



Knowledge | Support | Empowerment

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Region IX and New Jersey Chapter

Combined Newsletter

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October 2014



Reports from AAIDD members from New Jersey/Region 9

Presenters and attendees of the August Reinventing Quality Conference

The New American Movement for People with Disabilities (NAMPWD) attended the annual Reinventing Quality Conference, in Baltimore, Maryland which took place on August 3rd-5th 2014 at the Renaissance Baltimore Harborplace Hotel. This year's theme was appropriately titled "Ensuring Quality in Rapidly Changing Times." Among the attendees were Valerie Bradley, Amy Hewitt, Nancy Weiss, Sharon Lewis, Aaron Bishop, Dr. Barbara Wheeler, and many other

fantastic keynote speakers. On Monday August 4th, the New American Movement attended the plenary session, where they met astounding self-advocates Jessica and Caden Capitani, Sara Wolff, Julie Petty, and Rhonda White. Julie Petty discussed the importance of People First Language and stated,

"We all have different senses. Just because you can't use one, doesn't mean you can't use your other ones to speak. Just because you can't speak doesn't mean you don't have anything to say" Liz Weintraub

"What we call people shows how we treat them." Jessica Capitani, mother of Caden, highlighted the importance of advocating for her son as a parent, and ensuring that he has the life that every other child is given the opportunity to have. "I want to make sure all doors are open for him. I want him to go to college if that's what he decides to do, or support him in his dreams of becoming a rock star." Among another

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Reinventing Quality, October, 2014

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rock star on stage was self-advocate Vander Cherry, who currently works for the U.S. Department of Education in the Office of Federal Student Aid. Vander stated "Self-advocacy is not just about going to conferences but it is a movement; A movement in which families and advocates are working together as one. I've never seen anything like it!"

Throughout the course of the conference, the NAMPWD

attended various advocacy based workshops, such as "Self-advocacy: A Civil Rights Movement, Not a Social Club" where they met Bill Worrell, founder of People 1st in Canada, and self-advocate and SABE member Liz Weintraub and Betty Williams, former president of SABE. The NAMPWD

"we learn from the decisions we make, and the mistakes we learn from, only help to further direct us within our own lives. We all make mistakes and I don't think any one of us in this room is perfect."

team also attended "Strengthening Self-Advocacy" where they networked with Dawn Rudolph and learned more about how funding for self-advocacy groups works, and the continued need to strengthen various advocacy based organizations. The breakout session titled, "Building Real communities: The Work of Developmental Disabilities Councils," discussed the need to get advocates to vote and educated about their right to vote. It was no surprise to the NAMPWD team to

hear of individuals with disabilities being deprived of their right to vote, and the workshop titled "Supported Decision-Making: Respecting Ability" addressed the reasons as to why people with disabilities continue to be excluded from opportunities and rights given to the rest of us. Jonathan



Martinis, from Quality Trust for Individuals with Disabilities, reinforced the fact that, "we learn from the decisions we make, and the mistakes we learn from, only help to further direct us within our own lives. We all make

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mistakes and I don't think any one of us in this room is perfect." The session titled "Beyond Tokenism" was one of the most crucial workshops throughout the conference that the team attended. Mark Friedman, of Blue Fire Inc., stated that as one, we as a nation need to aggressively figure out how to create roles for our advocates and bring them to the forefront. The NAMPWD agreed that it is crucial that advocates serve on boards and lead the advocacy movement which directly impacts their lives. By the end of the conference, a profound and moving statement made by Liz Weintraub stuck with the NAMPWD team. "We all have many different senses. Just because you can't use one, doesn't mean you can't use your other ones to speak. And just because you can't speak doesn't mean you don't have anything to say. We need to listen, and listening does not mean waiting for your turn to speak." The NAMPWD team looks forward to the next Reinventing Quality conference, and will take what they have learned to continue advocating strong for individuals with

Reinventing Quality Conference

by Rebecca Clark

The 2014 Reinventing Quality Conference was worthwhile for all attendees. The plenary and concurrent breakout sessions provided conference attendees with a wealth of knowledge and a refreshed perspective on working with individuals with disabilities. The conference's theme, "Ensuring Quality in Rapidly Changing Times", reminded all service providers and professionals alike that at the end of the day we are impacting the lives of others and ensuring a quality of life that we all hope to have.

The opening plenary session was by far my favorite session of the conference. The session was held by a panel of self-advocates and family members: Julie Petty, Sara Wolf, Caden and Jessica Capitani, Rhonda and Trinity White, and Vander Cherry. These individuals provided the audience with great advice and insight. Julie Petty said that "what we call people is how we treat them", which is a strong statement towards the change that has been made in removing the "r-word" from our vocabulary. She also referred to self-advocacy as being not a program, but a movement. The various backgrounds of all panelists perfectly portrayed that no matter a self-advocate, a mother, a friend, a professional—we are all working towards creating the same change. Rhonda White also made a great point about exposing children with disabilities to the community to open various opportunities for them. She also said that it is not always about finding special classes or accommodations for your children, but rather helping the community to find ways to incorporate them.

The sessions I attended included, "Person-Centered Organizational, Systems, and Culture Change and the Value of Community-First Planning", "Monitoring in the Community Using Data and Advocacy", "Self-Advocacy Rights Education and Training", and "Transition Efforts in the Field: Post-secondary Models Deployed by Community-Based Organizations", but the session I found to be most effective was "Supported Decision-Making: Respecting Ability, Promoting Self-Determination". The session focused on guardianship and the various options available for family members, professionals, etc., to support individuals with supported decision-making instead of guardianship. Jonathan Martinis, the lawyer involved in the Jenny Hatch case, who helped her to become her own guardian, questioned guardianship and reminded us that it originally came from a time when it was still okay to call someone with an intellectual or developmental disability an imbecile. He challenged that it is not always necessary to protect individuals with disabilities from themselves, and just like everyone else, they should be allowed to learn from their mistakes.

Region 9 / NJ Chapter AAIDD combined meeting

The Region IX and NJ Chapter AAIDD will hold its next meeting at 3:00 PM on Thursday, November 20, 2014, at Community Access Unlimited, Library, 80 West Grand Street, Elizabeth, New Jersey.

We look forward to seeing you there.

**Self
Advocacy
- not a
program,
but a
movement**



Reinventing Quality Conference

by Linda Gately

The first break-out session I went to was entitled "Pushing the Boundaries of Olmstead". The first speaker, Elizabeth Priaulix gave an overview of the Olmstead litigation nationwide showing how the various disability rights entities in states throughout the country were interpreting the law, moving forward with settlements and going to court when settlements could not be reached. The session included significant cases involving services for children, older adults, individuals with mental health/psychiatric issues as well as those with intellectual/developmental disabilities. She noted that we can no longer say that Olmstead

applies to the physical environment where the person lives, but also where the person works and recreates. Additionally, whatever the setting we must look at the policies and whether they restrict a person's autonomy. In the case she was referring to, Marlo M. was moved from an apartment to a group home. Since the group home had more restrictive policies, the court ruled that Olmstead applied. Next Bob Flesher from the Center for Public Representation spoke about the New HCBS rule and how it may affect Olmstead. He also explained that the new rule will affect sheltered workshops and what we in New Jersey call "Traditional Day Services." He

said Olmstead may also apply to these services. He explained the recent decision by Department of Justice in US v Rhode Island (April 2014) where Rhode Island was found to have violated the Americans' with Disabilities Act by relying on Sheltered Workshops to the exclusion of more integrated alternatives. The settlement states that at least 2000 individuals with Intellectual /Developmental Disabilities must be moved from sheltered workshops into integrated employment. Integrated employment is described as individualized typical jobs in the community where individuals are compensated with at least minimum wage for an average of 20 hours per week. He also

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discussed how schools seem to be moving toward segregation again. As in *SS v City of Springfield, Mass.*(2014) where the suit alleges the ADA is violated as they are segregating kids with special needs in separate schools, subjecting them to disproportionate discipline, suspensions, expulsions and arrests. As well as denying them an equal educational opportunity. It was stated that 70% of children in detention have some form of disability. He also stated that the “autism farm / farmstead”, does not comply with the new HCBS because it is segregated and has all services in one location.

I attended the session relating to the HCBS Final Rule in Session C. The rule was adopted in March 2014 and states must come into compliance within five years but must submit a “transition plan” by March 2015 that includes an assessment, a remedial plan and public input into the plan. The new rule clearly outlines that a waiver service (such as day program) cannot be delivered in an institutional (or non-integrated) setting even if the person is living in an integrated community based setting. In addition to the requirements of the home environment; tenancy, privacy in bedroom, lockable doors, choice of roommates in living unit and freedom to have visitors any time a service must be based on individualized assessed need, a record of prior interventions/ supports, documentation of developmental disability, periodic review, informed consent, and assurance that intervention and supports will do no harm. All services must be provided in integrated settings so if “traditional day services” are to continue as an option, the programs must include opportunities to go into the community on a daily setting. The day program site should be where everyone meets before and after

the community activities, not where all the activities occur. If the setting is not integrated it will not be reimbursable. There is also a modification to the Fair Labor Standards Act which affects services delivered by DVRS that follows this same premise, so whether it is an employment or skill related program, the key to reimbursement will be an integrated setting with real employment or activities that individuals without disabilities also typically participate in. I see this as a major issue for New Jersey as historically we have relied on segregated day settings to provide a large portion of our day services. Additionally, a portion of the choices individuals in self direction choose fall into the category of segregated programs and activities making them unreimbursable under the new regulations.

During Session B I attended “Monitoring in the Community Using Data and Advocacy” which outlined the results and trends in the National Core Indicators in the last few years and the protection and advocacy organizations in each state. This session also discussed the new Final rule for the HCBS waiver, its implications and how it relates to the outcomes noted in the survey. They also pointed out that on the NCI website there is a document cross-walking the NCI questions and the HCBS waiver regulations that is very helpful.

The session on Supported Decision Making was excellent. The presenters outlined the alternatives to Guardianship and clearly explained why guardianship should be a last resort. There were quite a few self advocates in the room and they actively participated in the session. Jonathan Martinis is an attorney with the Quality Trust in Washington DC. He was an excellent presenter on this topic and is a dynamic speaker. He

would be a good person to speak to families if we wanted to have someone speak on this topic. He spoke of a recent case where he had guardianship rescinded and a young woman’s rights restored.

The last session I went to was on technology use for individuals with IDD. This session outlined technology that can be used in the home and community. Most of the technology was in the form of apps for your phone, computer or tablet or a system of sensors and video options that in combination could allow someone more independence as it could reduce the level of supervision by being able to monitor a person from a remote location. The technology could be useful in non-licensed settings in NJ but there might be issues if we utilized some of them in licensed settings.

Overall this was an excellent conference that I would encourage others to attend in the future. All of the sessions I attended had quality presenters and provided an abundance of information. I particularly enjoyed the receptions where we had the opportunity to speak with self advocates and family members.





Best Practices in Changing Times November 5, 2014

In collaboration with NJ and Region 9 AAIDD Chapters



An invitation to provider agencies, support coordinators, family members, self advocates and community leaders

New Jersey State Bar Association | One Constitution Square | New Brunswick, NJ

Conference Highlights

Keynote Speaker

Loretta Claiborne, Special Olympian

Loretta was born partially blind and intellectually challenged and unable to walk or talk until the age of four. Loretta's personal life story carries a message of hope and tolerance for all people. A few of her awards include two honorary doctorates, 26 completed marathons, the 1996 ESPY Award-Arthur Ashe Award for Courage and the subject of a Walt Disney Movie Production, "The Loretta Claiborne Story."



A Conversation with State Leaders on Changing Times

Update from CMS on Community Life



Alliance for the Betterment of Citizens with Disabilities
Empowering People. Proven. Shaping Policies

Best Practices in Changing Times

Workshop Topics will Include:

- Home & Community Support Services
- Integrated Health Care
- Self Advocates: My Vision, My Future
- Healthy Lifestyles
- Creative Employment
- Transition Planning for Adult Life
- Professional Behavioral Support: Home & Residential
- It's More than Just a Job

For more information call 609.581.8375
or e-mail at admin@abcdnj.org





SAVE the DATE



Alliance for the Betterment of
Citizens with Disabilities
Empowering People. Providers. Shaping Policies.

Best Practices in Changing Times

New Jersey Law Center | One Constitution Square | New Brunswick, NJ 08901-1520

November 5, 2014

An invitation to provider agencies, support coordinators, self advocates, family members and community leaders.

Conference Agenda

- 8:00-9:00** Registration-Continental Breakfast
- 9:00-9:15** Welcome
- 9:15-10:00** **Keynote, Loretta Claiborne, Special Olympian, Life Lessons**
- 10:00-10:15** Break
- 10:15-11:30** **Conversation with State Leaders: Transition, Employment and Interdepartmental Vision**
Jennifer Velez, Esq., Commissioner, New Jersey Department of Human Services
Dr. Allison Blake, Commissioner, New Jersey Department of Children & Family Services
Harold J. Wirths, Commissioner, New Jersey Department of Labor and Workforce-Invited
Moderator-Diane McComb, State Association Executives Forum Liaison, ANCOR
- 11:30-12:30** **CMS Update on Definition of Community**
Ralph Lollar, Director of the Division Long Term Services and Supports Disabled and Elderly Health Programs Group at CMS-invited
Moderator, Barbara Merrill, Vice President of Public Policy, ANCOR
- 12:30-1:15** Luncheon
- 1:15-2:30** **Workshop Sessions**
 - A-1 Supporting Individuals with Complex Physical, Medical and Behavioral Needs in Community and Home Settings**
Patricia Carlesimo, LADACIN Network
Bernadette Griswold, CAU
 - A-2 Self Advocates: My Vision, My Future**
Dennis Donatelli, ARCNI, Stanley Soden, Annie Mills
 - A-3 Innovative Integrated Health Care Models for Special Needs Populations**
Mark Mintz, M.D.; President, CEO & Founder
The Center for Neurological and Neurodevelopmental Health and the Clinical Research Center of New Jersey
 - A-4 Successful Employment in the General Workforce: Why & How**
Jennifer Joyce, Director of Employment, Transition, and Day Services, DDD;
Eileen Murray, Director, Art Access, Matheny; and
Jamie Douglas, Managing Director of Adult Services, Eden Autism
- 2:30-2:45** Break
- 2:45-4:00** **Workshop Sessions**
 - B-1 More Than Just a Job: Getting Employment Support Right Through Person Centered Practices**
Michael Steinbrook, M.A., Program Coordinator, Rutgers Robert Wood Johnson Medical School,
The Elizabeth M. Boggs Center for Developmental Disabilities
Bret Vaks, MBA, Training & Consultation Specialist, Rutgers Robert Wood Johnson Medical School,
The Elizabeth M. Boggs Center for Developmental Disabilities
 - B-2 Transition Planning for Adult Life**
Mercedes Witowsky, Associate Executive Director, Community Access Unlimited
Bill England, Disability Services and Advocacy, LLC
Tina Wiltsee, Avenues to Independent Living
 - B-3 Health and Wellness within Special Olympics New Jersey**
Andrea Picariello, Special Olympics New Jersey
Barbara Mintz, Barnabas Health
 - B-4 Behavioral Supports in Action**
Ellen Maniloff, BCBA, Youth Consultation Services
Aslam Ali, BCBA, Youth Consultation Services
Gavin Gear, Center for Family Supports
- 5:00-6:30** **Family Reception-Members of NJ Assembly Human Services Committee-Invited**

In collaboration with
NJ and Region 9
AAIDD Chapters



For more information call 609.581.8375 or e-mail at info@abcdnj.org



Alliance for the Betterment of
Citizens with Disabilities

Empowering People: Providers Shaping Policies

Best Practices in Changing Times 2014

REGISTRATION FORM

DHS/DDD has approved this conference for staff training.

NAME _____
AGENCY/AFFILIATION _____
AGENCY ADDRESS _____
CITY _____ STATE _____ ZIP _____
EMAIL ADDRESS _____
PHONE _____ TITLE _____

REGISTRATION FEES

ABCD Members: \$ 95 per person (includes Continental Breakfast & Lunch)

Non-members: \$150 per person (includes Continental Breakfast & Lunch)

Self-Advocates and Families: \$50 per person (includes Continental Breakfast & Lunch)

*Limited scholarships are available. Please contact ABCD, 609-581-8375 or email
admin@abcdnj.org*

Please specify if special accommodations are needed _____

Family Evening Reception (free of charge)...please check if attending _____

Circle your one choice for the following workshops in each session.

Session A 1:15-2:30

A-1 A-2 A-3 A-4

Session B 2:45-4:00

B-1 B-2 B-3 B-4

Registration deadline is *October 24th, 2014*. Registration may be made by credit card online or send a check, payable to: ABCD, 127 US Highway 206, Suite 18, Hamilton, NJ 08610

Note: Invoices or arrangements for multiple registrations from one agency may be made in advance by calling 609-581-8375 or email admin@abcdnj.org.

Reinventing Quality 2014 Pictures



Leadership Roster

AAIDD Installs its 2014-2015 Board of Directors

The American Association on Intellectual and Developmental Disabilities (AAIDD) is extremely pleased to announce its 2014–2015 Board of Directors, effective July 1, 2014. The Board of AAIDD is elected by its membership in annual elections.

The members of the 2014–2015 AAIDD Board of Directors are:

President: Amy Hewitt, PhD, FAAIDD

Director, Research and Training Center on Community Living, University of Minnesota, Minneapolis

President-Elect: Susan B. Palmer, PhD, FAAIDD

Research Professor, Beach Center on Disability, Kansas University Center on Developmental Disabilities, Lawrence, Kansas

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Coordinator, Summer Institute on Theology and Disability and Adjunct Professor, Center for Disability Studies, University of Texas

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Professor, Department of Special Education, Illinois State University, Normal, Illinois

At-Large Members:

David T. Helm, PhD, FAAIDD

Director of LEND, Institute for Community Inclusion/UCEDD, Boston Children's Hospital and University of Massachusetts Boston

Loui Lord Nelson, PhD, FAAIDD

Universal Design for Learning Specialist, University of Kansas, Lawrence, and Education Consultant, Indianapolis, Indiana

Susan L. Parish, PhD, MSW, FAAIDD

Nancy Lurie Marks Professor of Disability Policy and Director, Lurie Institute for Disability Policy, Brandeis University, Waltham, Massachusetts

Elizabeth A. Perkins, PhD, RNMH, FAAIDD

Associate Director and Research Assistant Professor, Florida Center for Inclusive Communities UCEDD, University of South Florida

Region IX Chapter

Bermuda:
Maryland:
New Jersey: Sidney W. Blanchard
Pennsylvania:
West Virginia:

Region IX Board

Chairperson: Sidney W. Blanchard
Chair Elect: Bernadette Griswold
Vice President: Alvin Cox
Secretary: Sheila McDowell
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Member-at-Large: Open
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New Jersey Chapter Board

Chairperson: Sidney W. Blanchard
Vice President: Bernadette Griswold
Secretary: Sheila McDowell
Treasurer: Mercedes Witowsky
Member-at-Large: Alvin Cox
Paul LaMaine
Open
Open

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



Say "YES!" to AAIDD.
Join/Renew Today!
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American Association on Intellectual and Developmental Disabilities

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Questions? Contact Jason Epstein at jepstein@aidd.org or 202-387-1968, ext 201.

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Student at:

(Required for student dues discount)

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Membership Categories:

\$50 International Electronic (NOT US/Canada)

\$75 Basic

\$125 Classic

Students enjoy a 20% discount on any of the above categories.

\$175 Standard

\$250 Premium

\$595 Corporate

Annual Dues \$ _____

Professional Interest Groups:

Membership in each Division, Special Interest Group, Action Network, or other group is \$10 each, except for Religion & Spirituality, which receives an additional journal. Place an "X" before any Group you want to join and total the fees.

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Gerontology

Genetics

Health & Wellness

Humanism

International

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Psychology

Religion & Spirituality (\$30)

Research

Social Work

Sexual/Social Concerns

Student & Early Career Professionals (no fee)

Technology

Total Cost of Special Interest Group \$ _____
Contribution to the Student Scholarship Fund \$ _____
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Return this invoice with payment and matching billing address via fax or mail. Renew online at www.aidd.org



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and that power is growing.