Dialogue

Volume 26 No. 4 Fall 2012

Consumer Spotlight

The Atherton Family

hortly before Sarah Atherton was due to give birth to their second son, she and her husband Jerad couldn't shake the concern that their first child – two-year-old Gavin – still was not speaking even a single word. Otherwise healthy and happy, Gavin continued to babble at an age when toddlers typically have begun building a vocabulary of individual words.

Gavin continued to babble at an age when toddlers typically have begun building a vocabulary.

Fortunately, their Kaiser Permanente pediatrician listened to their concerns and referred the Costa Mesa family to Regional Center of Orange County (RCOC) in November 2011. An assessment took place two weeks later and confirmed that Gavin had a developmental delay with speech. Since 2009, California has required a family's private medical insurance be tapped to pay for early intervention services (Early Start) like speech therapy, so RCOC provided a formal referral back to Kaiser. However, the Athertons' initial claim for services



The Atherton family: Jerad holds Gavin, while Sarah holds his then 8-month-old brother Carson. (right) Gavin enjoys taking a ride on his tricycle.

was denied because Gavin had not yet been through Kaiser's own assessment process.

It was a bit overwhelming for the young family, but Shelly Woodward, their RCOC service coordinator, was there to help.

"Shelly told us what we needed to do to file an appeal," said Sarah, who works part-time for a commercial coffee manufacturer in Santa Ana. Recognizing that days and weeks can be critical in a child's development, Shelly also helped them enroll Gavin in speech therapy, which RCOC funded while they appealed Kaiser's denial.

It wasn't long, however, before another concern surfaced. Just a few weeks later, the speech therapist then working with Gavin told the Athertons that their son should be evaluated for autism. Sarah and Jerad were devastated by the abrupt announcement.

See The Atherton Family on page 6

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.**

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> Upcoming 2013 Board Meetings January 10 • February 7 • March 7 April 4 • May 2 • June 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.

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Legislative Update

State Collaboration on Employment for People with Autism

Some 400 service providers, advocates, self-advocates and family members, along with staff from legislators, school districts and regional centers across California gathered in September for "A New Day 2012," the fourth Conference on Employment and Housing for People with Developmental Disabilities, sponsored by the Association of Regional Center Agencies (ARCA).

The group has recently stepped up its efforts in the area of employment for people with autism.

Each year, the conference provides a forum to share ideas, collaborate on best practices, and discuss priorities for action. This year, Regional Center of Orange County's Chief Operating Officer Janis White, Ed.D. participated in an autism-focused panel moderated by Lou Vismara, M.D., Policy Consultant for Senator Darrell Steinberg who leads the Senate Select Committee on Autism & Related Disorders.

The Select Committee, which includes Orange County's own State Senator Lou Correa, was formed in 2009 in response to the public health crisis of autism and has been working to foster statewide collaboration to better assist people with autism and their families. Among its accomplishments are several pieces of legislation, including SB 946 which now requires insurance plans to cover behavioral health treatments like ABA for people with autism. It has also been responsible for legislation to ensure police officers are trained to deal effectively with people who have autism (authored by Senator Correa), expand housing, and better train teachers educating students with autism.

The group has recently stepped up its efforts in the area of employment for people with autism, now considered one of the community's most pressing issues. Members of the panel led by Dr. Vismara shared some sobering statistics about what they called the "tsunami" of young adults with autism who will soon reach adulthood. Nationally, autism spectrum disorders (ASD) now affect one in 88 children. During the past 12 years, California school districts have experienced a more than one thousand percent increase in K-12 students with ASD. In the next decade, regional centers will see more than a 300 percent increase in the number of adults with autism.

While panel members cited numerous employment challenges facing those with autism, they also pointed to factors that can smooth the transition from school to the workplace. These include interagency collaboration to ensure that supports for work are in place, and that there is an emphasis on flexible, individualized services and supports. The panel also emphasized the critical role that parental and family supports play in helping an adult with autism find and keep a job.

Executive Director's Report

Reorganization Saves Money, Shifts People to Where They're Needed Most

By Larry Landauer, Executive Director

Regional Center of Orange County's (RCOC) mission as a nonprofit organization is, first and foremost, to serve the needs of the nearly 17,000 people with developmental disabilities and their families in Orange County. However, we are also a multimillion dollar enterprise that directly employs hundreds of staff. While we wouldn't qualify for the Fortune 500 if we were a profit-making operation, we're a lot bigger than a typical small business.

The sheer scale of our regional center's operation imposes a high level of responsibility for stewardship – a combination of sensitivity and responsiveness to the needs of the people we serve, with solid business savvy that gets the greatest efficiencies and best return on dollars we spend. Of course, California's ongoing fiscal crisis has highlighted the need for all state-funded entities to demonstrate stewardship, but careful and rigorous review is not new to RCOC. In fact, it is a continuous process.

Most recently, our staff analysis pointed to an opportunity to achieve more savings in staff salaries as we continue to transition to a more paperless office. So, in July and August, we instituted a reorganization. We eliminated 32 hourly positions and replaced them with a smaller number of full-time people who are better deployed to support RCOC's core function of delivering top-quality service



coordination to the individuals and families we serve.

Altogether, the changes we made will save more than \$482,000 a year. This is

on top of the \$816,000 annually we saved last year when we consolidated our South area operations into our headquarters office, and the \$350,000 per year we saved the year before when we performed another reorganization that eliminated several management positions. However, it is important to remember that these changes have never just been about cutting costs.

While the overall number of staff is smaller than before, we actually hired more service coordinators as part of this reorganization. We also strengthened staff for the Comfort Connection Family Resource Center. Both of these moves reflect the focus and value that RCOC places on serving families better.

As some people who have been RCOC consumers for a long time know, I began my career at RCOC as a service coordinator. I believed then, and still believe, that there is no more important role at RCOC than the service coordinator. They are most closely involved with families' day-to-day lives and better positioned than any of us to see both evolving needs and the impact of the many program changes and reforms that have been instituted in recent years by the Legislature.

Among the changes that we know has been a challenge for some RCOC families is the new requirement that SB 946 imposed, requiring private health insurance plans to cover behavioral health services like Applied Behavior Analysis (ABA) for people with autism. The new law is expected to save \$80 million a year – savings that might otherwise have come by cutting the budget for these services. However, the change does mean families must now become more familiar with the requirements of their insurance plans.

Altogether, the changes we made will save more than \$482,000 a year.

The good news is that our community has some experience with these situations. A few years ago, the Legislature passed a similar law that required families of children in Early Start to have services paid for by private insurance. While that presented challenges, RCOC's service coordinators gained valuable expertise in helping families deal with insurance companies. Now, as a result of our recent reorganization, I'm confident that RCOC's staff is better positioned than ever to help families meet SB 946's requirements.

DIALOGUE

Consumer Advisory Team Update

Consumers Helped Remove "R-word" from California Laws

By Sylvia Delgado, CAT Chair

hree cheers for the many consumers and others who helped to get AB 2370 and SB

1381 passed by the California Legislature and signed into law by the Governor!

These bills are now California law, and they require the "R-word" to be removed from our state's laws and regulations. Now, laws that had used the words "mental retardation" will instead use "intellectual disability" to describe the condition. AB 2370 was authored by our own Orange County Assemblyman Allan Mansoor and SB 1381 was by Senator Fran Pavley.

I wanted to talk about these new laws, because I think they are going to be really important to our community. At our last CAT meeting, when we talked about how the bills were passed and became law, everyone was very happy and there was a big round of applause!

We were all proud that we had spoken out in support



of the laws and had helped get them passed. We showed that we can be our own best advocates.

Many of us have also personally had

a lot of unpleasant experiences with the "R-word" and we'll be thrilled when it becomes unacceptable for people to use it. That negative word has been used to define us – as if consumers are nothing more than our disabilities. That is very hurtful, and it is wrong.

Many of us have also experienced discrimination because some people assume that having "mental retardation" means a person can't do anything. But countless consumers at RCOC and all over the world have shown that having an intellectual disability – mild, moderate or severe – doesn't mean you can't do things. In fact, almost every issue of this *Dialogue* newsletter shines a spotlight on individuals

Upcoming CAT Meeting Dates

November 21 December 19 (Holiday Luncheon) January 16 February 20

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.

with many different types of developmental disabilities who are living good lives and making wonderful contributions to our community.

One of the things I've learned over the years is that everybody has challenges, even if they don't have a disability. But those of us who do have disabilities don't need the additional handicap of a negative word or label holding us back, so passing these laws is a really good step forward.

Third Annual Summer Blast was a Hit!

ore than 600 consumers, along with their friends and family members, got together at KiwanisLand in Garden Grove for the third annual Summer Blast! The day of fun, food, music and dancing took place on Sat., July 28 from 2-7 p.m. It was organized by the non-profit Integrity House, with support from Regional Center of Orange County, and ticket sales covered all event costs.



Behavior Management Workshops to Resume in 2013

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). From the home page, click on Family Resources, then on Parent Training.

The Atherton Family (continued from page 1)

"We didn't know what to do, and were really distressed by the way it was handled," said Sarah. "But we went back to Shelly and she was really encouraging."

A full developmental assessment by Kaiser placed Gavin in a "gray area" that qualified him for speech therapy with Kaiser, but also indicated he might benefit from the social interaction that a quality preschool can provide.

Since 2009, California has required a family's private medical insurance be tapped to pay for early intervention services.

With RCOC's assistance, Gavin began getting help from Speech Pathology Associates (SPA, www. speechpathologyassociates.com), a service provider covered by their



Gavin and Sarah on his first day at pre-school.



Kaiser health plan. The Athertons also enrolled him part-time at Orange Tree Christian Preschool (www. orangetreechristianpreschool. com), a small preschool in Newport Beach that focuses on knowing each child and working with them as individuals to foster learning and social development. The two programs, together with his parents' complete support and engagement, have helped Gavin make excellent progress in just a few months' time.

With the help and encouragement of SPA's Barbara Moore and the staff at Orange Tree, "Gavin went from no words at two years, two months to three- and four-word sentences, laughing with his brother, and making eye contact," said Sarah. She said that she and Jerad have learned almost as much as Gavin, in terms of how to work with him to support the therapy he's receiving, as well as games to help engage him socially.

(left) Gavin enjoying reading with his grandmother, Sherry Luckett. (below) Gavin and Jerad like taking walks together.



It took a lot to spur Gavin's progress at first, but these parents appreciate the individual attention that helped to identify how their son learns best. When he first started going to SPA, Sarah would stay with him, to be a reassuring presence. Now, she said, he is so well-adjusted that he just waves 'bye mom' when she leaves because the therapy is play and it's fun for him.

"The services he has received have opened up his world," she said, noting that even people who don't know about the therapy he has received have commented on how Gavin has changed and blossomed. "He's excited about things. He's excited to see his grandparents and friends. He's excited and wants to give his teachers a hug."

Music is an important part of the family's life, since Jerad is a musician. Gavin's favorite is the popular Veggie Tales series and Sarah said that now he fully engages with the music and motions, something he didn't do even a couple of months ago.

Gavin will be turning three years old soon, and is scheduled for a full needs assessment by the school district. Like many parents, the Athertons find it difficult to watch assessments. They know the professionals are only seeking to uncover any problems that might exist so the child can get the help he needs, but as parents they're pulling for their child to succeed. They don't want him to need services, but they're not afraid to get help if it's warranted.

It's their positive attitude, along with the collaborative approach and complete dedication of both parents to their son's well-being that Shelly thinks will serve the Athertons and their children well, regardless of whether Gavin needs ongoing services.

The services he has received have opened up his world.

"With Early Start, it's a short window to make things happen," said Shelly. "Other parents can learn from their quick follow-through with referrals and appointments, and how they are carrying over into the home what they learn in therapy."

SB 946 and You: Insurance Tips for Parents

f your child needs behavioral health treatment, such as Applied Behavior Analysis (ABA), for autism, you may already be familiar with the new law SB 946 that recently went into effect. SB 946 requires private health plans to cover these treatments for those with autism, but it has brought challenges for some RCOC families, especially young families not accustomed to dealing with insurance companies.

Here are some tips that can help parents deal more effectively with insurance companies and ensure a smooth transition from regional center funding to insurance company funding of behavioral services.

- Autism Diagnosis is Required. The law requires health plans to cover these therapies because they are considered medicallynecessary, so a child must have a formal diagnosis of autism to be covered.
- In-Network vs. Out-of-Network. As with other medical care, it may require more paperwork and/or cost a lot more money to get services from a provider that is not in your health plan's network, so be sure to ask. If your current service provider isn't in your plan's network, your RCOC service coordinator can help identify alternatives.
- **Co-Pays and Deductibles.** Most health plans carry co-pays and deductibles. A co-pay is a fixed amount that the family pays at each visit, with the insurance company paying the balance. Usually, co-pays will be much

lower when a service provider is "in-network." The deductible is the amount a family must pay out-of-pocket before the insurance company covers medical expenses. Some plans have both individual and family deductibles and there may be separate deductibles for different types of medical services.

- Insurance Company Denials. If you receive a letter from your insurance company saying they won't cover behavioral services, it is important to appeal the denial right away and to contact your RCOC service coordinator. Often, a denial is reversed when proper paperwork is submitted with an appeal and your service coordinator can help by providing you with copies of the formal assessments that may be required.
- Open Enrollment. Most companies allow employees to make changes to their health insurance coverage once a year, during what's called "open enrollment." Often this takes place at year-end. With the changes brought by SB 946, it would be wise to reevaluate your plan so you can be sure it's still the best choice for your family's needs.

If you are having difficulty accessing behavioral services that are included in your child's Individual Program Plan (IPP), due to problems with your insurance company or any other reason, do not hesitate to contact your RCOC service coordinator for help.

Santa Ana, CA 92702-2010 P.O. Box 22010 Regional Center of Orange County

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The 2013 Spotlight Awards will include eleven categories: Community Partner, Self-Advocate (formerly Consumer), Elected Official, Employer, Direct Support Professional (formerly Frontline), Lifetime Achievement, Service

individuals and organizations

that excel in their service to people

with developmental disabilities

in Orange County. If you know a

person, group or organization that

deserves this special recognition,

now is the time to nominate them

for a Spotlight Award.

Servant Leadership. Descriptions of the award categories, along with nomination forms, can be found online at http://www.surveymonkey.com/s/ spotlightawards2013. They can also be downloaded from RCOC's website (www.rcocdd.com) and then submitted by mail, fax or email. To have nomination forms mailed to you, please call the RCOC Executive Office at (714) 796-5206. Consumers who would like help submitting

Regional Center of Orange County Locations

Professional Achievement), RCOC

Achievement, and E. Kurt Yeager

a nomination should contact their RCOC service coordinator.

is Monday, February 4, 2013. Award winners will be announced in mid-February and will receive their awards at the 2013 Spotlight Awards Ceremony and Gala at the Crowne Plaza Hotel in Anaheim on Friday, March 22.

More details, including ticket information, about the Spotlight Awards Ceremony and Gala is available at the RCOC website and will appear in the next issue of *Dialogue*.

Suite 100

The deadline to submit nominations

Nominations Now Being Accepted for Spotlight Awards ince 1997, the RCOC Spotlight Provider, Parent/Family Member, Awards have honored Healthcare Professional (formerly