possible to see if a new drug is useful. We need drugs that will successfully treat tumors without severe side effects, such as significant learning disabilities and short-term memory difficulties."

Even though a person can only ride once in the Tour of Hope, it's an experience that lasts a lifetime. Doron is looking forward to many more years of riding tandem with Ari around their La Cañada neighborhood so he too can experience the thrill of moving fast and feeling the wind in his face. "I hope this story serves as an inspiration to other families who are battling with cancer and dealing with the lifelong impact of cancer treatments. Just remember that a new chapter is written everyday," says Doron.

To learn more about the Tour of Hope and read Doron Kochavi's daily journal, visit www.tourofhope.org.

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 December, the following individuals received service awards: Hasmig Mandossian for 25 years; Dolores Sumilang for 20 years; Rowena Pangan and Ardis Adrian for 15 years; and Carmen Alabat, Joanne Bernal, Angelica Godoy, Cynthia Guerra, Candice Lamere, Jeannette Orlando, Edward Perez, Elsa Ramos, Patricia Rodriguez and Sona Topjian for five years of service to Lanterman Regional Center and the community.

The reason I have stayed at Lanterman for five years is because I enjoy working with our families, and I continue to learn from them. I have also enjoyed working with a great group of people in my units who have been very supportive throughout my career. My favorite memory is eating lunch with my Early Intervention co-workers and sharing funny stories. Abraham always had the funniest stories.

– **Edward Perez – 5 years, family support specialist, Koch♦ Young Resource Center**



From left, Hasmig Mandossian and Joanne Bernal

My five years at Lanterman has definitely been a roller coaster ride encompassing the good, the bad and the ugly, but all in all a rewarding experience.

– **Joanne Bernal – 5 years, intake specialist, Intake unit**



Ardis Adrian

I have stayed because of the nice people, clients, families and co-workers. A few of my favorite times are the holiday retreat, the picnics, the theater fests and the Achievable Walk, basically anytime our community has a get together.

– **Ardis Adrian – 15 years, nurse consultant and Medicaid Waiver coordinator, Clinical Services unit**

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.



Jeannette Orlando

My primary reason for staying at Lanterman is I like doing this, I like connecting resources in the community with our clients. My secondary reason is for the view – I have a great view of the Hollywood sign and the Griffith Park Observatory – that I look to for inspiration. I can’t say that I have a favorite memory, but what I enjoy most is interacting with everybody on a daily basis.

– **Jeannette Orlando – 5 years, resource specialist, Community Services unit**



Carmen Alabat, Edward Perez and Angelica Godoy (left to right)

Working here at Lanterman has been a positive experience. The reason I continue working here is because I truly care about the families we serve. Witnessing some of the milestones that our children finally achieve is truly amazing. I have met and advocated for many families during these past five years; and I continue to be reminded how important it is to work as a team, and to empower and support our parents with their children. However, what’s universal for all parents is that they want their children to belong and to be part of something. I believe that even if you affect the life of a few families, it’s all worth it because you have left that family with hope and a willingness to try no matter what obstacle may face them. I believe we should view “disabilities as possibilities.”

– **Carmen Alabat – 5 years, service coordinator, Foothill School Age unit**

Ten years ago, I chose to become a social worker because I wanted to help people. I wanted to have a career in which I would make a difference in a family’s life. Working as a service coordinator at Lanterman Regional Center for the past five years has given me that opportunity, and so much more. I can honestly say that I truly care for my clients and their families, and I think that most of my families appreciate the work that I do for them. Don’t get me wrong, the job can be more stressful than you can possibly imagine but the occasional thank you card, note or message from one of my families is enough to make it all worthwhile. Being surrounded by great co-workers and a great supervisor just makes it all even better.

– **Angelica Godoy – 5 years, service coordinator, Foothill School Age unit**

I enjoy working with the families in school age because they have so much hope and joy, and also seeing the families grow and evolve during the years they are with us. My favorite memory is of the most recent Social and Recreational Forum, and the on stage performance of a young lady who was at the forum with her family. Seeing the love, pride and commitment of the family to their daughter was very rewarding.

– **Candice Lamere – 5 years, regional manager, Foothill School Age Service Coordination unit**



From left, Candace Lamere, Cynthia Guerra and Dolores Sumilang

I enjoy seeing year after year how the children on my caseload progress, and witnessing how the support we provide them enables them to have a better life.

– **Cynthia Guerra – 5 years, service coordinator, Foothill School Age unit**

KEEN LA Launches Weekend Athletic Program at Elysian Park, Now Accepting Applications for Program Expansion



On a recent Sunday morning, the Adaptive Recreation Center at Elysian Park was filled with the sounds of bouncing basketballs, the swish of swings, and the encouraging words of the approximately 40 volunteer coaches playing with 16 children with special needs. It was all part of the Kids Enjoy Exercise Now Los Angeles program that launched this fall.

No matter which direction you looked, there were children playing, and right beside them, or in some cases running to catch up with them, were KEEN volunteers. The majority of the volunteers are attorneys and staff from the law firm of Sonnenschein Nath & Rosenthal LLP, as well as their family members and friends, and a few students from the University of Southern California School of Law.

“The majority of the children who participated in this first program session of KEEN LA have been diagnosed with autism, and more than anything, this program offers these children the opportunity to develop their social skills in a

supportive environment,” shares Marjorie Heller, executive director of KEEN LA.

Coaches challenged the athletes to try new things, such as the monkey bars, hula hoops, or practicing their dunk shot and bowling moves. In order to provide for an independent social and recreational setting for the athletes, parents are encouraged to use the program as a time for respite, and to allow the coaches and athletes to interact with each other on their own.

During the pilot program phase, KEEN LA will meet once a month, usually on the first Sunday of the month from 11 a.m. to noon. Starting in February or March 2006, KEEN LA will introduce a second session on the third Sunday of the month. KEEN LA is recruiting more athletes for its program expansion, especially children whose special needs require one-on-one coaching for their successful participation in various athletic activities. Following the formal commencement of the program next spring, KEEN LA hopes to maintain a one-to-one ratio of athletes to coaches. Accordingly, KEEN LA would like to

recruit additional volunteers who can donate time or funding for the program.

KEEN is an international, non-profit tax-exempt organization started in the United States in 1992 that is dedicated to providing specialized athletic programs in an open, unstructured environment for school-aged children and young adults with significant developmental disabilities. In many cases, the KEEN program frequently constitutes the only recreational and social activity for some athletes who are unable to participate in other programs. KEEN LA is one of two new programs starting this year, the other being St. Louis, Missouri, and will complement already existing programs in the Washington, D.C., Chicago and Kansas City metropolitan communities, as well as programs in England.

For more information about KEEN LA or to get a copy of the application for the KEEN LA program, call **213.892.2935** or e-mail KEEN@sonnenschein.com. Information about KEEN LA is also available at www.keenlosangeles.org. Information about KEEN USA is available at www.keenusa.org.

At 50, Howard McBroom Starts a New Chapter in Life

One year before he turned 50, Howard McBroom was diagnosed for the first time with autism. McBroom came to Lanterman Regional Center just over a year ago at the recommendation of his friend Derek. “Derek is a disability advocate and he noticed some things about me that made him think I might qualify for regional center services,” shares McBroom.

McBroom, who also suffered partial oxygen starvation while in his mother’s womb, has some balance, hearing, speech and motor coordination limitations. He prides himself on being outgoing and feels that he has “better social skills than most individuals and can connect with people.”

McBroom, who was born in Washington, D.C., but moved to Indiana at a very young age, graduated in 1977 with a bachelor’s degree in history from Indiana University at Bloomington. He then moved to Los Angeles where he worked at Curtin Security from 1977 to 2003, when the company closed its doors. He found another job with a security company, but was not comfortable with using a computer and left his new job after a short stint. He also worked at a city library from 1981 to 1995.

When asked how his life has changed since he joined the Lanterman community, McBroom shares, “I had great difficulty cleaning my old apartment in Burbank, but Marie, my service coordinator, helped me move into a place in Glendale that would be easier to manage. I like it and call it my cozy little cubby hole. I’m doing a lot better with aid from Modern Support Services.”

This past September, McBroom started taking the adult computer class offered by Lanterman Regional Center in partnership with the Los Angeles Unified School District, Division of Adult and Career Education, Los Angeles Community Adult School. McBroom is very comfortable taking public transportation and highly recommends trains as a good way to travel. “Multi-tasking is difficult for me, but I’d like to eventually get a job as a history tutor or proof reader to supplement my SSDI and my city disability,” notes McBroom.

McBroom enjoys reading history, particularly 20th century American and European history. His favorite history book is “The Longest Day: The Classic Epic of D-Day.” He also writes science fiction and is taking the



Howard McBroom

computer classes so he can type his stories and get them published. McBroom participates in a stand-up comedy group that does improv. “I am the number one fan of the World Wrist Wrestling Championship that is held in Reno, Nevada. I’ve watched wrist wrestling for 25 straight years, and see the championship in person every year,” says McBroom. He also volunteers as an usher on Wednesday nights and Sundays at SpiritWorks, his church in Burbank.

“Howard has been very open and receptive to the services Lanterman has offered him. He came from a bad situation, but has shown a tremendous amount of improvement since he’s been

with the Center. Volunteers from his church helped him get organized, find a new apartment and relocate, and he’s accepting Independent Living Skills services and is opening his case with the Department of Rehabilitation. Howard is now in a position where he can support others instead of being supported,” shares Marie McGinley, McBroom’s service coordinator.

“One thing that I’ve learned from being here at Lanterman is that it’s no fun having any kind of disability, but how fortunate I am compared to many others since I have friends that I can ask for help,” shares McBroom. “I’m really impressed by the people at Lanterman. They are really competent and caring, and are really performing a good service and really helping a lot of people.”

STAFF HIGHLIGHT

Ronna Kajikawa is the Maven of Training at Lanterman

“The truly engaged and talented people that come to work every day are the real asset of your company.”

— Curt Coffman, co-author of *“First, Break All the Rules: What the World’s Greatest Managers Do Differently”* and *“Follow This Path: How the World’s Greatest Organizations Drive Growth by Unleashing Human Potential”*

Ask anyone a question related to training and they’ll tell you, “Go ask Ronna.” So who is she? Ronna Kajikawa, who will be celebrating nine years at Lanterman on January 6, 2006, has been and will “happily continue to be” the assistant to the director of Training and Development at Lanterman.

Kajikawa, a graduate of the University of California, Los Angeles, with a bachelor’s degree in history, was born in Chicago, but grew up in the Pico/Olympic/Crenshaw/La Brea area of Los Angeles and attended school at Queen Anne Elementary, Wilshire Crest, John Burroughs Junior High and Los Angeles High School, all schools that are located within Lanterman’s catchment area. After receiving her bachelor’s degree, Kajikawa pursued an additional year of school to obtain her teaching credential. “Learning, teaching, planning and organizing are skills from my schooling that definitely relate to my job,” she says.

In addition to fulfilling her primary responsibility, which is to support the director of Training and Development, Maureen Wilson, on a daily basis and with special projects, Kajikawa is responsible for tracking the internal and external training attendance of all staff, parents, clients and service providers. Once requests for a conference/training have been approved, Kajikawa is responsible for registering attendees, requesting payment from the Center’s Accounting department, making travel arrangements if necessary, and notifying the person with all the details. The Training and Development department processes an average of 2,500 Lanterman community members per year who attend conferences or trainings.

She also assists in locating trainings and conferences for members of the Lanterman community who are looking for specific opportunities.



Ronna Kajikawa with her granddaughter, Maya Kajikawa

“Because part of my job is to make travel and accommodation arrangements for people attending out of town conferences, I also have the responsibility of coordinating travel arrangements for speakers presenting at Lanterman-sponsored events and for the *Perspectives* Film Festival,” explains Kajikawa. “Over the

last nine years, I’ve been very fortunate to have the opportunity to correspond with filmmakers, actors and disability experts from all over the world.”

When asked what the most rewarding part of her job is and what drives her to get up in the morning and come to work, Kajikawa shares, “The people I work with and the people I work for motivate me to get to work everyday. For me, the most rewarding part of my job is being able to assist people in gaining knowledge and in learning new things myself. I’ve worked in both the for-profit and non-profit world and I would much rather spend my energy and time in the human services arena.”

In her time at Lanterman, Kajikawa has been involved in the logistics for numerous events, but when she reflects on those that she considers major accomplishments the list is narrowed down to the following events: the last two Lanterman



Ronna Kajikawa

“Innovative Approaches,” a joint Lanterman and UCLA Neuropsychiatric Institute conference on treatment options for people with dual diagnoses. “I also value my work in assisting the director of Training and Development and the peer advocate in finding and developing curriculum on client personal safety, self-advocacy and women’s health issues,” adds Kajikawa.

For Kajikawa, the two biggest challenges of her job are locating the best trainings and conferences, as well as information that is available for the people requesting it, and finding a better way to get an intended audience to attend the training classes scheduled to meet the specific needs that have been identified. The one thing Kajikawa shares that would make her job easier is “if people got all their paperwork in on time and I didn’t have to chase after them.”

Unless she wins the lotto, professionally, Kajikawa would like to see herself exactly where she is. “As

Leadership Convocations, including the premier of the documentary, “We’re Here to Speak for Justice,” the Touchpoints™ Conference in 2001; the 2003 and 2004 *Perspectives* Film Festivals; and

far as work is concerned, I feel that my position in the Training and Development department is my best fit personally and professionally,” she adds. “In the next several years I would like to be happy, healthy and spending as much time as possible with Maya, my first grandchild born last October, and any future grandchildren.”

In addition to being a proud grandma, Kajikawa also has a grown son and daughter. Loren, along with his wife, Mika, and daughter, Maya, are living in Los Angeles while he finishes his doctoral degree in musicology at UCLA. Alisa is attending the University of California, San Diego and is majoring in Spanish. “She plans on attending the University of Grenada in Spain to boost her language skills, so I guess I know where I’ll be vacationing in 2006/2007,” says Kajikawa.

Kajikawa lives in Hollywood with her three cats – Mello, Micah and Annie. She loves to cook, and loves to dance, which she feels she doesn’t get to do often enough. “I’m grateful to have grown up a child of the 60s, but most importantly, I attended every single UCLA basketball home game from 1966 to 1971,” share Kajikawa. She’s looking forward to taking the Service Coordination and Advocacy Training offered through the Koch♦Young Resource Center. She adds, “I would like to be better informed about the service delivery system and have a better understanding of the workings of the Regional Center from all viewpoints.”

In response to a question about sharing an important life lesson, Kajikawa replied, “After my mother passed away, I found a note she had written on a scrap of paper tucked inside a book. I believe it is a lesson we might all benefit from – ‘I try to live so that someone will miss me when I am gone.’”

Holidays are for Sharing

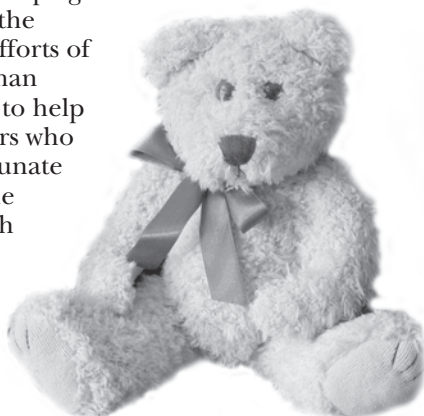
Continued from page 1

disasters. For example, the Red Cross raised over \$1.2 billion for Hurricane Katrina relief, but barely \$1.6 million for earthquake victims in Pakistan about a month later.

Jackie Ashman, director of Human Resources and the Volunteer Program, and coordinator of the *Holidays are for Sharing* campaign shares, “The situation is not looking good right now for the annual *Holidays are for Sharing* campaign. We started making phone calls to some of our biggest and most long-term supporters from previous campaigns even earlier in the year than we usually do and we heard over and over that they wouldn’t be making donations this year.”

This news coupled with the fact that all but a few Marines are deployed to Iraq from the Pico Rivera, November Battery, which is the group of Marine Corp Reservists that coordinate the annual Toys for Tots™ fundraising efforts that benefit Lanterman makes the success of the annual holiday campaign look bleak.

“We have been trying to figure out strategies so we can continue to meet the needs of all of the families served by Lanterman that need extra help during the holidays. Last year we were able to help close to 1,200 adults, children and their families, making it one of the most successful holiday campaigns in its 25 year history,” says Ashman. “The success of this year’s campaign will rely on the grassroots efforts of the Lanterman community to help our members who are less fortunate celebrate the holidays with traditional meals and gifts.”



Please Help HAFS

For 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/online_donations.asp.
- Send a tax-deductible contribution in the form of cash, check, money order or credit card.
- 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 Blvd., 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 or x. 613. One hundred percent of all donations go directly to the recipients.

Lanterman Helps People with Special Needs Impacted by Hurricane Katrina

Very few of us can say that we don't know someone who was impacted by the widespread devastation caused by Hurricane Katrina. For Maria Bosch, regional manager of the Pasadena/Community Living Options Unit at Lanterman, the hurricane hit particularly close to home. Before coming to California, Bosch worked at the Metropolitan Developmental Center in Belle Chasse in the Plaquemines Parish, which is in the New Orleans metro area.

As soon as she could get through, Bosch contacted her sister who works at Metropolitan Developmental Center to find out what she could do to help. While the Developmental Center survived Katrina, it sustained considerable damage from the subsequent flooding. The Center was home to about 400 clients, 300 of whom have a range of diagnoses, including mental retardation, autism, cerebral palsy, seizure disorder and related conditions, many with severe behavioral needs, and 100 who are medically fragile and non-ambulatory.

All the clients, including the medically fragile, were evacuated to Hammond Developmental Center in Hammond, Louisiana as quickly as possible. "The housing situation was far from ideal. They were staying in a location designed to hold at most 150 people, and although they had water, food and shower facilities, clients were sleeping on cots, and were crowded into small areas with no supplies for activities and entertainment," shares Bosch.



Bosch issued a plea for both cash donations and supplies. Lanterman's board of directors donated \$2,500 through the Lanterman Endowment

Fund, which was used to purchase large items, which were shipped directly to Hammond Developmental Center for use by the Metropolitan Developmental Center residents. Bosch also received both cash and supplies which

she packed and shipped to the displaced Metropolitan residents. The donated cash was used to pay for the shipping of collected items, including televisions, VCRs, toiletries, bedding, art supplies, books, clothes, furniture and many other necessities. "The majority of the cash donations and supplies were donated by Lanterman staff. Lanterman Developmental Center also contributed some bedding supplies," adds Bosch.



About 150 volunteer staff, including Metropolitan Developmental Center's chief administrator, a physician and psychologist, and nurses, psychology technicians and direct care staff evacuated with the clients. "The staff have been putting in at least 16-hour days in difficult and trying conditions, leaving their families and homes in the Orleans, Jefferson and Plaquemines parishes. For a long time, they had no idea if their own homes were even still there, or if their own families were safe," says Bosch.

At the earliest, Metropolitan Developmental Center residents are not expected to return home until the beginning of December. Bosch shares, "Except for the extensive damage caused by flooding, the Center held up and the hope is that the clients will be able to return home for the holidays." Although, based on the following anecdote, many of the Metropolitan clients thought that the holidays had come early, since when they moved to Hammond they were given a turkey dinner with all of the trimmings and they said that it was Thanksgiving. And when the donations started to arrive, they said it was Christmas, and that Santa had come, right on schedule. Of course when the donations kept coming day after day and week after week, they were a little confused and could not explain the neverending visits from Santa.

211 is Los Angeles County's Source for Health and Human Services Information

Do you need help finding emergency food and housing? Do you have a question about education resources or health care options in Los Angeles? What could be easier than dialing three digits, 2-1-1, to access a comprehensive source of health and human services available in Los Angeles County? The 211 LA County database has listings for more than 4,000 agencies and over 28,000 programs and services directed toward the solution of human service problems. The database is designed for use as part of an information and referral program, as well as for research about services and their availability in Los Angeles County. Listings contain information necessary to provide the best possible referral, such as a



description of the service being provided, eligibility requirements or exclusions, target groups, service area, restrictions, languages in which the services are offered, application procedures, hours, fees, service provider information, program and agency funding sources, and where applicable, agency or facility licensing information. Listings are neutral and are not intended to promote a particular service provider or program.

Agencies are surveyed annually to review and update their entries, and database listings are updated throughout the year when 211 LA County learns of, or is notified of, changes affecting services or providers.

2-1-1

Be Prepared for the Big One – Disaster Preparedness Planning is Crucial

California is one of the most seismically active regions in the world. And with all that seismic activity comes earthquakes – little ones, big ones and everything in between. Add to that the almost annual fires, subsequent flooding and mudslides, and the Southern California region is a disaster waiting to happen. The bottom line is that nobody is immune to natural disasters. The only thing you can do is to be prepared when one strikes.

In the event of a large-scale disaster or a localized one, safety concerns for Lanterman staff and visitors take priority. A disaster situation, such as a major earthquake, flooding, severe weather conditions, hazardous material spill, bomb threat, riots or fire, would cause Lanterman leadership to close the Center.

After a major natural disaster, it's very likely that local phone service will be interrupted. If the Regional Center's main telephone number is not operational, and you need to immediately contact someone on staff at Lanterman, call our emergency number at **1.800.657.3239** to receive instructions on how to communicate with staff at the Center.

While it's important that the Regional Center has a disaster preparedness plan in place to assist our staff and visitors, especially those with special needs, it's also important for individuals to have their own plan in place for their home and workplace. "It's hard enough to account for everything you need to consider when putting a disaster preparedness plan together, but when you add the component of special needs, it becomes that much more challenging to make sure that the plan addresses a person's most critical needs," shares Maureen Wilson, director of Training and Development, and coordinator of "Project Prepare."

Each year, the Regional Center conducts voluntary training seminars on disaster preparedness for clients, families and service providers. Through the Center's "Project Prepare," clients and independent living program staff receive disaster training specific to people with disabilities. Disaster kits are also distributed to clients at the training or through their independent living staff. For more information about training or disaster kits, contact your service coordinator or visit the training section of the Lanterman Web site at www.lanterman.org/training/default.asp.

Wilson adds, "Whether you're an adult client living independently in the community or a family with a child who is dependent on specialized medical equipment, it's important to be prepared. For help preparing for a disaster, contact your service coordinator who can assist you in securing needed items such as additional supplies of necessary medication or emergency back-up equipment."



Disaster Preparedness Tips for People with Special Needs

Here are a few considerations when planning for a disaster:

1. Add special items like necessary medication, extra wheelchair batteries, food and water for service animals, or other special equipment you might need to your standard disaster supplies.
2. Keep a copy of important documents and a list of the serial and model numbers of medical equipment or assistive devices in a water and fireproof container.
3. Ask your local community fire department, utility company and emergency management office about special assistance that may be available to you in an emergency.
4. Arrange for a neighbor or support person to check on you in a disaster.
5. Consider getting a medical alert system that will allow you to call for help in an emergency.

For more resources on disaster planning for people with disabilities visit the following Web sites:

City of Los Angeles, Emergency Preparedness Department

www.lacity.org/epd/epdpi2e.htm#2

Los Angeles Chapter, American Red Cross – Disaster Preparedness for People with Disabilities
www.redcross.org/services/disaster/beprepared/disability.html

Disaster Supply Kits and Other Essential Supplies - Checklist
www.redcross.org/services/disaster/beprepared/apendixa.html

Lanterman Regional Center Emergency Number: 1.800.657.3239

CAC NEWS

What Clients Think About Their ILS Workers



Earlier this year, the Consumer Advisory Committee, which 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, conducted a survey of clients to find out how they felt about the people who provide them with Independent Living Skills (ILS) services. Rather than send out a survey as Lanterman often does, the CAC decided to have people come together in a group to answer the questions since the response rate to surveys is usually low.

Personal invitations were sent to clients whose names were provided to the CAC by their service coordinators. Fifty-five clients were invited to participate, and 27 actually completed the survey. The survey consisted of eight statements and the group sessions offered participants a chance to discuss each question to make sure they understood what it meant. The survey asked clients to indicate whether a statement was true, sometimes true or not true in their situation.

“If all 27 people had said true to all the questions, this would have been very good. It would mean that ILS workers always do the things that they should do – like treat clients with respect and teach them what they want to learn,” shares Armen Frundzhyan, chair of the CAC. There were three questions that a lot of people responded to with sometimes true or not true:

- 2. My ILS worker is reliable.
- 5. My ILS worker knows everything he or she needs to know to be a good teacher.
- 8. I would ask for a different ILS worker if I didn’t like the one I was working with.

“Two of these are areas that ILS agencies should work on improving,” adds Frundzhyan. “They should try to get the ILS workers to be more reliable, like coming on time, and they should also make sure the ILS workers know everything they need to know to be good teachers.”

While the first two areas are in the domain of the agencies to improve, it’s the clients themselves that must do something about question number eight. “Clients need to understand that if they aren’t happy with their ILS worker it is OK for them to ask for another one,” explains MJ Kienast, assistant director and CAC staff advisor.



The Consumer Advisory Committee meets monthly on the second Monday of the month to discuss various issues that affect clients and their families, and to provide input and advice on the policies, services and programs to the board of directors. At all times the CAC has at least five members, but not more than 10. From left, Armen Frundzhyan, chair; Ray Drumheiser; MJ Kienast, CAC staff advisor; Ara Bezjian; Mary Flynn; Lorena Avalos, CAC secretary; and Marlene Guerron. Committee members not pictured are Anna Villasenor, Ralph Bingener and Sonia Aguilera.

During the meetings, the CAC also asked clients how many of them had ever changed ILS workers because they were not happy with the worker they had. Over half of the 20 clients who were asked said that they had changed ILS workers.

After reviewing the results of the survey the CAC decided they would like to use the information they collected to make an impact on ILS. They agreed that the information should be provided to both ILS providers and clients so that they could work together to promote the improvement of Independent Living Services.

So how can this be accomplished? The CAC agreed that they need to reach other clients and provide them with this and other information the CAC collects. The CAC would like to establish open communication with clients on an ongoing basis.

If you are a client of Lanterman Regional Center and have an issue that you think other clients would be interested in, you can write the CAC at:

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

or call CAC staff advisor, MJ Kienast, at **213.383.1300, x. 606** or e-mail mj.kienast@lanterman.org.

| SURVEY OF WHAT CLIENTS THINK ABOUT THEIR ILS WORKERS | | | |
|--|----------------------|--------------------------------|--------------------------|
| Statement | Number Saying “True” | Number Saying “Sometimes True” | Number Saying “Not True” |
| 1. My ILS worker treats me with respect. | 26 | 1 | 0 |
| 2. My ILS worker is reliable. | 16 | 9 | 2 |
| 3. My ILS worker is understanding. | 22 | 4 | 1 |
| 4. My ILS worker has a good attitude. | 25 | 1 | 1 |
| 5. My ILS worker knows everything he or she needs to know to be a good teacher. | 18 | 9 | 0 |
| 6. My ILS worker teaches me what I want to learn. | 22 | 4 | 1 |
| 7. My ILS worker is good at helping me deal with problems in my life. | 21 | 3 | 3 |
| 8. I would ask for a different ILS worker if I didn’t like the one I was working with. | 19 | 2 | 6 |

CAC to Focus Future Efforts on Access Services and Transportation Issues

Protection and Advocacy, Inc. and Access Services, Inc. reached a settlement in a suit that requires Access Services to collect complaint information and report back on the quality of their service. “The complaint process is not nearly as accessible as it should be for individuals with developmental disabilities,” says MJ Kienast, assistant director and Consumer Advisory Committee staff advisor.

The CAC has been talking about focusing their next project on transportation, and the timing is right for them to help get the word out about how to file a complaint with Access Services. Over the next several months, the CAC will be developing various ways to help clients file complaints more easily, and advocating with service coordinators and caregivers to help support clients in filing these complaints.

“The reality is that the services provided by Access Services are a generic resource and Lanterman Regional Center needs to be advocating for its use and figuring out ways to help,” adds Kienast. In the next CAC News feature, look for more information and tips from the CAC about how to file a complaint with Access Services.

Support Self-Advocacy, Subscribe to The Riot!

No one knows you better than you and no one can represent you better than you. Self-advocacy simply means that you understand your disability, know your strengths and weaknesses, and are able to tell others what you need to successfully participate in an activity, program or event. While the thought of speaking up for yourself and disclosing personal information about yourself and your disability to a complete stranger might sound embarrassing, scary or just uncomfortable, with practice you can not only become a self-advocate, but help others become one too.

Whether you are already a self-advocate or a self-advocate in the making, then “The Riot!,” a newsletter for “self-advocates,” is for you. It’s also for other people too, like parents, staff and policy makers. “The Riot!” is designed to entertain you; give you good information, such as articles that promote and support living in the community and being in charge of your own life; and for giving you, and other self-advocates, the opportunity to make your voice heard in a national forum.

“The Riot!” is published four times each year in January, April, July and October, and the best part, it’s free. “The Riot!” is produced by the Self-Advocate Leadership Network at the Human Services Research Institute. For more information and to subscribe to “The Riot!,” visit www.hsri.org/leaders/theriot.



Lanterman Representatives Visit Our Nation's Capitol to Make Our Voices Heard at Summit 2005



Lanterman's delegates, from left, Ervand Kestenian, client and board member; Kelly Vencill-Sanchez, parent; Melinda Sullivan, associate director of Client and Family Services; Jack Darakjian, service provider; and Enrique Roman, service coordinator, discuss some of the issues raised at the Summit. Helene Schultz, regional manager, was also part of the delegation, but is not pictured.

The end of September, six representatives from Lanterman Regional Center packed their bags and headed out to Washington, D.C. for the Alliance for Full Participation's first ever national Summit. The focus of Summit 2005 was to bring together those individuals and organizations committed to making the promises inherent in the Developmental Disabilities Act for Americans a reality.

AFP is a formal partnership of leading organizations serving the developmental disabilities field that share a common vision – to help create a better and more fulfilling quality of life for people with developmental disabilities. AFP's founding members include the following organizations: American Association on Mental Retardation (AAMR), American Network of Community Options and Resources (ANCOR), Association of University Centers on Disabilities (AUCD),

National Association of Councils on Developmental Disabilities (NACDD), National Alliance for Direct Support Professionals (NADSP), National Disability Rights Network (NDRN), The Arc of United States, The National Association of State Directors of Developmental Disabilities Services (NASDDDS), United Cerebral Palsy (UCP), The Council on Quality and Leadership, and Self-Advocates Becoming Empowered (SABE).

Approximately 2,000 individuals attended to help craft a new strategic policy and social agenda in support of the full participation of individuals with developmental disabilities in mainstream society. The five key areas important to full participation are: housing, transportation, education, employment and personal safety. For more information about AFP and the Summit, visit www.allianceforfullparticipation.org/public.

Lanterman's Partnership with Pasadena Public Library Grows, Functional Literacy Classes Added

It's very easy to take for granted scheduling appointments in our daily planners, reading directions for baking brownies, or picking up the calendar section of the newspaper to find out the show time for a new movie. For a large percentage of the adults with developmental disabilities, these daily experiences can be challenging – and not because they aren't capable of doing them, but because they were never taught how to read.

Just over two years ago, Lanterman Regional Center was selected as a community partner to help the Pasadena Public Library improve its services to people with developmental disabilities, their families and caregivers as part of a grant from the California State Library. Three key areas to focus on were identified:

- Improving literacy skills and information access
- Greater library staff sensitivity and awareness
- Enhancing the Pasadena Public Library's collections of materials of interest to people with developmental disabilities and their caregivers

Lisa Anand, resource and information specialist at Lanterman, explains, "Lanterman was able to assist the library in achieving the second two objectives within the grant term, but both parties knew that a greater investment would have to be made to move forward with improving literacy skills for our community." Pasadena Public Library, like many of the libraries throughout the State, offers an adult literacy tutoring program called "Pasadena Reads."

Anand adds, "The library staff have shared with us that it has been a challenge to include people with developmental disabilities in this program, although they would like to broaden the range of individuals they can serve."

In support of the grant objective to improve literacy skills, Lanterman Regional Center hired Barbara del Monico, a literacy specialist, to help strategize literacy development for adults with developmental disabilities. In order to determine next steps, del Monico, along with Anand and Sharon Shueman, a consultant for the Regional Center, conducted a survey of adult clients in

Pasadena to determine whether there was both an interest and a need for functional literacy education. Results of the survey confirmed that there was both the interest and the need for these skills.

Del Monico, who has a background in literacy instruction and special education, also reviewed existing state literacy programs for people with developmental disabilities and a broad range of literature before developing a curriculum framework that was specifically tailored to the needs of adults with developmental disabilities.



This new model focuses on introducing functional literacy skills rather than using a traditional literacy instruction model based on phonics. The curriculum is goal driven and lessons will be taught using a variety of modalities such as audio tapes, visual props, interactive class activities and computer software.

After two years of research and development, Lanterman Regional Center was prepared to launch a pilot functional literacy class for adults with developmental disabilities. The three key areas of focus for the class are reading for information, such as reading directions; reading for work, such as creating a resume; and reading for pleasure, such as Don Johnston's Start-to-Finish version of "A Christmas Carol." "The only thing missing was the staff to conduct the pilot class," says Anand. "Over the summer, Lanterman put out a Request for Proposals and selected a service provider who we felt could coordinate the pilot project and had the right staff to implement the class."

The chosen proposal was submitted by Jack Darakjian of Modern Support Services and the Association for Developmentally Disabled Armenians. Staffing for the project includes an assistive technology specialist who can advise on appropriate literacy software, as well as hardware to fit access needs; a tutor instructor who will provide a thorough training program for all tutors participating in the program; Barbara del Monico, to provide on-going literacy consultation to the instructor and tutors; and an instructor who will design and implement lesson plans using the curriculum framework and materials gathered by the aforementioned consultant.

"The Pasadena Public Library has remained a committed partner in the project and will provide the site for the class free of charge," notes Anand.

Classes will be starting in January and will be held once a week for five consecutive months for a total of 20 sessions. Students must be 18 years or older with a developmental disability, and they must commit to attending all sessions. "Some examples of subjects and skills that will be covered include, the newspaper, emergency information, budgeting, getting around, the driver's manual, shopping, preparing for a job, basic clerical tasks, using the library, personal correspondence, and calendars/agendas," shares Anand.

The Pasadena classes will be held from 9 a.m. to noon at the Pasadena Public Library's La Pintesca Branch located at 1355 North Raymond Avenue in Pasadena. Classes will start on Saturday, January 14, 2006 and continue through Saturday, May 27, 2006. Each student is required to bring their own volunteer tutor, such as a family member, friend or caregiver. Anand says, "The hope is that not only will the student take away valuable information from this class, but that the tutor will be able to help reinforce these skills outside the classroom. Additionally, by holding the class at the library, the natural environment for enhancing reading skills, students are becoming active patrons of their local library, and may be able to transition more seamlessly into a program like 'Pasadena Reads' upon completion of the literacy course."

In a subsequent effort, Lanterman is also partnering with the Los Angeles Unified School District, Division of Adult and Career Education to offer functional literacy classes in the Los Angeles area. These classes will be held at Lanterman Regional Center. There is no date set for the Los Angeles class to begin, but we are hoping to start after the holidays. Meeting times are still being determined as well, but will likely be weekday mornings.

Enrollment for both classes is closing soon, so contact Lisa Anand at **213.383.1300, x. 716** or lisa.anand@lantemran.org for more information about the classes and to register.



Lanterman Recruits an Interdisciplinary Team for the Assistive

Along with Marty Sweeney’s departure from the Assistive Technology Project in December comes a new way of delivering assistive technology services. “Marty’s departure has prompted us to reevaluate and restructure the AT Project to address the increasing demand for assistive technology-related services. In support of this transition, we’ve brought on board an interdisciplinary team,” shares Patricia Herrera, director of Family Support Services and the Koch ♦ Young Resource Center.

“The new team’s approach is built on the interdisciplinary model of training and clinical practice developed and applied for almost four decades at the University of Southern California’s University Center of Excellence in Developmental Disabilities at Childrens Hospital Los Angeles,” says Sonia K. Aller, Ph.D., C.C.C. Aller, the team manager, is a Communication Disorders faculty member at the USC UCEDD, a practicing speech-language pathologist, and the program director of the USC UCEDD’s “Tech for Tots™: Assistive Technology for Infants and Young Children.” The other team members are Kat Andrews, M.A., whose specialty is assistive technology within the field of vocational rehabilitation; Pablo Rizzo, A.A., AT assistant; Anna Holly, OTR, occupational therapist with an AT specialty; and Garik Gyuloglyan, computer support assistant.

The AT Project will provide assistive technology awareness and related resources and supports to individuals with developmental disabilities, their families, circles of support and service coordinators. The team will conduct one-on-one assistive technology, and augmentative and alternative communication, consultations; coordinate assistive technology workshops; and provide AT consultation support to the adult computer classes and the expanded AT/AAC lending library.

The interdisciplinary perspective allows the team to evaluate every aspect of a person’s functioning to determine which areas would benefit from assistive technology support. “One of the most important objectives of the team is to identify how assistive technology can contribute to the achievement of the goals outlined in the various person-centered plans,” explains Aller.

Learn more about the diverse backgrounds of the new Assistive Technology Project team members.

KAT ANDREWS

When you listen to Kat Andrews talk about all of her different professional experiences, it’s hard to believe that she’s only 28. Andrews has a bachelor’s degree in recreation with an emphasis on therapeutic recreation for special populations from California State University, Long Beach, which she followed up several years later with a master’s degree in rehabilitation counseling with an emphasis on assistive technology from San Diego State University.

Andrews divides her time between working at Holding Hands Pediatric Therapy and Diagnostics doing direct therapy, assessments and parent training, and participating with the Lanterman AT Project team. “While most of my educational and internship experience was with adults with special needs, I always wanted to work in pediatrics, especially doing play therapy with families,” says Andrews.

In addition to the experience she’s gained working at Holding Hands, Andrews also has professional experience working in locked psychiatric facilities and with group homes serving abused and neglected children, as well as consulting independently on behavioral intervention. She also worked for about three years in the field of vocational rehabilitation with the Center for Applied Rehabilitation Technology, better known as CART.

“I found out about the Assistive Technology Project when I attended a presentation on augmentative and alternative communication at Lanterman this past spring,” shares Andrews. “I was sitting next to Sonia at the presentation and afterwards, both Sonia and Marty approached me about whether I might be interested in consulting with the AT Project.”

Andrews’ experience with adapting workplace environments coupled with her experience helping parents learn new ways of playing with their child with special needs makes her a valuable member of the AT team. “What really interests me about assistive technology are the lower cost solutions to adapting a person’s environment,” add Andrews. “These are the solutions that are the most accessible, easiest to implement and in many cases have the best results.”

She’s also participated with a tri-lateral consortium, studying the social structure and the differences between how Canada, Mexico and the United States provide services to people with disabilities. “I think what I bring to the team is my experience with so many different jobs and cultures, and because I’ve never worked in a bureaucratic setting, I’ve always been free to think creatively and outside of the box when it comes to assistive technology solutions,” says Andrews.

GARIK GYULOGLYAN

Most of us know that person who can take a computer apart and put it back together again so it works better than before, who talks about locking out viruses and gets excited about great deals on software and hardware. For over six years, including his time as a volunteer, Garik Gyuloglyan has been this person to the Assistive Technology Project.

Gyuloglyan started out as a gamer, but because of his involvement with the AT Project, developed an interest in new adaptive technology software and hardware and its ability to assist people with special needs. His primary responsibilities are providing one-on-one support for the students in the adult computer classes held in partnership with the Los Angeles Unified School District’s Division of Adult and Career Education. “I shadow the

classes and keep an eye out for who might need help, and I troubleshoot any hardware problems that come up during the classes so they keep moving along,” adds Gyuloglyan. He also researches hardware and software so that the team knows how a particular assistive technology product can be used to support an individual client’s needs, and assists with the maintenance of the AT lab’s computer network.

Gyuloglyan obtained a certificate from Los Angeles City College for having taken classes to learn to become a webmaster. Gyuloglyan has a passion for anything that is technology-based, particularly the hardware side of computer technology, and he enjoys refurbishing computers.

He’s very interested in filmmaking, and has worked on several short films. Gyuloglyan is currently building a workstation for editing movies, and can’t wait until he can purchase the latest animation rendering software.

PABLO RIZZO

When Pablo Rizzo immigrated to California from Argentina six years ago, he spoke not a word of English. Committed to getting a job in the technology field, Rizzo took English classes for two years. He already had a background in technology from studying electronic engineering in Argentina for two years, followed by one year of instruction in computer systems analysis.

Once he had a solid grasp of English, Rizzo started taking classes at Pasadena City College to become a computer information systems programmer, and recently received his degree. He’s now taking classes in Web design and implementation at Los Angeles City College and will be pursuing the Assistive Technology Applications Certificate Program from the Center on Disabilities at California State University, Northridge.

“I’m looking forward to applying my computer background to assistive technology,” shares Rizzo. Several years ago, Rizzo was introduced to assistive technology through the adult computer classes held at Lanterman. He volunteered to teach a basic computer class for Spanish-speaking families at Lanterman while he was taking English classes. Rizzo’s role in the Assistive Technology Project is as the assistive technology assistant. He coordinates all of the consultations and scheduling, data entry and statistics, and researches the various software and hardware to ensure the best match is made for each individual’s unique assistive technology needs.

Prior to coming to the states, Rizzo, who had been swimming for over 10 years at the time, represented Argentina at the Paralympic Games held in Atlanta, Georgia in 1996. “I participated in a number of international swimming competitions and championships and was awarded a total of 56 medals over the course of my 10 years of competitive swimming,” adds Rizzo. Rizzo now has his water safety instructor certificate from the American Red Cross.

SONIA KONIALIAN ALLER

Dr. Sonia K. Aller, a speech-language pathologist with over 22 years of experience, received her doctorate in cognitive psychology, with emphases on information processing and memory, linguistics, early childhood development, and language development. This has provided her with a

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From left, the new multidisciplinary Assistive Technology Project team members are Garik Gyuloglyan, computer support assistant; Kat Andrews, whose specialty is assistive technology within the field of vocational rehabilitation; Dr. Sonia Aller, a speech-language pathologist, faculty member at the University of Southern California’s University Center of Excellence in Developmental Disabilities at Childrens Hospital Los Angeles, and AT Project team leader; and Pablo Rizzo, assistive technology assistant. Not pictured is Anna Holly, an occupational therapist with an AT specialty that consults with the AT Project.

Technology Project

broad perspective on developmental disabilities and interventions.

Aller, the Assistive Technology Project team manager, has been involved in the field of assistive technology since 1994. She was asked by the University of Southern California’s University Center on Excellence in Developmental Disabilities at Childrens Hospital Los Angeles to design an assistive technology component to be added to their interdisciplinary advanced training of interns and fellows in psychology, social work, nutrition, speech-language pathology, audiology, occupational and physical therapy, and pediatrics. “As assistive technology came into its own as a field, the UCEDD felt that it was important to make sure everyone was informed on the range of assistive technology interventions available for children with special needs,” says Aller.

As part of her preparation, Aller attended the Leadership in Technology Management program designed by the Center on Disabilities at California State University, Northridge. Individuals were trained in the hopes that they would develop programs around assistive technology that fit and met the diverse mandates of their organizations. Aller and her interdisciplinary training committee developed a pilot project funded by a grant from the federal Education Department, called “Tech for Tots™,” which was piloted at Lanterman several years ago. The grant produced several interdisciplinary curricula aimed at teaching how to integrate AT-based approaches into the intervention programs of very young children with developmental disabilities.

Aller’s primary role as project manager is to help families and adult clients of Lanterman define their goals and objectives, and then determine a plan for how the ATP can support their goals. “I’d like to broaden people’s understanding of the wide range that assistive technology covers and make it more accessible, since the most expensive device isn’t always the best solution” adds Aller. “Every person has unique needs and goals, and when we view their abilities from an interdisciplinary perspective, we get a clearer picture of how we can support them.”

ASSISTIVE TECHNOLOGY CONSULTATIONS

If you are interested in an assistive technology consultation or would like more information about the Assistive Technology Project, contact the Koch ♦ Young Resource Center at **213.383.1300, x. 730, 1.800.546.3676** or **kyrc@lanterman.org**.

Marty Sweeney is Movin’ On After Seven Years

After serving almost seven years as the director of the Assistive Technology Project of the Koch ♦ Young Resource Center, Marty Sweeney will be moving on in December. Sweeney was instrumental in developing the Assistive Technology Project as a resource for the Lanterman community, and without his hard work, dedication and passion for promoting and providing assistive technology resources to Lanterman clients and their families, the Project would not be the success it is today. So before Sweeney left, there were several questions we had to ask, but it sure isn’t easy to sum up the accomplishments and memories that accompany seven years of service to Lanterman.

What do you consider your biggest accomplishment as relates to the ATP?
I think my most significant accomplishment has been helping raise the awareness of the Lanterman community – clients, families, and the Center’s staff and board – about the significant and potentially life-transforming opportunities represented by computer and assistive technologies. Ten years ago technology wasn’t even on our collective radar screen when it came to someone with a developmental disability. Today we are using these powerful tools to promote early childhood development, communication, socialization, recreation, literacy and employment skills. And, this is just the beginning.

What will you miss the most about not being a part of the ATP anymore?
As a parent, I initially hesitated at the opportunity of disability becoming part of my professional life. I have a love/hate relationship with disability and worried that it would simply overwhelm me. However, after only six months it all fell into place for me. Working with the Lanterman community – families, children, teenagers, young and old adults alike – has been a deeply enriching experience for me. What many people miss in the experience of disability is the tremendous integrity and dignity that lies just beneath the surface. I was privileged to share in the lives of so many and it is what I will miss the most.



Marty Sweeney, right, with Garik Gyuloglyan who has meant a lot to the Assistive Technology Project, as well as to Sweeney. Sweeney, is saying farewell after nearly seven years as the director of the Project.

What is your most favorite memory of your time at Lanterman or most memorable moment, or both?
I think my most memorable moment occurred more than once, and would come as I first started working with someone. Often the person might not even be able to speak but there would be this shared glance of recognition when they knew that I knew, that we both knew, what was at stake. These were moments of recognition about potential and possibility, and I was offering that opportunity. These were moments often without words, yet they communicated so deeply both personal hope and need in the same moment.

I think my favorite memory is also a collective one, and reflects the experience of watching children grow, teenagers bloom, adults achieve new skills, and families finding ways to weave disability into their lives in loving and transforming ways. Disability is a wild card and takes us in so many different directions. My favorite memory is having had the opportunity to watch all of this unfold over the last seven years in the lives of the people I worked with and for.

As far as the future, what will you be doing after December?
Going undercover, playing rhythm guitar in a bar band, altering my medication, managing the Dodgers, and continuing to fight the good fight.



UCP’S AFFORDABLE ACCESSIBLE APARTMENTS TAKE SHAPE

UCP’s affordable, accessible apartment building located near Burbank’s downtown area is taking shape. Along with the Burbank Redevelopment Agency, UCP broke ground on the site last November. As of now, the apartments are scheduled to open before the spring of 2006 and all of the apartments are spoken for, which serves to illustrate the critical shortage of affordable housing that is currently available in decent neighborhoods. “Without affordable housing, the vision of full inclusion for people with developmental disabilities cannot be achieved because being able to live in your community is a cornerstone of being an active participant in that community,” shares Diane Anand, executive director. “We are pleased that the Association of Regional Center Agencies is making funding for affordable housing a legislative priority for the 2006 year.”

Support Your Direct Support Professional so They can Support You

Did you know that most of the nearly eight million Americans with developmental disabilities rely on private services and supports? And that the demand for direct support professionals is expected to grow 62 percent by 2010.

Currently, there are over 400,000 adults with developmental disabilities who live in residential settings nationwide, and one-quarter of them hold jobs and contribute to the communities where they live every day. Support professionals are the backbone of these community-based services and help ensure that people with developmental disabilities live enriching lives and are contributing members of their communities. Yet, this critical support network is at risk.

A 2002 study showed that support professional wages had increased only \$0.82 over eight years versus a \$4.16 wage increase for fast food workers over the same period. A study a year later showed that community-based support professionals made an average median wage of just \$8.68 an hour, over \$3 per hour less than the median wage for U.S. workers. The wages paid do not even meet the wage minimums for federal welfare-to-work programs.

In order to make ends meet, direct support professionals often work two jobs, and due to high health insurance premiums, many support professionals are unable to pay the employee portion of their premiums, so professional caregivers and their families often receive inadequate healthcare. And understandably, job turnover is 40 percent to 75 percent annually.

"We need to wake up and start caring about the people that care for us or our family members now, or that will care for us or someone we care about in the future," shares Diane Anand, executive director. "When you look at the sobering statistics of what direct support professionals are paid today and what individuals in related sectors are paid, you realize what a disservice we are doing to our loved ones with special needs."

In response to the current situation facing direct support professionals, ANCOR, the American Network of Community Options and Resources, along with United Cerebral Palsy, sponsored the WhoWillCare.net campaign to protect America's support professionals. You can also help gather

congressional support for the Direct Support Professional Wage Bill (H.R. 1264).

This federal bill will allow California to apply for additional Medicaid funding. Medicaid, the joint state and federal program, which is known as Medi-Cal in California, provides the vast majority of funding for support professionals, and the proposed bill will enable service providers to pay better wages to direct support professionals. Nationwide, there are over 600,000 individuals already on formal waiting lists for residential services and thousands more are being placed on these lists at the same time as providers are curtailing services. "While California currently has no waiting list, we are experiencing providers retiring or getting out of the residential care business, and because of the funding situation, it's getting harder to attract new providers," adds Anand. Additionally, nationwide, 650,000 people with disabilities are living at home with parents who are aging.

Please call or write to your elected official today and ask them to sign on as a co-sponsor of the Direct Support Professional Wage Bill (H.R. 1264). For more information about the professional caregiver crisis and to demonstrate your support for the millions of Americans with disabilities who need quality community-based support and the professionals who provide it, visit www.WhoWillCare.net or call **202.973.7114**.

ANCOR is a non-profit trade association representing and advocating on behalf of more than 800 private providers of services and supports for 385,000 Americans with disabilities. ANCOR is distinguished in the provider industry by its balance of leading practices, resources and advocacy for member agencies, and the people and families they serve and support. For more information about ANCOR, visit www.ancor.org.

UCP is one of the nation's leading organizations serving and advocating for the more than 54 million Americans with a variety of disabilities. Through its nationwide network, UCP offers services to individuals, families and communities, such as job training and placement, physical therapy, individual and family support, early intervention, social and recreation programs, community living, state and local referrals, and instruction on how to use technology to perform everyday tasks. For more information, visit www.ucp.org.

Helping Lanterman Families Plan for the Inevitable – Getting Older

We all know that the harsh reality is that with every year that passes, we get older. And while getting older is inevitable, there are a number of things we can do to plan for the future and make it easier to grow old gracefully. "If you are caring for a family member with a disability, it becomes especially important to anticipate and plan for both your own needs as you age, as well as your long-term ability to continue to provide care to someone else whose needs are changing," shares Maureen Wilson, director of Training and Development.

With more individuals with developmental disabilities continuing to live in the family home as they become adults, and the fact that these adults are living longer, the Programs and Services Committee at Lanterman Regional Center with support from Training and Development sponsored "Caring for an Adult Family Member with a Disability as You Age: Caregiver Information Fair and Seminar" this past October. The timeliness of the information fair was made more relevant by the ever-greater attention being called to the crisis that the nationwide system of direct support professionals in residential care is experiencing.

The event included representatives and resources from various community organizations, as well as speakers on topics such as navigating the health care system, legal considerations and financial planning, living options and family involvement, and support. Some of the local agencies involved were the City of Los Angeles Office on Aging, In-Home Supportive Services, Los Angeles County Area Agency on Aging, Center for Health Care Rights, Los Angeles County Caregivers Resource Center-USC, California Department of Insurance, Medicare Rx Access Network of California, Accredited Home Health Care, Hollywood Forever Life Stories, Koch ♦ Young Resource Center, Project Get Safe, and the Women's Reproductive Health and Self Advocacy Project.

Approximately 100 parents, clients, service providers and staff participated in the fair and an average of 25 parents attended the five educational presentations held throughout the day. A core group of 15 to 20 older parents of adult clients attended all of the presentations held throughout the day. "The organizations' representatives were grateful for the opportunity to share information about their services, and the attendees were equally grateful for the opportunity to become better informed about planning for the future," adds Wilson. For more information and resources on this topic, contact the Koch ♦ Young Resource Center.

Lending Component of Language, Communication and Technology Project to Launch Beginning of 2006

The end of last year, Lanterman received a grant from the Cranaleith Foundation to develop a project specifically focusing on language, communication and technology. The grant money was to be used to purchase additional assistive technology equipment focusing on language and communication that will be used for lending purposes, as well as to hire a project coordinator, establish a peer technology mentorship program, coordinate workshops, consult with speech and occupational therapists, and purchase storage and display furniture.

Prior to starting any construction of storage and display, the Center decided to visit other technology lending programs in the Southland. "A key program we visited is Goodwill of Orange County's Assistive Technology Exchange Center, widely known as ATEC, for a tour and to get an idea of what worked and what didn't as far as equipment and software lending programs and storage solutions," shares Patricia Herrera, director of Family Support Services. "Gregory Mathes, who heads ATEC, was instrumental in providing us with ideas and suggestions that enabled us to begin the storage build-out and establish lending policies."



The beginning of this year, Lanterman also began identifying the key experts in the field of augmentative and alternative communication to be able to consult with them on equipment purchases. A panel of experts was invited to

a meeting held in June to offer their advice and to consult on the range of language, speech and communication technologies that would be essential to creating a viable lending program. Experts who were able to attend included Mary Ann Glicksman, executive director, Computer Access Center; Gregory Mathes executive director, ATEC; Molly Doyle, Center for Applied Rehabilitation Technology at Rancho Los Amigos; and Sharon Jacobs-Cohen, Los Angeles Unified School District, Assistive Technology/Augmentative and Alternative Communication Program.

Cynthia Cottier, M.A., M.Ed., C.C.C., of Augmentative Communication Therapies and a widely known AAC expert, was hired to provide additional consultation in the area of AAC. "The grant from the Cranaleith Foundation, has been instrumental in enabling us to consult with Cynthia, and with her expertise, we are looking forward to creating a strong augmentative and alternative communication program here at Lanterman," says Herrera.

Also in June, a coordinator for the peer mentorship component of the project was hired. "Sandy Riancho, a Lanterman parent, and longtime peer support partner and support group leader will be key to the development of a support network of parents who are experienced in technology and can support families new to the world of assistive technology and AAC," adds Herrera.

After considerable research and numerous revisions of the concept drawings, the build-out of the storage and display solutions finally began the

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In October 2003, the California Disability Community Action Network was founded by Marty Omoto on the belief that no one’s voice is greater than another’s and no one’s rights were advanced or respected at the expense of another’s. This concept of “advocacy without borders” – advocacy that promotes unified action no matter the person or organization – was something that Omoto worked on starting in 2000 while he was legislative director for the California Coalition of UCP Associations. “UCP was helpful in making the concept a reality because they understood that meaningful advocacy could only happen if communities united and people connected on the issues of disability and rights,” adds Omoto.

While working in Sacramento as legislative director, Omoto started writing reports on what was happening with regulations and legislation at the State Capitol in language that the average person could understand. “At first the audience was the 13 UCP agencies in California and 20 or so individuals,” says Omoto. “By the end of the first year, I had over 2,000 people on the distribution list and today, as CDCAN enters the start of its third year, the Disability Rights Report, formerly UCP and later CDCAN Capitol News Reports, is distributed to 40,000 subscribers.”

Omoto has a very diverse background in the field of disabilities. He is a family member – his older sister, Alana, was born with developmental disabilities and later developed several physical disabilities. He was active in high school and college with disability rights issues, and in 1971 Omoto became the first volunteer Special Olympics area coordinator in his community. He also worked as a direct care worker in a community-based organization in Sacramento and later served on the agency’s board of directors through the 1970s and 1980s. Omoto also served as executive director of a non-profit agency that served low income and underserved communities, including people with disabilities, and worked as a staffer for the California Legislature in the 1980s. In addition to the full-time, coffee-intensive job as director of the CDCAN, Omoto serves on the boards of several community-based organizations serving people with disabilities.

“I think that the combination of my personal and professional experiences gives me a perspective that helps me see that people aren’t all that different from each other, and to see situations from different points of view,” shares Omoto. The CDCAN Disability Rights Report, connects thousands of people across the state with information on what is happening in Sacramento



CDCAN Director Marty Omoto

with issues that impact people with developmental and other disabilities, and seniors, including regional center funded services and supports, in-home supportive services, SSI/SSP, special education, adult education, employment, transportation, housing, health care, and Medi-Cal at the federal, state and local levels.

The reports are published as the need arises, which can be everyday, especially when the Legislature is in session and during the budget process. Omoto says, “I spend a lot of time at the Capitol, as well as monitoring hearings and meetings held by state and federal agencies dealing with disability issues. There’s also a massive amount of information that I read and analyze, and attempt to translate into everyday language or at least put the issue in context of how it impacts people with disabilities here in California. That isn’t always easy because information released by governments at all levels isn’t written to be understood. It can be difficult to cover everything that comes up and sometimes the criteria simply becomes whether I am able to be there for a particular hearing or meeting.”

Omoto’s drive and passion to create an advocacy effort that treats people equally and fairly, no matter who they are comes from his older sister. He shares the following anecdote:

We were close in age and went to school together. I saw how she was treated in junior high school special education – it was humiliating. I will never forget the look on her face when she was forced to clean toilets while other kids laughed. The school called it vocational education – but no other non-special education students had to do it. It was on that day that my role as advocate began, because up until then, my family never made my sister different from me and my brothers and sister. Other people did though. I won’t forget how she was taken advantage of by other people, by strangers. She was a child born in the 1950s before the Lanterman Act, before the Americans with Disabilities Act. There wasn’t anyone to help us then or through most of her years growing up in school, and the barriers were enormous, especially for my parents who had been released from the Japanese-American internment camps of World War II less than seven years before her birth.

Omoto’s older sister passed away in March 2003 and he didn’t think that it was possible to continue the work that he was doing, constantly asking himself, “What was the point?” “I felt desperate and lost, and thought it was the end of my world. I cannot explain the total devastation I felt, but then I remembered seeing the faces of the hundreds of people I’d met throughout my life, especially one person in particular – a mother who had lost her daughter with disabilities months earlier,” shares Omoto. “She came to a community meeting in Modesto and told me that she felt like giving up after her daughter died. But then she changed her mind – she didn’t want what happened to her daughter to happen to others. I realized it wasn’t outrage that motivated her – what I saw was love for her daughter – and hope that things could be better for others. So that changed me – and I hung on to that.”

Just as the healing process was beginning for Omoto and his family, his younger sister, Sheri, passed away unexpectedly in February of this year leaving behind four children, the youngest who is

12 and an adult child with physical disabilities. This was followed by a serious accident in July that made it harder for Omoto to concentrate amid his overwhelming grief. “But I remembered that mother. And I remembered all of the people I met, all of the parents of children with autism, all of the people with developmental disabilities, everyone that I’ve met over the years. All that helped. Somehow there is always hope even in tragedy,” says Omoto, adding, “Most of all, you don’t give up.”

The mission/vision of CDCAN is that one individual person can always make a difference, and regardless of how hard it may be or what barriers or tragedy they may face, when people connect and link with each other, anything can be overcome. Even sadness. It’s also a belief that the disability community should be united and not divided on the basis of the type of disability. “We all matter,” says Omoto.

When asked what is the biggest issue facing the disability community over the next three years and how he would like to see it resolved, Omoto shares, “Ultimately, I think it’s about the rights of people with disabilities, which is being challenged in many areas at all levels of government. Part of this issue is the funding for needed services and supports. It’s an on-going struggle. I think where our community could get smarter is on advocacy. To really become strong and effective in holding policymakers and each other accountable at every level, and while the struggle never ends, it does become easier to bear and provides the hope to overcome those barriers.”

“I think that the combination of my personal and professional experiences gives me a perspective that helps me see that people aren’t all that different from each other and to see situations from different points of view.”

– Marty Omoto

Lending Component

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end of summer. The storage and display were incorporated into the existing assistive technology lab at Lanterman, and this new solution will offer the Lanterman community greater access to the technologies available in the lab and is critical to having a successful loan program. For over one month, the assistive technology lab was under construction, but the end result is a highly organized collection of equipment, communication devices and software that will be available for lending the beginning of 2006.

In addition, Dr. Sonia Aller, a speech-language pathologist was also hired to assist with the overall implementation of the grant project and to provide management support for the Language, Communication and Technology Project.


Plans are in progress to start up an augmentative and alternative communication workshop series in 2006 as well. For more information about the Language, Communication and Technology Project, contact Dr. Sonia Aller at 213.383.1300, x. 722 or sonia.aller@lanterman.org. For information about the technology peer mentorship program, contact Sandy Riancho at 213.383.1300, x. 729 or sandy.riancho@lanterman.org. Look for profiles on Sandy Riancho and Cynthia Cottier in an upcoming edition of “Viewpoint.”

To help unite the statewide disability community and bring unity to the fight for disability rights, CDCAN, through a grant from the State Council on Developmental Disabilities, is linking community groups in nearly every area of the state with each other via the Internet. The focus is on a variety of issues, such as community services, special education, employment, transportation, crime and abuse, and housing, that impact people with developmental and other disabilities, their families, community-based organizations, workers and others. In addition to the community groups, interested individuals can connect with CDCAN through the Disability Rights Townhall Telemeetings, by either going to a site in their area or by calling in using a computer or toll-free phone line. Another way is to sign up to receive the electronic news reports Omoto sends out by sending an e-mail to martyomoto@rcip.com or by going to the CDCAN Web site at www.cdcan.us and clicking on “Join CDCAN.” The work of the CDCAN is primarily funded through private donations.

A long-term focus of the CDCAN is working towards the idea of a disability rights constitutional amendment in the California State Constitution. “We’ve talked about this last year, and others have brought it up and its worth pursuing,” shares Omoto. “Each of the short-term projects contributes to the longer term goal of building and maintaining a network of hundreds of thousands of people with disabilities, their families, community organizations and groups, and other advocates for the purpose of unified action, information sharing, and overcoming barriers through best practices, and accountability. And to do this with the motivation that hope never dies.”

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If you're one of the growing number of people who have long since given up having anything to do with paper-based financial transactions, Lanterman now offers the ability to donate online. Whether you're accruing airline miles for a trip to the tropics, gathering reward points for a weekend getaway at a spa resort, or even getting cash back from your credit card transactions, you can now support a good cause and get points at the same time.

Check out our new site at www.lanterman.org/donate/online donations.asp to make a secure online donation to support the *Holidays are for Sharing* campaign, the Help Fund, the Roberta Happe Memorial Internship, the Mentors and Technology Project, or to just make an unspecified donation.

**Be the First to Know and Help Us Save Money –
Join Lanterman's E-mail List**

Thirty-seven cents may not seem like a lot of money, but multiply that by 6,000, the approximate number of people Lanterman Regional Center serves, and that's \$2,200 for one mailing. While all mailings are not as large, Lanterman sends tens of thousands of pieces of mail via the United States Postal Service every year, and this adds up to a lot of money.



There's something you can do to help us save money – join Lanterman's e-mail list. Instead of waiting for "snail mail" to get important information about events, the budget or trainings, you could be the first to know with e-mail.

To join, send an e-mail to Vinita Anand at vinita.anand@lanterman.org. Please include in the message your name, the client's name and age, and the city you reside in, to help us target our e-mail messages more effectively.



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