

May 2008

Newsletter

State Sued Over Waiting List

The New Jersey Protection and Advocacy, Inc., ("NJPA") today filed a lawsuit in the United States District Court for the District of New Jersey against the New Jersey Department of Human Services for failure to comply with federal laws requiring states to provide services to the developmentally disabled in the most integrated setting. Lowenstein Sandler PC is representing NJPA on a pro bono basis.

In the suit, NJPA alleges that the State has systematically failed and refused to provide required services to thousands of developmentally disabled citizens who have sought community-based services-- rather than services provided in an institutional setting -- over the last decade. NJPA's suit specifically challenges the State's practice of "waitlisting" individuals who seek community services and placements. NJPA alleges that the waitlist for community services is illusory, as most of those waitlisted are never provided with community services and never come off the waitlist. Despite clear and ambiguous directions under the Americans with Disabilities Act that "states providing services to the developmentally disabled using Medicaid funding must do so with 'reasonable promptness' " many of the more than 8,000 qualified NJ citizens on the waitlist have been waiting for services for many years.

The complaint alleges that wait-listing eligible citizens is not a substitute for providing home and community-based services required by the state and in compliance with federal law. According to the complaint, most of the people on the waitlist live at home or with relatives, with little or no assistance. Though they do not need or want institutionalization, many face this prospect as their caregivers age and

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From the Desk of the Chapter President

There are currently over 8,000 people with developmental disabilities on the state waiting list for services and another 1,500 people in institutions who were determined prior to 1998 as being



better served in community placements. A number of states have closed all their institutions. A number of states have significantly increased funding to people with Disabilities, families and the service system. It is time for New Jersey to invest in the benefit of people with disabilities.

Additionally, an increase in Self-Determination and family support funding and the annual operating support of New Jersey Providers of Support is but one of a series of critical issues that must be resolved to maintain and improve the lives of people with disabilities in New Jersey. Other areas that significantly weaken the viability and stability of the community based service structure are:

- ◆ Adjusting annual operational funding support through cost indexing,
- ◆ Long-term capital needs and the intelligent use of them are for Olmstead expansion but also for existing community infrastructure needs to be addressed,
- ◆ Unfunded mandates need to be funded,
- ◆ Identifying and serving the need of an aging DD population with funding

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become unable to provide adequate care in the home.

Emmett Dwyer, NJP&A's Director of Litigation, said: "The failure of the state to provide community services for thousands of individuals has had a devastating effect. Thousands of people are stuck at home going nowhere, and many of them have been unnecessarily placed in institutions when their elder parents could no longer care for them. Ten years ago the Legislature demanded that the Commissioner of Human Services come up with a plan to end the waiting list by this year. The plan was drafted, and passed by the legislature, but they never funded it. At that time the waiting list was near 5,000 individuals, as of today it has grown to over 8,000. The irony of the situation is that it costs less to provide services to people in the community that it does to warehouse them in an institution."

Ethan Ellis, Hon. Chairman of the New Jersey Chapter, AAIDD and President of the Next Step: People With Disabilities for Social and Economic Justice stated that, "These individuals fail to get on the waiting list or may be waiting for inadequate or inappropriate services and supports...Many are desperate and placed under extraordinary stress." Moreover, "There are currently several thousand individuals in New Jersey who are on a waiting list for services they are entitled to but are not receiving." As a result of not receiving needed services, individuals "are being discriminated against by having the doors of societal inclusion and participation closed to them. While it appears that AAIDD's constituents live in the community, in reality they live in seclusion because they are being denied opportunities for full participation."

"Though they do not need or want institutionalization, many face this prospect as their caregivers age and become unable to provide adequate care in the home."

Noteworthy



- The next meeting of the New Jersey Chapter of AAIDD will be held on June 12, 2008, 3:00 PM—4:30 PM at the Community Access Unlimited Board Room, 80 West Grand Street, Elizabeth, NJ. Go to www.caunj.org for directions
- The National AAIDD Conference will be held May 28—30, 2008, Washington, DC. Go to www.aidd.org for details

Congratulations to Next Step!

Next Step: People with Disabilities for Social and Economic Justice for becoming an affiliated Chapter to the New Jersey Chapter of AAIDD. Welcome to twenty-five (25) new advocate members!

Welcome to the fifteen (15) new professional members of NJ AAIDD!

April 7, 2008

Letter from David A. Rotholz, President, National AAIDD

Dear AAIDD Leaders, Members, and Friends,

Earlier this year the AAIDD Board held a discussion of key issues covering a wide range of topics relevant to AAIDD, its collaborating partners, and our field in general. The agenda focused on our mission, key assumptions, strengths and weaknesses, potential future issues, and how to best position ourselves for a sustained vital national leadership role.

I am pleased to share with you a summary that reflects the consensus of the Board, staff, and invited guests who participated in the retreat. The information in the summary also provides the basis for our new strategic plan currently being developed. Please feel free to send your comments to me (drotholz@cdd.sc.edu), our executive director Doreen Croser (dcroser@aaidd.org) or any member of the Board (<http://www.aaidd.org/About/AAMR/leadership.shtml>).

What follows is a summary of the key areas of consensus from this meeting. We hope you find it informative and encouraging! This is a time of significant progress and contribution to the field by AAIDD. We believe our association is vibrant, vital, and fortunately in good financial condition.

KEY AREAS OF CONSENSUS (a full report will be forthcoming in the National Strategic Plan, available this spring)

There was unanimous agreement that AAIDD is a professional organization.

As much of the membership is likely to recall, this issue is not one on which there has always been agreement. However, when this issue was discussed in the work session, the Board, guests, and staff all shared the common view that AAIDD is a professional organization that provides a key leadership role for the field. While we continue to welcome and seek active participation from a wide spectrum of those involved and interested in intellectual and developmental disabilities, we do so from the perspective of the leading national professional association in our field.

Our AAIDD Mission Statement continues to serve us well.

AAIDD mission statement: AAIDD promotes progressive policies, sound research, effective practices and universal human rights for people with intellectual and developmental disabilities.

After review, we reaffirmed our position that the current mission statement appropriately conveys who we are why we engage in our activities

Our priorities are Leadership, Knowledge Dissemination, Technology and Partnerships.

These priorities reflect the most important areas of AAIDD focus. Each area encompasses a variety of related important efforts that are key to fulfillment of our mission.

AAIDD issues are global and of interest to disability professionals throughout the world, although we are not an international organization.

In this consensus statement we recognize the worldwide importance and impact of AAIDD's efforts. The contributions of our international colleagues and the numerous languages into which our journals and other

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Letter from David A. Rotholz

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publications are published continue to grow in numbers and diversity.

PRIORITIES

LEADERSHIP DEVELOPMENT and SUPPORT

Recruiting, developing and supporting current and future leaders is critically important to our Association and to the field. We also recognize that recruiting leaders is a "high touch" process.

We recognize that AAIDD is THE organization for professionals in the field of ID/DD. We are the source of knowledge-based leadership in our country and internationally.

Proactive leadership on emerging disability issues is important in our nation and internationally.

KNOWLEDGE DISSEMINATION

There were two key points of consensus in this area:

- ◆ AAIDD is a well-respected source of credible information both in the U.S. and internationally, and
- ◆ AAIDD offers a unique forum where professionals can disagree and debate differing points of view.

TECHNOLOGY

The retreat participants developed four statements to encapsulate our views on technology:

- ◆ Utilization of new technologies is essential in the modern world and must be a part of ongoing association business and professional activities.
- ◆ Technology will increase our ability to form communications networks among members and other interested individuals.
- ◆ Technology-enabled communications groups will help us to identify emerging issues in the field.
- ◆ Technology will increase our international presence by supporting knowledge dissemination.

PARTNERSHIPS

Partnerships are essential if AAIDD is to advance its priorities efficiently and effectively. Our engagement in partnerships with other disability network organizations and reaching out to others in the wider community will facilitate our ability to advance our priorities.

Steps Needed to Advance our Partnership Priority

- a) Fully implement our Cooperative Agreement with AUCD
- b) Continue our governmental affairs partnerships with The ARC, UCP, NACDDS, ANCOR, and AUCD
- c) Work with the Alliance for Full Participation in support of a 2010 Summit
- d) Expand our Cooperative Agreements

ADDITIONAL RELATED ISSUES/ITEMS

Business model:

- a) We should consider rethinking how we do business.

"AAIDD offers a unique forum where professionals can disagree and debate differing points of view."

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- b) It is important for AAIDD to create new revenue streams.
- c) AAIDD must continue to do work that adds value to the field.
- d) We should determine what percentage of our work can be pro bono and set priorities.

Membership:

- a) It may make sense for us to determine who are the AAIDD members.
- b) "Market through our Mission". Our approach has been to attract members through the value of our work.
- c) How can we best leverage our relationships with sister organizations for mutual benefit?
- d) It is time to examine our structure and benefits package.
- e) How can we enhance professional benefits to professional members?

Annual Meeting:

What must be done to make it more programmatically and financially viable

Product/Service Ideas:

Is it feasible and advisable to develop a non-technical magazine for ID/DD practitioners?

Advancing Our Agenda:

- a) Should there be more frequent face-to-face meetings of the Board (and guests)?
- b) Should we conduct more frequent "retreat activities" such as environmental scanning?
- c) Should AAIDD establish work groups and committees to address key issues from the retreat and the strategic plan?

NJAAIDD Minutes For March 27, 2008

◆ **Attendance: 11 Members in good standing**

◆ **Introduction of Officers**

President:	Sid Blanchard
Vice President:	Open
Secretary:	Bernadette Griswold
Treasurer:	Sheila McDowell
Member At Large:	Alvin Cox
Member At Large:	Mercedes Witowsky
Region IX Chairman:	Alvin Cox

◆ **Treasurer's Report:**

Revenue:	\$343
Expense:	\$525
Net Assets:	\$18,075

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NJAAIDD Minutes for March 27, 2008

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◆ Reports

1. State Activities Plan
2. Region IX Conference: Report given by Alvin Cox
3. Self-Advocacy Affiliate Chapter: twenty-five advocate members joined NJAAIDD
4. Workshop Plan:
 - Positive Behavior Supports: Fall date
 - Supports Intensity Scale: Fall date
 - Co-Sponsorships
 - Sue Motion to co-sponsor. Second: Aleyah. Passed*
 - Disability Policy Panel: **October 9, 2008 3:00 PM—5:00 PM**
 - Sam Motion: Send \$500 to National for the conference. Sheila Second. Passed.*
 - Sheila Motion: Sponsor up to \$300 an advocate or reps who belong to AAIDD to National Conference. Second Sam & Anil. Passed.*
 - Housing Workshop/Roundtable: **May 20, 2008**
 - Sam Motion: AAIDD co-sponsor. Second Sheila. Passed*
 - AAIDD Classification Manual:
 - Wait for new manual then hold workshops*
 - Future Meetings:
 1. Region 9: Plan for Regional Conference in 2009
 2. NJAAIDD: June 12, 2008, 3:00 PM
 3. National AAIDD: May 28-30, 2008, Washington, DC
 4. Midwinter Leadership Meeting: December 5-7, 2008, Washington, DC

◆ New Business

1. New Jersey AAIDD member, Karolina Scutari has produced a paper on a 'Case Comparison of the Application of the ADA by the Courts.' It is a current look at the issue with the way the ADA is being applied. For sample of the paper go to www.caunj.org and click on the link. Email Karolina Scutari at kscutari@gmail.com
2. May 30 NJARC Medical Conference
3. For June 30 Agenda of NJAAIDD
 - Advocacy capability of Chapter to respond to items like the Montclair Incident of rape
 - Building capacity of medical related professional best practices.

◆ State Activities Plan:

The July 1, 2008 to June 30, 2009 NJAAIDD State Activities Plan was filed with the National office.

The Goals for 2008—2009 are:

- Hold several workshops
- Build the National Conference
- Build participation in the Self-Advocacy Movement
- Engage in the New Jersey Service System and Advocacy Issues.

aaidd Membership Application

Send this application and your payment information to AAIDD, 444 N Capitol St, NW, #846, Washington, DC 20001-1512 or fax to (202) 387-2193 or join online at www.aaidd.org

Please print/type Mr. Ms. Dr. Rev. Sr.

Name Nickname _____

Office Home Street Address _____

City _____ State _____ Zip+4 _____
(_____) _____ (_____) _____

Phone _____ Fax _____

E-mail _____

Title Employer _____ Highest Degree _____

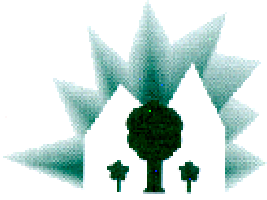
AAIDD MEMBERSHIP CATEGORIES & DUES (SELECT ONE)

<p>_____ Active Member-For disability professionals who wish to stay current on the latest developments in the field of intellectual and developmental disabilities. Includes our highly ranked journals <i>Intellectual Disability</i> and <i>the American Journal on Mental Retardation</i>; FYI-the Association's monthly electronic newsletter, and access to <i>Washington Watch</i>. Includes member discounts at conferences; discounts on books and other publications; and reduced rates for posting classified advertisements on AAIDD's Career Center, our online career service where resumes are posted for free. Active Member Dues \$160</p>	<p>_____ Active Sustaining Member-For current and future leaders in our field who wish to support research, policy, advocacy, and service the Mission of the Association. Active Sustaining Member Dues \$260</p>
<p>_____ Active Young Professional/Direct Support Professional Member-For college graduates who are new to the disability field and for individuals who are on the "frontlines" of service delivery and have incomes less than \$25,000 per year. Includes general Active Member benefits of, and on line access to either <input type="checkbox"/> <i>Intellectual Disability</i>, OR <input type="checkbox"/> <i>The American Journal on Mental Retardation</i>. Active Young Professional/Direct Support Professional Member Dues \$75</p>	<p>_____ Active Family Member/Self-Advocate Member-For individuals with disabilities and family members who have incomes less than \$25,000 per year. Includes general Active Member benefits of, and on line access to either <input type="checkbox"/> <i>Intellectual Disability</i>, OR <input type="checkbox"/> <i>The American Journal on Mental Retardation</i>. Active Family Member/Self-Advocate Member Dues \$75</p>
<p>Active Student Member-Reduced-price membership for full time students preparing for a disability related career. Requires confirmation of student standing from faculty advisor. Active member benefits. College/University _____ Graduation Date _____ Active Student Member Dues \$50</p>	<p>_____ Active Electronic Member-For electronically savvy disability professionals who wish to access their information by electronic means only. Active E-Member Dues \$160</p>

*Join the Conference of Professional Interests each division and special interest group is only \$10 each.
By joining these professional groups you can tailor your membership to benefit your needs.*

Administration	Communication Disorders	Community Services	Creative Arts Therapies
Direct Support Professionals	Education	Families	Genetics
Gerontology	Health & Wellness	Humanism	Legal Processes & Advocacy
Mental Health Services	Psychology	Religion & Spirituality	Sexual/Social Concerns
Social Work	Technology		

AAIDD 2008 Membership Dues (from one category above)		\$ _____
1. Conference _____	\$10 each	\$ _____
2. Conference _____	\$10 each	\$ _____
3. Conference _____	\$10 each	\$ _____
4. Conference _____	\$10 each	\$ _____
Credit Card Information: <input type="checkbox"/> Visa <input type="checkbox"/> MasterCard		Total Dues Enclosed \$ _____
Account Number _____		<input type="checkbox"/> Check enclosed payable to AAIDD
Name on Account _____	Signature _____	Expiration Date _____



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80 West Grand Street
Elizabeth, New Jersey
07202-1447

Return Service Requested

Phone: 908.354.3040
TTY/TF: 908.354.4629
Fax: 908.354.2665

www.caunj.org



New Jersey Chapter
c/o Sidney Blanchard
Community Access Unlimited, Inc.
80 west Grand Street
Elizabeth, NJ 07202

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

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



Say **"YES!"** to AAIDD. Join/Renew Today! www.aidd.org