

c/o Sidney Blanchard  
Community Access Institute  
88 West Grand Street  
Elizabeth, NJ 07202

Phone: (908) 354-3040  
Fax: (908) 354-3186  
Email: sblanchard@caunj.org

# NEW JERSEY CHAPTER AMERICAN ASSOCIATION ON INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

Formerly known as American Association on Mental Retardation

## Winter 2007

# Newsletter

## Civil Rights and Economic Rights

Presented by Ethan Ellis at a CAU Local Ownership Meeting  
on October 16, 2006

Our civil rights were first recognized in Title V, including Section 504, of the Rehabilitation Act of 1974.

Title V prohibited various forms of discrimination in federally operated or funded activities.

The Carter Administration refused to sign 504 regs. Then people with disabilities staged a month-long sit-in in the San Francisco federal building and others in Washington dogged Joseph Califano, Secretary of HEW, with picket signs every time he showed his face in public until he signed them.

Most provider and parent organizations sat on their hands during that struggle. They did not want to be associated with our 'extreme' tactics.

The American with Disabilities Act was drafted by Bob Bergdorf, a lawyer with a disability.

Justin Dart, son of a wealthy family, who had polio, visited all 50 states to rally people with disabilities to support it. He also led a steering committee that coordinated efforts, both among the provider lobbyists in Washington, DC, and disability groups around the country to get the bill passed.

However, the ADA was not passed until people with disabilities took direct action.

Members of ADAPT, who used wheelchairs, dragged themselves up the steps of the Capitol on their hands and knees in front of TV cameras until Congress passed it.

When George Bush would not sign it, two hundred of us, led by Dart, marched on the White House and held a candle-light vigil in the rain until Bush agreed to sign the bill.

I was there and I don't remember seeing any provider

(Continued on page 2)

## NJAAIDD Business News

Twenty-three members of NJAAIDD met on February 15, 2007. The following are the highlights:

- Treasurer Report: \$15,745
- NJAAIDD allocated \$2,000 towards the National Conference in honor of Bob Laux and Mark Straka. NJAAIDD requested Region IX to also make a contribution.
- Ethan Ellis was appointed as Chair of the National Self Advocate and Organizing Committee Action Group.
- The State AAIDD President is authorized to plan up to four state workshops: Positive Behavior Supports; Supports Intensity Scale; Housing; Advocacy.
- The NJAAIDD voted to endorse and support the planned NJP&A suit of New Jersey regarding the waiting list.

### Inside this issue:

<i>Civil Rights and Economic Rights</i>	<b>1</b>
<i>NJAAIDD Business News</i>	<b>1</b>
<i>New Jersey News</i>	<b>3</b>
<i>Notices</i>	<b>3</b>
<i>AAIDD Region IX Conference all for Papers</i>	<b>6</b>
<i>AAIDD Region IX Conference Proposal Submission Form</i>	<b>7</b>

## Civil Rights and Economic Rights

(Continued from page 1)

lobbyists. However, they were all over the White House lawn, invited, like several thousand of us, to celebrate the signing of the ADA.

Many of us thought the act would be our passport to freedom. We thought it would make us equal to everyone else.

That didn't happen. Today we are worse off than when the ADA was passed by any way you want to measure it:

- We are poorer; our average income is less than \$20,000 and 80% of us live below the poverty line;
- Less of us have jobs; only 13% of us work full-time all year and we earn less than \$12,000 for that work;
- More of us die from diseases that don't kill people who are better off, diseases that can be easily prevented or cured. We die because we can't get the health care or the health insurance that would keep us alive;
- More of us live in places that are unhealthy and unsafe; they make us sicker and kill us quicker. We are abused and attacked by violent people more than any other group because of where we are forced to live and because our disabilities make us easier targets.

Why?

We won our civil rights but we didn't win the economic rights to make them real.

What are economic rights?

- The right to a job that pays a living wage.
- The right to good health care.
- The right to decent, accessible, affordable housing.
- The right to a decent income if or when we can't work.

Why don't civil rights mean much without economic rights?

- It doesn't matter if the restaurant is accessible if you can't pay to eat there.
- It doesn't matter if you have the right to an education if no one will offer you a job.
- It doesn't matter if you find the doctor you need if he/she won't take Medicaid.
- It doesn't matter if you have the right to vote if you just dies of a disease that could have been prevented.

Right now, you may be looking at me saying to yourself, "What's that crip in the nice clothes and fancy tie talking about? He's not poor."

You're right, of course.

But I am what I call the 'escapees'. My life turned out better than most people like me.

Maybe it was because my family fought for me. Maybe I saw an opportunity that my brothers and sisters missed. Maybe I was just lucky.

For whatever reason, I got out of the horrible hole that most people with disabilities are still stuck in...and more of them are stuck in that hole now than in 1990.

**We won our  
civil rights but we  
didn't win the  
economic rights to  
make them real.**

Other groups face many of the same problems that we do. They struggle to win their civil rights but didn't get the economic rights to make those civil rights meaningful.

African-Americans won their civil rights in 1964 but most of them are worse off today than they were then. They are poorer, have less jobs, worse housing, suffer more violence and die more often from preventable diseases than they did 42 years ago.

The same is true for women and other minority groups that society doesn't value.

There are complicated reasons most of those people are still without economic rights. We need to know about those reasons. If we have time, we'll talk about that later.

We need to understand why most people with disabilities are still denied their economic rights.

In the 21<sup>st</sup> century, we are still being treated as objects rather than human beings. We still deal with the same prejudices that we have for thousands of years – since the beginning of recorded history.

Today we are treated as objects for another reason. We are the products of a gigantic human services industry that makes a trillion dollars a year providing us with services.

The services most of them provide us with make us more dependent than we need to be.

In 1985, Monroe Berkowitz, a Rutgers economics professor, added up all the money that was spent on people with disabilities. Then he analyzed what the money really did for and to us.

98.5% of all money spent on us made us more dependent on other people and programs. Only 1.5% of the total enabled us to be more independent.

That was before SSI, SSDI, Medicaid and Medicare. Those programs make us even more dependent.

Those programs and others like them keep most of us from earning a living. Without money in our pockets, we can't meet our most basic needs. We can't pay for housing, food, transportation, even recreation – the things that most people buy with the money they earn.

(Continued on page 4)

## New Jersey News

### Lawsuits:

1. NJP&A Federal Lawsuit against New Jersey seeking the release and support of New Jersey residents from unnecessary confinement in state institutions for people with developmental disabilities. Filed 9/29/05. In progress.
2. NJP&A Federal Lawsuit against New Jersey seeking the release on New Jersey residents from unnecessary confinement in state psychiatric institutions. Filed 4/05/05. In progress.
3. New Jersey Supreme Court overturned regulations that denied state aid for people with developmental disabilities who could not prove they were substantially impaired before age 22. Estimates of at least 19,000 New Jersey with developmental disabilities are living with older caregivers and never requested aid. Decision: 3/01/07
4. NJP&A Pending Litigation against New Jersey seeking to free New Jersey to provide services to those on the waiting list. Fact finding, pending.

## Notices

- ◆ New Jersey Equal Justice Conference: April 19, 2007. For information call: (732) 249-2525, extension 39
- ◆ National Conference: May 21 - 24, 2007, Atlanta, Georgia; website for information: [www.aaid.org](http://www.aaid.org)
- ◆ Region IX AAIDD Conference: September 6 & 7, 2007 at Willow Valley Conference Center, Lancaster, Pennsylvania. *For more information see page 6 and 7.*

**AAIDD 131st ANNUAL MEETING & EXHIBIT SHOW**

May 21-24, 2007

Sheraton Atlanta Hotel

"Supports For Quality Living"

## Civil Rights and Economic Rights

*(Continued from page 3)*

Instead, the disability industry provides us with those basics as services. It gets the money to provide those services from the government.

It convinces government that we need those services because we are too dependent to buy them on our own.

That industry depends on our dependency. If we weren't dependent on its services, it would go out of business and so would the hundreds of thousands of people it employs.

In Washington, that industry is represented by the Consortium for Citizens with Disabilities, a coalition of more than 120 national organizations.

Only a dozen of them are advocates for people with disabilities. Less than a handful is led by people with disabilities.

The rest, the vast majority, are actually trade associations of service providers whose main function is to lobby for the interests of those providers.

The people who represent us to the powerful in our nation's capital don't look like us, walk or roll or talk or think like us. We do not own our own movement.

The faces that Presidents, Senators, Congress-people, bureaucrats and other policy-makers see are not our faces. They are the faces of paid lobbyists without disabilities, often with little knowledge of our interests.

The things they say we want are not what we really want. Those are things that other people think we want or things that they really want for themselves but are using us to get.

And what is it they really want? In good times they want more money for services and in bad times they want to hold on to the service money they already have: Money for SSI and SSDI, money for Medicaid and Medicare, money for nursing homes, group homes and other institutions, money for special education, special transportation, special housing, special vocational services and sheltered workshops.

In short, they want money to continue and expand those service programs for people with disabilities that provide a living for their members.

At first blush, it might appear that that is what people with disabilities want too. SSI and SSDI don't provide enough money to live on. Medicaid and Medicare barely meet our health needs. Despite education and vocational rehabilitation, less than a third of us have jobs.

Look again and ask: is more of the same what we really want? I think not.

The simplest way off the disability dependency treadmill is to make healthcare and jobs basic economic rights, available to everyone. However, that option is not available in this hyper-materialistic society that values profits over people.

Another way off the disability dependency treadmill is to de-couple federal health insurance from SSI and SSDI. That would permit those of us who can't get private health insurance but can go to work to do so without risking medical conditions or medical bills that could kill us.

It would also continue to provide income maintenance and public health insurance for those who really can't

*(Continued on page 5)*

work as society constructs work now.

The public benefits from doing that are enormous and compelling. Millions of people with disabilities would go to work and pay taxes, instead of draining the treasury by collecting benefits.

Their medical expenses would decrease as their standard of living grew. They would fill a hole in the lower end of the labor market that we now recruit illegal immigrants to fill.

In its 30 years of existence, the Consortium has never made a serious attempt to get such legislation passed. It would put its members out of business.

Opposition to civil rights and economic rights legislation on economic grounds in this country is not unique to people with disabilities. It has been universal.

Other minority groups have been denied those same rights because they were more valuable as labor than as people. That's still true of immigrants today.

In this hyper-materialistic society, the most effective argument against the inclusion of any devalued group has been the fear that those already included will lose something by it.

Today we face the most dangerous threat of the last 50 years. The current administration is determined to cut off publicly funded services to all poor groups, including people with disabilities. We think those cuts are aimed at us and other poor people.

They are not. This administration has never thought of us and others as real people. In their eyes, we never counted.

Those cuts are really directed at the people who serve us. They are designed to put the disability industry and the other poverty industries out of business. They are aimed at the further destruction of the middle class in favor of the ultra-rich.

If we can find a way to join with the most progressive elements of those industries on a new basis of equality, we have a chance to overcome that threat.

That is the challenge. Will we take it?

Fully understanding it is not easy. It will require us to master the economics of disability and of other groups that have been marginalized. To do so, we will have to understand how the economics of these domestic oppressions fit into an even bigger picture.

We will have to understand how the disability industry is connected to even larger economic interests that now exert control over huge chunks of the rest of the world through the imperial power that our own country now wields practically without significant challenge.

Only when we do, will we understand in sufficient detail the enormity of the struggle we face to be fully accepted in American society as other, more privileged groups are.

# Call For Papers

## AAIDD REGION IX CONFERENCE IT'S *NOT* JUST BUSINESS AS USUAL

Thursday, September 6 – Friday, September 7, 2007

Willow Valley Resort and Conference Center, Lancaster, Pennsylvania

2416 Willow Street Pike, Lancaster, PA 17602, 1-800-444-1714, 1-717-464-2711, 1-717-464-0481

<http://www.willowvalley.com/> or <http://www.800padutch.com/z/wvinn.htm>

### THEME:

The focus of this year's conference will be on the use of best practices as well as on current and emerging trends in the field. AAIDD Region IX/PA Chapter invites proposals that address the issue of change from a variety of perspectives. Although all proposals will be considered, papers that address a better understanding of these changes will be given priority. We encourage the following individuals and groups to submit: *Family/Advocacy Organizations (Including Self-Advocacy), Academics, Clinicians/Therapists/Physicians, Providers, Attorneys, Governmental Entities*

### TYPES OF PRESENTATIONS:

- 1. Plenary Sessions:** Address issues of general interest to the group at large.
- 2. Special Theme Sessions:** Each session will be one and a half hours long. Each paper within the session should not exceed 15-20 minutes for presentation. At the conclusion of the presentations, time will be allotted for questions and discussion.
- 3. Workshops:** A few one and a half hour workshops will be allocated during the conference. These sessions should be tightly focused and have broad appeal.
- 4. Poster Sessions:** In order to provide presenters with the opportunity to fully discuss their work, poster presentations are encouraged. Posters will be displayed for an entire day.

### RULES FOR SUBMISSION:

All proposals must be submitted as early as possible, but must be received no later than Monday, April 30, 2007. Presenters will be notified of acceptance by Friday, June 15, 2007. At least the lead author of each accepted proposal is expected to attend and present at the session. **All** presenters must pay the meeting registration fee. **Please note that AAIDD requires the use of "People-First"**

### Language in all proposals.

A complete proposal consists of the following:

- 1. A Proposal Submission Form.**
- 2. A 50-75 Word Abstract** summarizing the information to be presented, which can be used in the conference brochure.
- 3. A 250-500 Word Summary** describing the work in more detail, which will be used to review the proposal. **Incomplete proposals will be returned to the lead author.**
- Proposals may be submitted either electronically to Dr. Paul Spangler at: [Paul.Spangler@phila.gov](mailto:Paul.Spangler@phila.gov) or by mail to: *Dr. Paul Spangler, Philadelphia County MRS, 701 Market Street, 5<sup>th</sup> Floor, Suite 5200, Philadelphia, PA 19106*
- 5. If you have any questions, please contact Dr. Paul Spangler at 215-685-5939 or Mr. Elliot Glickman at 215-685-5970 or by e-mail at: [Elliot.Glickman@phila.gov](mailto:Elliot.Glickman@phila.gov)**

### ADDITIONAL INFORMATION:

- 1) If you are interested in either individual or corporate sponsorship of this event, please contact:

Ms. Astrid Berry  
1-717-441-9508  
or e-mail her at:  
[aberry@nhsonline.org](mailto:aberry@nhsonline.org)

- 2) If you are interested in volunteering at this event, please contact:

Mr. Mike Powanda  
1-717-635-2704  
or e-mail him at:  
[mpowanda@keystonehumanservices.org](mailto:mpowanda@keystonehumanservices.org)

- 3) If you are interested in becoming a vendor/exhibitor at this event, please contact:

Mr. Mike Powanda  
1-717-635-2704  
or e-mail him at:  
[mpowanda@keystonehumanservices.org](mailto:mpowanda@keystonehumanservices.org)



**AAIDD REGION IX CONFERENCE – CALL FOR PAPERS**  
**IT'S *NOT* JUST BUSINESS AS USUAL**  
**Thursday, September 6 – Friday, September 7, 2007**  
**Willow Valley Resort and Conference Center, Lancaster, Pennsylvania**  
2416 Willow Street Pike, Lancaster, PA 17602, 1-800-444-1714, 1-717-464-2711, 1-717-464-0481  
<http://www.willowvalley.com/> or <http://www.800padutch.com/z/wvinn.htm>

**AAIDD REGION IX CONFERENCE PROPOSAL SUBMISSION FORM**

**Lead Author (Name/Title/Affiliation):**

**Additional Authors (no more than 4 additional presenters, Names/Titles/Affiliations):**

**Type of Presentation Circle One:**

Plenary Session

Special Theme Session

Workshop

Poster Session

**Title of Presentation:**

**Lead Author Contact Information (all information will be conveyed through the lead author):**

**Address:**

**Telephone:**

**Cell:**

**Fax:**

**E-Mail:**

**Please indicate what type of equipment you will bring with you or is required from the conference center:**

Please attach the following (**please note that AAIDD requires the use of "People-First" Language in all proposals**):  
**1. A 50-75 Word Abstract** summarizing the information to be presented, which can be used in the conference brochure.  
**2. A 250-500 Word Summary** describing the work in more detail, which will be used to review the proposal.



80 West Grand Street  
Elizabeth, New Jersey  
07202-1447

## *New Jersey Chapter American Association on Intellectual and Developmental Disabilities*

Formerly known as American Association on Mental Retardation

c/o Sidney Blanchard  
Community Access Institute  
88 West Grand Street  
Elizabeth, NJ 07202

Phone: 908-354-3040  
Fax: 908-354-3186  
Email: [sblanchard@caunj.org](mailto:sblanchard@caunj.org)

It's a powerful community,  
and that power is growing.

**Say "YES!" to AAIDD.**

**Join/Renew Today!**

**Join online at [www.aamr.org](http://www.aamr.org)**

**or**

**Complete, Mail or Fax  
enclosed application**

