

Dialogue

Volume 29 No. 1 Winter 2015



Consumer Spotlight

Sam Durbin and Jim Martin

any people might think that Sam Durbin and Jim Martin have little in common, other than the fact that both are Regional Center of Orange County consumers.

Sam's background was very difficult and included childhood abuse. He remembers living in an institution, later in a board and care facility, and then in a group home. As a young adult, he repeatedly ran away from residential settings where he had little freedom to make any of his own decisions. In fact, 20 years ago, he was actually homeless for a time.



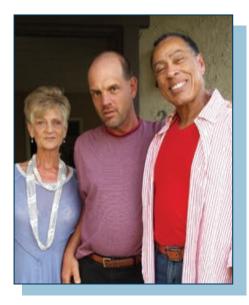
Sam Durbin (left) with Cathy DeMello

In contrast, Jim grew up in a loving home. Now 41 years old, he is still close to his mother and stepfather, Jan and Michael Riley. And though Jim has lived on his own for the past 11 years, he typically gets together with Jan and Michael several times a week for movie nights or to go out to dinner.

While these consumers' upbringing was not at all alike, and the paths they took to arrive where they are now in life are very different, Jim and Sam actually have quite a lot of important things in common.

Jim and Sam actually have quite a lot of important things in common.

Both live in their own apartments with the help of RCOC-funded services and supports, such as Independent Living Services (ILS) and Supported Living Services (SLS), which augment generic services they receive – including housing support in the form of HUD vouchers to help with rent. Both are firmly in charge of decision-making for their lives and futures. And both have strong circles of support, including both professionals and personal relationships with people who are committed to helping them live "self-determined" lives.



Jim Martin (center) with his parents Jan and Michael Riley

Jan Riley couldn't be more proud of her son's independence. She and Michael accepted Jim's decision when he let them know he was ready to move out of the family home.

"When the time came, he was ready to go," she said. "As a parent, it's hard to let go, but he's done really well."

Jim loves his job at Trader Joe's market, where he has worked for more than 12 years as a courtesy clerk with the support of a job coach from the Orange County Adult Achievement Center. He's proud to be an important member of the store's team and is well-liked by his co-workers. However, the ILS help Jim receives from the Orange County

(See Sam Durbin and Jim Martin on page 7)

Dialogue

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Upcoming 2015 Board MeetingsMarch 5 • May 7 • June 4

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

RCOC Administration

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Board Update

New Member Joins RCOC Board

am Nguyen has been elected to the RCOC Board of Directors to serve a one-year term through December 2015. The parent of a young daughter who receives Regional Center services, Tam owns and operates Advance Beauty College, a successful career college with campuses in Garden Grove and Laguna Hills. He also serves on the volunteer board of advisors for Behavioral Health Works, an autism service provider.

A medical doctor, Tam's educational background also includes an MBA from Cal State Fullerton. He also has considerable volunteer experience. Among the organizations he has served, as a board member or board leader, include: the Vietnamese American Chamber of Commerce, Cal State Fullerton Philanthropic Foundation Board of Governors, the Cal State Fullerton Executive Business Council, the American Association of Cosmetology Schools, and the Garden Grove Community Foundation. He has also served the Project Vietnam Foundation, both as a board member and volunteer delivering medical care to those living in poor rural villages in Vietnam.

RCOC Board Member Named to Task Force

Fernando Peña, an RCOC consumer and Board member, has been appointed to California's Developmental Services Task Force. The task force includes 26 consumers, advocates, regional center representatives, service providers, union representatives,

family members of developmental center residents, members of the Legislature and Department of Developmental Services staff. The group is charged with examining community services for those with developmentally disabilities and developing recommendations to strengthen the community care system. Among the issues to be explored are community rates, the impact of new state and federal laws and regulations and staffing levels at regional centers.

Budget Update

n January, Governor Brown released his proposed Lbudget for the 2015-2016 fiscal year. The Governor is not proposing any major increases to developmental services programs. However, he is planning to provide an additional \$159 million to cover regional centers' budget shortfall in the current year. His proposal also includes additional funds that regional centers will need during 2015-2016 to pay costs associated with new consumers entering the regional center system and higher costs for those already receiving services. The next step in the budget process takes place in mid-May when the Governor will issue his May Revise – a revision of his budget proposal that takes into account the latest information about the state's economic and budget situation. After that, the Governor and State Legislature will work together to complete the budget for the fiscal year that begins July 1, 2015. For more information, go to www.ebudget.ca.gov.

Executive Director's Report

RCOC Embraces Self-Determination for Consumers

By Larry Landauer, Executive Director

hen SB 468 passed and was signed into law back in the Fall of 2013, it set in motion the expansion of a statewide selfdetermination pilot program. This alternative to the traditional Regional Center service model has caused quite a lot of concern among consumers and families. With this in mind, we have included in this issue of *Dialogue* an update on the program and links to more information (see page 6) so those who are interested can follow the Department of Developmental Services' efforts to implement it.

At the same time, I want to assure those who rely on RCOC that the expanded pilot program need not change their relationship with us. No one will be forced to participate in the self-determination pilot.

You don't have to have self-funded services to live a self-determined life.

I also want to remind everyone we serve and all those with whom we do business that self-determination has actually been happening in our community for many years. Jim Martin and Sam Durbin, the consumers

whose stories we share in this issue's Consumer Spotlight, are just two examples of adults with developmental disabilities living meaningful, fulfilling, self-determined lives in our community. Past issues of *Dialogue*



feature many more, and every RCOC service coordinator can name countless others.

That's because the selfdetermination

movement took root here in Orange County (and in many other parts of California) long before SB 468 became law. With self-determination as a guiding principle, RCOC works in partnership with consumers and families. Through the Individual Program Plan (IPP) process, which is at the heart of the Lanterman Act, we learn about each consumer's hopes, dreams, needs and life circumstances. With that information, we work together with consumers and their circles of support on service plans to meet individual needs and facilitate personal choices.

Of course, like the rest of us, a consumer's circumstances can change, and needs and preferences may evolve over time. For example, some consumers may want to live independently as soon as they leave high school, while others like Jim may not be ready until later on. Some consumers like Sam need very little in the way Regional Center-funded services when they are younger, but may need additional support in areas such as

transportation when they are no longer able to get around on their own.

The IPP process recognizes the uniqueness of every individual, and I'm proud of our Regional Center's record of collaborating with consumers and families to devise highly-personalized services and supports that meet critical needs and comply with Lanterman Act requirements for good stewardship of tax dollars.

The self-determination movement took root here in Orange County long before SB 468 became law.

Unfortunately, some people seem to place disproportionate emphasis on the self-determination program's aim of putting the budget for services under the control of consumers and families, rather than Regional Centers. However, our view and our commitment, is that you don't have to have self-funded services to live a self-determined life. While RCOC is always here to provide counsel and expert guidance, assure quality services, and handle the multitude of administrative details that go with service funding, the consumers/ families we serve are always in the driver's seat.

Sam, who has been one of our community's most effective advocates and role models for self-determination, put it best when he said: "It [self-determination] isn't about the money. It's about the people – my peers – and what people do with their lives."

Consumer Advisory Team Update

Special Olympics World Games 2015

By Sylvia Delgado, CAT Chair

ike many other consumers, I have a soft spot for the Special Olympics. I have participated in many events, and it was always a lot of fun to compete and meet new people. That's why I was so excited to hear that the Special Olympics World Games is taking place in Los Angeles this year.

The Opening Ceremonies will take place on July 25 at the Los Angeles Memorial Coliseum, which is the same place that Opening Ceremonies took place for

the Olympic Games in 1932 and 1984. Then, the various sporting events will take place at locations throughout Los Angeles through August 2,

2015. Around
7,000 athletes
from 177
countries will
be participating
and some events
will even be
broadcast on
ESPN!

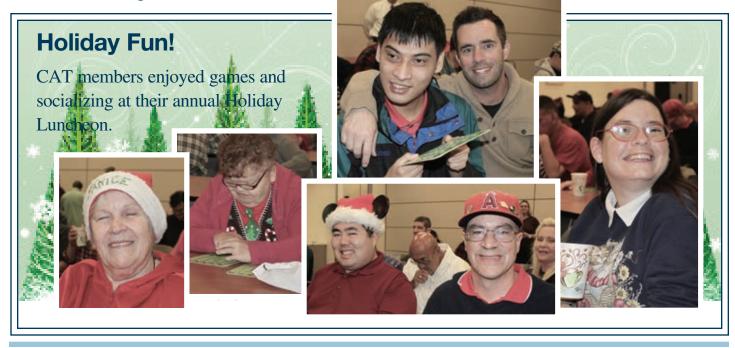
But the fun begins even before the Opening Ceremonies, because there will be three days of pre-game activities in dozens of cities in Southern California that will host delegations. Many Orange County cities will be among the host cities that will be organizing fun sports and cultural activities for the athletes.

Upcoming CAT Meeting Dates

March 18 April 15 May 20 June 17

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

The website to get more information on the Special Olympics World Games is www.la2015.org.



Behavior Management Workshops for Parents

Regional Center of Orange County offers these workshops at no cost to parents. To gain the most value from them, parents are encouraged to attend all sessions in a series. The Behavior Management workshop covers essential 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. The Social Skills Training workshop is focused on helping parents nurture social skills among children. Parents are actively involved, and invited to discuss the specific behavioral challenges they are confronting. Advance reservations are required and group size is typically 8-15 families.

Contact your service coordinator or Julieann Garcia 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.

Behavior Management Workshop (5 sessions)

Presented in English by Dr. Tu

When: Tuesday evenings – March 24, March 31, April 7, April 14, April 21

(NOTE: Toilet training is the focus of the last session of this workshop)

Time: 6:30 – 9:00 p.m.

Location: RCOC Westminster Office, 5555 Garden Grove Blvd., Ste. 100

Social Skills Training (6 sessions, focused on ages 5 - 11)

Presented in English by Footprints

When: Tuesday evenings – April 21, April 28, May 5, May 12, May 19, May 26

(NOTE: Toilet training is the focus of the last session of this workshop)

Time: 6:30 – 9:00 p.m.

Location: RCOC Santa Ana Office, 1525 N. Tustin Ave.

Parking is located in the structure across from the RCOC office building

Behavior Management Workshop (5 sessions)

Presented in Spanish by Dr. Ana Lorenz

When: Tuesday evenings – June 2, June 9, June 16, June 23 June 30

(NOTE: Toilet training is the focus of the last session of this workshop)

Time: 6:30 – 9:00 p.m.

Location: RCOC Westminster Office, 5555 Garden Grove Blvd., Ste. 100

Plan to Attend: Technology and Autism

COC will host a presentation by Dr. Gregory Abowd, Distinguished Professor in the School of Interactive Computing at Georgia Tech. Dr. Abowd currently serves as the Director of the Health Systems Institute, a joint Georgia Tech/Emory University research institute investigating the impact of technologies on healthcare delivery. He is the father of two boys with autism, and has worked over the past decade to apply new technologies to address challenges in the diagnosis, treatment and research relating to autism and other developmental disabilities.

The presentation will take place on **March 23 from 4:00 – 8:00 p.m.** at RCOC's headquarters office in Santa Ana. Cost is \$30 per person or \$70 for professionals applying for continuing education hours. Cost includes a boxed meal. For more information and to register, visit RCOC's website (www.rcocdd.com) or call Jacqui Knudsen at (714) 796-5299.

California Takes Steps Toward Launching Self-Determination Program

n the last day of 2014, the Department of Developmental Services (DDS) submitted its application for federal funding for California's statewide Self-Determination Program. The Self-Determination Program was created by SB 468, which was signed into law in 2013. It is a voluntary program and an alternative to the traditional way of providing regional center services.

Since the law requires that the program receive federal funding to be implemented, the state's application for federal funds means that process is now underway. However, the federal government has 90 days to perform its initial review and most people expect the federal government to request additional information before deciding whether or not to approve California's application.

If and when the federal government approves California's plan, there will also be a period when DDS creates informational materials about the program and regional centers are trained in the mechanics of the program.

So, while it could be quite some time before the Self-Determination Program is actually rolled out, it has generated a considerable amount of interest – as well as some concern – among consumers and families across the state.

Here are some key things to know about the program at this point:

Individual Budgets

With the Self-Determination
Program, consumers and families will
work with an individual budget that
they can use to purchase the services
and supports they need to implement
their Individual Program Plan (IPP).
Though there may be case-by-case
adjustments, in general the annual
individual budget will be the total
amount of purchase of service
expenditures the regional center has
spent on the consumer's behalf during
the previous 12 months.

It is important to note that, as with traditional service arrangements, there will still be significant restrictions on how the individual budget funds can be spent. For example, funds can only be spent on services and supports that are eligible for federal funds. Like existing regional center requirements, self-determination services and supports can only be used when generic services and supports are not available. In addition, participants will be required to use financial management service providers (vendored by regional centers) to assist with payments and to provide employee-related services, such as tax withholding.

Limits on Participation

The Self-Determination Program will begin small. Phased in over three years, it will serve a maximum of 2,500 consumers statewide to start. Consumers in all regional center catchment areas will be able to participate; however, the process for selecting and enrolling these initial participants has not been finalized.

More Information from **DDS**

Recognizing the high level of interest the program has generated, DDS has created a special section on its website devoted entirely to the Self-Determination Program. That section includes the law, along with regular updates on the status of implementation and Frequently Asked Questions.

If you'd like to learn more, you can visit the DDS site (www.dds.ca.gov). From the home page, click on the Self-Determination Program link on the left. Those who would like to receive regular updates and register their interest in participating can email DDS to express their interest. The email address and instructions appear in the Frequently Asked Questions section of the website.

Get Your Tickets for Spotlight Awards 2015

ark your calendar and plan to attend the 2015 Spotlight
Awards Ceremony and Gala! The event will take place on
Friday, March 20, 2015 at 6 p.m. at the Embassy Suites,
11767 Harbor Blvd. (Please note the new location.) Individual tickets
cost \$45 and table sponsorships are available, beginning at \$1,200
for a table of 10. Check the RCOC website at www.rcocdd.com for
additional information or you can call Integrity House at (714) 818-6937
for tickets and information. The deadline for reservations is March 13.
No tickets will be sold at the door. See you there!

Sam Durbin and Jim Martin (cont. from pg. 1)

Adult Achievement Center also helps him enjoy his time off.

Often, he walks or rides his bike to do his shopping and do errands. He also likes to ride his bike to the local library. A fan of classic jazz music, Jim checks out music CDs that he's able to listen to at home. Though he doesn't read, he enjoys books with the library's great selection of audiobooks, and he has a huge collection of movie DVDs that he enjoys watching at his own home and with his family.

"His priorities drive how we support him," said Jennifer Casteel, the RCOC staff member who was Jim's service coordinator until she was recently promoted to a new position. "He defines what's valuable to him and that's how it should be."



Jim often rides his bike to work and to do errands

Jeff Johnson, who has been Sam's service coordinator since 2006, agrees and notes that Sam is involved with every decision he wants to make for himself.

"I make suggestions, offer ideas and educate Sam about different choices, but he still has control," said Jeff.

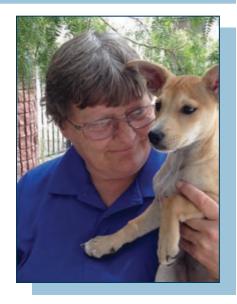
Facilitating these types of choices – ones that people without disabilities take for granted – is the essence of self-determination, a movement that Sam has participated in for much of his adult life.

"Don't let anybody tell you that you can't do it."

"People want to live the life that they want," said Sam, who has spoken on the subject to professional and consumer groups, legislators and other policymakers in Sacramento,

San Francisco, Washington, DC, and many other places.

Over the years, his advocacy has included serving on RCOC's Board of Directors, chairing RCOC's Consumer Advisory Team, and chairing the Department of Developmental Service's Consumer Advisory Committee. He's also a founding member of Alliance of Abilities, the nonprofit organization that started the Integrity House clubhouse where Sam now works with longtime friend Cathy DeMello. He has even written two books on the subject, which he says are "about helping other people to see that they can live amazing, self-determined lives."



Sam enjoys spending time with Koby, his puppy

"[Self-determination] is a burning deep within us that motivates us to be independent, responsible, equal human beings," he said. "My peers have dreams and goals and through self-determination, their dreams and goals can be met."

For Jim, a year or so of preparations that involved both his family and RCOC helped to ensure a smooth transition when he first moved out of the family home, but all agree it was worth the effort.

Both are firmly in charge of decision-making for their lives and futures.

"I'm glad I live by myself," said Jim.

Sam's advice for other consumers thinking about taking a more active role in making more decisions for themselves is simple: "Don't let anybody tell you that you can't do it," he said.



Dialogue Newsletter



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Regional Center of Orange County Locations

Santa Ana Office

Orange Office

Westminster Office

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

3111 N. Tustin, Suite 150 24-hr Phone: (714) 796-3700 5555 Garden Grove Blvd., Suite 100 24-hr Phone: (714) 796-2900

OC Parents Exploring New Residential Option for Aging Adults

n Orange County alone, there are nearly 700 adults with _developmental disabilities who are age 45 or older and live with their parents. Many of these adults came of age before options like Independent Living Services (ILS) and Supported Living Services (SLS) were common choices. For others, it was simply their preferred choice to continue living in the family home.

The great news is that the vast majority of these adult consumers are thriving and can expect to live much longer lives than used to be the case for people with developmental disabilities.

However, this longevity also means their aging parents may not always be able to care for them. With this in mind, RCOC has an active effort underway to help these families plan for the day when the parents – either through death or their own disability - will no longer be able to care for their loved ones.

A dedicated group of Orange County parents is also working to develop a new residential option for these older consumers. Their idea is to borrow from the assisted living model that has been so successful in meeting the needs and preferences of typical adults who are no longer able to live

independently, but do not need the high-level care provided at nursing homes. The parents call this longterm supported living community FUTURES, and they currently envision creating it on state-owned Fairview Developmental Center land.

Rhys Burchill, a long-time advocate and retired local Area Board Executive Director, is among the parents spearheading the effort and the nonprofit organization created to explore the concept's feasibility. Those interested in learning more about the FUTURES community can contact Rhys at RMorganCorp@yahoo.com.