

ARIZONA CENTER
FOR DISABILITY LAW

meeting the
challenge

2003

REPORT TO THE COMMUNITY

July 2003

Dear Friends:

I don't need to tell you that we are in the midst of difficult times. Recent changes in this country's political, economic and legal landscape are threatening the well being of people with disabilities across Arizona. While preparing to publish our 2003 Annual Report chronicling the great progress we have made in the struggle for equality for persons with disabilities, we continue to cast a wary eye on those changes that have already occurred and those on the horizon that could have negative implications for Arizonans with disabilities. State budgetary woes have already resulted in cutbacks to services and increased financial contributions by families with limited resources. Proposed federal legislation could jeopardize the right to a free appropriate public education enjoyed by children with disabilities over the last 20 years. In addition, an often contradictory array of appellate court decisions are calling into question many of the protections offered by disability rights laws. Not surprisingly, these external challenges have also had a very direct internal effect on the Center's work, as we have experienced an increase in demand for assistance and additional strains on resources.

But, as people say, every challenge presents an opportunity. And at the Arizona Center for Disability Law, we welcome this opportunity. As the following pages demonstrate, over the course of the last year, we have met these challenges by continuing to:

- Advocate for individuals with disabilities and their families one by one to ensure that they have access to the community, education, housing, mental health, and health care services and employment opportunities .
- Educate the disability community across the state about their legal rights and obligations as well as how to be a successful self-advocate.
- Challenge policies and practices that negatively impact people with disabilities through advocacy, negotiation, and litigation.
- Join with other disability groups and individuals throughout Arizona to create positive public policy for people with disabilities.

Please join us in taking a look at what we have done over the past year to meet the legal, political and economic challenges facing people with disabilities in Arizona. While we would like to think otherwise, we anticipate that the coming year will bring an equal number of new obstacles. But, you can rest assured, that we fully intend to continue to look at each new challenge as yet another opportunity for change and another chance to be a voice for people with disabilities in trying times.

Sincerely,



Leslie J. Cohen
Executive Director

letter from the director



through **litigation &**
systems change

Of the over 3,500 calls the Arizona Center for Disability Law receives each year, very few of them actually end up in litigation. Information and referral, advice, negotiation, mediation and administrative processes take care of the vast majority of problems presented to Center staff. However, sometimes nothing short of litigation will work to change a policy that is disastrous to people with disabilities. *Schulz v. Biedess* is a case in point. For years, the Center has received requests for assistance from Arizona Health Care Cost Containment System (AHCCCS) beneficiaries, because the state Medicaid program refuses to cover diapers for individuals who are incontinent as a result of their disabilities. In most other states, diapers are covered as a preventative medical supply, at least for individuals under 21 years of age, under the EPSDT (Early, Periodic Screening, Diagnosis and Treatment) provisions of the Medicaid statute.

The policy of the AHCCCS administration, which has been set out in appeal decisions, is that incontinence supplies are not medically necessary to “prevent” skin breakdown with risk of infection, but only to “treat” skin breakdown after it has occurred. Since parents are unwilling to risk their children’s physical and emotional well-being by allowing skin breakdown to occur, they buy the needed incontinence supplies with their own, often limited, funds.

We have represented AHCCCS beneficiaries in individual cases to show that they fell within the exception to Arizona’s non-coverage policy. This strategy has worked for those individuals, but AHCCCS has not changed the policy as a result. Now we have decided to take on the policy itself, and bring a class action law suit to require AHCCCS to cover diapers as a preventative health measure for individuals under 21 who need them as a result of disability.

At seven years old, Timothy Schulz is one such individual. Timothy lives at home in Tucson with his mother, father and brother who provide complete care for his cerebral palsy and other medical conditions. Due to his disabilities, he is incontinent and his family physician has prescribed diapers to prevent skin breakdown and infection. Until the family moved to Arizona two years ago, incontinence briefs had regularly been provided by the Florida Medicaid agency. Not in Arizona. For this reason, Timothy, along with other children with disabilities who need incontinence supplies, have joined in the law suit to challenge the AHCCCS policy.



The Schulz’s weren’t used to having to fight for each and every service and the family welcomed the assistance of the Center. According to Timothy’s mom, with the Center’s help, they have been able to “make people stand back and take notice,” which, in turn, has resulted in a happier, healthier life for their son.

The number of individuals who could potentially be impacted by the Center’s systems change litigation activities conducted from July 1, 2002 to June 30, 2003

52,000

through
outreach

&
advocacy training

“Knowledge is happiness, because to have knowledge—broad, deep knowledge—is to know true ends from false, and lofty things from low.”

Helen Keller, The Story of My Life

The Arizona Center for Disability Law takes Helen Keller’s words to heart in providing comprehensive legal rights information and advocacy training statewide to the disability community. From our training entitled, “Know Your Rights in the Vocational Rehabilitation System” to our workshop on “How to Develop an Effective Individual Education Plan (IEP),” the Center’s educational presentations give consumers the knowledge they need to navigate the laws and regulations governing the provision of services. Complimenting these trainings are a full range of instructional guides on educational rights, housing, employment, the Americans with Disabilities Act (ADA), health care and mental health issues, which can be accessed on our web site at www.acdl.com.

The number of people empowered through education and outreach from July 1, 2002 - June 30, 2003.

In August 2002, the Arizona Center for Disability Law received a three-year grant to provide protection and advocacy services for individuals with traumatic brain injury (TBI) and their families. Although the Center has assisted people with TBI in the past, the new grant has allowed us to provide focused outreach to this community and tailor our advocacy assistance to the particular needs of individuals with TBI. Unlike many other disabilities, TBI is often a “hidden disability,” not readily noticed upon casual conversation with someone. However, for many people with TBI, their ability to reason, to remember things or even carry out daily tasks such as driving may be impacted by their brain injury. In addition, the variable nature of the disability requires special tools for advocacy. In preparation for the June 2003, half-day conference co-sponsored with the Governor’s Council on Spinal and Head Injuries for individuals with traumatic brain injury and their family members, Center staff worked with consultant and TBI expert Sue Wolf to develop training materials that were sensitive to some of the challenges faced by people with TBI.

Over 100 people attended the conference, which featured workshops on topics such as: understanding TBI, accessing health care, assistive technology and special education. Attendee responses on the workshop evaluation forms reveal the wealth of valuable information offered at the conference. As one participant stated, “I learned that parents CAN advocate and know what to do for their child with TBI!” By all accounts, the first annual TBI conference was an overwhelming success!

by **providing help**
one individual at a time

The first step for most people calling the Center each year is one of the Center's well-trained Intake Specialists. With particular expertise in a subject area, such as employment or education, these frontline staff are able to solve many caller issues by providing rights based information, making a few phone calls or writing a letter on the caller's behalf. Over 3,000 people with disabilities and their families are assisted each year by the Center on a short-term basis. Getting fast, accurate information on how to file an appeal with the mental health system, how to request a service at a child's individualized education plan (IEP) meeting, or how to request an accommodation from one's employer, can make a real difference for people with disabilities effectively advocating for themselves.

Opening the Door to Independence

Jared's father, John, first contacted the Center ten years ago with a question about his son's rights as a student receiving special education services. The public school in Sierra Vista that Jared was attending had refused to follow through with his individualized education plan (IEP). John talked to an advocate at the Center and then used the Center's written materials to develop a letter to the school and the State Department of Education, demanding compliance with his son's IEP.

Over the years, John has obtained individual assistance from the Center on a number of different occasions. In addition to contacting the Center about special education issues, John has turned to the Center for help when in need of information such as what health care benefits would be available to Jared once he turned eighteen. Most recently, John contacted the Center to ask why Jared was having such a hard time acquiring a driver's license. Natalie Franklin, the Intake Specialist on the Center's Access Team, explained that Jared would have to obtain specific documentation from his doctor prior to obtaining a license, since his parents are still acting as his guardian.

According to John, "[t]he information and materials provided by the Center over the last ten years have proven to be invaluable." It is our hope that his sentiments will ring true once again in the coming months, as Jared gets ready to hit the road with his new license and take the next step toward becoming an independent, productive adult.

As an Intake Specialist for the Access Team, Natalie Franklin, under the supervision of an attorney, assists individuals with disabilities who have been denied access to services, programs and facilities, including housing and transportation. According to Natalie, the best part of the job is seeing the results of her work. Whether it means watching an individual with a mobility impairment finally enter a restaurant using a newly installed ramp, helping a person who is deaf obtain an interpreter or witnessing a young man like Jared take the next step toward independence, that moment of success makes her work worthwhile.



3308
*The number of individuals
 provided with brief assistance*

from July 1, 2002 to June 30, 2003.



through public policy

A year and a half ago, the Center embarked on a project with six other disability organizations interested in improving the coordination of the community's public policy advocacy efforts. With the goal of making public policy advocacy more understandable and accessible to individuals with disabilities and their families, the Center took the lead in organizing workshops, developing e-mail alerts and analyzing legislative developments affecting persons with disabilities.

By the 2003 State legislative session, the Arizona Disability Advocacy Coalition's (AzDAC) members included 16 disability advocacy organizations from around the state, dedicated to encouraging more people with disabilities throughout Arizona to become involved in the policy making process. To that end, AzDAC organized a workshop during the 2003 session on potential cuts to the 2003 budget that could negatively impact people with disabilities. This workshop, attended by over 60 people, featured speakers from Governor Napolitano's office as well as officials from state agencies and the Joint Legislative Budget Committee. At the workshop, attendees got a first hand look at the fiscal crisis facing the State and heard about a number of advocacy strategies – many of which ultimately helped to save funding for vital programs that serve people with disabilities.



"I really feel that all of us calling, writing and e-mailing our legislators about how we would be affected by the cuts really made a difference," states Erika, who had little experience as a public policy activist prior to being connected to AzDAC's network. In the coming year, the Center will continue to work with Erika and other Arizonans who share an interest in making sure that individuals with disabilities do not bear the brunt of hard economic times in the State and are able to successfully maintain the services and supports they so desperately need.

making positive
LEGISLATIVE
changes: *House Bill 2181*

"Millie," a young adult with Down's syndrome, has a job at Basha's, shares an apartment with a friend and can ride the bus on her own.

"Chas," a young adult with mental retardation, lives in a highly structured group home, has limited ability to communicate and needs a lot of supervision.

Clearly, "Millie" and "Chas" do not require the same degree of oversight or control over their lives to remain safe. But prior to this past legislative session, full guardianships were routinely established for individuals like "Chas" who really needs a full guardian as well as individuals like "Millie" who retains the capacity to make decisions about many areas of her life. To address this issue, the Center worked closely with others from the disability community throughout the legislative session to ensure the passage of House Bill 2181.

The new law requires that the Court, when establishing a guardianship, first consider whether an individual could be better served by other, less restrictive legal options, such as conservatorship or power of attorney. In addition, it requires the Court to consider whether a limited guardianship, that allows the individual to retain certain decision-making authority independent of their guardian, would be more appropriate than taking away all civil rights – such as the right to marry and the right to drive a vehicle – if a full guardianship is granted.

Signed by Governor Janet Napolitano on April 14, 2003, the new law will allow individuals with disabilities throughout Arizona to continue to receive the support that they need, while maximizing their independence and involvement in community life.

budget *for the fiscal year ending* SEPTEMBER 30, 2003

INCOME

Federal Grants

	<u>Amount</u>
Administration on Developmental Disabilities (A.D.D.)	\$ 529,268
Protection and Advocacy for Individuals with Mental Illness (P.A.I.M.I.)	\$ 509,864
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.)	\$ 71,000
Governor's Council on Development Disabilities (G.C.D.D.)	\$ 110,833
TBI Protection & Advocacy (T.B.I.)	\$ 50,000
Protection and Advocacy Services to Social Security Beneficiaries (PABSS)	\$ 100,000
TOTAL FEDERAL FUNDING.	\$ 1,821,080

Other Funding

Employment Advocacy Fund	\$ 111,852
Attorney Fees, Interest on Reserve Accounts, Other Income, Draw from Reserve Accounts	\$ 706,277
TOTAL OTHER FUNDING	\$ 818,129

TOTAL INCOME. **\$ 2,639,209**

Expenses

Accounting Fees	\$ 12,000
Advertising	\$ 3,215
Advisory, Board, Staff and Other Meetings	\$ 5,201
Consultants/Interpreters Fees	\$ 45,690
Copying/Printing	\$ 38,990
Disability Database	\$ 3,001
Equipment Rental/Repair	\$ 20,702
Insurance - Professional Liability	\$ 23,146
Litigation	\$ 35,228
Office Furniture & Fixtures	\$ 7,814
Office Supplies	\$ 32,072
Rent	\$ 145,537
Postage	\$ 14,142
Reference Materials	\$ 28,015
Telephone	\$ 30,114
Salaries and Related Expenses	\$ 2,127,241
Professional Dues/Development	\$ 27,356
Travel	\$ 34,745
Fundraising/Special Events	\$ 5,000

TOTAL EXPENSES. **\$ 2,639,209**

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.

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The 2003 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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