
Advocacy Director's Report

December 10, 2010 Report

This report represents a summary of the work Disability Rights California advocacy programs and projects reported through October 31, 2010; 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

Highlights of our press coverage

- *The Sacramento Bee* adopted our bottom line that “trusted community mental health clinics cannot be replaced by unknown county employees.” *The Bee* featured at least five in-depth stories and two editorials throughout July, August, and September about the county’s fragmenting mental health system, the shortsightedness of underfunding critical services and “shelving the nonprofit contractors.”
- The *San Francisco Chronicle* (August 19 and 25) and the *Los Angeles Times* (October 7) took up our call to question the Governor’s purpose in adding 16 crimes, including misdemeanors, that would disqualify an individual from providing IHSS.

Communications Goals: Goal 1, 2

Disability Rights California Staff: Barbara Duncan

Grant/Funding Source(s): Trust Fund

Other issues during September

In September, the issue of Californians with disabilities suing businesses for access violations resurfaced when the *Los Angeles Times* (September 18) and the NPR's *This American Life* covered the issue. NPR titled its disability segment "The Squeaky Wheelchair Gets the Grease." Advocacy director Margaret Johnson was interviewed for both stories, but the NPR program with 1.7 million listeners is still reverberating, as it was broadcast at least 3 weekends during the month. The host, Ira Glass, commented at the end that because there is no superagency to enforce the ADA, it forces all Californians to seek their own justice.

On September 20, the now state-recognized Remembrance Day to honor the thousands of Californians who died anonymously in state institutions and hospitals was held at nine different sites. Every year the attendance grows and the press shows increased interest in the California Memorial Project.

Communications Goals: Goal 1, 2

Disability Rights California Staff: Barbara Duncan, Margaret Johnson

Grant/Funding Source(s): Trust Fund

Olmstead Summit

At the end of the month, Disability Rights California cosponsored with the California Foundation for Independent Living Centers (CFILC). Forty-five invitees from around the state attended the Summit, designed to review the current state of Olmstead implementation. Its purpose was to generate ideas for moving Olmstead implementation forward, and to motivate advocates from a range of organizations, including independent living centers and senior organizations.

A professional trainer in communications and social messaging reminded the group of what she saw as the disability field's primary messaging conflict: presenting the population as "vulnerable" to protect benefits, while at the same time not wanting to be perceived as "sick" or "weak." She also reported on research showing that

presenting a demand or a need as a “right” was not necessarily effective with the public in the current political atmosphere.

Communications Goals: Goal 1

Public Policy Advocacy Goals: Goal 4

Disability Rights California Staff: Barbara Duncan, Deborah Doctor

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

AB 3632 Budget Cut and Mandate Suspension

In the FY10-11 California budget, the governor blue-penciled \$133 million for mental health services needed by special education students. He also suspended the mandate on county mental health agencies to provide educationally needed services for students in special education programs. His action led to confusion about who was responsible for mental health services resulting in some students losing or being denied services. Within 2 weeks, together with other advocates, we filed a class action suit to keep these critical services in place, issuing a press release on October 21. From October 21-27, we got coverage from at least 15 media outlets, including Associated Press, *Sign on San Diego*, *Channel 7 ABC News*, the *San Francisco Chronicle*, the *Los Angeles Times* and several health or legal papers and blogs.

Communications Goals: Goal 2

Disability Rights California Staff: Barbara Duncan, Margaret Johnson

Grant/Funding Source(s): Trust Fund

Website trends August through October

Website visits reflected concern about the future of IHSS: two of the top five search queries were “IHSS” and “can parents be IHSS providers?” IHSS showed up twice in the top ten publications in English – one concerning “nuts and bolts,” and the other about “protective supervision;” and appeared twice in the top 10 publications in Spanish.

The number of unique website visitors rose by about 1000 this quarter to 53,531, breaking down to around 17,800 a month. Of the roughly 580 visitors a day, the majority (about 60%) are new.

New on the [Top 10 publications](#) this quarter is the *Peer Self Advocacy Training Manual* and among those returning to the list are the *Restraint and Seclusion* investigation, our *5 year Advocacy Plan* and *Psychiatric Service and Emotional Support Animals*.

Communications Goals: Goal 3

Disability Rights California Staff: Barbara Duncan

Grant/Funding Source(s): Trust Fund

Tracking and Updating Legislation and Budget Information on the Web

Throughout the legislative year, we updated the website with the newest position letters, budget fact sheets, budget summaries, and charts. Now that the legislative session has ended and the budget signed, we listed the final disposition of select bills. We finalized budget summaries and charts to reflect the outcome of the budget process. Our legislative web page has this current information:

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

Communication Goals: Goal 2, 3

Disability Rights California Staff: Brandon Tartaglia, Barbara Duncan

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

Publications Update

Publication Web Pages: We worked on cleaning up our publication web pages and improved overall accessibility by removing or updating dead web links, moving externally referenced materials to their own web pages, and simplifying complicated page layouts.

Online Publication Indexes: We reformatted and updated the online publication indexes. Two indexes are provided online, one listing publications alphabetically by title and the other by publication number. The new index versions contain greater accessibility, allow users more freedom to open publications directly from inside the

index and provide a user-friendly experience by removing unnecessary data. A system of updating the indexes each month is now in place too.

Public Education Goals: Goal 2, Objective A

Disability Rights California Staff: Adam Borovkoff

Grant/Funding Source(s): 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 reported here, check our home page and legislative website: <http://www.disabilityrightsca.org/> and <http://www.disabilityrightsca.org/legislature/index.htm>

California Budget:

See previous Advocacy Director Reports for background information on the California budget:

<http://www.disabilityrightsca.org/advocacy/advocacyreports.htm>

In the early morning of October 8 after marathon sessions of the Assembly and Senate, and 100 days after the deadline, the state Legislature passed the FY 10-11 budget, which the governor signed later in the day. This budget addresses the \$18 billion gap between revenues and expenses through cuts, new federal funds, loans, transfers, and fund shifts. It reflected, in large part, an agreement reached a few days earlier by “The Big Five” – the leaders of the legislature and the governor. The budget delay affected people with disabilities: some lived in fear of possible cuts; others could not get services from providers who were unpaid after July 1 and reduced services or shut their doors.

The budget, while not perfect, preserved essential services used by people with disabilities. For example, in May the governor had proposed a 50% cut in In-Home Supportive Services (IHSS); the enacted budget included a 3.6% cut and, significantly, confirmed the right of IHSS consumers to hire workers of their own choosing. Between May and October, Disability Rights California worked diligently alongside other advocates, consumers, and legislative staff, to minimize the cuts to IHSS and maximize the protections built into the “trailer bill” which laid out the changes to IHSS.

Because of ongoing legislative advocacy by advocates and negotiations by legislative leadership, many other proposed cuts to

programs that affect people with disabilities were rejected. However, the budget approved by the legislature was not signed intact. The governor cut significant programs affecting people with disabilities, including \$133 million dollars, which was to reimburse county mental health departments for back monies owed to them for providing mental health related services to special education students. He also suspended the mandate on counties to provide these educationally necessary services.

We created a chart that shows the outcomes of the enacted budget. It covers the major budget items affecting people with disabilities. See the chart here:

<http://www.disabilityrightsca.org/legislature/budget/2010/May%20Revise%20Chart%20updated%208-13-10%20final.htm>

In the coming year we will work with other advocates and organizations on strategies – legal, legislative, or both – to roll back some of the budget cuts and vetoes.

Public Policy Goals: Goal 3

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

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

Health Care

1115 waiver: See February 6, 2010 and September 24, 2010 Advocacy Director Reports for background information on the Medicaid 1115 waiver.

We worked with other advocates to improve the state's Medicaid 1115 waiver as it applies to people with disabilities. The administration agreed to one important concession regarding the mandatory enrollment of people with disabilities into Medi-Cal managed care: allowing the new enrollees to retain their existing medical providers as long as the providers are willing to accept payment from the state. We were also concerned that not all medical providers comply with state and federal disability access requirements.

We asked the state and legislature to slow down the enrollment and require proof of readiness from the plans to serve the new population, among other protections, and press our case with high-level staff at CMS, which had to approve the waiver. The legislature passed and the governor signed the waiver elements as part of the budget package, with a start date of June 1 instead of February 1 for the mandatory enrollment of persons with disabilities.

CMS has just approved the waiver, and it appears they addressed some of our access concerns, as evidenced in this excerpt from the Terms and Conditions of the waiver:

Physical Accessibility – The State will ensure, using the facility site review tool, that each plan has physically accessible accommodations or contingency plans to meet the array of needs of all individuals who require accessible offices, examination or diagnostic equipment and other accommodations as a result of their disability or condition, and that they are advised of their obligations under the Americans with Disabilities Act and other applicable Federal statutes and rules regarding accessibility.

Public Policy Goals: Goal 5

Disability Rights California Staff: Brandon Tartaglia, Deborah Doctor

Grant/Funding Source(s): Equal Access

Nursing home funding

We worked to reform the nursing home reimbursement system to improve quality of care for residents. The administration agreed to end the guaranteed profit for nursing homes and to decrease reimbursement for some expenses that bear no relationship to the care given the residents. However, the newly enacted budget calls for a “pay for performance” system, desired by the industry. Under the proposal, facilities with a documented record of abuse, neglect, and even death of residents could receive bonuses if they meet criteria such as sufficient staffing. We are working with other advocates to slow down the rush to enact this bonus system and to insist on incentives that reward the best quality in all aspects of resident life.

Public Policy Goals: Goal 5

Disability Rights California Staff: Deborah Doctor

Grant/Funding Source(s): Equal Access

Closure of Lanterman Developmental Center Included in the Final Budget

See June 25, 2010 Advocacy Director Report for background information on the Lanterman Developmental Center closure.

The final budget adopts the closure of Lanterman Developmental Center. Residents will transition into the community. The budget bill language expanded Adult Residential Facilities for Persons with Special Health Care Needs (also known as 962 Homes) to accommodate the transition of Lanterman residents. The budget did not adopt the proposal to expand the 962 homes beyond individuals transitioning from Lanterman Developmental Center. Lanterman Developmental Center staff will contract out to the community to ensure continuity of care for transitioning residents. We plan to advocate for the statewide expansion of 962 homes in the coming legislative year.

Public Policy Goals: Goal 3

Disability Rights California Staff: Evelyn Abouhassan

Grant/Funding Source(s): Trust Fund

Trailer Bill Language Requiring Notice of Exemptions and Exceptions Adopted as Part of the Budget

See June 25, 2010 Advocacy Director Report for background information on the notice issue.

We collaborated with Association of Regional Center Agencies (ARCA) and other stakeholders on budget legislation that requires regional centers to provide notice to consumers and families about exceptions and exemptions in the law and the process for requesting them.

Through our collaborative efforts and ongoing advocacy, legislation was adopted as part of the FY10-11 Budget that requires regional

center clients and their families be given notice about the exceptions and exemptions.

Public Policy Goals: Goal 3

Disability Rights California Staff: Evelyn Abouhassan

Grant/Funding Source(s): Trust Fund

Budget Advocacy to Preserve the Mandate for Behavioral Intervention Plans

See September 24, 2010 Advocacy Director Report for background information on behavioral intervention plans.

The governor proposed to suspend most Kindergarten through twelfth grade mandates to relieve pressure on the state general fund. In response, the Legislative Analyst's Office (LAO) put forward alternative proposals for overall reform of state mandates, including eliminating state mandated funding related to behavioral intervention planning (BIPs). We worked with budget committee staff and LAO representatives on the bill language. We stressed the importance of BIPs and negotiated language that released the state from the mandate while preserving the underlying state statute and related regulations that implement federal special education requirements. The governor signed the bill in October when he signed the budget.

Public Policy Goals: Goal 3, 4

Disability Rights California Staff: Evelyn Abouhassan, Catherine Blakemore, Brandon Tartaglia, Maggie Roberts, Lauren Giardina, Stephen Rosenbaum

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

Informational Hearing: Status of Employment of Persons with Developmental Disabilities

The Assembly Select Committee on Workforce Development within the Developmental Disabilities Community examines the status of and barriers to employment for individuals with developmental disabilities. Recently, we worked with legislative staff to help frame the agenda and find witnesses for an upcoming select committee hearing. We worked collaboratively with a representative from

University of Southern California University Center for Excellence in Developmental Disabilities to prepare oral and written testimony on the importance of postsecondary educational opportunities for persons with developmental disabilities. The testimony focused on the link between postsecondary education options and increased employment choices and retention for persons with developmental disabilities. We also helped legislative staff obtain expert testimony from employed individuals with developmental disabilities.

Public Policy Goals: Goal 3, 4, 6

Disability Rights California Staff: Evelyn Abouhassan

Grant/Funding Source(s): Trust Fund

Advocates Meet with Department of Developmental Services to Provide Input on Regional Center Directive

See September 24, 2010 Advocacy Director Report for background information on AB 2702.

Sponsored by The Arc, the intent of the bill was to make sure that the Individual Program Plan (IPP) process is followed when services are changed pursuant to the budget trailer bill passed for FY 09-10 (advocates were aware the IPP process was not always followed by regional centers).

The bill did not make it through the legislative process; however, we were able to negotiate with Department of Developmental Services to develop a program advisory for distribution to regional centers. The advisory, which we helped draft, explains what regional centers must do in regards to the IPP process before implementing changes in services because of last year's budget bill.

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

Disability Rights California Staff: Evelyn Abouhassan, Catherine Blakemore

Grant/Funding Source(s): Trust Fund

SELF-ADVOCACY ACTIVITIES

PEER SELF ADVOCACY

Patton State Hospital Library Project

With our assistance, self-advocacy group members at Patton State Hospital are working to develop a peer self-advocacy section in all three resident libraries. Updated Disability Rights California and other self-help publications will be available, in addition to the final version of the Peer-Advocacy Resource Master Book once finalized. On an ongoing basis, group members will monitor the library materials and update publications as needed.

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

Disability Rights California Staff: Garnet Magnus

Grant/Funding Source(s): PAIMI

Privacy and Confidentiality in Self-Advocacy Groups

We met with program staff at an acute care facility in Irvine to discuss our access rights to facilities. We explained the need and benefits of providing peer self-advocacy services without the presence of staff at self-advocacy group meetings, such as confidentiality and protection of group members from staff retaliation, so that open discussion among group participants can occur. As a result, two weekly workshops begin in October.

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

Disability Rights California Staff: Garnet Magnus, Robyn Gantsweg

Grant/Funding Source(s): PAIMI

Disability Rights California Staff Member Receives Reward

SHARE! (Self Help and Recovery Exchange), whose mission is to help people in Los Angeles pursue personal growth and change,

presented an award to Rosy Tellez for her efforts to teach self-advocacy knowledge and skills to people in the monolingual Spanish-speaking community. Rosy Tellez has been facilitating self-advocacy groups and presenting outreaches and workshops throughout the Los Angeles area for over 5 years.

Peer-Self-Advocacy Goal: Goal 1, Objective B (Outreach, Education and Training)

Disability Rights California Staff: Rosy Tellez

Grant/Funding Source(s): PAIMI

Self Advocacy Groups Continue to Grow and Prosper

Attendance has been steadily increasing at the Crestwood Treatment Center and the NVCSS Second Home in Redding and the Crestwood Center in Sacramento. The groups discussed a variety of topics, including Patient's Rights, LPS Conservatorship, the History of the Consumer/Survivor Movement and Discharge Planning. Because of the self-advocacy group work, several people are scheduled for discharge into the community.

Peer Self-Advocacy Goals: Goal 1, Objective B

Disability Rights California Staff: Mark Olberg, Louis Williamson

Grant/Funding Source(s): PAIMI

DEVELOPMENTAL DISABILITIES PEER SELF ADVOCACY

Clients Helped to Understand IPP Rights

One of the people we helped this quarter was Colleen¹. Colleen asked for assistance in understanding her Individual Program Plan (IPP) appeal rights and right to aid paid pending. Colleen had received a proposed service reduction that was improperly noticed and with which she did not agree. We worked with Colleen and her support people to understand notice rights, the IPP process, and how to request aid paid pending.

We also assisted Dana who requested information about her rights to appropriate medical services and how to get these services as part of her IPP. We helped Dana understand her IPP rights, how to get services no longer available through Medi-Cal put into her IPP, and to know her appeal rights.

Developmental Disabilities Peer/Self Advocacy Goals: Goal 1
Objective A

Disability Rights California Staff: Marinda Reed, Maria Marquez,
Scott Barron

Grant/Funding Source(s): PADD

Busy Training Schedule This Quarter

During the last quarter of the fiscal year, we provided 33 trainings serving approximately 854 people. Training, presentation and outreach topics included; Self Advocacy, The California Memorial Project, Abuse Prevention, Individual Program Plan Rights, Appeal Process Rights, Rights in Facilities, Rights to be Free from the Effects of Stigma and Discrimination, Emergency Preparedness, Crime Prevention, Changes to the Lanterman Act, Transition Service Rights and Voting Rights in addition to information about Disability Rights California and our services.

¹ Names have been changed to protect client confidentiality.

Since this was an election year, we worked with community groups, self-advocacy groups, providers, and developmental centers to spread the word about the importance of civic participation and voting rights for people with disabilities. We conducted 15 nonpartisan voting rights, civic participation, and poll monitoring trainings affecting approximately 396 people. We presented at several self-advocacy conferences. Participants learned about the importance of voting, how to register, about voting access requirements, about different ways to vote such as by mail or with adaptive voting equipment, and about the right to receive help to vote. Participants were given information about how to research candidates or issues and how to access non-partisan voter information such as the easy voter guide.

We presented at the Fiesta Educativa Conference to a group of family members and youth with disabilities about transition rights and the importance of developing transition plans for high school aged youth. The presentation included information on service options and rights after leaving high school.

We gave trainings on a variety of topics to people who live at Lanterman Developmental Center to help them understand what community based services exist as they are transitioned into the community.

Developmental Disabilities Peer/Self Advocacy Goals: Goal 1
Objective B

Disability Rights California Staff: Marinda Reed, Maria Marquez, Daniel Meadows, Scott Barron, Brenda Calderon, Jenny Olson, Alicia Mendoza

Grant/Funding Source(s): PADD, PAVA

Stigma and Discrimination Trainings

See December 2010 Outreach Newsletter for more information on these trainings.

We worked to develop a training module on stigma and discrimination faced by people who have life experience and labels representative of both the developmental disability and mental health consumer communities. This quarter we piloted the training and, as a result, will

be refining the training and training other Disability Rights California staff on the module in order to provide more training in the coming year.

Developmental Disabilities Peer/Self Advocacy Goals: Goal 2, Objective A

Peer Self-Advocacy Goals: Goal 1, Objective B

Disability Rights California Staff: Marinda Reed, Maria Marquez, Scott Barron, Jenny Olson, Alicia Mendoza, David Solis, Garnet Magnus, Robyn Gantsweg, Rob Chittenden

Grant/Funding Source(s): PADD, PAIMI

CALIFORNIA MEMORIAL PROJECT

First California Memorial Project (CMP) Remembrance Ceremony Held in Camarillo

Spearheaded by the efforts of Camarillo resident and Disability Rights California Legislation Committee Public Member Laura Rasey Miller and Disability Rights California staff, the first annual CMP Remembrance Day Ceremony was held on the former grounds of Camarillo State Hospital. After months of negotiating with officials at the California State University – Channel Islands to hold the ceremony at the former hospital's site, over 100 people attended the evening event. Guest speakers included Harriet Weigel, from The Arc-Ventura, and two former residents of Camarillo State Hospital, Celinda Jungheim and Vernon Montoya, who spoke about their personal experiences while living at the institution. Poetry readings, songs, a moment of silence and the release of balloons into moonlit sky completed the event.

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

Disability Rights California Staff: Laura Rasey Miller, Robyn Gantsweg, Senobia Pichardo

Grant/Funding Source(s): PAIMI

Remembrance Day at Napa State Hospital

For the first time, we held a Remembrance Day at Napa State Hospital's secured treatment area for individuals on forensic commitments. About 15 residents and 2 staff attended. An individual played the flute, another played a keyboard and several people read poems remembering friends who died at Napa. There was a moment of silence and at the end of the ceremony, a person played the guitar and refreshments were served.

Peer Self-Advocacy Goals: Goal 1, Objective B

Disability Rights California Staff: Debi Davis

Grant/Funding Source(s): PAIMI