



Dialogue

Volume 17, No. 1
Winter 2003

From the Executive Director

Changes Looming on the Developmental Services Landscape

By Bill Bowman

Here is the latest on the state budget crisis as it relates to services for people with developmental disabilities. As I



write this in February, our state legislature is dealing with balancing the current budget for the fiscal year ending June 30, 2003. In December the governor proposed some mid-year cuts to regional centers, Medi-Cal, and Department of Rehabilitation, but so far the legislature has tabled those, while continuing to wrangle over tax and vehicle license fee increases.

Near-Term Concerns

While it would be wonderful for

people with developmental disabilities to be insulated from additional funding reductions, it's not likely given the sheer enormity of the state's budget problems. Because of the good stewardship of tax dollars in Orange County accomplished by consumers and families working conscientiously with the Regional Center, we are holding our own so far this year. The dollars are so tight, however, that some regional centers in the state may actually run out of money before the end of this fiscal year.

Longer-Term Worries

Beyond our current difficulties is the governor's proposed budget for 2003-04, which the legislature will start discussing in March. In it, the governor is proposing methods for reducing expenditures that will be quite challenging to the developmental services system and will be of particular concern to families with young children.

The primary issues that concern us are parental co-payments for services

and the implementation of statewide purchase of service standards. As you will see, it appears as if services to people with developmental disabilities – which have enjoyed a long history of support from both the Democrats and Republicans – are finally succumbing to reductions in ways we could not have imagined even a year ago.

The most monumental shift in funding is the parental co-pay. Please read Karen Chen's article on page 3 for the details. In Orange County, the people who would be affected by this are the parents of the 4,478 children between ages 3 and 17 who live at home. Many of these families would not be able to afford some or all of the services their child needs. If you doubt the seriousness of this proposal, consider that the governor proposes to add 26 new staff positions to the Department of Developmental Services (DDS) within the next year just to manage this new program.

See "Changes," page 3

Consumer Spotlight Trevor Hall Gets Around

When someone asks 11-year-old Trevor Hall a question, his 9-year-old brother, Aaron, often answers for him. Aaron doesn't think twice about it — it's just quicker and easier to do that when your brother has a speech delay because of cerebral palsy. Still, their mom Naomi corrects Aaron, saying, "Trevor can talk. Let him say it."

Although Trevor has difficulty speaking clearly and in complete sentences, it doesn't take a long conversation to learn a lot about him. His mischievous grin and the gleam in his eyes as he talks about knocking down old buildings with toy dump trucks and "offroading" on one tire in his wheelchair reveal his adventure-some spirit.

Trevor's mom, Naomi Hall, works at Comfort Connection Family Resource Center (see story, page 8). She

See "Trevor," page 9



Trevor Hall is a daredevil who loves visiting his aunt and uncle on their farm in Minnesota where he can ride in the tractor scoop and go boating on the lake nearby.

What's Inside This Issue

<i>Message from the Executive Director</i>	1
<i>Consumer Spotlight - Trevor Hall Gets Around</i>	1
<i>Going to the Dentist?</i>	2
<i>Free Tax Assistance Available</i>	2
<i>RCOC Legislative Update</i>	3

Just for Consumers

<i>R.A.D.D. Review Join Tele-Friend to Meet Someone New</i>	4
<i>Recreation Opportunities for Adults - South County</i>	4
<i>Consumer Advisory Team Update</i>	5
<i>Safety Stu's Corner - Staying Safe on the Bus</i>	5

Parent and Family Pages

<i>Support Group List</i>	6
<i>What's the IDEA? Special Education Assessments</i>	7
<i>The Changing Face of Family Support</i>	7

Other Features

<i>Comfort Connection Welcomes You</i>	8
<i>Important Things to Know</i>	11
<i>Family Support Survey</i>	11

Free Tax Assistance Available

The Internal Revenue Service (IRS) offers free tax assistance through Volunteer Income Tax Assistance (VITA) and Tax Counseling for the Elderly (TCE). Volunteers prepare federal and state income tax returns for low income, senior, physically challenged, and non-English-speaking taxpayers.

RCOC has a list of the sites where

this service is available, so you can call your service coordinator to find the location nearest you. You can also call IRS Customer Service at (800) 829-1040 to ask for the VITA or TCE site near you.

Note: Consumers or their families may be eligible for an Earned Income Tax Credit or Long-term Caregiver Credit. VITA volunteers are trained to assist with claiming these credits.

Going to the Dentist?

Here are some recommendations that may help make visits to the dentist more comfortable for people with disabilities.

1. When you call for a dental appointment, describe the person's disabilities and any behavior problems.

√ Ask about the payment methods and types of insurance they accept. Take insurance information to the appointment.

√ If applicable, ask if the office and exam rooms are accessible for wheelchairs or other specialized equipment.

√ Ask if the office can send the medical history to complete ahead of time.

Include medications and update medical history at every visit.

√ Ask for an appointment time when the person is most rested and the dental office is least busy.

√ Ask what behavior management techniques or sedation they use if the individual is uncooperative due to behaviors, or physical or mental disabilities.

2. Know the date and purpose of the patient's last dental visit.

3. Get written consent from the person's legal guardian or conservator for any dental procedure if that person is not going to the appointment. For people who have behavior problems or have refused dental care in the past and need immediate treatment, you may need to get specific consent for medication to sedate the person.

Looking for a Dentist?

Regional Center of Orange County has a list of dentists who have special interest or skill in caring for people with disabilities. To obtain the list, please contact Patricia Arnold, information specialist at Comfort Connection Family Resource Center at (714) 558-5400.

Budget Proposal Hits Home

By Karen Chen,
RCOC Board of Directors

Along with thousands of others who depend on state funding, we received the Governor's 2003-04 Budget with a heavy heart. Cuts in health and human services were unavoidable in light of how large the state deficit loomed. Nevertheless, the regional center population is projected to increase by 10,870 consumers statewide, to a total of 193,100. To address the increase, the Governor's Budget includes proposals to offset the significant growth in caseload expenditures and control the future growth of regional center costs. One



of the proposals is sure to hit every young consumer families' wallet: Implementation of parental co-payments for minor children with developmental disabilities.

The proposed budget includes \$31.6 million in new revenue from families receiving services and supports in the community through implementation of co-payments that would require parents to share in the cost of providing services to their children. The co-payment would apply to families with developmentally disabled children ages 3-17 who live at home. The amount of the co-payment would be assessed on a sliding scale based on income, and applied only to families earning more than 200% of the federal poverty level. Thus, a family of four making \$50,000 a year would be responsible for 10 percent of that number, or \$5000 of the cost of services their child receives. Many families with young children with developmental disabilities care for them at home, not only because of

cost-efficiency, but understandably to keep them near at such a tender age. However, with the new proposed parental co-payment plan, a family may become overwhelmed by the accumulated payments and be unable to afford to care for their child in the comfort of their own home. This proposal appears as though to penalize those who utilize in-home care, despite the fact that out-of-home care is much more costly.

As alarming as this all sounds, it is still only a proposal in the Governor's Budget. Both the State Senate and Assembly will have to agree to it in order for it to be established. It is likely that the health and human services proposals will be taken up during the regular budget hearings beginning sometime in March. There is still time, albeit very limited, to contact your local state legislator and voice your concerns. For assistance, please contact Karen Taylor via email at ktaylor@rcocdd.com or call (714) 796-5208.

Changes (from page 1)

The other subject of concern is the \$100 million reduction in purchase of service expenditures. The governor suggests that this can be done through uniform spending standards statewide, but nobody in the administration has yet come up with how they would accomplish that goal. The purchase of service portion of our budget is the money used to pay for services provided to the people we serve. The reason statewide standards are of concern to us is that they diminish the local control intended by the Lanterman Act. Regional centers were designed to address the needs unique to their local communities. For example, a regional center serving a metropolitan area may have access to cost effective public transportation while a regional center in a

rural area might depend on more expensive transportation options. Statewide uniform standards would limit the flexibility of regional centers and the people they serve to determine the accessible resources.

What You Can Do

Now, more than ever, if you are interested in preserving the promise of the Lanterman Act and retaining fully funded services, you need to take action and make your voice heard in Sacramento. You need to let the governor, your state senator and your assembly member know how these funding changes would affect your family – and your son's or your daughter's life. Whether you're the parent of a child newly diagnosed with autism or the parent of an adult with Down syndrome and you have fought many battles already, this looms as the single largest battle

since the Lanterman Act was created.

If you want to join the growing group of parents, service providers and others who are uniting in grassroots legislative efforts, contact RCOC's Communications Coordinator, Karen Taylor, by e-mail at ktaylor@rcocdd.com or by phone at (714) 796-5208. We have an e-mail alert list so we can quickly let people know when it's timely to write or call our elected officials. We will likely be arranging legislative visits here in Orange County or in Sacramento. We may even need to organize rallies to bring attention to our situation.

Working together with intelligent and consistent effort, we can convey a unified message to Sacramento. Please contact us as mentioned above. Prepare to take action to preserve services for people with developmental disabilities.

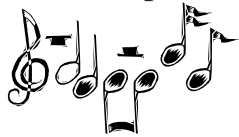
R.A.D.D. Review

Tele-Friend – Join Now to Meet New People

If you're a Regional Center consumer, you might want to meet new friends who live near you by joining Tele-Friend. We suggest that you always meet in a public place and that you provide your own transportation.

To place an ad about yourself in the Tele-Friend list, call (714) 796-5270 for the form that you need.

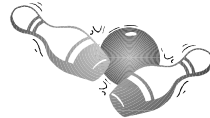
If you would like to talk to any of the people listed here, call (714) 796-5270 for a Tele-Friend list. You must be a Regional Center consumer or parent to respond.



Daryl of Anaheim ... “I am a 40-year-old woman, and I like watching movies, listening to music, making greeting cards on my computer, working in my puzzle book and going bowling. I work at a restaurant.”

Valerie of Buena Park ... “I like to cook, go bike riding, exercise, eat right and go shopping. I don't work right now, but I do drive.”

Dennis of Fullerton ... “I like to watch movies, watch baseball and basketball, and I like to go bowling. I am 45, I drive and have my own apartment and car.”



Daniel of Fullerton ... “I am a 27-year-old man, and I like to listen to music, watch movies and cook. I also like to ride my bike, swim, bowl, fish, lift weights, roller skate, and talk on the phone. I like to go to amusement parks and am looking for a girlfriend. I work in customer service at Home Depot and I have my own apartment.”

Maria Luisa of Tustin ... “I like listening to music, watching movies and TV, chatting on the computer and e-mailing, cooking, window shopping, camping, and bicycle riding. I am 29 years old and I live with my family.”



Recreation Opportunities for Adults with Disabilities in South Orange County

Here are some ideas for fun things to do. If you want to know about more activities in any part of Orange County, RCOOC has a Recreation Resource Guide that lists lots of interesting things to do. To get a copy, call Comfort Connection at (714) 558-5400 and ask for one. The guide is available in English, Spanish and Vietnamese. A \$3.00 donation is requested but not required.

◆ Vocational Visions Clubhouse provides social recreation in Mission Viejo. Contact Monty Starks at (949) 455-4697 or 837-7280. The Clubhouse is open Monday through Friday from 2:30 to 8:00 p.m., Saturday noon to 7:00 p.m. and Sunday, 1:00 to 6:00 p.m. Activities include playing pool, games and relaxing. Membership is \$20 per month.

◆ Laguna Art Museum, 307 Cliff Drive, Laguna Beach; located one block from the beach. The museum is open every day except Wednesday from 11:00 a.m. to 5:00 p.m. Admission is \$7 for adults, \$5 for students with ID and seniors 60 and over. The museum is wheelchair accessible. For more information, call (949) 494-6531 or see the Web site at www.lagunaartmuseum.org.

◆ Teens with Special Needs is a social program offered by the City of Laguna Hills providing dances, movies, excursions, and art classes for young adults ages 13 to 22. The contact is Kimberly Monach at (949) 707-2600. The fees vary from \$1 to \$3 for dances, \$3 to \$11 for excursions and \$30 to \$35 for art programs.

Consumer Advisory Team Update

Note: Sam Durbin was not available to write the article for this issue. Sam thanks Juda Carter, RCOC staff liaison to CAT, for providing the information for this column.

The CAT members voted to develop a service project to volunteer with children with disabilities. They will explore working with Special Olympics or volunteering for children's programs through PROUD (Parents Regional Outreach for Understanding Down Syndrome). In addition, a couple members of the team will participate in the in-service for day program

providers entitled "Meaningful Activities for Day Programs". They will give their ideas about what kinds of activities are appropriate for day programs.

The team has invited Jane Reifer, the passenger advocate for the Orange County Transportation Authority (OCTA), to speak at its March meeting. She will answer consumers' questions about riding the bus.

CAT meetings are held on the second Wednesday of the month from 10:00 a.m. to noon at RCOC's East/Central office, 801 Civic Center Drive, Santa Ana. If you would like to attend the meeting, please call Betty Bath at (714) 796-5263 to make sure the date hasn't changed.



CAT Team Members

Safety Stu's Corner

Staying Safe on the Bus

Hello Safety Friends:

This month it's time for a little bus safety talk.

Let's start from the top — the bus stop. Remember, always be aware of your surroundings; you know, don't play catch with the football or walk around with a headset on. When you hop aboard the bus, try to pick a seat near the bus driver.

If you are sitting on the bus and the person next to you starts asking you questions, like, "Where do you live or work?" or "What time do you go to school?" do not give him or her that information. If s/he continues to ask questions, you can say, "It is not



appropriate for me to give you that information." If the person continues to bother you, then you should move to the closest seat to the bus driver. If that person follows you, then tell the bus driver that person is bothering you.

If someone on the bus is bothering you, please don't get off the bus before your stop. That is how some people get lost. Make sure you still get off at your bus stop. When you get off at your bus stop, if that person gets off the bus and walks your way, go into the nearest store and ask for help.

What do you do if the bus driver is mean to you or inappropriate? First get out of the situation safely and then speak to someone, such as a caseworker, caregiver, parent, or someone else you trust. Explain to them what you feel. If they say, "don't worry about it" or "you are making too much out of it," and you are not happy with their response, as

always, tell someone else. The people at GET SAFE and Regional Center care about you, and that is why we teach you about safety.

If you have a friend who hasn't had the chance to yell "**Backoff**" or talk about safety, please share your safety tips with her or him, so s/he will **GET SAFE** like YOU! We are doing ongoing trainings, so keep an eye out for **GET SAFE™**, or if you want training, ask your service coordinator to contact us at info@getsafeusa.com.

If you have a safety question for Safety Stu and the Safety Team, write to us at Regional Center of Orange County, P.O. Box 22010, Santa Ana, CA 92702. If we use your question in Safety Stu's corner, we will send you a safety T-shirt, absolutely free.

Thanks for staying safe,
Safety Stu



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.
- ❖ **Aging Parents Support Group** - For parents who have older adult consumers of RCOC. Contact Joan Abrams, (714) 796-5312.
- ❖ **Ain't Misbehavin'** - A support network of parents interested in exchanging information on behavioral issues. Group is currently on hold. Assistance needed to plan and organize meetings. If you are interested in helping, call Anna Larson at (714) 889-7221.
- ❖ **Asperger Syndrome** - Contact Caroline Wilson, (562) 425-2292 or South County call Dr. Kyle Pontius, (949) 862-6006.
- ❖ **Autism Support Groups** - Huntington Beach area, contact Leaza Howe, (714) 841-6766; North County, contact Paula Peterson, (714) 288-9005; South County, contact Beverly Lee, (949) 249-9277; Newly diagnosed autism, contact Claire Miller, (310) 543-0662.
- ❖ **Cerebral Palsy** - For info. & support, meetings & groups, contact Family Support Services at UCPA, (714) 557-1291.
- ❖ **Chinese Parent Support Group** - For mandarin speaking parents of RCOC consumers. Contact Kitty Tsan at (949) 588-0123.
- ❖ **Circle of Support** - A monthly meeting for consumers, parents and assistants. Contact Gary and Claudia Eien, (714) 648-4185.
- ❖ **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, e-mail dads@adsi.net.
- ❖ **Epilepsy Family Support (See Parents of Kids with Epilepsy)**
- ❖ **Epilepsy Social Support Group** - To help fulfill the needs of those with epilepsy. Call Pat Porter, (949) 631-4333 for meeting info.
- ❖ **Family Visions** - For parents of visually impaired children. Contact Karin Crilly, (714) 573-8880, ext. 109.
- ❖ **Fathers Support Network** - For fathers of children with special needs. Call Jeff Braun, Family Support Network, (714) 543-7600.
- ❖ **First Evangelical Free Church Disabilities Ministry** - Numerous programs. 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.
- ❖ **Friendship Ministries** - Christian group at Orange County Worship Center for teenagers and adults with developmental disabilities; call the church at (714) 547-9631.
- ❖ **Guys and Gals Group** - An educational/recreational group for adult consumers. Contact Lena Lynch, (714) 246-8878.
- ❖ **Hearts United Grandparents Raising Grandchildren (HUG)** - Contact Irene Kontz, (714) 636-5430.
- ❖ **Mitochondrial Disease Group** - For parents & family members. Contact Lissa Mirand, (562) 920-9981.
- ❖ **Mom's Group** - A networking group for moms in North Orange County. Contact Jill Riley, (714) 288-1566.
- ❖ **Mommy Network** - South County (Dads are welcome). Call Julie McLain, (949) 888-1820 or Tina Muller, (949) 454-8573.
- ❖ **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** - For more information, 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.
- ❖ **Orange County Parents of Disabled Multiples** - For parents of twins, triplets, etc. 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 Kids with Epilepsy** - A support group. Contact Mary Repp at (949) 582-8404.
- ❖ **P.R.O.U.D. - Parents Regional Outreach for Understanding Downs-** Support for parents of children with Down syndrome. (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.
- ❖ **Team of Advocates for Special Kids (TASK)** - Educational assistance and support for parents. 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.
- ❖ **Welcome Orientation** - Informational tour of Comfort Connection Family Resource Center. Call Naomi Hall, (714) 558-5402 or Jacqui Kerze, (714) 796-5299.

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
-

What's The IDEA?

The Purpose of Special Education Assessments

By *Juda Carter, M.A.*
RCOC Education Training and Standards Coordinator

In the last issue of *Dialogue I* wrote about "Least Restrictive Environment". This edition will look at assess-



ments for special education. The assessment process can be a confusing and overwhelming one for parents. Assessments are utilized by school staff to determine the child's eligibility for special education services. They are also used to evaluate a student's present level of performance to determine the appropriate goals and objectives to enhance a student's educational progress.

Initial assessments to determine eligibility should look at the "whole child". Medical information and

standardized testing should be included. The process can also include observations by professionals and the family's information and observations of the child. A multi-disciplinary team approach is the most effective use of assessment. Assessments can also be utilized to determine if a child may benefit from additional supports such as speech and language services, occupational therapy or adaptive physical education.

How can you as a parent be informed and active in the assessment process? Here are a few helpful hints to remember:

1. A school district cannot assess your child without your written consent. From the date of receipt of your written consent, the district has 50 calendar days to complete the assessment and hold an IEP based upon the assessment results.

2. Parents should have the opportunity to review assessments in advance of the IEP meeting so that they may be better prepared to discuss the results. A parent can inform the school that they would like a

copy of the assessment prior to the IEP.

3. Parents should feel free to ask questions about the assessments that are utilized. What does the assessment measure? How is the data gathered?

4. Parents may request an assessment from a district at any time. Parents should put their request in writing. The district will provide the parent with the consent to assess form within 15 days of the written request for assessment. The 50 day time frame will begin once the school district receives the consent.

5. Parents may obtain an independent assessment if they do not agree with the school district assessment. Your local school district can inform you about guidelines for independent assessments.

Remember, being proactive in any activity with your child in special education will allow you to collaborate with your school to assure your child receives excellent educational services.

Next issue: "Related Services in an IEP."

The Changing Face of Parent Support

At the Regional Center we understand that families struggling with the challenges of raising special needs children have a need for extra emotional support. Over the years we have offered help in a variety of ways, but families have told us that even more support is needed. We recognize that our efforts to meet this need must be more intense and innovative than before. That's where Dr. Nancy McGovern comes in.

Dr. McGovern (who prefers to be called Nancy) is experienced in offering support to families, having facilitated many parent support

groups. Nancy has provided a parent support component to the Interagency Autism Assessment Center (IAC) in Laguna Niguel since it opened several years ago. She is a clinical psychologist employed by the Orange County Behavioral Health Care Agency (aka County Mental Health). RCOC has contracted with that agency to use Nancy's ser-

vices for a year. Nancy's mission while at RCOC is to help us develop a program where we can provide more comprehensive parent support.

See "Parent Support" on page 10



Dr. Nancy McGovern (center) meets with Comfort Connection staff members Patricia Arnold, left, and Hedy Hansen.

Comfort Connection Welcomes You

Comfort Connection is a place that is meant to be comfortable and comforting for families of children with special needs. Comfort Connection is a Family Resource Center (FRC) located next to the lobby of Regional Center of Orange County's Santa Ana office at 801 Civic Center Drive West. It is a separate entity from the Regional Center, but staff members of both organizations work closely together to share information and resources to assist families.

At Comfort Connection you'll meet staff members who are also parents of special needs children, and you'll find educational books and videotapes available for check-out, computers with Internet access, comfortable chairs, and a colorful playroom for children. Although Comfort Connection services are geared toward families who have children birth to three years of age born at risk for or with disabilities, everyone is welcome there. Many of the books, videotapes and other resource materials cover issues and topics pertaining to school-age children and teenagers. Also, Jacqui Kerze, RCOC's family support coordinator, has her office at Comfort Connection so that she can provide support to the families of children over age three that come in.

Hedy Hansen, Comfort Connection's executive director, recently ordered many new books and videotapes with grant funding. The topics vary from general parenting to behavior interventions to nutrition.

The Comfort Connection team looks forward to meeting you. Front row from left, Naomi Hall, Sandi Ames, Martha Gallegos. Back row from left: Patti Arnold, Jacqui Kerze (RCOC), Maria Pecina, Naomi Russell, and Hedy Hansen.



Also included are materials on autism and school interventions, educational advocacy, medication and kids, community resources for people with disabilities, and sensory integration, among many others. The age range covered by the materials goes from early childhood to young adulthood.

Hedy says, "Families want to know what to expect. It's helpful to get you thinking about five years ahead of where your child is now."

To allow you to get acquainted with the people who work at Comfort Connection, here are short biographical sketches about each of them. They are there for you, so please feel free to stop by Monday through Friday between 9:00 a.m. and 4:00 p.m. or call (714) 558-5400. You can also visit Comfort Connection's Web site at www.comfortconnection.org.

Hedy Hansen, Executive Director: Hedy has worked at Comfort Connection for five years, the last 2½ as executive director. She is parent of 13 year old Steven who has autism. Hedy was appointed to the Federal Interagency Coordinating Council

(FICC) by the U.S. Secretary of Education from 1999 to 2002 (see www.fed-icc.org for more information). She was appointed by the governor in August 2002 to the State ICC where she serves as co-chair of the Public Awareness Committee.

Sandi Ames, Public Awareness/Parent Resource Coordinator:

Sandi joined FRC three years ago. She facilitates parent-professional trainings, creates Comfort Connection's newsletter, and coordinates agency outreach opportunities. Her son, Cory, is 13 years old and daughter Shanel is 9 years old and has Down syndrome. Sandi is coordinator of I CAN (Collaborate/Advocate/Navigate), a mentorship program for parents of children ages 2 to 6. She provides training and support during the transition process into preschool and kindergarten.

Patricia Arnold, Information Specialist: Patti has been with Comfort Connection for 1½ years. She fills multiple roles as librarian, secretary, researcher and provider of parent-to-parent support. She says, "I like to tell parents that if we do not have what they are looking for, I can find it for them." Patti is a mentor for Parent Connection, the program that connects parents with other parents to share experiences and resources. She is mom to Christofer who is 10 and has autism.

See "Comfort," next page

Trevor (from page 1)

seems to take the challenge of her son's disability in stride. Her calm demeanor can provide reassurance to anxious parents that life goes on and your family can continue to function and enjoy life.

Naomi says, "I wouldn't have asked for this or wished it on my son, but you deal with what you're given and you do the best you can — take it a day at a time. I want my son to focus on the positive."

Trevor's parents first noticed delays in his development when he was about six months old. He couldn't hold his head up and wasn't gaining weight. When he was eight months old and still not improving, his doctor referred them to the Regional Center. Trevor started receiving occupational and physical therapy through California Children Services and RCOC. At 10 months old he was diagnosed with cerebral palsy (CP). The therapies helped him progress in his development and when he was three years old the school district started providing services.

Naomi says, "The services have been really nice. They (RCOC and school district) see that he has a need and have done what was needed."

Now Trevor is in sixth grade and is doing well in a special day class. He has a learning disability and doesn't

read yet, but he is learning his letters and letter combinations. He is also progressing in math, science and social studies. Socially, Trevor is doing very well. He and his classmates mingle with the other children during recess and lunch, as well as in the library and computer lab. They all have friends in other classrooms.

His teacher, Tony Perez, comments, "Trevor is very popular with the girls. They love to help him." Tony also says that Trevor is doing an excellent job using his walker at recess and lunch. Although Trevor uses a wheelchair most of the time, the walker helps him with muscle control, flexibility and coordination.

Naomi is honest about the challenges that Trevor experiences because of his disability. She says that accepting his disability and asking for help are difficult for him. Trevor has a form of CP that causes him to have involuntary jerky movements, especially when he gets excited (as when he watches an action movie or talks about speedboats, four-wheelers and snowmobiles). He gets easily frustrated, which can lead to behavior problems. She has taken behavior management classes to better handle the situation.

Disability or not, Trevor is all boy. He and Aaron share many of the same interests. They both like cars, trucks and going to construction sites. They both play baseball, Trevor in the Challenger league and Aaron in Little League. Naomi notes that Aaron is good about including his brother in whatever he is playing, whether outside or in the house. The boys differ in that Aaron is more into video games, while Trevor doesn't like to sit still very long. He likes to be out and about — at the park, the beach, even the grocery store.

Trevor's aspiration when he grows up? To own a construction company so that he can drive the bulldozers and operate the crane.



From left, Aaron, Naomi and Trevor Hall enjoy an outing at Mission San Juan Capistrano.

Comfort (from previous page)

Martha Gallegos, Hispanic Outreach Coordinator: Martha has been with Comfort Connection since 1994 providing hospital and community outreach as well as parent support to both Spanish- and English-speaking families. Martha has two sons and two daughters. Her second daughter, Christina, was premature and had many complications at birth.

She is now doing well and is included in regular classrooms in high school. Martha has facilitated and coordinated Fiesta Familiar meetings. **Naomi Hall, Parent Connection Manager:** Naomi has been at the FRC for 5½ years. She has two sons, Aaron, 9, and Trevor, 11 (see Consumer Spotlight on page 1). Naomi says, "Through my experience with Early Start and Special Education

services, plus my involvement in community activities, I am glad to be able to help others find resources and support." Naomi co-chairs the Family Support Services committee of the interagency group, CRIBS. **Maria Pecina, Parent Support and Parent Connection Coordinator:** Maria has been with the FRC for five years. She provides parent-to-parent

See 'Comfort,' page 10

Parent Support (from page 7)

She is talking – and more important, listening – to many people to discover where the needs are, how they can best be addressed and what form(s) family support needs to take.

Nancy says, “Many people want to remain independent and don’t like to ask for help. But being a parent, especially a parent of a child with special needs, you can’t always do it alone. All the information Regional Center has gathered recently shows how powerful parent support can be, and that parents want more support. How well parents cope with their situation is often tied to the social support they receive.”

Dr. Janis White is RCOC’s associate executive director and oversees the whole range of consumer services. She says, “We’ve been assessing family service needs by conducting parent focus groups as well as looking at survey data and information from our Proposition 10 study on early intervention services. These tools have validated our ongoing belief that family support is vital to the success of children with developmental disabilities. We are so happy to have Nancy on board to help us take our efforts to the next level.”

In order for Nancy to be most effective in her task, she needs feed-

back. That’s where you come in, if you’re a parent of an RCOC consumer. There’s a short survey included in this newsletter for that purpose. If you would rather have a conversation about this issue, feel free to contact Nancy either through your service coordinator or directly at (714) 796-5396. Perhaps you feel strongly about the need for more family support but you don’t know exactly how to communicate what you’re feeling. Nancy is available to talk with you in a supportive role and help you express your needs. As a consultant and advisor to the Regional Center, she is not involved in the decision-making for approval of services.

Parents have described Nancy as very approachable, warm and solution-oriented. She knows, though, that she can’t “fix” every problem, and she realizes the value of sometimes just “being there” to listen, to care.

She says, “I see myself having a dual role at the Regional Center. As a psychologist, I can facilitate ongoing support groups, and with my clinical background I can help families and service coordinators problem solve difficult issues.”

Nancy considers herself to be at the beginning stages of exploring options for family support. She recognizes that one size does not fit all.

RCOC has many great opportunities for parent support such as Parent Connection, where parents who are new to Regional Center can talk to other parents who offer support and resources from their own experience. Another avenue of support is Comfort Connection Family Resource Center (see article on Comfort Connection in this issue). But maybe for one reason or another it’s been hard for you to find other parents you relate to or the existing supports don’t meet your needs. Nancy is looking at these issues and others that parents raise to try to develop new and different support alternatives. From her own experience, though, she knows that small, informal groups allow parents to interact with each other and bond in a “safe” environment. She is very interested in helping parents start a daytime support group. She is also working closely with the staff at Comfort Connection Family Resource Center to search for new approaches to family support.

If you have any ideas that can help guide the Regional Center in this area, please make contact with us through your service coordinator, the enclosed survey (on page 11), or directly with Dr. Nancy McGovern at (714) 796-5396. She is here to listen to your concerns.

Comfort (from page 9)

support, information and referral and is involved in community outreach activities. Maria has three children, and her youngest, Jennifer, 6, has Down syndrome. Maria organized Grupo de Apoyo Síndrome de Down “Arcoiris,” a support group for Spanish-speaking parents of children with Down syndrome.

Naomi Russell, Parent Support/Parent Connection Coordinator: Naomi has been at Comfort Connec-

tion four years. She provides parent-to-parent support and trains parent mentors for the Parent Connection program. She is mom of Austin, 10, who has Down syndrome, and Daniel, 22 months, who currently has a speech delay. Naomi also has two step-children. Naomi co-chairs the Family Support Services subcommittee of CRIBS and is on the Parent Leadership Council.

Jacqui Kerze, RCOC Family Support Coordinator: Jacqui has

worked at RCOC for five years. Although not on the staff of Comfort Connection, Jacqui and the Comfort Connection staff members work closely together to provide seamless expertise and understanding to families of children with special needs from birth through adulthood. Jacqui can provide parents with information, referrals and support. Jacqui’s direct telephone number is (714) 796-5299. Jacqui is the parent of 8-year-old Michael who has Down syndrome.

Important Things to Know...

Aging parents support group in South County. Joan Abrams, RCOC's gerontology specialist, would like to start a monthly support group for aging parents in South Orange County. If you are interested, please call Joan at (714) 796-5312. The meetings would provide an opportunity for parents of adult children with developmental disabilities, living either at home or out of home, to get acquainted. Guest speakers would be invited and topics of discussion could include quality assurance standards for group homes,

problem behaviors and special needs trusts.

Get a free child safety seat inspection. Car crashes are the number one cause of death of children, and field studies have shown that eight of ten children are incorrectly buckled in. To find a free inspection location near you, call toll-free 1(866) SEAT-CHECK or log on to www.seatcheck.org. Both the toll-free number and the Web site offer information in Spanish as well as English.

Religious education for children with autism ... St. Bonaventure Catholic Church in Huntington Beach is now offering specialized religious education classes for children with autism. This program allows parents to attend Mass while their children receive individual attention to learn about the love of God. All children are welcome. For more information, please call Virginia in the St. Bonaventure Religious Education office at (714) 846-1187.



Family Support Survey

(Return in the attached postage-paid envelope)

1. Would you attend a parent support group if it were available? Yes No
2. If yes, would day or evening be better? Day Evening
3. Would you be interested in a quarterly information meeting with a large group? Yes No
4. Would you be interested in a small, informal meeting with other parents of children with similar needs that meets on a regular basis? Yes No
5. What kind of support would be helpful to you? _____

6. Other comments: _____

7. Would you like someone to contact you about your need for family support? Yes No

Optional (Unless you answered Yes to question 7)

Name: _____ Consumer's Name: _____

Telephone Number: (____) _____

Board of Directors 2002 - 2003

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

2002-2003 Board Meetings:

❖ May 1 ❖

*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

San Juan Capistrano Office

26311 Junipero Serra Road, Ste. 180
24-hour phone no.: (949) 234-8800
TDD: (949) 488-3399

Santa Ana Office

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

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, H.R. Director
Cinda Bottorf, Developmental
Resources Director
Arleen Downing, MD, Medical Dir.
Larry Landauer, Consumer and
Community Resources Director
Ed Scherer, Information Services Dir.
Patricia Glancy, 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!

R.A.D.D. Review

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