# Dialogue

Volume 31 No.4 Fall 2017

#### In the Spotlight

## **Albert Ford**

Heading off to bed for a good night's sleep is something many of us take for granted. But for 59-year-old Albert Ford – a former resident of Fairview Developmental Center who has a profound intellectual disability, cerebral palsy and epilepsy – sleep has always been a challenge.

# He suffered brain damage from a lack of oxygen.

Even as a small child living in Buena Park, he refused to sleep in his bed. With his seizures and head-banging behavior, Albert's parents were concerned for his safety. His older brother, Mark Ford, said the situation was so worrisome that their father,



Albert (left) receives frequent visits from his older brother Mark Ford (right) who lives in Texas.

who was police officer at the time, even built special beds to try to keep Albert safe in bed overnight.

Nothing worked, though, and eventually his family and the staff at Fairview reluctantly accepted that Albert would not sleep in a bed. So, when the staff at the Luray Home in Long Beach, where Albert has lived since transitioning out of Fairview in March 2017, emailed Mark and their elderly mother a photo of Albert sleeping in his bed in his bedroom, it brought tears of joy to their eyes.

#### See Albert Ford on page 7.

## It's Time to Submit Spotlight Award Nominations!

ickets will be going on sale soon, so mark your calendar and plan to attend RCOC's 21st Annual Spotlight Awards Gala on **Friday, March 2**!

In the meantime, be sure to get your nominations in for the people, organizations or businesses you think deserve recognition for the great work they do for people with developmental disabilities in Orange County. To nominate someone for a Spotlight Award, simply go to RCOC's website where you can learn about the different award categories and submit your nominations online, in English, Spanish or Vietnamese.

If you're a person served by RCOC and would like to nominate someone for a Spotlight Award, contact your service coordinator for help.

Remember, the deadline for nominations is January 12, 2018, so don't wait!

## Dialogue

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#### **Upcoming 2018 Board Meetings**

January 11 • March 1 May 3 • June 7

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

#### **RCOC** Administration

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### **ABLE Act Update**

alifornia's ABLE Act Program (CalABLE), authorized by a law signed by Governor Brown in October 2015, was expected to be underway and available to California families this year. Unfortunately, the program has encountered delays related to its RFP (Request for Proposals) process and did not launch in October 2017 as anticipated.

The California law followed federal legislation allowing tax-free savings accounts for those with disabilities.

The California law followed federal legislation allowing tax-free savings accounts for those with disabilities. These accounts are envisioned as a means for families to set aside money for their loved ones' future needs, without making them ineligible for government benefits. Currently, to qualify for federal SSI (Supplemental Security Income), an individual cannot have assets over \$2,000 and a couple cannot have more than \$3,000; however, under the new federal law, families can now set aside up to \$100,000 (\$14,000 per year) in these special accounts, without making their loved ones ineligible for SSI.

CalABLE, the entity created to implement these tax-advantaged accounts in California, indicated that it had encountered difficulties finding an investment management firm for the accounts since - unlike other states – our law limited enrollment to California residents. However, the Governor recently signed legislation (AB 384) that allows CalABLE to administer accounts for those in other states, eliminating that barrier. Importantly, that new legislation also clarified that when a person's ABLE account exceeds the \$100,000 cap, that person still remains eligible for Medi-Cal.

New legislation also clarified that when a person's ABLE account exceeds the \$100,000 cap, that person still remains eligible for Medi-Cal.

Current materials on the program note that CalABLE is expected to be open for business Fall 2017 or early Winter 2018. For the latest information, visit the California State Treasurer's website at www.treasurer.ca.gov/able.

# Executive Director's Report

## Fairview Transitions Take Time and Careful Planning

By Larry Landauer, Executive Director

B ack in June of 1999, the U.S. Supreme Court handed down its landmark Olmstead decision, which required that people with disabilities be served in the least restrictive setting appropriate for them. That decision lent powerful momentum to a movement that had already taken hold, to support parents of children with special needs in their efforts to raise their children at home, and to provide adults with developmental disabilities with the services and supports they need in the community.

The Olmstead decision required that people with disabilities be served in the least restrictive setting.

Over the 18 years since Olmstead, we in California have gradually transitioned thousands of individuals from the state's developmental centers into more home-like settings in the community. From a peak of 2,700 residents in 1967, Orange County's own Fairview Developmental Center housed just 159 residents at the end of August – that's 80 fewer than in the spring of 2016.

Among those welcomed this past year into communities across California was Albert Ford, the subject of our cover story. Like Albert, many of the Fairview residents who are still awaiting homes in the community have very significant challenges, including complex medical needs. While the vast majority of people RCOC serves are able to live happy and healthy lives in



typical homes and apartments or in group homes, many Fairview residents need specialized housing like Luray Home in Long Beach, where Albert lives.

In addition to a higher staff to resident ratio, these homes have access to a professional team that may include a range of highly-trained experts, from licensed vocational nurses to physical therapists, occupational therapists, and more.

RCOC is currently working with several very dedicated service providers to develop a number of specialized homes in Orange County, some of them specifically to accommodate Fairview residents who will be transitioning into the community. In addition, our Fairview Resource Group brings together RCOC's own experts in psychology, behavior analysis and nursing to support the planning teams evaluating each individual's options so they can make wise decisions.

We have no doubt that we will succeed in meeting the 2019 Fairview closure deadline agreed to by the Department of Developmental Services and the federal government. RCOC, DDS, Fairview staff, our fellow regional centers, California's outstanding network of service providers and many other advocates and stakeholders are all working together on this goal. However, it's very important to us that families know that their involvement is both important and welcome. We also want them to know that the process for transitioning their loved ones is thoughtful, comprehensive, and very carefully managed.

We are pleased to report that our transition activities and other Orange County programs and processes have recently received significant, positive attention from both state-level officials and legislators.

The process for transitioning their loved ones is thoughtful, comprehensive, and very carefully managed.

The Harbor Village apartment complex in Costa Mesa, in particular (home to many people served by RCOC), is an excellent example of prudent development of state-owned property to create affordable housing for adults with developmental disabilities. Since the overwhelming majority of adults with developmental disabilities statewide have very low incomes, few issues are more pressing for them than the shortage of affordable housing.

As its remaining developmental centers prepare for closure, California would be wise to consider replicating the successful Harbor Village model, leveraging state-owned property statewide to provide safe, affordable places for people with developmental disabilities to live in our communities.

#### Person to Person

## **Self-Determination** for All!

By Sylvia Delgado, PAC Chair and Jess Corey, RCOC Peer Advocate

ello everybody! We hope you've had a fun and safe summer!

Things have been super busy here at the **Regional Center of** Orange County. With so much going on, we want to share some more exciting news about self-determination

and to reflect on what it means to us.

#### California's Self-Determination Program is still moving forward.

First, we want you to know California's Self-Determination Program is still moving forward. In fact, the Department of Developmental Services recently hosted trainings on how to conduct the selfdetermination informational meetings that will help people decide if they might want to be among the program's 2,500 participants.

As we see it, self-determination, like person centered planning

and person centered thinking, is all about making the choices you want to make and, most importantly, it's about freedom. California's Self-



Sylvia Delgado



Jess Corey

that's awesome, but we think it's important to remember that a lot of people, including the two of us, have already chosen to live selfdetermined lives. Jess knew what it was

like to not have power over his own choices, and how great it felt to take control. It took him

11 years to get into his current apartment, where he has lived since March 2014. The feeling of accomplishment when he spent his first night in his own place is indescribable!

#### A lot of people have already chosen to live self-determined lives.

Sylvia points out that selfdetermination also applies to everyday decisions, like what you wear. When she was younger, she remembers her mother often picking out her outfits for special occasions or parties, saying "If you don't look good, I don't look good." That was frustrating and made her feel powerless. Now, she's thrilled to be making her own choices about what she wears!

As with Albert, the individual on our front cover, Regional Center is working with lots of people to help them move out of Fairview Developmental Center and into the community. The principles of selfdetermination and person centered thinking are helping us to do our best to make awesome things happen for them!

#### Self-determination also applies to everyday decisions.

After all, everyone deserves a chance to be comfortable in an environment where they have the freedom to be themselves and to explore the things they like with the people they love.

## **5th Annual Self-Determination** Conference

COC will partner with Integrity House to present the 5th Annual Self-Determination/Self-Advocacy Conference this winter. For details, check the RCOC website (www. rcocdd.com) or ask your RCOC service coordinator.

#### Moving on at 3...Transition Workshops for Parents

Every family with a child in Early Start receives transition services to help prepare for the changes that will take place when the child turns three years old and Early Start services end. Many parents say this support is invaluable in helping them understand the differences between Early Start and the schoolbased education services children with special needs receive from public school districts from the age of three through age 22. The upcoming workshops listed below are offered in English, however, interpreters for other languages can be provided upon request. For more information and to RSVP, please contact Patricia Garcia at (714) 558-5400 or pgarcia@rcocdd.com.

## NOTE: Child care is not provided, so please do not bring children to the workshops.

**Thursday, November 16** 6:30 to 8:30 p.m. Harper Preschool Assessment Center 425 E. 18th Street in Costa Mesa

#### Wednesday, January 31

9:30 to 11:30 a.m.
Brea-Olinda Unified School District
Brea Civic & Cultural Center
1 Civic Center Circle (Second Level) in Brea
Free underground parking accessible between
the Center and Embassy Suites Hotel.

## Navigating Through Challenging Behavior...Workshop for Parents

antrums happen, and when they do, they can be frustrating, confusing and draining. If you are experiencing them with your child, you are not alone. Understanding why your child behaves the way he or she does is the first step to finding solutions. Attend this free workshop and learn strategies that can help you improve your child's behavior. The workshop is offered in English, however, interpreters for other languages can be provided upon request. For more information and to RSVP, please contact Patricia Garcia at (714) 558-5400 or pgarcia@rcocdd.com.

# NOTE: Child care is not provided, so please do not bring children to the workshop.

**Thursday, February 15** 6:30 to 8:30 p.m. Regional Center of Orange County 1525 N. Tustin Avenue in Santa Ana *Free parking in the structure across from the RCOC office building.* 

#### Behavior Management Workshops

ue to the holidays, there will be no Behavior Management Workshops during November and December. The workshops will resume after the first of the year. For the most up-to-date information, visit the Monthly Calendar on the RCOC website (www.rcocdd.com).

## Do We Have Your Current Email Address?

RCOC's Comfort Connection Family Resource Center regularly sends brief emails to interested families about a range of local programs and activities available to families. For example, we recently shared details about a program operated by the Mission Viejo Rotary Club to introduce children with special needs to the fun of deep sea fishing! To learn about opportunities in your local community, please be sure to update your email address with your RCOC service coordinator.

## Everyday Wellness: Wash Your Hands

old and flu season is in full swing, and the best way to keep from getting sick and spreading germs is to wash your hands well and often with soap and water. Here's a tip to make sure you are lathering and scrubbing your

hands long enough: scrub for as long as it takes you to sing the "Happy Birthday to You" song twice. That will be right about 20 seconds!

#### Good News for Respite Users in 2018

Properties of the terms of term

To cope with California's budget crisis and the Great Recession, the Legislature enacted significant restrictions on respite.

Since 2009, state law has prohibited regional centers from authorizing more than 21 days of out-of-home respite services per fiscal year and more than 90 hours of in-home respite per quarter, unless an exemption was granted. We are pleased to report that California's greatly-improved financial situation led the Legislature to repeal those restrictions, effective January 1, 2018. This repeal was part of the budget deal for the current fiscal year.

California's greatly-improved financial situation led the Legislature to repeal those restrictions.

This change does not require RCOC to change its Purchase of Service (POS) guidelines for respite services, since our regional center previously allowed exemptions to authorize a greater number of respite hours on a case-by-case basis. However, what many in the community find most exciting about this news is that the change provides families statewide with some much-needed flexibility. Previously, the limitations made it nearly impossible for some families to string together a significant block of respite hours to, for example, allow them to travel or be away from home for very long. This presented a particular hardship for working parents who might need to take extended business trips, as well as those with family obligations away from home. It also made even a simple vacation extremely complicated, if not impossible.

The change provides families statewide with some much-needed flexibility.

If you have any questions or concerns about respite services or any other issue concerning a family member served by RCOC, please be sure to contact your service coordinator for help.

#### Backpack Giveaway Offers Families a Jump-Start to the First Day of School

In advance of the new school year, RCOC hosted its Fourth Annual Backpack Giveaway which provided free backpacks, school supplies and back-to-school tips for 150 Orange County children with developmental disabilities and their families. All of the supplies were donated by Premier Healthcare Services, which provides services to some



RCOC families and to many others statewide, while volunteers helped children pick out their backpacks.

The event took place at and was organized by RCOC's Comfort Connection Family Resource Center, which worked with service coordinators to identify children we serve from low-income families and others who are financiallystressed. Those families were then contacted by Comfort Connection and invited to participate. Some families were even interviewed by the several local media outlets that covered the event, including the Orange County Register, KCAL television and KCBS television.

#### Albert Ford (continued from page 1)

"He felt so at home and so welcome," Mark said, noting that it gives his mother and their entire family great peace to know their beloved family member is in such a caring and nurturing environment. "He has just flourished!"



As a baby, Albert's medical needs were not immediately apparent.

Albert's RCOC Service Coordinator Mary Carlson said the Luray Home, which is operated by The Mentor Network and is home to two other men besides Albert, was ideal for him because it is equipped and staffed to meet the needs of people with complex medical needs. During waking hours, there are two staff supporting the three men, and at night there is one staff member on site.

Though Albert has been disabled since birth, his brother said some of his medical needs were not immediately apparent.

"When Albert came home from the hospital, he looked happy and healthy, but he's never spoken," said Mark, describing how his mother had been blindfolded during the birth and that later his parents were informed by hospital staff that the umbilical cord had been wrapped around Albert's neck. Since there was no oxygen in the hospital room where he was delivered, he suffered brain damage from a lack of oxygen.

Even with the serious challenges he faced, his family did everything they could to help Albert. Mark noted that his parents eventually filed for bankruptcy and never recovered financially from putting everything they had into caring for Albert.

It had obviously been a very difficult decision for this loving family to place Albert in the developmental center, but that was a different time.



The Ford family visited Albert regularly when he lived in Fairview Developmental Center.

In 1963, when Albert was six, their mother gave birth to Matthew, the third of her four sons. With almost no resources for parents of children with special needs, their pediatrician maintained that his mother could not properly care for her newborn and Albert and Mark. Still, every member of the family struggled emotionally after Albert left, with nine-year-old Mark wondering what he did wrong to cause his little brother to be sent away.

Given that Albert lived at Fairview for 53 years and appeared happy

and well cared for there, it is natural to wonder what it is about his new home that has enabled him to have blossomed so quickly, in an entirely new environment. Darcy Farias, facility manager for Luray Home, thinks Albert is simply a naturally happy person. However, both she and Mark also think the freedom Albert now experiences has played a big role in his successful transition.

"It's freedom that brought on this new awakening for him," said Mark, who noted that Albert is enjoying many new experiences, such as aqua-therapy, that were not available to him earlier.

"He has the opportunity to explore the home without restrictions, to go at his own pace, and to rearrange his room as he likes," Darcy added. In contrast, at the developmental center where the staff had many more people to oversee, Albert was mostly restricted to one common area and there were a lot of things he couldn't do and things he couldn't touch.

Mark, a physician who practices in Texas, and his wife have always visited Albert regularly and been very involved with him. They and all of Albert's family were resistant at first to the idea of his leaving Fairview. In fact, a number of years ago their mother had been on a task force formed to ensure funding to keep Fairview open. But the lengthy and thoughtful transition process changed their minds and persuaded them that the people working on the transition truly cared about Albert.

"We went into it with a chip on our shoulder," he said. "We were so wrong. It's been a blessing every day, and the communication has been great."



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#### **Regional Center of Orange County Locations**

Santa Ana Office

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

10803 Hope Street, Suite A 24-hr Phone: (714) 796-2900

#### Company Support Needed: Wish Tree Brightens the Holidays for Those We Serve

re you or your company looking for a fun way to help others during the holidays? If so, we hope you'll consider supporting RCOC's Wish Tree program. Each year, Wish Tree helps brighten the holiday season for more than a thousand individuals served by RCOC.

The Wish Tree begins when service coordinators contact low-income individuals and families served by RCOC and identify their holiday gift requests, such as children's toys, clothes, store gift cards and movie tickets. Individual Wish Tree supporters – as well as companies, churches and volunteer organizations – then purchase the requested items, wrap them, and deliver them to RCOC. Volunteers make sure the gifts are delivered in time for the holidays.

If you would like to help, but don't have time to purchase and wrap gifts, you can still participate by making a financial contribution that will be used by volunteer shoppers to fulfill specific wishes. Checks should be made out to "Brian's Fund," and mailed to RCOC, P.O. Box 22010, Santa Ana, CA-92702-2010.

If you would like to **donate** to the Wish Tree program, contact Thao Mailloux at (714) 796-5330 or email wishtree2@rcocdd.com. To be considered as a Wish Tree gift recipient, contact your service coordinator.