

Consumer Spotlight Making Sense of a Mysterious Ailment

The Regional Center serves people of all ages who have developmental disabilities. Generally, developmental disability means mental retardation, cerebral palsy, autism or severe epilepsy. Less evident is that sometimes the disability is related to an underlying, more pervasive condition. That is the case with five-year-old Timmy Addison, who has a seizure disorder, autism and global developmental delay – all associated with tuberous sclerosis.

The name tuberous sclerosis comes from the disorder's most common manifestation of tuberous-looking lesions, or tumors, in various organs. Simply put, the disorder consists of the abnormal growth of normal cells and can occur anywhere in the body. The incidence is estimated at one in 6,000 people and the severity of symptoms varies greatly. On the surface it resembles cancer, and the danger does exist that the tumors may become malignant. The difference, however, as Timmy's mother Lee Ann explains, can be likened to the two sets of brakes on a car: in normal cells, both sets of brakes control cell growth. In cancerous cells, both sets of brakes are broken, so the abnormal growth is completely unchecked. In tuberous sclerosis, one brake is broken and one brake works, resulting in benign tumors.

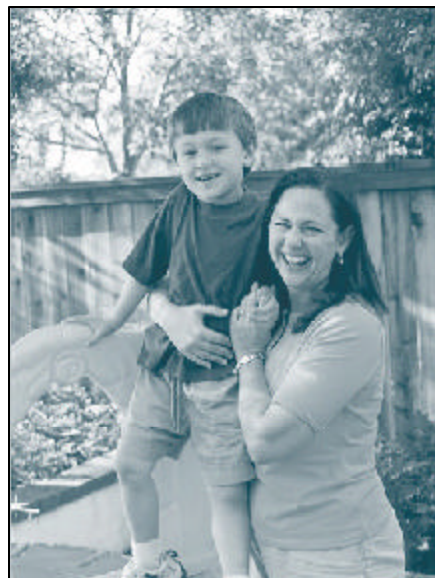
Timmy was tested for seizures at eight months of age when Lee Ann

described his twitching spells to the doctor as convulsions. At nine months, after having an MRI of his brain, Timmy was diagnosed with tuberous sclerosis. His seizures soon escalated to more than 100 per day.

Timmy has tumors in his brain and lesions on his skin (white spots that look like ashleaf-shaped birthmarks). He also has 11 doctors – about half a dozen of which he sees regularly. They range from a pediatrician to a neuro-ophthalmologist. Although the brain tumors caused infantile seizures, until recently Timmy was seizure-free after he joined a three-year study at UCLA in June 1997 and received a medication called Vigabatrin. He completed the study protocol and now takes Lamictal to control his seizures. Timmy's speech, motor skills and cognitive ability lag about a year behind his chronological age.

How does all of this affect Timmy's quality of life? Like any

See Consumer Spotlight, page 7



Timmy Addison and his mother, Lee Ann, enjoy a sunny day in their backyard.

Community Resource Center to Hold Open House

Please join us on Friday, September 28th between 12:00 to 7:00 p.m. or Saturday, September 29th between 11:00 a.m. to 2:00 p.m. for our official Open House celebration.

Comfort Connection Family Resource Center and Family Support Services of Regional Center of Orange County



are pleased to invite you to the opening of our collaborative Community Resource Center located at 801 Civic Center West in Santa Ana, on the first floor of RCOC's administrative and East Area offices.

Now that we have combined resources, our new library is full of videos, books and other materials to assist both parents and professionals. Materials can still be checked out for three weeks at a time. We also have two computers available to assist those interested in accessing information on the Internet.

Families will especially enjoy our new playroom that is designed to keep little ones entertained while parents review materials or meet with our parent support staff.

We hope that you will stop by for fun and refreshments, meet our staff and see all that our new home has to offer. For more information, please call (714) 558-5400. We request that you RSVP to the same number so we can plan for your visit, but walk-ins are certainly welcome.

What's Inside This Issue

<i>Consumer Spotlight - Making Sense of a Mysterious Ailment</i>	1
<i>Core Indicators Project Underway</i>	2
<i>Message from the Executive Director</i>	3

Just for Consumers

<i>R.A.D.D. Review Are You Looking for a Tele-Friend?</i>	4
<i>Consumer Advisory Committee Has a New Name</i>	5
<i>Opportunities for Fun</i>	5

Parent and Family Pages

<i>Support Group List</i>	6
<i>Thank You, Parent Connection Volunteers</i>	7

Other Features

<i>Special Incident Reporting Now Centralized</i>	8
<i>Local Hero</i>	8
<i>After-School Care Survey</i>	9
<i>Family Needs Survey</i>	10
<i>Important Things to Know</i>	11

Core Indicators Project Underway

All parents and RCOC service providers will receive a survey in the mail by early September that is associated with the Core Indicators Project (CIP) in which Regional Center of Orange County is participating. This annual survey replaces the multiple satisfaction surveys families have been receiving from the Regional Center and will be repeated every year in August.

You may recall that in last summer's issue of *Dialogue*, Executive Director Bill Bowman explained that CIP is a research tool used by several states to assess the quality of services delivered to people with developmental disabilities. It involves gathering data from parents, vendors and adult consumers about how

adequately those services meet people's needs.

While parents and service providers receive written questionnaires, information will be obtained from consumers through the use of face-to-face interviews with a random sample of at least 600 adults. The interviews will be conducted by family members and other people with developmental disabilities in order to make the process as comfortable as possible for those being interviewed. The interviews will consist of talking about various aspects of the person's life to assess the overall level and standard of care in Orange County.

Once the information is collected, it will be reviewed by RCOC staff and compared with national norms to

determine our strengths and challenges. An advisory committee composed of parents, people with developmental disabilities and RCOC vendors will take the information gathered and make policy recommendations to the RCOC Board of Directors with the goal of improving services.

This is your opportunity to provide valuable input, so please take a few moments to complete and return the survey when you receive it. If you have questions about the survey or the Core Indicators Project, please call Mark Antenucci, RCOC director of outcomes at (714) 796-5254.

Critical Legislation Pending for People with Developmental Disabilities

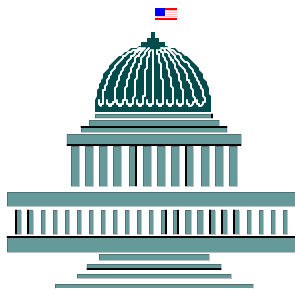
By Bill Bowman

In the last issue of *Dialogue*, I wrote about the state's need to renovate the physical plants of the five developmental centers (DCs) or identify alternative resources for serving the people who live in them. The ink on *Dialogue* was barely dry when new legislation was introduced in the state assembly that addresses this very subject in an innovative and responsible way. Assembly bill 896 by Dion Aroner was written with the assistance of consultant Art Bolton who was a staff member of Assemblyman Frank Lanterman in the 1960s and 70s when the landmark Lanterman Act was crafted.



You can read the text of the bill on the Internet at www.leginfo.ca.gov.

First and foremost, the purpose of this legislation is to bring equity to the



funding of services between people in the community and those in institutions. That does not mean taking something away from those in the DCs and giving it to those in the community. It's about creating better resources for everybody with developmental disabilities in California. In fact, in response to the concerns of DC residents' parents, the bill has

been amended to ensure that families are included in the individual program planning process and that additional monitoring of consumers' safety and well-being be provided as needed.

AB 896 would unify the developmental services system from two budgets — regional centers and developmental centers — into a single pool of funds that would be administered by the regional centers. It provides for the orderly transfer of most DC residents into the community over a six-year period.

AB 896 is virtually the only hope we have at this time for resources to improve the developmental services system in California.

An additional provision of AB 896 should pique the interest of many families with autistic children and others desperate for additional help. The bill requires regional centers to establish community augmentation and resource enhancement accounts (CARE) to improve services for consumers in the community with urgent unmet needs.

This legislation also requires the state of California to "catch up" to other states that take full advantage of matching federal funds through community based waivers. Gaining access to more federal dollars would allow us to improve the quality of community programs and raise wages for direct care workers.

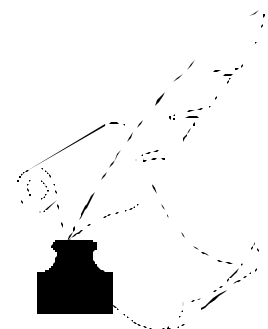
AB 896 is virtually the only hope we have at this time for resources to improve the system for all people with developmental disabilities in California — not just those who live in

the community. With the energy crisis looming, there is little chance of increased funding for developmental services on the horizon.

Change can be difficult, uncomfortable, even frightening. I am as concerned for the welfare of the consumers who reside in the institutions as I am for those in the community. I want each and every one of them to be safe, well cared for and provided with choices about how they live. I want their family members to feel confident that their children are receiving the best care available from qualified providers.

AB 896 is scheduled to be voted on by the Senate Health and Human Services Committee on August 22. By the time you read this, AB 896 may have passed out of that committee and moved to the Senate Appropriations Committee. If it passes there it will go to the full Senate for vote. It is critical that you contact your state senator immediately to express your opinion on this bill. You can identify your senator online at www.senate.ca.gov or call the Registrar of Voters at (714) 567-7600.

If you support this bill, you can access a sample letter on the RCOC Website at www.rcocdd.com or call your service coordinator to receive a copy by mail.



R.A.D.D. Review

Are You Looking for a Tele-Friend?

If you a consumer of the Regional Center of Orange County, you might be interested in Tele-Friend. The purpose of Tele-Friend is to help consumers meet new people who live nearby.

We suggest that you always meet in a public place and that you provide your own transportation.

To place an ad in Tele-Friend, call (714) 796-5270 for the form you need. Here are some people who want "Tele-Friends."

Billy of Anaheim ... (Age 30) "At home I like to listen to my CDs and watch videos. I like going to Disneyland, Knott's Berry Farm, bowling, Special Olympics, the movies, dances, and shopping malls. I take buses everywhere. I also enjoy traveling. I live with my parents and do janitorial work at the Seal Beach Naval Air Weapon Station."

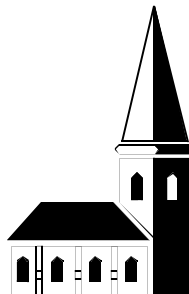


Tammy of Costa Mesa ... "At home I like to play Nintendo games, watch videos and watch World Wrestling Federation on TV. I also like to ride bikes to the beach and go out on the town. I like going to Disneyland.

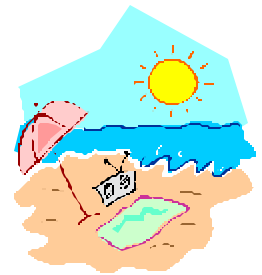


I like a guy to respect me because I am a Mormon. I work at Marshall's and I am 41 years old."

Michael of Orange ... "I work at Disneyland. I like bowling, dancing, amusement parks, eating out, talking, roller skating, and going to church. I have a car and driver's license. Someday I would like to get married. I live with my sister and her family. I am 30 years old."



Minh of Huntington Beach: "I am a 31-year-old man, and I like to cook, bake, walk at the beach, go to the gym and watch TV. I work at the library as a page and I live with my parents."



David of Anaheim ... "I like to listen to 50's and 60's music. I like to watch video movies like comedies and musicals. I work in the cafeteria at a college. I am 35 years old and live in my own apartment."



If you would like to talk to any of the people listed above, call (714) 796-5270. We will send you a roster of RCOC consumers who have placed ads. You must be a Regional Center consumer or parent to respond.

Consumer Advisory Committee Has a New Name

By Sam Durbin, committee president



It's official – at our May meeting, the Consumer Advisory Committee

members voted to rename ourselves the Consumer Advisory Team (CAT). We all decided that we are more of a team because we work together.

We plan to order red polo shirts with a design on the front that will have printed “RCOC Consumer Advisory Team,” a picture of a cat and the words, “Hear Us Roar.”

Fund Raiser

To raise money for the polo shirts and for the Self-Determination conference we plan to hold at RCOC in December, the Team is having a car wash on Saturday, September 8 from 10 a.m. to 4 p.m. at Orange County ARC, 225 West Carl Karcher Way, Anaheim. Tickets will be sold ahead of time for a suggested donation of \$5. We plan to make it a fun day with popcorn, music, and hopefully, a dunk tank so we can soak the RCOC management team. Get your ticket or just come out for a fun afternoon! Call Betty Bath at (714) 796-5263

to buy a ticket.

Important Legislation

There's a bill in the state legislature in Sacramento called AB 896 that will combine the budgets of the regional centers and the developmental centers to improve services for everybody. The CAT members do not want to offend anybody, but we all feel very strongly about not wanting to give money to build up the institutions but instead have more community-based living opportunities.

Team Meetings

Since we started holding the Consumer Advisory Team meetings at different locations, more people have been able to attend. Recent meetings have been held at RCOC's North, South and West offices as well as Mainstream Independent Living Services in Anaheim, Integrity House in Fullerton and Project Independence in Costa Mesa. If other programs would like to host a meeting, please call Betty at (714) 796-5263.

The next CAT meeting will be Wednesday, September 12 at 10:00 a.m. at Orange County ARC in Anaheim. If you would like to attend, please reserve a spot by calling Betty Bath at (714) 796-5263.

Opportunities for Fun

Adults with developmental disabilities are welcome to join the fun outings offered by Project Independence through its **Access to Adventure** program. Recent group events included The Orange County Fair, Pageant of the Masters, a bowling tournament and a summer concert at Hart Park in Orange.

Transportation to some of the activities is provided from hub locations in Anaheim, Costa Mesa and Laguna Hills.

To find out more and to receive the *Adventure Announcements* newsletter, call Allison Mitchell, Access to Adventure coordinator, at (714) 708-2296. There are varying costs as well as eligibility criteria for Access to Adventure activities.

The **City of Irvine** offers fun activities for people with disabilities, including several dances a year as well as hikes at places such as Laguna Coast Wilderness Park and Bommer Canyon. The city has a bowling league and holds etiquette classes. Most activities are also open to non-Irvine residents. You can put your name and address on the mailing list to receive fliers about these events. For more information, call Disability Services at (949) 724-6732.

Parent/ Support Groups *Grupos para Padres*

For meeting times and locations, see the monthly RCOC Community Calendar that comes in the mail to you, or call the group contact or Jacqui Kerze at RCOC, (714) 796-5299.

- ❖ **A Touch of Love** - For limb deficient children and their families. (800) 493-5462. Hablamos español
- ❖ **Ain't Misbehavin'** - A support network of parents interested in exchanging information on behavioral issues. Call (714) 889-7260
- ❖ **Asperger Syndrome** - Contact Caroline Wilson, (562) 425-2292 or South County call (949) 454-6302
- ❖ **Autism Support Groups** - Newly diagnosed autism, contact (310) 543-0662; Huntington Beach, contact Leaza Howe, (714) 841-6766
North County, contact Paula Peterson, (714) 288-9005; South County, contact Beverly Lee, (949) 249-9277
- ❖ **Cerebral Palsy** - For info. & support, meetings & groups, contact Family Support Services at UCPA, (714) 557-1291
- ❖ **Chinese Parent Support Group for the Disabled** - Contact Kitty Tsan at (949) 588-0123
- ❖ **CLASP (California League of Angelman Syndrome Parents)** - Contact Katie Hendren, (714) 962-4152
- ❖ **Compassionate Friends** - For parents who have experienced the loss of a child. Call Roy Redman, (714) 993-6708
- ❖ **DADS' Group** - For fathers of children with autism and related disorders. Call Norm Booth, (714) 961-1315
- ❖ **Epilepsy Connection** - We connect people to resources and information. Call Paulette Motzko at (714) 998-0391
- ❖ **Family Visions** - For parents of visually impaired children. Contact Karin Crilly, (714) 573-8880, ext. 109
- ❖ **Fathers Support Network** - Contact Jeff Braun at the Family Support Network, (714) 543-7600
- ❖ **First Evangelical Free Church Disabilities Ministry** - Contact Connie Hutchinson, (714) 529-5544
- ❖ **Fragile X Group** - For parents or family members of people with Fragile X. Contact Sali Farber at (714) 544-9551
- ❖ **Guys and Gals Group** - A recreational group for adult consumers. Contact Lena Lynch, (714) 796-5213 or Jacqui Kerze, (714) 796-5299
- ❖ **Hearts of Hope** - For parents of children with congenital heart defects. Contact Kris Krieger at (949) 348-2848
- ❖ **Hearts United Grandparents Raising Grandchildren (HUG)** - Contact Irene Kontz, (714) 636-5430
- ❖ **Mitochondrial Disease Group** - Call Sherry Clitheroe, (714) 968-9373, Lissa Mirand, (562) 929-8851, or Karen Ortiz, (909) 335-0721
- ❖ **Mom's Group** - For moms of children with autism in North Orange County. Contact Jill Riley, (714) 288-1566
- ❖ **Mommy Network** - South County. Contact Julie McLain at (949) 888-1820 or Tina Muller by e-mail at oncewas2@home.com
- ❖ **Moving on at 3 Parent Group** - To support and educate parents of children transitioning from Early Start services. Contact RCOC's John Zeimantz at (714) 796-5339
- ❖ **Non-Ketotic Hyperglycinemia (NKH) Family Support Group** - Contact Tammy L. Hanna (714) 444-4454
- ❖ **One In A Million Kids** - For parents of children with rare or undiagnosed disorders. Call Georgia or Gary Freedman-Harvey, (310) 588-2562 – not a support group but does assist over the phone
- ❖ **Orange County Parents of Disabled Multiples** - Contact Bree Dennis at (909) 734-3616
- ❖ **Parent Connection** - To connect with other parents of RCOC consumers (Eng., Spanish & Vietnamese), call (888) FRC-BABY
- ❖ **Parents of Children in Residential Placement** - For parents of RCOC consumers. Call Jacqui Kerze, (714) 796-5299
- ❖ **Parents of Kids with Epilepsy** - A support group. Contact Mary Repp at (949) 462-1927
- ❖ **P.R.O.U.D. - Parents Regional Outreach for Understanding Downs** - Call the hotline at (714) 547-2895
- ❖ **Rett Syndrome Group** - Contact Rebecca Craft, (949) 856-9320 or Susan McLaughlin, (949) 858-8411
- ❖ **Sibshop** - Workshop for siblings ages 8-13 of children with special needs. Call Kathleen McFarlin, (714) 557-1291
- ❖ **Single Parent Group** - For single parents of children with special needs. Contact Jacqui Kerze, (714) 796-5299
- ❖ **Spina Bifida Support Group** - Contact Brandy Van Hook at (714) 840-4303
- ❖ **Team of Advocates for Special Kids (TASK)** - Educational assistance and support for parents of children to ages 3 to 22.
Call (714) 533-TASK (8275)
- ❖ **Tuberous Sclerosis** - Support group for families. Contact Lee Ann Addison for more information, (949) 495-7126
- ❖ **Vietnamese Parent Support Group** - Contact Queenie Hoang at (714) 557-1291; pager number (714) 664-6899
- ❖ **Williams Syndrome** - Support for families of people with Williams Syndrome. Call Darlene Ginnett, (562) 598-5559

Grupos En Español

- ❖ **Grupo de Autismo Angeles** - Para más información llame a Gloria y Jose Hernandez, (714) 995-1955
 - ❖ **Grupo Arcoiris Síndrome de Down** - Para más información llame a Maria Piceno, (714) 558-5400
 - ❖ **Hacia Los 3 Años...Transición** - Un grupo de padres con niños recibiendo Servicios de Intervencion Temprana Para Educacion y Apoyo durante el proceso de transición. Para más información llame a Consuela Morales (714) 685-5514
 - ❖ **Noche de las Madres** - Para más información llame a Barbara Dominguez (714) 998-4912
 - ❖ **Nuevos Horizontes** - Para más información llame a Barbara Dominguez, (714) 998-4912
-

Thank You, Parent Connection Volunteers

On Sunday afternoon, June 10, Parent Connection volunteers enjoyed a picnic lunch and appreciation ceremony at the Santa Ana Zoo, hosted by United Cerebral Palsy Association of Orange County (UCPA). While the adults relaxed, the children had their faces painted and romped in an inflatable jumper. Families also got complimentary entrance to tour the zoo.

Counting volunteers and their families, about 250 children and adults participated in the event that recognized about 75 volunteers.

Parent Connection is a program sponsored by the Regional Center and coordinated by UCPA that recruits and trains parents of children with developmental disabilities to provide emotional support to parents who are new to the Regional Center. Parent Connection welcomes any parents willing to spend a little time on the phone listening and offering compassion and reassurance. Particularly needed at this time are parents of children under six years of age.

For more information about this program in English or Spanish, call (888) 372-2229.



Andy Nguyen and his mother Michell Dinh relax at a picnic table at the Santa Ana Zoo.

Consumer Spotlight

(from page 1)

five-year-old, he is blissfully unaware of the seriousness of his condition.

His RCOC service coordinator, Judy Bercovici, describes Timmy as “a bundle of love, a joyous little boy.”

Timmy loves playing with his toy trains, digging in his sandbox and stroking Mommy’s hair. He’s also talkative and outgoing like his mom.

Lee Ann, on the other hand, bears the psychological weight of the potentially life-threatening ailment afflicting her only child. Not one to fret or wring her hands, Lee Ann has taken charge of Timmy’s medical care by acting as the team coordinator among his many doctors.

She says, “It’s a full time job, but I feel very resourceful. I educate myself all the time. I look for doctors who will listen to me and realize that I know more about this than they do.”

Lee Ann has also helped educate RCOC staff about tuberous sclerosis by speaking about the condition at an Area meeting last year.

Service Coordinator Judy says, “Lee Ann is very, very amazing in the support she provides for other parents as well as for her son.”

Lee Ann leads the Orange County chapter of the Tuberous Sclerosis Alliance. She helps raise funds for research and facilitates a support group for parents that includes eight families so far. Last year Lee Ann raised \$4,000 with a letter campaign.

Lee Ann and her husband Jim try to give Timmy as normal a life as possible despite the many intrusive medical appointments. Lee Ann arranges play dates with friends, Timmy plays outside in the neighborhood and he goes to school in an autism-specific classroom.

“We do as many typical activities as possible,” says Lee Ann. “I treat him like a normal kid, especially behaviorally.”

Maintaining a balanced life is more challenging for Timmy’s parents. Fortunately, Lee Ann says, “I have a fantastic husband.” Jim’s plate is full as he works toward a master’s degree in business in addition to his full-time job. Lee Ann’s schedule can also get crazy as she deals with the extra responsibilities of having a special needs child: working with the school district, Regional Center, doctors and HMOs. In addition is the nagging worry that Timmy’s body may develop more tumors or that the

tumors in his brain may cause hydrocephalus. The Addisons remain vigilant for symptoms such as vomiting.

Lee Ann comforts herself with the realization that “the prognosis given at diagnosis is usually the worst picture.” She also knows that the work she does with the Tuberous Sclerosis Alliance contributes to medical advancements with the hope of finding a cure. She derives fulfillment from providing support and education to other parents in similar circumstances. And once a month she indulges in a diversion where she can relax and draw comfort from others: the support group at ICEC (Intervention Center for Early Childhood), where Timmy received early intervention services.

Although the future of Timmy’s health is uncertain, one thing is sure: Lee Ann and Jim Addison will continue to pursue the best care and treatment available for their son and work toward a cure of this insidious disease.

For more information about Tuberous Sclerosis, visit the TS Alliance Web page at www.tsalliance.org or call (800) 495-7126. To learn about the Orange County support group, call Lee Ann Addison at (949) 495-7126.

Special Incident Reporting Now Centralized

Protecting the safety and rights of people with developmental disabilities is one of the Regional Center's responsibilities. One way of carrying out that responsibility is by the use of Special Incident Reports (SIRs).

Special Incident Reporting is the process utilized by service providers to notify the Regional Center of serious incidents involving RCOC consumers. Such situations include serious injury or illness, suspected abuse, and death. California law requires that special incidents be reported to the Regional Center within 24 hours of occurrence.

Previously, a service provider such as the consumer's day program or

residential facility reported special incidents to the consumer's service coordinator. The service coordinator would then notify others that needed to be involved, such as RCOC medical staff, Quality Assurance or Adult Protective Services. The process could be cumbersome if more than one consumer and service coordinator were involved, necessitating numerous reports.

On July 1, 2001, RCOC instituted a centralized SIR procedure designed to streamline the reporting process and better track information. As of that date, all SIRs are to be submitted to a single location by telephone and facsimile, where they will be gathered by Leslie Walker, the SIR

coordinator. Leslie will notify staff, including the service coordinator and area manager, of the special incident. For those incidents that must be reported to the State, Leslie will complete RCOC's report.

Having a single point of contact is more convenient for service providers and more efficient overall. The SIR information will be kept in a database to assist RCOC in identifying trends and patterns that can be analyzed in several ways. The data will be useful to help RCOC staff see the "big picture" and make agency-wide improvements as well as better serve each person involved by preventing certain events from recurring.

Local Hero

Thanks to the clear thinking of a Regional Center consumer, two alleged convenience store robbers were apprehended recently. On January 14 of this year, at about 2:00 in the morning, Adam Meltcher, who is legally blind and has other disabilities, was working behind the counter in a local convenience store when he was approached by a man dressed in black who asked, "Do you sell beer?" Adam directed him to the liquor section.

Another man entered the store and asked for cigarettes. The man then pulled out a 45-caliber pistol and demanded that Adam give him the money out of two cash registers. The amount was less than \$50, so the gunman told Adam to open the safe. He couldn't because he didn't have a key, and when pressed further by the man, Adam revealed that he could get bundles of small bills out of a slot by pressing a button under the counter. The man told Adam to give him a

bundle of four 10-dollar bills, so Adam complied and at the same time pressed the silent alarm button to alert the police. The man wanted additional money, so Adam pressed the button again and reported that it would take a minute or two for the bills to come out. He did his best to stall for time because he knew the police response would take three to four minutes. In the meantime, the robber's partner joined him and set two cases of beer on the counter.

As the men were leaving the store, 13 police cars pulled up with guns drawn. The man with the pistol ran across the street but was apprehended by police. His partner lay down on the

floor and surrendered to the officers. It turned out that the gun was not loaded, but the men had several outstanding warrants for armed robbery in Las Vegas and Los Angeles.

A police officer asked Adam if he was afraid, and he replied, "Not really," but when he arrived home and realized what could have happened, he decided to look for a safer job. Adam was fortunate that he was not harmed, but he learned a lesson about working in such an environment in the middle of the night. "You can get killed working here," was his assessment.



Adam Meltcher poses next to a life-size poster of Elvis Presley in his apartment.

Please complete this brief survey if you have a family member who receives RCOC services and is between 3 and 17 years old.

After-School Care Survey

Dear Family Member,

In formulating our Performance Contract Objectives, we at RCOC received input from the community that some families have had a difficult time obtaining after-school resources for their children who receive RCOC services. In response to the growing need for after-school care resources, we ask your assistance with the following brief survey.

The information we collect will be posted on the RCOC Website so that other families can benefit from it. If you have any questions, please feel free to contact Jacqui Kerze, Family Support Coordinator, at (714) 796-5299.

1. Do you currently use after-school care for your family member who receives RCOC services?

- Yes (go to Q. 3) No (go to Q. 2)

2. Do you need after-school care?

- Yes No

3. Please complete the following if you are willing to share the name and address of the after-school care provider you utilize.

Name _____

Address _____

City _____ Zip _____

Phone Number _____

4. What is the age range of your family member who receives RCOC services?

- 3-7 years old 8-12 years old 13-17 years old

Please return this survey in the attached postage-paid envelope or fax to (714) 542-5634.

Thank you for assisting us in providing valuable information for the families and consumers we serve.

Please complete this 2-question survey if you have a child living at home who is an RCOC consumer between the ages of 3 to 17 years.

Family Needs Survey

Your response will help RCOC better identify the service needs of our consumers. The service areas currently being considered are:

- **In-home parent training for behavior intervention**

Definition: In-home parent training is a service where a professional visits the family home to provide information and strategies to assist parents to better manage their child's behavior.

- **Out-of-home respite services**

Definition: Out-of-home respite is identical to in-home except that the respite service is provided outside of the family's home. Examples include a day care center, recreational facility or a residential facility dedicated to respite services.

Definition of Respite Service: Intermittent temporary care to consumers with developmental disabilities in order to relieve families of the constant responsibility of caring for a family member with a developmental disability.

1. Do you have a need for in-home parent training for behavior intervention?

Yes No

If yes, please check your language preference if it is other than English

Spanish Vietnamese Other (please specify) _____

Comments: _____

2. Do you have a need for out-of-home respite options? Yes No

Comments: _____

The following information is optional:

Name _____ Telephone No. _____

Address: _____

Please return this survey in the attached postage-paid envelope or fax to (714) 541-0346.

Thank you for your assistance in identifying the service needs of RCOC consumers and families.

Important Things to Know...

Community Meetings... Every year the Regional Center submits performance contract goals and objectives to the Department of Developmental Services. The purpose of these goals and objectives is to improve and expand services in nine general areas, including living options, family support, education/lifelong learning, work/leisure, prevention/early intervention and others. To help formulate its goals, RCOC holds public meetings to solicit input from RCOC consumers, families, vendors and other interested parties. This year the meetings will be held: Aug. 20 at the RCOC Westminster office, in English and Vietnamese; Aug. 21 at RCOC's Orange office in English only; Aug. 22 at RCOC's Santa Ana office in English, Spanish and Vietnamese; and Aug. 23 at RCOC's San Juan Capistrano office in English only. See back page for addresses. For more information, call Betty Bath at (714) 796-5263.

If you haven't already, send in your response card for the **fifth annual Spotlight Awards dinner dance** on Friday, September 14, 6 p.m. to midnight at the Irvine Marriott Hotel. Tickets are \$40 and must be purchased in advance. Come out for a festive evening and support the nominees being recognized for their work on behalf of people with developmental disabilities. For more information, call Betty Bath at (714) 796-5263.

Coastline Community College offers Special Education classes at its Costa Mesa center. The Fall semester starts August 27 so call (714) 241-6214 to find out more about classes in computers, the Internet, reading and writing, social skills and

consumer skills (shopping, budgeting and banking skills.)

RCOC South Area Office has Moved. On August 6 the RCOC South Area office opened its new doors at 26311 Junipero Serra Road, Suite 180, in San Juan Capistrano. The consumers and families served by that office were sent a letter notifying them of the change. The office is located off Interstate 5, Junipero Serra exit, next to the Kaiser Permanente building. Good news – parking is free! At the time of the *Dialogue* printing, the new telephone number was not available, but the office can still be reached at this time by calling the old phone number. The new phone number will be printed on the back page of the next issue of *Dialogue*.

A presentation by B.J. Freeman, Ph.D. called "Autism: Present and Future" will be held on October 24 from 4 p.m. to 8 p.m. at RCOC, 801 Civic Center Drive, Santa Ana. Dr. Freeman, an internationally known authority on autism, is professor of Medical Psychology at the UCLA School of Medicine and director of the Autism Evaluation Clinic at UCLA. Dr. Freeman will present current and promising treatment approaches and will discuss indicators regarding long term outcomes. Practical information on how to develop an appropriate treatment plan will be presented. Cost is \$30 per person. Pre-registration is required and seating is limited so register early by calling Toni Wilson, (714) 796-5330 or Dr. Janis White at (714) 796-5256.

The six-week class, "Program Coordination for the Developmentally Disabled" will be held on six consecutive Wednesdays from 7 p.m. to 10 p.m. starting October 3 at the RCOC North Area office, 3111 N. Tustin Street, Suite 150, Orange. If you are interested in learning more about RCOC services and possibly becoming a parent/partner service coordinator, call Emily Tactay at (714) 796-5248 to register or obtain more information.

A reminder that **RCOC's Community Calendar** is sent each month to consumers, family members and service providers. The calendar is also available on RCOC's Web site at www.rcocdd.com. Remember to refer to the calendar for information on seminars, support groups, service provider training and various other meetings. Some recent activities listed in the calendar include the National Down Syndrome Society's 2001 National Conference, training for Community Care Providers on Social Security Benefits, and information about Sunshine Twirlers, a square dance class for people with disabilities.

If you would like to list an event in the Community Calendar, contact Jan Draper at (714) 796-5270 for a request form and a schedule timeline. Please note that the deadline to submit information for the calendar is about eight weeks before the month of the event.

Helpful Website...

To shop for wheelchairs and other mobility products at discount prices, check out www.spinlife.com, or call SpinLife for a catalog of products at (800) 850-0335.

Board of Directors 2000-2001

Richard Peterson, President ❖ **Holly Nogales**, Vice President
Steve Sherman, Treasurer ❖ **Stephen Brees**, Secretary
Vicki Amantea ❖ **Karen Chen** ❖ **Nancy Creelman**
Patricia Daley ❖ **Christian Dubia, Jr.** ❖ **Sam Durbin** ❖ **C. Terrence Fletke**
Joyce Hearn ❖ **John Kuricaj** ❖ **Joe Preston** ❖ **Kim Vuong**

2001 Board Meetings:

Sept. 6 ❖ Oct. 4 ❖ Nov. 1 ❖ No meeting in December

*The board of directors meets at 6:00 p.m. at 801 Civic Center Drive West, Santa Ana.
The public is welcome.*

The Regional Center of Orange County has four locations to serve you:

Orange Office

3111 N. Tustin Street, Suite 150
24-hour phone no.: (714) 685-5555
TDD: (714) 685-5575

Santa Ana Office

801 Civic Center Dr. West
24-hour phone no.: (714) 796-5100
TDD: (714) 667-6021

San Juan Capistrano Office

26311 Junipero Serra Road, Ste. 180
24-hour phone no.: (949) 699-1900
TDD: (949) 699-3367

Westminster Office

13950 Milton Ave., Suite 200
24-hour phone no.: (714) 889-7200
TDD: (714) 889-7234

RCOC Web site: www.rcocdd.com

*Dialogue is normally published four times per year for consumers, families, service providers, and members of the community by the Regional Center of Orange County. We welcome your ideas, contributions and suggestions. Please send all correspondence to: **Karen Taylor**, Dialogue Editor, Regional Center of Orange County, P.O. Box 22010, Santa Ana, CA 92702 or call her at (714) 796-5208.*

Regional Center of Orange County Administration

Bill Bowman, Executive Director
Janis White, Associate Executive Dir.
Bette Baber, Administrative Director
John Abernatha, Human Resources
Director
Mark Antenucci, Outcomes Director
Arleen Downing, MD, Medical Dir.
Larry Landauer, Consumer and
Community Resources Director
Ed Scherer, Information Services Dir.
Chuck Dillenbeck, Intake Manager
Adam Gottdank, North Area Manager
Rosalinda Lopez, East-Central Area
Manager
Keli Radford, West Area Manager
Amy Williams, South Area Manager

*The Regional Center of
Orange County is a nonprofit,
private agency that contracts with
the California Department of
Developmental Services to provide
services to individuals with
developmental disabilities.*

Look for Tele-Friends on page 4!

Dialogue Newsletter

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

NON-PROFIT
ORGANIZATION
U.S. POSTAGE
PAID
SANTA ANA, CA
PERMIT NO. 1285