

Denied surgery by HMO, Natane  
and her mother, Marie after  
successful operation



**We advocate, educate, investigate  
and litigate to advance disability rights**



Above DRC Board members: back row, left to right: Stephan Szpajda; Amy Kalivas, Chair; Herb Anderson; Diana Nelson, Chief Financial Officer; Jose Flores; Judy Mark and David Oster. Front row: Izetta Jackson, President; Angela van Ostran; Diana Honig, Secretary; and Billy Hall. Other 2013 Board members who were not present for the photo: Leslie Napper, Robyn Siers, Manjit Singh, Eduardo Vega and Jane Zerbi.

The Board is also served by Public Members: PAIMI Advisory Council - Terri Bercasio, Lisle Boomer, Debra Cosby-McFarland, Joseph Hall, Pamela Romano, Dennis Wall; OCRA advisory committee - Lakeisha Burke, Jean Townsend; Legislation Committee - Toni Jensen, Suzette Lin, David Oster, Brendan Peacock, Shannon Ramsay; Program and Planning Committee - Sabrina Gwen, Cathay Liu, Donald Spencer. (photo: Ahren Nunag)

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Cover photo by Ricardo Jauregui

## New DRC fellow tackles discrimination

Anna Krieger is the new DRC Civil Rights Litigation Fellow, thanks to generous contributions by our pro bono partners, Cooley LLP and Morrison & Foerster LLP. Anna was immediately successful with Laila Calderone, a client who needed Bandaid, her dog because the dog is trained to reduce her mental health disability symptoms. Her landlord was unsympathetic, advising Laila to adopt a cat instead. Anna helped Laila explain to her landlord that housing law prohibits discrimination against residents who need service dogs. Shown here is Bandaid, now allowed to live in Laila's apartment. Laila wrote thanking Anna, "I could not have done it without you."

Anna is also helping us ensure the In-Home Supportive Services program accommodates blind and visually impaired recipients by providing forms and information in formats that are accessible to them.



Bandaid

# 2013 Opportunity to fight for rights, not just a fair budget

by Catherine Blakemore

In recent years we focused on stopping budget cuts that were threatening critical services for Californians with disabilities. In 2013, after helping reduce cuts to In-Home Supportive Services and vital mental health and community based services, we had the chance to work with the legislature to strengthen services and rights.

Our most far-reaching outcome of 2013 was passage of three DRC sponsored bills, each crafted to fix a problem or increase service options. One law (SB 651) ensures that individuals living in state institutions have access to independent sexual assault exams; another (SB 468) gives people with developmental disabilities more control over their services through individual budgets. The third (SB 555) helps people who don't speak English find out about regional center services. Details about our legislative successes on page 4.

Our attorneys and advocates are supporting the statewide implementation of the federal parity law - requiring mental health services to be covered by insurance to the same extent as physical health services. We filed an amicus (friend of the court) brief in a case against a large insurer and produced fact sheets and policy papers. Details on page 10.

We had many successes this year in helping people leave institutions (see pages 5 and 8), partly because of changes we worked for in the law. Now, our clients' rights advocates can participate in regional center meetings and court proceedings for individuals who are institutionalized.

We continue to tackle discrimination - and success stories include helping a woman forced to



Three executive directors celebrate the successful advocacy event they founded: Disability Capitol Action Day. Left to right: Catherine Blakemore, DRC; Teresa Favuzzi, California Foundation for Independent Living Centers; and Virginia Knowlton Marcus of Maryland Disability Law Center and formerly of DRC.

leave a rescue mission (page 10), an immigrant become a citizen and a worker claim his full wages (both on page 5). We helped individuals get vital supports: making sure a 2-year-old got a critical eye operation (page 6); and working with a regional center to ensure that its service notices are easier to read (page 10). In February, DRC was featured in a TV news investigation of disability discrimination in heart transplants at leading California hospitals.

We thank you for your support. As our federal funds are reduced, please consider making a donation to help us continue this vital work: <http://www.disabilityrightsca.org/about/donate.htm>

# advocate

## **DRC bills expand services for people with developmental disabilities and protections for those living in state institutions**



Harvey Lapin; Mike Clark; Mark Polit of the State Council on Developmental Disability, Judy Mark, board member of DRC; Connie Lapin, former DRC board president; April Lopez, Governor's appointee to the Developmental Disability Legislative Committee; Catherine Blakemore; Evelyn Abouhassan, DRC senior legislative advocate; Teresa Trujillo, former legislative director for Sen. Bill Emerson; and former Sen. Bill Emerson, author of the bill.

Three consumer-focused bills sponsored by DRC were signed into law by the Governor this fall, representing untold hours of research, advocacy, and negotiations. We worked with consumers, family members and other advocacy groups to make sure the bills passed.

Shown is a photo of the Governor's signing ceremony for SB 468. This bill created a new self-determination service option. Regional Center consumers will be provided with an individual budget and increased flexibility to purchase services they find most useful to live and work in the community. Judy Mark said, "This law creates increased choices for consumers, including my 16-year-old son who has autism."

DRC sponsored SB 555 to make sure that consumers and families using regional center services are provided with information and services in their native language. California has a rich support system for people with developmental disabilities. But, consumers and families who do not speak English need information in their native language to better navigate the full menu of services and supports.

A third sponsored bill, SB 651, helps residents of state hospitals and developmental centers who allege they have been sexually assaulted. The new law ensures they are given immediate off-site medical exams by staff experienced in gathering sexual assault evidence. The law also sets penalties for non-compliance. The bill's author, Sen. Fran Pavley, said "this law will protect Californians from abuse, while holding both perpetrators and state caretakers accountable."

## Unpaid wages recovered



Jimmy Pereira, employed by his school's WorkAbility program, kept close track of his work hours. He knew he was not being paid for all the hours he worked and reported this to management, but there was no re-

sponse. He contacted us and Client's Rights Advocate Leinani Walter and Assistant Client's Rights Advocate Christine Hager helped Jimmy draft a letter demanding back wages. The program repaid the wages. Pereira's persistence and courage were recognized by the DRC Board in 2013.

## With our help, Raquel leaves an institution behind

In 2012 when Raquel Washington, a young adult, was placed in a developmental center, Hannah Liddell, Clients' Rights Advocate, was informed. That happened because DRC was successful in changing the law to limit institutionalization and ensuring that clients' rights advocates are notified of placements in developmental centers. Hanna advocated that Raquel leave the center and she did so in August 2013 with the full support of her Individual Program Plan team.

Raquel's supported living provider, a member of the IPP team, helped her find an apartment and assisted her transition back into the community. She loves her new home, which is nearer her family. Our publication, *New Laws to Help People Stay Out of Institutions*, describes the law that limits institutionalization in California.

## Celebrating citizenship



Shown here is Ran Chen, celebrating passing his citizenship exam. After his state financial assistance abruptly stopped, Ran contacted us and Office of Clients' Rights Advocacy (OCRA) attorney Jackie Dai

found he could qualify for a Cash Assistance Program for Immigrants (CAPI) with disabilities. Shortly after receiving the benefit, he passed his citizenship exam. As a citizen, Ran will be eligible for social security benefits and other programs that can help him live in the community.



Your support for our work  
will benefit Californians  
with disabilities  
[www.disabilityrightsca.org](http://www.disabilityrightsca.org)

## Computer class moved to accessible site in state hospital

State hospital resident Arnie Mendonsa wanted to join an onsite computer class but it was held in a room that he could not get to in his wheelchair. After DRC intervention, the class was moved to an accessible area of the hospital.



## Toddler gets corneal transplant and retinal surgery

Two-year-old Natane needed a corneal transplant and retinal surgery but her family's HMO refused coverage.

After DRC Senior Attorney Marilyn Holle intervened, the surgery was covered and Natane, now four years old, navigates her world with much more mobility. In fact, the surgery was so successful, doctors have just operated on her other eye.

We also helped Natane's mother, Marie, get the specialized indoor and outdoor glasses Natane needs. Natane is an enthusiastic participant in programs provided by the Foundation for the Junior Blind and the Frances Blend School.

## Stroke survivor, who worked on Voyager spacecraft, restarts career

David Karchem, a computer technology designer/manager for 30 years and who once worked on cutting



edge spacecraft, survived a stroke. It wasn't possible to continue as a manager of software development, so he looked into other careers. During his rehabilitation, he became fascinated by software and robotic devices that help reconnect brain synapses after stroke or brain injury.

He requested support from the Department of Rehabilitation (DOR) to pursue these interests as a second career. Professionals in this field recommended a masters degree in Assistive Technology, but his DOR counselor stated that a second certificate was sufficient. His DOR case was closed without resolution.

When he contacted DRC, Rebecca Hoyt, a Client Assistance Program (CAP) advocate, helped him develop a new Individual Plan for Employment with a more comprehensive scope of services. Mr. Karchem was accepted into the renowned Masters of Science in Assistive Technology program at California State University at Northridge (CSUN).

## We help a homeless artist find his way



When Teo first began attending La Hora del Cafe, a weekly DRC-supported peer self advocacy group, he was homeless and unemployed. Now living in an apartment and partially supporting himself through his artwork, Teo says his interactions with this group gave him the support and confidence to develop the skills he needed to rebuild his life.

## Spanish media cover DRC event

In September 2013 the California Memorial Project Remembrance Day was held to honor people who died anonymously in state institutions. Ceremonies involving self-advocates and community leaders were held at 10 sites throughout the state. For the first time since this project started in 2002, the Latino media covered the event in depth, including a feature by the influential La Opinion about Spanish speaking youth with mental health disabilities. DRC Trainer Senobia Pichardo pointed out that while the event focuses on

the past, serious problems exist today, such as the number of minority youth who cannot get mental health services and end up in state hospitals or commit suicide. She said, “There is a stigma attached to young Latinos - if they act differently, people assume it is because they belong to gangs or are drug addicts.”

## Training about voting with a disability

DRC advocate Scott Barron and attorney Hillary Sklar gave voting rights training last summer at several Independent Living Centers in the Los Angeles area as part of a leadership course. One training involved four groups of 13-20 young people with disabilities who learned about voting eligibility criteria, registration and casting a ballot. Afterwards the group checked out accessible voting equipment at the LA Registrar’s office.



Tho Vinh Banh, DRC staff attorney, leads voting training

## Disability Rights California celebrates 35 years 1978 - 2013 Highlights

**1977-78:** investigative TV series on abuse in institutions results in federal Developmental Disabilities Act... all states required to name protection and advocacy agency... 1978 Gov Jerry Brown designates DRC, then called Protection & Advocacy, Inc as statewide agency.

**1979-1985:** we help stop deregulation of Education of All Handicapped Children Act... help get home-based services for children on SSI... launch popular “how to advocate for your rights” publications... we play role in major victory, the Social Security Reform Act... our bill passes to improve fair hearings for people with developmental disabilities.

**1986-1990:** we now help people with mental health disabilities and set up peer self-advocacy services... file Zebley amicus brief, successfully challenges federal SSI standards for children... file Coffelt class action to speed pace of individuals leaving state institutions... shooting of man in mental health crisis spurs our advocacy for expanded police training.

**1991-1995:** we set up Office of Patients’ Rights to serve state hospital residents... our re-

view of state hospital deaths brings new restraint procedures... our bills pass to conform state law with Americans with Disabilities Act... our bill on Fair Housing for People with Disabilities passes... Coffelt suit settles, affecting 2300 living in state institutions - since, thousands have moved out... we help Sandra Jensen become first person with Down syndrome to receive heart transplant.

**1996 - 2000:** our suit results in Chanda Smith consent decree improving services for 80,000 disabled students in LA... our class action against Bay Area Rapid Transit settles, achieves better access for 40,000 riders... we set up Office of Clients’ Rights Advocacy to help people with developmental disabilities get services... following scalding death at psychiatric facility - we get new regs for water temperature controls... our services extended to people with all disabilities.

**2001 - 2005:** our Emily Q case means 1000 young people receive wrap-around therapeutic behavior services... start work on access to voting issues... begin services for Social Security beneficiaries and those with traumatic brain injuries...

### Woman spends decades in institutions being over-medicated and losing ability to walk until DRC intervenes



Arthur and Nancy at her group home

Letter to DRC: “*You may not remember me but my sister and I will never forget you.*” That was how Mary started her letter to us in the fall of 2013 about how well her sister, Nancy, is now doing in a nearby small group home and how thrilled they both are to reconnect. Nancy spent nearly 20 years in a locked facility in Humboldt County, then was transferred to another smaller institution in the Bay Area. Due to many years of apparently

support Prop 63, creating Mental Health Services Act to extend community based services... our report on deaths from prone restraints brings standards for use in health care facilities.

**2006 -2010:** Remembrance ceremonies create awareness of 40,000 who died in state institutions... Our name changes to Disability Rights California... judge halts cuts in response to our Oster class action to prevent 20% reduction of In-Home Supportive Service hours for 300,000 recipients... our Darling case filed to stop elimination of center-based adult health services for 35,000... we help defeat bill limiting rights to sue for lack of architectural accessibility.

**2011-2013:** Napper class action settles - keeps community mental health clinics open for 6000 in Sacramento... we begin employment-related assistance statewide to those needing Dept of Rehabilitation services... we join 100 LA groups to halt restriction of supported housing... Darling case settles, we help hundreds with successful appeals for new community based health services... we present perspective of state hospital residents at town forums... our bill passes requiring state institutions to report all abuse and unexplained deaths to police... Oster case settled, with less harmful cuts of 8% in IHSS hours.

## Clients served, issues resolved

**In 1979** 2000 received DRC services; by the end of our first decade, we had directly assisted **38,000** people

**by 2008** the end of our third decade, we had assisted approximately **500,000** Californians

**in 2013** we resolved approximately **23,600** requests for help.

## Beginning with a few staff in Sacramento in 1978, we added offices as follows:

- 1980 - Los Angeles
- 1985 - Oakland
- 1992 - in 5 state hospitals
- 1999 - in or nearby 21 regional centers
- 2001 - San Diego
- 2008 - Fresno

**In 2013 the DRC staff was approximately 200**

too much medication, she lost her ability to walk and her interest in communicating. She was in the smaller facility for another 10 years.

After watching her sister deteriorate, Mary wrote to DRC where she was connected to Lynne Page, Clients' Rights Advocate. Lynne helped Mary request an Individual Program Plan (IPP) for Nancy and got the IPP process moving forward. An IPP has goals agreed to by the consumer, the consumer's support staff and the regional center, to make sure the consumer is being treated in the least restrictive setting possible.

After Nancy was moved to the group home in another region, Arthur Lipscomb became her advocate. He visited Nancy and spoke with her about being in the group home - she said she especially liked being able "to see her sister." Mary concluded her letter to us: *"After your intervention, Nancy was started on an IPP, then taken off medications, and moved to a group home not far from me, and where she enjoys community center activities. She is walking again --her transformation is a miracle. We are taking my sister to Los Angeles for family visits over the holidays."*

## Shelter further endangers woman in hiding

Avril Banyan, who was sheltering at a rescue mission, was asked to leave. Because of a psychiatric disability, she was considered “too sick” to participate in the required program of the mission. Since the only place she had to go was back home to her abuser, this discrimination created a life and death situation for Avril. DRC attorney Ann Menasche filed suit and settlement is in process.

## Parity law welcome: helps more to access mental health services

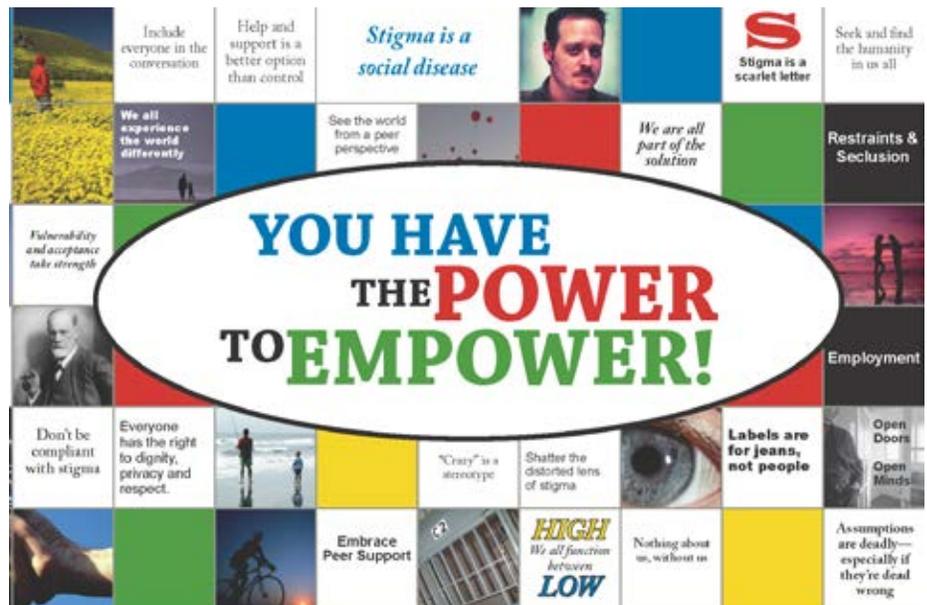
After many years of advocacy, federal and state law now requires parity between physical and mental health services. DRC is working to make sure the laws become better known and implemented statewide. We know lack of coverage means many people go without needed mental health services.

In 2013, as a result of a grant from California Mental Health Services Authority. (CalMHSA - Prop 63), we submitted an Amicus (friend of the court) Brief (Rea v Blue Shield) to support a case promoting parity or equality of insurance coverage. We argued that if only services that parallel physical health services are funded, then many effective mental health services will not be covered. For exam-

ple, there are proven interventions and therapies for children and youth with mental health crises that have no parallels in physical health. If young people are denied these services while the debate about parallel coverage continues, their recovery will be seriously delayed.

## 27,000 regional center clients to get improved service notices

More timely and easier to read notices about services for people with developmental disabilities is a main result of the new agreement between DRC and the Inland Regional Center. DRC Managing Attorney Maria Iriarte said, “Improved notices of eligibility for services or right to appeal decisions are examples of how we are working together so clients in San Bernardino and Riverside counties are better informed.”



This graphic was created by DRC staff to use in CalMHSA trainings in how to counter stigma. The creative team included Adam Borovkoff, Robyn Gantsweg and Diana Duffy.

### Institution violates use of restraints

Cassie Mathison, a young woman with both developmental and mental health disabilities, was admitted to a large locked skilled nursing facility called an Institute for Mental Disease (IMD) following difficulties in her community placement. She reported being kicked in the groin by staff and when we investigated, we also saw a deep laceration in her arm. We noted the IMD had several violations of rules considering use of restraints, and revisiting 6 weeks later, found the same violations. Leslie Morrison, DRC director of investigations, filed complaints with both the Centers for Medicare and Medicaid Services and the California Department of Health and anticipate completion of their review in March 2014.

### Unpardonable delays in Dept of Public Health abuse investigations

DRC has conducted more than 200 investigations into abuse of people with disabilities in long term care facilities and currently has 12 open cases. Leslie Morrison testified about many years of unpardonable delays in Department of Public Health investigations. She noted that “DPH cases often languish in a bureaucratic quagmire, awaiting resolution from upper level management...”

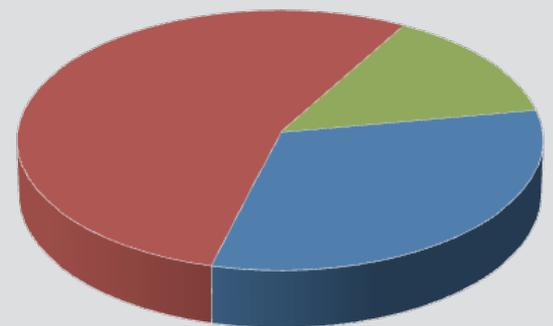
Our comprehensive review of DPH handling of investigations found troubling examples of delay, including the July 2010 case where a 30 year old with paraplegia died from uncontrolled bleeding. Only years later did DPH acknowledge lack of monitoring of blood thinning drugs; two deaths at one facility within 18 months because staff failed to respond when patients became disconnected from ventilators; and another case where 3 years lapsed between the rape of a patient and citation of the incident. We are exploring ways to require the DPH to finish investigations faster and report abusive providers of care to their licensing boards.

Revenue and Support	Amount	%
U.S. Federal Grants	\$9,842,549	45%
State of California DDS/DSH	\$6,688,390	31%
The California State Bar	\$2,176,757	10%
Program Income/Attorney Fees	\$1,445,883	7%
Miscellaneous Income/Other Contracts/Interest Income	\$1,275,921	6%
Donations	\$172,242	1%
<b>Total Revenues</b>	<b>\$21,601,742</b>	<b>100%</b>

Expenses	Amount	%
Program Services	\$17,932,193	89%
General and Administrative	\$2,289,855	11%
<b>Total Expenses</b>	<b>\$20,222,048</b>	<b>100%</b>

Change in Net Assets                    \$1,379,694

### Major Programs Expenditures by Primary Disability



- Mental Health
- Developmental Disability
- Physical, Learning & Sensory Disabilities

## DRC Fast Facts 2013

Last year we resolved more than **23,600** issues. Of that total, around **10,700** concerned developmental disabilities and **8400** concerned people with mental health disabilities.

Our staff participated in **1140** training and community outreach events, reaching around **67,000** people with information in many languages about our services.

DRC receives at least **2000** requests for assistance a month. In 2013 people most often asked for help with:

- regional centers (**4400**)
- education (**3200**)
- health related (**3100**)
- privacy and personal autonomy (**3000**)
- income maintenance (**2400**)
- abuse (**1400**)
- and housing (**1000**)

In addition, we estimate around **411,300** Californians were positively impacted by our class action and impact litigation. In 2013 more than **160,000** visited our website and accessed publications in multiple languages.

### Thanks to our probono partners:

Brancart & Brancart  
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Hadsell, Stormer, Richardson & Renick LLP  
Heller Ehrman LLP  
Law Offices of Amy Vandeveld  
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