

ARIZONA CENTER
FOR DISABILITY LAW

moving
forward

2004

REPORT TO THE COMMUNITY

December 2004

Dear Friends,

As I began thinking about our annual report to the community for 2004, the first image that came to mind was that we were barely treading water – threats to the rights of people with disabilities still abound. On a daily basis we are opposing employment practices based on stigma and stereotype, educating school districts on their obligations to children with disabilities and fighting for better mental health and disability related services. With threats to funding for programs for people with disabilities, cut-backs in services, and changes to federal law governing disabled children’s education – it feels like success to stay in one spot.

Yet when I started to think back over where we had come over the past several years, it was quite a different image that came to mind. Many years ago, when I was new to this work, I received a call from a group home for people with developmental disabilities. Folks from the group home had gone to the local community pool and were refused entrance because they “looked funny” and “acted different.” This was before the Americans with Disabilities Act and frankly, I didn’t have a very good answer for them on how to stop the discrimination. Today, I would not only have an answer, but could help them as well. Like the recent complaint we filed with the Arizona Attorney General’s Office, on behalf of a young man with developmental disabilities who was removed from a shopping mall because his vocalizations were perceived as “too loud” and “scaring” other patrons.

So today, with the publication of our Report to the Community 2004, I want to celebrate our movement forward in protecting and advocating for the rights of individuals with disabilities in Arizona. For every issue we still need to tackle, there is another where we have been successful. There isn’t room in this Annual Report to tell you about every success story. We’ve chosen to highlight only some of the many accomplishments of our staff and the real progress made for people with disabilities.

I can assure you that in 2005, the Center will meet the challenges ahead with a multitude of tactics that will include coalition building, legislative and regulatory changes, much needed one-on-one advocacy assistance and litigation. We will be there for the growing number of Arizonans who need our help and we will move forward!

Sincerely,



Leslie J. Cohen
Executive Director

letter from the director



through public policy

IDEA Changes Ahead

Every day, Center staff use the federal Individuals with Disabilities Education Act (IDEA) as the primary tool for advising families of children with disabilities on their legal rights to a free, appropriate public education as well as how to take action when necessary to enforce those rights.

On December 3, 2004, President Bush signed into law the first overhaul of the IDEA in seven years. The revised IDEA creates a mixture of gains and losses for parents and children with special education needs.

- Once again, Congress has failed to fully fund the IDEA. Although the reauthorized Act calls on the federal government to reimburse school districts 40 percent of their special education costs, this is merely aspirational and not mandatory. Yearly federal appropriations have never contributed more than 20 percent.
- Short-term objectives and benchmarks have been replaced with quarterly progress reports and measurable annual goals.
- Changes in disciplinary procedures have strictly curtailed the use of the “stay put” provision that has been in place for over 25 years. “Stay put” provided consistency to students. Parents could request that their child not be removed from their current placement pending the outcome of an appeal. Students who now violate school codes will have to remain in an interim placement pending an appeal of the manifestation determination. The hearing must occur within 20 days.

On the positive side, the new IDEA will increase the number of certified special education teachers, expand access to assistive technology, and sanction states that do not comply with the law.

The law retains continued services for students placed in alternative settings, attorney fee reimbursements for parents who prevail in due process hearings and functional behavior assessments.

The passage of the bill does not signal an end to the process. The Center, along with the National Association of Protection and Advocacy Systems, will monitor and participate in the rule making process from the beginning to the end to ensure that we do not miss any opportunity for the expansion of legal rights for children and parents.

A Harris Poll conducted for the National Organization on Disability in September 2004 showed that twenty-one percent of U.S. adults with disabilities—representing more than eight million potential voters—say they have been unable to vote in presidential or congressional elections due to barriers faced either at, or in getting to, the polls.

Center Advances Voter Access During 2004 Elections

In Arizona, the U.S. Census Bureau estimated that there are 902,252 residents with disabilities in Arizona (19.3% of the population). 824,286 are of voting age and only 278,609 individuals with disabilities voted in the 2000 election.

The Arizona Center for Disability Law continued to be part of the implementation of the Help America Vote Act by providing protection and advocacy services to increase voter registration, voter rights and voter accessibility during the 2004 elections.

Throughout the year, the Center sponsored voter registration drives and voter empowerment workshops that reached over 500 individuals. Center staff and volunteers surveyed polling sites in Maricopa and Pima counties. Accessibility problems included lack of accessible parking, slopes that exceeded federal requirements, narrow entrances and lack of curb cuts. The Center met with staff from state and county election officials to discuss access issues. Center staff also participated in statewide and local Election Protection Committees, designed to monitor polling sites on election day.

Making A Difference — Honoring Our Allies

State Representative Pete Hershberger (R-26) was honored at the Arizona Center for Disability Law’s Annual Tucson Spring Event on April 1, 2004 for his leadership in reforming Arizona guardianship laws including a revision of limited guardianship laws in 2003 and an attempt in 2004 to include voting rights for individuals under a limited guardianship. The voting rights bill passed the Senate but failed to make it out of the House Judiciary Committee. If the law had passed, it would have allowed the Court to decide, when assessing an individual’s capacity, whether the individual may retain the right to vote in addition to other rights while under a limited guardianship. Another effort will be made in 2005 to advance voting rights legislation.

through

outreach

& *advocacy training*

The number of people empowered through training and outreach from October 1, 2003 - Sept. 30, 2004.

4,634

The Arizona Center for Disability is the only nonprofit public interest law firm providing free comprehensive legal rights information and advocacy training statewide to the disability community. In fiscal year 2004, Center staff traveled across the state to deliver training on such topics as:

- Rights for People with Serious Mental Illness*
- Legal Options for Adults with Disabilities*
- Five Letters Every Parent of a Child with a Disability Needs to Know How to Write*
- Your Employment Rights Under the Americans with Disabilities Act*
- Your Rights as a Client or Applicant of the State Vocational Rehabilitation System*
- What You Need to Know to Avoid a Social Security Benefit Overpayment*

Complimenting these trainings are a full range of instructional guides on educational rights, housing, employment, the Americans with Disabilities Act, health care and mental health issues, which can be accessed on our web site at www.acdl.com.

Navigating the Health Care Maze

Complicated health insurance coverage rules often make it difficult for individuals with disabilities to obtain the health care they need. The Arizona Center for Disability Law has always been at the forefront of advocating for better health care for people with disabilities. In 2004, the Arizona Center for Disability Law received a two-year grant from the Nina Mason Pulliam Charitable Trust to provide self-advocacy training, one-on-one counseling and printed health care guides to Arizonans with disabilities. This new grant has allowed us to publish new self-advocacy guides which are available free of charge by calling the Center or visiting our website. The Center is also sponsoring a series of trainings on how consumers can advocate for themselves in health care appeals. To view a complete list of Center sponsored training and self-advocacy guides, visit www.acdl.com.

2004 TBI Conference a success

The second annual Traumatic Brain Injury Conference was another success. Funded in part by the Arizona Center for Disability Law and the Governor's Council on Spinal and Head Injuries, the conference expanded its programming in 2004 from a half-day to a full-day event. 200 people attended the conference, doubling attendance from 2003. The Conference provides an opportunity for family members and individuals with traumatic brain injury to meet each other and share their stories as well as learn about resources statewide. Executive Director Leslie Cohen welcomed conferees and Center staff presented four workshops including: Overcoming Barriers; Navigating the Health Care System; Developing Successful School Plans; You Can Make A Difference.



At a ceremony in March 2004, the Center received a \$65,000 grant from Nina Mason Pulliam Charitable Trust. "As the Trust begins its seventh year of funding, we are most pleased with the long-term impact of our grant dollars and the relationships and programs established with our family of grantees," said Trustee Carol Peden Schatt. "Nina would have been so proud of the work her dollars are supporting today." Pictured left to right are: Trustee Frank E. Russell, Center Executive Director Leslie Cohen, Trustees Nancy M. Russell and Carol P. Schatt.

through litigation & systems change

Arizona Center for Disability Law Redoubles Effort on Arnold v. Sarn

In a groundbreaking decision in 1989, the Arizona Supreme Court ruled in Arnold v. Sarn that “Arizona has failed to meet its moral and legal obligations to our state’s chronically mentally ill population.” Unanimously, the Court held that individuals with serious mental illness have a legal right to mental health treatment in the community and that the State of Arizona and Maricopa County had failed to provide that treatment. Since that time, the Center as counsel for the plaintiffs, along with its co-counsel, has been working to make the promise of the Arnold case a reality in Arizona. Although some improvements to the system and its funding have been made, the Center is continuing to work toward ensuring that the defendants fully implement the court’s orders. This would ultimately result in individuals with serious mental illness who reside in Maricopa County receiving the appropriate services that will support their recovery.

In August of 2004, the Arnold v. Sarn Court Monitor issued a report on the independent audit conducted earlier in the year. The report describes a service planning and delivery system in serious disarray and concludes that the Arizona Department of Health Services (ADHS) has failed to adequately oversee the system. On the majority of quality indicators, the system has regressed since the last full audit in 2000. Of greatest concern is that the majority of class members are not receiving individualized service planning and appropriate mental health services.

In the past several months, much activity has occurred surrounding: 1) a corrective action plan, which includes intensive mentoring at the service clinics; 2) interim and end dates for compliance; and 3) consumer and family member involvement. In October, 2004, Maricopa County Superior Court Judge Bernard Dougherty ordered the state to comply with a Corrective Action Plan (CAP), which is a shorter-term plan to address the current deficiencies in the system. The CAP contains a strategy called intensive mentoring, to address the service planning deficiencies at the clinics of Value Options (VO), Maricopa County’s Regional Behavioral Health Authority. A team of mentors, which includes peer and family member mentors, have begun working at five of the twenty-three VO clinics, in an effort to improve not only the culture of the clinics, but also the service planning process and the way staff interacts with consumers. The mentoring teams will expand to work at the remaining 18 clinics over the coming months.

On December 17, 2004, the court adopted as an additional order a negotiated agreement that provides for an end date to the case and interim compliance dates for the remaining obligations of the defendants. The Center plans to enhance its monitoring of ADHS’ activities, including budget issues. Additionally, the Court Monitor will conduct “spot reviews,” in addition to conducting the annual audit, to monitor compliance with the orders. ADHS has reported that it plans to provide more rigorous oversight of VO.

The Center has been working with consumers, family members and consumer advocates to learn about their concerns, most of which are addressed by the court’s existing orders. Over the next several months, the Center will also participate in discussions with ADHS and consumers and family members regarding three areas of concern that fall outside of the Court’s orders: pharmacy issues; peer oversight of the system as a whole; and VO’s expenditures.

The Center and co-counsel the Center for Public Representation and the Arizona Center for Law in the Public Interest, remain fully committed to a variety of strategies to ensure the defendants correct the deficiencies in the system and comply with the court’s orders in this case.

Arizona Center for Disability Law Advances Employment Rights of People with Cognitive Disabilities

An estimated 2.5 million people in the United States have an intellectual disability – approximately 1% of the population. Estimates also indicate that only 31% of individuals with intellectual disabilities are employed, although many more want to work. The Center is hard at work making sure that individuals with mental disabilities are not discriminated against in the workplace because of fear or stereotypes.

In August 2004, the Arizona Center for Disability Law and the U.S. Equal Employment Opportunity Commission (EEOC) settled a federal lawsuit against the Clarion Hotel in Tucson. The Center and the EEOC sued the Clarion Hotel alleging that the hotel discriminated and retaliated against five employees because of their developmental disabilities, which included mental retardation and Downs Syndrome. The Consent Decree provided monetary compensation to the clients, attorney fees to the Center, and ordered the Clarion to train its employees, develop a disability and anti-retaliation policy, designate an employee responsible for addressing any claims of discrimination and post notices regarding its nondiscrimination policies. Plaintiff Juan Rivera, former Clarion Hotel employee (right) with J.J. Rico, staff attorney (left) are pictured in front of the Clarion Hotel.



by providing help one individual at a time



CENTER ADVICE Lines At Work

Each year the Arizona Center for Disability Law receives over 3,000 calls from people with disabilities and their families seeking information and assistance from navigating complicated special education rules to learning how to request a reasonable accommodation at work.

The Center staffs numerous advice lines that provide free information and assistance in the areas of health care and developmental disability services, employment, housing, ADA accessibility, assistive technology, special education and mental health services. A phone call with our trained advocates is sometimes all the help someone needs to protect their rights.

- The parent of a 16 year old child with multiple disabilities called the Special Education Hotline because her child was placed in an elementary school classroom with no special education services. With the information and support from the hotline, the parent was able to advocate for her child to be placed at a neighborhood school with proper education support. The child now receives speech and occupational therapy to improve communication skills and participates in a regular education environment for part of the school day.

- A person with numerous disabilities, including Rheumatoid Arthritis, multiple joint replacements and severe deformity of her feet, ankles and knees contacted the Center to get help to secure much needed durable medical equipment. Her motorized wheelchair of 20 years had become too old to repair and her doctors requested a new motorized wheelchair as well as orthopedic shoes to assist with the management of the deformity of her feet and ankles. Her AHCCCS plan denied the request. Center staff appealed the denial and the client now has a new electric scooter and orthopedic shoes.

- A 45 year old woman with a mental illness received a Social Security Insurance overpayment notice of \$173. The client sought information and advice on how to avoid overpayments and obtain a waiver of the current overpayment. Center staff contacted Social Security and verified that the client did qualify for a waiver of her overpayment. The Center also provided advice to the client on what to do to avoid an overpayment in the future.

As the Special Education Hotline Coordinator, Diane Nydick, managed 1,685 calls in 2004 from parents and students seeking information and counseling about special education in Arizona.

1,685

CENTER STAFF NIXES Special Treatment Plan

The Arizona Center for Disability Law received 604 calls for information and assistance on mental health issues in 2004. But that is not the only way the Center identifies and addresses systemic problems. Our mental health advocates make weekly visits to University Physicians Hospital at Kino in Tucson and the Arizona State Hospital in Phoenix.

As a result of the Center's routine outreach at the Arizona State Hospital, staff discovered that hospital personnel used "Special Treatment Plans" to circumvent seclusion and restraint regulations.

Regulations require that seclusion and restraint cannot be used as a means of coercion, discipline, convenience or retaliation. Seclusion and restraint can only be ordered by a doctor and should be used rarely and only for short periods of consecutive time.

Center staff identified at least 20 individuals who were subjected to "special treatment plans," approximately half of whom were children. In most cases, "special treatment plans" were used to control and retaliate against noncompliant patients. In the worst cases, some individuals were kept in seclusion for up to six weeks. Center attorneys and advocates pressured the Arizona Department of Health Services and the Arizona State Hospital to discontinue the use of "Special Treatment Plans" and to utilize appropriate behavior management and treatment plans for patients.

budget *for the fiscal year ending* SEPTEMBER 30, 2004

INCOME

Federal Grants

	<u>Amount</u>	<u>% of Total</u>
Administration on Developmental Disabilities (A.D.D.)	\$ 539,854	
Protection and Advocacy for Individuals with Mental Illness (P.A.I.M.I.)	\$ 540,074	
Client Assistance Program (C.A.P.)	\$ 189,624	
Protection and Advocacy for Individual Rights (P.A.I.R.)	\$ 260,491	
Assistive Technology Access Program (A.T.)	\$ 78,000	
Governor's Council on Development Disabilities (G.C.D.D.)	\$ 86,000	
Help America Vote Act (H.A.V.A.)	\$ 34,766	
TBI Protection & Advocacy (T.B.I.)	\$ 50,734	
Protection and Advocacy Services to Social Security Beneficiaries (P.A.B.S.S.)	\$ 100,000	
TOTAL FEDERAL FUNDING	\$ 1,879,543	73.63%

Other Funding

Employment Advocacy Fund	\$	0.00%
Attorney Fees, Interest on Reserve Accounts, Other Income, Draw from Reserve Accounts	\$ 673,243	26.37%
TOTAL OTHER FUNDING	\$ 673,243	26.37%

TOTAL INCOME	\$ 2,552,786	100.00%
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Expenses

Accounting Fees	\$ 12,000	0.47%
Advertising	\$ 3,000	0.12%
Advisory, Board, Staff and Other Meetings	\$ 4,600	0.18%
Consultants/Interpreters Fees	\$ 30,135	1.18%
Copying/Printing	\$ 30,310	1.19%
Disability Database	\$ 3,750	0.15%
Equipment Rental/Repair	\$ 20,047	0.79%
Insurance - Professional Liability	\$ 25,735	1.01%
Litigation	\$ 35,000	1.37%
Office Furniture/Fixtures	\$ 8,601	0.34%
Office Supplies	\$ 38,415	1.50%
Rent	\$ 162,926	6.38%
Postage	\$ 14,250	0.56%
Reference Materials	\$ 17,065	0.67%
Telephone	\$ 30,256	1.19%
Salaries and Related Expenses	\$ 2,037,021	79.80%
Professional Dues/Development	\$ 23,572	0.92%
Travel	\$ 51,103	2.00%
Fundraising/Special Events	\$ 5,000	0.20%
TOTAL EXPENSES	\$ 2,552,786	100.00%

our mission

The Arizona Center for Disability Law advocates for the legal rights of persons with disabilities to be free from abuse, neglect and discrimination and to have access to education, health care, housing, jobs and other services in order to maximize independence and achieve equality.

3839 North Third Street, #209
Phoenix, Arizona 85012
(602) 274-6287 (voice/TTY)
1-800-927-2260 (voice/TTY)
(602) 274-6779 (fax)

100 North Stone Avenue, Suite 305
Tucson, Arizona 85701
(520) 327-9547 (voice/TTY)
1-800-922-1447 (voice/TTY)
(520) 884-0992 (fax)

www.acdl.com
center@acdl.com

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The 2004 Annual Report is an official publication of the Arizona Center for Disability Law. The views set forth in this report do not necessarily reflect the views or opinions of those agencies or organizations that fund the Center's work.

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