

Consumer Spotlight

Joey Knutson

When Joseph “Joey” Knutson was born in 1965, the rubella vaccine had not yet been introduced and the United States was experiencing an epidemic that saw 12.5 million cases of the disease. The epidemic led to thousands of fetal deaths and an estimated 20,000 children being born with congenital rubella syndrome (CRS), which can affect all organs but is most commonly associated with deafness and intellectual disability. Joey was one of those children.

While pregnant with Joey, her first child, his mother had contracted rubella while babysitting for some family friends. However, it wasn't until he was a toddler that Joey's parents realized he wasn't responding normally. Initially, it was thought that Joey's only disability was deafness.

While pregnant with Joey, her first child, his mother had contracted rubella.

With little in the way of support available for families in their situation, the Knutsons moved from Washington State to California, eventually enrolling Joey at the



Joey with his birthday cake.

California School for the Deaf in Riverside, where he learned some sign language. Over time, though, it became clear that Joey had issues beyond his inability to hear and speak.

“My parents spent every dime they had trying to find out ‘what’s going on with Joey,’” said Tim Knutson, Joey’s younger brother, who remembers him doing things like chewing on wood furniture and other unusual behaviors – though, to Tim, as a child, nothing seemed out of the ordinary.

“He was my friend,” Tim said simply, noting that it wasn’t until he began to

outgrow his older brother that Joey’s challenges became apparent to him.

As Joey entered his teen years, his difficult behaviors included head-banging which made him a danger to himself, so his parents made the difficult decision to admit him to Camarillo Developmental Center at the age of 14. Eventually, Joey was diagnosed with autism and severe intellectual disability and he came to live at Fairview Developmental Center, where he was closer to his family who resided in Orange County. He was at Fairview for 27 years.

Eventually, Joey was diagnosed with autism and severe intellectual disability.

While Joey was at Fairview, the family took part in numerous activities at the developmental center. In addition, Joey would typically spend one weekend a month, as well as holidays, with the family. However, it wasn’t until the boys’ father passed away in 2006 that Tim became more

See **Joey Knutson** on page 7.

Dialogue

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Upcoming 2015 Board Meetings

September 3 • November 5

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

Two New Members Join RCOC Board

Marcell Bassett and Magnolia "Noly" Guardamondo were elected to the RCOC Board of Directors at the June 4 meeting. These two new volunteers will serve one-year terms beginning July 1, 2015.

An RCOC consumer who has autism, Marcell has many accomplishments and interests. He has attended college and has worked at IKEA for 19 years.

Though he has never before served on a Board, Marcell is proud to be actively involved in his



Marcell Bassett

program, Project Independence, which has helped him learn to live independently and advocate for himself. Also active in his church, Marcell serves as an usher. He has many hobbies, including running marathons, playing guitar, meeting new people, visiting friends, art, and watching his favorite television shows and movies. Marcell also enjoys swimming and learning new things through his laptop computer – even sharing his thoughts through a blog that he emails to his friends.

"I have experience being in a program, and I also have a job coach," he noted on his Board application. "This gives me a perspective that will help RCOC grow and receive new ideas."

Noly is the parent of an RCOC consumer who has Down syndrome and is on the autism spectrum.



Magnolia "Noly" Guardamondo

A licensed Marriage and Family Therapist with a Master's degree in Clinical Psychology, Noly is executive director for UP of Southern California, which provides school support, education, parenting classes, social skills classes and counseling to families and individuals with disabilities and other challenges. Previously, she served as Chief Operating Officer of UCP-OC. In both roles, she has worked closely with boards of directors, developing a deep understanding of how they work and their purpose. In her free time, Noly enjoys gardening, scrapbooking, traveling and spending time with her family.

In her personal statement describing why she wished to serve on the Board, Noly said: "I would like to give back and be of service to an organization that has given my child and my family so much over the years."

Executive Director's Report

Fairview DC Closure to Bring More Affordable Housing

By Larry Landauer, Executive Director

This year's state budget deal brought much more than a simple allocation of dollars and cents for the developmental disabilities community. Among its many other provisions, the budget begins the process of closing Sonoma Developmental Center by the end of 2018. It also plans for the closure of Fairview Developmental Center in Costa Mesa and the non-secure treatment portion of Porterville Developmental Center, with the last closure to be completed in 2021.

The imminent closure of Fairview signifies the end of an era.

The imminent closure of these developmental centers, especially Fairview, signifies the end of an era. For most RCOC consumers who were born in recent decades -- when the regional center system came into its own and offered alternatives to institutions -- the idea of life apart from the community and their typical peers is very foreign. However, when it first opened in 1959, Fairview was the state's newest developmental center. At the outset, it had the capacity to house 2,622 people and was intended to house some 4,125

people. That never happened. The actual population peaked in 1967 at 2,700 people and has fallen steadily as high quality residential options for people with even the severest disabilities blossomed in communities across California.



For many years, Regional Center staff have worked collaboratively with staff at Fairview to transition developmental

center residents into the community. As of June 24, there were just 275 residents. Of these, 80 are waiting to join their peers living in less restrictive settings in Orange County, along with one resident of Porterville Developmental Center. The experience of Joseph "Joey" Knutson, who is featured in our Consumer Spotlight in this issue, is representative of the good life that awaits them.

That's not the only good news. This year's budget also sets aside up to 20 acres of the Fairview property to be developed into 245 much-needed housing units. The law contains an important provision requiring that 20 percent of these units be available and affordable to regional center consumers. The project will be called Shannon's Mountain. With housing in Orange County among the costliest in the state, this is a big win for us. It is expected to yield many good quality apartments for RCOC consumers, who will live side-by-side with families and individuals without

disabilities, similar to the highly-successful 39-acre Harbor Village complex.

Since the cost to provide services in the community is far less than in the developmental centers, the state will reap millions of dollars in savings from these closures. Thus, we are also gratified that the Legislature declared its intent that savings derived from the developmental center closures should benefit consumers. To help ensure that happens, it directed that lease revenues from Fairview Developmental Center housing projects be used by the Department of Developmental Services (DDS) to support consumers, including subsidizing rent, and authorized creation of a trust fund for DDS to deposit revenues from those housing projects.

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All who have worked so hard over the decades to realize the vision of the Lanterman Act will have much to celebrate in 2021. And while we certainly hope that future budgets will make up some of the financial ground service providers lost through years of budget cuts, we have reason to appreciate what our elected leaders have done this budget year to ensure that a good life in the community is accessible to all Californians with developmental disabilities.

Consumer Corner

Consumers' Advisory Committee Off to a Great Start

By Fernando Peña, CAC Chair and Jyusse Corey, RCOC Consumer Advocate

We are excited to announce that the first Consumers' Advisory Committee (CAC) meeting took place in July. You may remember that in the last issue of *Dialogue*, Larry Landauer announced that RCOC's Board of Directors created this new Committee as a way of giving consumers an even greater opportunity to have a strong voice on important issues.

RCOC Board Chair Alan Martin appointed Board member Fernando Peña to chair the new committee. Other



Fernando Peña



Jyusse Corey

committee members include RCOC Board members Peter Kuo and Palak Shah, Consumer Advocacy Team (CAT) chair Sylvia Delgado, Sam Durbin, Stephen Gersten, Sean Sullivan and RCOC Consumer Advocate Jyusse "Jess" Corey.

The CAC's focus will be on giving voice to the more than 9,700 adults served by RCOC by gathering information about what is important to them, advocating on their behalf about those issues, helping organize events that expand their knowledge, and helping them develop self-advocacy and leadership skills.

At our first meeting, we decided that employment and self-determination should be topics on every month's CAC agenda. We also volunteered to help Integrity House organize and

advertise the Third Annual Self-Determination Conference in October.

We want to be sure that adults in every living arrangement have a voice on the CAC. So, the Board is looking for one or two people who live in group homes to serve on the committee. If you live in a group home and think you might want to participate on the CAC, please let your RCOC service coordinator know.

We are excited about the new CAC and we hope you are too!

Consumer Advocacy Team Meetings

September 16 • December 16

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



Plan to Attend: Third Annual Self-Determination Conference on Sat., Oct. 24

If you're an adult consumer, be sure to save the date and plan to attend the Third Annual Self-Determination Conference on Sat., Oct. 24 from 9 a.m. – 4:30 p.m. at the Elks Club, 212 Elks Lane in Santa Ana. Organized by and for consumers and supported by RCOC, this year's conference will feature special guest keynote speaker Santi Rogers, who is the Director of California's Department of Developmental Services (DDS). The focus of the conference is *Living The Good Life: My Life, My Way*. For more information and to register, contact Integrity House at (714) 542-0855 or go to their website at www.allianceofabilities.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 Tracy Vaughan 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.

Social Skills Training

(6 sessions, focused on ages 12-18)

Presented in English by Melissa Sweitzer

When: Thursday evenings – Aug. 6, Aug. 13, Aug. 20, Aug. 27, Sept. 3, Sept. 10

Time: 6:30 – 9:00 p.m.

Location: RCOC Orange Office
3111 N. Tustin St., Ste. 150

Behavior Management Workshop

(5 sessions)

Presented in English by Footprints

When: Tuesday evenings – Sept. 15, Sept. 22, Sept. 29, Oct. 6, Oct. 13

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

Time: 6:30 – 9:00 p.m.

Location: RCOC Orange Office
3111 N. Tustin St., Ste. 150

Behavior Management Workshop

(5 sessions)

Presented in Spanish by Footprints

When: Tuesday evenings – Oct. 13, Oct. 20, Oct. 27, Nov. 3, Nov. 10

(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

Fiesta Educativa

Fiesta Educativa Orange County, an advocacy organization that helps Spanish-speaking families access services for their children with special needs, will host its 15th annual conference on Sept. 28, 2015 from 9 a.m. – 3 p.m. at Anaheim Community Center located at 250 E. Center St., Anaheim, CA 92805. This event is supported by RCOC. For more information and to register, please contact Cecilia Mercado at (714) 533-5815 or cmercado@fiestaeducativa.org.

We're on the Move!

The RCOC office currently located in Westminster is moving to Cypress.

The new address will be
**10803 Hope Street,
Cypress, CA 90630.**

Phone numbers and email addresses will stay the same.

Self-Determination Program Makes Progress

Back in 2013, the State Legislature passed SB 468, which set in motion the creation of California's Self-Determination Program. A voluntary program, it is envisioned as an alternative to the traditional way of providing regional center services. It will, in essence, allow a consumer or family – working with a financial manager – to act as their own service coordinator.

California's Self-Determination Program is envisioned as an alternative to the traditional way of providing regional center services.

The law requires that the program receive federal funding to be implemented, and the first step in that process took place at the end of last year, when the Department of Developmental Services (DDS) submitted California's application for federal funding. Since then, the federal government and DDS have had several conversations about California's plan. While the decision makers at the federal Centers for Medicare and Medicaid Services (CMS) have indicated their conceptual agreement with the plan, there are still several more steps that must take place before it is known whether federal funding will be forthcoming. For example, when and if CMS directs DDS to move forward with the application, the application will be posted on the Department's website

for 30 days prior to being formally submitted to CMS. Then, CMS will have 90 days to approve, deny, or request additional information which could extend the review period.

In the meantime, regional centers and others throughout the state are moving forward on other requirements of the law.

Orange County Names Local Advisory Committee

In an effort to ensure effective implementation of the Self-Determination Program and facilitate sharing best practices and training materials, each regional center is required to establish a Local Advisory Committee including consumers, family members, and the regional center consumer advocate, as well as other advocates and community leaders who reflect the area's diversity.

Orange County's committee has already been formed and held its first meeting at the end of June. Committee members appointed by RCOC's Executive Director Larry Landauer include: parents Rhys Burchill and April Lopez, consumer Sam Durbin, RCOC's Consumer Advocate Jyusse "Jess" Corey and Training and Organizational Specialist Nicole Barrios, who will provide staffing/support. Committee members appointed by Susan Eastman, manager of Orange County's Regional Office of the State Council on Developmental Disabilities, include: consumers Daniel Harrington and

Tim Jin, and parents Andrea Kumetz-Coleman and Michael Rillera. Client Rights Advocate Jacqueline Miller is also on the committee.

Budget Lifts Participation Limit

When the original legislation was passed, enrollment in the Self-Determination Program was limited to a maximum of 2,500 consumers during the three-year phase-in period. However, the recently-passed budget "trailer" bill addressing developmental services issues changed that. It authorized the Department of Finance to increase the number of people in the program. It also specified that the program would also be open to people leaving California's developmental centers to live in the community.

More Information from DDS

DDS has created a special section on its website devoted entirely to the Self-Determination Program. That section includes the law, itself, 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.

Joey Knutson continued from page 1.

involved in the details of his brother's living arrangements, becoming Joey's co-conservator with their mother.

Their mother was a firm believer that Fairview was the best place for her son to live, but Tim wasn't so sure. And when the Orange County Public Defender insisted that Joey could be well-served and have his needs met in a less restrictive setting in the community, Tim was open to the idea of him living in a group home environment: "I'd rather be one of four, than one of four hundred" is the way he puts it. He brought that perspective to his active involvement in the transition process and to the process of selecting Joey's new home.

"Tim really wants what's best for his brother," said Scott Sweaza, who has been Joey's RCOC service coordinator for the past two years and worked with him on the transition. "He was Joey's advocate to get him out [of Fairview] as soon as possible."

Though ownership of the group home where Joey now lives has changed since he first moved there in February of 2014, Tim can't speak highly



Joey with Santa Claus.



Joey (right) with his brother Tim on a family trip to Tijuana.

enough of the new owner and staff at Bella Claire Home.

"I know there were staff at Fairview who loved him, but there's huge value in the close-knit, family-like environment where he lives now," said Tim, who says that he feels like part of the home's extended family.

He said that it's many small things that add up to make a big difference in Joey's life, from the tasty meals that are prepared, to having his own bedroom and bathroom, to simply being able to go outside when he wants to get some fresh air.

Tim also believes the day program Joey attends at Progressive Community & Vocational Services is better for him than what he experienced at the developmental center.

"The day program is ideally suited to him," he said. "I think it's important for people, including Joey, to feel there is a purpose for them and at the day program they tailor things for him."

Sadly, the Knutsons' mother passed away unexpectedly just a few months ago and Tim is now Joey's sole

conservator. Tim, his wife Jennifer and their two teenage children, Christian and Emma, are now Joey's only family.

Joey loved his mother dearly, and is still getting used to the fact that when Tim and his family come to visit and take him for outings, he isn't going to see his mother. However, Tim is confident that he will get used to these new routines, and looks forward to being able to have Joey for overnight visits with his family in the future.

Tim is now Joey's sole conservator.

He encourages others with family members who will be transitioning out of Fairview to embrace the process. "Get involved. Visit the proposed group homes and day programs so you are familiar with their operations and feel comfortable with the staff.

"Look at the transition as an opportunity for your brother or son to have a more intimate, more personally tailored environment," he said.



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Regional Center of Orange County Locations

Santa Ana Office

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

Orange Office

3111 N. Tustin, Suite 150
 24-hr Phone: (714) 796-3700

Westminster Office

5555 Garden Grove Blvd., Suite 100
 24-hr Phone: (714) 796-2900

State Budget Update

On June 24, Governor Brown signed the package of bills that make up the state budget for fiscal year 2015-2016, along with various “trailer bills” needed to implement the budget. Though the State Legislature had previously voted to increase significantly the dollars going to fund regional center services, those increases were largely removed from the final budget deal. Instead, the actual budget will only include funds to make up for budget

deficiencies from past years and increases to cover projected growth in the number of regional center consumers. Fortunately, the budget also authorizes regional centers to negotiate service provider rate adjustments to implement California’s new paid sick leave law with those who weren’t already providing that benefit to their staff.

The Governor also called on the Legislature to convene a special session on health care financing.

In his proclamation on the subject, he asked the Legislature to enact “permanent and sustainable funding” to pay for, among other things, rate increases for those who provide services to people with developmental disabilities.

In addition, the budget advances the closure of Sonoma Developmental Center, Fairview Developmental Center and a portion of Porterville Developmental Center (see Executive Director’s Report on page 3).

