

DRW Progress Report

Taking Seriously the Saying: **“Nothing About Us Without Us”**



Disability Rights Washington
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2008

DRW works independently and with others for results that matter

This is an election year and all the candidates have been talking about change. People with disabilities want change as well. But not just any change. They want change that is true to the saying “nothing about without us”.

At DRW, our job is to produce change by listening carefully, planning our work wisely, and acting. Three factors combine to make DRW unique in this state: 1. the access and authority granted by our federal mandates (see bottom of page 6) ; 2. our expertise in disability related law and membership in the National Disabilities Rights Network; and 3. our perspective derived from the viewpoints of people with disabilities.

In some circumstances, we work independently through individual representation. But most of the time we work with others - individuals and entities - to improve the systems that provide supports and services and to protect and expand the rights of people with disabilities.

The following (pages 2, 3 and 4) include recent results achieved by DRW and its allies. These examples were chosen to illustrate the broad array of issues on which we work and the different ways in which we act independently as well as in coalition with others.

Restoring the definition of disability — After an unexpected and adverse decision (*McClarty v. Totem Electric*) by the Washington State Supreme Court narrowing the disability definition in Washington’s anti-discrimination laws, many legislators felt the intent of the Legislature had been misinterpreted.

DRW worked with the Washington State Human Rights Commission, Central Washington Disability Resources, Washington Rehabilitation Council, Association of Centers for Independent Living, Governor’s Committee on Disability Issues and Employment, Washington State Trial Lawyers Association, Paralyzed Veterans of America, University of Washington School of Law, self-advocates throughout Washington, and many other entities to restore the definition of disability to what the Legislature had originally intended.

These partners worked closely with the Legislature to develop wording for a definition that would convey what the Legislature intended when they first included people with disabilities in the protection offered by Washington’s antidiscrimination laws. The effort ended with success as the Legislature passed a broad definition of disability and the Governor signed the bill.

Asserting Ashley’s rights — What has become known in the media as “Ashley’s Treatment” is a combination of three medical procedures performed on a young girl (six years old in this instance): breast bud removal, a hysterectomy, and growth attenuation hormone treatment. In performing at least part of these procedures without a court order, the law was broken and Ashley’s fundamental rights were violated.

There were some unique features to DRW’s effort related to “Ashley’s Treatment”. First, we recognized immediately that this was going to be an issue that stirred the passions of the disability community. So we convened an “Ashley Treatment” advisory group consisting of representatives from People First of Washington, Self Advocates of Washington and the Washington State Developmental Disabilities Council. This group met on several occasions and provided guidance for our efforts.

Second, we wanted the outcome to be a model for all hospitals throughout the world. We worked quietly, assertively and successfully with the hospital to write a report and establish policies all hospitals could use to protect the fundamental rights of their patients – future Ashleys.

More successful results

Students win right to return to a community school — DRW and a partner successfully settled a lawsuit filed to secure a free appropriate public education in the least restrictive environment for students who lived at Francis Haddon Morgan Center (FHMC) in Bremerton. The collective actions or inactions of the three defendants – Bremerton School District, Office of Superintendent of Public Instruction and Department of Social and Health Services – forced these students from their community school into the segregated setting of an FHMC classroom.

This case illustrates two different ways DRW partners with others. First, after the case was initially dismissed at the federal district court level, DRW secured the pro bono services of Seth Galanter, an attorney with the Washington, D.C. law firm of Morrison & Foerster LLP and he led the effort to appeal the case to the 9th Circuit Court of Appeals in San Francisco.

Second, we coordinated our efforts with the Arc of Washington, Developmental Disabilities Council and Washington State Special Education Coalition who had all been involved with similar issues in other arenas – a division of labor that addressed a complicated issue on several fronts.

Halting housing discrimination — DRW joined the Northwest Justice Project and Washington State in a petition to Tacoma’s Growth Management Hearings Board opposing an ordinance that discriminated against people with mental illness and other disabilities. As a result of negotiations with the City of Tacoma, the City agreed to remove the term and definition for “permanent supportive housing” and to remove the conditional use permit requirements for categories of housing for people with disabilities. These were items that led to discrimination against people with disabilities.

While DRW and the Northwest Justice Project are not always on the same side of an issue with the State, the alliance on this issue is an example of the willingness of all parties to work cooperatively on issues when common ground can be found.

Moving toward parity in health insurance coverage for mental illness — DRW partnered with 140 organizations to put the finishing touches on our efforts to obtain parity in health insurance coverage for mental illness. Two major changes in health insurance became law and will improve access to mental health care. Mental health parity is now required for commercial group health plans offered by an employer of two or more employees and it is required for individual health policies purchased from an insurance carrier. With the expansion of mental health parity into these two markets, an additional 500,000 people will have access to mental health services.

This effort is an example of DRW starting a coalition with a very specific purpose in mind. Four of the founding members of this coalition saw this effort through from its beginning in 1997 to its conclusion in 2008: Betty Schwieterman of DRW, Laura Grosburg of the Washington State Coalition of Mental Health Professionals and Consumers, Lucy Homans of the Washington State Psychological Association, and Eleanor Owen of the Mental Health Association of Washington.

Securing a speech generating device is a breakthrough — DRW represented a minor child with autism seeking assistance in getting funding for a DynaVox 5 speech generating device recommended by the child’s speech language specialist. DRW represented the child at a fair hearing but the funding was initially denied. As the grandparents sought private funding, Medicaid reversed its denial and funded the device. This is a significant outcome as the Medicaid program has been reluctant in the past to approve funding for a speech generating device for children or adults with autism. This result is an example of how DRW strategically uses individual representation to benefit as many people as possible.

More successful results

Introducing disability history into our schools — DRW joined self-advocates and others throughout Washington in a successful effort to require that each October, public schools, colleges, and universities conduct and promote educational activities that provide instruction, awareness and understanding of disability history and people with disabilities. The activities may include school assemblies or speakers.

In some coalitions DRW takes a leading role and in others our role is more of a supportive one. In this effort, members of People of Washington, Self Advocates of Washington, Self Advocates in Leadership, Self Advocates in Motion and Governor's Committee on Disability Issues and Employment led the way with entities such as DRW, Arc of Washington, Developmental Disabilities Council, and Washington State Special Education Coalition offering their support.

Closing the gaps in traumatic brain injury services — DRW participated in a coalition effort to improve supports and services for people with traumatic brain injuries through the creation of a fund supported by a \$2.00 surcharge on traffic tickets. The fund supports information and referral services, mutual support groups, a public awareness campaign and a statewide Council for long term planning.

More so than other efforts it was individuals and not entities that were instrumental in creating this change. People like Tommy Manning, Constance Miller and Penny Condoll were able to talk about the gaps in the availability of supports and services for people with traumatic brain injuries from their own personal experience and that is what made the difference with policy makers.

Wheelchair and systemic change obtained — After an exhaustive effort, DRW successfully helped a young woman obtain funding for a specialized wheelchair that will allow her to complete college and become employed. This college student was seeking funding for a Permobil power wheelchair with a built-in stander to meet her medical needs for standing and reduction of spasticity.

As a result of negotiations, the funders, representing two agencies, agreed to cooperate in future cases where shared agency funding is appropriate, increasing the availability of assistive technology funding for persons with both a medical and a vocational need. This is another example of using individual representation to help a group of people in the future.

Courts to get an access coordinator — Surprisingly, courts – where justice is supposed to be served – have all too often been inaccessible to people with disabilities. And not just architecturally but in a variety of ways. Over the last several years, this has been a signature issue for DRW and some its allies including the Governor's Committee on Disability Issues and Employment and Project PAS-Port for Change.

During DRW involvement with this issue, progress has been made in improving the accessibility of our courts. This year, DRW was instrumental in securing a new position in the Administrative Office of the Courts – an Access Coordinator. The Coordinator must: 1. review the needs of courts statewide for training and other assistance required to provide access and accommodation for persons with disabilities; 2. provide guidance and assistance upon request; and 3. identify appropriate assistive devices and establish a system to improve courts' access to such devices.

What DRW is working on now

Right now DRW is engaged in over 150 projects and cases. At our Board's direction and in response to public comment, we emphasize group advocacy over individual advocacy because our experience demonstrates it produces better results for more people and allows us to stretch our limited dollars. Listed below are a few of our major projects. See the Current Priorities insert for all the issues currently being addressed by DRW.

Bettering investigations and the initial response to abuse — DRW is working with People First of Washington, Self Advocates for Washington, Self Advocates In Leadership, Developmental Disabilities Council, Governor's Committee on Disability Issues and Employment, Long-Term Care Ombudsman, Aging and Disability Services Administration, Residential Care Services, Home and Community Services, Division of Developmental Disabilities, Department of Health, Office of the Attorney General and others to improve the response to abuse of persons with disabilities and seniors in our state.

Transitioning from school — Youth with disabilities, in transition from school to life in the community, are connected to young adult mentors with disabilities through the Self Advocacy in Motion Project. Throughout the year, youth with disabilities obtain information on employment advocacy, advocacy with job coaches or vendors, benefits and relevant work incentives, and transition goal planning. Adult self-advocates inspire youth to plan for vacation homes, self-employment, fulfilling careers, self-determined lives and independent living.

Making caucus voting accessible — DRW is using a part of the Help America Vote Act (HAVA) funding in an effort to improve the accessibility of voting in the Democratic and Republican caucuses.

Improving access to domestic violence and sexual assault related services — The Washington State Coalition Against Domestic Violence, Abused Deaf Women's Advocacy Services, Washington Coalition of Sexual Assault Programs, and DRW have formed a partnership and received funding to improve accessibility of services for survivors of domestic assault and sexual violence who have disabilities.

Resource Advocacy

DRW resource attorneys and legal interns continue to provide information, referral and short term assistance to those who contact us. Here are a few compliments we've received about their work:

"We greatly appreciate the help, assistance and quality of staff of DRW."

"DRW provides a great resource."

"The help from DRW was excellent."

"God bless you - thank you."

"DRW answered questions I didn't even know I had."

You can comment on our priorities

See the enclosed Current Priorities insert for details on the 2008 Priorities of DRW. If you would like to provide suggestions for our 2009 Priorities, use the Priority Input Form on the opposite side of that insert and return it to DRW.

FY 2007 Expenditures

Annual Audit by Peterson Sullivan PLLC

Salaries & Benefits	\$1,275,004
Travel	85,441
Communications	28,758
Occupancy	148,748
Consultants	53,472
Insurance	9,789
Printing & Supplies	30,594
Legal Fees	46,278
Public & Staff Trainings	29,471
Publications & Dues	18,455
Postage & Shipping	12,057
Equipment Rental & Repair	30,955
Miscellaneous	30,924
Depreciation	17,256
Self Determination Contract	<u>50,000</u>
TOTAL	\$1,867,202

FY 2008 Funding Pie

Total Budget: \$1,955,149

Funding Sources

Below is a list of our funding sources and the legal citations for the formula grants created in federal statute and/or regulation. It is also the explanation of acronyms in the pie chart above.

- PADD** Protection & Advocacy for Individuals with Developmental Disabilities
42 U.S.C. Sections 15001 - 15045 (2003) 45 C.F.R. Sections 1385.1 - 1386.25 (2003)
- PAIMI** Protection & Advocacy for Individuals with Mental Illness
42 U.S.C. Sections 10801 - 10827 (2003) 45 C.F.R. Sections 51.1 - 51.46 (2003)
- PAIR** Protection & Advocacy for Individual Rights (PAIR)
29 U.S.C. Section 794e (2003) 34 C.F.R. Sections 381.1 - 381.33 (2003)
- PAAT** Protection & Advocacy for Assistive Technology (PAAT)
29 U.S.C. Sections 3001 - 3058 (2003) 34 C.F.R. 345.1 - 345.63 (2003)
- PATBI** Protection & Advocacy for Individuals with Traumatic Brain Injuries (PATBI)
42 U.S.C. 300d - 300d-53 (2003)
- PABSS** Protection & Advocacy for Beneficiaries of Social Security (PABSS)
42 U.S.C. 1320b-20-1320-21 (2003)
- PAVA** Help America Vote Act -Title II, Subtitle D, Part 5, of HAVA 42 U.S.C. 15461-62
- OTHER** DRW receives a few very small grants.
- DOJ** The Department of Justice funds a project related to sexual assault and domestic violence.
- GF** The General Fund consists of private donations (included under "Other" in the pie chart).

DRW Staff

Andrea Kadlec (since 1999) – Director of Community Relations with assignments related to self determination.

Betty Schwieterman (since 1982) – Director of Systems Advocacy, grant coordinator and council liaison.

Brian Dahl (since 2002) – Contract employee for accommodation services and board and council support.

Craig Awmiller (since 2001) – An investigator working on abuse/neglect investigations in addition to court ordered and routine facility monitoring.

David Carlson (since 2004) - Associate Director of Legal Advocacy and Director of Resource Advocacy, and attorney.

David Girard (since 2008) - Contract attorney co-counseling on selected cases.

David Lord (since 1994) – Director of Public Policy and attorney.

Emily Cooper (since 2006) – Senior Resource Advocacy Attorney also working on individual cases.

Jessica McDanel (since 2006) – Administrator, board and council support, and webmaster.

Mark Stroh (since 1990) – Executive Director, grant coordinator, and board and council liaison.

Mike Smith (since 1991) – An Attorney and grant coordinator.

Mona Rennie (since 2004) – Legal secretary in charge of records management and legal calendaring.

Regan Bailey (since 2007) – Director of Legal Advocacy and attorney.

Stacie Siebrecht (since 1999) – Associate Director of Legal Advocacy and attorney.

Susan Kas (since 2006) – An Attorney working on legal group advocacy and investigations.

Tom Hazeltine (since 1991) – Controller and a certified public accountant.

Zach Burr (since 2007) - An Attorney working on resource and individual advocacy.

DRW Volunteers and Interns

We thank the people who are currently volunteering or have volunteered in the past year or so.

Evangeline Abadinas	Angela Crawford	Cathy MacKinnon	Kate Sheffield
Nick Allen	Terry Dorn	Crystal Manning	Keith Shierk
Jacob Baldwin	William Fale	Dwight McClain	Pat Shivers
Marlo Berger	Lori Gendron	Marcaill Moody-Burks	Nichole Smith
Juristine Betts	Aaron Gimse	Yvonne Moore	Shannon Sommer
Rachel Brehm	Charles Gourde	Larry Moss	Frank Sullivan
Trevor Buehler	Sonja Hardenbrook	Maggie Oliver	Jennifer Symms
Carolyn Burkhart	Pete Harrison	Michael Oliver	Mary Pat Treuthart
Claire Michelle Burns	Ron Helgesen	Dylan Orr	Dorothy Trueblood
Wanda Burns	Aaron Hernandez	Andrea Parra	Tha Win
Kaci Callahan	Jenny Houghton-McAuliffe	Jeannie Peck	Christina Wong
Siv Carlson	Hillary Jorgensen	Mike Raymond	Valerie Wootton
Peggy Cobb	Ali Khaksar	Laurie Scott	
Deanna Condon	Stephanie Landaas	Colleen Shea-Brown	

Some Nice Words for DRW and Opposing Counsel

“If I hear too much praise on people, maybe they think it lacks sincerity. But you all have really impressed me, both when we were at Western State and holding court there and with the work that you have done. It is a model, I would hope, of how lawyers as officers of the court should work together to solve these kinds of problems, and I have really, really been impressed. You are to be commended . . . and your clients ought to be very appreciative of the work that you’ve done.”

- U.S. District Court Judge

Ways You Can Help

Volunteer

DRW has a variety of ways in which you can contribute to the success of our advocacy efforts. They are listed below but are described in greater detail in the enclosed “Volunteer Opportunities” insert. You may apply for these opportunities using the Volunteer Application on the opposite side of the insert. To get involved, you can:

1. Apply to be a member of our Select Finance Committee
2. Become a Fund Raising Event Coordinator
3. Volunteer to work on a fund raising event
4. Provide pro bono legal services
5. Apply to be an intern or work study student
6. Serve on the DRW Board or one of our advisory councils
7. Contribute to our website development
8. Suggest another way you could volunteer at DRW

Donate

The demand for DRW advocacy continues to exceed the resources available to provide it. Important issues are put on the backburner due to a lack of resources. Some activities such as lobbying are required to be funded by private donations. All of this is why DRW is always grateful for private donations. To help, you can:

1. Visit our website and use your credit card to make a donation
2. Designate your United Way or any payroll-deducted donation to DRW
3. Include Disability Rights Washington in your estate planning
4. Use the enclosed envelope to send a donation check
5. Purchase a Friends of DRW hat, t-shirt and/or sweatshirt
6. Go to our website and learn how a portion of your online shopping purchases could be donated to DRW.