



Advocating for  
disability civil rights  
since 1979

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DISABILITY RIGHTS EDUCATION & DEFENSE FUND

# **ANNUAL REPORT 2008 - 2009**

# A BREAKTHROUGH CIVIL RIGHTS VICTORY

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## **Court to Social Security Administration — Federal Law Requires Effective Communication**

We won! On October 20, 2009, Judge William Alsup of the US District Court, Northern District of California in San Francisco, granted final judgment in favor of the American Council of the Blind (ACB) and over 3,000,000 blind or visually impaired individuals, represented by DREDF and co-counsel Howrey, LLP.

The Court ruled that the Social Security Administration (SSA) must provide blind and visually impaired SSI recipients, retirement benefits recipients, and representative payees a choice of receiving notices and other communications in the alternative formats of Braille, navigable CDs, or a telephone call from an SSA representative. Prior to the lawsuit, SSA failed to provide its communications in alternative formats that would enable people with visual impairments to have equal access to the agency's programs, resulting in the loss of critical benefits and privacy.

This ruling signals a major victory for the disability rights movement, and it sets precedent for the obligations of other federal and state agencies to provide alternative formats and effective communication to people who are blind or have visual impairments.

# PUBLIC POLICY — SETTING THE AGENDA

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## New Administration — New Opportunities

The new Administration and Congress in Washington bring opportunities to improve federal disability policy.

### Disability Community Policy Statement

In December 2008, DREDF joined a broad coalition of disability advocacy organizations to present to then President-Elect Obama summaries of nine critical policy issues facing Americans with disabilities. We submitted statements, including background of the issue, and long and short term goals for the Administration on the following key policy areas: employment, education, health care, home and community-based

services (HCBS), disability research, civil rights, human rights, emergency preparedness, response, and recovery needs, and genetic science and technology.

To read the statements in their entirety, see:

<http://www.dredf.org/highlights/DisabilityPolicyStatements.pdf>.

### White House Meeting

After submitting the statements, DREDF and representatives from other members of the coalition were invited to meet with senior advisors from the Office of the President, the Office of the First Lady, the Domestic Policy Council, the National Economic Council, the Office of Science and Technology, the Office of Management and Budget, and the Office of Public Liaison in April 2009. The

meeting provided an opportunity for the Administration to respond to our December policy statements and present their disability agenda with the promise to continue working with our community. The Administration has since made good on their word, inviting DREDF to a number of policy meetings, including a discussion with Attorney General Eric Holder.

### Meeting with US Attorney General

DREDF and eight other advocates from leading disability organizations met with Attorney General Eric Holder on September 9, 2009 to continue the discussion of disability rights priorities for the Obama Administration.

Specific priorities for the Department of Justice (DOJ) include:

- Framing disability issues as civil and human rights issues
- Ensuring consistency across the DOJ on disability rights issues

- Leading by example in the recruitment and retention of workers with disabilities
- Enforcing the ADA and other civil rights laws that protect people with disabilities
- Enforcing the right to equal access to information and communication technology for people with disabilities
- Improving interactions between law enforcement and the criminal and civil legal system and people with disabilities
- Carefully vetting disability records as part of the judicial nomination selection process
- Incorporating into practice and policy the integration and civil rights of people with disabilities across all divisions of the DOJ

These open communications with the new Administration give us access to policymakers in Washington at the highest levels and the means to hold them accountable for addressing the priorities of the disability community.

## Health Care Access

DREDF's Health Care Equity for People with Disabilities initiative tackles the complex problem of health disparities and deeply entrenched inequities in health care services and programs for people with disabilities living in the US. This year, DREDF continued its work with groundbreaking research, collaborations with California health plans and providers, and state and federal public policy advocacy.

## Research

- Utilizing extensive research to build the case for health policy reform, DREDF led the team that generated one of the most thorough and comprehensive examinations of disability and health in the US today. The report, entitled *The State of Health Care for People with Disabilities* and released on September 30, 2009, was written on behalf of the National Council on Disability, the Federal agency that makes disability policy recommendations to the Administration and Congress. The report argues for immediate action to enhance health care provider education, improve clinical research, enhance payment systems, and remove procedural and physical barriers to receiving quality health care services. (Several of the report's recommendations have been included in health care reform legislation passed by the Obama Administration in 2010.)
- DREDF also published articles in leading medical journals, including a commentary in *PM&R*, the new journal of the American Academy of Physical Medicine and Rehabilitation. Prior to these contributions, only a small number of publications had examined the health care crisis for people with disabilities from a broad structural and civil rights perspective.

## **Federal Health Care Reform Legislation**

- A number of DREDF's recommendations are included in health care reform legislation debated in 2009 and enacted in 2010 including federal data collection on health facility accessibility and inclusion of disability, for the first time, in health disparity research.

## **State Health Care Legislation**

DREDF drafted state legislation calling for removal of low annual benefit limits (about \$2000) by private insurers on durable medical equipment (DME) such as motorized wheelchairs, ventilators, lifts, and hospital beds. Although the bill passed in 2008 with bipartisan support, it was not signed by the Governor. Reintroduced in 2009, the bill fell victim to the state budget crisis and failed to pass out of the finance committee. DME is essential to the lives and independence of many members of the disability community, both of which are jeopardized when unreasonably low coverage limits make equipment unattainable. Passing legislation to remove low benefit limits remains a priority for DREDF.

## **California Health Plans and Providers**

- To ensure that health plans serving low-income communities identify and meet the needs of plan members with disabilities, we continued a multi-year alliance with the San Francisco Health Plan (SFHP). This year we drafted a programmatic survey that SFHP has used to evaluate the capacity of its primary care physician (PCP) network to serve people with disabilities, developed a training curriculum and trained SFHP trainers, and drafted model policies and procedures for PCPs.
- We established a similar alliance with LifeLong Health Care, a direct health services provider for low-income communities in Alameda County. In partnership with LifeLong, DREDF conducted focus groups with patients with disabilities; advised on a programmatic access evaluation of LifeLong's clinics; and drafted recommendations for improvements that will be considered during the organization's strategic planning process and by the board of directors.

These alliances with local health plan providers are creating replicable models that can be exported around the state and the nation.

## **Alliances with Other Advocates**

- DREDF was instrumental in launching The Barrier Free Healthcare Initiative (TBFHI) along with other advocates, non-profit organizations, legal service providers, and lawyers. TBFHI works to develop and support legal advocacy and policy initiatives that will eliminate the physical and programmatic barriers that people with disabilities face in obtaining healthcare. Visit the website to follow our progress: <http://thebarrierfreehealthcareinitiative.org/>
- As a member of the leadership team of the Disability Health Coalition ([www.disabilityhealthcoalition.org](http://www.disabilityhealthcoalition.org)), DREDF is working with other disability advocacy

organizations in California to ensure that disability rights issues are included in state legislation and policy concerning health care.

## Bioethics and Reproductive Rights

DREDF works with Generations Ahead ([www.generations-ahead.org](http://www.generations-ahead.org)) and the Center on Genetics and Society ([www.geneticsandsociety.org](http://www.geneticsandsociety.org)) to provide a disability and human rights perspective on the impacts of new genetic and reproductive technologies. Technological advances have redrawn the lines between the theoretical and the possible, and this critical new area for the disability rights movement requires an open dialogue between the scientific and the civil rights communities.

In March 2009, DREDF attended a convening on disability and genetic technologies in Chicago at which we helped establish a series of workgroups to address critical issues in the field. We have taken an active role in the Public Education and Media Workgroup, preparing public education and opinion pieces on what it means to have a disability or to have a child with a disability.

We are also active in workgroups focused on:

- Improving curriculum on disability and genetic testing in medical schools and schools for genetic counselors and other health professionals
- Implementing the Prenatally and Postnatally Diagnosed Conditions Awareness Act - read more about the Act here: [www.dredf.org/InfoSheetBrownbackKennedy.pdf](http://www.dredf.org/InfoSheetBrownbackKennedy.pdf)
- Engaging in dialogue with reproductive rights and reproductive justice advocates
- Establishing parity in federal disability research between basic scientific investigations of the causes of disabling conditions and quality of life and participation-based research involving people with disabilities

## Assisted Suicide

DREDF is a leading opponent of the legalization of assisted suicide and euthanasia. This year, DREDF's work with community organizers, legislators, the press, and the public helped prevent the legalization of assisted suicide and the passage of related laws in Montana, Maryland, Wisconsin, and New Hampshire. We collaborate across the country with other advocates on this issue because we believe that the legalization of assisted suicide endangers the values

at the core of the disability rights movement: independence, autonomy, choice, equality, justice, and fairness.

Visit DREDF's assisted suicide webpage for an in-depth look at our position: [http://www.dredf.org/assisted\\_suicide/index.shtml](http://www.dredf.org/assisted_suicide/index.shtml) and look for DREDF's article, "Killing Us Softly: The Dangers of Legalizing Assisted Suicide," published in the Disability and Health Journal's special issue on assisted suicide in 2009.

## **Transportation Access**

DREDF helped to develop American Public Transportation Association (APTA) standards to make it easier for people with disabilities, who often depend on public transportation, to navigate the system. Because knowledge of transit system rules and riders' rights is crucial for ensuring that people can use accessible public transportation safely

and conveniently, we provided training through a Distance Learning Session on ADA Paratransit for Easter Seals Project ACTION. We also have a cooperative agreement with the Federal Transit Agency (FTA) to write a series of ADA Transportation technical assistance guides, which will be published in 2010.

## **Diabetes Care in School**

DREDF has been working diligently with the American Diabetes Association to develop legislation that would enable trained personnel to administer insulin to children with diabetes. Although very few schools have a nurse available on a full-time basis, the American Nurses' Association (ANA) continues to push for legislation that would require nurses for the administration of many lifesaving

drugs, including insulin. DREDF will continue working with the ADA and members of the Assembly Select Committee on Child/Adolescent Health & Safety to develop consensus for the need for legislation regarding diabetes care in CA's public schools, beginning with a November 2009 hearing on the subject organized by Assemblymember Isadore Hall.

## **ADA Amendments Act Regulations**

Negotiators for the disability and business communities worked together on language for the ADA Amendments Act of 2008 (formerly called the ADA Restoration Act). DREDF participated for several years in policy discussions with others around the country to make sure that this new law improves employment protections for people with disabilities.

However, because regulations provide the critical technical, operational, and legal

details necessary to implement laws, DREDF's work does not end with the drafting or passage of legislation and we are preparing comments to be submitted on the EEOC's proposed regulations. Our comments will be posted on our website at [www.dredf.org/programs/public\\_policy.shtml](http://www.dredf.org/programs/public_policy.shtml).

# LEGAL ADVOCACY — DEFENDING RIGHTS

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## Monitoring Diabetes Care

DREDF has been fighting for years to ensure that children with diabetes can receive the care they need, including insulin administration, in California public schools. As part of our landmark settlement with the California Department of Education (CDE) on behalf of the American Diabetes Association (ADA), DREDF continues to monitor diabetes care throughout the state. Since the settlement, DREDF has provided direct assistance to over 300 families to ensure that their children are receiving appropriate diabetes care and services in CA's public schools. In addition, through a partnership with the Juvenile Diabetes Research Foundation (JDRF), DREDF

participated in a series of educational outreach events across the state.

Although a state judge ruled in favor of four nurse organizations who filed suit against the CDE to overturn part of the settlement, the California Court of Appeals has ruled that the trial court's ruling is "stayed" while the ADA and CDE appeal the ruling. While this is not a decision on the merits of the case, it does mean that the Legal Advisory on the Rights of Students with Diabetes in California's K – 12 Public Schools, issued as part of the original settlement with the CDE, remains in effect until the appeal is decided.

## Community Inclusion

Residents of Laguna Honda won the right to community-based housing and service options in San Francisco when the US District Court for the Northern District of California approved a settlement in *Chambers et al. v. the City and County of*

*San Francisco*, the class action filed in 2006 to prevent unnecessary institutionalization of people with disabilities. The settlement brings us closer to ending forced institutionalization of individuals with disabilities.

## California Legal Services

DREDF trains, supports, and collaborates with legal aid attorneys across California as part of our California Legal Services Support Center (IOLTA). As an active member of the Legal Aid Association of California, the state organization of legal services nonprofits, we collaborate on a range of issues including affordable

housing, marriage equality, education rights in state prisons, patients' right to see their medical records, and immigration rights. We oppose discrimination and prejudice in all forms and are committed to working in solidarity with the broader civil and human rights movements.

## Amicus Briefs

Each year DREDF files or joins other groups to submit *Amicus Curiae* ("Friend of the Court") Briefs in disability rights and other civil rights cases where the court's decision will have implications for the rights of people with disabilities. In 2009, DREDF joined coalitions to file *Amicus* Briefs or support letters in the following cases:

- *Vaughn v. City of Antioch*
- *Hohider v. United Parcel Service*
- *Roby v. McKesson HBOC*
- *Baxter v. Montana*
- *Surrey v. TrueBeginnings, LLC*
- *Turner v. Association of American Medical Colleges*
- *Munson v. Del Taco, Inc.*
- *State of Arizona v. Harkins Amusement Enterprises*
- *Moeller v. Taco Bell*
- *Antoninetti v. Chipotle Mexican Grill, Inc.*
- *USA v. AMC Entertainment*

# CHILDREN & FAMILY ADVOCACY

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## Parent Training and Information Center (PTI)

DREDF's Education Advocates train parents, families, youth, and professionals about their rights under state and federal laws so they can use the law as a tool to help children succeed in school and reach their potential.

DREDF provides direct assistance to families in Alameda, Contra Costa, and Yolo County, California but the training materials and resources available on our website are applicable nation wide. With more than one third of the families we assist coming from minority communities, DREDF materials are available in English, Spanish, and Chinese.

Between October 1, 2008 and September 30, 2009 DREDF Education Advocates:

- Helped 883 families navigate the Special Education system and advocate for their children's rights
- Taught 602 families about their rights under IDEA in 39 trainings
- Published five issues of our electronic newsletter, Special Edition, providing critical information to 4,383 households

## Current Challenges — Dramatic Increase in Use of Isolation and Restraint

DREDF Education Advocates have seen a startling rise in calls from parents and guardians reporting isolation of children and use of restraints at school. PTIs around the nation report the same increase in calls, and the GAO 2009 report, "Seclusions and Restraints: Selected Cases of Death and Abuse at Public and Private Schools and Treatment Centers," is chilling.

DREDF is working on multiple fronts to end this abusive practice.

DREDF Education Advocates work with families and schools on an individual basis to replace the use of restraints and isolation with behavior plans that will help children thrive. DREDF assisted Congressman George Miller, Chair of the House Committee on Education & Labor, to draft federal legislation to stop these practices. (On December 9, 2009, members of Congress introduced bills to limit the use of seclusion and restraint in US schools. **The Preventing Harmful Restraint and Seclusion in Schools Act of 2009** (H.R. 4247, S. 2860) in the House of Representatives follows [a report by the Government Accountability Office](#) (GAO) regarding the misuse of seclusion and restraint that found hundreds of cases of alleged abuse and death. George Miller (D-CA), Chair, Committee on Education and Labor, and Cathy McMorris Rodgers, (R-WA), member of the Committee introduced [H.R. 4247](#). Christopher Dodd (D-CT), Chair, HELP Subcommittee on Children and Families, introduced [S. 2860](#) in the Senate) Our ability to provide immediate assistance to families while also working behind the scenes to change policy is part of what makes DREDF unique and effective.

## **Foster Youth Resources for Education (FYRE)**

Our Foster Youth Resources for Education (FYRE) project has seen an exponential increase in demand for services as word travels through the foster youth community about our commitment and knowledge. Thanks to our outreach efforts and positive recommendations this year we:

- Worked with 235 foster parents, kinship care givers, social workers, and other professionals to support foster children in school
- Presented 12 workshops on the rights of foster youth with disabilities at school and in the child welfare system
- Formed partnerships with the California Foster Parent Association, Casey Family Programs, and the US Office of Special Education Programs (OSEP) to share knowledge, experiences, and strategies for improving the education of foster youth with disabilities

## **Clearinghouse on Foster Youth with Disabilities and Transition**

High school is a tough period for most youth, but high school foster youth in special education face even greater challenges as they contend with two complex advocacy-driven systems: special education and child welfare. Difficult to navigate individually, the lack of coordination between the systems tends to compound the existing problems of frequent school changes, loss of school records, and poor monitoring of academic progress. These barriers disrupt their education and ultimately their transition to independent adulthood. Less than 3% of foster youth go to college and 46% do not finish high school.

**DREDF started the Clearinghouse to improve coordination and communication between the special education and foster care systems.**

Through the Clearinghouse, DREDF:

- Trains all the stakeholders in the system—foster parents, kinship caregivers, older foster youth, and social service professionals—about special education rights
- Trains special education and disability advocates on the rights of youth in foster care

# DISABILITY & MEDIA ALLIANCE PROJECT

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Despite significant legislative and legal advances for people with disabilities, the representation of disability in popular culture and news media remains dominated by stereotypes.

Understanding the power of media to influence public opinion, DREDF created the Disability & Media Alliance Project (D-MAP) to build relationships with the media in order to promote more accurate representations of disability. As other civil rights movements have demonstrated, partnership with the media is proving critical to changing perceptions, eliminating discrimination, raising public awareness, and ending prejudice and stigma surrounding disability.

The D-MAP team has made great progress in raising awareness in the media industry of the problematic coverage of disability and working within the disability community to gather and leverage support for the project. We have already met with CNN, NBC, NPR, BBC News America, and the Washington Post to develop relationships with their editorial and professional development staffs. We have also assembled an Experts Panel of sources for reporters, a web-based set of resources for journalists, and a website and blog.

Keep up with developments at <http://www.d-map.org> or join the discussion on one of DREDF's social media outlets.

Visit DREDF on

Facebook: <http://www.facebook.com/DREDF.org>  
YouTube: <http://www.youtube.com/user/DREDFvideo>  
Twitter: <http://twitter.com/DREDF>

## INTERNATIONAL

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DREDF shares its expertise to support disability communities and advance disability and human rights around the world. Over the past year, DREDF:

- Led workshops for women with disabilities from 24 developing countries on community organizing, systems change, and advocacy as part of Mobility International USA's (MIUSA) Women's Institute on Leadership and Disability (WILD)
- Traveled to Stockholm, Sweden to speak about the independent living movement at a conference on independent living strategies.
- Led workshops on disability and human rights for people with disabilities in Bahrain through the Bahrain Disabled Sports Federation Professional Exchange
- Presented inclusive education workshops in Uganda
- Worked with MIUSA's Building an Inclusive Development Community (BIDC) in Colombia

# COMMUNITY LEADERSHIP AWARD

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The San Francisco Foundation honored DREDF co-founder and Senior Policy Advisor Mary Lou Breslin with the Robert C. Kirkwood Community Leadership Award on September 22, 2009. The Foundation recognized Mary Lou for her outstanding community service, commitment, and inspired leadership. We couldn't agree more with their decision! You can watch the video about Mary Lou from the awards ceremony at <http://www.sff.org/programs/awards-programs/community-leadership-awards>.

## 30<sup>TH</sup> ANNIVERSARY CELEBRATION

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On August 26, 2009, nearly 300 guests gathered at the Four Seasons Hotel in San Francisco to celebrate DREDF's 30th Anniversary and pay tribute to the life and work of Senator Edward M. Kennedy. While we are deeply saddened by Senator Kennedy's death, it was a comfort to gather with friends and colleagues to honor his legacy.

As our Master of Ceremonies, Michael E. Iskowitz, former Chief Counsel to Senator Kennedy, said, "[Senator Kennedy] loved DREDF very much – its mission and its people – and he would say that there is no better way to pay tribute to his memory than to celebrate DREDF and to support this organization in carrying the torch into a new dawn."

Following opening remarks by Mr. Iskowitz, the program spotlighted DREDF's family advocacy with testimonies by DREDF clients, Jorge Flores and Jacqueline Jackson, father and grandmother, respectively, to children with disabilities. Although Congressman Patrick Kennedy (D--RI) could not attend as planned, we were honored to have Congressman George Miller (D--CA), Chairman of the House Education and Labor Committee, speak in place of his friend and colleague. Congressman Miller worked side by side with the Lion of the Senate for 35 years.

A video tribute to Senator Kennedy, produced by DREDF Executive Director, Susan Henderson, and DREDF Web Master, Dave Nold, followed. You can view the tribute video to Senator Kennedy on the DREDF YouTube page at <http://www.youtube.com/user/DREDFvideo>.

# FINANCIALS

Even in a tough economy, DREDF has remained fiscally strong by diversifying our income and conserving resources — every penny counts, and our infrastructure and overhead stay lean. Contributors like you enable us to educate and assist people with disabilities and advance disability rights. Your support, enthusiasm, and long-term vision are vitally important to DREDF's health and future. Thank you!

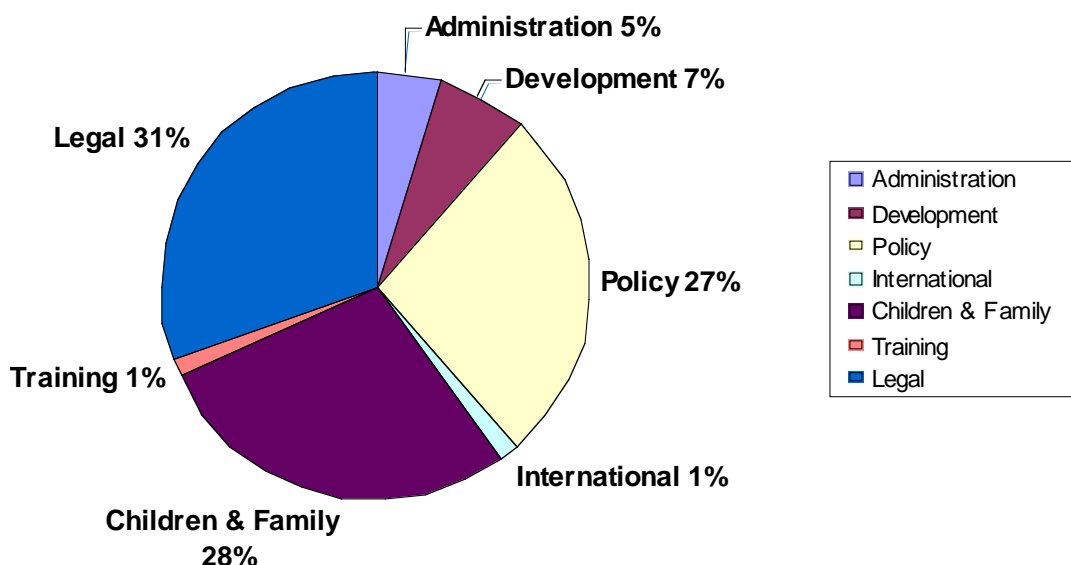
## Support and Revenue

Foundation and community grants	153,000	
Contributions	218,461	
<b>Total Grants and Contributions</b>	<b>\$ 371,461</b>	
Government contracts	414,663	
State Bar contract	201,390	
Legal fees	65,153	
Training and publication fees	21,758	
Investment income	(2,665)	
Interest and dividends	1,370	
<b>Total Revenue</b>	<b>\$ 701,669</b>	
<b>Total Support and Revenue</b>	<b>\$ 1,073,130</b>	

## Expenses

Program	1,328,164	
General and administrative	72,618	
Fundraising	102,524	
<b>Total Expenses</b>	<b>\$ 1,503,306</b>	
<b>Net Loss</b>	<b>\$ (430,176)</b>	

## Expenses by Program



# CONTRIBUTORS

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**October 1, 2008 – September 30, 2009**

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