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Region IX and New Jersey Chapter

Combined Newsletter

Summer 2015



Reports from AAIDD members from New Jersey/Region 9

My Experience By Annie Sims, Advocate

On May 31, 2015, I went to Louisville, Kentucky. The hotel was very nice. I went to the President's reception that evening. On June 1, 2015 I got ready to go to my first Monday morning meeting at 9:00 a.m. They talked about a lot of things. During the first part, they gave out awards. The awards went to people that did their job a long time and had been doing AAIDD jobs too. I had a second meeting at 10:00 a.m. At that meeting I learned about The Riot ! at the Human Services Research Institute and things that I could look up on the computer, but I did not understand that part of the program. I learned about the CMS and

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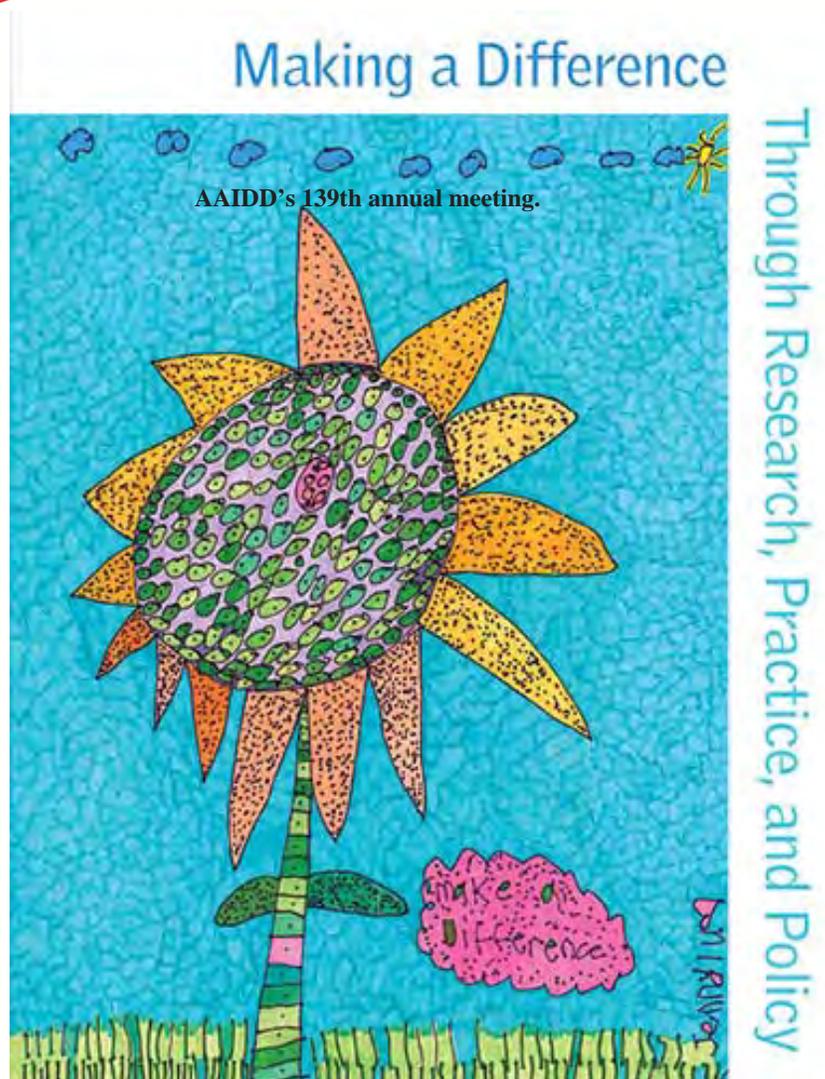
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guidance for self advocates about the new rules for home and community based services from a self advocate's perspective. At the third meeting that I went to they talked about how to get planning support for people with developmental disabilities at home and also for their school, job, and doctor appointments.

After the meetings were over, the staff took us out for lunch in the same hotel where the conference was held. The food was very good. Staff were very good to me. They made me laugh. They took me out to a nice store and restaurants. I had a wonderful time in downtown Louisville, but I was happy to get on the plane to New Jersey and arrive safe.





technology wasn't just another fancy device to brag about but something that clearly could give great capabilities to someone living with a disability.

Technology – The “Future of Supports”

Billy Busch – Assistant Executive Director of Membership Development

From the opening remarks of Margaret Nygren at AAIDD’s 2015 national conference it was apparent that the advancement of technology was going to play a huge role in current and future supports for people with intellectual and physical disabilities. This was confirmed with the announcement of their partnering with ANCOR for this year’s Technology Summit and Showcase in October. Throughout the 4 days many different individuals spoke about using technology to help support individuals. Others challenged us to find ways to help individuals access this type of support. Robin Jones, from

the Great Lakes ADA and Accessible IT Center, gave an update on ADA stating new technology will be at the forefront of where ADA will go in the future.

Again technology was prevalent in the poster board presentations where 6 different

boards focused on technology. Ewelina Oksien, RN and I presented on Educating People with Disabilities and DSP’s on Health and Wellness. We used Fitbit trackers as our information gathering tool and mode for giving our participants feedback. Other boards included using Google Glass, Systems for Electronic Support, Telemedicine, and Assistive Technology.

In the closing plenary session David O’Hara, PhD CEO of the Westchester Institute for Human Development spoke about technology, the healthcare system, and how advancements in technology can make a meaningful difference in those individuals’ lives. It became clear to me that technology wasn’t just another fancy device to brag about but something that clearly could give great capabilities to someone living with a disability.

the advancement of technology is going to play a huge role in current and future supports for people with intellectual and physical disabilities





The Death Penalty and Intellectual Disability- Shattering the Myths with Scientific Evidence

Myrna Milán, Community Organizer

Region IX committee members were present at the preconference session – Focus on the Death Penalty.

Panelist at this session provided an overview of AAIDD's leadership in addressing issues concerning intellectual disability in capital cases. The panelists were significant contributors to a recent AAIDD publication of an authoritative resource on this topic, *The Death Penalty and Intellectual Disability*. The AAIDD panelist also referred to the significant role played by AAIDD in court cases by filing amicus curiae (friends of the court) briefs. Discussion focused on a comparison of the Supreme Court decision in *Atkins v. Virginia* in 2002, prohibiting the execution of individuals with intellectual disability and its 2014 decision in *Hall v. Florida*, requiring the use of

scientific and medical consensus concerning intelligence and the nature and diagnosis of ID.

Panelist spoke about the need to address the common misconceptions held by the public and professionals within the judicial system about intellectual disability. They alluded to the fact that in the criminal justice system, common misconceptions, myths, and stereotypes can often outweigh the scientific evidence. The tendency is for defense attorneys to seek out experts on intellectual disability, not the prosecution. The challenge of educating the public, in particular members of the judiciary to guide consideration of scientific evidence was discussed with concrete examples of where it has been met with resistance.

**in the criminal justice system,
common misconceptions, myths,
and stereotypes can often
outweigh the scientific evidence.**

During the question and answer period of this session, my recommendation to the panelists was to introduce the recent AAIDD publication to law school professors who may decide to incorporate the scientific evidence approach to their respective criminal law class curriculums. If successful, this may contribute to shaping the attitudes of future generations of adjudicators and help swing the pendulum toward reliance on scientific evidence when handling cases involving people with intellectual disabilities.



Myrna Milan, and self advocates Annie Sims and Myrta Rosa.

Each group presented at the poster presentation at the Annual Meeting this year on June 2, 2015 focusing on sexuality beliefs, health & technology within the DD population, and Advocacy as a major focal point for people with disabilities. The poster presentation session and reception was a positive experience which allowed attendees to speak with presenters and explore various topics. The whole team was able to meet with professionals in the field who not only expressed an interest in working with Community Access Unlimited in the future, but also requested the teams to join different Special Interest Groups within AAIDD.

Each Region IX committee ensured they networked and became members within the Special Interest Groups at the AAIDD Annual Meeting. Alicia Ann Caesar and Aisha Arroyo attended the AAIDD Multicultural SIG. The SIG chair, Ellis Paul Craig requested the assistance of Ms. Caesar and Ms. Arroyo in revamping the interest in the SIG within the media. The plan is for Ms. Caesar and Ms. Arroyo to create a Facebook page for the Multicultural SIG in hopes to strike interest for more people to join the group.

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WHAT DO YOU BELIEVE? DIRECT SUPPORT PROFESSIONALS' BELIEFS ON RELATIONSHIPS & SEXUALITY

Alicia-Ann Caesar & Aisha Arroyo

Educating People with Intellectual and Developmental Disabilities and Direct Support Staff on Nutrition, Health, and Wellness.

Ewelina Oksien & William Busch

New American Movement for People with Developmental Disabilities

Myrna Milan, Annie Sims, & Myrta Rosa

AAIDD 2015 in Louisville, Kentucky- the 139th Annual Meeting was held this year at the Galt Hotel in Louisville, KY.

Alicia-Ann Caesar, Director of Quality Assurance and Aisha Arroyo, Assistant Executive Director represented the Relationships and Sexuality Committee of Community Access Unlimited and AAIDD Region IX, New Jersey at this year's meeting. William Busch, AED of Membership Services and Ewelina Oksien represented the Nursing & Technology Supports Committees. In addition, The New American Movement for People with Developmental Disabilities was in attendance at the Annual meeting this year with Community Organizer,





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In addition, Ms. Caesar and Ms. Arroyo also reached out to Chair of AAIDD's Sexuality and Social

Concerns SIG Charles Archer to ensure their membership within the SIG. The team is planning to meet with Mr. Archer very soon to discuss workshops in the near future that both Region 9 and Region 10 colleagues can attend in regards to Sexuality.

William Busch and Ewelina Oksien also reached out to Health & Wellness SIG Chair, Melissa DiSipio to become a part of the group. The team is very interested in bringing their ideas to the Health & Wellness SIG. Ms. Oksien also was able to attain contacts with colleagues who had an interest in starting a Nursing SIG within AAIDD. Ms. Oksien spoke with Vincent Chesney, Chairperson of Mental Health Special Interest Group. Ms. Oksien spoke with Mr. Chesney about trying to get more nursing professionals to come to the conference to speak about health promotion and the nurses' role in the

AAIDD community. Other key topics discussed were about the importance of spreading awareness on an international level regarding the discrimination against people with intellectual and developmental disabilities and the advancements countries such as Poland have made in reducing the stigma. A nursing SIG would make it possible for professionals in the field to provide collective input, research, and information regarding health promotion, education, and disease prevention. Ms. Oksien is very excited to assist with making a Nursing SIG manifest within AAIDD.

Overall, the team is very excited on the future goals and plans each committee has strived to meet at the Annual Conference. The team will be very busy this year, ensuring that they keep updated with their SIGs as well as ensuring their goals for future workshops are attained in 2015.

The Region IX and NJ Chapter AAIDD will hold its next meeting at 2:00 PM on Thursday, August 20, 2015, at Community Access Unlimited, Cafeteria, 80 West Grand Street, Elizabeth, New Jersey, (908) 354-304.

We look forward to seeing you there.

New Jersey Chapter Board

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	Open
	Open

AAIDD REGION 9 AND NJ CHAPTER COMBINED MEETING THURSDAY May 21, 2015

Attendance: 24 in attendance

Minutes of January 15, 2015 meeting

Financial Report: Region IX: \$29,451
 NJ Chapter: \$17,951

Activities Report:

- Upcoming National AAIDD Conference
- NJ Advocacy
- Changes in NJ DDD System
- ABCD Nov, 2015 Conference preparation

Call for Material for Region 9 and NJ Chapter Newsletter

AAIDD Committee Reports/Activities submitted:

- Group Dynamics
- Intellectual Disabilities:
- Nursing and Supports: HRST System in Action
- Positive Behavior Supports
- Relationships and Sexuality Committee
- Technology Supports: Chair
- Youth with DDD Committee: Chairs - Adolescent Network Newsletter
- Social Integration: Chairs - Religion Newsletter
- Support Intensity Scale: Chairs (move to compare NJ DDRT Rates Current to Tier Rates Future, correlation analysis)
- Employment Committee: Chairs
- APSE 2015 National Conference
- AAIDD National Conference June 1-4, 2015 Louisville, KY Participants

Group Dynamics of Human Interactions

Chair: Tony Provenzano

The Group Dynamics committee is scheduled to meet on June 2, 2015. In this meeting they will review the training evaluations from the last two training dates held on April 10th and May 11th. The next training is scheduled on June 3, 2015. Emily Gately is the newest trainer and the committee is still searching for one more. The core trainers are Tony Provenzano, Keith Radzion, and Jeremy Lefever. The training remains as an intensive and interactive 8 hour workshop. The training includes Carl Rogers' Active Listening Model, Transactional Analysis, and trauma (Post traumatic stress disorder). The morning exercise dives into internal vs. external conflicts. The remainder of the morning session covers ego states and life scripts. The afternoon session consists of trauma and active listening. The training involves some lecturing and role plays, but mostly consists of individual and group work and discussion. Also, in order to tie in specific points throughout the training, video clips from movies such as Citizen Kane, Frost/Nixon, Big, and Antwone Fisher are shown at specific points during the workshop to generate interest and make the subject matter easier for participants to relate with.

Intellectual Disability

Chair: Paul LaMaine

The training is quite comprehensive and inclusive of Intellectual Disability; 4 groups consisting of Group 1: Definitions of Intellectual Disability, Group 2: Diagnosis and Classification of Intellectual Disability, Adaptive Functioning, Professional Judgment and Implication for Practice, Group 3: Systems of Supports and Group 4: Experiences with Discrimination, People First Language and Self-Advocacy.

All groups have developed and completed outlines, including power point presentations, along with hand outs to facilitate development and training of Intellectual Disability. Established are groups that include a basic understanding of intellectual disability, variations in definition under law, classification, and system of supports. Groups 1, 2 and 3 distribute a multiple choice competency assessment which includes 24 questions and group 4 has a group activity identifying various people who have an intellectual disability. Group 4 also educates the class about Discrimination, People First Language, Self Advocacy and overall System Change. Our design is for 24 questions, so everyone is most capable of understanding AAIDD's formal outline and understanding of Intellectual Disability. Each group has varied class activities/participation and exercises assigned that really involve a lot of class participation and really helps everyone to have even a greater understanding of Intellectual Disability. The committee and training is a very good way of getting a lot of class participation.

Overall, this is a 1 day training of 6 -7 hours aimed at developing a comprehensive framework for understanding intellectual disabilities, understanding of the methodology for classification, for experts on systems of support. There is also a training targeting support staff, to create awareness: Definition of Intellectual Disability, highlighting experiences with discrimination, increased system of support and encourage system change.

The committee's current goal is to increase awareness in the community and have trainings for personnel at hospitals, schools, emergency personnel, families, etc. Also, evaluation of how the current changes in the way supports are provided as a whole will be affected by the new fee for service model and how individuals will be assessed, and how waiver eligibility will overall be influencing the ways we support today will be discussed in upcoming trainings.

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This training is offered every other month for new supervisors, behaviorists and nurses. The current trainers are Paul LaMaine, Charlene Walker, Myrta Rosa, Sobeyda Cerrato-Lopez, LaTanya Suber-Alcloque and Jeremy Lefever

The upcoming training dates are June 23, July 15, and August 12, 2015. (Full day trainings).

Our committee is all newly trained, and we are promoting a family member to have some formal discussion as well at the end of each training for about half an hour.

Nursing and Supports

Chair: Rosemary Schaefer

The original request for better education in regards to Nutrition/Physical Health & Diabetes has been completed. Training was assembled and was originally taught by the nurses. It's been over two years now since its inception. We are constantly looking for new advances on the topics and then we update the trainings as needed. The training PowerPoint and test have been relocated to the intranet for easier access day or night. The education for the people with disabilities continues to be a one on one with the nurses so it's more person centered and geared towards how each may learn. Group sessions will soon be introduced in collaboration with behaviorists. We feel this will help each member understand that they are not alone in their endeavor with better food choices and health goals/recommendations from their primary care physicians. The intervention/control system was created, approved and rolled out to the nurses so that they may keep watch over important items such as members A1C's, weight, labs, diet compliance etc.

A new addition to this AAIDD project was taken on voluntarily by one of CAU's RN's, Ewelina Oksien. She did a poster on: Health Promotion: Educating People with Intellectual and Developmental Disabilities, Direct Support Staff, and Caregivers on Nutrition, Health and Wellness. The A FitBit Tracker idea was presented by William Busch (with the AAIDD Technology committee), that makes this an interesting endeavor! Data collection just wrapped up and analysis has begun so that it can all be presented on the future conference poster.

Regularly scheduled reporting and fidelity checks were the final portion that this committee had to tackle and thru the HRST system we feel that we will have a better handle on the medical complexity at each site. The system was funded by a grant, approved for roll out and is now at the 99% mark. HRST rolled out their online training to the QA/nurses first and then went onto the supervisory staff and direct care staff at the programs. The RN's have taken the extra training step needed on how to validate scores between a 3 to a 6.

Positive Behavior Support

Chair: Tracy Honig

The committee has met all their original goals. A self-instruct on the most commonly seen behaviors and how to address them was completed. One behaviorist is currently able to do the Positive Behavior Supports 2 day training, and 3 additional behaviorists will be starting the train the trainer process on May 21st, 2015. The Positive Behavior Supports refresher course is currently being offered twice a month, and we are working to train all CAU employees. As of today, we have held over 20 classes and are getting a lot of

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positive feedback from the course attendees. Two new trainings are being created by the committee: Overview of Applied Behavior Analysis and training marketed to local police departments. Once completed, the overview of ABA training will be conducted with employees that currently go out to do in-home supports. For the police department training, the committee is reaching out to local police departments to find out what trainings they currently receive and will first be meeting with key employees to find out what their specific questions may be related to the community we serve.

The Relationships and Sexuality Committee

Co-Chairs: Aisha Arroyo and Alicia Ann Caesar

The Relationships & Sexuality Committee currently has 6 members. The committee attended the CFLE Sex Education Conference on December 3- 5th 2014. The Committee is in the process of preparing for the Annual CAU Sex Ed Conference to be held in fall 2015. Relationships & Sexuality Committee invited the YWCA to speak on Domestic Violence. The committee's current action items include a new policy and procedure regarding relationships and sexuality that the committee team has completed. We are also in the process of updating the training and citing all resources attached to our curriculum. The committee continues to train new staff on the curriculum of Relationship & Sexuality.

The Committee presented at the 2015 Annual AAIDD Conference in Louisville, Kentucky to present their newest poster themed "What do you believe? Direct Support professional Beliefs on Relationships and Sexuality." The Committee plans to continue to network as they had done last year, with the numerous researchers and mentor, Leslie Walker – Hirsch, who are interested in working with CAU's Relationship & Sexuality Committee to discuss future endeavors and collaborations. In addition to resources, the committee has stocked up on supplies to demonstrate demos to all for self empowerment for female and male members. The committee has also been looking into grants as well and an LGBTIQ support groups for members. The committee continues to collect the various conflict examples and resolutions that staff counselors come up with in the training to utilize for an article to submit to AAIDD. R&S Chair Person Alicia Ann completed a presentation on Relationships and Sexuality and had an Information table at the Nassan's Place first annual Autism Support Group Retreat on April 18, 2015. In attendance were 19 Parents of People with Disabilities. The Parents all participated in completing a survey for our committee which was used in our AAIDD Project.

Technology Supports

Chair: William Busch

The AAIDD Technology Committee continues to research new adaptive devices and are currently looking into are clothing that monitors numerous biometrics, such as heart rate, blood pressure, also utilizing an iphone or ipad that monitors your health and automatically links the health monitoring directly to the Doctor. Additionally with the newly released Apple Watch we will continue to see more advancement with health monitoring. The committee will be continuing its research on this and other smart watches. We continue researching "smart homes" that will provide additional monitoring while in the home. The technology committee met on February 24th and discussed all of our projects for 2015. We are implementing a technology handbook which will feature types of equipment as well as companies that provide the services. We are going to discuss a You Tube channel to highlight our members and the success they have through technology. On June 2nd we presented our data at the AAIDD National Conference in Kentucky.

Youth with DDD Committee

Chair: Rolando Zorrilla

The Youth with DDD Committee is continuing to collaborate with the NJ Alliance for Children, Youth, and Families (NJACYF). Since the last meeting this Committee has successfully coordinated the second annual statewide symposium titled, "Meeting the Needs of Youth with Different Abilities: Intellectual Disability Services in New Jersey." It was a half day symposium held on March 26, 2015 at the Mercer County Community College Conference Center. The goal of the symposium was to bring together experts in the field to discuss the current services and provide recommendations for the future of intellectual disability services in New Jersey. The committee is scheduled to meet again on July 16, 2015.

Social Integration

Chair: Maxine DaCosta

The Social Integration Committee continues to meet monthly and discuss new opportunities to build social capital and be more connected to local community where they live, work, worship, shop, vote, and entertain. Our last meeting was held on April 14, 2015, and we discussed social integration opportunities for the upcoming months.

On March 19, 2015, several committee members along with several people with disabilities attended the full Union County Interfaith Coordinating Council (UCICC) Meeting at Connecticut Farms Presbyterian Church in Union NJ. The mission of the UCICC is to promote the building of bonds within the interfaith community by fostering the inclusion and welcoming of others regardless of faith, race or disability and to be proactive on social issues. While at the UCICC Meeting, The Social Integration Committee was able to connect council member David Brown and a young mother in his region (fourth ward) of Rahway with needed support for her young son.

The committee has planned a block party for 8/28/15, to be held at Cristiani St. in Roselle, New Jersey. The committee also continues to plan for an Advocacy Day to be held in the early fall of 2015 at Peterstown Community Center in Elizabeth, New Jersey. Outreach efforts are being increased to include the community at large to include local politicians, recreation, fire and police departments. They will be given the opportunity to talk about the role they play in people with disabilities' lives.

Employment Area Committee

Chair: Fredia McKinney

The Employment Committee has been working diligently to gain connections and active employment opportunities in the community for people with disabilities. The Employment Committee continues to work towards developing jobs within the local community. In addition to our recent placements at CVS pharmacy, NJ All People Equal, and Walmart the committee is working on a new relationship with the Irvington Board of Education. As a result of this connection we have successfully begun employment for 2 and we are working on a third. We attended a job fair at Union County College in May of 2015 where we have also made a connection with the Marriott with hope to find employment opportunities there in the near future. We are continuing to build positive rapport with the local DVRS offices in the hopes of expansion to other locations.

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The committee continues to attend various trainings throughout the state of New Jersey, including a webinar series that focuses on the transitioning into employment first. We attended the NJAPSE Conference on March 20, 2015 and are looking to attend the National NJAPSE Conference in June of 2015.

Committee member, Fredia McKinnie, currently sits on the Workforce Investment Board (WIB) Disabilities Committee and attends its meetings. This committee allows for members of the WIB to discuss ways in which to increase employment amongst people with disabilities. The committee is currently working to create a working resource guide that can be provided to local business to educate them on the services and supports that are available to their business for hiring persons with disabilities. The last committee meeting was held on March 30 2015 which was attended.

Keeping Up With AAIDD



Like us on Facebook to connect with AAIDD and network with other disability professionals.



Twitter is a great way to stay connected to AAIDD. We regularly post information about upcoming events and publications in addition to keeping you updated on the latest in national disability news.



LinkedIn has the world's largest professional network on the Internet. Joining our group is a great way to connect with professionals in the field with whom you might not come in contact otherwise.



You will find a wide variety of videos on topics ranging from the justice system and intellectual disability to special education best practices to classification and intellectual disability.



Pinterest provides a space for users to organize and share images. We are continually building up our pinboards so you can share our images with others and spread the word about AAIDD news, events, and resources.

AAIDD Annual Conference, June, 2015







2015 ANCOR & AAIDD Technology Summit & Showcase

October 16, 2015, at the Omni Interlocken Resort, Denver (Broomfield), Colorado

Two “back to back” events are being held October 15-16, 2015 in Denver, Colorado:

The Coleman Institute Annual Conference and the ANCOR & AAIDD Technology Summit and Showcase.

The events will be held in the same hotel.

Participants must register separately for each event they plan to attend.

2015 Coleman Institute Conference
on Cognitive Disability and Technology
(October 15, 2015)

“Inequality and the Rights of People with Cognitive Disabilities to Technology and Information Access”

While there is no registration fee to attend the Coleman Conference, everyone who plans to attend must register.

Register for the Coleman Conference

Its free, but you must register to attend!

[Click here to register](#)
for the
Coleman Conference

**ANCOR & AAIDD
Technology Summit and Showcase**
(October 16, 2015)

AAIDD and ANCOR are offering reduced registration fees for their members.

Register for the Technology Summit

ANCOR members should register on the [ANCOR Website](#) to get the member discount.

[AAIDD Members or Non-Members Register Now](#)

Last day to register online: October 12, 2015

Registration Fees:
\$275 AAIDD and ANCOR Members
\$425 Non Members

For registration questions, please contact Corinne at ccarpenter@aaidd.org or 202-387-1968 ext. 201

SAVE THE DATE



140th AAIDD Annual Meeting
June 2-6, 2016 | Atlanta, Georgia



The AAIDD Annual Meeting, provides researchers, clinicians, practitioners, educators, policymakers, local, state and federal agencies, and advocates with cutting edge research, effective practices, and valuable information on important policy initiatives.



Knowledge Support Empowerment

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Dues Invoice

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

Mr. Ms. Dr. Rev. Sr. (Please indicate)

First Name:

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Last Name:

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Address:

Date of Birth:

City:

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Annual Dues

Membership Categories:

\$50 International Electronic (*NOT US/Canada*)

\$175 Standard

\$75 Basic

\$250 Premium

\$125 Classic

\$595 Corporate

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

Annual Dues \$ _____

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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.

Administration

Gerontology

Multicultural Concerns

Creative Arts Therapies

Genetics

Psychology

Communication Disorders

Health & Wellness

Religion & Spirituality (**\$30**)

Community Services

Humanism

Research

Direct Support Professionals

International

Social Work

Education

Legal Process & Advocacy

Sexual/Social Concerns

Families

Mental Health Services

Student & Early Career Professionals (**no fee**)

Technology

Total Cost of Special Interest Group \$ _____
Contribution to the Student Scholarship Fund \$ _____
Donation to AAIDD \$ _____
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