



Knowledge | Support | Empowerment

In this issue:

<i>AAIDD Conference from a Self-Advocate Viewpoint</i>	Cover
<i>Relationships &amp; Sexuality in People with Developmental Disabilities</i>	Page 2
<i>AAIDD Conference Report by NAMPWD</i>	Page 3
<i>AAIDD Conference Report by Jo Anna Hamilton, RN, C</i>	Page 4
<i>ABCD Save the Date: Best Practices in Changing Times</i>	Page 6
<i>AAIDD Conference Pictures</i>	Page 7
<i>Conferences and Events</i>	Page 8
<i>AAIDD 2014-2015 Board of Directors</i>	Page 9
<i>AAIDD Leadership Roster</i>	Page 9
<i>About AAIDD / Mission</i>	Page 10
<i>Join/Renew Your Membership with AAIDD</i>	Page 11

## Region IX and New Jersey Chapter

Combined Newsletter

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## Reports from AAIDD members from New Jersey/Region 9

### Presenters and Attendees of the June 23-26, 2014 AAIDD Annual Meeting

#### **AAIDD Conference from a Self-Advocate Viewpoint**

Annie Sims and Myrta Rosa, attended the AAIDD Conference in Orlando Florida from June 22<sup>nd</sup>-26<sup>th</sup>. We were at the conference in Florida, where we went to workshops and learned about so many things for the first time. We met Bill Gaventa and Amy Hewitt, as well as a lady named Pat, and we spoke about self-advocacy. Everyone wanted to know more about us so we told them about ourselves and what we do. We met speakers from other advocacy groups in other states, who shared their stories

about their lives. We spoke with other attendees about how other groups run their meetings, and we met a member from the DD Council in another state who spoke about their experiences. We went to workshops where we learned about different things other advocacy groups are doing, so we can bring back and share with our members. In the morning we went to breakfast, where they gave out awards, and we had such a good time that morning. We also went to the education division luncheon, and presented a poster about self-advocacy and the New American Movement. We told people how

we got involved in self-advocacy and how they too can become leaders in their own groups. During the Presidents reception, we met other self-advocates, and got filmed for an AAIDD video clip. "Annie and I spoke about self-advocacy and how to better interact with people with disabilities," Myrta Rosa states. "We went to workshops but could not understand a lot of things, but met a lot of people during a presentation," Annie Sims recalls. The exhibit table was our favorite part. We met so many other people from different states. We had such a good time!



Alicia Ann Caesar, Rebecca Clark, Aisha Arroyo, Jo Anna Hamilton meeting with Leslie Walker Hirsch (center)

## Relationships & Sexuality in People with Developmental Disabilities Poster Board

*Report by Aisha Arroyo & Alicia Ann Caesar*

AAIDD 2014 in Orlando, Florida- the 138<sup>th</sup> Annual Meeting only had one workshop designated to Sexuality, but nearly every session revolved around positive relationship development between all the various facets of Human Services; Direct Support Professionals and those they support to Academics and Self-Advocates in the field.

Aisha Arroyo, Assistant Executive Director and Alicia-Ann Caesar, Director of Quality Assurance represented the Relationships and Sexuality Committee of Community Access Unlimited and AAIDD Region IX, New Jersey at this year's meeting. Their poster outlined the way in which Community Access Unlimited bridges the gap of education and support regarding the relationships and sexuality of those their agency supports and their staff.

The Relationships and Sexuality Committee found over the last two years of training staff and working with the agency's Behavioral Department a real need to have an open dialogue regarding the following topics: conflict resolution, building healthy relationships, personal

boundaries, respect and consent, comprehensive sexuality education.

Some of the highlights of this year's AAIDD Annual Meeting was getting to meet with the Relationships and Sexuality Committee Mentor Leslie Walker-Hirsch, and meeting the newly appointed Chair of AAIDD's Sexuality and Social Concerns SIG Charles Archer. Attendees were also introduced to the Human Services Research Institute's publication of The Riot!, which gave out free copies of their 10<sup>th</sup> Anniversary Edition, "Best of 2004-2014 Relationships & Romance." Copies of this work were brought back for the agency's Self-Advocate Chat Center.

The poster presentation session and reception was a positive experience which allowed attendees to speak with presenters and explore various topics. Aisha and Alicia-Ann met with professionals in the field who not only expressed an interest in working with Community Access Unlimited in the future but shared their insights on and experiences with this topic. These conversations and this year's workshop on Sexuality validated the agency's course of staff training and member support.



Chair of AAIDD Sex & Social Concern SIG Charles Archer and Dr. George Turner of Turner Professional Group



Relationships & Sexuality Poster Presentation, Leslie Walker Hirsch with Alicia Ann Caesar

## AAIDD Conference

*Report by The New American Movement for People with Disabilities (NAMPWD)*

The New American Movement for People with Disabilities attended the 138<sup>th</sup> Annual American Association of Intellectual and Developmental Disabilities (AAIDD) meeting, which took place on June 23<sup>rd</sup>-26<sup>th</sup> 2014. Community Organizers met James Thompson, current President of AAIDD, and Amy Hewitt, President-Elect and Conference Chair. NAMPWD also had the pleasure of meeting Valerie J. Bradley and Cathy Ficker Terrill, who hosted Monday's pre-conference session titled "Quality Management, Centers for Medicare and Medicaid Services (CMS) and Managed Care", in which they stressed the importance and need for person-centered approaches and long-term support services for individuals with disabilities. The NAMPWD attended the Assembly of Geographic Interests, where they networked with Susan Palmer, who is on the AAIDD Board of Directors, and discussed updates with regards to Region 9 and the State of New Jersey. The NAMPWD was privileged enough to meet Darryl Hill, author of *A History and Sociology of the Willowbrook State School* and Associate Professor for the Department of Psychology at the College of Staten Island as well as Jerri McCandless, Director of Member Relations and Board Development for ANCOR. The NAMPWD team held an **exhibit table** throughout the conference and presented their **poster** presentation which explored the importance behind self-advocacy, the significance and need behind shutting down of institutions, continued advocacy to increase voter participation and funding for DD services, and overall mission statement. The NAMPWD was delighted and grateful to meet and network with a variety of service providers, presenters, and researchers from all over the country, as well as AAIDD board members such as William Gaventa, FAAIDD Vice President and member of the Board of Directors. The NAMPWD left a lasting impression on many attendees and presenters who attended this year's Annual AAIDD meeting, and was among the only attendees in which self-advocates shared their stories and were the face behind a movement.



NAMPWD: Myrta Rosa, Annie Simms and Doris Fernandez



Talking NAMPWDD with Amy Hewitt, President - AAIDD



Rebecca Clark, Myrta Rosa, Annie Simms NAMPWD Table



## AAIDD Conference

*From Jo Anna Hamilton, RN. C*

I attended the AAIDD conference in Orlando, Florida from June 22 through June 26, 2014, and was fortunate to be an active participant, not only on all the superb conferences that were offered, but also as a representative of CAU in the persona of a presenter.

The pre conference sessions that I attended on Monday, 6/23, included the open membership meeting and Leadership Forum and also the Conference of Professional Interest groups. Both sessions were instrumental in acclimating me to the upcoming schedules, and also for networking and meeting with people from across the country who have the same interests and desire the same outcomes for the I/DD population as we at CAU do. That same afternoon I attended the conference titled "Person Centered approaches to end of life care: Advanced Care Planning, Palliative Care, Hospice Care, and Bereavement care". I approached this session as a Nurse, but came away from it with a new understanding of how the person with a I/DD approaches the dying process, the choices that can be made and the care needed in dealing with this sensitive subject. It was a very interesting session, especially from a nurse's point of view. Later in the afternoon, I attended a session that really opened my eyes entitled "Embracing the complexity of the Past: Understanding the dark side of our history". The session was moderated by two authors and it encapsulated the birth of DC's especially Willowbrook State School in NY, and the consequences that occurred to people that were placed in these institutions for their entire life. It was very disturbing but necessary to have the audience knows what our past has been and how far we have become as a society that is sensitive to the needs of all people.

Tuesday 6/24, I had the privilege of attending a roundtable discussion with the Health and Wellness Group and was introduced to Melissa DiSipio, MSA, FAAIDD, from the Philadelphia Mental Health Care Corporation. She reviewed the health systems changes that are current and was the moderator for an elite group of clinicians from around the US on changes that have occurred and will be occurring for the DD population on the future. I also attended the session on Atkins, a class action court case that defined the death penalty and repercussions for

people with me/DD. This session was informative as it applies to the laws concerning IQ and how the governmental laws see people with a disability through different eyes when it pertains to the law.

The other sessions I attended for 6/24 were: Dental Care, Health and systems and it was GREAT! I had the opportunity to ask many questions and became involved in a lively discussion about dental health for people with me /DD.

I also attended the Research Symposium on Women's Health, and listened to a woman with severe physical and developmental disabilities describe her experiences in this complicated field.

Wednesday June 24, I delivered my presentation to an audience of about 25-30 people, along with Diane McComb , MAA from the Delmarva Foundation and Jim Vail, MBA from Mainstay. The session was informative and lively, my presentation was about the Health Risk Screening Toll that CAU has started to implement in order to deliver optimal direct care, and the information I provided highlighted the ease of the HRST system, its benefits and the ongoing assessments that can be delivered to our members. My presentation was limited to 15 minutes, but there were many questions afterward, and I also was approached long after the presentation by

*(Continued on page 5)*



*HRST, Inc. founder Karen Green McGowan, RN (far right) and our Director of Operations, Johnathon Crumley pose with Ms. JoAnna Hamilton at the AAIDD conference in Orlando, FL. Ms. Hamilton is a valued HRST user who presented at the conference on the benefits of the HRST and how it is being used with her agency, Community Access Unlimited in New Jersey*

many conference attendees to talk more about the HRST. One person in particular, Beverly Jenkins, from ELSEVIER was very interested and we exchanged email information. The same day I attended the Medicaid Managed Care for IDD session which had 3 components to it: Overview, State Activity and Research and Implementation, and the presenters were informative and concise in the explanations of this confusing subject. I ended the conference day by attending the closing plenary remarks by the President of AAIDD, Amy Hewitt, PhD, FAAIDD.

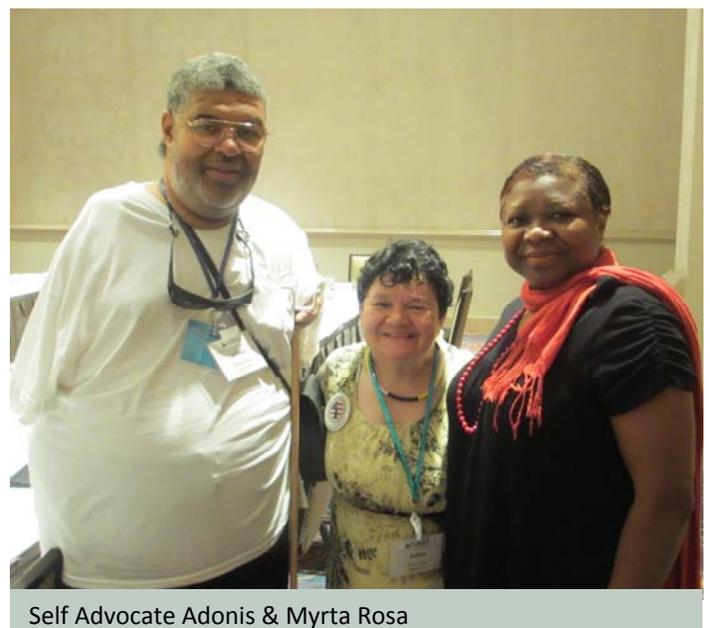
I am so grateful for being selected not only to attend this wonderful conference in beautiful Orlando, but also to be given the opportunity to deliver a presentation for CAU, and to have that presentation well received, and also to have been able to network with many people over the 3 days, make connections in the health related field of I/DD and to collaborate with professionals that share our ideals. Our CAU group also had the pleasure of meeting with Leslie Walker-Hirsch and sharing an evening with her discussing upcoming seminars and events that would include CAU Sexuality committee. I personally met and networked with people involved in health care and social services for the I/DD population including Melissa DiSipio, Deidre Muldoon from the Center for Development and Disability in Albuquerque, NM., Beverly Jenkins from ELSEVIER in Georgia, Jonathan Crumley from HRST in Florida, Karen McGowan the creator of the HRST, Diane McComb from Delmarva, Maryland., Jim Vail from Mainstay in Illinois., Erica Thomas from Georgetown University in Washington, DC., Louise Iwaishi, MD, Honolulu HI., Peter Smith, MD from Chicago., and Amy Hewitt,, PhD, President of AAIDD.

The exhibits and posters were fantastic, and our CAU posters were heavily trafficked throughout the exhibit evening.

Once again, I would like to thank you for affording me this opportunity for learning and growth for my profession.



Aisha Arroyo, CAU and Jonathan Crumley - HRST



Self Advocate Adonis & Myrta Rosa



Reading Panel



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

SAVE the DATE

## 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. Providers 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](mailto:admin@abcdnj.org)





## 2014 AAIDD Annual Meeting



## CONFERENCES & EVENTS



**AAIDD co-sponsored**  
August 3-5, 2014 in Baltimore, MD—  
**Registration Now Open!**



[Arc 2014 National Convention](#)  
**AAIDD exhibiting**  
September 30-October 2, 2014 in New Orleans, LA



[14th Annual Coleman Institute National Conference](#) - **AAIDD co-sponsored**  
October 9, 2014 in Broomfield, CO

# 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

**Vice President: William C. Gaventa, Jr., MDiv, FAAIDD**

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

**Secretary-Treasurer: Patti N. Martin, MEd**

Executive Director, Montgomery 31 Board, Montgomery, Alabama

**Past President: James Thompson, PhD, FAAIDD**

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:	Ellen E. Douglas
Maryland:	Jennifer Wagner
New Jersey:	Sidney W. Blanchard
Pennsylvania:	Michael L. Powanda
West Virginia:	Gabriel A. Nardi

### Region IX Board

Chairperson:	Sidney W. Blanchard
Chair Elect:	Bernadette Griswold
Vice President:	Alvin Cox
Secretary:	Sheila McDowell
Treasurer:	Mercedes Witowsky
Immediate Past Chair:	Paul F. Spangler
Member-at-Large:	Open
Assembly Representative:	Open

### 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!  
[www.aidd.org](http://www.aidd.org)

## About AAIDD

Since 1876, the American Association on Intellectual and Developmental Disabilities (AAIDD) has been providing worldwide leadership in the field of intellectual and developmental disabilities. We're a powerful community of leaders with a strong voice and important [mission](#).

AAIDD, (formerly AAMR -- American Association of Mental Retardation) is the oldest and largest interdisciplinary organization of professionals and citizens concerned about intellectual and developmental disabilities.

**We're tireless promoters of progressive policies, sound research, effective practices and universal human rights for people with intellectual and developmental disabilities.**

With membership over 5,000 strong in the United States and in 55 countries worldwide, AAIDD is the leader in advocating quality of life and rights for those with intellectual disabilities. **Our top-tier [member benefits](#) such as professional training, publications and supports** are created by and for professionals who support people with intellectual and developmental disabilities.

As a member, you'll **get the professional edge and network you need** -- AAIDD members are an impressive group of dedicated professionals, boasting advanced degrees and extensive field experience.

### Mission Statement

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

### Take advantage of a host of professional benefits designed specifically for you

AAIDD is **the** definitive membership organization and the authoritative source of information for those in the intellectual disability profession. Our membership is over 5,000 professionals strong, in over 55 countries around the world. Joining AAIDD lets you tap into a network of top professionals who can help you find a job, show you the ropes, and deepen your involvement in your profession.



Margaret Nygren, EdD  
Executive Director and CEO





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Say "YES" to AAIDD. Join/Renew Today! [www.aaidd.org](http://www.aaidd.org)



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