Portia Iversen's “Strange Son” Offers Hope and Insight into the World of Autism

LATE ONE NIGHT, 12 YEARS AGO, ON THE VERGE of being worn out and demoralized with the limited progress that their son Dov was making with the various autism therapies, Portia Iversen and Jonathan Shestack decided to start a foundation that would focus on autism research. With sheer determination and passion driven by the desire to help their son, Iversen and Shestack grew this foundation into one of the largest nonprofit-governmental funding resources for autism research worldwide — Cure Autism Now.

Even though she had no background in science, her last science class having been in the seventh grade, Iversen focused on the scientific aspects of autism, while her husband took on the politics of lobbying for more money to be spent on autism. In her quest to gain as much information about autism, not only to help her son, but to help the millions of other children affected by autism, Iversen spent hours reading journals at UCLA’s and USC’s science libraries, and attending scientific conferences and society meetings.

It was at one of these meetings that Iversen heard about Tito Mukhopadhyay, an Indian boy with severe autism who was nonverbal, but whose mother Soma had taught to read, write and communicate. It became Iversen's mission to track down Tito and his mother, in order to help her son, but to help the millions of other children affected by autism, Iversen spent hours reading journals at UCLA's and USC’s science libraries, and attending scientific conferences and society meetings.

Shestack decided to start a foundation that would focus on autism research. The primary purpose of the Autism Team is twofold. The team will focus on increasing the level of expertise among Lanterman professionals and other staff about autism-related disorders and their effective treatment. It will also work to develop the capacity among individuals and organizations within the community to better serve children and adults with autism in an integrated setting. An ongoing responsibility of the team will be to oversee activities intended to improve the quality of services provided in the community.

Moradi and Johnson will assist service coordinators with clinical referrals and advise the Center’s Intake and Assessment unit on best practice guidelines for the screening, diagnosis and assessment of individuals with ASD. They will also coordinate and manage the clinical application of best practice guidelines, provide technical assistance to local clinicians and service providers specializing in ASD, and will participate in the ASD Learning Collaborative.

Staff Highlight

Staff Highlight

Lanterman’s Nurses Work to Ensure that Health Needs of Clients Young and Old are Addressed

LANTERMAN IS COMMITTED TO ENSURING THAT OUR CHILDREN AND ADULTS HAVE THE BEST POSSIBLE health. This is a major goal of our Clinical Services department, and the department is privileged to have a team of four highly qualified nurse consultants, each of whom has specific responsibilities for the health-related needs of the Center’s clients. During the course of a typical year these nurses shoulder a diverse and challenging workload that includes among other activities over 400 visits to individual homes and facilities, almost 400 nursing assessments and follow-ups, and attendance at over 350 individual program planning meetings.

All of the nurses are responsible for training Regional Center staff, clients and caregivers on a variety of health issues, such as medication administration, and diabetes prevention and care. They also provide hundreds of formal and informal individual consultations to service coordinators and service providers. They stress the importance of being able to assess the whole person, how to ask health-related questions and get informative answers, and how to make determinations about when to make a referral to the nursing staff. And all of these responsibilities involve reviewing thousands of health-related reports on individual clients.

Each of these remarkable women has a rich and varied experience in the field of nursing. Their skills and strengths complement each other well and ensure that the Clinical Services department is able to meet the challenging and ever-changing health care needs of the individuals with developmental disabilities that Lanterman serves,” says Gwen Jordan, director of Clinical Services.

The following are profiles on Grace Kotchounian, Ardis Adrian, Anita Arcilla-Gutierrez and Wanda Okunsanya that include their past professional experiences, current responsibilities, and the reasons behind why they do what they do.

Save the Date!

Community Meetings Being Held in September

See page 4

See story on page 6

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Continued on page 17

Continued on page 10
One of our core values at Lanterman is leadership. We define it as: “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.”

Webster defines the word lead as “to guide by showing the way, to precede, to introduce by going first.” That could easily be a description of our regional center system which began more than 40 years ago through the tireless, dedicated – one might say dogged – commitment of parents seeking a better way for their children.

This edition of “Viewpoint” features two stories about parents who are leading the way for this generation of children. One is Portia Iversen who, with her husband Jonathan Shetstall, started Cure Autism Now, an organization that provides funding for research into autism. Another is the story of Patricia O’Brien White, her husband Jim White, and Roger Kalffer who co-founded the Down Syndrome Research and Treatment Foundation to promote research into Down syndrome.

Different people, different experiences, but one major value in common – their deep devotion to leadership, and through that to create a community-owned organization, one in which each stakeholder assumes a personal responsibility, and through that to create a renewable source of leadership. We must now take up this challenge and use it to make a difference – not just for ourselves, but for others.

The story of the regional center system is really the story of parents who have consistently pushed the envelope of possibility to make things happen, to develop something in the community that had never been done before – and to strive for the betterment of the whole.

That tradition survives to this day. New parents are not taking on a lack of services nor looking for an alternative to institutions. Instead, they are trying to tackle the root causes of developmental disabilities themselves, seeking to push society into finding answers and developing cures.

At Lanterman, we have worked to be a community-owned organization, one in which each stakeholder assumes a personal responsibility, and through that to create a renewable source of leadership. We must now focus on encouraging and engaging the young parents entering our system to take their place at the head of the column, to “lead the way for others.”

Parents have always made the difference. They were our roots – and they are our future.

The Director's Viewpoint
Parents Have Always Made the Difference

The BUDGET UPDATE

We Finally Have a Budget

As this newsletter goes to press, the budget has just been adopted by the Legislature, nearly eight weeks overdue, and is on its way to the Governor for signature. This is the second latest budget in decades and while Governor Schwarzenegger’s administration and the majority of the Legislature, particularly the Democrats, were in agreement on key components, adoption was held up because California is one of only three states that requires a two-thirds majority to enact a spending plan.

For the fiscal year just ended in June, 2006-07, a budget reconciliation bill that was enacted has allowed regional center contracts to be amended to cover any projected deficits. As we entered late spring, Lanterman’s projected deficit had been in excess of $2 million, out of an overall POS budget of more than $90 million. For 2007-08, regional centers have received cash advances from the Medi-Cal emergency fund as allowed by law. However, those funds were exhausted and many centers, including Lanterman, had to activate their lines of credit through their banks. It is important to note that the state does not reimburse regional centers for the cost of this borrowing, so it is a high risk strategy.

We anticipate the budget will contain the following items relating to regional centers that were presented in the Governor’s May revision proposal, however, he has line-item veto power and could reduce certain funding:

**Operations**
- An increase of $14.3 million for a projected increase of 8,050 clients statewide
- An additional $1.1 million statewide for staffing related to the implementation of self-directed services
- No cost of living or other such increases for regional centers

**Purchase of Services**
- An increase of $287.3 million statewide, and of this amount, $322.1 million is for an increased number of clients served and increased service utilization
- There is about a $73 million increase related to placing individuals from state developmental centers into the community
- The state plans on saving $44 million due to changing how reimbursements are made to certain classes of residential providers who operate intermediate care facilities
- There are no rate increases other than the continuation of increases related to the minimum wage and others put into place last year
- There is a small amount allocated for the implementation of self-directed services
- Rate freezes and previously imposed cost-containment strategies are slated to continue

Prior year unallocated reductions in both Purchase of Services and Operations continue.

Given the continuing stressors to the system and lack of significant increases other than those related to serving new clients:
- Service providers will continue having difficulty in meeting service standards and paying staff a living wage
- Regional centers will continue to have difficulty in recruiting and retaining service providers and staff

Despite these challenges, the Regional Center has continued to provide services and supports without interruption, as we have for over 40 years.

Lanterman Recognizes Support Group Facilitators’ Contributions During Recent Training

During the summer, many of Lanterman’s regularly scheduled trainings and support groups will go on hiatus for a month, creating the perfect opportunity for the Center to offer support and training to our otherwise busy support group facilitators. This August, 20 parent and service coordinator support group facilitators attended training specially designed to meet their needs.

The training was presented by a panel of facilitators, including Manushak Enezliyan from the Armenian Autism Alliance, Monica Mauriz from the Early Autism Alliance, Maria Richardson, founder of FUERZA, and the featured speaker, also emphasized parent leadership, motivation and the opportunities support groups have to make a difference.

Out of Lanterman’s 19 support groups, 10 groups were represented. All of the facilitators received awards for their years of service and commitment to the Lanterman community.

“Support group facilitators need ‘support’ too, and in speaking with some of my counterparts, we really felt this was a nice opportunity to learn more about what other support groups are doing, what types of educational presentations are available, the do’s and don’ts, and the fruits of empowerment,” shares Riancho, who is also a resource and information associate at Lanterman.

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Rene Chacana, assistant director, Koch Young Resource Center, shares: “The major emphasis of the training was on support group facilitation, including what is a support group and what are the goals, how to provide the highest quality support, ground rules for support groups, following the four-part format, and the role of the facilitator. The presenters also focused on how to recognize and nurture leadership potential in a support group, and what leadership opportunities are available within the Lanterman community.”

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Lanterman Community Attends Grassroots Day in Sacramento

Most of us have a basic understanding of the state legislative process – voters elect a representative that they feel shares the same values and positions on issues that they do, and they send them to Sacramento to represent their interests when making decisions about new legislation, how their tax dollars are spent and what services are provided.

But how do legislators know what specific issues are important to their constituents, especially in this era of term limits? Many larger organizations and major industries employ lobbyists to ensure their legislators are informed about various issues and companies that would benefit them. In some cases, professional lobbyists also provide a living wage, recruiting and retaining staff, and how legislative decisions in Sacramento directly affect our ability to support clients such as Howard to achieve their fullest potential.

Two New Members in June

The beginning of summer is a very busy time for Lanterman – the start of a new fiscal year. And with the end of the fiscal year comes a new budget, new challenges and new additions to our board of directors. In June, two new board members were elected to Lanterman’s board, each bringing with them a unique set of skills and experiences.

The Lanterman community is delighted to welcome John Erdos and Howard McBroom, and looks forward to the perspective, guidance and leadership these individuals will be providing during their terms on the board of directors. Following is a bio that offers a look at both the personal and professional experiences of Erdos. A bio on McBroom will appear in individuals will be providing during their terms on the board of directors. Following is a bio that offers a look at both the personal and professional experiences of Erdos. A bio on McBroom will appear in

John Erdos’ Financial Background Combines with His Spirit of Volunteerism to Benefit Lanterman Community

According to the Bureau of Labor

Statistics of the U.S. Department of Labor, between September 2005 and 2006, about 61.2 million people (26.7 percent of the total U.S. population) volunteered for an organization at least once between September 2005 and September 2006. Many of these volunteers spent their time assisting a group or organization, and Lanterman is no exception to being one of these non-profits that depends on volunteers for their assistance. Lanterman’s support groups, facilities, Peer Support Partners, and board and committee members all carry out their work as volunteers and provide a valuable service to the Lanterman community. And Lanterman’s newest board member, John Erdos, has a long history of direct volunteer participation dating back to his high school years.

A 2003 graduate of the University of Notre Dame, Erdos majored in Finance and received a Bachelor of Business Administration. While in college, Erdos was a member of the Notre Dame Investment Club and the Student International Business Council. He also joined the National Honor Society, a service-based organization, of which he is now a life member. During the summer before his senior year, Erdos worked as a Private-Client Services intern at Bear, Steams & Co., Inc., and was hired as a Private-Client Services assistant after his graduation.

In this position, Erdos participated as a member of the Compliance Department in the supervision of all broker trades, served as a portfolio control assistant with the Capital Group Companies, and was promoted towards the end of his first year to Portfolio Control associate, part of a global team and is responsible for executing market transactions and investment convictions for institutional clients around the world. In this role he has various duties that expose him to proprietary investment products, equity analysis and discussion, and international markets.

The Capital Group Companies have a strong commitment to community support and giving, including a matching gifts program, community service leave, and company-sponsored volunteer opportunities. And in 2006, Erdos became a member of the Capital Group Non-Profit Leadership Steering Committee, attended the 10-month course offered by the Ronan Volunteer Leadership Development Program that provides board training experience and fosters lifelong service in the governance of non-profit organizations, and joined Lanterman’s

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 Luciano Aulicino at 213.383.1300, x. 690 or paulicino@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, 2225 East 60th Street, Los Angeles in advance at 213.383.1300, x. 665 or flara@lanterman.org so you can be placed on the list of attendees. We look forward to your visit.

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Meet the People Behind the Titles: Frank Lara

As manager of the Executive Unit at Lanterman Regional Center, Frank Lara is an integral member of our leadership team. He feels it’s important for everyone in our community to have a better idea of the person behind the title and his responsibilities, so “Viewpoint” recently met with Lara and asked about projects in the works, as well as the biggest challenges and most rewarding aspects of his job.

He joined Lanterman in January 1990 as an administrative assistant to the director of Operations, now Executive Services and Community Services, then he moved on to Legal Services and in September 1991 became Lanterman’s Operations manager, a position he held for eight years before accepting the position of assistant to the executive director, which is now called the Executive Unit manager. Lara shares, “I told myself when I accepted the position that I wasn’t going to stay very long. I’ve never worked in non-profit, only in the fields of banking and insurance as an assistant to senior leadership, but somehow I’ve been one the Center’s key players all along.”

“My experience working in some of the other departments in the Center set the foundation for my present role supporting the executive director, and has made me a more informed and knowledgeable adviser,” says Lara.

In his current position, Lara works directly with the executive director and has overall responsibility for organizing a diverse and demanding day-to-day workload of the executive office, as well as monitoring and evaluating daily needs within the Executive Unit as a whole. “Where Diane Anand’s focus goes, my function goes. She is working in a dynamic and ever-changing environment and having the creative freedom to address the various projects and challenges, and working together as a team to pull together the solutions,” he adds.

Lara also supervises the four executive assistants that provide administrative support within the Executive Unit for the two associate directors, two assistant directors, appeals and complaints, and human resources, and he provides support and coordination to the board of directors and its various committees.

And, when someone at the Center has a question that no one else has a ready answer to, they all say, “Just ask Frank,” and almost always, he knows the answer or who does. “No matter how small or how big a request, it really makes this job for me when I know that I’ve been able to help somebody,” shares Lara.

When asked if he had any favorite projects that he’d worked on, he replied, “I truly enjoy all of the things that I do and the challenges that come with this job, however, if I had to pick, I would say that coordinating the move from our old building to our current location, and ensuring that it was a seamless and stress-free transition that resulted in very little down time for the Center, was one of the more challenging but also very rewarding projects that I’ve worked on.” Lara has been an instrumental figure at all of the Center’s recent special events: Perspectives, the 40th anniversary celebrations and events, and many other smaller events. He is currently coordinating the Center’s facility expansion at our current location, a two-year project which is expected to be implemented some time in 2009.

Lara, a native of the Los Angeles area, now lives in Atwater Village. In his free time, he enjoys both interior and exterior design, not only working on his house and garden, but also assisting his friends with their interior and exterior design projects.
Lanterman’s Autism Team

Continued from page 1

Broughton-Rodriguez will serve as the primary point of contact at Lanterman on ASD issues and will be the critical link between families, their service coordinators, and the clinical professionals and service providers. She will also work with ASD coordinators at other regional centers to create a statewide network to exchange information on best practices and their application through intake and service coordination. Finally, she will advise local agencies, such as schools, mental health agencies, child protective services, and local law enforcement on ASD issues.

Currently, the team is conducting a needs assessment to determine what services exist for children and adults with autism, in what areas these services are located, and what areas there is need for service development and quality improvement. This phase includes interviews with Lanterman clients and their families, service coordinators, and service providers who primarily work with individuals with autism. Moradi notes: "Thus far as a system, we have been very reactive in how we have addressed ASD. We are hoping that this initiative will enable us to be more proactive in addressing the needs of people with ASD." Johnson adds: "We want everyone touched by ASD to recognize that they are a stakeholder in this initiative. They are the people who can give us the most helpful insights. We have some idea of where the gaps in resources are and what areas require improvement, but we want to make sure we are not missing anything."

The results of the needs assessment will give the Center the information necessary to move on to the development part of this project. The information will enable the team to focus its development efforts in areas of greatest need as Lanterman attempts to improve the capacity of the community service system to effectively serve individuals with autism.

Following are profiles of the members of the Autism Team.

Mandy Moradi

Dr. Mandy Moradi’s experience in the field of autism began during her undergraduate years at the University of California, Los Angeles, where she was pursuing a bachelor’s degree in psychology with an emphasis on developmental disabilities. While at UCLA she worked under the direct supervision of Dr. Ivar Lovaas, a pioneer in the application of Applied Behavioral Analysis (ABA) to the treatment of children with autism.

After graduating from UCLA, Moradi earned her Doctor of Philosophy (Ph.D) from the California School of Professional Psychology and completed two fellowships. The first fellowship was funded by the Department of Developmental Services through the University of Washington’s Applied Programs. It is known as the University Center for Excellence in Developmental Disabilities, where she worked in a wide variety of areas related to developmental disabilities and gained a connection to regional centers. Her second fellowship was in diagnosis and testing at the Resse-Davis Child Study Center in Los Angeles.

Soon after finishing this second fellowship, about eight years ago, Moradi took a position as a clinical psychologist at Lanterman. She also maintains an independent practice working with children and teenagers with autism. Of her experiences she says: “I’ve completed numerous diagnostic evaluations of young children and have provided ongoing therapy for high-functioning teens on the autism spectrum. I also have experience in training others, reviewing treatment plans, and working with service providers, families and service coordinators.”

Jean Johnson

Dr. Jean Johnson studied autism as both an undergraduate and a graduate student at the University of California, Santa Barbara. She participated in autism research with Dr. Robert Koegel, a nationally-recognized expert on autism treatment and director of the UCSB Koegel Autism Center, an institute dedicated to clinical research on autism treatment. In this position she developed expertise in a number of research programs and research on the effectiveness of treatment techniques.

Johnson joined the regional center system in 1989, serving as a staff member at North Los Angeles County Regional Center. She came to Lanterman in 1995 as a manager for the Early Intervention unit. Johnson subsequently worked at Villa Esperanza in Pasadena as director of Education Programs specializing in the development and implementation of educational programs for children with autism.

“My interests and passions lie in early identification and intervention,” she states. Most recently, she was a member of the Intake unit at Lanterman where she conducted psycho-social evaluations. These evaluations are an integral component of the intake and assessment process through which eligibility for regional center services is determined.

Johnson is a published researcher and a mother of five. Erin Broughton-Rodriguez

Erin Broughton-Rodriguez brings to the ASD program coordinator position an extensive knowledge about sensory needs and experience as both a service provider to regional center clients and service coordinator. A graduate of San Diego State University, she has bachelor’s degrees in psychology and dance, and a master’s degree from UCLA in movement therapy emphasizing healing and therapy in children with special needs.

After completing her education, Broughton-Rodriguez spent two years with Pasadena Child Development Associates conducting music and movement therapy, social skills groups, and intake assessments. From PCDA, she moved to Dynamic Autism Therapies where she did in-home and school therapy, working directly with clients, as well as teaching their parents and teachers therapeutic techniques.

In 2005, Broughton-Rodriguez joined Lanterman as a service coordinator working with clients between the ages of 14 and 30. “I really started to see the needs of this particular age group in the autism population, and was concerned with the difficulty that exists in finding resources,” she explains.

Hasmig Mandossian

Hasmig Mandossian has the educational background and the breadth of experience necessary to oversee the activities of Lanterman’s autism initiative. She was recently promoted to assistant director of Intake and Assessment after 25 years working at Lanterman in a variety of positions. In addition, she has both undergraduate and graduate degrees in psychology from the American University in Lebanon, as well as a master’s degree in counseling psychology from Pepperdine University.

She believes that her academic experience in two countries has provided her with the clinical knowledge and skills to work with families from diverse backgrounds and situations. “I also have experience working with children and a regional manager here at Lanterman,” she shares. “This provides me with a good perspective on how the Autism Team can fit into the overall operational environment of the Center. I also have experience working with clinicians making diagnoses as part of a multi-disciplinary eligibility team. And I’ve attended a lot of trainings related to ASD.”

Mandossian is very pleased with the make-up of her team. “We are fortunate that our team is comprised of professionals who have experience working with autism in many different capacities and who also have knowledge and experience acquired in a wide range of roles within the regional center system,” she adds.

CAC News

Looking for a Few Good Men and Women to Join the CAC

Lanterman’s Consumer Advisory Committee is looking for a few good men and women who are clients of the Center to join as members. The CAC 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.

If you are interested in exploring the possibility of membership, contact your service coordinator and ask them to set up an opportunity for you to attend a CAC meeting. The CAC meets the second Monday of every month at 4:30 p.m. at Lanterman Regional Center.

DDS Web site Features “Consumer Corner”

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

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

Which is it? – Consumer or Client

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

Michael Miyazaki couldn’t be happier than when he is in water. “He took to swimming like a fish to water at about 2 years old,” shares his mother Sharlene Miyazaki, “and as Michael grew older, it seemed to us that swimming would be a great way to reach out and engage him, and use his interest in this activity to work with him on basic skills development.”

Swimming also helps keep 8-year-old Michael physically fit. “One of the side effects of the medication that he’s on is weight gain, and this helps him stay in shape, and it also helps him burn up his energy so that he sleeps better at night,” explains Sharlene.

At the early stages, even the very basic aspects of structured swimming were a challenge to Michael. His instructor of four years, Gabriela Ziolkowski, shares: “When we first started out, I let him be who he was, I followed his lead and built a relationship with him. As I felt I was in a position to instruct him, we then started working on the very basics.”

Ziolkowski started Michael out on a pretend island by the stairs that she gradually moved farther and farther out towards the center of the pool, challenging Michael to swim a little farther each time. But he still didn’t like to put his head underwater, so she blocked off the island with the floating lane and farther out towards the center of the pool, moved farther on a position to in a Special Olympics meet. I think he is beginning to feel competitive in some areas, but for now, our next step is going to be working towards actively being able to handle the social aspects of swimming at a large facility. There is definitely a protocol to be followed as well as rules that are expected, and getting Mikey to obey these rules is the next big challenge,” shares Ziolkowski.

In addition to lessons twice a week, Michael and his mother also participate in a swim group held in the therapeutic pool at the Center. She shares: “All the special education children in Michael’s class and their families participate in this swim group on Fridays. It gives them an opportunity to have a play group since most of them don’t have anyone to play with, and it gives the parents an opportunity to talk about everything – what works, what doesn’t work, what happened in school, accomplishments, failures – it’s really supportive.” As part of the swim group, they play games, use floats, sing songs – all in the water.

“When ever you are trying to teach a child with autism a new skill, whether it’s related to behavior or a new swimming skill, you have to have patience and keep trying new approaches to get them motivated. And you have to have it one step at a time. For a long time, we were wondering if any of the stuff we were doing was working, and then all of a sudden when Michael hit about 5, something clicked and he’s been progressively improving ever since,” adds Sharlene.

For more information about the Rose Bowl Aquatics Center and the various programs they offer, visit www.rosebowlaquatics.org.

The Get Fit! Project – Not Just a Memory

Although the Get Fit! Games are just a memory, the Get Fit! Project is still going strong. Margarita Blanco, project coordinator, shares: “The Get Fit! pilot was a success but, we didn’t want it to end after one year. We realize that healthy lifestyle changes may take longer than a year to flourish, so we wanted to find a way to continue to provide information, support, and encouragement for our clients. The ‘Get Fit! Journal’ and ‘Get Fit! Cookbook’ are just the beginning of tools that are being designed with our clients and their continued fitness in mind.”

The “Get Fit! Cookbook: A Guide to Healthy Eating for Adults with Disabilities,” is written in an easy to understand format and features recipes that are simpler versions of traditional recipes that use fewer ingredients and fewer steps. The first section of the cookbook has an educational component that covers proper food storage, sample serving sizes, the food group pyramid, and how to prepare a balanced meal, and rules for the kitchen. In addition, it features images of tools used in the kitchen, as well as pictures and definitions of commonly used kitchen/recipe words.

The recipes feature an ingredients and tools list, and the recipes are broken down into steps with full color photos, and tips for how to combine this recipe with other food items to make a meal. After the featured recipes, the last section of the cookbook focuses on the best food choices when dining out, making the best selection from a vending machine, and the best snack choices at the movies. It also includes a reproducible shopping list and daily diary.

“Cookbook recipes/menus are merely suggestions for nutritionally-balanced meals, and they are not designed for people with special dietary needs. Clients and service providers should always consult with a physician or dietician regarding an individualized nutrition and exercise needs,” says Blanco.

The Get Fit! participants also received a Get Fit Journal! It is a workbook in a pictorial format that allows participants to check off and track daily mood, exercise habits, water intake, their intake of fruits and vegetables, and junk food. The journal contains 60 days of daily journal entries, and two reproducible journal pages – a daily format and a more advanced weekly format. The “Get Fit! Project is currently in its second phase, which entails modifying and adapting the pilot curriculum for three specific audiences: independent and supported living, group residential homes, and day programs. In addition, a Web site is also under construction to provide access to information and additional tools for clients, service providers and family members.

The Get Fit! Web site (www.getfitca.org) will be updated and live by the end of the year. It currently includes an online calendar to track physical activity, a fitness challenge idea, fitness and nutrition tips, and a recipe. Ultimately, the three curriculum formats, the “Get Fit! Cookbook” and the “Get Fit! Journal” will be available on this site, along with other tools, including a Body Mass Index (BMI) calculator, links to fitness/nutrition-related community resources, as well as recommended books and videos, and much, much more. If you are interested in the “Get Fit! Cookbook,” there are copies available for circulation through the Koch & Young Resource Center.

Recreational Activities in Integrated Settings Provide Wonderful Benefits

For all people, keeping physically active, whether in organized sports activities or by just walking the dog, not only helps keep our bodies healthy but also provides mental health benefits. And for individuals with special needs, these activities also provide added opportunities to excel in non-academic areas, build self-confidence and self-esteem, work on social skills, and make friends. The key is to find the right activity that piques the child’s or adult’s interest.
Joshua Markell Chosen as a People to People Sports Ambassador to Represent the United States at the 2007 Youth Friendship Games in Holland

Think back and try to remember the first time you said goodbye to your parents and headed off on an adventure without them. Do you remember what you were thinking, the emotions you were experiencing, and silently wondering how it was going to go?

On Thursday, July 19, 14-year-old Joshua Markell said goodbye to his parents at Los Angeles World Airport, boarded a plane and headed off to Holland for 10 days as a Junior Sports Ambassador in the People to People Sports Ambassador programs representing the United States in soccer at the 2007 Youth Friendship Games.

“Joshua really enjoys playing soccer the best he possibly can, and has improved tremendously since he first started with AYSO six years ago, but he doesn’t have cut through or be the one to approach to the game. After his interview, I privately asked the interviewer about the philosophy of the Sports Ambassador programs. He was astounded that what they were looking for in a player was someone who put their all into doing well and would be a good representative for the United States.”

Joshua was notified of his acceptance into the People to People Sports Ambassador programs in March of this year. “As part of the program, Joshua was expected to prepare physically and mentally prior to his departure with a rigorous two-week conditioning and nutrition plan and by preparing a five-minute presentation on one aspect of Holland,” adds Jon Markell, Joshua’s father. “My favorite subject is language arts, history and science,” shares Joshua. “I chose to do my presentation on the history of Holland’s windmills, and found out a lot about this topic on the Internet. My teacher at The Frostig School was very pleased with my presentation to my school class for extra credit.”

In addition to traveling in the United States, Joshua had done some international traveling, including to Mexico and Thailand, and highly encourages others to go on their own adventures. He adds, “I’ve always wanted to travel around the world, see other countries, by new foods, and meet the people, and see how other’s go about their everyday lives. I have referred to what is different about them, and what ways we have that are similar.” His parents joke, “We’re watching ‘Desperate Housewives,’ and Joshua’s watching shows on history, the military, cooking ‘science and travel.’”

“When I was in high school, I had the opportunity to spend several months abroad,” shares Carolyn. “It had a huge impact on my life. I became more mature and self-confident, and appreciative of the unique experiences and richness of diversity, and I wanted Joshua to have this same experience, and really felt that the People Program would give him the opportunity to have this experience.”

When Joshua boarded the plane, he embarked on both a mental and physical journey. It was his first time traveling without his parents, being away from home for more than one right, budgeting and managing his own finances, sharing a room with a roommate, and just negotiating his everyday interactions, all on his own. He also explored Amsterdam and the surrounding towns and cities.

Joshua says: “I saw the windmills, went on a boat tour of the canals, saw some ancient sailing ships, and took a tour of a gouda cheese factory and wooden shoe factory, and went to the Van Gogh Museum and Rijksmuseum, the Anne Frank House, and Amsterdam Airport, boarded a plane and headed off to Holland.”

The People to People program was founded by President Dwight D. Eisenhower in 1956 to promote the vision of world peace with the hope that by enabling ordinary citizens of different nations to communicate directly, this would promote knowledge and understanding, and thereby help them appreciate their differences and find a way to live in peace. And Sports Ambassadors have fostered this vision of peace through understanding since 2000, using the camaraderie of sport to gain maturity and a greater connection to the people and cultures of the world.

People to People Sports Ambassador programs are an athletic, educational travel experience that cultivates personal growth and development, while providing leadership and life lessons through sport.

“Potential ambassadors are nominated for consideration, and must submit letters of recommendation and go through an interview process,” shares Carolyn.

Mark Your Calendars for the Assistive Technology and Augmentative Alternative Communication Workshop Series

This workshop series hosted by Lanterman and ATEC is designed for parent-professional teams to participate in together and will focus on a variety of topics including AT/AAC for infants and toddlers, school-aged children, adults, as well as how it can be employed with specific disabilities. For additional information and to register for the AT/AAC workshop that best are interested, contact Rosanna Flores at ATEC at 714.547.6301, x. 496.

AT/AAC in Early Development (Birth to 3 Years) MONDAY, SEPTEMBER 24, 2007 6:30 p.m. to 8:30 p.m. Pasadena Child Development Associates 620 North Lake Avenue, Pasadena, CA 91103

AT/AAC in the School Years (3 Years and Up) MONDAY, OCTOBER 15, 2007 10 a.m. to noon Breeze Foundation 184 South Bimini Place, Los Angeles, CA 90004

Building Blocks – General AT/AAC for Individuals with Down Syndrome, Autism and Cerebral Palsy TBD – 2008

Assistive Technology Fair – Service Provider Exhibits and AT Demos TBD – 2008

WHAT IS AT?

Assistive technology (AT) can be anything homemade, purchased off the shelf, modified or commercial device that is used to help an individual with learning, working and interacting socially. These devices include the entire range of supportive tools and equipment from everyday devices, adapted toys, computers, powered mobility, augmentative communication devices, special and gaming devices, and computer and video games that can be used by a person when they are not able to use speech to effectively communicate in their daily lives.

WHAT IS AAC?

Augmentative Alternative Communication (AAC) stands for any type of “low-tech” to “high-tech” solution that is used by a person when they are not able to use speech to communicate in their daily lives.

WHAT ARE CIRCLES OF SUPPORT?

Circles of support – parents, family members, caregivers, therapists, teachers and friends – working together as a team, jointly developing goals and objectives, is the most effective way to implement AT/AAC solutions and achieve the greatest benefit for the individual.
DSRTF Funds Research to Support the Development of Treatments to Improve Cognition in Individuals with Down Syndrome

JUST OVER FOUR YEARS AGO, THE international research effort to sequence and map all of the genes in human beings, better known as the Human Genome Project, was completed, providing researchers with a genetic blueprint for the structure, organization and function of the entire set of human genes—the basic set of inheritable “instructions” for the development and function of a human being.

The completion of this project served to open up exciting areas of research that otherwise would not have been possible, especially in the field of disabilities caused by genetic variations. About a year after the completion of HGP, Patricia O’Brien White, her husband Jim White, and Roger Kafker co-founded the Down Syndrome Research and Treatment Foundation.

“When our daughter was born with Down syndrome, my husband and I were surprised to learn about how little funding, from both the public and private sectors, was applied to Down syndrome cognition research. We met some very dedicated researchers who had been studying Down syndrome for a long time, but it was difficult to attract new, talented researchers without more funding. We concluded that it was time to create a fundraising entity that was focused on re-energizing Down syndrome cognition research, so that more scientists could apply their talents to this genetics, brain research and cell biology to the study of impaired cognition in Down syndrome,” shares Patricia O’Brien White on the DSRTF Web site.

The mission of DSRTF is to stimulate biomedical research that will accelerate the development of treatments to significantly improve cognition for individuals with Down syndrome, and by improving their memory, learning and speech, this will hopefully allow them to participate more successfully in school, lead more active and independent lives, and prevent early cognitive decline.

DSRTF supports multi-disciplinary research and encourages frequent collaboration among scientists in different areas. The organization’s commitment to fund research that brings together scientists from related disciplines and different institutions has attracted new interest in the field of Down syndrome cognition research and has led to a number of unique partnerships.

Since its founding three years ago, DSRTF has raised more than $1.5 million in private funds for Down syndrome cognition research; influenced an additional $4 million plus from public and private sources for Down syndrome studies or cognition research resources; developed a grassroots fundraising network throughout the country that includes well over 1,000 donors; launched the Adopt-a-Mouse program that raises awareness of the need for funds and for specific resources, like mouse models, to enable this research to take place; hosted a number of educational and fundraising events across the country; and sponsored Congressional testimony about the importance and promise of Down syndrome cognition research, and played a lead role in a National Institutes of Health workshop to determine funding priorities for Down syndrome research.

While the exciting progress that has been made in the field of genetics is encouraging, it also underscores the neglect that the field suffered until just recently, and indicates the strong potential for identifying treatments in the near future.

For more information about Down syndrome cognition research, progress that is being made in the field, and how you can support DSRTF’s mission, visit www.dsrtf.org.

Eleven years ago, Danny Wolf was diagnosed with global developmental delays and began early intervention services at Lanterman. “It took about a year to get over the shock of my child having special needs,” shares Michelle Wolf, Danny’s mother, “but I knew early on that I wanted to get involved. I’d always worked in the non-profit or government fields, but because of my background, I gravitated toward governance-related opportunities.”

When Danny was about 4, Michelle was elected to Lanterman’s board of directors, a position she held for four years. She also served on Area Board 10’s board of directors, and had an opportunity to participate in the Leadership Education in Neurodevelopmental Disabilities training through the University of Southern California University Center for Excellence in Developmental Disabilities at Children’s Hospital Los Angeles.

“I was looking to become involved somewhere I could share the experiences and knowledge that I’d gained,” says Michelle. “About this same time, through my job at the Jewish Federation of Greater Los Angeles, I began working closely with Jewish Family Service of Los Angeles, a social services agency JFSLA was assessing community needs in the area of developmental disabilities and realized that a central resource for families was needed.”

Michelle was asked to establish a task force to figure out how best to support these families, and out of this came the idea for HaMercaz, which means “The Center” in Hebrew. “A number of people were having trouble finding a place for their child with special needs in the Jewish community, so we put our heads together and came up with the idea of creating a one-stop centralized resource for Jewish families raising a child with special needs,” she adds. Michelle is now the administrative coordinator for HaMercaz, which includes fundraising and publicity activities.

HaMercaz is a virtual center accessed by calling a single-toll-free number (866.287.8030) or via e-mail (hamercaz@jfsla.org) that connects families to a world of support. HaMercaz offers help for families with newly-diagnosed children, ongoing assistance and support for families from birth through age 22, connections to a network of community agencies and resources, as well as special needs programs in the Jewish community at synagogues, schools and camps, and support groups.

Michelle shares: “We have support groups for mothers, fathers, mothers and grandparents of children and grandparents with special needs that are offered at various locations throughout the city and San Fernando Valley.

Danny Wolf (front, right) enjoying time at Camp JCA Shalom, which is a part of the HaMercaz project.

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

It’s very easy to subscribe to Lanterman’s e-mail bulletins. Simply visit www.lanterman.org and click on “Subscribe” to provide us with your e-mail address. You will automatically be signed up to receive e-mail bulletins about information related to Lanterman Regional Center’s general activities and events.

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

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

HaMercaz offers a one-stop approach for Jewish families raising a child with special needs to access resources and support.

HaMercaz offers a one-stop approach for Jewish families raising a child with special needs to access resources and support.

The central resource for Jewish children with special needs and the families who love them.

Michelle Wolf is the administrative coordinator for HaMercaz.
Lanterman Partners with KIT Los Angeles to Make Successful Inclusion a Reality in Community-Based Programs for School-Age Children

WHAT EXACTLY IS INCLUSION? How is it defined? When is it considered successful? The answers to these and hundreds of other questions related to inclusion have been posed up to the perception of the person or individual answering them.

Ten years ago, a non-profit organization called Kids Included Together, also known as KIT, was founded in San Diego on a promise to increase opportunities for children with and without disabilities to access recreational, child development and youth development programs together, outside of regular school hours.

KIT’s philosophy on inclusion is: “Inclusion is the right of each person to have choice and to belong. It is a process and not a product. Inclusion supports a philosophy of interdependence and respect for difference...Inclusion communicates something more than ‘integration.’ It means all children, participating in their neighborhood; whether it is school, after school, child care, religious, or recreation programs. Inclusion implies that all people are welcome and each of us reach out to others who are different from ourselves. Inclusion is more than letting in or adding on. Inclusion conveys the idea that we appreciate each other, that we see each other’s gifts, and that we value being together. Inclusion is about systems change...Inclusion is a belief in every person’s inherent right to participate fully in society. Inclusion implies acceptance of differences. It means welcoming and valuing a person who would otherwise be excluded.”

“Over the years, we’ve explored many different options and strategies to include people with developmental disabilities in their communities,” says Diane Anand, executive director. “And one of the things we’ve discovered along the way is that just because a person is physically present in the community does not mean they are truly included in their communities. Just as strategies and processes exist to nurture and develop personal relationships, inclusion also must be approached in such a fashion. KIT has the experience and knowledge to be able to provide the training and technical assistance necessary to begin laying the foundation for children with special needs to be ‘truly’ included in community programs.”

KIT specializes in providing best practices training for community-based youth organizations committed to including children with disabilities into their existing recreational, social and child care programs. “KIT is not intended to provide services for children that need one-to-one support, but rather, to provide training to employees and staff of organizations already in our community, as well as technical assistance and organizational support to facilitate change and overcome the obstacles to inclusion,” explains Haleh Hashemzadeh, assistant director of Client and Family Services, and Lanterman’s point person for the implementation of the KIT program.

KIT continues to expand its successful inclusion strategies to community-based organizations with the opening of the new National Training Center on Inclusion in San Diego, and duplicating their expertise around the country. KIT Los Angeles is the first chapter of KIT, following the design of KIT San Diego, based on the needs of Greater Los Angeles. Lanterman has partnered with the KIT Los Angeles team to pilot our program with our community. KIT will provide five community training or site-specific training workshops and multiple hours of technical assistance that are either child or site specific and/or for organizational change and leadership.

The training will focus on KIT’s four core modules: Introduction to Inclusion, which defines inclusion, as well as the benefits, barriers, philosophy and history, Respectful Accommodations, which provides strategies to support individual children with a variety of disabilities, Positive Behavior Support, which reviews techniques for prevention-based support for children with challenging behaviors, and Partnering with Families, which develops collaborative partnerships with families while addressing concerns for safety, as well as confidentiality and respectful communication. There are a number of other workshop topics available that focus on activities such as autism, social skills and other areas that facilitate inclusion, and fostering friendships between children with and without disabilities.

For more information about KIT visit www.kitonline.org. They can also be reached at info@kitonline.org or 858.225.5680. If you are a community-based organization that operates within Lanterman’s service area and are interested in being considered to be included in the KIT Los Angeles program, contact Haleh Hashemzadeh at hhahemzadeh@lanterman.org or 213.383.1300, x. 642.

Meet the KIT Los Angeles Team

Sherry Beamer
Sherry Beamer, coordinator, has worked with people with disabilities and the organizations that serve them for 20 years. Beamer holds a master’s degree in social work administration from the Jane Addams School of Social Work at the University of Illinois, Chicago. The focus of her work is to assure the inclusion of people with disabilities to be productive participating members of society by providing technical assistance to service organizations to transform their practices. She has a keen understanding of the disability service systems and has worked in a variety of settings, including regional centers, direct service provider advocacy organizations, and academic institutions. She will provide training on the core modules and will be the lead technical assistant.

Becky Tschirgi
Becky Tschirgi is a highly dedicated and creative trainer and consultant with 30 years experience working in diverse programs serving persons with varying disabilities and those with economic disadvantages. She has demonstrated expertise in developing, teaching, consulting and monitoring short and long-term training programs and workshops. Her educational background includes a PET-RA Certificate (Post Employment Training in Rehabilitation Administration), a master’s degree in rehabilitation administration (MRA), and a bachelor’s degree in social work. Tschirgi will provide training on the core modules and will be a technical assistant.

Dawn Grabowski
Dawn Grabowski is a motivational speaker through her company “Shattering Images.” She holds a bachelor’s degree from Stetson University in Florida. Her motivational presentations focus on passion and persistence. She is also a stand-up comedian and actress, and through her passion and persistence wrote, produced and financed on stage two films. Grabowski has been included her entire life. She is a co-trainer for the KIT core module on Introduction to Inclusion.

Lolita Recillas
Lolita Recillas is a mother of a young man who is blind and has autism, and who is included in many of life’s activities. Her native language is Spanish, and she is bilingual English. She is currently a parent mentor for Hathaway Services, and was a parent mentor for Los Angeles Unified School District, the Blind Children’s Center and the Eastern Los Angeles Family Resource Center. She started the successful “Raices Hispanas” parent support group at the Blind Children’s Center that assisted families to recognize the strengths and challenges they face as new members of the American society with a child with disabilities. Recillas is a highly respected trainer who will help providers understand that parents are a valuable resource for programmatic success and that collaboration and ongoing communication is critical for inclusion. She will be a trainer for the KIT core modules on Introduction to Inclusion and Partnering with Families.

Kathy McCullough
Kathy McCullough has worked with people with disabilities with behavioral challenges for 15 years. She holds a bachelor’s degree in sociology, and is completing her master’s degree in public administration at the University of La Verne. McCullough is currently the after school program manager. She has demonstrated expertise in developing, teaching, consulting and monitoring short and long-term training programs and workshops. For adults with behavior challenges for the Mentor Network. She also worked to include children with disabilities in community out-of-school time programs with the United Way. McCullough has been included her entire life. She will train on the KIT core modules of Respectful Accommodations and Positive Behavior Support.

John Jacobs
John Jacobs is a recognized leader in the disability community. He is a living example of the history of inclusion, experiencing school and community inclusion in Los Angeles before it was mandated. Jacobs is a favorite among the KIT Los Angeles trainers, entertaining audiences with his stories of how community members misinterpret his competence because of his disability, and openly sharing how disability affects his functioning and the creative adaptations he has designed to live his life independently. Jacobs is a co-trainer for the KIT core module on Introduction to Inclusion.
Ardis Adrian

Two decades ago, Grace Kotchounian joined Lanterman as a nurse consultant. A graduate of California State University, Los Angeles, with a bachelor’s degree in nursing, Kotchounian also pursued her graduate degree at the Neuropsychiatric Institute (NPI). The teenagers would be hospitalized at UCLA for six months to one year, participating in intensive treatments. The change in their behavior over time was quite remarkable,” shares Kotchounian.

Almost 30 years later, Kotchounian is still working at NPI, helping Lanterman meet the mental health needs of the Center’s clients. Each Friday, NPI holds a clinic for individuals with developmental disabilities to identify any existing mental health issues and make treatment recommendations to help clients and their caregivers manage their mental health in the least restrictive way possible. Kotchounian manages all of the referrals to the clinic, reviewing the client’s information, and interviewing the caregiver(s) prior to their arrival at the clinic. She attends the clinic to make sure it runs smoothly and also assists with the pharmacological evaluations.

Kotchounian shares: “If necessary, I also do site visits to observe the kinds of environments the client is exposed to and what unique concerns may be present. I also coordinate follow-up to ensure that the doctor’s recommendations are being implemented by the caregivers at home.

In addition to being the primary liaison for NPI, Kotchounian also works with clients who live independently, and in private homes and community care facilities, managing their other health issues. She also does informal training with the Los Angeles area psychiatric hospitals to help them better handle individuals who have a dual diagnosis of mental health and a developmental disability.

She says: “Mental health care in Los Angeles has always been a challenge. It is difficult to find psychiatrists who are interested in treating people who have both developmental disability and mental health diagnoses. There is a complex relationship that exists between the psychiatrists, the psychiatric hospitals and the Department of Mental Health in the Los Angeles area.

“The impact of the 45 Lanterman clients that Clinical Services adopted one year through the Holidays for Sharing Adopt-a-Family program is that they have moved from a more restricted to less restricted environment. They have moved from a skilled nursing facility to a less restrictive way of life and be out in the community,” she explains.

Kotchounian grew up in Lebanon and has lived in the Pasadena area since 1972. She shares: “In the 20 plus years that I have been here, Lanterman has become like a second home. You know that in the good times and also in times of personal crisis, you have the support of your peers.”

Out of the many memories she has, Kotchounian recalls going shopping together for the 45 Lanterman clients that Clinical Services adopted one year through the Holidays for Sharing Adopt-a-Family program. She adds, “With all the losses that we have throughout the course of our life, you have to live for the day and always appreciate the things we have throughout the course of our life. There are stringent eligibility criteria and individuals have to be re-assessed regularly. It is a very labor intensive process. Approximately one-third of the Regional Center’s funding comes from waiver dollars, and currently there are over 1,700 individuals at Lanterman whose services are funded through the waiver.”

Adrian is primarily involved in conducting evaluations to determine the service needs for each individual, which can include homemaker, home health, personal care, nutrition, environmental modifications, skilled nursing, specialized medical equipment/supplies, family training, residential care, adult foster care, supported living and adult supported living, physical therapy, occupational therapy, speech/hearing/language, psychology, respiratory therapy, communication aids, crisis intervention, vehicle adaptation, nutritional consultation, and day treatment.

“It’s challenging when you realize what the need is, but the resources don’t exist to meet that need. In an ideal world, there would be places, similar to Childrens Hospital Los Angeles, for adults. It could be a special clinic, or some other general resource, but it would be a place where there is access to all of the specialists in one location. A clinician could see a neurologist, orthopedist and endocrinologist, preventive female care, and even oral care,” she shares.

Adrian lives in the San Fernando Valley. She is the mother of four boys. In her free time, she enjoys traveling with her family, baking and gardening. She also served in the Peace Corps as a nurse in Ecuador, where she learned to speak Spanish, a skill she now uses daily while at Lanterman. Every year during the holidays, the Lanterman staff looks forward to enjoying her many kinds of homemade fudge and rum cake.

Anita Arcilla-Gutierrez

Before joining Lanterman six years ago as a nurse consultant, Anita Arcilla-Gutierrez worked as a department manager in an acute care hospital.

With a master’s degree in health care administration and a Master of Science in Nursing, Arcilla-Gutierrez also has hands-on experience in pediatric, medical-surgical, oncological, home health and hospice nursing. She is the current president of the Developmental Disabilities (NPI) Nurses Association, Southern California Chapter.

At Lanterman, Arcilla-Gutierrez works with clients from birth onwards. Her main areas of focus are supporting the Early Intervention services at Lanterman, and also working closely with both the intermediate care facilities and the skilled nursing facilities. She also works closely with home health agencies. Arcilla-Gutierrez does whole nurse assessment review for all applicants in Los Angeles, and especially in Early Intervention, this is important for the coordination of in-home services.

She adds: “Many of the clients we have living in skilled nursing facilities are not elderly, but simply have skilled nursing care needs due to their medical needs. It’s especially important in situations like this that the Regional Center is closely involved and educates the SNF staff on the importance of helping clients maintain their skills and abilities, and as much independence as possible.”

That old saying, “An ounce of prevention is worth a pound of cure,” is never truer than when you are dealing with a health-related crisis. “The biggest challenge we all face is ensuring that service coordinators and service providers see the earlier signs and come to us before things are in crisis rather than after the fact. We like to be involved from the beginning and focus on prevention rather than dealing from crisis to crisis,” notes Arcilla-Gutierrez.

For Arcilla-Gutierrez, one of the most rewarding aspects of her job is when a baby she has met in the neonatal intensive care unit graduates out of Early Intervention because they have met and/or exceeded all of the necessary developmental milestones. She also enjoys hearing success stories from service coordinators that demonstrate their learning in the area of health. And she finds it very rewarding when a client is able to move out of a skilled nursing facility into a less restrictive setting.

“One of the greatest challenges we face is the challenge of time. When you plan a visit for an hour or two to a home, you don’t really know what to expect. Many times parents are in crisis, and you need to give them time to express their emotions and frustrations. What is needed is to be sensitive to cultural habits and needs, build a relationship with the family and then focus on the health issues. You have to allow the person and their caregivers to express themselves, and you have to listen to them before they are ready to hear you,” shares Arcilla-Gutierrez.

Another challenge that all of the nurses have to consider is the health-related resources they have access to. Arcilla-Gutierrez adds: “As technology advances, more medically fragile babies are being saved, while at the same time the resources necessary to care for them are more challenging to find. Currently, there is an extreme shortage of home health nurses, and families are caught in the middle. So instead of working with families, it’s really important that we see what resources they have access to and build from there. It empowers them more if we are sensitive to what they can use, what resources they have. We have always to validate where they are at and what they are feeling.”

In the time that Arcilla-Gutierrez has been at Lanterman, there are two things that stand out – the work environment and the team spirit: “All of us have been a staff nurse or worked in higher middle management, and everything that I’ve done before in my profession is being challenged by this job. When you’re at the hospital, everything is at your fingertips, and it’s very humbling when you see parents telling you that they don’t think they can provide care without access to all of these resources. It forces you to think critically to meet the needs of clients in environments that are not perfect. And you really come to appreciate families and caregivers that live to caring for their family member with special needs.”

Since moving to the United States from the Philippines, Arcilla-Gutierrez has lived in California. She enjoys spending her free time doing volunteer work and chauffeuring her two children around to various activities. She also enjoys dancing. “This job has taught me respect for the life that they have, rather than wishing for what I don’t have. Being a widow is hard, but I’ve learned to embrace it. It’s an almost perfect world,” she adds.

Wanda Okunsanya

Although she’s only been with Lanterman for several weeks, Wanda Okunsanya brings with her a rich background that combines bachelor’s degrees in child development and African American studies, with special education experience, a degree in nursing, and experience working as a nurse in public county hospitals and military hospitals.
Lanterman Nurses Address Health of Clients

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While attending California State University, Northridge, to obtain her bachelor's degrees, Okunsanya also worked at the California Department of Education's Diagnostic Center, Southern California. About one year after graduating in 1987, while still working at the Diagnostic Center, Okunsanya joined the Army Reserve. She adds, "After finishing my bachelor's, I asked for guidance, and the doors opened up, and it just seemed like joining the military, even though I was 31, was the way to go. It was definitely going to be a challenge, but a good challenge, and with discipline, it has led me to where I'm at now."

The Army trained her as a field medic and after completing her training, Okunsanya pursued her nursing degree though the Los Angeles County College of Nursing and Allied Health (formerly the Los Angeles County Medical Center School of Nursing), which offers a two-year hospital-based associate degree nursing program.

Earlier this summer, Okunsanya celebrated 20 years as a Reservist. She recently finished over four years of active duty service, including a two-year tour as a transition nurse in post-partum nursing at Fort Hood in Texas. She is now attached to the 349th Combat Support Hospital in Bell, California.

"This is my dream job – I get to work with both children and adults and blend my different skill sets and educational experiences together in one job. It's wonderful," says Okunsanya, who will primarily be working with clients living in residential care facilities. "While it will be challenging learning how to access the different resources that are available and how the system works, I'm looking forward to bringing everything together and making sure that the needs of the clients are accomplished. I've found that my military experiences, by regularly placing me in new situations, have provided me with the training and skills to connect the dots and really make sure what I'm doing works, and that I know how to access and synthesize everything."

A recent experience that Okunsanya had was at an Operation Purple camp near Santa Barbara, which is designed for military children, especially those who have a parent deployed. "I'd never done camp nursing, and it really teaches you to be flexible and adapt, and it takes you out of your comfort zone. It was a very humbling experience and I learned to never underestimate the ingenuity that a camp nurse and other nurses who don't work in the well-controlled hospital environment are required to display. It also made me realize that everything doesn't always fit into a neat little package," she shares.

Even after 20 years, Okunsanya regularly does physical training and still sings cadences as she runs. She adds, "The way the military teaches you about health and the importance of staying in shape physically, it really changes your lifelong health and nutrition habits." Born in South Central Los Angeles, Okunsanya has lived in a number of cities in the United States, and currently resides in Westchester. She has two children and one grandchild. In her free time, Okunsanya loves to sing karaoke, particularly the oldies but goodies, and also likes poetry, reading and attending plays.

Portia Iversen's "Strange Son"

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bedroom keeping vigil, or awaiting the answer from a scientist who you are hoping will agree to study autism, or chasing after Tito as he runs through the house, and even whether Soma's pointing method was a very humbling experience and I learned to never underestimate the ingenuity that a camp nurse and other nurses who don't work in the well-controlled hospital environment are required to display. It also made me realize that everything doesn't always fit into a neat little package," she shares.

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Use Your PrepGuide to Prepare for the Next Major Disaster or Emergency

IT HAS BEEN MORE THAN 13 YEARS SINCE THE last major earthquake in the Los Angeles area. And, in addition to earthquakes, our area is known for fire danger in the summer and mudslides in the winter. Are you and your family prepared for the next emergency or natural disaster?

Inserted in this newsletter is a PrepGuide booklet, originally prepared by the Salvation Army but customized for the regional centers, that provides emergency preparedness information, as well as a place to keep basic data particular to you and your family that can help you when you most need it.

Use your “Home Safety Emergency Plan” to help you get prepared to be self-sufficient for at least three days to one week following a disaster and/or emergency. Preparation is the key to your survival and the survival of those you care for, and this booklet will help you be confident that you know what to do in an emergency.

The booklet features sections that provide tips and places to record information in the following categories:

- Emergency contacts, communication plan and household members info
- Child and pet safety, as well as service provider contacts and reunion procedures
- Special needs, health care providers and medication list
- First aid information
- What to do before, during and after an emergency
- What to do specifically during earthquakes, tsunamis, floods and flash floods, winter storms, tornadoes, lightning, extreme heat, hurricanes, fire, and chemical and biological agents
- How to create a shelter-in-place and escape from fire
- Utility instructions and household map
- Home safety checklist, including housing structure and ground stability, home security, fire safety, medication and chemical safety, and neighborhood safety
- Emergency supply checklist

Remember, in the event of a large natural disaster or emergency, you cannot count on an immediate response from public officials for each individual situation, so it is in your own best interest to be as prepared as you can be. The preparations you do now will reduce personal and material loss in the future. So don’t delay. Create your safety net now and be prepared.

The booklet is magnetized so you can keep it in a place that’s handy and visible, such as your refrigerator.

Preparedness Month
This September is the fourth annual National Preparedness Month, a nationwide initiative sponsored by the Department of Homeland Security to encourage Americans to take simple steps to prepare for emergencies. This year, National Preparedness Month focuses on back-to-school planning, business preparedness, multicultural preparedness, and home and family preparedness. To assist with preparedness planning, Lessons Learned Information Sharing, LLIS.gov, has created the National Preparedness Month resource page to share important information about these issues. In addition, many LLIS.gov topic-specific resource pages feature special sections highlighting information related to National Preparedness Month, planning or community preparedness.

To access the National Preparedness Month page, visit www.LLIS.gov and click on National Preparedness Month under Featured Topics. They also welcome any thoughts, questions or suggestions that you may have at nationalprepmonth@llis.dhs.gov.

Fill Out the Home Safety Emergency Plan
Use Your PrepGuide
 Mauldin

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