

Viewpoint

Legislative **ALERT!**

Be aware of SB 1332, perhaps the most important piece of legislation affecting our consumers and their families during the 2000 session of the Legislature.

Our service system is in crisis - caused in part by the unprecedented rate of staff turnover in our community-based day programs and in-home respite agencies. These agencies have not had an adjustment in their rates for about ten years. The direct care staff are for the most part underpaid for the jobs they do and the responsibility they accept. As a result, qualified staff have moved on to other fields.

SB 1332 would provide for a 20% rate adjustment for in-home respite service agencies, or individuals providing those services, and for community-based day program agencies for the 2000-01 fiscal year. It would also require those agencies to reimburse their direct care service workers to provide for a 20% increase for salary, wages, and benefits.

It is imperative that we let the Legislature and the Governor know that without this rate adjustment the crisis in our system will only grow larger. Programs cannot continue to operate without adequate staff to provide care.

Please write or call the following legislators and let them know you support this bill. Tell them that we

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Lanterman's Investment in Educational Advocacy

Lorenzo who has a diagnosis of Autism Spectrum Disorder is a consumer of Lanterman Regional Center. Lorenzo lives with his mother, Gia, who gave up a successful position as a corporate recruiter and opened her own business in order to be able to invest the time needed to assist her son to develop into as independent a person as he can. During this 1999 - 2000 school year, Lorenzo was receiving one hour a week of speech therapy from the school district and his mother was paying for two additional hours herself. She had been told by the school district that there were no full inclusion kindergarten spaces available for children with special needs. That was when she turned to the regional center for assistance. One of the services that Lanterman provides for its consumers is advocacy, including educational advocacy. The Lanterman/Pepperdine Special



Gia & Lorenzo Antonio

Education Law Clinic provides much of the educational advocacy. In 1996, Lanterman approached Pepperdine about forming a partnership wherein Lanterman would provide the funding and Pepperdine would provide the personnel to establish the Special Education Law Clinic. The Clinic began as a pilot project in 1996 and was formally established on an ongoing basis in January of 1999. It provides education advocacy and information to empower parents, as well as training for Service Coordinators to help

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Lanterman's Investment in Educational Advocacy

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enhance their advocacy skills. The goal is to ensure that children with disabilities receive appropriate education and related services as required by law.

Paul Roberts from the Law Clinic advocated on Lorenzo's behalf and as a result the district agreed to provide Lorenzo with a rich, full program. The program includes: placement in a full

inclusion public kindergarten class five days a week; a full-time aide with experience in discrete trial; an inclusion specialist who supervises the entire program; two hours a week of private individual speech therapy; one hour a week of group speech therapy; one hour a week clinic-based and one hour a week school based occupational therapy; and a physical therapy assessment.

Gia is convinced that Paul's advocacy for Lorenzo made it possible for him to receive all the educational services he needs.

For more information on the Lanterman/Pepperdine Law Clinic, contact Pat Huth, Lanterman's Director of Legal Services, at 213/383-1300 ext. 609.

Legislative Alert!

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need these additional funds so that your family member and/or friend can have qualified, experienced people working with them.

Letters should be addressed as listed below. And be sure to include: Sacramento, CA 95814

Senator Wes Chesbro
Capitol Bldg # 3070

Senator Jackie Speier
Capitol Bldg #2032

Senator John Burton, President pro Tem
Capitol Bldg. # 205

Senator Byron D. Sher
Capitol Bldg # 2082

Senator Adam Schiff
Capitol Bldg # 5080

Senator Tom Hayden
Capitol Bldg # 2080

Senator Richard Polanco
Capitol Bldg # 313

Assembly Member Dion Aroner
Capitol Bldg # 2163

Assembly Member Scott Wildman
Capitol Bldg #3091

Assembly Member Jack Scott
Capitol Bldg # 4146

Assembly Member Antonio Villaraigosa, Spkr of the House
Capitol Bldg # 219

Assembly Member Gil Cedillo
Capitol Bldg # 5016

Assembly Member Wally Knox
Capitol Bldg # 6025

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Reflections of an Intern

by Alice West

I could not have asked for a better internship experience than I had at Lanterman Regional Center. As a graduate student in the UCLA School of Public Health, I was required to complete an internship to gain practical experience in the field. When I researched the usual options for internships, however, I realized that no internships had been established that focused on the health of individuals with developmental disabilities. I became interested in Lanterman Regional Center because of their commitment to projects that promote the health and well-being of individuals with developmental disabilities.

Lanterman offered me the opportunity to utilize my public health skills to create a *Transition to Adulthood Guide* for families. This project required me to

quickly become an expert on the topic of transition. I learned to conduct focus group discussions with consumers, families, service coordinators, school professionals, and other community members. In addition, I gained skills in developing the content and format for this guide.

On a personal level, the most beneficial part of my internship was the mentoring that I received. I had the opportunity to work with inspiring professionals who demonstrated expertise, commitment, and compassion every day on their job. They encouraged me to learn new skills and to develop myself as a leader. I participated in Lanterman's Summer Leadership Institute, which helped me to clarify my professional goals. The regional center continues to provide me support



Alice West

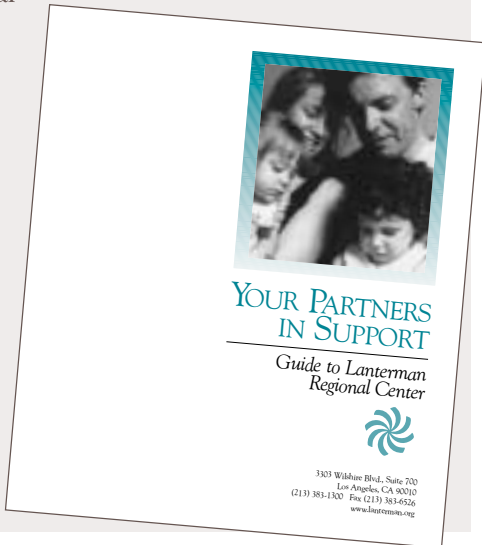
in my goal to develop programs to improve the health and well-being of individuals with developmental disabilities. I look forward to continuing to work with Lanterman Regional Center to develop projects in the area of Public Health.

Editor's note: We at Lanterman Regional Center could not have asked for a better intern than Alice West. Her enthusiasm, commitment and organization really made the Transition insert to our Guide to Services happen. We couldn't have done it as well without her.

Facing Transition? Information is on the way ...

We're pleased to announce the completion of a special insert to our Guide to Services focused on the Transition from High School to Adulthood. It's filled with practical information for families and individual

consumers. Families in our community who have a child between the ages of 12-22 should look for this important insert soon.



Join the Human Race!

You can walk, run, use your wheelchair or sponsor someone in the 13th

Annual Human Race. Your assistance will benefit the **Lanterman Help Fund!** The 5K/10K race, held in Downtown Los Angeles, is scheduled for Saturday, June 3, 2000. The 5K race will be at 7:45 a.m., the 10K at 8:30 a.m. and the Munchkin Mile for children will start promptly at 10:00 a.m. All children who participate – strollers are encouraged too – in the Munchkin Mile will receive a medal. Sponsor sheets will be available at our Human Resources unit. Be sure to note on your registration and pledge form that you are collecting pledges for Frank D. Lanterman Regional Center. For more information, please contact Jackie Ashman, ext. 684 or Schella Radford, ext. 613 at (213) 383-1300.



KCET Airs Regional Center Documentary

On February 27th, the documentary *We're Here to Speak for Justice:*

Founding California's Regional Centers was aired on Los Angeles public television station KCET. The film was produced and directed by award winning filmmaker Theodore Braun, Senior Lecturer at USC's School of Cinema-Television, and is the result of a partnership between Union Bank of California, Lanterman, Golden Gate and Harbor Regional Centers, and The University of Southern California School of Cinema-Television. According



to KCET, the documentary rated extremely well for a Sunday afternoon.

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

It's the story of impassioned parents, dynamic professionals and legendary state legislators who worked together to open the doors, bring down the old system, and forge a new, more humane and

responsive way to improve the quality of life for people with developmental disabilities and their families.

We regret that some of you did not receive notification of the airing in time to see the film. If you would like to view the documentary, copies are available for loan in the Koch•Young Family Resource Center or can be purchased through Lanterman Regional Center. Please call Roberta Happe at (213) 383-1300 ext. 716.

In addition, San Francisco PBS station KQED plans to air the piece on April 30 at 1:00 p.m. and May 2 at 11:00 p.m. If you have family or friends in the Bay Area, please let them know about this important program. It is also possible that KCET will air *We're Here to Speak for Justice* in the future. We'll keep you informed.

DDS Greenlights Two Lanterman Wellness Initiative Projects

We're pleased to announce that the Department of Developmental Services (DDS) has selected two proposals submitted by Lanterman Regional Center for funding in the current year's round of Wellness Initiative Projects.

The first is titled *Abilities: Sexual Exploitation and Abuse Prevention*. It is an unfortunate reality that people with disabilities are often easy victims of sexual assault or exploitation. Educating people with developmental disabilities on awareness, self-defense, and assertiveness and reporting is

essential to reducing their risk of sexual assault or exploitation.

Abilities will provide individuals with developmental disabilities the knowledge and skills necessary to prevent and protect themselves against sexual assault or exploitation. The program will also teach people how to access medical, legal and support services in the event of sexual assault.

The second project is the *Lanterman-UCLA Peer Advocacy for the Reproductive Health of Women with Developmental Disabilities*. Women with developmental disabilities must have access to information that can help them make informed

choices regarding their health. This project will improve the reproductive health of women with developmental disabilities through Peer Support Training, Reproductive Health and Self-Advocacy Training, and Health Care Provider Training.

The program will be open to women consumers, as well as medical professionals. For more information on these wellness projects, contact Maureen Wilson, Director, Training and Development at (213) 383-1300 Ext. 719.

You Spoke We Listened...

One of the ongoing requests from our Lanterman community is the desire for continued access to current information about various developmental disabilities. To that end, we're pleased to announce two special projects: The Autism Resource Guide and the Down Syndrome Information Packets.

Both of these projects have been created through partnerships with community groups, and funded by Lanterman Regional Center.

Creating the Autism Power Pak

Imagine hearing that your child has just been diagnosed with Autism. There's denial, frustration — and questions. Where do you turn? What do you do next? How do you mobilize your resources to rescue your child from the lonely, frightening world of the "A-word?"

The Foothill Autism Alliance, Inc., realized the need for a truly comprehensive guide that would empower parents and other caregivers to find those supports that make the difference between a



life of constant struggle, and one filled with positive possibilities. They approached Lanterman Regional Center with their vision and were met with overwhelming approval. And so, with funding from the regional center and elbow grease from the Foothill Autism Alliance, the Autism Power Pak was born.

The Power Pak will bring together in one place a virtual cornucopia of resources, including: medical Autism professionals, special needs attorneys, financial planners, pediatric optometrists, neurologists, dentists, kid-friendly barbers, educational consultants and therapists, as well as calendars and reference material.

Quality Information and Resources on Down Syndrome

The Down Syndrome Association of Los Angeles (DSALA) is leading a team developing an information packet on Down Syndrome that will be distributed to physicians, nurses, medical students and other professionals. This project is being sponsored by the Affiliate Advisory Board of the National Down Syndrome

Society. Members of the team include Down Syndrome organizations from San Francisco, San Diego, Orange County and Las Vegas. The goal is to provide the information packets to individuals and organizations

throughout California and Nevada, including all California regional centers.

Lanterman Regional Center is working in partnership with the team, providing funds and other support for the project.

According to Darryl Mikuni, Board Member, Down Syndrome

Association of Los Angeles and team participant, "We determined that there was a significant interest in developing a standardized information packet that provided medical professionals with the most accurate and up-to-date information on Down Syndrome. Based on meetings at a national conference, we concluded that the most effective way to approach this project is through collaboration with organizations with similar missions. By working together on development and distribution, we will be able to produce high quality materials at a relatively low cost."

Other Lanterman Special Projects include:

- Continuing the development of our Assistive Technology Lab
- Providing consumers and families online access to information
- Training and development of the Touchpoints Model for early intervention families and professional staff
- Developing and implementing an intervention model to address coping with a family member with a disability
- Start-up assistance for consumers moving out on their own for the first time

For more information on these and other Special Projects, please contact Patricia Herrera, Director of Family Support Services at (213) 383-1300, Ext. 718.



My Sister Eveline

By Peter Landry

For the past 13 years I have had a little sister that played a big part in my life. She overcame many challenges and accomplished things that weren't thought possible for her when she was born. She was never supposed to sit, crawl or walk, but learned to walk about the house with relative ease. She was improving every year on things such as bending down to pick things up, and going up and down stairs. Even though she never talked, everyone who knew her knows that she was always a happy person and a joy to be around. She had many friends at school and was good at interacting with people,

*Eveline &
Pete Landry*



even though she didn't talk. Though she had many challenges, she was always a happily active little girl.

In my eyes, and the eyes of many others, Eveline had a very good life. It might be disappointing to some people, myself included, that she never got to experience some of the great things in life that many of us have been able to do. But she didn't know that, and it didn't make her any less happy, so why should it make me unhappy? She was just fine playing with her favorite toys, going to school with her friends, and waiting for her brother and her dad to come home so she can greet them with a big smile and a hug. That was enough for her, and that's what counts.

Even though my sister presented me with many challenges and had many challenges presented to her, I always just saw her as my sister, a part of my everyday life. Every time I saw her, she had a smile for me, and she didn't ever get mad at me, no matter what I did. Other people might think she was special or unusual because she had disabilities, but I see her as special and unusual because she was my sister.

Sibling Support Network

Lanterman is in the process of organizing opportunities for brothers and sisters of children with developmental disabilities to come together to share experiences and obtain peer support. This year we are planning workshops for parents and siblings on Sibling Support. Currently Olivia Hernandez, Family Support Specialist and four Service Coordinators — Maribel Ortiz, Dora Saki, Lourdes Tabullo and Yvonne Villa are meeting to develop a plan to provide Sibling Groups in the Lanterman community. To add your name to the list of families interested in this project, please contact Olivia Hernandez at (213) 383-1300, ext. 705. You can also log on to the Sibling Project web site based at Children's Hospital and Regional Medical Center in Seattle, Washington at <http://www.chmc.org/departmt/sibsupp/sibshoppage.htm>

Profiles



Steven P. Beltran

Attorney Steven Beltran is the father of three daughters, including Katie, a 10-year old with Autism. He comes to the Board with more than 20 years of experience with the regional center system, both as a parent and as a professional.

Steven spent several years as the Clients' Rights Advocate at Eastern Los Angeles Regional Center and continues to offer classes and workshops to parent groups on estate planning for individuals with developmental disabilities. He is also active as a volunteer presenter for the Koch♦Young Family Resource Center on Service Coordination and Advocacy, as well as a participant in the Fiesta Educativa. He is focused on client rights and family support, and is also very involved with the Spanish-speaking Lanterman community.

"I'm very interested in children with disabilities who are dependents of the court," he says, "I feel there is much that can be done in terms of outreach and continuity of services, and that is one of my focuses as a member of the Lanterman Board of Directors." Speaking of the Board, Steven notes it is a well-organized group with extremely high standards for both themselves and the regional center.

He is a member of the California State Bar Association, California Consumer Attorney's Association, Los Angeles County Bar Association, Los Angeles County Mexican-American Bar Association, Los Angeles County Juvenile Court Bar Association, Los Angeles County Probate Volunteers' Panel, and Hastings College La Raza Alumni Association.



Chris Kearley

Chris Kearley lives in Los Angeles where he works for Deloitte & Touche LLP. He has his B.S. in Accounting from Loyola Marymount, and an M.B.T. in Taxation from USC. He has a five-year-old son and three-year-old daughter.

Chris is no stranger to volunteering in the community, having been a member of the Salvation Army Advisory Council since 1990. "I have served as a lead tax advisor to numerous tax-exempt organizations through my employment at Deloitte & Touche," he says, "and I look forward to bringing this experience with a wide variety of nonprofit organizations to my work as a Board Member of Lanterman Regional Center."

"The other thing I think is exciting about the Lanterman Board of Directors is its diversity," he continues. "Each member brings a unique perspective and set of experiences to the Board which together help us ensure the community we serve receives quality services. I am both proud and happy to be associated with such a committed and dedicated group of individuals as we work together to improve the lives of people with developmental disabilities."

Take Advantage of Many Recreation Opportunities

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The summer months will be here shortly, inspiring people to find fun leisure activities for themselves or their family members. Some of these resources are vendored programs, meaning they have a contract with the regional center and are experienced in working with people with developmental disabilities. Other programs are generic, in that they work with the community at large, but are willing to work with families to include children and young adults with disabilities into their programs.

Many community programs are also willing to extend their services to people with disabilities; they may just need some guidance and support themselves. If you need help with inclusion in leisure activities, please ask your Service Coordinator for some assistance.

A new resource we've discovered is the California Science Center located at 700 State Drive in Exposition Park. You can reach them at (213) 744-7444 or check their Web site at www.casciencectr.org.

The Science Center offers a variety of classes that are organized by age range and interest. Each class has a fee, but scholarships are available to qualified individuals. The Science Center has shown creativity and flexibility in serving children with disabilities, and in some cases has arranged for volunteers to provide additional hands-on assistance and supervision. Parents are encouraged to discuss their child's specific needs before signing up for a class.

Generic Resources

LA Parks and Recreation offers adaptive swimming for children on Saturdays only at E.G. Roberts' Swimming Pool. For more information please call (323) 936-8483. For other

SUMMER'S COM

locations, contact the Aquatics Office at (323) 906-7953.

Plaza de la Raza offers art and cultural experiences, including music, theater, dance and visual arts. This program is open to the general public, but is willing to work with parents who want to include their child. Call Maria Jimenez at (323) 223-2475 for more details.

Hollywood YMCA offers a variety of activities and is open to including people with developmental disabilities into their regular programs. They are located at 1553 N. Schrader and can be reached at (213) 386-8570; ask for Jorge Adradia.

Jewish Big Brothers Association offers residential summer camps for Jewish boys and girls with disabilities, ages 5 to 12. For more information, please call (213) 761-8675.

www.schoolsout.org promotes leisure opportunities in the Pasadena and Altadena areas. Their Web site focuses on children between the ages of 5 and 17, and has activities such as arts and crafts, music and sports.

Boys & Girls Club of Pasadena, located at 3230 E. Del Mar Blvd., mainstreams individuals on a case by case basis into their camps, computer tutoring, crafts and sports programs. Their after-school program is for ages 5-17, and in the summer it can be a full day, including swimming. For a schedule of activities, you can call (626) 449-1953.

Adaptive Recreation Program of Pasadena sponsors a variety of recreational activities year round for teens and young adults. They offer specialized camp opportunities, as well as including individuals with disabilities into camps run by the Department. For more information, call Jackie Arnett at (626) 398-1257.

Burbank's **Pickwick Recreation Center** does not have organized programs for people with developmental disabilities; however, the recreation center offers a variety of activities, including bowling and equestrian. Call (818) 845-3199 for further details.

Glendale YMCA offers a variety of programs and classes including swimming. Contact Barbara Bourland at (818) 242-4155.

Jewish Programs for the Disabled (Chaverim) offers activities throughout the Los Angeles area for Jewish adults with developmental disabilities. Activities include bowling, miniature golf, music, dances and seasonal dinners. Call (818) 884-1092 for more information.

New Directions is a travel agency located in Santa Barbara that provides vacation travel plans for people with developmental disabilities. These are actual day and overnight trips. David McKeand and Jeanne Mohle are the coordinators and can be reached at (805) 967-2841 to be put on their mailing list.

Holiday Bowling Center, located at 3730 Crenshaw Blvd., offers special programs for adults with disabilities at discounted rates on Saturday mornings. Please call (323) 295-4325 to confirm times.

Eagle Rock Little League has been including young children in the T-ball division. Practices are at Yosemite playground. For more information call Joel Zimmerle at (323) 258-6536.

Kidspace is a participatory museum located at 390 S. El Molino in Pasadena and geared for ages 2-11. Call (626) 449-9143 for time and fee schedule.

The Museum of Flying is located in Santa Monica and is a great activity for older children who love airplanes. Call (310) 392-8822 for more details.

MINING QUICKLY

Special Olympics is a year-round program focusing on a variety of sports activities. Call the Culver City office at (310) 215-8380 to learn about seasonal activities.

Santa Fe Dam Recreation Area, located in East San Gabriel Valley, offers outdoor camping and fishing. Trails are designed for hikers who are blind or in wheelchairs. For more information, call (626) 334-1065.

Foothill/Pasadena Area

Holy Family C.A.M.P. (Children with Autism Making Progress) located in South Pasadena is a six-week day camp. Please call (626) 744-7949 for further information.

South Pasadena YMCA offers special swimming lessons; call (626) 799-9119 for more information.

LL Frank Center, sponsored by Crippled Children's Services, offers a day camp in Pasadena. Call (626) 449-5661 for more information.

Lucille Cowle Swimming School offers swimming lessons from June - August. To get more information, call (818) 848-7206.

Tom Sawyer Camp, Inc. in Altadena offers summer day camp. Call (626) 794-1156 for a schedule.

Los Angeles Area

Etta Israel - Camp Mosh located in Los Angeles provides day camp opportunities for children. Please call (310) 285-0909 for more information.

Elysian Park Therapeutic Recreation Center, located near Dodger Stadium, provides day camp opportunities for children and young adults. You can reach them at (323) 226-1402 for further information.

L.A. Goal is located in Culver City and provides a variety of leisure opportunities for adults.

Call (310) 838-5275 to get a schedule of events.

Jeffrey Foundation in Los Angeles offers day camp opportunities for school age individuals. For details, call (323) 965-7536 and ask to speak with Linda Battler.

Tumbleweed Day Camp offers a day camp located in the West L.A. area for children, ages 4 - 14. It also offers Beach Club and Sports Camp programs. Registration for summer begins as early as March and April. For a schedule of activities and fee structure, call Noel Torres at (310) 472-7474.

UCLA offers a Movie Day Camp for individuals with developmental disabilities between the ages of 10 - 18. Call (323) 206-6150 for more information.

Southern California Area

Camp Joan Mier and Camp Paivika are both sponsored by Crippled Children's Society, and offer a variety of camping experiences for children ages 7 - 12, teens and young adults. For a schedule of camp dates, call Wendy Feldman at (626) 396-1010.

Easter Seals offers a residential camp program at various camps in San Diego County. Call (619) 336-0630 for more information.

Exceptional Children's Foundation offers residential camp opportunities in the San Bernardino Mountains. Call (213) 735-1421 for details.

Jay Nolan offers both day and residential camp opportunities. Call (818) 361-6400 for details.

Southern California Network coordinates camping trips for families with infants and pre-school children with visual impairments. Call (714) 573-8888 for more information.

Special People's Foundation provides travel and camping services for people with developmental disabilities. Call (310) 618-1833 for more information.

These are just some of the resources families can access from the Electronic Resource Directory located in the Koch•Young Family Resource Center. The staff at the Help Desk can assist you with specific information.

Social Recreation Information Forums

Lanterman's Community Advisory Councils are again sponsoring leisure and recreation forums where people can learn about local, community-based recreation opportunities. This is an opportunity for families to get their questions answered regarding cost, inclusion possibilities and more.

The Pasadena/Glendale/Foothill Councils will be sponsoring their Social Recreation Information Forum

**Saturday, May 13, 2000
9:00 a.m. - 12:00 noon**

Pasadena City College
Community Education Center
3035 E. Foothill Blvd., Pasadena

For information, contact Robert Erio at (213) 383-1300, ext. 619, or John Stack at ext. 620.

The Hollywood/Wilshire and Central Advisory Councils are also sponsoring a Recreation Forum

**Tuesday, May 9, 2000
9:00 - 11:30 a.m.**

**Early Intervention
Community Based Programs
12:30 - 2:30 p.m.
Adult Social/Recreation
Resources**

Braille Institute Auditorium
**741 Vermont Ave
(near Melrose Blvd.), Los Angeles**
parking is off New Hampshire

For information, contact Sam Suzuki at (213) 383-1300, ext. 559 or Sheila Brogan, ext. 514.

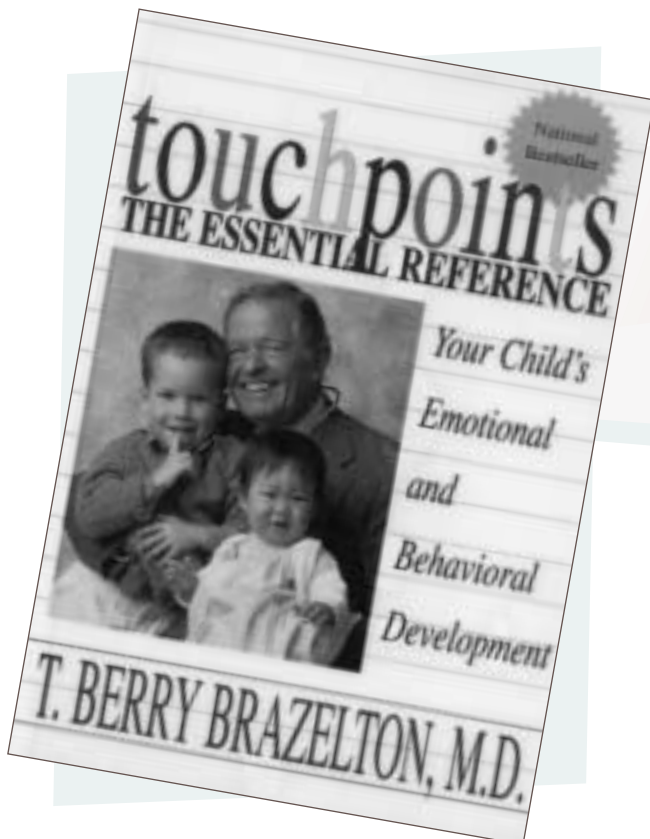
New Resources Available in the Koch•Young Family Resource Center

Touchpoints **The Essential Reference**

by T. Berry Brazelton, MD

"Touchpoints offers parents a complete understanding of child development from a physical, cognitive, emotional, and behavioral point of view."* An exceptional source of information on a child's development from birth to six years of age, the book is broken into three sections. The first, *Touchpoints of Development*, chronologically follows the basic stages of early childhood. Part Two, *Challenges to Development*, is an alphabetical reference helping caregivers to navigate potential problems. The third section, *Allies in Development*, focuses on the roles of individuals in a child's life.

*Brazelton, T. Berry. *Touchpoints The Essential Reference*. Reading, Mass.: Perseus Books, 1992.



Expecting Adam: **A true story of birth, rebirth and everyday magic**

by Martha Beck

Reviewed By Ronna Kajikawa

This absorbing story is about two fast-track Harvard graduate students who find themselves and their world turned upside down by the unexpected conception and birth of their second child, Adam. They find out during the pregnancy that Adam has Down Syndrome and are advised to terminate the pregnancy. Yet at this point, the couple are already having psychic connections with each other and with a spiritual being whom they feel has something to do with the fetus.

I highly recommend this book, not just as a story about a child with Down Syndrome, but as an uplifting, tearful, yet joyful reading experience. Whether you are religious or not, believe in angels or not, you will laugh, cry and be overjoyed by Adam and his family.

Pervasive Developmental Disorders: Finding a Diagnosis and Getting Help

by Mitzi Waltz

Pervasive Developmental Disorders (PDDs) include autism and a range of other neurological disorders. While at least 250,000 Americans have been diagnosed with PDD-NOS — one-third of whom are children — twice as many may remain undiagnosed or misdiagnosed. Parents of a young child with undiagnosed PDD may suspect any number of things, from autism to severe allergies.

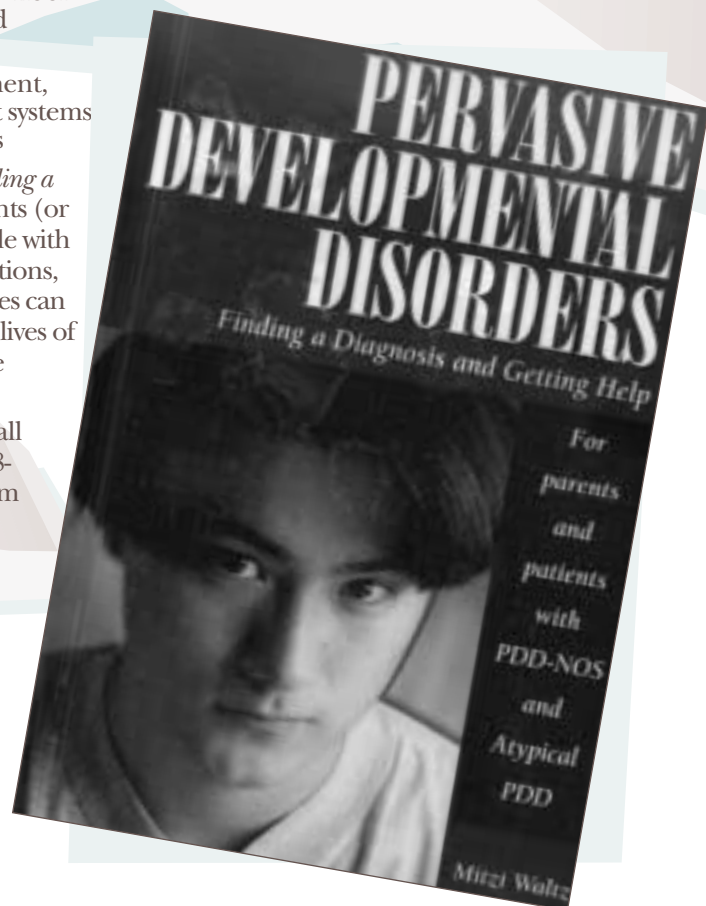
Weaving in a range of stories from parents who are raising children with PDDs, author Mitzi Waltz covers topics such as:

- Getting a diagnosis, including preparing for a diagnostic interview in a medical, psychiatric, or school setting, with description of all diagnostic tests and checklists/questions used by professionals
- Treatment options such as: medications and supplements; sensory integration; occupational, physical, and speech therapy; behavior modification; “floor time,” play and talk therapy; and parenting techniques
- Coping with diagnosis and treatment, including emotions and support systems insurance and educational plans

Pervasive Developmental Disorders: Finding a Diagnosis and Getting Help is for parents (or newly diagnosed adults) who struggle with this neurological condition. Medications, therapies and educational techniques can address symptoms and improve the lives of people with PDD. In some cases, the results can be spectacular.

For ordering information, please call Patient-Centered Guides at 800-998-9938 or visit www.patientcenters.com

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Spotlight on Consumers . . .

One's appeared on a top-rated television program; the other is going to be a featured speaker. They're both remarkable young people — who also happen to be Lanterman consumers.

Andre Wilson in the ER...

Sixteen-year-old Andre Wilson played the part of Jake on a recent ER episode. Directed by series star Anthony Edwards, the storyline deals in part with two brothers trying to make it on their own, since their father is gone and their mother lives on the street. One of them, Jake, has a developmental disability.

Andre does a marvelous job in a role that requires some strong emotional scenes. And because it's a speaking part, he's now qualified for Screen Actors Guild membership. He's also got his headshots, and is registered with

Media Access, an agency for individuals with disabilities who want to go into the entertainment field.

Andre comes by his talent naturally. His mother Yvonne is a student filmmaker. "He was in all my films," she says, "Andre's a born actor!"

According to her, Andre loved his experience and wants to play a broader range of roles, not just ones dealing with disabilities. So who knows, we may soon be announcing more television appearances by Andre Wilson!

Jessica Morris Speaks at Fundraiser

In a different sort of public forum, Jessica Morris is slated to be a special speaker at the Down Syndrome fundraiser in Los Angeles April 14th. Sharing the podium with Jessica at the \$150.00 a plate event will be

Jessica Morris



Tracy Ullman, Chris Burke and guest speaker Actor/Producer Rhea Perlman.

Jessica's a poised 15-year-old who attends Fairfax High School where she's involved in the Best Buddies program.

And this isn't her first public speaking engagement.

She also gave a speech at her Graduation from Palms Middle School last year. According to reports, there was "not a dry eye" in the house.

The luncheon is an annual event of the Down Syndrome Association of Los Angeles honoring women's commitment to volunteerism. The fundraiser supports education, research and advocacy programs that benefit people with Down Syndrome.



Andre Wilson (third from left) with cast members of ER, Courtesy Warner Bros. Television

Have You Seen the Lanterman Website Lately?

Lanterman Regional Center is proud to announce two new additions to www.lanterman.org. The first is an Alert area, designed to highlight important information for the Lanterman community. Currently in the Alert area is California State Senate Bill 1332. This legislative alert gives important information on this bill as well as the ability to e-mail key legislators with your opinion on the bill. For more information on this bill, go to our website or turn to page 1 of this edition of the Viewpoint.

The second new addition to the site is information on *"We're Here To Speak For Justice"* including a form to order the video. The site also gives an overview of the documentary and its producer/director Ted Braun.

Planned additions to the website include: the Koch•Young Family Resource Center Library

Collection, allowing the Lanterman community to search the collection from outside the regional center, and the Electronic Resource Directory —

giving individuals the ability to find resources in their area.

Keep checking www.lanterman.org for these and other changes!



So What Exactly IS An Advocacy Group? And How Can It Help Me?

Around the regional center, you often hear and read about something called "Advocacy Groups." But what are they - and how can they make a difference in your or your family member's life?

First off, advocacy groups are support groups for individuals where they acquire skills that will assist them in advocating for themselves. In other words, they're a very important part of what we call empowerment.

Secondly, they're organized around specific expressed needs and interests, and provide a way for consumers to take more charge of their lives.

There are currently two non-residential advocacy groups available for our consumers: Lanterman - The Achievers, and the Mid-Wilshire group. In addition, there are many different consumer councils attached to residential or day programs.

We're trying to reach out and develop even more of these groups for our consumers, but we need your input. Lanterman Consumer Advocate Erick Homiak is looking for individuals interested in starting an advocacy group in Pasadena.

If you or someone you know is interested in this group — or in any other consumer advocacy group — please contact Erick Homiak at (213) 383-1300 ext. 743.

Someone Cares

Local Family/Consumer Support Groups

ADULT SIBLING SUPPORT GROUP

Call for details

Contact: *Olivia Hernandez (213) 383-100 Ext. 705*

ARMENIAN PARENT GROUP

Quarterly meetings – Glendale Area

Call For dates & details

Contact: *Rima Shahoian (818) 548-4349*

Shoghig Dikjian (213) 383-1300 Ext. 546

Maral Tahmizian (213) 383-1300 Ext. 674

ARMENIAN PARENT SUPPORT GROUP

Monthly meetings at group members' homes in the Glendale area

Monthly — Last Friday 11:00 a.m. – 1:00 p.m.

Contact: *Rima Shahoian (818) 548-4349*

Shoghig Dikjian (213) 383-1300 Ext. 546

Maral Tahmizian (213) 383-1300 Ext. 674

AUTISM SOCIETY OF AMERICA

San Gabriel Valley Chapter Support Group

1167 N. Reeder Ave., Covina

Monthly — Wednesday, 7:30 p.m.

Contact: *Patricia Kreysler (626) 447-3452*

BEHAVIOR MANAGEMENT PARENT SUPPORT GROUP

Call for details

Contact: *Olivia Hernandez (213) 383-1300 Ext. 705*

CONSUMER RESIDENT COUNCIL AND SELF ADVOCACY GROUP

Good Faith Manor #3

Every other Wednesday, 5:00 p.m.

Contact: *Rovena Cruz (213) 386-2408*

daDA FATHERS REGIONAL SUPPORT NETWORK

Call for details

Contact: *Marty Sweeney (323) 933-2983*

DOWN SYNDROME SAN GABRIEL VALLEY PARENT SUPPORT GROUP WITH CHILDREN UNDER SEVEN

Church of Brethren

1041 N. Altadena Drive

Pasadena, 91107

Monthly — 2nd Thursday, 7:00 p.m. – 9:00 p.m.

Contact: *Darryl Mikuni & Pat Van de Veer*

(626) 398-0942

Olivia Hernandez (213) 383-1300 Ext. 705

EARLY INTERVENTION SPANISH SPEAKING PARENT SUPPORT GROUP

Lanterman Regional Center

3303 Wilshire Blvd., Ste. 700

Monthly — 2nd Wednesday, 9:30 a.m. – 11:30 a.m.

Contact: *Rose Chacana (213) 383-1300 Ext. 526*

Monica Mauriz (213) 383-1300 Ext. 519

FAMILIES AND FRIENDS OF PERSONS WITH DISABILITIES

St. Dominic's Community Center

2002 Merton Ave., Eagle Rock

Monthly — 1st Friday, 7:30 p.m.

Contact: *Emma Guanlao (323) 259-8332*

Esther Martinez (323) 254-6413

FOOTHILL AUTISM ALLIANCE NETWORK RESOURCE MEETINGS

BCR-230 E. Amherst Drive

Burbank, CA 91505

Monthly — 2nd Wednesday, 7:00 p.m.

Contact: *Sue Brooks (818) 66-AUTISM*

(818) 662-8847

FRAGILE X PARENT SUPPORT GROUP

Call for dates and details

Monthly, 7:00 p.m.

Contact: *(818) 754-4227 Voicemail*

GAY AND LESBIAN ADULT SUPPORT GROUP

Lanterman Regional Center

3303 Wilshire Blvd., Ste. 700

Monthly — 2nd Wednesday, 4:00 p.m. – 5:00 p.m.

Contact: *Joe Perales (213) 383-1300 Ext. 555*

Melinda Anders (213) 383-1300 Ext. 506

GLENDALE/BURBANK/FOOTHILL PARENT SUPPORT GROUP

Monthly — 1st Wednesday, 10:00 a.m.

Call for location

Contact: *Jennifer Wyre (213) 383-1300 Ext. 679*

Nora Chitilian (213) 383-1300 Ext. 675

GRUPO DE APOYO PARA EL MANEJO DE LA CONDUCTA

(Spanish-Speaking Behavior Management Group)

Shriners Hospital

3160 Geneva St. (Virgil and Third St.),

Los Angeles

Ultimo martes de cada mes

7:00 p.m. – 9:00 p.m.

Contact: *Francisca Arias (213) 965-0379*

Ramona Vella (213) 383-1300 Ext. 577

HOLLYWOOD/WILSHIRE PARENT SUPPORT GROUP

Lanterman Regional Center

3303 Wilshire Blvd., Ste. 700

Monthly — 3rd Tuesday, 10:00 a.m.

Contact: *Gloria Persinski (323) 469-1398*

or (323) 462-0850

Jessye Davis (213) 383-1300 Ext. 549

Ramon Martinez (213) 383-1300 Ext. 532

INCLUSION IN REGULAR CLASSES SUPPORT NETWORK

Locations and times vary each month —

call for next meeting

Contact: *Sam Suzuki (213) 383-1300 Ext. 559*

INDEPENDENT LIVING ADULT CONSUMER GROUP

Call for dates and details

Contact: *Rosemarie Navarro (213) 383-1300 Ext. 626*

JAPANESE-SPEAKING PARENTS ASSOCIATION OF CHILDREN WITH CHALLENGES

Little Tokyo Service Center

231 East Third Street,

Suite G-104

Los Angeles, CA 90013

Monthly — 3rd Saturday, 9:30 a.m.

Contact: *Mariko Magami (818) 249-1726*

Michiko Wilkins (818) 557-0728

KOREAN PARENT SUPPORT GROUP

Asian Advocate for Special People

Lanterman Regional Center

3303 Wilshire Blvd., Ste. 700

Monthly — 2nd Monday, 6:30 p.m. – 8:30 p.m.

Contact: *Suki Chang (213) 999-3981*

Susan Han (213) 383-1300 Ext. 545

Alanah Kim (213) 383-1300 Ext. 531

"PADRES UNIDOS LANTERMAN"

Spanish-Speaking Support Group

(Grupo en Español)

Children's Hospital of Los Angeles

Conference Room "D"

Monthly — 2nd Tuesday, 7:00 p.m. – 9:00 p.m.

Contact: *Yolanda Gonzalez (213) 389-6038*

Joe Perales (213) 383-1300 Ext. 555

MEETING SCHEDULE

REACH

(Respecting Encouraging and Affirming Choices in Housing)
2606 Foothill Blvd.
La Crescenta, CA 91214
Monthly — 3rd Wednesday, 7:00 p.m.
Contact: Maria Leinenweber (818) 248-8624
Emma Guanlao (323) 259-8332

RETT SYNDROME SUPPORT GROUP

Pasadena Area
Quarterly Meetings
Call for dates and details
Contact: Marie Hyland (626) 790-4836
Pep Stenberg (626) 355-5334

SPANISH-SPEAKING PARENT GROUP "LA ESPERANZA"

(Grupo Semanal en Español)
Lanterman Regional Center
3303 Wilshire Blvd., Ste. 700
Weekly — Monday, 9:00 a.m.
Contact: Yolanda Hernandez (562) 928-5324
Primitivo Jacobo (323) 464-3689
Bertha Rios (323) 666-3489
Nilda Lopapa (213) 383-1300 Ext. 554

SPANISH-SPEAKING PARENT SUPPORT GROUP

Salvin Special Education Center
1925 S. Budlong Ave.
Los Angeles
Call for dates, 9:30 a.m. – 11:30 a.m.
Contact: Gloria Perez (213) 383-1300 Ext. 556

TEATRO ILUSIÓN

(Grupo Semanal en Español)
Shriner's Hospital
3360 Geneva St. (Virgil & Third St.),
Los Angeles
Weekly — Friday's, 6:00 p.m. – 8:00 p.m.
Contact: Yolanda Hernandez (562) 928-5324

COMMUNITY ADVISORY COUNCILS

Our Community Advisory Councils serve as a link to the community. They provide input on policies, services and programs and offer opportunities for consumers, parents, service providers and staff to network. If you have an interest in serving in the council for your area or in attending meetings, contact:

Lanterman Regional Managers at (213) 383-1300.

CENTRAL REGION

Third Tuesday of the month
10:00 - 11:30 a.m.
Ysidra Guiterrez, Ext.557

GLENDALE REGION

Second Tuesday of the month
6:30 - 8:00 p.m.
M.J. Kienast, Ext. 617

HOLLYWOOD/WILSHIRE REGION

Third Tuesday of the month
10:00 - 11:30 a.m.
Sam Suzuki Ext. 559

PASADENA REGION

Third Tuesday of the month
6:30 - 8:00 p.m.
Robert Erio, Ext. 619

ORIENTATION MEETINGS

Lanterman provides monthly orientation meetings to welcome all new families and adult consumers. We provide an introduction to the Lanterman service delivery system as well as to the Koch•Young Family Resource Center. Orientation is also available quarterly for those families with children transitioning to preschool (2½ years). For a complete 2000 schedule of monthly Orientation meetings, please contact the Koch•Young Family Resource Center at (800) 546-3676.

If you are interested in starting a support group but don't know how to take the first step, call
The Koch•Young Family Resource Center
for information:

1-800-546-3676

QUARTERLY TRAININGS

SERVICE COORDINATION AND ADVOCACY TRAINING

Ten hour course for Lanterman families to better enable them to advocate and assist their family member with a disability. Coordinated by the Center's Family Support Services Unit. Training courses offered quarterly.

APRIL 2000

BCR
230 Amherst Dr.
Burbank, CA 91504
Apr. 4,11,18,25, May 2
7:00 – 9:00 p.m.

MAY 2000

Glendale Unified School District
223 N. Jackson St. Room 103
Glendale, CA 91206
May 3,10,17,24,31
7:00 – 9:00 p.m.

JUNE 2000

Pasadena Board of Education
351 S. Hudson Ave. Pasadena, CA 91109
June 1,8,15,22,29
7:00 – 9:00 p.m.

SEPTEMBER 2000 — SPANISH

Lanterman Regional Center
3303 Wilshire Blvd., Ste. 700
Los Angeles, CA 90010
Sept. 12,19,26 Oct. 3, 10
9:30 – 11:30 a.m.

NOVEMBER 2000 — KOREAN

Lanterman Regional Center
3303 Wilshire Blvd., Ste. 700
Los Angeles, CA 90010
Nov. 6,13,20,27 Dec. 4
7:00 – 9:00 p.m.

Contact: Your Service Coordinator or Olivia Hernandez (213) 383-1300 Ext. 705

PEER SUPPORT TRAINING

Twelve hour training for individuals who have experience with developmental disabilities and want to provide one on one support by phone or in person to new or referred families. Training is coordinated by Lanterman's Family Support Services Unit.

Contact: Olivia Hernandez (213) 383-1300 Ext. 705

BEHAVIOR MANAGEMENT WORKSHOPS

Twenty hour training developed for Lanterman Regional Center families by the UCLA University Affiliated Program. In this workshop, you will learn strategies to manage problem behaviors. This program is intended to be proactive in its strategies. More serious behavior issues should be discussed with your Service Coordinator.

Board Welcomes Your Attendance at Its Meetings

Please be aware that anyone in the community is welcome to attend the Regional Center Board of Directors meeting which is conducted on the fourth Wednesday of every month at 6:00 p.m. Meetings are held at Lanterman Regional Center. Please call Frank Lara in advance at (213) 383-1300, Ext. 665 so that you can be put on the list of attendees. We look forward to your visit.

Upcoming Inclusion / Mainstreaming Information Session

Lanterman Regional Center will be offering a School Inclusion/Mainstreaming Information Seminar in the coming months. Parents, general education staff and special education staff interested in learning more through networking, sharing of "best practices", and mutual problem solving should attend this event.

May 16, 2000 — Tuesday
6:30 p.m. — 8:30 p.m.
Villa Esperanza's Braun Center
2116 East Villa St.
Pasadena, CA 91107
(626) 449-2919

For more information, contact (213) 383-1300 and speak to Sam Suzuki, ext. 559 or Stephanie Pinkus, ext. 686

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Viewpoint

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