



# Dialogue

Volume 22 No. 1  
Winter 2008

## Consumer Spotlight

### John Correa

Even if you never spoke with John Correa about what he likes to do in his free time, his face would give him away. With a dazzling smile shining out from a bright, sun-tanned face, there is no way to disguise the fact that this RCOC consumer loves the outdoors! And it is no surprise that he, as an avid outdoorsman, also loves working at REI. REI is a leading retailer of outdoor gear for everything from skiing and snowboarding, to hiking, camping and cycling.



John Correa enjoys his job as a stock specialist with outdoor equipment retailer REI.

the store. With job coaching, as well as independent living support, from Project Independence, John has worked at REI for about a year.

and appreciate working for a company that makes people with developmental disabilities part of their work force," he said.

Along with liking the work he does and the people he works with at REI, John enjoys participating in the many outdoor-oriented activities the company sponsors in the community. For example, he joined a group that spent a day cleaning up the Bolsa Chica Wetlands. Last year, he also joined Matt and his family on a trip to Big Bear where they volunteered at the Special Olympics.

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***John enjoys participating in the many outdoor-oriented activities the company sponsors.***

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### ***Employees with disabilities help to improve employee morale.***

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"I enjoy every minute of it," he said about his job as a stock specialist. In this position, John is responsible for unloading merchandise that arrives in the morning, preparing it for display, and getting it to its proper place in

Matt Patwell, the REI manager who hired John, actively makes contacts with other retailers and shares his personal experiences to convey the benefits of hiring adults with developmental disabilities.

In addition to being dependable, hard-working, positive employees, Matt said that REI's employees with disabilities help to improve employee morale: "Other staff truly like working with their disabled peers,

Harriet Butler, John's service coordinator, admitted that she was surprised when John told her that he wanted to take the job at REI, because it meant leaving a job where he was both well-liked and was being paid a higher wage. When she asked him why he would give up a job that paid so well, he told her: "It's not about the money, it's about my happiness."

See **John Correa** page 9

## Dialogue

*Dialogue* is published four times per year by the Regional Center of Orange County for people with developmental disabilities, their families and service providers.

*Dialogue* can also be read online at RCOC's Web site: [www.rcocdd.com](http://www.rcocdd.com).

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### 2008 Board Meetings

March 6 • May 1 • July 10

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The public is invited to attend. Meetings begin at 6 p.m. and are held in the Regional Center Board Room at 801 Civic Center Drive West, Santa Ana.

### RCOC Administration

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## The Lanterman Promise

When some people talk about the advantages of living in California, they may mention things like the sunny weather and living near the ocean. But for those with developmental disabilities and their families, one of the very best things about living here is the Lanterman Developmental Disabilities Services Act.

Enacted in 1969, the Lanterman Act remains unique in the nation.

No other state has made a similar promise of community-based services and supports for people with developmental disabilities. And no other state has anything like our locally-controlled regional centers that develop resources to meet local needs, advocate on behalf of consumers and families, help them to evaluate a variety of service providers and to access the services and supports they need, and provide local quality assurance.

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***Enacted in 1969, the Lanterman Act remains unique in the nation.***

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By comparison, in most states, services and supports for people with developmental disabilities are not provided to all who need them. Services are rationed in states that

have a policy of providing services to those with "the most critical needs" first. Legislatures frequently do not provide enough funding to meet everyone's needs, so even those deemed eligible for services are placed on long waiting lists. Some states provide no funding at all – for a person's services to be paid for by the government, he or she must qualify for Medicaid. And, while some states offer something called "service coordination" or "case management," in many places it bears little resemblance to the lifelong connection to services that Californians have.



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***Services are rationed in some states.***

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With California again facing a fiscal emergency, the community is facing challenges to Lanterman principles that could have long-term consequences. So, now is a good time for consumers and families to get better acquainted with the Lanterman Act.

To view and download the Lanterman Act, go to the Department of Developmental Services Web site ([www.dds.ca.gov](http://www.dds.ca.gov)) and click on "Laws and Regulations."

The more you know about the Lanterman promise, the better equipped you will be to defend it.

## State's Fiscal Emergency Reflected in Governor's Budget Proposal

By Bill Bowman, Chief Executive Officer

**T**ake a quick glance at the Governor's budget proposal for

fiscal year 2008-09, and it looks pretty good for people with developmental disabilities.

The state is facing a \$14.5

billion deficit. And, while the Governor called for an across-the-board 10 percent cut to almost all departments and programs, the regional center system was largely spared.



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*From a longer-term perspective, we see some troubling language in the budget proposals.*

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Nonetheless, when one takes a more in-depth look, there are issues of great concern. For example, some of the departments being asked to absorb the biggest cuts have powerful constituencies. They may succeed in defeating or reducing the size of the cuts to their programs. Since the state constitution requires the budget to be balanced, any cuts they are able to

defeat will have to come from somewhere else. We will need to be vigilant to ensure that people with disabilities do not end up making up the difference.

From a longer-term perspective, though, we see some troubling language in the budget proposals for developmental services.

### Some Proposals May Affect the Lanterman Promise

The Governor does not propose to "suspend" the Lanterman Act. However, some of his proposals, cast as budget reduction measures, represent major changes to the system that will undermine key Lanterman principles.

Unlike a simple cut to the amount of dollars for services and supports, which can be restored once the budget crisis has passed, many of the system changes being considered would fundamentally and permanently change the way consumers and families receive services and supports.

### Self-Determination and SDS Are Not the Same

In states where it is available, Self-Directed Services (SDS) is seen as an alternative model of service delivery to increase flexibility to meet varying consumer needs. In contrast, California's launch of Self-Directed Services (SDS) is presented as a cost-containment measure. It is assumed that consumers who opt for SDS will cost the state less money than those served in typical ways. However, California's version of SDS asks

consumers to give up a lot in exchange for greater control of the dollars.

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*Many of the system changes being considered would fundamentally and permanently change the way consumers and families receive services and supports.*

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SDS consumers will have a limited budget, and will not be able to use current regional center service providers. They will be required to find vendors and negotiate the price for services, without the benefit of regional centers' buying power. They will also be asked to perform the paperwork necessary to oversee their service providers, and to do so without regional center quality assurance staff.

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*For Lanterman principles to prevail it is essential for people in our community to participate.*

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While the community should welcome SDS as an alternative, it is important that we do not confuse Self-Directed Services with self-determination, a concept that has for many years guided the regional centers' person-centered planning process.

### Participate in the Budget Discussion

In May, the Governor will submit a revision of his budget proposal (the

## Consumer Advisory Team Update

### CAT Team Ends 2007 with Holiday Party

By Jay Connor, CAT Chairman

**W**e in the Consumer Advisory Team have a fun tradition. Each year, we make our December meeting a holiday luncheon. In keeping with the season, we share some holiday cheer with old friends, while also enjoying social time to get better acquainted with new members of the Team.

We have the meeting at a place where everyone can have something they like to eat. This year, as last year, we met at HomeTown Buffet. As you can see from these photos, we all enjoyed great company as well as great food!

The Consumer Advisory Team is always very welcoming of new members. So, if you think you might be interested in getting to know some new people, and learning more about important issues for consumers, please consider attending our next meeting.

### Upcoming CAT Meeting Dates

March 19

April 16

May 21

June 18

July 16

CAT meetings are from 10 a.m. to noon at RCOC's Santa Ana office, 801 Civic Center Drive West. Call Betty Bath at (714) 796-5316 ahead of time to let her know you will be there.



Above: (left) Robert Provencher and Bridget Mueller (right)

Right: Betty Bath (left) and CAT Chairman Jay Connor (right)



Left: Julie Bakulich

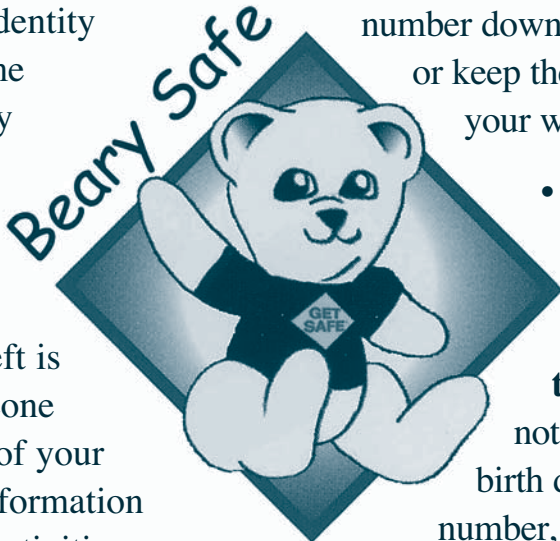
Below: Tom Baron (left) and Mary Ayres (right)



## Let's Prevent Identity Theft

In this Safety Corner, we are talking about identity theft. Let me first start by telling you what that means. Identity theft is when someone uses some of your personal information for illegal activities. Personal information can include your name, birth date, or social security number, as well as bank account numbers and PINs (personal identification numbers). When someone steals this kind of information from you, that person has stolen your identity – which can cause some major damage!

One way this can happen is when you get money or make deposits at an ATM, so here are some tips to be extra safe:



- **Memorize your PIN (personal identification number used with your bank cards) as soon as possible.** Do not write the number down on the card or keep the number in your wallet or purse.

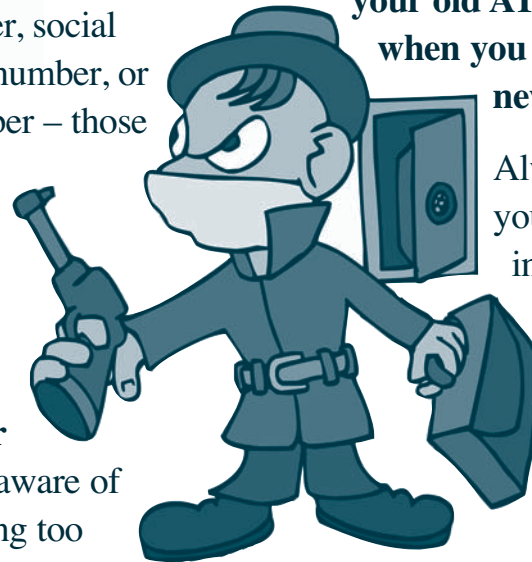
- **Use a PIN that would be hard for others to guess.** Do not use your birth date, phone number, social security number, or house number – those would be easy for someone to guess.

- **Watch out for “shoulder surfers.”** Be aware of people standing too close to you when you are using the ATM machine. A shoulder surfing thief can watch as you enter your PIN, so always cover your hand while you enter your PIN!

- **Do not use an ATM that looks like it may have been fooled around with.** If your card gets stuck in an ATM, call your bank right away.

- **Keep your ATM receipts.** Your receipts can help you track your activity and make sure there is not anything fishy going on. Remember to shred your receipts when you are ready to throw them away.

- **Carefully cut up or shred your old ATM card when you get a new one.**



Always protect your personal information as much as you would protect yourself from others.

*Until we talk again,  
The Safety Team!*

*Safety Stu, Stevie, Jessie,  
Beary Safe and Roy*

## Work Initiative Update: Expanding Employment Opportunities

**W**hen most people finish school, they are eager to enter the working world. For many, a job signals adulthood and increasing independence. It can also build confidence and new skills. According to RCOC Chief Operating Officer Janis White, Ed.D., whose doctoral dissertation centered around the school-to-work transition, this is another area in which typical young people and those with developmental disabilities are strikingly similar.

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*Studies show that even adults with severe disabilities can be successful in the work place.*

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“When people with developmental disabilities have real jobs, it enhances their self-esteem and affects how parents and others view them,” she said. Both Janis’ research and many other studies show that even adults with severe disabilities can be successful in the work place. It is simply a matter of matching the individual with the right job and the right combination of supports.

RCOC’s Work Initiative is aimed at helping make that match for more consumers in two ways: enhancing vendors’ ability to provide employment supports; and increasing awareness among Orange County



Project Independence Executive Director Debbie Marsteller (left), Grandparents Autism Network (GAN) founder Bonnie Gillman (center) and IABA Chief Services Officer Linda Seppala at a recent workshop for GAN members on the benefits to employers of hiring people with disabilities.

businesses about the benefits of employing people with disabilities.

### Enhancing Vendor Capacity

“We want more vendors to focus on employment because that’s what consumers are asking for,” said LeeAnn Christian, Ph.D., RCOC’s Director of Organizational Effectiveness, noting that 68 percent of RCOC adult consumers surveyed said they would like to have a paid job and earn money.

“This is not to the exclusion of other activities and not to devalue other program activities,” she emphasized. “But rather an effort to be responsive to consumer and family needs.”

For vendors to stay in business over the long-term, she said, they are going to have to offer programs that people want – and more and more adult consumers want paid work.

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*“We want more vendors to focus on employment because that’s what consumers are asking for.”*

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Since RCOC’s Board of Directors made consumer employment a priority for the organization, several vendors that previously offered no employment component to their day programs have stepped up and committed to developing this capacity.

“What we’re talking about is a shift in philosophy,” said LeeAnn. “Moving toward a model where people with developmental disabilities, including those with severe behavioral or physical challenges, are in the community doing the things that typical adults do.”

## Help from Grandparents

The Grandparent Autism Network ([www.GANinfo.org](http://www.GANinfo.org)), founded by Bonnie Gillman, will play an important role in generating interest among Orange County employers. In February, service providers Linda Seppala of IABA and Debbie Marsteller of Project Independence delivered a presentation to GAN about the benefits of hiring RCOC consumers.

“The grandparents can help the business community understand that it makes good business sense to hire people with developmental disabilities,” Linda said, noting that grandparents who are interested in doing outreach on their own may use the presentation that she and Debbie developed. Or, if they simply have contacts in the business community they want to pass on, RCOC will follow-up on those leads.

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***GAN’s involvement can greatly expand employment opportunities for RCOC consumers.***

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With several hundred members, many of them prominent figures in Orange

County’s business community, GAN’s involvement can greatly expand employment opportunities for RCOC consumers.



“There is real potential to make inroads into new industries where we don’t have established relationships, and to develop corporate-level commitments with some businesses we work with on a local basis,” Linda said.

## One-Stop “Shopping”

To answer questions business owners might have, and help expedite the process for those interested in employing RCOC consumers, RCOC is developing a section for its Web site ([www.rcocdd.com](http://www.rcocdd.com)) specifically on this topic.

“This will offer ‘one-stop shopping’ for prospective employers and ensure that we follow-up promptly on every lead that GAN and others generate,” said Janis. “It also keeps a level

playing field for all of the service providers.”

## Measuring Progress

Soon after the Work Initiative was launched, RCOC began collecting data from service providers in order to establish a baseline that will be used to measure the initiative’s effectiveness in increasing work opportunities for consumers, and helping them to get jobs.

Also, under the direction of CSU Long Beach professor, Dr. David Whitney, students pursuing their Master’s degrees (Milady Arenales, Jenni Smith and Stephanie Wahl) will soon begin assisting RCOC

with surveys of consumers and family members, as well as RCOC staff, regarding their expectations and perceptions about work for people with developmental disabilities. LeeAnn said this data will be used to help guide the development of community and staff education tools. It will also be shared with service providers, who may garner insights that will help them in creating or modifying their program designs.

## For More Information

Consumers or families interested in learning more about employment opportunities should contact their service coordinator. If you or someone you know is interested in employing an RCOC consumer, contact Janis White at [jwhite@rcocdd.com](mailto:jwhite@rcocdd.com) (714) 796-5256.

## Behavior Management Workshops for Parents

**B**ehavior Management Workshops are being offered in the coming months by Regional Center of Orange County. These activities are offered at no cost to parents. To gain the most value from the workshops, parents are encouraged to attend all sessions in a series.

The five-session workshops (Behavior Management Workshop with Toilet Training) cover essential principles of positive behavior management, with a practical focus on helping parents of children with developmental disabilities change their own behavior and that of their children. The focus of the fifth session is toilet training. The seven-session “Social Skills Training” workshop is focused on helping parents nurture social skills among children. This particular session focuses on children 5-11 years old.

In all of the workshops, parents are actively involved, and invited to discuss the specific behavioral challenges they are confronting. Advance reservations are required and group size is typically limited to 40-45 families. Contact your service coordinator or Thelma Day at (714) 796-5223 for additional information regarding dates, times and locations, and to register.

***NOTE: Child care is not provided, so please do not bring children to the workshops.***

### **Social Skills Training Workshop – Focus on Ages 5 through 11 years (7 sessions)**

Presented in English by Erin Davis, M.A. (Behavioral Support Partnership)

**When:** Thursday evenings– March 6, March, 13, March 20, March 27, April 3, April 10 and May 1

**Time:** 6:30 – 9 p.m.

**Location:** RCOC Irvine Office  
46 Discovery, Suite 200

### **Behavior Management Workshop with Toilet Training (5 sessions)**

Presented in English by Joyce Tu, Ed.D, BCBA

**When:** Tuesday evenings – April 1, April 8, April 15, April 22 and April 29

**Time:** 6:30 – 9 p.m.

**Location:** RCOC Santa Ana Office  
801 Civic Center Drive West

### **Behavior Management Workshop with Toilet Training (5 sessions)**

Presented in Spanish by Ana Lorenz, Ph.D.

**When:** Thursday evenings – May 1, May 8, May 15, May 22 and May 29

**Time:** 6:30 – 9 p.m.

**Location:** RCOC Westminster Office  
13950 Milton Avenue, Suite 200



**John Correa**

*(continued from page 1)*

In fact, it seems that everyone who knows John describes him that way: happy.

“John is incredible,” said Harriet. “He’s the most positive man in the world.”

Now living with a roommate in a two-bedroom apartment in Costa Mesa, John moved to Orange County from the San Fernando Valley in late 2006. Over the years, he had worked at several companies, including Albertson’s, Home Depot and Magic Mountain.

However, with his parents now living in Arizona, he wanted to be nearer to a brother who resides in Huntington Beach. In addition to his Orange County-based brother, John has two other brothers and two sisters. He also has several nephews and nieces he enjoys visiting. It was especially exciting for John when the whole family got together in Arizona a year ago to celebrate his parents’ 50th wedding anniversary.



John and his family gathered in Arizona last year to celebrate his parents’ 50th anniversary. Pictured here are John with all of his brothers and sisters, from left to right, Keith, Mark, Debbie, Matt, Sheila, and John.

St. John the Baptist Catholic Church in Costa Mesa, where he is a Eucharistic minister.



John with his job coach, Andrew Negus from Project Independence.

Eventually, John thinks he may want to transfer to a university where he can work toward becoming a counselor for other students with disabilities on campus. With such a positive outlook on life and a great sense of humor, John has a lot to share with both disabled and non-disabled peers.

“Enjoy life to the fullest. That’s my motto,” John said.

“And don’t give up on yourself,” he continued. “We all have obstacles in life, and we just have to overcome them.”

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***“There are two things that are very important to me – faith and family.”***

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“There are two things that are very important to me — faith and family,” he said. In addition to the outdoor activities he enjoys so much, John likes to read inspirational books. He is also very involved with his church,

John also takes classes at Orange Coast College. In keeping with his liking for the outdoors, he has taken swimming classes as he is working to become certified in ornamental horticulture. He also aims to earn an associate’s degree in that field. His favorite plant is the rose.

“I love the smell and the way it looks,” he said.

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***“Enjoy life to the fullest. That’s my motto.”***

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According to Harriet, “People like John make coming to work so awesome, because I know he’s going to say something that will either make me laugh or make me think.”

## RCOC Consumer Participates in Epilepsy Clinical Trial

The Epilepsy Foundation estimates that there are around three million Americans with epilepsy, sometimes called “seizure disorder.” For most, medications can help control their seizures, while others may get relief with surgery to remove a small section of the brain where their seizures originate. For those with uncontrolled seizures, such as Jad Kamal, a new type of brain implant called the RNS™ System — from a company called NeuroPace — may hold promise.

Now living in his own apartment in Laguna Niguel not far from his parents, Jasmina and Eyad Kamal, 27-year-old Jad had his first seizure when he was six. At the time, the family was living in Saudi Arabia, where his father was working. Seeking diagnosis and effective treatment for Jad, the family consulted with a series of doctors, in several different countries where they traveled for Eyad’s work and to get help for Jad.

“Doctors tried to do the best they could for him,” said Jasmina.

“But the treatment with different medications, while they might have some short-term effect, did not work.”

Jad’s condition continued to worsen, as he experienced more and more severe seizures. He was frequently hospitalized, sometimes several times a year. When the family moved to the U.S., their quest to help Jad live as normally as possible continued. He underwent various treatments, including surgery in 1998. Nothing worked. Worse yet, he required years of intense speech and physical therapy to relearn how to speak and to regain use of his left side — capacities lost from the surgery.

But as severe as the challenges have been, Jad and his family remained committed to working with their doctors to explore options that might lessen the seizures.



Jad Kamal

Last year, when they learned that Jad qualified for the clinical research study for the RNS™ System, they enrolled immediately. The matchbook-size device was placed in his skull in late October by doctors undertaking the study at the Adult Comprehensive Epilepsy Program at USC’s Keck School of Medicine.

The device is like a pacemaker for the brain. With electrodes placed within the brain, it is designed to detect the beginnings of a seizure and then deliver a

small electrical charge that stops it or stops it from spreading to other parts of the brain. Software in the device records the person’s brain activity, and allows it to be programmed wirelessly so the doctor can change the device’s settings in response to the individual’s brain activity.

The study is set-up to ensure the results are valid, so at this point neither the Kamals nor Jad’s doctors know whether his device is turned on or off. But each evening, as data from Jad’s device gets downloaded and transmitted to the doctors at USC, Jad and his family

are hopeful about the potential it offers to help him — and others — live a more normal life.

For information about the RNS System and to learn more about whether you or someone you know might be a candidate for the study, please talk to your or your family member’s neurologist, call 1-866-903-3678 or visit [www.seizurestudy.com](http://www.seizurestudy.com). Or, visit the company’s site at [www.neuropace.com](http://www.neuropace.com) and click on the “clinical trials” tab for contact information and links to institutions that are participating in the study.

To learn more about epilepsy, visit the American Epilepsy Society at [www.aesnet.org](http://www.aesnet.org) or The Epilepsy Foundation at [www.epilepsyfoundation.org](http://www.epilepsyfoundation.org). Another informative resource is The Epilepsy Therapy Project’s site at [www.epilepsy.org](http://www.epilepsy.org).



## From Heartache to Hope

Comfort Connection Family Resource Center will be hosting “From Heartache to Hope,” a presentation by Stacey B. Thacker, a Licensed Marriage and Family Therapist. In this interactive presentation, Stacey will outline the emotional impact of disability on the family. Participants will gain important skills for enhancing their relationships, and strengthening family bonds.

With more than 15 years experience in the area of family support, Stacey specializes in working with families who have children with disabilities and/or special health care needs. She and her husband John have been married 28 years and raised six children, one of whom had multiple disabilities.

**April 10 from 6 to 8:30 p.m.** in Board Room B of RCOC’s Santa Ana office, 801 Civic Center Drive, Suite 100.

Please RSVP to Jacqui Kerze at (714) 796-5299 or **[Jkerze@rcocdd.com](mailto:Jkerze@rcocdd.com)**. Spanish and Vietnamese translation will be available upon advance request.

The event is free to RCOC families and will take place on **Thursday**,

### CEO's Corner

*(continued from page 3)*

“May Revise”). That document will be the starting point for budget negotiations in Sacramento.

Between now and May, we will be making our concerns known to the Administration and to legislators. We hope to influence the discussion by helping them see the impact of their decisions on the day-to-day lives of people with developmental disabilities and their families.

For Lanterman principles to prevail, however, it is essential for people in our community – not just elected officials and state employees in Sacramento – to participate. So, we will also provide timely analyses and advisories to consumers, families and service providers who are interested in having their voices heard. If you are interested in receiving these advisories, please send an email to **[leginfo@rcocdd.com](mailto:leginfo@rcocdd.com)** and type “LIST” in the subject line.

## Emergency Readiness Workshops in May

RCOC is joining with the Area Board, the Dayle McIntosh Center and Orange County Adult Protective Services to host free workshops for consumers and families on Emergency and Disaster Preparedness. The workshops will be led by nationally-recognized trainer Anna Marie Jones. The personal readiness information they cover is applicable to all types of emergencies, from a major earthquake to fires that may require evacuation.

The half-day workshops (one morning session and one afternoon session on each day) are scheduled for Wed., May 14 at a community center within the Leisure World complex in Laguna Woods and Friday, May 16 at the Anaheim Community Center.

For more information and to register, please visit the RCOC Web site (**[www.rcocdd.com](http://www.rcocdd.com)**) and click on RCOC Calendar. You may also contact Kim Pham with Adult Protective Services at (714) 825-3111 or **[disastertraining@ssa.ocgov.com](mailto:disastertraining@ssa.ocgov.com)** with questions and to register.

*NOTE: Separate workshops will take place for RCOC staff, residential and day program providers, and staff from other County agencies. Service providers should call Delia Lona at (714) 796-5244 with questions regarding schedule and fees, and to register.*

# RCOC Thanks the 2007 Spotlight Award Sponsors For Their Generosity

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*Thank You!*

## Regional Center of Orange County Locations

Santa Ana Office	Orange Office	Irvine Office	Westminster Office
801 Civic Center Dr. West 24-hr Phone: (714) 796-5100	3111 N. Tustin, Suite 150 24-hr Phone: (714) 796-3700	46 Discovery, Suite 200 24-hr Phone: (714) 796-4060	13950 Milton Ave., Suite 200 24-hr Phone: (714) 796-2900

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## Dialogue Newsletter

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