
Advocacy Director's Report

December 10, 2011 Report

This report represents a summary of the work Disability Rights California advocacy programs and projects reported through October 15, 2011; some activities on the legislative and press front may be more current. I would like to thank those who provided the material to make this report possible.

COMMUNICATIONS

ADHC media coverage

The growing concern about maintaining independence in the face of eroding support for community-based care services was predominant in disability related news coverage this quarter. As in the previous quarter, there were numerous local reports (e.g., Modesto Bee, Riverside Press Enterprise, San Bernardino Sun) documenting the family crisis caused by closing Adult Day Health Care (ADHC) centers, most mentioned our case to stop these cuts.

The NY Times/Bay Citizen issued an in-depth article on October 27 about the cuts, quoting a DRC attorney's reminder to the governor that "If you eliminate this program without providing adequate alternative services to keep people in their homes, this is a violation of the Americans with Disabilities Act."

Communications Goals: Goal 1, 2

Disability Rights California Staff: Barbara Duncan

Grant/Funding Source(s): Trust Fund

Other media highlights include:

During August (KPBS & Capitol Public Radio 8/10/2011) and continuing throughout the quarter, advocates voiced concern that the state's low level of revenues will soon cause trigger cuts to In-Home Supportive Services -- as high as a 20% across the board reduction in hours of assistance. This would threaten thousands of Californians' ability to remain in their homes.

On the legislative level, there were several articles and op-eds (e.g., Sacramento Bee, 8/26/2011) published in support of California's bill (supported by DRC and now signed by the governor) to make it possible for nonmedical school personnel to administer medication to stop students' epilepsy seizures.

On October 6, there was media coverage of the governor signing a bill repealing the Schwarzenegger administration plan to fingerprint the estimated 450,000 IHSS recipients as an expensive but questionable anti-fraud effort. We sponsored this bill and stressed the folly of spending at least \$41 million of critical IHSS funding in this way.

In August, the tragic death of a young, homeless man from a Fullerton police beating resulted in coverage. Included were a few op-eds and news articles claiming that full implementation of Laura's Law (AB 1421) would have prevented the death of the victim, who reportedly had a mental health disability. A DRC co-written op-ed emphasizing the need for better police training on working with people in crisis was published on October 5 by the LA Daily News. We are now submitting letters to the editor in other news outlets in an effort to counter the media efforts of the Laura's Law proponents.

In September, our press release and outreach to many local communities resulted in good turnout for the California Memorial Project's Remembrance Day honoring Californians who lived and died in state institutions. The Ventura County Star (9/19/2011) recognized DRC for its role in organizing the event and collaborating with a local university to support the ceremonies taking place on its campus, which was previously the site of Camarillo State Hospital.

Communications Goals: Goal 1, 2
Disability Rights California Staff: Barbara Duncan
Grant/Funding Source(s): Trust Fund

Website trends

We advanced slightly over last quarter, attracting an additional 2,000 readers, totaling 55,530. These visitors also viewed 10,000 more pages on the website, using the top search terms of IHSS (constant across the last 12 months), Laura's Law (first time this appears in top 5), Lanterman Act and related Rights Under the Lanterman Act publication, and conservatorship. In addition to viewing news and checking out jobs, readers visited many of our publications, most frequently concerning special education, our fact sheets on budget cuts, entitlement programs and restraint and seclusion. A slightly increased number of visitors to our Spanish website mirrored most of these concerns, selecting our fact sheets on budget cuts, 18 tips to a successful IEP, IHSS nuts and bolts, and Special Education Rights and Responsibilities.

Communications Goals: Goal 3
Disability Rights California Staff: Barbara Duncan, Adam Borovkoff
Grant/Funding Source(s): Trust Fund, Equal Access

Making improvements

Simplifying and updating the look of our homepage and making it easier to find our most important information is the goal of a communications subcommittee of the DRC Board working with our staff. The webmaster will be implementing changes throughout November and December.

Communications Goals: Goal 3
Disability Rights California Staff: Barbara Duncan
Grant/Funding Source(s): Trust Fund

Special Education: Rights and Responsibilities is now complete and available online

The new fully-revised edition of Special Education: Rights and Responsibilities (SERR) has been made more accessible, is posted online and is being translated into Spanish. The popular CD of our most

requested publication has been redesigned and made more accessible. Additional topic-specific CDs of other publications are in the works.

Public Education Goals: Goal 1, Objective B; Goal 2, Objective A

Disability Rights California Staff: Adam Borovkoff

Grant/Funding Source(s): Trust Fund, Equal Access

LEGISLATIVE ACTIVITIES

NOTE: Legislative activities are current at the time this report is prepared; however, the legislature moves quickly and things can change overnight. For the most current information about legislative activities, check our homepage and legislative website:

<http://www.disabilityrightsca.org/> and

<http://www.disabilityrightsca.org/legislature/index.htm>

Medi-Cal budget advocacy

We are working with the Department of Health Care Services (DHCS) and other stakeholders on the implementation of the “soft cap” of seven physician and clinic visits, which became law in the last round of state budget cuts. We want to ensure proper notice goes out to all parties involved, with understandable language, common questions answered, and demonstrative examples of how the limit would work. We are also advocating for a webpage specifically devoted to the "soft cap" limit to contain all appropriate information.

Public Policy Goals: Goals 3, 4

Disability Rights California Staff: Brandon Tartaglia, Sujatha Branch, Dan Brzovic, Lisa Concoff-Kronbeck

Grant/Funding Source(s): Trust Fund

Highlights of key legislation

SB 161 (Huff): This bill allows non-nursing personnel to administer emergency anti-seizure medication only in cases where a staff member at the school site has volunteered to do so. We supported this bill with letters and testimony at hearings. We worked with the Epilepsy Foundation and the author’s office to help address the opposition to the bill. We attended press conferences in support of the legislation. Despite the heavy opposition, advocates were able to get the bill through the legislature and to the governor. The governor signed the bill on October 7th.

SB 368 (Liu): This bill enables a dependency or delinquency judge to appoint a responsible person to be the authorized representative for regional center matters. Historically, children and youth have had difficulty obtaining regional center services in dependency and delinquency court.

One reason is the lack of a responsible person with legal rights to access regional center files, request individual program plan (IPP) meetings, sign IPPs, and request hearings. SB 368 will correct that.

SB 368 also amends trailer bill language adopted as part of the enacted budget bill. Assembly Bill 104 (the trailer bill) amended Section 709 of the Welfare and Institutions Code to involve regional centers in delinquency matters of children and youth suspected of having a developmental disability. Unfortunately, these amendments led to confusion about competency evaluations and regional center eligibility. SB 368 clarifies the July 1, 2011 amendments and the language of Welfare and Institutions Code Section 709 by mandating a referral to the local regional center for an eligibility determination separate from a competency evaluation. This “clean up language” ensures that children and youth in the delinquency system with developmental disabilities are appropriately and routinely referred to local regional centers for an eligibility determination and, if appropriate, subsequent services and supports. We supported this bill by working with the author’s office and the sponsor (Public Counsel) as the bill moved through the legislature via support letters and hearing testimonies. Governor Brown signed SB 368.

AB 136 (Beall): This bill requires the Public Utilities Commission to expand the Deaf and Disabled Telecommunications Program to include assistance to individuals with speech disabilities, including help to purchase speech-generating devices, accessories, mounting systems, and specialized telecommunications equipment. We supported this legislation through letters, testimony at hearings, and worked with the author’s office to make AB 136 as expansive as possible. Although the final bill requires one objectionable provision—that an individual first check with third-party insurance before the PUC will cover the equipment—it was needed to keep the bill moving. We supported the bill in spite of this provision because it will make it easier for people with disabilities to get the equipment they need.

AB 519 (Hernandez): This bill, in its current form, defines restraint and seclusion in school settings and establishes minimally safe practice standards in schools comparable to restrictions in all other settings (see June 2011 Advocacy Director Report for more information). We worked with the author’s office and attended stakeholder meetings on the measure. Other groups involved include other disability advocacy

groups, representatives from the public school special education community, and representatives from non-public schools. While not the sponsor of the legislation, we are working with the author's office and stakeholders to find areas of consensus. AB 519 is now a two-year bill so stakeholders can work out the details of the bill language. The goal is to find areas of agreement among the various stakeholders and amend the bill so that it can be heard in the legislature in the early part of the year.

SB 946 (Steinberg): This bill requires that every health care service plan and health insurance policy issued, amended, or renewed after 1/1/2012 that provides hospital, medical, or surgical coverage, shall cover behavioral health treatment for pervasive developmental disorder or autism (PDD/A).

The bill also provides that when final rules are issued for the federal health care law (the Patient Protection and Affordable Care Act [PPACA]), California would not require any benefits exceeding the essential health benefits required of all health plans and insurers. If the federal rules are defined prior to July 1, 2014, the provisions in this bill would sunset prior to that date. We supported this bill, which was a last minute "gut and amend" and sent letters to the governor urging signature. The bill was signed into law.

SB 930 (Evans): This bill repeals 3 of the 10 "anti-fraud" measures passed by the legislature in 2009 in response to unsubstantiated but persistent allegations of fraud in the In-Home Supportive Services (IHSS) program. The three provisions are: (1) fingerprinting of IHSS consumers; (2) fingerprinting of consumers and home care workers on every IHSS timesheet; and (3) prohibiting the use of postal boxes by home care providers. (See previous Advocacy Director Reports for more detail.) We and our co-sponsors (SEIU, UDW, and the California Association of Public Authorities) accepted one amendment which makes it easier for information about provider criminal backgrounds to be shared among DOJ, DSS and the Public Authorities. Governor Brown signed the bill.

AB 889 (Ammiano): This bill would change the working conditions for domestic workers (including personal care assistants), who are not covered by overtime and other wage and hour rules, and would mandate certain benefits. (See details in the September 2011 Advocacy Report.) The author took many amendments to limit the scope and costs of the bill, but almost all disability groups and many others remained opposed. The author

decided to make it a two-year bill to allow further negotiations. We will be involved in those negotiations before the end of 2011 and remain hopeful for a compromise which would allow us to remove our opposition.

SB 109 (Gaines) and SB 304 (Kehoe): These bills would have authorized all mail elections. Since all mail elections are not accessible to some people with disabilities, such as people who cannot read, we opposed these bills. The federal Help America Vote Act requires that states ensure voters with disabilities are able to vote privately and independently. Both bills failed in their houses of origin.

AB 30 (Hayashi) and SB 60 (Evans): These bills were in reaction to the security issues raised by the deaths at Napa State Hospital. AB 30 proposed security plans for state hospitals and SB 60 proposed putting a risk assessment in place for state hospital admissions. We worked to ensure due process rights were part of the bills. Ultimately, both bills were held in the Assembly Appropriations Committee.

AB 366 (Allen), AB 1114 (Lowenthal), and SB 795 (Blakeslee): These bills all addressed the requirements and protections for involuntarily medicating a person in a state hospital or prison. We worked with the authors, sponsors, and stakeholders on these bills to ensure that involuntary medication can only be given in specific circumstances. We also worked to ensure there were adequate due process rights to challenge the administration of involuntary medication. Ultimately, we succeeded in getting protections in AB 366 and AB 1114 so we could have a neutral position on them; both bills have been signed by the governor. SB 795 was held in the Senate Public Safety Committee.

SB 9 (Yee): This bill would give courts the ability to reconsider an individual's original sentence of life without parole for a crime committed prior to age 18 in light of mitigating factors, including the existence of a cognitive impairment. We supported this bill. It has been held on the Assembly floor.

SB 794 (Blakeslee): This bill would have added a section to the Penal Code so that a person confined to a state hospital who commits a battery upon a peace officer or employee of a state hospital by gassing (gassing is intentionally throwing bodily fluids at another person) is guilty of aggravated battery, whether or not the conduct resulted in the infliction of serious bodily injury. This bill treats state hospital residents the same way as prisoners

with regard to the crime of gassing. We opposed the bill. It is still in the Senate Public Safety Committee.

SB 783 (Dutton): This bill would have established notice requirements before a person could bring an action against a business for a violation of California disability access laws. We opposed the bill because it impaired the ability of people with disabilities to pursue legal actions to enforce their right to full and equal access to the services and goods of a business. It failed to pass out of the Senate Judiciary Committee.

Public Policy Goals: Goals 2, 3, 4

Disability Rights California Staff: Deborah Doctor, Brandon Tartaglia, Evelyn Abouhassan, Margaret Johnson

Grant/Funding Source(s): Equal Access, Trust Fund

SELF-ADVOCACY ACTIVITIES

DEVELOPMENTAL DISABILITIES PEER SELF-ADVOCACY

Summer and early fall trainings

During the report period, DDPSA program staff provided two trainings and outreaches on topics such as voting rights, civic participation, and the California Memorial Project.

In the course of providing training and outreaches, we provided information about individual and developmental service system rights and our services to approximately 46 people and to groups such as United Cerebral Palsy.

Developmental Disabilities Peer Self-Advocacy Goals: Goal 1, Objective B

Disability Rights California Staff: Daniel Meadows, Scott Barron
Grant/Funding Source: PADD, PAVA

We participated in a leadership training to promote advocacy on behalf of underserved communities

The USC University Center for Excellence in Developmental Disabilities (USC UCEDD) at Children's Hospital Los Angeles is one of the agencies funded under the Developmental Disabilities Act. One of USC UCEDD's purposes is to provide leadership in strengthening family-centered, consumer responsive, culturally-competent services and systems for the benefit of individuals and their families. During this reporting period, USC UCEDD hosted a cultural competent leadership training called "Star Power" for advocates. The training raised awareness about power and privilege and what the experience of people who are less powerful feel like and how people who have power feel and why this maintains a system of haves and have-nots.

Developmental Disabilities Peer Self-Advocacy Goals: Goal 2, Objective A (Systems Advocacy)

Developmental Disabilities Peer Self-Advocacy staff: Scott Barron
Grant/Funding Source(s): PADD

PEER SELF-ADVOCACY

Presentation at the 19th Annual Patton State Hospital Forensic Mental Health Conference

On September 29, PSA program staff presented a workshop at the 19th Annual Patton State Hospital Forensic Mental Health Conference. Using a PowerPoint presentation called “Peer Self-Advocacy Programs – Unique Services and Strategies for Assisting Mental Health Clients,” the training provided an overview of peer self-advocacy services for approximately 85 attendees who included peer and family advocates, law enforcement, private and county mental health providers and San Bernardino’s Conditional Release Program (CONREP) staff. The goals and objectives of the workshop fulfilled the requirements for participants to obtain continuing education credits. Approximately 200 publications were distributed to Patton State Hospital residents, staff, and community service providers, including materials such as, Disability Rights California brochures, California Memorial Project Remembrance Ceremony announcements, and contact information for our Los Angeles Regional Office. During the conference, we networked with San Bernardino’s CONREP staff and arranged a workshop in November and began discussions about having an ongoing PSA self-advocacy group for new parolees.

Peer Self-Advocacy: Goal 1, Objectives A, B (Materials Development & Outreach and Education)

Disability Rights California Staff: Garnet Magnus, David Solis, Robyn Gantsweg

Grant/Funding Source(s): PAIMI

El Progreso self-advocacy group participates on the San Pedro Wellness Center Board

Members of the self-advocacy group, “El Progreso” in San Pedro, told us that they did not feel respected by the clinic where they receive treatment because their concerns and needs were ignored by clinic staff. Through work in the self-advocacy group, they learned how to promote their own voices and represent their needs for services by participating on the San

Pedro Wellness Center's Board. We provided materials in Spanish to facilitate discussion about ways to participate on the Board to have an opportunity to play a greater role in making decisions that affect them. They also learned how to be effective Board members and discussed strategies for resolving issues or disagreements that might arise. As a result of the training, many group members participated in their first Board meeting. With this experience, they now feel they have value as individuals and as a group and feel that their voices are being heard and respected.

Peer Self-Advocacy: Goal 1, Objective B (Self-Advocacy Groups)

Disability Rights California Staff: Senobia Pichardo

Grant/Funding Source(s): PAIMI

Group members get off conservatorship

Clients who seek to get off of conservatorship are required to show proof that they are not "gravely disabled" and can take care of themselves. Many self-advocacy group members at the Crestwood Treatment Center in Redding are learning the knowledge and skills they need to demonstrate to a judge that they are not gravely disabled. As a result of our training and assistance, many group members successfully completed action plans and a form we developed called "How to Show that I am Not Gravely Disabled" to use at their next conservatorship hearing so they can regain their independence and right to make decisions about their lives.

Peer Self-Advocacy: Goal 1, Objective B (Self-Advocacy Groups)

Disability Rights California Staff: Mark Olberg

Grant/Funding Source(s): PAIMI

Self-advocacy group members are successful in leaving facility:

Through participation in self-advocacy group discussions and training, residents at the Crestwood Center in Sacramento learned strategies and skills to be discharged from the facility. Provided with information about resources for housing, medical services and local referral agencies, three group members got out of the facility and moved back to their counties of origin. Their success shows the effectiveness of self-advocacy in helping clients to exercise their rights and live independently in the community.

Peer Self-Advocacy: Goal 1, Objective B (Self-Advocacy Groups)

Disability Rights California Staff: David Solis

Grant/Funding Source(s): PAIMI

Increasing voter turnout

Based on surveys completed last year by mental health clients regarding voting needs and activities, the Peer-to-Peer Voting Advocacy and Outreach Project was created to empower, educate, and encourage individuals to take a more active role in civic participation and the voting process. Materials have been drafted, including study guides on “Getting to Know your Government,” “Why My Vote” and “How to Facilitate a New Self-Advocacy Group,” with the goal of teaching peers to train other peers to increase voter turnout. To introduce the project and get feedback regarding consumers’ experiences with the voting process, we conducted two workshops with the Behavioral Health Administration, Mental Health Services Act program staff and Peer Center participants in San Bernardino County. Approximately 23 consumers and nine service providers attended the workshops and discussed strategies for encouraging peers to learn about voting issues. Plans are in place to provide train-the-trainer voting workshops to clients at five Peer Centers throughout San Bernardino County so that peers can help one another vote in upcoming elections.

Peer Self-Advocacy: Goal 1, Objectives A & B (Materials Development & Outreach and Education)

Disability Rights California Staff: Garnet Magnus

Grant/Funding Source(s): PAVA

CALIFORNIA MEMORIAL PROJECT

California Memorial Project Remembrance Day Ceremonies Held Throughout the State

The California Memorial Project (CMP) held its 9th Annual Remembrance Day ceremonies on September 19 to honor and restore dignity to people with psychiatric and developmental disabilities who lived and died at state hospitals and developmental centers throughout California. Staff from Disability Rights California's peer self advocacy program and developmental disabilities peer self advocacy program, in collaboration with the California Network of Mental Health Clients, People First of California, community organizations and individuals, planned and coordinated 11 events at 10 sites where people who lived in state institutions are buried.

Some of the community collaborators in addition to the California Network of Mental Health Clients and People First of California, included the following: Manteca – Valley CAPS (a day program for adults with disabilities) and Modesto CAPS; Stockton – Sonora Thumbs Up (a day program for adults with disabilities), San Joaquin County Behavioral Health, Area Board VI, and the State Council on Developmental Disabilities; Sonoma – Wellness and Advocacy Center (a peer run center); Agnews – People First Santa Clara Chapter, Community Integrated Work Program, and Housing Choices Coalition Santa Clara; Camarillo – Laura Rasey Miller volunteered to plan, coordinate and present at the event; and, Ukiah – Bridge Drop In Center in the Lake County, Manzanita Services – United Methodist Church, People First Ukiah Chapter, Redwood Coast Regional Center, and the Ukiah Board of Supervisors.

The ceremonies featured numerous speakers, including mental health clients, people with developmental disabilities, family members and advocates from local communities. Other activities included a guided meditation, poem recitations, musical performers and a moment of silence followed by a symbolic release of balloons. At the Stockton ceremony Disability Rights California staff spoke about the history of the California Memorial Project and why it is important to honor those who have died. Another ceremony was held at Park View Cemetery in Manteca where 1,302 people's remains are buried. We hope to upgrade the current headstone at this site in the near future. Speakers at Metropolitan State

Hospital in Norwalk shared personal stories about their experiences with mental illness and the history of institutionalization in the 1920s and 1930s.

In addition, dedication ceremonies were held for two memorial plaques - one at the campus of California State University-Channel Islands and one at Ivy Lawn Memorial Park in Ventura, and a large granite monument that was placed at Patton State Hospital's cemetery, which was accomplished with the help of our staff, Patton State Hospital staff, California's Department of Mental Health and the Patton Restoration Team. Over 600 people participated in the events statewide, and several media outlets provided coverage for the ceremonies, including the Ukiah Daily News and the Ventura County Star.

Communications Goal: Goal 1, 2

Peer Self-Advocacy: Goal 2, Objective A (California Memorial Project)

Developmental Disabilities Peer Self-Advocacy: Goal 2, Objective A

Disability Rights California Staff: Jenny Olson, Alicia Mendoza, Daniel Meadows, Yvonne McGough, Martha Cook, David Solis, Leonard Alfaro, Debi Davis, Senobia Pichardo, Rosy Tellez, Brenda Calderon, Garnet Magnus, Sheryl Bradford, Robyn Gantsweg

Grant/Funding Source(s): PAIMI, PADD