



# Dialogue

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## Consumer Spotlight

### John Baker

John Baker lives what many people would call a glamorous life. He counts among his close friends Olympic champions and winners of state, national and international beauty pageants. He has traveled to Europe and Canada, attending the world's premiere figure skating championships. He has used his communications expertise to help pageant contestants prepare for the all-important interview portion of their contests. John also happens to be a Regional Center of Orange County (RCOC) consumer, who has cerebral palsy and uses a wheelchair.



John with Alyssa Campanella, Miss USA 2011, at a press conference in Las Vegas.

Though he needs full-time assistance for all of his daily living needs, and has many difficult medical issues that he deals with on a daily basis, John is very much in charge of his own life. In fact, his RCOC Service Coordinator Mary Ellen Garcia holds him up as a role model for self-determination and self-advocacy. And his mother, Joann Baker, considers herself fortunate to have been blessed with such an amazing son: "He sees something he wants and he just goes for it!" she said.

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*Though he needs full-time assistance, John is very much in charge of his own life.*

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Now 50 years old, John lives with his mother in Yorba Linda, but he was born in Queens, New York and raised on New York's Long Island. The youngest of three children, John was always treated exactly the same as his brother Kevin and sister Jeanne. That included his parents' expectation that he would get a good education. When his father passed away 27 years ago, the family moved to California to be closer to Joann's family and to enable John to go to college at California State University at Fullerton, where



John on the ice with international skating star Kurt Browning in 2001.

he earned his Bachelor's degree and Chapman University, where he received a Master's degree in English and Communications.

Describing John's childhood, Joann recalls a family filled with love. "My husband was a wonderful man and a fantastic father," she said, also noting that when they were children, John's siblings always included him in their play and other activities in the neighborhood.

"I never thought of myself as that different," John said. To this day, he is still close to both his brother, who now lives in St. Louis, and Jeanne who helps him with personal care and other assistance on weekends.

See **John Baker** on page 7

## 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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Hilda Mendez  
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Hilda Sramek

### Upcoming 2013-2014 Board Meetings

November 7 • January 9  
February 6 • March 6

The public is invited to attend RCOC board meetings. They begin at 6 p.m. and are held in the Regional Center Board Room at RCOC's headquarters in the Tustin Centre Tower complex, located at 1525 North Tustin Avenue in Santa Ana.

### RCOC Administration

Larry Landauer, *Executive Director*  
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## Board Update

### Two New Members Join RCOC Board

At the May 6, 2013 meeting, Cristina Alba and Hilda Mendez were elected to the RCOC Board of Directors. These two new volunteers will serve one-year terms through June 30, 2014.

Currently in her second year of law school, Cristina works as a law clerk at an immigration law firm. Though she does not have a family member with developmental disabilities, she developed an appreciation for the abilities of those RCOC serves while growing up with a family friend who has autism. Cristina is also passionate about community service. While a teenager, she volunteered as part of a youth group that cared for children with epilepsy while their parents attended educational meetings. And in college, she tutored a young man who had suffered severe brain trauma.



Cristina Alba



Hilda Mendez

Hilda is the grandmother of a boy who has developmental disabilities. A community relations professional, Hilda works for MOMS Orange County, which provides access to prenatal care, health screenings, health education, and referral services to low income pregnant women. She is also active in numerous Orange County community organizations, including the Hispanic Chamber of Commerce, CalOptima's Community Alliance, Special Olympics, and various faith-based collaboratives. She also has served on the boards of Angels

of Hope and the Survivors of Human Trafficking Foundation, and on State Senator Lou Correa's special needs committee.

At the same meeting during which Cristina and Hilda were elected to the Board, Alan Martin, who served on the Board for a number of years in the past, rejoined the board. The parent of an RCOC consumer, Alan's term runs through July 12, 2016.

### DDS Director to Retire

Terri Delgadillo, who has served as Director of the Department of Developmental Services (DDS) for the past seven years, has announced that she will be retiring from state service due to personal health issues. Her health permitting, Director Delgadillo has agreed to stay on through the end of the year to assist in the transition for her successor, who has not yet been announced.

## Executive Director's Report

# Lanterman Act Supports Self-Determination

By Larry Landauer, Executive Director

In recent months, there has been a lot of talk in the developmental services community about SB 468, which will implement a statewide self-determination program for people with developmental disabilities who receive services through regional centers. SB 468 was passed by both houses of the state legislature and signed by the governor on October 9.

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***No one will be forced into SB 468's self-determination program.***

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Basically, what this new legislation will do is expand the self-determination pilot program that has been underway in California since 1998 and currently serves about 200 consumers in different parts of the state. When it is enacted on January 1, 2014, more consumers will have the option of coordinating their own services and supports, largely independent from the regional center. Eventually, all consumers will be able to participate, though the number of participants will be capped at 2,500 for the first three years.

While this option is attractive to some, it certainly is not for everyone.



In the midst of much concern about how the legislation will affect existing consumer and family services, I want to assure those we serve that no one

will be forced into SB 468's self-determination program. Everyone RCOC serves will continue to receive the services and supports they need.

Importantly, those services will continue to be fully individualized, flexible, and person-centered. Consumers and families will continue to be in the driver's seat. RCOC's service coordinators will continue to be there to provide support and advice, working collaboratively with consumers, families and service providers to meet needs in the best way possible.

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***Everyone RCOC serves will continue to receive the services and supports they need.***

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Does that sound like "self-determination" to you? It does to us, too. In fact, the philosophy of self-determination for people with developmental disabilities has been alive and well at RCOC for nearly two decades. We have, for example, been partnering with consumers and service providers on customized day programs since 1995. And, we have been able to find ways to meet

consumer and family needs to hire their own direct care staff.

These and countless other innovations have taken place in response to changing needs and expectations of those we serve. We didn't need a special piece of legislation to do any of it. Instead, our community has been driven and guided by the Lanterman Act, which clearly defines the regional center's role and places the consumer/family at the center of everything we do.

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***Our community has been driven and guided by the Lanterman Act.***

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It begins and ends with the Individual Program Plan (IPP) process. Based on a consumer's hopes and dreams for the future, as well as an assessment of his or her needs, preferences and life choices, the IPP specifies the person's goals and details the services and supports necessary to make it happen. During this process, RCOC brings significant knowledge and experience to bear in helping families and adults with developmental disabilities envision the possibilities for their lives and chart a course for the future.

Though RCOC is not, technically, a "service provider" our position is that regional center service coordination is the first, and most fundamental, of services envisioned by the Lanterman Act. So, whether or not SB 468 had become law, we will continue to do our best to deliver outstanding service that helps to improve the lives of people with developmental disabilities and their families.

## Consumer Advisory Team Update

### RCOC Performance Contract: It's About Accountability

By Sylvia Delgado, CAT Chair

**D**o you ever wonder how the State of California decides whether regional centers are doing a good job? Well, there are a lot of ways, but one of the most important is the performance contract process. So, I was happy that Jack Stanton, RCOC's Manager, Consumer and Community Resources, was able to do a presentation about it at our August CAT meeting.

Jack talked about how each of California's 21 regional centers get input on what should be in their center's contract. The process includes public meetings, and surveying and talking with consumers, family members, service providers and others in the community. This input is important because the contract expresses each



regional center's key priorities for the year and spells out the specific ways the center plans to achieve its goals.

Each regional center's contract is different, but RCOC's performance contract for 2014 includes six categories. Most of these relate to where

adults and children with developmental disabilities live. This strong focus on residential services reflects our community's desire for all people with developmental disabilities to live as independently as possible. Other important areas that are also being considered relate to employment for people with developmental disabilities, and access to medical and dental services.

As a consumer myself, I think the performance contract is important because it is a good way to measure what the regional center is doing, and how well it's doing it. For example, moving people out of the developmental centers is really important to me, and

### Upcoming CAT Meeting Dates

November 20

December 18

(Holiday Luncheon)

January 15

February 19

CAT meetings are from 10 a.m. to noon at RCOC's Santa Ana office, located at 1525 North Tustin Avenue. Call Kelly Rico at (714) 796-5330 ahead of time to let her know you will be there.

I know it's important to a lot of other consumers as well. We can look at the numbers in the report RCOC prepares each year and see right away how much progress the center is making toward getting those consumers out of the developmental centers and into less-restrictive settings in the community.

If you would like to know more about RCOC's performance contract, ask your service coordinator. He or she will have the answers, or will forward your questions to Jack Stanton.

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## NCI Surveys Focus Attention on Self-Advocacy

One of the many ways RCOC stays on top of the evolving needs of the people we serve is through surveys performed by the National Core Indicators (NCI) project. While RCOC was the first regional center to participate in NCI, now all 21 regional centers receive survey data about their consumers' life experiences and their satisfaction with the services and supports they receive.

Recently, the surveys have brought a lot of attention to the subject of self-advocacy. RCOC Chief Clinical Officer Dr. LeeAnn Christian, who oversees NCI for RCOC, said that is, in part, due to the fact that only seven percent of the consumers interviewed said they had participated in self-advocacy meetings, events or conferences. Meanwhile, the state average was 19 percent.

“Typically, RCOC posts better scores, so we did some follow up surveys to learn more about our adult consumers' views on self-advocacy,” she said. “What



we found is that while our consumers may not be attending as many self-advocacy events as others, many are very comfortable speaking up for themselves at home, at work, in the community and in their IPP meetings.”

RCOC's consumers also have strong views about the purpose of self-advocacy activities. An overwhelming majority, 93%, said it was to make life better for people with disabilities, and 81% said it was to help them grow as a person.

At the same time, the follow up survey did show room for improvement. For example, three quarters of those surveyed said they wanted to attend self-advocacy events. After reviewing the survey results, RCOC and its NCI-

focused advisory group have taken several steps to respond to consumers. For example, RCOC will be helping to sponsor a self-advocacy conference. Taking place in October, the event is being developed by and for adults with developmental disabilities. In addition, more resources about self-advocacy activities throughout Orange County will be added to RCOC's website and shared on the regional center's Facebook page.

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“RCOC believes that consumers have the right to make decisions about all aspects of their lives,” said LeeAnn. “The NCI surveys help us better understand how we can facilitate that process, and expand opportunities for our consumers to develop their self-advocacy skills.”

# SAVE THE DATE!

## Recent Progress in Understanding the Causes and Courses of Autism

With so many researchers investigating so many diverse paths to better understand autism, it can be difficult for anyone to stay up-to-date on the latest scientific findings about the condition. To help both parents and professionals with an interest in autism, Regional Center of Orange County will be hosting an educational seminar entitled *Recent Progress in Understanding the Causes and Course of Autism*.

One of the autism community's leading experts, David G. Amaral, Ph.D., is the featured speaker. Dr. Amaral is a Distinguished Professor of Psychiatry at the University of California, Davis. Since 1998, he has also been the research director at the M.I.N.D. Institute, where he has been engaged in interdisciplinary research into the causes and

treatment of autism and related neurodevelopmental disorders. Dr. Amaral joined the UC Davis faculty in 1991. Since 1995, he has been a professor of psychiatry in the UC Davis School of Medicine, with an appointment to the Center for Neuroscience. Dr. Amaral earned his Bachelor's degree in Psychology from Northwestern University and his Ph.D. in Neurobiology and Psychology from the University of Rochester.

This educational event is presented in collaboration with the Interagency Autism Group, the Orange County Health Care Agency, and the Center for Autism and Neurodevelopmental Disorders of Southern California. It will take place on **Thursday, January 23, 2014 from 4-8 p.m.** at RCOC's Santa Ana headquarters. Space is limited, so pre-registration is required.



David G. Amaral, Ph.D.

The registration cost is \$30.00 and includes a boxed meal. Professionals applying for continuing education hours pay an additional \$30.00 fee. In-home respite may be available for parents, so if you need respite to attend, please contact your service coordinator.

For more information and to register, visit RCOC's website ([www.rcocdd.com](http://www.rcocdd.com)) or call Kelly Rico at (714) 796-5330.



## Behavior Management Workshops to Resume in 2014

Due to the holiday season, there will be no Behavior Management Workshops in November or December. These workshops, which RCOC offers free to parents, will resume after the first of the year. A schedule of upcoming workshops will be printed in the next issue of *Dialogue* and will be posted on RCOC's website ([www.rcocdd.com](http://www.rcocdd.com)). From the home page, click on Family Support, then on Parent Training.

**John Baker** (continued from page 1)

Growing up, John and his mother enjoyed watching figure skating and pageants on television. Following those twin passions, the pair has traveled the world – sometimes as the guests of friends – on tour groups for people who love skating.



John with (L-R) his sister Jeanne Poggensee, Donald Trump, John's brother-in-law John Poggensee and mother Joann Baker at the Miss USA after-party in 2009.

Often, they have encountered difficult circumstances. One example took place 25 years ago, when they traveled to Budapest, Hungary to attend the 1988 World Figure Skating Championships. At the time, the country was still under Communist rule, with little in the way of accessible facilities. In order to board a train to leave the country, John's tour group friends actually had to pick him up out of his chair and pass him through a window to get him to his seat!

As he tells the story, John's great sense of humor about life and his

disability comes through. "What else could I do?" he laughs. "The other option was to be stuck in Communist Budapest."

For the past 15 years, John has maintained a website ([www.jhbonline.net](http://www.jhbonline.net)) that is devoted to his interests. It began as a tribute to his dear friend, figure skating legend Kurt Browning. Over the years, the site has evolved to feature extensive coverage and photos of pageants and other topics that are important to John.

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***"You need to recognize that you're just as good as other people."***

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In addition to attending numerous pageants, John is happy to have been able to contribute to the success of a number of pageant contestants. One of the highlights of his pageant career was as a member of "Team Alyssa" – the group of people who helped Alyssa Campanella, Miss California 2011 prepare for and then go on to win the Miss USA title.

Since both John and his mother are getting a little older, they don't travel as much as they did in the past. However, they still regularly attend pageants and skating events that aren't too far from home.

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***"I never thought of myself as that different."***

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When asked about the advice he would share with other consumers who might be struggling to become



John with his brother Kevin Baker in New York City in 2004.

more independent, or more involved with the community, John reflected on his personal experience.

"You need to create your own self-image," he said. "It has to come from inside you first. You need to recognize that you're just as good as other people. When you see yourself as part of the community in general, then you start to look at yourself differently and see yourself as someone who can contribute to the community."

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***"When you see yourself as someone who is able to contribute, you open doors for yourself."***

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"The most important thing is to find something that you're passionate about, and involve yourself in something that's not always about you," he continued. "When you see yourself as someone who is able to contribute, you open doors for yourself."

# Toy Tips Workshop for Parents

Just in time for the holiday shopping season, RCOC's Comfort Connection Family Resource Center will be hosting a free workshop to help parents select toys for children with special needs. The workshop will cover practical, inexpensive ways to adapt common toys such as books, puzzles and more to suit children of varying abilities. Parents will also receive specific tips on which types of toys might work best for their children.

Presented by Team of Advocates for Special Kids (TASK), the workshop will take place on Thurs., Dec. 5 from 9:30 a.m. to noon at RCOC's Santa Ana headquarters. Reservations are required and Spanish and Vietnamese translation will be available if requested in advance. Unfortunately, child care is not provided, so please do not bring children to the workshop.

For more information and to register, contact Patricia Garcia at (714) 558-5400 or [pgarcia@rcocdd.com](mailto:pgarcia@rcocdd.com).



## Regional Center of Orange County Locations

### Santa Ana Office

1525 N. Tustin Avenue  
24-hr Phone: (714) 796-5100

### Orange Office

3111 N. Tustin, Suite 150  
24-hr Phone: (714) 796-3700

### Westminster Office

5555 Garden Grove Blvd., Suite 100  
24-hr Phone: (714) 796-2900

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