



California Supported Living Network

Advocating For The Systemic Development Of Quality Supported Living Services For Californians With Developmental Disabilities.

O U R V I S I O N

To ensure that supported living remains a viable option for people with developmental disabilities, we envision a united group of service providers, consumers, families and members of the community speaking with one strong voice advocating for supported living services throughout the State of California.

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Letter From The Chair

Donna Bettencourt



From time to time, I pause to think about what we have accomplished to date, and what we have yet to do. I wonder also who will come after me, in my agency, to keep pursuing that vision, that people with developmental disabilities can live in a home of their own and can work in the community. I have seen a revolution “evolve” in my 35 years in this field, and I want to make sure the revolution continues after me. I think about the staff who work for our agency, and whether or not one of them will pick up the torch when I leave.

Last week, I read from Enlightened Leadership: Getting to the Heart of Change by Ed Oakley and Doug Krug. In that book, they tell a story, and it goes like this:

“Years ago we heard a story about three men laying brick at a work site. All three had the same tools, mortar of identical consistency and materials that were alike. Yet, the men somehow appeared different to an observer.

Curious, the observer asked the first worker, “What are you doing?”

“Layin’ brick”, the laborer grumbled. “It’s a paycheck even if it is hard work.”

“What are you doing?” the observer asked the next man.

“Well,” the second man worker replied, “I’m one of the construction people, and we are putting together the east wall of a structure.”

“What are you doing?” the observer queried the third worker.

“I’m helping to build a cathedral,” said the man. He wiped his



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brow and spoke excitedly. “And someday, right where we are standing the spires will rise high above us, and people will be meeting to worship and to be educated.”

Mr. Waterman concludes, “The differences the observer noticed in the men were variations in attitude. The first worker held a job. The second man had acquiesced to common goals. The third man had bought in and become aligned with a powerful purpose and vision.”

There are people who work for our supported living agency who are there for the job, and for the paycheck. There are others who understand their job duties, and who perform them very well. Then, there are others who understand that the work they do at the agency goes well beyond the particular “brick” they are laying today, whether it be a problem solved, or a shift covered, or a duty performed for the day. They are pursuing a powerful purpose and vision, and giving it flesh and structure today so that what they build is there tomorrow, and for many more tomorrows. Those are the ones I want to take my place when I go to that great sabbatical in the sky!

W i l l t h e R e a l J o a q u i n C a r s o n P l e a s e C o m e H o m e ?

B y D i a n a P a s t o r a C a r s o n



Last weekend I spent about thirty minutes gouging out fungus from between my brother’s toes and toenails after clipping off the thick, crusty, ends of the nails. “Great way to spend an afternoon,” you might be thinking. But giving half an hour of my time, doing something stomach-turning, is the least I can do when compared to the six wasted years it has taken for Joaquin’s toenails to become completely encrusted with fungus behind the institutional walls. While I’ve been relaxing in my flip flops, making friends, and fulfilling my dreams, he’s been locked up, waiting for our weekend visits, wearing close-toed shoes and growing fungus on his feet.

How did this amazing brother of mine end up institutionalized? He is the definition of handsome and the epitome of charming. He is funny in a Jim Carey kind of way. He is patient like Job. He is loving: my BFF. And Joaquin is strong: even stronger than those toenails.

Joaquin’s beauty and charm are easy to prove. Aside from his current toes, Joaquin is a looker. He’s the kind of guy that walks into a room and turns heads with his vibrant personality. He likes the pretty ladies too. I remember once, Joaquin was waiting in a line at the fair, smiling and making eyes at a young woman in another line. Within minutes, she walked over and handed him a slip of paper with her phone number on it. Yes. He’s a Casanova. Some qualities are obvious. Others may be harder to spot.

Joaquin is one of the funniest people I know. But to get his humor, you have to really know him and understand the meaning behind his oftentimes non-literal words. His smile and laughter sometimes bring me to tears.

Joaquin is patient. He has endured endless hours, days, and years of boredom in a warehouse of dehumanized fellow prisoners... a loud and impersonal environment that would drive most of us to complete insanity. And yes, every now and then, he becomes frustrated to the point of “behaviors.” So to notice his patience, you have to be aware of it and watch for evidence of it. With open eyes, you will see it.

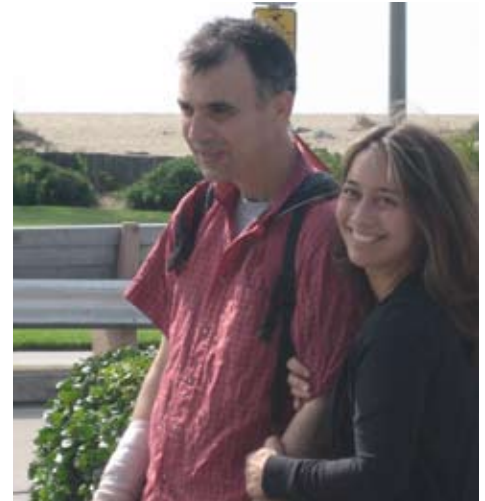


Joaquin is lovable, much loved, and loving. His love is a driving force in our family. Yet to be impacted by his love, to truly receive his love, you must first acknowledge its existence.

Joaquin is a man of fortitude and character. Yet to know his strength, you must first consider all that he has endured in the name of behaviorism, reasonability, and expertise. To see his character, you must listen to, look for, and understand his creative, verbal and non-verbal responses to his past and present. He never gives up on helping us to see the real Joaquin.

Compare the above description of Joaquin with the inane clinical accounts of “screaming, biting self,” and “grabbing others.” These descriptors are like fungus, growing where it should not be growing. And they didn’t just appear overnight. The fungal image of Joaquin developed over many, many years, out of segregated schooling, failed behavior modification techniques, non-personalized “support plans,” and distorted perceptions of who Joaquin is and should be. This is the fungus that caused his institutionalization.

Today, our family and friends are working to gouge out the old attitudinal fungus, break through years of hardened, cracked judgments, and bring Joaquin home to his community. In that home, there’ll be no time or energy wasted on fungus. He’ll be wearing flip-flops with his friends.



** Joaquin Carson was recently denied funding for Supported Living Services. His family and friends, including Disability Rights California and Life Works Supported Living Agency in San Diego, are appealing this decision while working on other options for giving Joaquin his life back. Joaquin’s mother promised him a steak dinner for his homecoming. One of Joaquin’s favorite phrases is “Steak is coming!” See video clips of Joaquin on You Tube under the name “SteakIsComing.”*

Legislative Update

By Carol McKinney
Co-Chairs, Governmental Affairs



Once again, the Governor’s May revise of the budget has services and supports to people with developmental disabilities on the cutting block. Instead of utilizing the Stakeholder process this year, DDS recommended that the \$25 million reduction come from a 1.25% cut to providers and regional centers. This cut translates to approximately \$43 million in total funds due to the loss of federal waiver dollars.

Additional reductions in the revision:

- Reduce SSI to \$830 effective July 1, 2010
- \$750 million reduction to IHSS to be determined by a Stakeholder group
- \$750 million medi-cal cost containment