



Dialogue

Volume 21 No. 2
Spring 2007

Consumer Spotlight

Rod Wilson

Many people who knew 46-year-old Rod Wilson a decade ago probably would not recognize him if they met him today. Not because his appearance has changed all that much. Rather, it is because Rod – today pleasant and fun to be with – once engaged in aggressive behaviors so serious that they eventually led to his placement in Fairview Developmental Center for 14½ years.

Now, on any given day, one might expect to see Rod out in the community working at his paper recycling job, having lunch with his parents at one of his favorite fast food restaurants, or playing a round of golf at the public course near his home.

His large and loving family has been with him every step of the way.

Perhaps most remarkable, “People feel safe with Rod,” said Christopher Potter, administrator of Anacapa House, the Independent Options home where Rod has lived for the past two and a half years. “He has a commanding presence, but one is struck by his gentleness.”

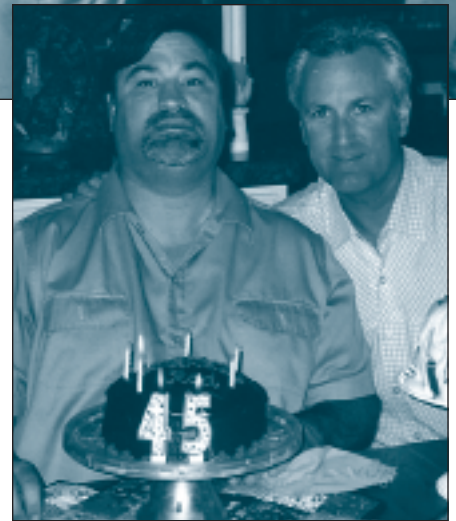


Rod Wilson (center) with mother Jeanette Wilson (left) and father Guy Wilson (right)

Rod’s journey to the happy life he lives in the community has been long and often difficult, but his large and loving family has been with him every step of the way.

One of nine children born to Guy and Jeanette Wilson, Rod has mild mental retardation and was four years old before he was diagnosed with autism. It was 1964 and most pediatricians were not familiar with autism. There were no public school programs, no behavior management services, no training for parents, and no medications to help children with autism.

In the Wilson household, though, there was no shortage of love.



Rod (left) and brother Robert (right)

Rod’s brothers and sisters were as dedicated as his parents were to working with him and doing the best they could with him. He and his brother Robert, who is a year older, were especially close. However, as Rod became a teenager, new problems began to emerge. His size and aggressive behaviors put him, his siblings and others at risk. Though the

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Dialogue

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Dialogue can also be read online at RCOC's Web site: www.rcocdd.com.

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2007 Board Meetings

July 12 • September 6 • November 1
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.

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RCOC Legislative Update

Proposed Legislation Will Affect RCOC Families

By Wendel Starkey,
RCOC Board of Directors



The current legislative session offers at least three important reasons for RCOC consumers, family members, and service providers to be active and informed participants in California's legislative process.

I am referring, specifically, to three bills that are now making their way through the legislative process: AB 1128, AB 1192 and AB 1427.

AB 1128 has the potential to bring about major and far-reaching changes in the developmental services system.

At first glance, that may look like an alphabet soup! But it is not as complicated as it might look. And, to help make it easier, RCOC has also included brief information about the bills in a story that begins on Page 6 of this newsletter (*State Legislation: Bills to Watch*).

While there are many proposed laws dealing with developmental services and issues, I wanted to call your attention to these because I think they have the greatest potential to affect

the community care system upon which we all depend. Some could make things much better. Some could result in significant setbacks for our community. Others simply bear very close scrutiny at this point.

For example, **AB 1128** has the potential to bring about major and far-reaching changes in the

developmental services system, so everyone who receives or delivers services in the community has a great deal at stake in its outcome. Another bill, **AB 1192**, would create a valuable new tool to help screen-out prospective workers who might abuse people with developmental disabilities.

I encourage you to learn more about all three of the bills discussed in this issue, and make your views known to our State Legislators and the Governor. In California, we have the Lanterman Act promise of services and supports because a dedicated group of citizens and elected leaders partnered together decades ago to make it happen. As beneficiaries of that promise, we owe it to our predecessors as well as those who come after us to do our part to keep the regional center system strong and effective.



State Budget Contains Good and Bad News for Consumers

By Bill Bowman, Chief Executive Officer

January is the time of year that signifies the “opening bid” on budget negotiations. That is when the Governor publishes his initial budget proposal for the new fiscal year that will begin July 1. However, it is not until May, when the Administration issues a revised budget proposal – based on more current economic data and information — that budget discussions begin in earnest.

Once a budget agreement is reached, we will be able to report with certainty on our situation for the 2007-08 fiscal year. In the meantime, I would like to share RCOC's perspective on what we have seen so far. It appears there is some fairly good news, but we also have some concerns.

Regional Center Budgets Hold Steady

The current proposal by the Administration does not call for any new cuts to community services. And, if the Legislature agrees, regional centers will receive



additional funds to cover the increasing number of Californians with developmental disabilities who receive services in the community (that is, the increased “caseload”). Additionally, regional centers are expected to receive funds to cover our current year deficit that resulted, in part, from mid-year rate adjustments for some service providers.

It appears there is some fairly good news, but we also have some concerns.

This is very positive, given the state's continuing deficit and many pressing needs. It is important to note, though, that while the dollar amount of the budget is expected to increase, our buying power will not go up. In fact, the regional centers' buying power is likely to decrease somewhat. That is because, as every family on a budget knows, costs — for rent, insurance, fuel, and so on — are always increasing. The state budget does not, however, provide any cost-of-living increase to ensure that our buying power keeps up with the higher costs of doing business.

The current proposal by the Administration does not call for any new cuts to community services.

That will be a challenge, but one that we fully intend to meet in order to ensure consumer and family needs are met. Our major disappointment,

though, is that we see great opportunities for innovation in Orange County, and our flexibility to pursue such creative new approaches is limited in the current budget environment.

State Supplemental Payments (SSP) May Fall Behind

For the many adults with developmental disabilities who rely on federal Supplemental Security Income (SSI) and State Supplemental Payments (SSP) grants to pay for the necessities of life, regular cost-of-living increases in both programs are essential to maintaining their independence. This is particularly true in high-cost areas like Orange County.

For Californians with developmental disabilities, every dollar counts.

While it appears the scheduled federal SSI increase will be unaffected, we were very disappointed to see the Governor propose suspending the SSP cost-of-living increase that would otherwise take effect Jan. 1, 2008.

For Californians with developmental disabilities — especially those who live independently and those who desire greater independence — every dollar counts. We are encouraging the Governor and Legislature to come to a timely agreement that restores the SSP cost-of-living increase, and also keeps the regional center funding intact.

Consumer Advisory Team Update

Spring Meetings Focus on Community Involvement

By Jay Connor, CAT Chairman

During the Spring, the Consumer Advisory Team (CAT) meetings included a lot of opportunities for our members to learn more about how our government works. Guest speakers also gave presentations on ways that consumers can be more involved and active in the community.

In March, we were honored to host Eileen DePuy, who attended the CAT meeting on behalf of Orange County Board of Supervisors Chairman Chris Norby. Ms. DePuy spoke to us about what the Board of Supervisors does. She also talked about some of Supervisor Norby's activities on behalf of people with disabilities.



At the same meeting, Candace Smith from Adult Protective Services talked with us about the work done by APS to help protect people with disabilities and seniors from injury, neglect or abuse.

We also enjoyed a presentation on self-advocacy by Liz Lyons of People First® of California. Maybe you have heard of the group. It is an organization of people with developmental disabilities who help others learn to be self-advocates. You can learn more about People First® of California and their statewide convention, scheduled for June 8-10 in Sacramento, by visiting their Web site at www.peoplefirstca.org.

Among the highlights of our April meeting was a presentation about a new state law that is meant to help site-based day programs transition into community-based programs. The presentation was given by Scarlett von Thenen, a former RCOC service coordinator who now works for our local Area Board XI.

Upcoming CAT Meeting Dates

June 20

July 18

August 15

September 19

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) 796-5263 ahead of time to let her know you will be there.

The list of speakers we have scheduled for the summer will be just as interesting as these were. We will also have many fun activities, so plan to join us!

The Consumer Advisory Team (CAT) is a group of consumers that meets once a month. The group discusses issues that are important to RCOC consumers, like advocacy and independence. The CAT chairman advises the RCOC board of directors about the group's concerns.

Consumer Advocate Team

Do you know what to do if someone hurts you, or if you are in trouble? Safety Stu has a new program called the **Get Safe Consumer Advocate Team** that is here to help. Here are answers to some questions you might have about the Team.

WHEN CAN THE TEAM HELP ME?

If someone has hurt you, or you think they might hurt you, the Team can help. We can also help if you have done something wrong that

breaks the law, or if you are accused of doing something wrong that breaks the law.

HOW DO I GET THE TEAM TO HELP ME?

If you think you need help or may be in trouble with the law, call your service coordinator right away! Even if you are not sure that what happened to you is a big deal or if it is against the law, go ahead and call your service coordinator. Your service coordinator will know if the Team can help you.

WHAT WILL THE TEAM DO TO HELP ME?

The first thing the Team manager will do is meet with

you to find out what happened and how we can help.

The situation could be very complicated, so the Team manager will help you to understand what is going on. The manager will also get you any other help that you need. A big part of the manager's job is to make sure that your rights are protected, so he or she will also go with you to meetings and to court.

Sometimes, life can be hard and painful. It is a lot easier, though, when someone is there to help. So remember, always call your service coordinator if you think you might need help from the Get Safe Consumer Advocate Team.

*Until next time
Safety Friends,
Safety Stu, the GET SAFE™
team, and Beary Safe*



State Legislation: Bills to Watch

Voting in elections is just one of the ways to help shape our state and communities.

By becoming informed and taking a stand on proposed new laws, all of us can play a part in helping to improve the lives of Californians with developmental disabilities and their families.

Here are three bills that RCOC considers noteworthy:

AB 1128 Lanterman Act Blue Ribbon Commission

“AB 1128 may be the most significant bill of the season for people with developmental disabilities,” said Wendel Starkey, chairman of the RCOC Board of Directors’ Legislative Committee. AB 1128 would create a Blue Ribbon Commission to review and make recommendations to amend the Lanterman Act.



“Nothing is more fundamental to the well-being of people with developmental disabilities than the Lanterman Act promise of services and supports in the community,” he continued. “We need to be vigilant to ensure that any Commission formed would work to advance the progress we have made – especially in terms of community inclusion — and would not roll back any of the hard-won gains we have made.”

AB 1192 Developmental Services Consumer Abuse Registry

AB 1192 would create a Developmental Services Consumer Abuse Registry, similar to a system that is already in place for child care workers. The bill is important because it will create another tool, in addition to the current routine background checks, to help screen-out prospective workers who might abuse people with developmental disabilities.

Access to the registry would be available not just to service providers and regional centers, but also to

For More Information

If you are interested in learning more about these or any other bills proposed in the state legislature, visit the California State Legislature’s Web site at www.legislature.ca.gov or the non-partisan California Legislative Counsel’s site at www.leginfo.ca.gov. You can search for individual bills and find out where they stand in the legislative process.

To learn more about the legislative process in California, including the steps involved for a bill to become law, visit www.capitolmuseum.ca.gov and click on the “Citizens’ Guide” link.

consumers, families and others who employ workers to deliver services to people with developmental disabilities.

AB 1427 Workforce Training Pilot Program

AB 1427 would enlist six pre-determined regional centers to participate in a pilot workforce training project involving direct care staff. The bill is controversial. That is because many service providers, consumers and families view any type of centralized or state-imposed training effort as having the potential to limit their choices in the selection of direct care workers.

Locating Your Elected Representatives

There are two ways that you can find out which California Assembly Member and Senator represent you.

On the Internet, go to www.legislature.ca.gov and look for the “Find My District” section on the home page. By entering your address, you can find out the name and contact information for your state senator and assembly member.

You can call the Orange County Registrar of Voters at (714) 567-7586 to find out which elected officials represent you. The Registrar’s Web site at www.ocvote.org offers information in English, Spanish, Korean and Chinese.

Contacting Elected Officials

The experts say that the very best way to let your elected officials know your views about a particular piece of legislation is to write a letter and mail it either to their local district office or their office in Sacramento.

Keep the letter short – no more than one page – and only talk about one bill per letter. Focus on why you support or oppose the bill, and always maintain a respectful tone. It is helpful if you reference the bill number you are addressing at the top of the page.

If you do not have the time to write a letter, you can call the elected



official's office and leave your message with the person who answers the phone. E-mail is not recommended for commenting on legislation.

South Area Office Moves to Irvine

Regional Center of Orange County's South County office, previously located in San Juan Capistrano, has moved to Irvine. The new address is:

**46 Discovery, Suite 200
Irvine, California 92618**

The office's phone number has not changed. The 24-hour telephone number is still **(714) 796-4060**.



When an Injury Does Not Indicate Abuse

There is no question that abusing a child or adult with a developmental disability is always wrong. It is important that all in our community are vigilant to the signs and symptoms of abuse, and promptly report known or suspected abuse.

The situation is not so clear, however, when a family member has a condition or behaviors that can lead to unintentional injuries or bruising. To a neighbor or other person unfamiliar with the situation, the results of an innocent accident can look like child abuse. It can become even more complicated when Child Protective Services or Adult Protective Services is called in to investigate.

“There have been situations when law enforcement has shown up at a family's home in the middle of the night, and threatened to remove a child from the home,” said Larry Landauer, RCOC's Consumer/Community Resources Director. “While we all support efforts to protect children from true abuse, it is very traumatic for a loving parent to be accused wrongly of such a terrible thing.”

If your family finds itself caught up in this type of situation, help is available from RCOC. Our staff are trained to assist in making the crucial distinction between actual abuse and unfortunate, but understandable, injury.



Now is the Time to Make Plans for Summer Camp

Camp can offer excellent opportunities for a child or adult with developmental disabilities to cultivate important social skills. It can also foster independence and, as many who have been to camp know, it can be lots of fun! Just as important, camp can be the source of many wonderful memories and a place for developing friendships that may last a lifetime.

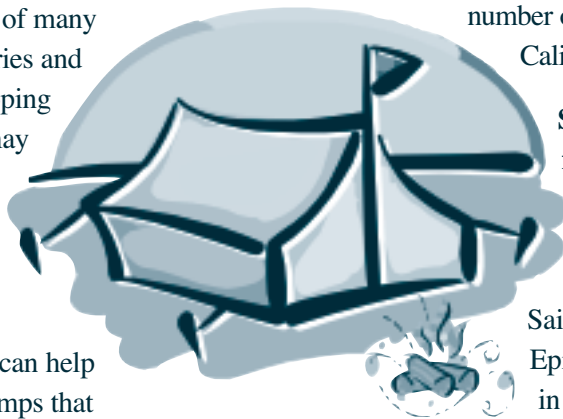
Comfort Connection Family Resource Center (CCFRC) can help families locate camps that are geared toward those with special needs or that can make accommodations to serve those with disabilities. We can also help if you are having difficulty planning summer recreation activities for your child, teen or adult family member.

Below are snapshots of just a few summer camp resources that may be useful to parents:

One excellent resource is the **American Camping Association**. This nonprofit camp accrediting association offers a great deal of helpful information to parents interested in enrolling a child in camp. The organization's CampParents bilingual (English and Spanish) Web site includes a

camp locator, camp planner, and lots of expert advice.

The City of Irvine's Disability Services unit, part of the City's Community Services Department, offers a number of camps and other summer recreation opportunities for children and adults with disabilities. Under "Recreation Programs," the Disability Services Web site features a downloadable flyer of upcoming events and an extensive list of recreation opportunities, including a number of Southern California camps.



Special Camp for Special Kids is a day camp facilitated at Saint Margaret's Episcopal School in San Juan

Capistrano. It offers

week-long sessions, pairing campers with volunteer counselors in a 1:1 ratio for a variety of recreational activities and day trips.

Finally, the **Girl Scout Council of Orange County** encourages placing girls with disabilities into typical troops. In addition, the camps can accommodate a wide variety of special needs.

While RCOC does not fund recreation activities, it may be possible for eligible families to utilize parent vendored respite to cover the cost of camp. So, if you are considering camp, be sure to check with your service coordinator to see if this might be an option for you.

For More Information

To pick up a copy of Comfort Connection Family Resource Center's four-page listing of **Camp Resources** or an updated **RCOC Recreation Resource Guide**, stop by the Center at 801 Civic Center Drive West in Santa Ana. We are open from 9 a.m. to 4 p.m. Monday through Friday.

To learn more about the programs mentioned in this story, you can contact:

American Camping Association
Southern California/Hawaii
www.acasocal.org

Or go directly to:
www.campparents.org

City of Irvine
Community Services Dept.
Disability Services
www.irvinedisabilityservices.org

Special Camp for Special Kids
(949) 661-0108
www.specialcamp.org

Girl Scout Council
of Orange County
(714) 979-7900 – general line
(714) 979-3339 – Spanish
(714) 979-3033 – Vietnamese
www.gscoc.org

Fun In The Sun . . . But Play It Safe

Skin cancer is the most common type of cancer. More than 800,000 people are affected by it each year. Fortunately, when found early, most skin cancers can be cured. By far, the sun causes most skin cancers. And with the weather heating up as we head into the summer months, many of you will be spending time in the beautiful

California sunshine. Take these precautions to protect your skin from irreversible damage:

1. **Don't get too much sun.**
Especially try to avoid the sun's strongest rays from 10 a.m. to 3 p.m.
2. **Cover up.** Wear wide-brimmed hats, and light-colored clothing.
3. **Use sunscreen with a Sun Protection Factor of at least 15** on any areas of skin exposed to the sun. Apply it at least 15 to 30 minutes before going

into the sun. Reapply every two hours, and after swimming or sweating.

4. **Make sure children are protected while out in the sun.**
5. **Beware of cloudy days; you can still get burned.**
6. **The sun's rays can reach through three feet of water,** so even though you feel cool in the water, use caution so you don't burn.
7. **Don't use sunlamps or tanning parlors.** They can be just as harmful as the sun.



Self Care of Sunburns:

- Watch for signs of possible dehydration or heat stroke.
- Drink plenty of fluids.
- Cool baths or cool compresses can help reduce the pain of a sunburn.
- Apply lotion to help relieve itching.

When to Call the Doctor:

- If you or your child develops many blisters.
- A fever greater than 102° develops.
- Dizziness or visual problems occur after you are no longer exposed to sun.

Who is Likely to Get Skin Cancer?

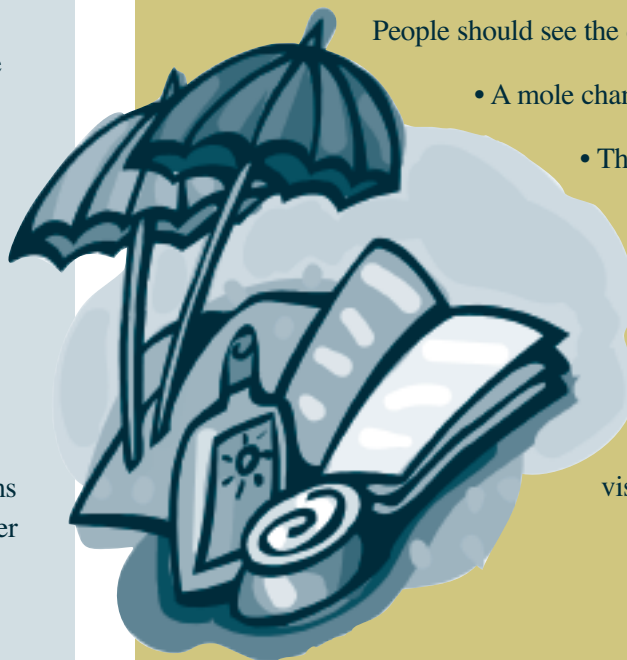
People who sunburn easily, have fair skin, or have red or blonde hair, get skin cancer most often. It is less common in people with black or deep brown skin. However, anyone who spends a lot of time in the sun can get skin cancer. Ninety percent of skin cancers occur on parts of the body not usually covered with clothing—the hands, forearms, and ears. People of all ages should protect themselves from the sun.

When should you be concerned?

People should see the doctor if:

- A mole changes size, shape, or color.
- There is an unusual growth on the skin.
- The skin changes color in certain spots.

These are changes that may be due to the sun, or signs of skin cancer, and would be worth a visit to the doctor.



Rod Wilson (continued from page 1)

Wilsons were fiercely protective of their son, there were few options in the 1970s. They made the difficult decision to place Rod in a residential facility.

The family missed him terribly. All hoped that professionals might be able to help him, but a succession of eight different facilities failed. Over time, Rod got worse, and in 1990 he was placed in the Fairview Developmental Center.

“When he got to Fairview, we didn’t think they could help,” said Jeanette. “He had been on so many medications, but they did a great job with him.”



Rod enjoys riding his bike on Sundays.

The Wilsons are grateful to the Fairview employees who dedicated themselves to working with Rod. Two of the staff have maintained the relationship, taking Rod to the Orange County Fair every year.

“He wouldn’t go on any rides at first,” said Jeanette. “Now, he tries one new ride each year.”

In light of Rod’s past and his long-time aversion to change, there

were concerns about how he would respond to the freedom to make the choices that are part of life in the community. But when the time came, he was ready.

“He immediately took to the choices offered to him in the less restrictive

environment,” said Christopher, noting that Rod particularly liked the fact that – as the home’s first resident – he was able to choose his own room. “I think he had the sense that he had a lot of control.”

“Rod continually tells us that he’s happy and content there,” said Jeanette. “He would never say that before [about the places he lived previously]. When we go out or he comes to visit, he is always eager to get back to Anacapa, to his own home.”

The home is ideal for someone with Rod’s meticulous nature. Even as a child, he liked to help out around the house. With a bedroom and bathroom of his own, he takes great pride in keeping his environment neat and clean. He enjoys having visitors, and is the perfect host, inviting guests to sit in his favorite chair and taking them on tours of the home and to see his room.

Rod’s parents credit Gloria Wildman, an RCOC Developmental Center Coordinator, with persuading them to give community life a chance.



Rod (left) at work at his recycling job with Ryan Danielson, Behavioral Resources Group Program Manager.

“We were very reluctant and apprehensive. It took some time to convince us, but Gloria was very persistent,” said Guy. “Now, we’re very happy that we did.”

Gloria emphasized that the timeframe for transitioning people from Fairview into the community is based entirely on the individual consumer’s needs. It is a careful, deliberate process.

“Rod attended a day program in the community for about a year before moving out of Fairview,” she said, noting that the Behavior Resources Group pre-vocational skills program he attends was selected because it fits well with Rod’s preference for being active and being outdoors.

By all accounts, Rod Wilson’s is a success story. He is thriving and has improved even more since moving into the community.

Christopher contends that Rod, himself, deserves the most credit for his success in the community. “He has matured and has learned some very important coping skills. He is a gentle man.”

Free Workshops for RCOC Parents

Free Behavior Management Workshops are being offered throughout the Spring and Summer by Regional Center of Orange County. Four- and five- session workshops cover basic 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. When a fifth session is offered, the focus of the fifth session is toilet training. In addition, RCOC offers a seven-session workshop that is focused on helping parents to nurture social skills among children aged 13-18.

In all of the workshops, parents are actively involved, and invited to discuss the specific behavioral challenges they are confronting. Parents are encouraged to attend all sessions in a workshop series. Advance reservations are required and group size is typically limited to 40-45 families. Contact 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.

Families Needed For Operation Housecall

You don't have to be a professional educator or a doctor to help teach tomorrow's physicians about what it is like to live with a developmental disability, or to have a child with special needs. All you have to do is participate in Operation Housecall.

Operation Housecall is a collaborative effort between Area Board XI and the University of California, Irvine (UCI) College of Medicine. Initiated in 2001, it is aimed at improving medical school education by increasing students' understanding about the lives and medical needs of children and adults with developmental disabilities. The program enlists both adults with developmental disabilities who live independently and parents of children

with special needs to educate first year medical students about the unique challenges they face in accessing medical care.

"No teaching experience is necessary," said Scarlett von Thenen who is in charge of Operation

Housecall for Area Board XI.

"All that a family or adult consumer needs to do is spend a couple of hours with a medical student

who will come to their home and speak with them. The student will be eager to learn from you about your family's experiences."

Medical students who participate in the program report learning a great deal from the families and individuals who "teach" in the program — some have even called the experience inspiring.

If you are interesting in participating in Operation Housecall, call Scarlett von Thenen with Area Board XI at (714) 558-4404, ext. 3. She can tell you more about the program and send you an application.

Save the Date for Spotlight!

Be sure to mark your calendar and tell your friends! The 2007 Regional Center of Orange County Spotlight Awards is scheduled for Friday, October 5. And, we have a new location — this year's event will be at the Hyatt Regency Irvine. Entries must be postmarked by August 31, 2007, so download the nomination package from RCOC's Web site at www.rcocdd.com or look for the package that will be included with the next issue of *Dialogue*.

Note for consumers: If you would like help filling out the nomination form, please contact your RCOC service coordinator.



RCOC Families Enjoy Recreation Resource Fair

More than 300 RCOC consumers and their family members took part in the 3rd Annual Recreation Resource Fair & Adventure Day on March 17 at Oak Canyon Lake in Orange. Organized and presented by RCOC and its Comfort Connection Family Resource Center, as well as Pathways to Adventure, the event provided opportunities for children and their parents to learn the basics of family camping and fishing. Participants even had the opportunity to catch a real fish! The free event was made possible through generous sponsorship by REI and support from more than a dozen corporations.

Pictured (L-R): Five-year old Shashank S. Kaushik, with his father Mysore Subash and mother Roopashree Haridas, enjoyed learning to fish at the event.

Regional Center of Orange County Locations

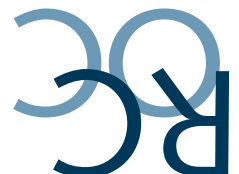
Santa Ana Office	Orange Office	Irvine Office	Westminster Office
801 Civic Center Dr. West 24-hr Phone: (714) 796-5100	3111 N. Tustin, Suite 150 24-hr Phone: (714) 796-3700	46 Discovery, Suite 200 24-hr Phone: (714) 796-4060	13950 Milton Ave., Suite 200 24-hr Phone: (714) 796-2900

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Dialogue Newsletter

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