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# Advocacy Director's Report

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Summer 2009

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This report primarily represents a summary of the work Disability Rights California Advocacy Director Units have reported through April 31, 2009; some activities on the legislative front may be more current. I'd like to thank those who provided the material to make this report possible.

## COMMUNICATIONS

This quarter our communications efforts centered on alerts about the impact of the disproportionate budget cuts on seniors and people with disabilities, on outreach to promote the Legislations Unit's analysis of the cuts and to encourage participation in the protests, sidewalk rallies and coalition strategizing throughout the state. We also widely disseminated announcements of the settlements of two class action suits – *Capitol People First v. Department of Developmental Services* and *Martinez v. Astrue* -- and publicized our voter hotline, held in May.

Due to avid media interest in the national reports released on the dangers of restraint and seclusion of schoolchildren, Disability Rights California continued to get coverage of both its investigations into these practices and its sponsored bill to introduce safeguards. Highlights follow.

### Press Releases

- **March 17** – we joined other advocacy groups in objecting to the settlement of a suit, which would ban Segways from use in any Disney park, and require people who needed to use this type of mobility device to rent one from Disney.
- **April 13** – together with co-counsel, we announced settlement of a nationwide suit against the Social Security Administration (SSA) (*Martinez v. Astrue*) for ignoring its own policy on “fleeing

felons” in order to prevent people with outstanding warrants, often decades old, from obtaining benefits. The SSA policy called for checking that the applicant had fled to avoid punishment for a felony. The results are that SSA agreed to pay some back claims, to restore others to benefits and as of April 1, to cease applying the illegal policy. We are helping to find California applicants who were wrongly denied benefits.

- **April 27** – together with co-counsel, we announced settlement of a large class action case (*Capitol People First v. Department of Developmental Services et al*) that will make it easier for many of the 7000 Californians with developmental disabilities living in institutions to obtain services from the state in finding and transitioning to less restrictive environments. The case, filed in 2002, required intensive efforts to obtain agreement with the state –during this economic crisis--to upgrade their efforts to assist institutionalized people to exercise their rights to live in the community.

### **Communications Goals: 3**

**Disability Rights California Staff:** Barbara Duncan, Fred Nisen, Marilyn Holle, Tim Poe; Barbara Dickey, Ellen Goldblatt, Will Leiner  
**Grant Funding Source:** Trust Fund

### **Media coverage of our issues**

- **February 11** -- press coverage of our involvement in San Diego rally for economic justice, as part of the Disability Action Coalition,
- **March 24** – closing of Agnews Developmental Center after 120 years got wide coverage and our Executive Director issued statement thanking relevant state officials for making it happen;
- **March 31** – Congress announced probe in response to National Disability Rights Network's national report on restraint and seclusion and CBS series on “The Quiet Room,” including comments by Leslie Morrison about traumatic effect of shutting children in small, dark rooms;
- **April 1** -- coverage by Sacramento press of a rally by the IHSS Coalition to restore funds for caretakers, was modest compared to more extensive coverage that month of county investigations of fraud in the program;

- **April 15** – *Youth Law News* featured a report on the appointment of a Special Master to oversee implementation of the settlement of *Katie A v Bonta*, referring to our press releases on the case.

### **Communications Goals: 3**

**Disability Rights California Staff:** Barbara Duncan Ann Menasche; Cathy Blakemore; Leslie Morrison; Deborah Doctor

**Grant Funding Source:** Trust Fund

### **Website**

#### **Expanded use of our website, [www.disabilityrightscalifornia.org](http://www.disabilityrightscalifornia.org)**

During this quarter, visits to the Disability Rights California website soared, perhaps reflecting the avalanche of “bad news” we were obliged to feature, as well as the tightening economy. Unique visits to the home page news were 19,684 in February, 29,261 in March and 32,750 in April. Similarly, visits to the jobs section climbed from 2,212 in February, to 3,261 in March, to 9,355 in April.

In March, for the first time, the homepage of our Spanish language website, showed up in the top 10 pages visited, reaching the 8<sup>th</sup> position with 688 visitors.

The media coverage drove visits to our publications as well: downloads of our report on Restraint & Seclusion in California Schools was in the top 3 for all 3 months, whereas it usually does not make the top 10. Other publications in the top 5 this quarter were: Our Advocacy Plan, Special Education Rights & Responsibilities, IHSS Fair Hearings & Assessment Packet, You Can Vote even If You Can't Sign Your Name and Rights Under the Lanterman Act.

#### **Using the website to promote our activities**

In addition to posting regular reminders about voting and our various analyses of the impact of the budget cuts, the website was also used to promote participation in Capitol Action Day, and provide information about regional outreaches, the annual report, and protests about the offensively named business, Psycho Donuts, in Campbell.

### **Communications Goals: 3**

**Disability Rights California Staff:** Barb Duncan, contractors Ruth Ordas and Hizuru Cruz  
**Grant Funding Source:** Trust Fund

## LEGISLATIVE ACTIVITIES

**IMPORTANT NOTE:** Legislative activities are current at the time this report is prepared, however, the legislature moves quickly and things can change overnight, so for the most current information on bills or other activities reported here, check Disability Rights California's legislative website:  
<http://www.disabilityrightsca.org/legislature/legislation/2008-2009/index.htm>

### **Budget**

For most up to date information about the budget:  
[http://www.disabilityrightsca.org/news/Budget\\_Crisis-2008.htm#analyses](http://www.disabilityrightsca.org/news/Budget_Crisis-2008.htm#analyses)

For the first time ever, the governor and the legislature introduced, negotiated, and passed an 18 month budget deal to address an estimated \$42 billion budget shortfall through June of 2010. The budget deal was enacted secretly and hastily behind closed doors, with little or no public input.

As expected, the budget deal included many harmful cuts to social programs that affect people with disabilities. The budget included some tax increases, as well as several complicated assumptions and contingencies. One, called "the trigger", linked more cuts and some temporary tax hikes to an arbitrary threshold for the amount of money coming from the federal stimulus package, or the American Recovery and Reinvestment Act of 2009 (ARRA). Other components of the budget deal included a series of ballot measures that, if enacted, would borrow and swap from other funding sources to fill in the remaining shortfall.

The "trigger" mechanism tied several more devastating cuts to the amount of money that would come from the ARRA. It required at least \$10 billion from the federal government to be available to offset general fund budget spending. According to the statute, the state treasurer and the director of finance were to interpret, and decide, by

April 1, 2009, whether or not the federal legislation would yield the \$10 billion. Disability Rights California staff and other advocates fought to persuade the treasurer and director of finance that ARRA would provide ample funding. The state ultimately decided that the threshold was not reached.

With the state's fiscal climate moving from bad to worse, the Governor released his May budget revision early, on May 14<sup>th</sup>. It contained more proposed cuts to programs affecting people with disabilities, including further cuts to In Home Supportive Services and SSI/SSP; some cuts were made contingent on the outcome of the propositions in the California special election. When the propositions failed, and with no signs of economic recovery, the administration announced that the current budget shortfall has grown to \$24.3 billion.

The Governor not only affirmed his determination to make all the previously proposed cuts, but added more, which would shred and discard what's left of the safety net for poor Californians, including the complete elimination of CalWorks and Healthy Families, along with many others.

**Public Policy:** Goals 3, 4, 5, 6

**PAI Staff:** Evelyn Abouhassan, Deborah Doctor, Margaret Johnson, Brandon Tartaglia

**Grant/Funding Source(s):** Equal Access

### **Significant Work and Advocacy on the Developmental Disabilities Budget**

In response to the governor's budget that passed on February 20, 2009, the Department of Developmental Services (DDS) convened stakeholders – including Disability Rights California – to meet and review proposals to achieve 100 million in budget cuts in the DDS budget... We reviewed these fifteen proposals in more detail and provided comments and suggestions to other stakeholders and DDS concerning the changes and the trailer bill language provided by DDS to implement the programmatic changes. Some of these proposals are changes in the way transportation is provided to regional center clients, increases in the parental fee program for children placed in out of home placement, and the utilization of Neighborhood Preschools instead of interdisciplinary programs which would provide needed services to infants and toddlers in integrated, natural

environments at a savings to the state. We also met with key legislative budget staff to present written comments and suggestions as to the budget proposals and ideas to achieve future savings in the DDS system and testified in legislative budget hearings.

Since the release of the Governor's May Revision there are additional proposed cuts in the DDS budget. Advocates will be tracking and speaking out against cuts that harm persons with disabilities.

**Public Policy Goals:** 3, 4, 5, 6

**Disability Rights California Staff:** Evelyn Abouhassan, Catherine Blakemore

**Grant/Funding Source(s):** Equal Access

### **Disability Capital Action Day**

Capitol Action Day 2009 took place on May 27. Advocates from Disability Rights California, California Foundation of Independent Living Centers, and others sponsored and organized the event. The theme of the event was the tenth anniversary of the *Olmstead* decision, which upheld the ADA's community integration mandate. There was a wonderful turnout and individuals were able to testify at budget hearings and go on legislative visits to make their voices heard. This is particularly important considering the unprecedented threats not only to community living but to their lives, embodied in the enacted and proposed budget cuts.

**Public Policy Goals:** 4, 6

**Disability Rights California Staff:** Brandon Tartaglia, Deborah Doctor

**Grant/Funding Source(s):** Equal Access

### **AB 214: Durable Medical Equipment (DME)**

AB 214 is our Durable Medical Equipment bill, co-sponsored with DREDF and the MS Society, It mandates that health insurers offer DME coverage in employer-based and individual plans and eliminates any caps on DME coverage which are below the overall policy cap. Several legislators signed on as co-authors after Assemblyman Wes Chesbro, shepherded the bill through the Assembly Health Committee.

Enthusiastic support for AB 214 has come from disability and senior groups and providers of DME; predictably the insurance industry and

health plans have opposed the bill, as they do any mandate bills. The MS Society has made this bill its top priority and its members visited every legislator in May to seek support.

Our hopes for passage and governor's signature are bolstered by newly released statistics from the Department of Health Care Services, which show significant cost-shifting on DME from the private health industry to Medi-Cal. Around 11% of people on Medi-Cal have other insurance coverage; in 2008, Medi-Cal spend around \$6.5 million dollars (half of it General Fund) on DME for that group. If AB 214 were law, most if not all of those DME expenses would have been borne by the private insurers rather than by the taxpayers through Medi-Cal. Unfortunately AB 214 did not make it out of Assembly Appropriations.

**Public Policy Goals:** 2, 3, 4, 6

**Disability Rights California Staff:** Deborah Doctor

**Grant/Funding Source(s):** Equal Access

**Sponsored Legislation: AB 1538: Legislation to Protect Students and Staff from the Dangers of the Use of Seclusion and Restraint in Schools**

AB 1538 (Ma, Chesbro) would provide minimal protections as to the use of seclusion and restraint in schools. We convened a stakeholder process to address concerns, primarily centered on the seclusion portions of the bill. Representatives from the SELPAS, the nonpublic schools and legislative staff from both authors' offices were present. Based on stakeholder concerns, we amended the bill to address only the use of restraints in schools.

In the Assembly Education Committee on April 22, 2009, a grandparent testified about the harm her grandson experienced because of the practices which are the subject of the bill. The bill passed out of committee and we will continue to work with stakeholders to address amendments taken in the assembly education committee related to the IEP process as well as any additional concerns as the bill moves through the legislative process. We sought and received letters of support from such groups as the Arc of California, the Association of Regional Center Agencies (ACRA), Disability Rights Education and Defense Fund (DREDF) and the National Disability Rights Network (NDRN).

**Public Policy Goals:** 2, 3, 4, 6

**Disability Rights California Staff:** Evelyn Abouhassan, Leslie Morrison, Catherine Blakemore

**Grant/Funding Source(s):** Equal Access

**Concerns With Out Of State for Profit Residential Placements for Children with Disabilities**

AB 421 (Beall) would allow California counties to seek and receive reimbursement for out- of-state placements in for-profit facilities. Currently, state law disallows such claims.

Disability Rights California's concerns about AB 421 have two bases: 1) We believe that out of state for-profit facilities often lack appropriate oversight and accountability. We want to ensure that adequate protections are put in place to minimize health and safety risks when students with disabilities are placed in programs that are long distances from their families; therefore we want policy changes that increase the monitoring of such placements. 2) We think this legislation would make it much easier for counties and districts to place special education students in out-of-state residential facilities. While all residential educational placements are highly restrictive, out-of-state placements are the most restrictive because children in facilities far from home are isolated from regular interactions with family, friends, and other children without disabilities.

We met with the author's office and Assembly Education Committee staff to request amendments regarding reporting of injuries to and deaths of California children placed in out-of-state for-profit facilities. Because the sponsors and author did not accept our amendments, we opposed the bill in the Assembly Human Services Committee and the Assembly Education Committee. The bill is currently set to be heard in the Assembly Appropriations Committee.

**Public Policy Goals:** 3, 6

**Disability Rights California Staff:** Evelyn Abouhassan, Brandon Tartaglia

**Grant/Funding Source(s):** Equal Access

**Sponsored Legislation: AB 287: Employment First Legislation**

AB 287 (Beall and co-authors: Buchanan, Eng, Fuentes,

Portantino, Yama) essentially does three things: sets forth an Employment First policy; establishes a standing Employment First Committee to be formed by The State Council on Developmental Disabilities; and directs regional centers to begin the conversation regarding employment opportunities with the consumer starting at age 14. Each of these provisions will help advance the agenda of expanding employment opportunities for people with developmental disabilities.

The bill is co-sponsored with us by the State Council on Developmental Disabilities and the Association of Regional Centers Agencies. Along with our co-sponsors we have visited legislators and testified in committees about the bill.

The bill has passed out of the Assembly Human Services and Appropriation Committees and is now on the floor of the Assembly. It is expected to move next to the Senate Human Services Committee.

**Public Policy Goals:** 2, 3, 4, 6

**Disability Rights California Staff:** Margaret Johnson, Jonathan Elson

**Grant/Funding Source(s):** Equal Access

# **SELF ADVOCACY ACTIVITIES**

## **DEVELOPMENTAL DISABILITIES PEER SELF ADVOCACY**

We provided 18 trainings, presentations and outreaches on a variety of topics such as; Self Advocacy, Rights of people served by day programs and who live in facilities, Independent Living Services (ILS), Abuse Prevention, Individual Program Plan (IPP) Rights, Effective Strategies for IPP Rights in Tight Budget Times, Boardmanship and Becoming an Effective Self Advocacy Leader in addition to outreaches regarding Disability Rights California, OCRA and DDPSAU services to approximately 614 people to groups such as: The ARC of San Francisco, GOALS services, CAPC services, Abilities First, the Alan Short Center, Westside Regional Center, Yuba Sutter People First, the Cal –TASH conference, Imperial Valley People First Conference, Fairview Developmental Center, Porterville Developmental Center, The Self Advocacy Coordination Project in Sacramento, Sonoma Developmental Center and Eastern Los Angeles Regional Center.

**DDPSA Goals:** 1, Objective A-C

**Disability Rights California Staff:** Daniel Meadows, Maria Marquez, Marinda Reed and Scott Barron

**Grant/Funding Source(s):** PADD

### **Kelly Gee<sup>1</sup> Needed Help Resolving Concerns with her Service Provider**

We assisted Kelly Gee to resolve concerns she was having with her service provider and strengthen her self advocacy skills. We met with Kelly Gee to discuss her concerns about the quality of her services and the communication difficulties she was having with her provider. Kelly Gee was provided with information about her service rights and we helped her identify possible strategies to resolve the communication concerns.

**DDPSA Goals:** 1, Objective A

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<sup>1</sup> Names are changed to protect our clients' privacy.

**Disability Rights California Staff:** Marinda Reed  
**Grant/Funding Source(s):** PADD

### **Cal-TASH and Imperial Valley People First Conference Workshops**

We provided training to 17 people on effective IPP development during challenging budget times at the Cal-TASH conference in Long Beach. The Cal-TASH conference provides training to people with disabilities, family members and professionals with a special emphasis on the needs of school age children and transition age youth. It is especially important for people to have the tools and strategies they need for effective IPP development and to have a clear understanding of the appeal rights offered by the Lanterman Act. Participants were provided with information, strategies and materials so they would be better prepared to advocate for themselves at their next IPP.

DDPSAU and OCRA staff provided Self Advocacy Leadership training to 17 participants at the Imperial Valley People First Conference. This conference provides critically needed self advocacy skills training in an isolated region of California. Most participants are Spanish speaking and live either in their family homes or in group home settings. We conducted a work shop that provided an overview of the importance of self advocacy and effective leadership skills for people who may be new to self advocacy. Participants were also provided with easily understood materials about self advocacy and leadership skills.

**DDPSA Goals:** 1, Objective B

**Disability Rights California Staff:** Marinda Reed, Maria Marquez, Daniel Meadows and Scott Barron  
**Grant/Funding Source(s):** PADD

### **Work on Abuse Prevention Publication**

The right to be free from abuse and to have the tools to get help for yourself or someone you know who may be encountering abuse are important rights for people with developmental disabilities. We are working on an abuse prevention publication to serve the needs of our clients and to compliment one of our most sought after trainings. The development of abuse prevention publication is being led by Scott Barron who joined the Unit January. He is based in Los Angeles.

**DDPSA Goals:** 1, Objectives C

**Disability Rights California Staff:** Marinda Reed, Maria Marquez, Daniel Meadows and Scott Barron

**Grant/Funding Source(s):** PADD

## **PEER SELF ADVOCACY**

### **PSA Outreaches to the Community**

Receiving a request from participants in the Los Angeles North East Wellness Center self-advocacy group who have children with autism, PSA staff collaborated with other Disability Rights California staff to provide a booth with information about our organization and services at the “Autism Speaks” fundraiser in Elysian Park in East Los Angeles. This was the first time we participated at this event, which was an excellent opportunity to reach out to people from the developmental disability community and share with them the importance of self-advocacy skills. Other outreaches were conducted in the Latino community: 3 trainings for Department of Mental Health participants in “Herramientas para la Abogacia.”

**PSA Goals:** 1, Objective B

**PSA Staff:** Rosy Tellez, Senobia Pichardo

**Grant/Funding Source(s):** PAIMI

### **New PSA Self-Advocacy Group forming in San Diego County**

With our technical assistance and guidance, members of the San Diego Veterans self-advocacy group have begun outreach to current and former military service members in Oceanside, which is in the northern part of San Diego County, in order to start a self advocacy group. This location will provide greater access to many veterans who live and work at nearby Camp Pendleton. It is an opportunity for current self-advocacy group members to take a leadership role, using their self-advocacy skills to advertise, organize and recruit new members for the self-advocacy group.

**PSA Goals:** 1, Objective C

**PSA Staff:** Michael McPherson

**Grant/Funding Source(s):** PAIMI

## **Facility Voting Project**

We created, in collaboration with other staff at Disability Rights California, a voter information packet to educate facility operators about resident voting rights so they can assist residents with voter registration and civic participation. Packets were distributed to acute care and residential facilities in Los Angeles, Kern, San Bernardino and Riverside Counties. Following the distribution of the packet, we will provide on-site voter trainings and outreach. We will evaluate the effectiveness of the project at its conclusion in order to determine if we want to approach facilities in other parts of the state.

**PSA Goals:** 1, Objective A

**PSA Staff:** Garnet Magnus

**Grant/Funding Source(s):** PAVA

## **Self-Advocacy in Action**

In San Bernardino, the Pathways to Recovery Peer Center self-advocacy group members, with our assistance, learned about and developed Wellness Recovery Action Plans (WRAP's), which include crisis plans to promote and safeguard their wellness and recovery. A WRAP is a self-designed plan for staying well, and for helping a person feel better when they are not feeling well, to increase personal responsibility and control over their own life, and help them make their life be the way they want it to be.

Many have given completed Advance Directives to their agents and physicians. Advance Directives allow an individual to appoint an agent and provide guidance about mental health and physical health decisions when the person is no longer able to make their own choices.

The group is now learning about the Ticket to Work Program. The Ticket to Work Program provides most people receiving Social Security benefits more choices for receiving employment services. Under this program, the Social Security Administration (SSA) issues tickets to eligible beneficiaries who, in turn, may choose to assign those tickets to an Employment Network of their choice to obtain employment services, vocational rehabilitation services, or other support services necessary to achieve a work goal. A speaker from Goodwill Industries, a designated Social Security Administration employment benefits developer, provided participants with

information about how to obtain employment and how work might affect their social security benefits. In addition, some self-advocacy group members will be developing a PASS (Plan to Achieve Self-Sufficiency) with help from the Department of Vocational Rehabilitation. A PASS allows an individual receiving SSI to set aside income to accomplish SSA approved career or educational goals.

**PSA Goals:** 1, Objective B

**PSA Staff:** Garnet Magnus

**Grant/Funding Source(s):** PAIMI

### **PSA Staff Presentation on Self-Advocacy and Technology**

Last month, as part of the California Health Incentives Improvement Project (CHIIP) conference in Anaheim, we presented information about how mental health clients can use technology to advocate for themselves. Showing video clips of self-advocacy group members from the San Diego Corner Clubhouse and the San Diego Veterans group, we demonstrated for the audience how clients can use computers to learn about and apply for their own Social Security benefits by accessing information and completing the worksheets on the Social Security Administration's website. This is one of the ways that we teach group members about the importance and usefulness of technology in self advocacy.

**PSA Goals:** 1, Objective B

**PSA Staff:** Michael McPherson

**Grant/Funding Source(s):** PAIMI

### **Outreach at Napa State Hospital**

In April, we conducted outreaches to 8 units at Napa in order to inform residents about the services available at the Napa Self Help office. As a result of the outreach - attendance at the self advocacy group increased from an average of 17 people per week to an average of 28 people per week.

**PSA Goals:** 1, Objective C

**PSA Staff:** Debi Davis

**Grant/Funding Source(s):** PAIMI

**Self-Advocacy Groups in Redding Are Growing:  
NVCSS Second Home Self-Advocacy Group &  
Crestwood Redding Self-Advocacy Group**

Attendance has increased to 10-15 clients per meeting per group. It is twice what it used to be. Clients at the self advocacy groups have been learning about patients' rights, employment rights, housing rights, public benefit rights, and discharge planning among other things.

**PSA Goals:** 1, Objective C

**PSA Staff:** Mark Olberg

**Funding Source:** PAIMI

**New Self-Advocacy Group in Sacramento at the American River  
Behavioral Health Center**

A self-advocacy group has begun at American River Behavioral Health Center. During these first few months, members have learned about and discussed topics varying from stigma and discrimination, employment rights and available community resources and medication issues and how to advocate for oneself.

**PSA Goals:** 1, Objective C

**PSA Staff:** Lou Williamson

**Funding Source:** PAIMI

**Plans Underway for United Women's Conference in Central  
Valley:**

**Woodlake Women's Association**

**Asociación de Mujeres Unidas – Coalinga**

**Asociación de Mujeres Unidas – Huron**

This quarter, all three groups have begun the planning process for 2009's United Women's Conference to be held in October in Huron CA. The exact date and time for the 1-day conference is still to be determined. Activities planned for the conference include Mexican folk dances, personal testimonies, rights trainings and presentations about services by local community based organizations.

**PSA Goals:** 1, Objective C

**PSA Staff:** David Solis

**Funding Source:** PAIMI

## **CALIFORNIA MEMORIAL PROJECT**

### **California Memorial Project Plans Three New Memorials**

The Peer/Self-Advocacy Units' as part of the California Memorial Project have begun working on monuments for the following 3 sites Patton, Ukiah and Napa. We have been working with peers, consumers, community members and local vendors to design the monuments. A target date for completion is September 2009 with an unveiling on Remembrance Day. Plans for this year's Remembrance Day are underway. Remembrance Day will be held at 9 locations across the state of California on September 21, 2009.

**PSA Goals:** 2, Objective A

**PSA Staff:** Martha Cook, Rob Chittenden, Yvonne McGough, Sharon Schmidt, Alicia Mendoza, Miriam Farris, David Solis, Gabby Morales, Robyn Gantsweg, Senobia Pichardo, Rosie Tellez, Garnet Magnus, Sheryl Bradford, Michael McPherson, Daniel Meadows, Marinda Reed, Jenny Olson,

**Funding Source(s):** PAIMI, PADD