

Consumer Spotlight

Jacqueline Carrillo

By all accounts, it was a normal pregnancy and a delivery without complications. Mariana Chavelas followed her doctor's orders carefully. She, her husband Juan Carrillo, and their daughter Jennifer were excited about welcoming a new member to their loving family. So, it was a tremendous shock when baby Jacqueline ("Jackie") was born with holoprosencephaly, a severe brain defect where the two sides of the brain do not properly separate during fetal development.

Doctors predicted she would not live more than a few months.

Holoprosencephaly can cause profound impairments, and specialists assured the family that nothing could have been done to prevent it. However, the most devastating news came two days after Jackie was born: Mariana and Juan were told that Jackie's condition was terminal. Doctors predicted she would not live more than a few months, and the family reluctantly agreed to hospice care and authorized a Do Not Resuscitate order.



Jackie (front) with her sister Jennifer and brothers, baby Mathew and Angel.

Twelve years later, Jackie has defied the odds and is thriving in her family's Buena Park home with her eight-year-old brother Angel and baby brother Mathew.

When telling their story (through a translator), however, Mariana and Juan describe frustration with medical professionals who were not optimistic about their daughter's chances for survival, and appreciation for the help they received from RCOC.

The journey to bring Jackie home ended this past March, but it actually began when she was discharged from the hospital where she was born.

Jackie's hospice team thought she would soon pass away from heart failure. In fact, her condition was so fragile and her medical needs were so intense that Mariana and Juan made the difficult

choice to have their daughter cared for by professionals at a sub-acute medical facility. RCOC's health resources group nurses assisted the family in getting the appropriate services, advocating for Jackie with medical professionals, and sometimes acting as a translator.

However, Jackie's parents never gave up on bringing her back home. And in the spring of 2013, the time was right to begin the process.

"Once we decided to do it, there was no going back," said Juan, who cares for Jackie and her brothers during the day and works at night, while Mariana works days and cares for the children at night.

Jackie has defied the odds.

A team that included sub-acute care facility staff, RCOC Registered Nurse Amy Hamm and Service Coordinator Nora Ramos worked with the family to help prepare for Jackie's homecoming. The training Mariana and Juan received included things like feeding Jackie and administering medications through her G-tube, and keeping her tracheotomy tube clean and clear.

See **Jacqueline Carrillo** on back page

Dialogue

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Dialogue can also be read online at RCOC's Web site: www.rcocdd.com.

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Upcoming Board Meetings

September 4 • October 2 • November 6
January 8 • February 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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Budget Update

The California Legislature met its deadlines for passing a state budget for the 2014-2015 fiscal year that began on July 1, 2014. RCOC was disappointed that the budget agreement reached between the Legislature and Governor Brown did not include rate increases for service providers who have been struggling with stagnant rates for some years now. However, the budget agreement did include money to pay the cost of services and supports for new consumers (increased caseloads). And there was some more welcome news for people with developmental disabilities and their families. Here are a few highlights:

Early Start Restored

Several years ago, to reduce costs, the State narrowed eligibility for infants and toddlers to qualify for Early Start services. As of January 1, 2015, eligibility will return to what it was in 2009. This means that many more children who are at risk of having a developmental disability will have access to early intervention services through regional centers.

Minimum Wage Increases

The State will fund service providers' costs directly related to California's minimum wage increase which took effect on July 1. Similarly, it will cover the cost for staff overtime pay for supported living services, in-home respite and personal attendant services through IHSS that will be incurred

when federal overtime requirements go into effect on January 1, 2015.

Payment of Insurance Deductibles

When the State passed a law requiring private health insurance plans to cover Applied Behavior Analysis (ABA) therapy for autism, regional centers were allowed to pay copayments and coinsurance for low income consumers under certain circumstances. However, they were prohibited from paying health insurance deductibles. In the current year's budget agreement, that prohibition was lifted and in some situations regional centers can now pay health plan deductibles.

Budget Information Online

For more details and information about the state budget, visit the Department of Finance's budget website (www.ebudget.ca.gov). To read more about the budget for regional centers and developmental centers, visit the Department of Developmental Services website (www.dds.ca.gov) and click on the "Budget Information" link on the home page.



Executive Director's Report

RCOC Service Coordinators Are Supported by Many Experts

By Larry Landauer, Executive Director

When consumers and family members think about Regional Center of Orange County (RCOC), they probably think first and foremost about their service coordinator.

The service coordinator is, after all, their primary point of contact with the Regional Center and the person they turn to first when they have a question or concern about services or service providers, or a problem they need resolved.

For the people we serve, help is just a phone call, email or text message away.

Meeting the needs of people with developmental disabilities and their families is the reason we exist. So, we take pride in the fact that, for the people we serve, help is just a phone call, email or text message away. We are proud that our service coordinators are among the best in the state. They are top-notch professionals who are caring and compassionate, knowledgeable about developmental disabilities, and passionate about meeting people's genuine needs.

However, while we try to make it as simple as possible for people to get needed help and support, the

developmental services system, itself, is not simple. The medical, psychological, behavioral and developmental needs of consumers can be quite complex. Family circumstances and living situations can also be complicated.



Frankly, as well-informed and dedicated as our service coordinators are, there's just no way any one individual can be expert in all

of the diverse scenarios today's service coordinators encounter.

That is why RCOC also employs experts who act as resources to support service coordinators in their efforts to provide consumers, families, and planning teams with the very best information about available services and supports. We have a wide range of experts that service coordinators may access for help with Early Start, day programs, living options, behavioral services, health-related concerns, and much more.

Our health resources group, which is profiled in this issue of *Dialogue*, is often active behind the scenes to help families facing medical, psychological, behavioral and developmental challenges. The Carrillo family, whose story appears in our Consumer Spotlight cover story, is an example of how the depth of expertise backing up our service coordinators can make an enormous difference in a consumer's life.

While the Carrillo family's situation is particularly complex, there are hundreds of stories of lives changed for the better and critical needs met because of the

dedicated experts who support our service coordinators.

We have, for example, a staff member who is extremely knowledgeable about benefit programs. Nearly all of the adults RCOC serves rely heavily on programs such as these for necessities of life, and she works with service coordinators to help ensure consumers understand and meet the many requirements agencies have for those who receive assistance through IHSS, Medi-Cal and Social Security, for example.

Though we work hard to make it a smooth transition for children moving from Early Start with RCOC to special education programs operated by public schools, there can still be difficulties. So, we have special education advocates who help ensure that children receive the services and supports they need throughout their school-age years, while equipping parents with the knowledge and skills they need to be effective advocates.

RCOC employs experts who act as resources to support service coordinators.

We also have staff members with special expertise with housing, employment and legal issues (in the event a consumer becomes involved with law enforcement).

In fact, for virtually all aspects of a consumer's life, from childhood and throughout their lifetime, RCOC service coordinators have access to expert resources to help consumers thrive in the community.

Consumer Advisory Team Update

Meet RCOC's New Consumer Advocate

By Sylvia Delgado, CAT Chair

Anyone who has read very many of my columns knows that self-advocacy is a high priority for me. I believe that people with developmental disabilities are our own best advocates. That's one of the reasons I'm excited about attending the upcoming State Council on Developmental Disabilities meeting in Sacramento, and why I try to encourage others to speak up and share their views at these



Jyusse "Jesse" Corey

and similar events. It's also why it was such a pleasure at our Consumer Advisory Team (CAT) meeting to host the two consumers who were finalists for the RCOC consumer

advocate position that came open when Brian Story resigned.

Jyusse "Jesse" Corey, who was selected for the job, gave a short

presentation about himself and his views about why self-advocacy is important. He also spent time visiting with the CAT members, and really seemed to enjoy himself. I'm just getting to know Jesse, but I think he's going to bring a lot of enthusiasm to the job!

The consumer advocate position is a part-time job that involves helping fellow consumers with problems and providing consumers and their families with information on self-advocacy and RCOC services and supports. In his new job, Jesse will also consult with others at RCOC, advocating for consumers and sharing consumers' perspectives and concerns, and helping review the National

Upcoming CAT Meeting Dates

September 17

October 15

November 19

December 17

(Holiday Luncheon)

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.

Core Indicators consumer and family survey results.

People with developmental disabilities are our own best advocates.

Jesse started work on June 9. If you want to learn more about self-advocacy, or if you have a problem or question about RCOC services and supports, please contact him. He is very knowledgeable and eager to help. To reach Jesse, call (714) 796-5135 or email him at jcorey@rcocdd.com.

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.

In all of the workshops, 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 – Focus on Ages 12 through 18 Years (6 sessions)

Presented in English by

Behavioral Support Partnership

When: Monday evenings –
Sept. 8, Sept. 15,
Sept. 22, Sept. 29,
Oct. 6 & Oct. 13

Time: 6:30 – 9:00 p.m.

Location: RCOC Santa Ana
Office
1525 N. Tustin Ave.
*Parking is located in
the structure across
from RCOC office
building*

Behavior Management Workshop (5 sessions)

*Presented in Spanish by
Dr. Ana Lorenz*

When: Tuesday evenings –
Sept. 9, Sept. 16,
Sept. 23, Sept. 30,
and Oct. 7

*(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

Behavior Management Workshop (5 sessions)

*Presented in English by
Coyne & Associates*

When: Tuesday evenings –
Oct. 7, Oct. 14,
Oct. 21, Oct. 28,
and Nov. 4

*(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

Selecting RCOC's Consumer Advocate

To make sure all of the consumers who applied for the consumer advocate position were able to compete fairly for the job, RCOC's interview team followed a thorough selection process. The four-step process began with 15 applicants. After each step, some of the candidates were eliminated and a smaller number moved forward to the next step.

First, all candidates were asked to respond, in writing or audio recording, to these two questions: What does self-advocacy mean to you? Describe what it means to be a good RCOC Consumer Advocate.

Next, six of the candidates were interviewed by telephone. Then, the top two finalists had in-person meetings with the interview team. The final step for those two was to give a five-minute presentation about themselves at the Consumer Advisory Team (CAT) meeting.

Health Resources Group Helps Consumers Live Healthier, More Productive Lives

This issue's cover story about consumer Jackie Carrillo and her family's dedication to caring for her at home is a dramatic one that shares some of the ways RCOC's health resources group supports the individuals and families RCOC serves.

The group's depth of experience and long-time relationships with others in the community can often expedite help for a family, even for services not funded by RCOC.

The health resources group is led by RCOC's Chief Clinical Officer Dr. LeeAnn Christian, herself a board certified behavior analyst, and is composed of 18 professionals representing a variety of disciplines. Specifically, the group includes Chief Medical Officer Dr. Peter Himber, along with psychologists, nurses, behavior analysts, a speech-language pathologist, a physical therapist and support staff.

Members of the group play a crucial role in identifying children and adults who are eligible for regional center services, as well as promoting health and wellness and enhancing consumers' overall development.

"A lot of the work our group does is behind the scenes. We serve as a source of information, resources and support for service coordinators as they help coordinate and secure services for their consumers and families," said LeeAnn. "It's gratifying to know we're making a big difference in people's lives."

On a daily basis, RCOC service coordinators call on health resources group specialists to provide their expert opinion about the most effective and appropriate services and supports for individual consumers, and to help them advocate on behalf of consumers' health needs.

For example, Nurse Amy Hamm is the person service coordinators call when there is a consumer whose medical needs are so intensive that they need to live in a sub-acute residential facility (a place that is a step below a hospital, but provides higher level care than a skilled nursing facility). Amy regularly joins service coordinators for onsite visits, often meeting with medical professionals to advocate for consumers' needs, and helping families to understand the details of their family member's medical conditions.

LeeAnn also points out that the group's depth of experience and long-time relationships with others in the community can often expedite help for a family, even for services not funded by RCOC. Their help getting California Children's Services to fund the cost of the special bed that enabled Jackie Carrillo to live in her family's home is one example.

Another example might be when a family calls their service coordinator seeking psychiatric help and medications for a consumer, or perhaps dental services. The service coordinator consults individuals in the health resources group to identify clinics or individual practitioners who welcome patients with developmental disabilities and either accept Medi-Cal or deliver services at a low cost.

Sometimes the health resources group gets involved when a service provider is facing a particularly difficult challenge with a consumer and wants to consult with a professional colleague. LeeAnn cited an example of an Early Start consumer who was receiving speech therapy.

"The speech therapist felt the child was not benefitting from therapy and required a more intensive program," she said. "When our speech-language pathologist and one of our behavior analysts visited the family and observed the situation, they both felt ABA (Applied Behavior Analysis) services should also be provided to the child." Within six months of receiving both ABA services and speech therapy, the boy made significant progress in his language development.

"One of the keys to our success is the collaborative relationships we have with service providers," said LeeAnn. "RCOC specialists and their professional colleagues in the community regularly brainstorm and problem-solve challenging situations with the same goal in mind – providing quality services that result in positive outcomes for the people we serve."

Fun in the Sun at Summer Blast!

Sat., June 21 was filled with fun, food, music and dancing for the more than 300 consumers, friends and family members who gathered at KiwanisLand in Garden Grove for the fourth annual Summer Blast! With costs underwritten by a major event sponsor, the event was organized by the non-profit Integrity House with support from Regional Center of Orange County.



Adolescence and Autism

R COC will host one of the nation's leading experts on autism and adolescence on Oct. 16 from 4-8 p.m. at our Santa Ana headquarters office. Dr. Peter Gerhardt will deliver a presentation entitled *Adolescence and Autism: Behavioral Expectations in the Transition from School to Work*. The cost to attend is \$30 per person, including a box dinner. An additional \$30 is required for professionals applying for continuing education (CE) hours. Pre-registration is required. For more information and to register, please call Jennifer Casteel at (714) 796-5330. No child care will be provided.

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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

Jacqueline Carrillo (cont. from pg. 1)

A major challenge the team had to overcome was securing an appropriate bed for Jackie at home. The type of cerebral palsy she has causes her to flail her arms and legs, so she needs a specially-cushioned bed. The family’s request for the bed was denied by both Medi-Cal and California Children’s Services (CCS), until RCOC’s Amy Hamm identified and helped to expedite correction of a diagnostic coding error in the CCS system.

“Everything is possible if you have faith and are united as a family.”

Mariana and Juan say the challenges of caring for Jackie are significant, even with nursing and respite support, but Juan says they work together as a team to support one another. As Mariana says, “Everything is possible if you have faith and are united as a family.”



Jackie (front) with (back L-R) Service Coordinator Nora Ramos and parents Mariana Chavelas and Juan Carrillo.