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### **AUCD 2008 Annual Meeting & Conference**

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## WELCOME

### A Message from the 2008 AUCD Board President

Welcome to the AUCD 2008 Annual Meeting. It is in these times of major change in our economy and political climate that it is good to have a clear sense of the road ahead. This meeting offers you as a professional, consumer, family member, and/or public administrator a chance to hear from colleagues and leaders in the disability arena on what has worked, what is working now, and what will work in the future. While we cannot predict the future, our lessons of the past and our efforts of today can most assuredly shape the future.

The AUCD Annual Meeting is a time for learning from others, sharing experiences, and networking with colleagues and friends. This year's Conference will allow you to do all of this and more. Our plenary sessions will embrace strategies for change; consider post election strategies to support our interests in research, education, service, and policy; and consider the interrelationship of public health and disability as we frame our efforts in the years to come. Inclusion is what it is about for families and persons with disabilities and Dan Habib will share his family's views and perspectives on their journey to full inclusion for Samuel.



As you will hear and see, we are on a road to the future, one on which the signs are just now being printed but the final address is clear for us. We are seeking equality and inclusion for all. The presentations that you will attend will reinforce our organizational mission, our program directions, and our individual investments. Yes, we are approaching a time of change and within that time period we must be clear about our direction and drive to reach our goals. This Annual Meeting will serve as a chance for all to catch our breath in the middle of this whirlwind and look forward to setting the course for the coming years for AUCD, our individual centers, and, most importantly, for persons with disabilities and their families.

Within the uncertainty of the times we look forward to our colleagues at this Annual Meeting to reinforce our commitment, share with us new routes to success, and reaffirm that we are all on the same journey: one that ends in greater opportunities for person with disabilities and their families. Enjoy the Annual Meeting and please network, ask questions, and make new friends over the coming few days.

I would like to thank Michael Gamel-McCormick and the Planning Committee as well as all of those who have assisted our Association in creating such an exciting event. I would also like to thank those who have agreed to come and share through posters, presentations, and informal communication the stories of our research, education, service, and policy activities. Lastly, and by no means least, I would like to thank all of the AUCD staff who have invested many many hours in framing this event.

Enjoy the Annual Meeting!

William E. Kiernan, PhD

President, AUCD Board of Directors

William E. Kelinan

## WELCOME

### A Message from the 2008 AUCD Conference Chair

Dear Colleagues,

I offer you a hearty welcome to the 2008 Annual Meeting and Conference of the Association of University Centers on Disabilities (AUCD). Our annual meeting highlights the strength of our diversity—teachers and trainers, researchers and scholars, service providers and advocates, policy makers and historians, artisans and visionaries; all from throughout this great country and this vast world coming together. It takes that diverse group of individuals to forge our way forward in the field of disabilities; to Pave the Way on Pathways for Research, Education, Service and Policy, as highlighted by this year's meeting and conference theme.

The past months have brought about great change; a new federal government will take its seat in January and the economic climate has changed drastically since we last

came together a year ago. In many ways we are both more fragile in our fiscal capacity as a field and nation and even more connected with one another and our colleagues throughout the world. This creates great opportunity in the times ahead.

This year's annual meeting will provide you with some of the ideas and tools to pave the way to a brighter future. We have four plenary sessions, over 35 concurrent sessions and over 80 poster sessions during our meeting. New this year is a Media Room where over 10 videos and films highlight the work of AUCD members, celebrate the lives of persons with disabilities, and address the difficult issues for those with disabilities. If we are to create a positive path forward, we need to use all of the tools at our disposal and harnessing media is another way to communicate our efforts and vision.

I would be remiss if I did not thank the many people who have helped to make this meeting a possibility, not the least of whom are Crystal Pariseau and Laura Martin. To them and to all of the volunteers, presenters and staff at AUCD, many thanks.

As you participate in the proceedings of the 2008 AUCD Annual Meeting and Conference, please take the time to renew relationships, build new relationships and seize opportunities so that we can pave the way for a better world for all persons with disabilities, their families, and our communities.

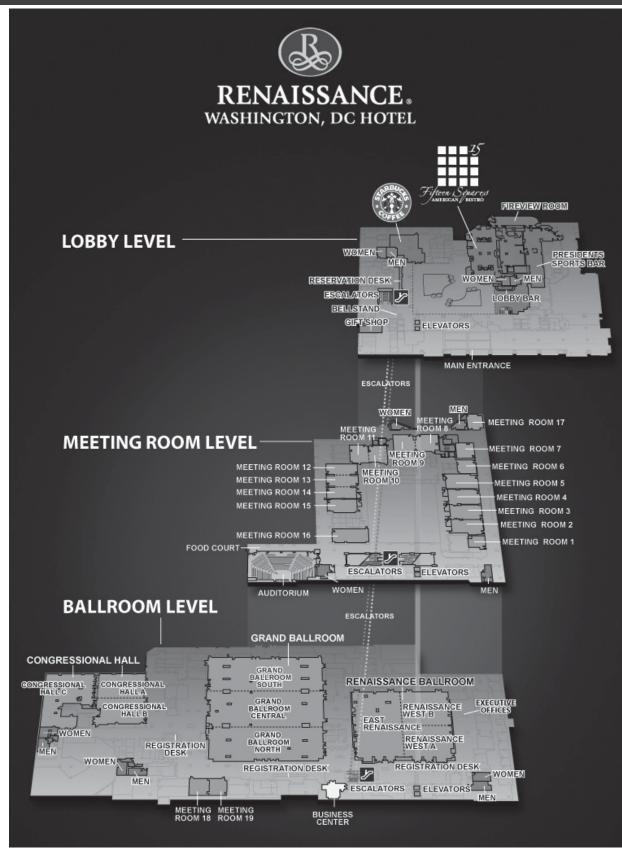
My best wishes for a magnificent meeting,

U.T. Count - M. Execuit

Michael Gamel-McCormick, PhD

President-Elect, AUCD Board of Directors

## CONFERENCE MAP



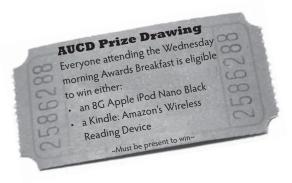
All Ballrooms are located on the Ballroom Level of the hotel.

All Meeting Rooms (MR) are located on the Meeting Room Level of the hotel.

See page 4 for a map of the hotel.

Saturday, November 8, 2008		
AUCD Board of Directors Meeting	4:00 pm – 8:00 pm	Congressional B
AUCD Board of Directors Dinner	8:00 pm – 9:00 pm	Congressional A
Sunday, November 9, 2008		
Exhibitors Open	8:00 am – 5:00 pm	MR Level Foyer
Registration	9:00 am – 6:00 pm	Renaissance
		Registration Desk
Speaker Ready Room	9:00 am – 6:00 pm	MR 1
COCA Meeting	10:00 am – 1:00 pm	Renaissance West A
NTDC Meeting	10:00 am – 1:00 pm	Renaissance West B
CIS Meeting	10:00 am – 1:00 pm	MR 5
Workshops (Tickets Required, See pages 9-12 for descriptions)		
Health Services Transitions: Process and Perspectives	2:00 pm – 4:00 pm	MR 4
UCEDDs and LENDs: Stepping up to Leadership in Developmental	2.00	MR 16
Disabilities	2:00 pm – 4:00 pm	
Evidence Based Practices in Autism: Making it Real for School Teams	2:00 pm - 5:00 pm	Renaissance East
ADD National Training Initiative - A National Gateway to Self	2.00	Congressional B
Determination	2:00 pm – 5:00 pm	
Think College: Postsecondary Education Options for Students with	2.00	Congressional A
Intellectual Disabilities	2:00 pm – 5:00 pm	
Early Childhood Intervention for Infants and Young Children: Have We	2:00 pm – 6:00 pm	MR 10 & 11
Lost our Way?	2.00 pm = 0.00 pm	
Creating Change One State at a Time: Experiences of State ID/DD	4:00 pm – 6:00 pm	MR 8 & 9
Agencies and the UCEDDs in Expanding Employment for Consumers	4.00 piii – 0.00 piii	
Supporting Siblings Across the Life Cycle: Emerging Research, Service, and	4.00 (.00	MR 15
Policy Perspectives	4:00 pm – 6:00 pm	
NIRS Database Workshop and Data Coordinators Meeting	4:00 pm - 6:00 pm	Renaissance West B
Legislative Affairs Committee	4:30 pm - 6:00 pm	MR 12 & 13
New Attendee Orientation	5:45 pm – 6:15 pm	MR 3
Legislative Affairs Briefing (Open to All)	6:00 pm – 7:00 pm	Renaissance West A
COCA/Social Sunday Evening Meeting	7:00 pm – 9:00 pm	Renaissance West A
LEND Autism Grantees Meeting	7:00 pm – 9:00 pm	Renaissance East

Monday, November 10, 2008		
Registration	7:00 am – 5:30 pm	Renaissance Registration Desk
Speaker Ready Room	7:00 am – 5:30 pm	MR 1
Hosted Continental Breakfast	7:30 am – 9:00 am	Renaissance Foyer
LEND Directors Breakfast and Meeting	7:30 am – 9:00 am	Renaissance West A
UCEDD Directors Breakfast and Meeting	7:30 am – 9:00 am	Renaissance West B
Exhibitors Open	8:00 am – 5:00 pm	MR Level Foyer
Multicultural Council Meeting	8:00 am – 11:00 am	MR 12 & 13
NCEDC Meeting	8:00 am – 11:00 am	Congressional A
CORE Meeting	9:00 am – 11:00 am	Congressional B
UCEDD and LEND Directors Meeting and Lunch	9:00 am – 1:00 pm	Renaissance East
Media Room Open (See pages 61-64 for media schedule)	11:30 am – 5:00 pm	MR 16
Concurrent Sessions (Group A)	11:30 am – 12:30 pm	
(See pages 20-21 for session descriptions and locations)		
Training Symposium (Tickets Required; See page 13 for description)		Grand Central Ballroom
Widening and Strengthening Pathways through Universal Design	1.00	
Valerie Fletcher, Executive Director, Adaptive Environments	1:30 pm – 5:00 pm	
Co-sponsored by the Coleman Institute for Cognitive Disabilities		
Program Committee Meeting	1:30 pm – 3:00 pm	MR 6
Plenary Session:		
Where Do We Go From Here? Advocacy for Research After the Election		Renaissance Ballroom
Mary Woolley, Research!America	5:30 pm – 7:00 pm	
(See page 14 for session description)		
Welcome Reception	7:30 pm – 9:00 pm	Renaissance Foyer
Trainee Reception	8:00 pm – 9:30 pm	MR 8 & 9
Special Interest Group Meetings	8:00 pm – 9:00 pm	
Emergency Preparedness SIG		MR 2
Health and Disability SIG		MR 3
Family Support 360 SIG		MR 5
CCUTPDD SIG		MR 6
Postsecondary Education SIG		MR 15



Tuesday, November 11, 2008		
Registration	7:00 am – 5:00 pm	Renaissance Registration Desk
Speaker Ready Room	7:00 am – 6:00 pm	MR 1
Exhibitors Open	8:00 am – 5:00 pm	MR Level
Hosted Continental Breakfast	7:00 am – 9:00 am	Renaissance Foyer
Committee/Special Interest Group Meetings	7:30 am – 8:45 am	
Act Early Summit Meeting		MR 2
LEND Family Faculty Meeting		MR 15
ADD Grantees Meeting		MR 12-13-14
Plenary Session: A Public Health Response to Disability in America		
Edwin Trevathan, MD, MPH & Gloria Krahn, PhD; NCBDDD, CDC	9:00 am – 10:00 am	Renaissance Ballroom
(See page 15 for session description)		
Media Room Open (see pages 61-64 for media schedule)	10:15 am – 3:45 pm	MR 16
Concurrent Sessions (Group B)	10.15 11.20	
(See pages 22-25 for session descriptions and locations)	10:15 am – 11:30 am	
Cash Sale Lunch Available	11:30 am – 12:30 pm	Renaissance Foyer
Poster Set-up	11:30 am – 4:00 pm	Congressional Hall
Committee/Special Interest Group Meetings		
Autism SIG	11:35 am – 12:45 pm	Renaissance Ballroom
Spiritual Supports Network SIG	11:45 am – 12:45 pm	MR 6
Communications Committee	11:45 am – 1:00 pm	MR 7
Concurrent Sessions (Group C)	1.00 2.15	
(See pages 26-29 for session descriptions and locations)	1:00 pm – 2:15 pm	
Concurrent Sessions (Group D)	2.20 2.45	
(See pages 30-33 for session descriptions and locations)	2:30 pm – 3:45 pm	
Plenary Session: Including Samuel		
Dan Habib, Filmmaker in Residence at the Institute on Disability at the	400 500	Renaissance Ballroom
University of New Hampshire	4:00 pm – 5:30 pm	
(See page 16 for session description)		
Poster Session & Reception		
See pages 35-60 for a listing of posters, a session map, and information on	5:30 pm – 9:00 pm	Congressional Hall
how both poster presenters and conference attendees can win great prizes!	1 1	
Committee/Special Interest Group Meetings	8:00 pm – 9:00 pm	
International Committee		MR 3
Victims/Abuse SIG		MR 4
Aging SIG		MR 5
Poster Take Down	9:00 pm	Congressional Hall

Wednesday, November 12		
Degistration	7:00 am – 11:00 am	Renaissance
Registration	7.00 dili = 11.00 dili	Registration Desk
AUCD Business Meeting and Awards Breakfast	8:00 am – 10:00 am	Renaissance Ballroom
Plenary Session: 2008 Election Outcome: Future Direction of Disability Policy		
Nathan Gonzales, Political Editor: The Rothenberg Political Report		
Marty Ford, Chair: Consortium for Citizens with Disabilities	10:30 am – 12:00 pm	Renaissance Ballroom
Julio Abreu, Senior Director of Government Affairs: Mental Health America		
(See page 17 for session description)		
AUCD Board of Directors Lunch	12:30 pm – 1:15 pm	Congressional A
AUCD Board of Directors Meeting	1:30 pm – 5:00 pm	Congressional B



#### Health Services Transitions: Process and Perspectives

2:00 pm - 4:00 pm

Room: MR 4

- > John Reiss, PhD; Associate Professor of Pediatrics; Institute for Child Health Policy, University of Florida; Gainesville, FL
- Cory Nourie, MSS, MLSP; Patient Transition Social Work Coordinator; Nemours/Alfred I. duPont Hospital for Children; Wilmington, DE
- > Ilka K. Riddle, PhD; Project Director, Healthy Delawareans with Disabilities: Bridging the Gap; Center for Disabilities Studies, University of Delaware; Newark, DE

This workshop will introduce participants to the issues and barriers experienced by professionals, youth with disabilities and special health care needs, and families during the process of moving from the pediatric to the adult health care system. Attendees will learn about a) the different dynamics of the pediatric and adult care systems; b) the changing roles of professionals, family members, and youth with disabilities and special health care needs throughout the transition process; and c) the supporting roles individuals working with youth and families can play in improving the health care transition process. Workshop attendees will participate in transition exercises, apply learned materials, and be provided with resources that will enhance their ability to facilitate the development and successful implementation of health care transition plans.

#### UCEDDs and LENDs: Stepping up to Leadership in Developmental Disabilities

2:00 pm - 4:00 pm

Room: MR 16

- > Steven M. Eidelman, MBA, MSW; Co-Director, National Leadership Consortium on Developmental Disabilities, Center for Disabilities Studies, University of Delaware; Newark, DE
- > Nancy Weiss, MSW; Co-Director, National Leadership Consortium on Developmental Disabilities, Center for Disabilities Studies, University of Delaware;

  Newark, DE
- > Nancy Thaler, MS; Executive Director, National Association of State Directors of Developmental Disabilities Services; Alexandria, VA
- > Renee Pietrangelo, PhD; Chief Executive Officer, American Network of Community Options and Resources; Alexandria, VA

This workshop will focus on the issues related to leadership and transition of leadership of developmental disabilities agencies, government offices, advocacy groups, and other entities. Strategies will be presented that UCEDDs and LENDs can use to purposefully develop leaders in systems and organizations providing services, supports, advocacy, and regulation and funding of supports for people with intellectual and developmental disabilities. Strategies for working with non-UCEDD/LEND groups such as state Developmental Disabilities offices, private providers, and advocacy groups will be addressed.

All Workshops are on Sunday,

November 9, 2008.

Tickets are Required

#### Evidence-Based Practices in Autism: Making it Real for School Teams

2:00 pm – 5:00 pm Room: Renaissance East

- > Linda Tuchman-Ginsberg, PhD; Program Director for Early Childhood Professional Development and Co-Investigator for the National Professional Development Center on Autism Spectrum Disorders; Waisman Center UCEDD, University of Wisconsin; Madison, WI
- > Ann Cox, PhD; Scientist, National Professional Development Center on Autism Spectrum Disorders; University of North Carolina at Chapel Hill; Chapel Hill, NC
- > Len Abbeduto, PhD; Associate Director for Behavioral Sciences, UCEDD Director, Co-Investigator for the NPDC-ASD; Waisman Center UCEDD & IDDRC, University of Wisconsin; Madison, WI
- > Cathy Pratt, PhD; Director, Indiana Resource Center on Autism; Indiana University; Bloomington, IN
- > Gail R. Houle, PhD; Associate Division Director; Office of Special Education Programs; Washington, DC

The purpose of this session is to share information about the National Professional Development Center on Autism Spectrum Disorders to demonstrate an approach to professional development that is designed to promote the use of evidence-based practices for children and adolescents with ASD. We will address the processes used to identify the evidence-based practices, the list of selected practices, and resources developed to assist in the implementation of these practices. We will describe our partnerships with states and the ways we are working with school teams, including what we are learning about the selection and appropriate implementation of evidence-based practices within the daily routines and activities of educational and other settings. Video clips of Center practices will be included. Time for questions and discussion will be built into the session.

#### National Training Initiative: Consortium to Scale-up Self Determination

2:00 pm – 5:00 pm Room: Congressional B

- > Carl Calkins, PhD; UMKC Institute for Human Development; Kansas City, MO
- > Ansley Bacon, PhD; Westchester Institute for Human Development; Valhalla, NY
- > Tamar Heller, PhD; Institute on Disability and Human Development; Chicago, IL
- > Jennifer Johnson; Administration on Developmental Disabilities; Washington, DC
- > Tom McVeigh, MS; UMKC Institute for Human Development; Kansas City, MO
- > Laura Walker, BA; UMKC Institute for Human Development; Kansas City, MO

This pre-conference workshop will introduce participants to the conceptual framework and beliefs that will guide the development of a National Gateway to Self-Determination, a National Training Initiative funded by the Administration on Developmental Disabilities. In addition, the workshop will provide an overview of initiatives planned to support the scaling-up of self-determination on the national level through all three phases of the project. Workshop participants will also engage in facilitated discussions regarding such issues as available resources and gaps, implementation strategies, and UCEDD partnerships, and sustainability.

All Workshops are on Sunday,
November 9, 2008.
Tickets are Required

#### Think College: Postsecondary Education Options for Students with Intellectual Disabilities

2:00 pm – 5:00 pm Room: Congressional A

- > Debra Hart, MS, Institute for Community Inclusion, University of Massachusetts; Boston, MA
- > Cate Weir, MEd, Institute for Community Inclusion, University of Massachusetts; Boston, MA
- > Maria Paiewonsky, EDd, Institute for Community Inclusion, University of Massachusetts; Boston, MA
- > Meg Grigal, PhD, TransCen, Inc.; Rockville, MD
- > Molly Boyle, MEd, Massachusetts Bay Community College; Boston, MA

This session will provide participants with an overview of the current "State of the Practice," related to supporting students with intellectual disabilities in postsecondary education. Preliminary findings from two OSEP funded research and innovation projects will be presented. Further, examples from Massachusetts Bay Community College on how to create access to inclusive courses related to students' career goals and the college community will be presented. Next, new amendments to the Higher Education Opportunities Act will be detailed and discussed. Participants will also learn about two new national projects funded by the National Institute on Disability Rehabilitation Research and by the Administration on Developmental Disabilities, which will provide technical assistance, training, and research on a national scale. Finally, participants will receive a set of evidence-based, objective Quality Indicators that have been drafted to be used to define, create, or expand high-quality postsecondary education services to support positive post-school outcomes for students with disabilities.

#### Early Childhood Intervention for Infants and Young Children: Have We Lost our Way?

2:00 pm - 6:00 pm Room: MR 10 & 11

- > Mary Beth Bruder, PhD; UCEDD Director; A.J. Pappanikou Center for Excellence in Developmental Disabilities; Farmington, CT
- > Michael Conn Powers, PhD; Center Director, Early Childhood Center; Indiana Institute on Disability and Community; Bloomington, IN
- > Cordelia Robinson, PhD, RN; UCEDD Director, JFK Partners; Aurora, CO
- > Steve Rosenberg; Aurora, CO
- > Lise Fox, PhD; UCEDD Director, Florida Center for Inclusive Communities; Tampa, FL

Early childhood intervention is a field that has evolved over 40 years, and this history has provided a philosophical foundation which has guided both service delivery and the training of professionals. In particular, three critical components of early childhood intervention for infants and young children will be discussed in this workshop: family centered services, team process, and natural learning opportunities. Both the philosophical foundation of each component and the current evidence base from which to guide practice will be addressed. Emerging issues will also be discussed, such as the challenges of accountability in reporting valid early childhood outcomes to Office of Special Education Programs, collaborations with state early childhood initiatives, and the emergence of special populations such as children in CAPTA and children with ASD. Recommendations will be provided for the future evolution of the field, in particular interdisciplinary pre-service and in service training models for those who will provide early childhood intervention services.

### Creating Change One State at a Time: Experiences of State ID/DD Agencies and the UCEDDs in Expanding Employment for Consumers

4:00 pm – 6:00 pm Room: MR 8 & 9

- > John Butterworth, PhD; Senior Program Manager, Institute for Community Inclusion; Boston, MA
- > Bill Kiernan, PhD; Director, Institute for Community Inclusion; Boston, MA
- > Nancy Thaler, MS; Executive Director, National Association of Directors of Developmental Disabilities Services (NASDDDS); Alexandria, VA

This session will examine lessons learned in implementing state level strategy and policy to expand integrated employment opportunities. A framework for employment will be presented, and activities of the State Employment Leadership Network, a collaborative partnership of 16 state developmental disability agencies committed to employment growth, will be highlighted. Presenters will discuss ways in which UCEDDs can partner in areas of training, capacity development, and model demonstration at a state and local level. Topics for discussion include development of an employment-first policy, leadership, capacity development, use of data to facilitate systemic change, investment in training and technical assistance, interagency collaboration, support innovation, and outcome measurement. Ways of engaging schools, public Vocational Rehabilitation Agencies, and One Stop Career Centers will be examined. Participants will also explore ways of collaborating with the state intellectual disability/developmental disability agencies to enhance employment outcomes in their home state.

#### Supporting Siblings across the Life Cycle: Emerging Research, Service, and Policy Perspectives

4:00 pm - 6:00 pm

Room: MR 15

- > Tamar Heller, PhD; Director & Professor, Institute on Disability and Human Development, University of Illinois at Chicago; Chicago, IL
- > Tom Fish, PhD, Family and Employment Services, Nisonger Center, Ohio State University; Columbus, OH
- > Katie Keiling, Community Support Coordinator, Institute on Disability and Human Development, University of Illinois at Chicago; Chicago, IL

This presentation will describe exciting national and local efforts to better involve, inform, and understand brothers and sisters of people with intellectual and developmental disabilities. Established three years ago, the Sibling Leadership Network is comprised of siblings and professionals who are launching a national agenda to support siblings in their roles as the next generation of care givers, supporters, and advocates for people with disabilities. The Leadership Network held its first national conference in Washington, DC last November and has subsequently produced a series of three white papers on research, services, and policy issues. The latest findings, model programs, and recommendations from the white papers as well as future plans for the Leadership Network and local efforts will be presented.

#### NIRS Database Workshop and Data Coordinators Meeting

4:00 pm - 6:00 pm

Room: Renaissance West B

- > Margaret Nygren, EdD; Technical Assistance Director, AUCD; Silver Spring, MD
- > Ray Gurganus, Senior Programmer; Community IT Innovators; Washington, DC
- > Danielle Onunkwo; Technical Assistance Specialist, AUCD; Silver Spring, MD

This workshop will highlight the changes and updates made to NIRS for the FY09 iteration and will feature a discussion on proposed revisions to the trainee follow up survey and strategies for increasing survey response rates. The session will provide participants the opportunity to ask questions and offer suggestions for continued improvement.

All Workshops are on Sunday,
November 9, 2008.
Tickets are Required

### TRAINING SYMPOSIUM

# Widening and Strengthening Pathways through Universal Design

Universal design benefits people of all ages and abilities. Whether you are designing a new path, expanding an existing road, or creating a superhighway, the application of Universal Design Principles will ensure your Center's pathways are useable by all UCEDD/LEND constituents regardless of age, ability, or situation. The intent of universal design is to simplify life for everyone by making products, communications, and built environments usable by as many people as possible at little or no extra cost, without the need for adaptation or specialized design.

The 2008 AUCD Training Symposium will discuss the basic principles of universal design and their current application in research, training, service, dissemination, and systems change efforts of the Network. After a keynote and/or panel presentations, attendees will be able to participate in a discussion group led by UCEDD/LEND experts and collaborators.

#### Keynote Presentation by Valerie Fletcher, Adaptive Environments

Valerie Fletcher is Executive Director of the Institute for Human Centered Design, an international educational non-profit organization based in Boston, Massachusetts and founded in 1978. Their mission is to advance the role of design in expanding opportunity and enhancing experience for people of all ages and abilities. Design includes the spectrum of design disciplines from urban design, architecture and landscape architecture to product and information design.

#### Coleman Institute for Cognitive Disabilities Panel

- > David Braddock, PhD, Coleman Institute; Boulder, CO: Moderator
- > Clayton Lewis, PhD, Coleman Institute; Boulder, CO: Cognitive Disability & Technology
- > Brian Brown, AbleLink Technologies; Colorado Springs, CO: Web Accessibility
- > Jeff Darling, Rest Assured; Lafayette, IN: Smart Homes
- > Duane Tempel, Sound Response; Madison, WI: Smart Homes

Monday, November 10

1:30 pm - 5:00 pm

The 2008 AUCD Training Symposium is supported in part by a co-sponsorship from:



# Where Do We Go From Here? Advocacy for Research After the Election

Mary Woolley, Research!America Monday, November 10, 5:30 pm – 7:00 pm



Mary Woolley is the president of Research! America, a non-profit, membership supported grassroots public education and advocacy



organization committed to making medical and health research, including research to prevent disease and disability and to promote health, a much higher national priority. Under her leadership, Research!America's membership has more than quadrupled as it has earned the attention and respect of research, media, and community leaders with its signature public opinion surveys and advocacy resource materials.

Woolley is an elected member of the Institute of Medicine and a fellow of the American Association for the Advancement of Science. She serves on several boards and committees, including the Institute of Medicine Health Sciences Policy Board, the National Council for Johns Hopkins Nursing, and the Board of Overseers of the Harvard School of Public Health. She is a founding member of the

Board of Associates of the Whitehead Institute for Biomedical Research. Woolley has served as president of the Association of Independent Research Institutes, as editor of the Journal of the Society of Research Administrators, as a reviewer for the National Institutes of Health and National Science Foundation and as a consultant to several research organizations.

Woolley has a 30-year editorial and publication history on science advocacy and research related topics. Her opeds and letters to the editor are published in newspapers and magazines from coast to coast and she has been published in Science, Nature, Issues in Science and Technology, The New England Journal of Medicine, The Journal of the American Medical Association, The Scientist, and other research-oriented periodicals. She is a sought-after speaker and is frequently interviewed by science, news and policy journalists.

For her work on behalf of medical research, she has been honored as a Woman of Vision by the American Committee for the Weizmann Institute of Science and is a recipient of the Distinguished Contribution to Research Administration Award from the Society for Research Administrators. She has received the American Hospital Association Silver Touchstone Award for Public Affairs Programming, the Columbia University College of Physicians and Surgeons Dean's Award for Distinguished Service, the Federation of American Societies for Experimental Biology Special Award for Science Advocacy, the Friends of the National Institute for Nursing Research Health Advocacy Award and the Awareness and Advocacy Award from the Clinical Research Forum.

Woolley became administrator of the Medical Research Institute of San Francisco in 1981, and in 1986 was named the Institute's executive director and CEO. Woolley has served as president and CEO of Research! America since 1990.

Plenary Sessions are located in the Renaissance Ballroom

Plenary sessions continued on next page

### A Public Health Response to Disability in America

Edwin Trevathan, MD, MPH, Director: NCBDDD, CDC

Gloria Krahn, PhD, Director: Division of Human Development and Disability at the NCBDDD, CDC

Tuesday, November 11, 9:00 am -10:00 am



Edwin Trevathan, MD, MPH, serves as the Director of the National Center on Birth Defects and Developmental Disabilities (NCBDDD) at the Centers for Disease Control and Prevention (CDC). The NCBDDD seeks to improve the lives of people with congenital and genetic disorders, disabilities, neurodevelopmental disorders, and blood disorders. The NCBDDD's work includes identifying the causes of and preventing birth defects, such as brain and spinal cord malformations and congenital heart disease--both major causes of lifelong morbidity and infant mortality. The NCBDDD also performs monitoring of rates of neurodevelopmental disabilities such as autism and cerebral palsy, and performs public health research aimed at identifying preventable risk factors for developing these and other disabilities. NCBDDD, with its partners throughout the US, promotes the health and well-being among people of all ages with disabilities.

Prior to returning to CDC, Dr. Trevathan was Professor of Neurology and Pediatrics and Director of the Division of Pediatric and Developmental Neurology at Washington University in St. Louis. He also served as the Neurologist-in-Chief at St. Louis Children's Hospital. In addition to his experience at Washington University in St. Louis, he has also served as a partner in a child neurology private practice group in Atlanta, and was a professor and Associate Director for Clinical Services in the Department of Neurology at University of Kentucky College of Medicine.

Dr. Trevathan received his MD and MPH at Emory University and completed his residency training at Yale University in pediatrics, and at Massachusetts General Hospital in neurology and child neurology. He was an epilepsy and neurophysiology fellow at Boston Children's Hospital. Dr. Trevathan worked at CDC from 1987 to 1989 as an Epidemic Intelligence Service (EIS) Officer in birth defects and developmental disabilities.



Dr. Gloria Krahn is the Director of the Division of Human Development and Disability at the National Center on Birth Defects and Developmental Disabilities (NCBDDD) at the Centers for Disease Control and Prevention (CDC). Prior to joining the NCBDDD, she served as the Director of Oregon Institute on Disability & Development UCEDD & LEND, Professor of Pediatrics and Public Health & Preventive Medicine at Oregon Health & Science University and the Associate Director of the Child Development and Rehabilitation Center, Oregon Health & Science University.

Dr. Krahn received her PhD from the University of Manitoba in 1980 and completed her Postdoctoral residency in Medical Psychology at Oregon Health & Science University from 1980-82. She received her MPH from the University of California at Berkeley in 1994. In the

past, she has served as the president of AUCD, chair of American Public Health Association's Disability Section, and vice-chair of the National Association of Rehabilitation Research and Training Centers

### **Including Samuel**

Dan Habib, Filmmaker in Residence at the Institute on Disability at the University of New Hampshire

Tuesday, November 11, 4:00 pm - 5:30 pm

Photojournalist Dan Habib rarely thought about the inclusion of children with disabilities before he had his son Samuel. Now he thinks about inclusion every day. Habib documented his family's efforts to include Samuel in every facet of their lives, a journey that transforms each of them.

Including Samuel also chronicles the lives of four other people with disabilities including autism, schizophrenia and cerebral palsy. Habib, who narrates the film, said creating Including Samuel forced him to face his own prejudices head-on. 'When I saw people who didn't look like me, or talk like me, you know what crept into my head? I often saw them as less smart, less capable, and not worth getting to know. Is that how the world would see Samuel?'

Dan Habib is the director, producer and cinematographer of the new documentary, Including Samuel. The film won the 2007 Positive Images in Media

award from TASH, an international group committed to the full inclusion of people with disabilities. The film was named "Best Documentary" at the 2007 Somewhat North of Boston Film Festival, and has been featured on National Public Radio's (NPR) All Things Considered, and in the Washington Post and the Boston Globe. Exceptional Parent Magazine said "Including Samuel is a must see film."

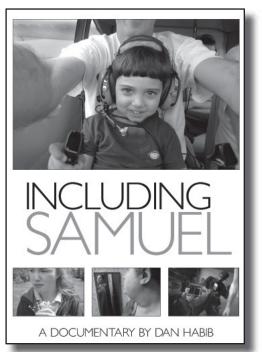


Habib is Filmmaker in Residence at the Institute on Disability at the University of New Hampshire (UNH), an AUCD member UCEDD and LEND. Until joining UNH in April of 2008, Habib was the photography editor of the Concord Monitor since 1995. In 2006 and 2008 he was named the national Photography Editor of the Year for papers under 100,000 circulation. He was a staff photographer with the Monitor from 1988-1992.

Between his stints at the Monitor, Habib freelanced and created a multi-media documentary project titled "Teen Sexuality in a Culture of Confusion" (www.danhabib.com). His freelance work, including extensive documentary work in China, has appeared in numerous publications, including Time, Newsweek, Yankee, Life, Boston Magazine, Mother Jones, and the New York Times.

Habib has been named New Hampshire Photographer of the Year six times. He has been a judge of Pulitzer Prizes, Pictures of the Year, Best of Photojournalism and White House News Photographer's Association. He was one of 10 young photojournalists from around the world chosen for the 1995 World Press Masterclass in Amsterdam.

Habib and his wife, Betsy, live in Concord, New Hampshire, with their sons Isaiah, 11, and Samuel, 8.



# 2008 Election Outcome: Future Direction of Disability Policy

Nathan Gonzales, Political Editor: The Rothenberg Political Report

Marty Ford, Chair: Consortium for Citizens with Disabilities

Julio Abreu, Senior Director of Government Affairs: Mental Health America (invited)

Moderator: William Kiernan, PhD, Director; Institute for Community Inclusion; Boston, MA

Wednesday, November 12, 10:30 am -12:00 pm



Nathan Gonzales is political editor of The Rothenberg Political Report, a non-partisan political newsletter covering U.S. House, Senate and gubernatorial campaigns, Presidential politics and political developments. He has been with the Report since June 2001. Nathan is also a Contributing Writer for Roll Call, the Capitol Hill newspaper.

Since 2002, Nathan has worked as an off-air consultant for ABC NEWS on their Election Night Decision Desk. Previously, he worked for CNN as both unit coordinator in the all politics.com unit and later associate producer for CNN's "Capital Gang." Nathan, an Oregon native, holds an MA from George Washington University, a BA from Vanguard University, and has interned in the White House Press Office. He is married with one child and lives in Washington, DC.

Marty Ford is the Director of Legal Advocacy for The Arc and United Cerebral Palsy (UCP) Disability Policy Collaboration. She has over 23 years of experience in federal public policy issues affecting people with disabilities. Ms. Ford represents both The Arc of the United States and UCP on Capitol Hill and in the federal agencies on issues affecting people with disabilities in long term services and supports, the Supplemental Security Income program, Social Security disability issues, and immigration and naturalization issues. She is currently the Chair of the Consortium for Citizens with Disabilities (CCD), a coalition of over 100 national organizations working on federal disability policy issues. She also serves as Co-Chair of the CCD Task Forces on Social Security and on Long Term Services and Supports. She is a member of the National Academy of Social Insurance and the American Bar Association. She received her JD from the George Washington University National Law Center, her MS from Pratt Institute, and her BA from the University of Virginia.

Julio Abreu is the Senior Director of Government Affairs for Mental Health America, and has advocated for public health and civil rights issues for the last fifteen years. Julio currently sits on the Board of CCD, is the current President of CCD for Health Funding, and is a Co-Chair of the Mental Health Liaison Group. In addition, Julio has teamed with the Congressional Black and

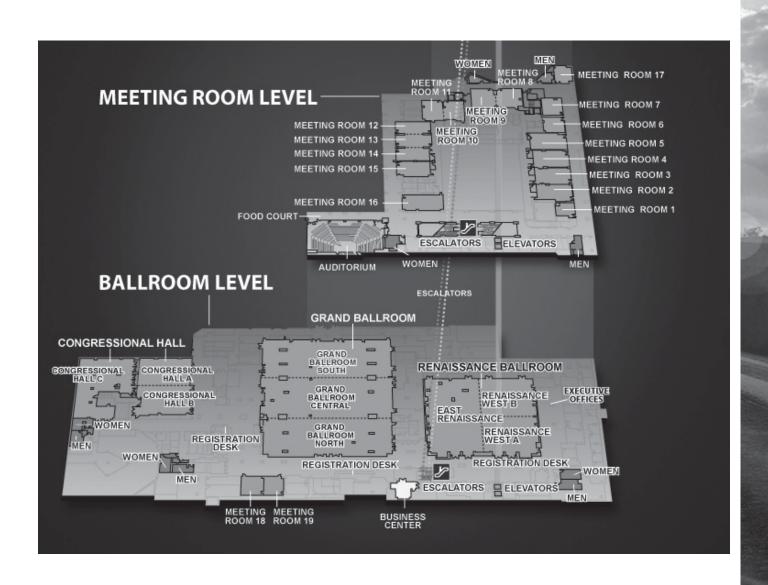
Hispanic Caucuses on a variety of initiatives. Prior to coming to Mental Health America, Julio worked for AIDS Action and the Human Rights Campaign. He also worked in the Legislative Operations office of the US House of Representatives.

Plenary Sessions are located in the Renaissance Ballroom

# Notes







### Monday, November 10

11:30am – 12:30pm

#### Using Universal Design to Teach Universal Design: Next Steps toward a Vision of Radical Inclusion

Meeting Room: 2

- > Tina Passman, PhD; Center for Community Inclusion and Disability Studies; Orono, ME
- > Valerie Smith, PhD; Center for Community Inclusion and Disability Studies; Orono, ME

What happens when Universal Design (UD) is the course content as well as the delivery medium? In this question-based online course, we address the sociopolitical context behind the principles of UD. How do we live/perform UD? What does Universal Design have to do with creating a sustainable human ecology?

#### **Building Statewide Capacity for Parents with Disabilities to Succeed**

Meeting Room: 3

- > Susan Yuan, PhD; Center on Disability and Community Inclusion; Burlington, VT
- > Bernadette Irwin; Kennedy Krieger Institute; Baltimore, MD

Participants will a) identify seven types of support in comprehensive statewide capacity to assist parents with disabilities to raise their children successfully at home, b) identify resources to build capacity in their own states, and c) respond to an invitation to collect data on successful outcomes for families resulting from the implementation of comprehensive supports.

#### Studying Psychosocial Interventions Targeting Anxiety Reduction in Children with Autism Spectrum Disorders

Meeting Room: 4

- > Susan Hepburn, PhD; JFK Partners; Aurora, CO
- > Judy Reaven, PhD; JFK Partners; Aurora, CO
- > Audrey Blakeley-Smith, PhD; JFK Partners; Aurora, CO

This presentation will describe three related papers from a team of clinical psychologists who are working together to develop and study an original, family-focused, manualized intervention aimed towards anxiety reduction in children with high-functioning ASD. Intervention methods, preliminary data, and research challenges will be discussed.

### Paving the Way to Access Tomorrow: Using E-Mentoring and Assistive Technologies for Increasing Achievement and Transition Outcomes

Meeting Room: 5

> Margo Izzo, PhD; Nisonger Center; Columbus, OH

The Access Tomorrow Project provides open-source assistive technology to students with disabilities to access an online information technology literacy and transition program. Students use the internet to conduct research to develop valid career goals and self-directed transition portfolios. Students communicate with mentors electronically to validate their transition plans. We will show a short video of students and mentors who have participated in the e-mentoring program in leiu of consumer participation on site.

#### A Spectrum of Sexuality: Values, Attitudes, Education, Rights, Responsibilities, and Consequences

Meeting Room: 8

- > Beverly Frantz, EdD; Institute on Disabilities; Philadelphia, PA
- > Diane Perry, Parent; Institute on Disabilities; Philadelphia, PA

From womb to tomb, sexuality is a central aspect of being human. It is experienced and expressed in thoughts, desires, attitudes, behaviors, roles, relationships, responsibilities and consequences. This session will address the importance of understanding the fluidity of boundaries, touch, language and sexual development as it relates to natural and criminal consequences.

### Bridging the Gap between Research and Practice: Social Skills Training for Children with Fetal Alcohol Spectrum Disorders

Meeting Room: 9

> Mary J. O'Connor, PhD; Tarjan Center; Los Angeles, CA

Children with prenatal alcohol exposure have poor peer relationships associated with negative psychosocial outcomes. Results of Project Best Buddies, a CDC-funded effectiveness trial introducing an evidence-based social skills treatment into a community mental health agency will be presented. Results demonstrate the successful translation of university-based research into community practice.

#### Virtual Pathways in Disability Studies: Using Second Life to Rethink Disability and Diversity

Meeting Room: 10 & 11

- > Elizabeth DePoy, PhD; Center for Community Inclusion and Disability Studies; Orono, ME
- > Stephen Gilson, PhD; Center for Community Inclusion and Disability Studies; Orono, ME

This session will present the use of Second Life, a virtual world, as a pedagogical strategy to help disability studies students expand theoretical paradigms of disability, experience limitations of bodies or backgrounds approaches to disability, and fashion new ideas and strategies for disability inclusion that are relevant to the 21st century.

#### Using Data to Manage and Assure the Quality and Responsiveness of State Medicaid Waiver Programs

Meeting Room: 15

- > Charles Moseley, EdD; National Association of State Directors of Developmental Disabilities Services; Alexandria, VA
- > Val Bradley; Human Services Research Institute; Cambridge, MA
- > Celia Feinstein, MA; Institute on Disabilities; Philadelphia, PA

Over half of all state developmental disability agencies gather key performance data on consumer characteristics, service use, and individual satisfaction through the National Core Indicators (NCI) program. This session will discuss NCI outcome and performance data with respect to key population, service and support variables. National and state examples will be provided.

### Tuesday, November 11

10:15am - 11:30am

#### Personnel Preparation Policy and Practice in Early Intervention and Pre School Education Center Overview

Meeting Room: 2

- > Mary Beth Bruder, PhD; A.J. Pappanikou Center; Farmington, CT
- > Cristina Mogro-Wilson, PhD; A.J. Pappanikou Center; Farmington, CT
- > Bonnie Lynch, EdD; A.J. Pappanikou Center; Farmington, CT

This presentation will provide an overview of the 10 studies completed as part of the Personnel Preparation Policy and Practice in Early Intervention and Pre School Education Center and the critical gaps in current knowledge identified through these studies.

#### The IAN Project: New Strategies for Involving Families, Individuals, and Care Providers in Disability Research

Meeting Room: 3

- > Paul Law, MD, MPH, MS; Kennedy Krieger Institute; Baltimore, MD
- > Cheryl Cohen; Kennedy Krieger Institute; Baltimore, MD

This presentation will illustrate how the IAN Project brings the community and researchers together to accelerate research, how autism professionals can benefit, and how other disability communities can implement similar strategies.

#### Challenges Facing Professional Organizations in Developmental Disabilities

Meeting Room: 4

- > Greg Olley, PhD; Center for Development and Learning; Chapel Hill, NC
- > Michael Wehmeyer, PhD; Kansas Intellectual and Developmental Disabilities Research Center; Lawrence, KS
- > Len J. Abbeduto, PhD; Waisman Center; Madison, WI
- > Michael Gamel McCormick, PhD; Center for Disabilities Studies; Newark, DE

This year AUCD members are in leadership roles of several professional organizations in developmental disabilities. These leaders will lead a discussion of the challenges facing these organizations and strategies by which we can collaborate to address the needs of our professions in the future.

Meeting Room: 5

#### New Developments in Person Centered Planning and Crisis Intervention

> Steven Reiss, PhD; World Society of Motivation Scientists and Professionals; Columbus, OH

This session will describe progress in assessing what people want from life and how they prioritize what they want. The session will consider implications of such assessments for person centered planning and crisis intervention

### Crisis, What Crisis? Supporting Individuals with Developmental Disabilities and Mental Health Issues Living in the Community.

> Paul White, MA; Waisman Center; Madison, WI

Waisman Center has provided consultation on Positive Behavioral Supports for people with developmental disabilities for two decades. A critical component of those supports is The Crisis Response Program. When challenging behaviors occur with sufficient intensity people with developmental disabilities are a risk for incarceration or institutionalization. The Crisis Response Program has created a number of supports that can be mobilized quickly to assure continued participation in community life.

#### Two Training Models for Special Education Advocates: Working with Families of Children with Disabilities

Meeting Room: 8

- > Meghan Burke, Trainee; Vanderbilt Kennedy Center; Nashville, TN
- > Barbara Wheeler, PhD; USC UCEDD and the CHILD Center; Los Angeles, CA

This session will describe two programs, one at the USC UCEDD and one at the Vanderbilt UCEDD, that provide training in special education advocacy. The session will discuss the various components of each training type, including similarities and differences and strengths and weaknesses.

### Paving the Way for Evidence-Based Practice: Successful Strategies for Building Research Capacity and Transporting Research Findings into Practice

Meeting Room: 9

> Joan Zlotnik, PhD, ACSW; Institute for the Advancement of Social Work Research; Washington, DC

Strengthening the pathways between research and practice requires multiple strategies and partnerships between academia and communities. This session will provide information on models for building research capacity and the identification and transportation of evidence-based practices into community settings.

#### **AUCD and Easter Seals Collaboration**

Meeting Room: 10 & 11

- > Ann Cameron Caldwell, PhD; Easter Seals, Inc.; Washington, DC
- > Patricia Wright, PhD, MPH; Easter Seals, Inc.; Washington, DC

In the shrinking globe, it is important to establish and leverage collaboration among organizations that share similar missions. Easter Seals and AUCD are two such organizations. This session will discuss how these two organizations can collaborate to more effectively serve and support people with disabilities.

Concurrent listings continued on next page

#### Cross Border Initiative: Working with Communities on the US/Mexico Border

Meeting Room: 12

- > Leslie Cohen, JD; Sonoran UCEDD; Tucson, AZ
- > Juan Zepeda, Outreach Coordinator, Sistema Nacional de Desarrollo Integral de la Familia, Nogales, Sonora, Mexico

How can a UCEDD develop relevant and culturally competent training and projects in a border region? The Sonoran UCEDD will describe its journey in assessing the need/strengths of the communities, developing a border conference on disability and developing long-term sustainable projects in the border region.

#### Families in a Person Centered System: Beyond the Money

Meeting Room: 13

- > Shelley Dumas, PhD; Center for Disability Studies; Austin, TX
- > Laura Buckner, MEd; Center for Disability Studies; Austin, TX
- > Dawn Machonis; Partnership for People with Disabilities; Richmond, VA
- > Michael Steinbruck, MA; Elizabeth M. Boggs Center on Developmental Disabilities; New Brunswick, NJ
- > Tera Yoder, EdD; Partnership for People with Disabilities; Richmond, VA
- > Susan Yuan, PhD; Center on Disability and Community Inclusion; Burlington, VT

Families are the single largest group of support providers. What are their roles in person centered systems? What support do they need beyond funding? They can be partners in assuring quality. Discover how UCEDDs can work to equip families to successfully enhance or take on roles within person centered systems.

#### Current Research on Disasters and Individuals with Disabilities

Meeting Room: 14

- > Laura Stough, PhD; Center on Disability and Development; College Station, TX
- > Tony Cahill, PhD; Center for Development and Disability; Albuquerque, NM
- > Keith Christensen, MS; Center for Persons with Disabilities; Logan, UT
- > Amy Hewitt, PhD; Institute on Community Integration; Minneapolis, MN
- > Amy Sharp, PhD; Center on Disability and Development; College Station, TX

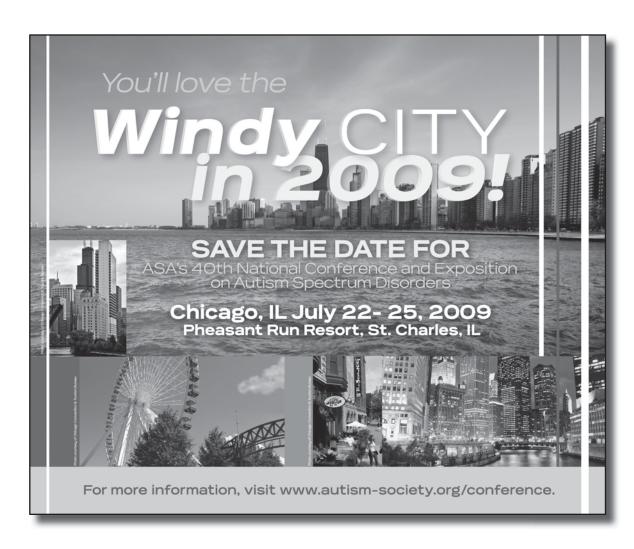
This panel of researchers will discuss current empirical studies conducted within the AUCD network that examine the factors that disproportionately place individuals with disabilities at risk before, during, and following disaster.

### The Friend to Friend Program: A School-Based Relational Aggression Prevention Program Designed through Participatory Action Research

Meeting Room: 15

- > Stephen Leff, PhD; Children's Seashore House; Philadelphia, PA
- > Rebecca Lakin, PhD, Former LEND Fellow; Children's Seashore House; Philadelphia, PA
- > Saburah Abdul-Kabir, Self-Advocate, Family Member/Community Partner; Children's Seashore House; Philadelphia, PA
- > Brooke Paskewich, PsyD; Children's Seashore House; Philadelphia, PA

In this presentation the authors will describe how they used a participatory action research paradigm to combine empirically-based intervention research and psychological theory with key stakeholder feedback to design a school-based relational aggression intervention, Friend to Friend, for inner-city relationally aggressive girls.





### Tuesday, November 11

1:00pm - 2:15pm

Changing Demography of the Disability Field, the Role of Associations, and Opportunities for Students and Young Professionals

Meeting Room: 2

- > Joe Caldwell, PhD; Association of University Centers on Disabilities; Silver Spring, MD
- > Karrie Shogren, PhD; American Association on Intellectual and Developmental Disabilities (AAIDD); Washington, DC
- Tammie Picklesimer, MEd; AUCD Policy Fellow; Center on Disability Studies; Honolulu, HI
- > Glenn Fujiura, PhD; Institute on Disability and Human Development; Chicago, IL
- > Bill Kiernan, PhD; Institute for Community Inclusion; Boston, MA
- > Shea Obremski; Kansas University Center on Developmental Disabilities; Lawrence, KS
- > Tracy Mann, MA; AUCD/NCBDDD Fellow; Centers for Disease Control and Prevention; Atlanta, GA

This session highlights demographic shifts creating concern about the aging of the disability field and the next generation of leaders. It features an interactive discussion among students, early career professionals, and more established professionals concerning the role of associations, mentorship, and career development. Participants will also learn about new resources developed by the AAIDD and AUCD Joint Workgroup on Students and Early Career Professionals.

#### The Multi-Disciplinary UCEDD

Meeting Room: 3

- > David Mitchell, PhD; Institute on Disabilities; Philadelphia, PA
- > Carol Marfisi, MS; Institute on Disabilities; Philadelphia, PA
- > Michael Dorn, PhD; Institute on Disabilities; Philadelphia, PA
- > Sharon Snyder, PhD; Institute on Disability and Human Development; Chicago, IL

This panel will present the idea of the multi-disciplinary UCEDD. Meaningful access for college students with disabilities is not just wheelchair ramps or captioning services. Course content must also reflect the experiences of people with disabilities as part of the university's diversity mission.

#### Capacity Building for Early Identification of Children with Developmental Delays or Disabilities

Meeting Room: 4

- > Rae Sprague, MS, OTR; Waisman Center; Madison, WI
- > Arianna Keil, MD, Parent; Waisman Center; Madison, WI
- > Linda Tuchman-Ginsberg, PhD; Waisman Center; Madison, WI
- > Anne Bradford Harris, PhD; Waisman Center; Madison, WI
- > Lynn Levin, MSSW; Waisman Center; Madison, WI

This session will address how early identification of very young children with developmental concerns can be improved through training on early identification and developmental screening for both inservice and preservice personnel. The focus will be on the importance reaching physicians, nurses, child care providers, and trainees to build community capacity.



#### **Creating Community Change: Two Case Studies**

Meeting Room: 5

- > Keith Christensen; Center for Persons with Disabilities; Logan, UT
- > Fred Orelove, PhD; Partnership for People with Disabilities; Richmond, VA
- > Vicki Beatty; Partnership for People with Disabilities; Richmond, VA
- > Carol Wolf; School Board; Richmond, VA

Creating positive changes for and with people with disabilities in their communities requires an understanding of social, legal, and political processes. We describe two different situations: a) a method of engaging in socially equitable community planning for independent living; and b) A story of how parents, citizens, lawyers, and politicians fought successfully to make school buildings accessible in an urban school district.

#### What Does It Take? Improving Housing Choices for Medicaid-Eligible Mississippians Needing Long-Term Care

Meeting Room: 8

- > Alma Ellis; Institute for Disability Studies; Hattiesburg, MS
- > Royal Walker, Jr., JD; Institute for Disability Studies; Hattiesburg, MS

Research reveals Mississippi spends the highest percentage of Medicaid long-term care dollars in the nation on institutional services; the lowest on home- and community-based waivers. There is a lack of both affordable, accessible housing and community-based services. This presentation will focus on the research and recommendations guiding systems change.

### Cultural Responsive Research Method with Asian Pacific Islander Americans Experiencing Developmental Disabilities and their Families

Meeting Room: 9

- > Dian Baker, PhD(c), APRN; UC Davis M.I.N.D. Institute; Sacramento, CA
- > Elizabeth Miller, MD, PhD; UC Davis M.I.N.D. Institute; Sacramento, CA

Cultural responsive research with underserved Asian Pacific Islander American groups will be discussed. Attendees will gain knowledge regarding how to establish and maintain relationships with underserved communities to facilitate research as well as cultural responsive services. Results from key informant and consumer focus groups will be shared.

#### Paving the Virtual Path: Using Technology to Link Trainees across the AUCD Network

Meeting Room: 10 & 11

- > Elizabeth Bishop, MSSW; Boling Center for Developmental Disabilities; Memphis, TN
- > Katie Keiling, trainee; Institute on Disability & Human Development; Chicago, IL
- > Steve Koch, PhD, Riley Child Development Center; Indianapolis, IN

The Central Conference Training Consortium piloted a virtual poster session series, allowing trainees from participating UCEDD and LEND programs to present on research, clinical and leadership activities. Presentations were interactively webcast to nine network centers across the Consortium. This presentation will share the format, participant feedback, and discuss next steps.



Meeting Room: 12

- > Amy Sharp, PhD; Center on Disability and Development; College Station, TX
- > Laura Stough, PhD; Center on Disability and Development; College Station, TX
- > Mike Benz, PhD; Center on Disability and Development; College Station, TX
- > Aaron Resch, MEd, Trainee; Center on Disability and Development; College Station, TX

Most directories of community resources are out of date the moment they are published. We have developed an online directory that functions in a wiki-like manner. The Directory of Community Resources (DCR) is a locally referenced, currently accurate directory. The DCR houses statewide resources that are categorized using a taxonomy based on functional support needs.

#### Building Capacity in Minority Disability Parent-to-Parent Organizations: A Travel Log

Meeting Room: 13

- > Fran Goldfarb, MA, CHES; USC UCEDD and The CHILD Center; Los Angeles, CA
- > Barbara Wheeler, PhD; USC UCEDD and The CHILD Center; Los Angeles, CA

Community-based Minority Disability Organizations are frequently the portal to under-served populations. However, these organizations often need training and support to develop effective programs and create a sustainable infrastructure for their critical services. This presentation will share lessons learned and successful strategies for building the capacity of minority disability organizations.

#### Positive Behavior Support Projects at UCEDDs: Current Examples and their Application to the UCEDD Mission

Meeting Room: 14

- > David Rotholz, PhD; Center for Disability Resources; Columbia, SC
- > Rachel Freeman, PhD; Kansas University Center on Developmental Disabilities; Lawrence, KS
- > Kelly Donnelly, MPA; Center for Human Development; Anchorage, AK

Positive behavior support (PBS) represents an area highly relevant to training, service, and research with people who have intellectual and developmental disabilities. This session will provide information on current PBS projects at UCEDDs in South Carolina, Kansas, and Alaska with opportunities for discussion and generation of ideas on possible collaboration.

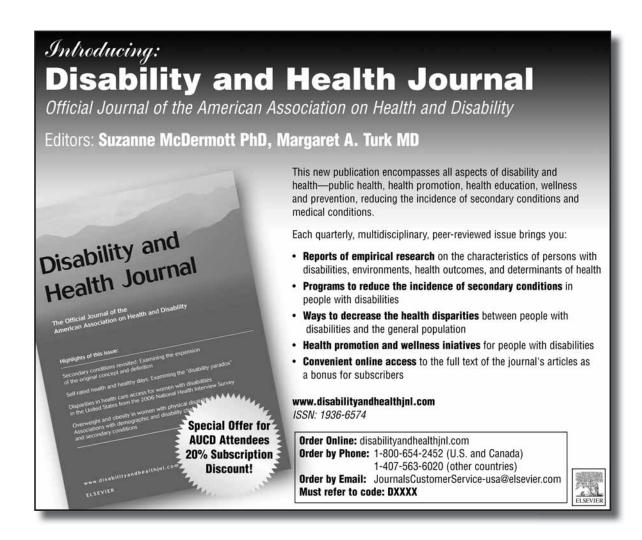


#### Autism Spectrum Disorder in Young Children: A Visual Training Guide

Meeting Room: 15

> Patricia Towle, PhD; Westchester Institute for Human Development; Valhalla, NY

This session will present a new video-based system for detection of autism spectrum disorder (ASD) based on videos of young children with and without ASD. The target audience for this presentation is those who work with trainees at the graduate, post-graduate, and pre-professional level, in both clinical and academic settings.



### Tuesday, November 11

2:30pm - 3:45pm

Promoting Family-Centered/Family-Directed Practices that are Culturally and Linguistically Competent: Current Training Tools, Tips and Resources

Meeting Room: 2

- > Barbara Levitz, MS; Westchester Institute for Human Development; Valhalla, NY
- > Laura Kavanagh, MPP; Maternal and Child Health Bureau; Washington, DC
- > Tawara D. Goode, MA; National Center for Cultural Competence, Georgetown UCEDD; Washington, DC
- > Mark A. Smith, MS; Munroe-Meyer Institute for Genetics and Rehabilitation; Omaha, NE
- > Tanya Baker-McCue, MEd; Center for Development and Disability; Albuquerque, NM

This is an interactive, hands-on session on how to design and implement training for Maternal Child Health and other professionals on family-centered/family-directed practices that are culturally and linguistically competent. The Maternal and Child Health Bureau's Family Centered/Family Directed Practices Workgroup will discuss new products including training indicators, teaching/curriculum resources, field experiences, self-assessment tools, and establishing family advisory groups.

#### **Act Early Regional Summits**

Meeting Room: 3

- > Georgina Peacock, MD; Centers for Disease Control and Prevention; Atlanta, GA
- > Sue Lin, MS; Association of University Centers on Disabilities; Silver Spring, MD

This session will provide an opportunity to learn about the Act Early Regional Summits held in the past year and provide a forum for discussion about future summits.

#### Building the Capacity of Programs to Promote Social Development and Address the Challenging Behavior of Young Children with Disabilities

Meeting Room: 4

 $\,>\,$  Lise Fox, PhD; Florida Center for Inclusive Communities; Tampa, FL

The Technical Assistance Center on Social Emotional Intervention for Young Children offers systems, programs, and practitioner resources for promoting young children's social competence and addressing challenging behavior. The Project Director for the Center will discuss the intervention approach and provide information essential to the delivery of intervention services. Program examples will be described.



Concurrent listings continued on next page

#### Forging the Path for the Direct Support Professional Workforce

Meeting Room: 5

- > Amy Hewitt, PhD; Institute on Community Integration; Minneapolis, MN
- > Katie Keiling, BA; Institute on Disability & Human Development; Chicago, IL
- > Colleen Mclaughlin, MEd; Elizabeth M. Boggs Center on Developmental Disabilities; New Brunswick, NJ
- > Tec Chapman; Missouri Division of MRDD; Jefferson City, MO
- > Carl Calkins, PhD; Institute for Human Development; Kansas City, MO
- > Judy Struck, MA; Center for Disabilities; Sioux Falls, SD

The need to address Direct Support Professional (DSP) workforce training and development is well recognized. Six UCEDD programs are working with stakeholders to use the College of Direct Support. This presentation will provide the opportunity to review accomplishments and challenges as well as discuss DSP training and workforce development.

#### Making Arts Work: Art as a Viable Career Choice

Meeting Room: 8

- > Stephanie Moore; VSA arts; Washington, DC
- > Olivia Raynor, PhD; Tarjan Center; Los Angeles, CA
- > Heike Boeltzig, MSc; Institute for Community Inclusion; Boston, MA
- > Morris Trannen; Rise Program; Glen Burnie, MD
- > Katie Miller, Artist; Washington, DC

Strategies and program models to support students and young adults with disabilities as they pursue careers in the arts will be addressed. This session will share recommendations based on national, state and community based initiatives, as well as the experience of an emerging visual artist with Asperger's syndrome.

### Promoting Inclusion and Social Relationships for Youth with Developmental Disabilities in Classroom, After-School, and Community-Based Settings: Promising Practices

Meeting Room: 9

- > Erik Carter, PhD; Waisman Center; Madison, WI
- > Beth Swedeen, Parent; Waisman Center; Madison, WI
- > Colleen Kurkowski, Former Trainee; Waisman Center; Madison, WI

This panel will discuss findings and recommendations from a series of intervention studies aimed at promoting inclusion and social relationships for youth with developmental disabilities in classrooms through peer support arrangements, extracurricular activities using natural support strategies, and in jobs by connecting educators with the broader community.

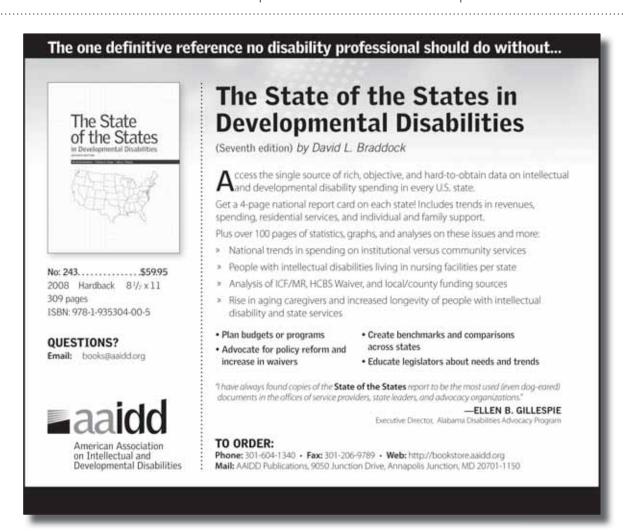


### Opportunities for Collaboration: The Role of Three UCEDDs in Designing and Implementing Early Childhood Professional Development Systems

Meeting Room: 12

- > Deana Buck, MEd; Partnership for People with Disabilities; Richmond, VA
- > Mary Lynn White; Partnership for People with Disabilities; Richmond, VA
- > Sandy Wilberger, MEd; Partnership for People with Disabilities; Richmond, VA
- > Mette Pedersen, MEd; Center for Development and Disability; Albuquerque, NM
- > Sophie Bertrand, MA; Center for Development and Disability; Albuquerque, NM
- > Laurie Westlake, PhD; Wyoming INstitute for Disabilities; Laramie, WY
- > Rick Hufnagel; Wyoming INstitute for Disabilities; Laramie, WY

This session will provide an opportunity to learn from the University Centers for Excellence in Developmental Disabilities (UCEDD) in Virginia, New Mexico and Wyoming that are actively involved in early childhood professional development systems in their states. Each UCEDD will share their experiences and ideas that could be implemented in other states.



### The Abuse, Neglect, and Exploitation of Individuals with Developmental Disabilities: Trends in Definition, Policy, and Prevention

Meeting Room: 13

- > Donna Gilles, EdD; Partnership for People with Disabilities; Richmond, VA
- > Bernice Allen, PhD; Partnership for People with Disabilities; Richmond, VA
- > Barb Trader; TASH; Washington, DC

The presenters will provide a three-pronged overview of current issues in the maltreatment of people with developmental disabilities: a description of forms and prevalence of abuse, neglect, and exploitation; a discussion of abuse as it occurs in the name of treatment; and an outline of current national policies, legislation, and funding mechanisms.

#### A National Assessment of Transition Policies and Practices in State Vocation Rehabilitation (VR) Agencies

Meeting Room: 14

> David R. Johnson, PhD; Institute on Community Integration; Minneapolis, MN

This session will focus on the results of a study conducted by The Study Group Inc., the Institute on Community Integration, and Colorado State University. The purpose of this study was to provide the US Department of Education's Rehabilitation Services Administration with a descriptive national picture of promising transition policies and practices for youth with disabilities among state vocation rehabilitation agencies nationwide.

#### National Service and the Inclusion of People with Disabilities

Meeting Room: 15

- > Joseph Evans, PhD; Munroe-Meyer Institute for Genetics and Rehabilitation; Omaha, NE
- > Paula Sotnik; Institute for Community Inclusion; Boston, MA
- > Jason Wheeler; Institute for Community Inclusion; Boston, MA

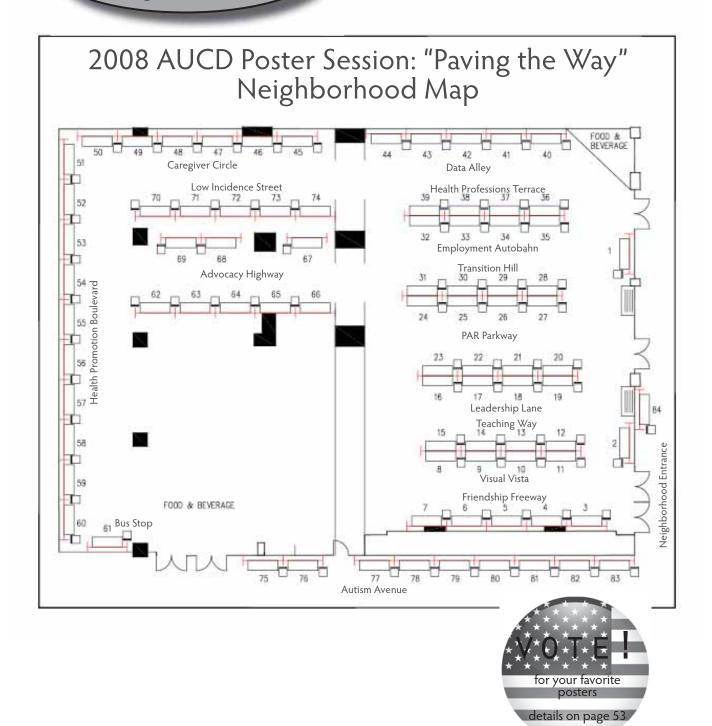
Across the country, UCEDDs and LENDs are actively promoting the inclusion of people with disabilities in responding to critical community needs within their state. This session will highlight national efforts to increase the participation of people with disabilities in service, highlight effective community collaborations and will provide a case model for how this is being done by the Munroe-Meyer Institute.

# Notes



## Posters

Tuesday, November 11, 2008 5:30 pm - 9:00 pm Congressional Ballroom



### Posters

### Friendship Freeway

Poster 4

#### Increasing Disability Awareness and Effective Communication in Agencies

- > Marilyn Hammond, PhD; Center for Persons with Disabilities; Logan, UT
- > Sachin Pavithran, MS; Center for Persons with Disabilities; Logan, UT

This poster will describe the development and implementation of a statewide training project on disability awareness, effective communication, assistive technology and resources targeted to agencies, including senior centers, libraries, volunteers, Medicaid employees, extension agents and city offices at twelve locations.

Poster 5

#### Positive Behavioral Interventions and Supports: A Promising High School Reform Strategy

- > JoAnne Malloy, MSW; Institute on Disability; Concord, NH
- > Maria Agorastou, MSW; Institute on Disability; Concord, NH
- > Jonathan Drake, MSW; Institute on Disability; Concord, NH

This poster will describe New Hampshire's dropout prevention initiative, Achievement in Prevention and Excellence (APEX), and its impact on school wide discipline and individual student outcomes for youth with the most significant challenges. The APEX model uses Positive Behavioral Interventions and Supports and an individualized model for student-led, school-to-career services.

Poster 6

#### Development and Evaluation of a Disability Awareness Workshop for College Students

- > Diane Hall, PhD; Towson University Department of Family Studies and Community Development; Towson, MD
- > Lisa Martinelli, ATR-BC, CCLS; Towson University Department of Family Studies and Community Development; Towson, MD
- > Cheryl Gottlieb; Towson University Department of Family Studies and Community Development; Towson, MD
- > Cynthia Vejar, PhD; Towson University Department of Family Studies and Community Development; Towson, MD

A Family Studies and Community Development major worked with a faculty member and a university committee to develop and evaluate a workshop for students to a) increase knowledge about ableism, b) provide exposure to classroom learning and fieldwork challenges, and c) increase students' knowledge of professional human service worker skills.

Poster 7

#### Evidence-Based Strategies to Promote Social Interactions and Peer Relationships across the Gradespan

- > Erik Carter, PhD; Waisman Center; Madison, WI
- > Colleen Kurkowski; Waisman Center; Madison, WI

This poster will present a critical analysis of interventions aimed at promoting peer interaction among elementary, middle, and high school students with and without developmental disabilities (e.g., autism, intellectual disabilities, multiple disabilities). In addition, presenters will outline critical gaps in the research literature, as well as offer recommendations for practitioners interested in promoting social relationships among students.

### Visual Vista

Poster 8

#### Responding to Diversity: A Technological Pathway to Inclusive Health Promotion

- > Stephen Gilson, PhD; Center for Community Inclusion and Disability Studies; Orono, ME
- > Elizabeth DePoy, PhD; Center for Community Inclusion and Disability Studies; Orono, ME
- > Robert Kitchin, MSW; Center for Community Inclusion and Disability Studies; Orono, ME

In concert with the conference theme, Paving the Way, the purpose of this poster is to illustrate and critically evaluate an innovative web-based portal designed to expand full access to health education, knowledge, and communication globally, with particular attention to the elimination of literacy and access barriers.

Poster 9

#### Implementing Innovative Uses of Assistive Technologies in the Classroom

> Jamie Hayhurst-Marshall; Center for Excellence in Disabilities; Morgantown, WV

During the 2007-2008 school year, the West Virginia Assistive Technology System awarded mini-grants to West Virginia public schools, educators and Regional Education Service Agency staff to implement projects using assistive technology to improve outcomes for students with IEPs or 504 plans. Grants were awarded for new projects using assistive technology to: support inclusion in educational environments, improve social and other recreational outcomes, and support students in transitions through school.

Poster 10

## ArtReach: An Inclusive Program Providing the Opportunity for Self-Expression and Communication through the Visual Arts

- > Matthew Braun, MA, CCC-SLP; Center for Child Health and Development; Kansas City, KS
- > Phyllis Young, MSEd; Center for Child Health and Development; Kansas City, KS
- > Louann Rinner, MSEd, OTR/L; Center for Child Health and Development; Kansas City, KS

ArtReach, a unique collaborative effort offers a series of art-making workshops for children with and without disabilities. Faculty and LEND trainees from Kansas University's Center for Child Health and Development prepared Kemper Museum volunteers on how to support people with disabilities and were an integral support at the ArtReach workshops.

Poster 11

#### Reactions of Adults with Disabilities to the Nintendo® Wii Gaming System

> Linda Madsen, MS; North Dakota Center for Persons with Disabilities; Minot, ND

This presentation discusses the reactions and challenges faced by six adults with varying disabilities as they played Wii games.

### Teaching Way

Poster 2

#### Mississippi's Postsecondary Education Training and Technical Assistance Initiative: Yesterday, Today, and Tomorrow

> Charles Hughes, MBA; Institute for Disability Studies; Hattiesburg, MS

This poster session will present a description of how Mississippi's UCEDD has provided over 20 years of training and technical assistance to administrators, faculty, staff, and students at the state's universities and community colleges. Sample surveys/results, materials, and products will be displayed.

Poster 12

#### The Missouri Integrated Model: A Framework for Teaching ALL Students

> Ronda Jenson, PhD; Institute for Human Development; Kansas City, MO

This poster will introduce the Missouri Integrated Model (MIM) as a framework for supporting the academic success of students with and without disabilities. The MIM is a framework that integrates the evidence-based practices and qualities of effective schools, responsive intervention, and successful systems change into a process for supporting all learners.



Poster 13

### Student Assistance Response (STAR) Team: An Individualized and Consultative Process Approach to Facilitating Inclusion in K-12 Environments

> Bonnie Lynch, EdD; A.J. Pappanikou Center; Farmington, CT

STAR was designed and implemented to increase the time students with significant disabilities spent in general education settings. One hundred fifty-five students, their families, and school personnel participated in this collaborative consultation process with action plans for implementation. Lessons learned and results of outcomes by time, type of disability, and referral will be presented.

#### Poster 14

#### Is Inclusion Still Relevant? Changes in Discourse and Direction since No Child Left Behind (NCLB)

- > Matthew Wappett, PhD; Center on Disabilities and Human Development; Moscow, ID
- > Jen Magelky-Seiler, MS; Center on Disabilities and Human Development; Moscow, ID

Since 2004 students with disabilities have participated in school-wide accountability measures, but anecdotal evidence seems to indicate that they are, once again, being excluded from the regular education classroom because regular education teachers don't feel like they can teach students with disabilities the requisite content they need to perform satisfactorily on high stakes assessments. Thus, although advocates achieved the goal of inclusion in accountability measures it seems that they have, unwittingly, compromised the goal of inclusion for students with disabilities in the regular education classroom and curriculum.

#### Poster 15

#### Should Part C Early Intervention Services be extended to Children Ages 3-5?

- > Jean Johnson, DPH; Center on Disability Studies; Honolulu, HI
- > Beppie Shapiro, PhD; Center on Disability Studies; Honolulu, HI
- > Lily Matsubara, MS; Center on Disability Studies; Honolulu, HI

A statewide survey in Hawai'i asked for family assessment of the transition process from Individuals with Disabilities Education Act Part C early intervention services to Part B preschool special education services. The results of this study provide a basis for assessing transition policies serving children ages 3 to 5 years.



#### **Journal of Neurodevelopmental Disorders**

Advancing Interdisciplinary Research

#### Editor-in-Chief:

Joseph Piven, MD University of North Carolina at Chapel Hill

#### NEW FOR 2009 – now accepting papers

The aim of the *Journal of Neurodevelopmental Disorders* is to provide a forum for interdisciplinary research aimed at the integration of knowledge across a number of neurodevelopmental disorders; underlying pathogenetic mechanisms; and scientific disciplines relevant to understanding the pathogenesis of neurodevelopmental disorders. Treatment studies, informed by knowledge about pathogenesis will be relevant subjects for publication. Research on typical development that has implications for neurodevelopmental disorders will also be seen as relevant subjects for this Journal.

There exist natural barriers between disciplines that make such interactive and collaborative efforts difficult. As advances in research require more and more interdisciplinary science, we believe this Journal can provide novel ways of juxtaposing and communicating findings that will further our understanding of these complex neurodevelopmental conditions.

for submission and further information, please visit us online at: springer.com/11689

### Leadership Lane

Poster 16

#### **Under Construction: Leaders for Tomorrow**

- > Kelleen Smith; Center for Persons with Disabilities; Logan, UT
- > Bryce Fifield, PhD; Center for Persons with Disabilities; Logan, UT

Since its inception over 35 years ago, the Center for Persons with Disabilities (CPD) has helped pave the way in the disability field. Currently operating over 65 cutting-edge projects, the CPD works to impact policy and practice. An important part of this work includes innovative projects that build leaders for tomorrow.

Poster 17

#### The Leadership Puzzle Piece Program: Encouraging Leadership in Employees and Trainees in Everyday Experiences

- > Matt Reese, PhD; Center for Child Health and Development; Kansas City, KS
- > Louann Rinner, MSEd; Center for Child Health and Development; Kansas City, KS
- > Matthew Braun, MA, CCC-SLP; Center for Child Health and Development; Kansas City, KS
- > Norb Belz, MHSA; Center for Child Health and Development; Kansas City, KS

This poster describes one strategy used to promote leadership behaviors in employees and trainees at the Kansas LEND program. Individuals complete puzzle pieces describing first-hand observations of leadership in peers. Monthly Center meetings provide a forum to acknowledge contributions by reading puzzle pieces and drawing one to win a prize.

Poster 18

## Contributions to Community Change for People with Disabilities Made by Graduates of the Leadership in Disability Studies Program



- > Terri Glenn, Trainee; Institute for Human Development; Kansas City, MO
- > Michael McCarthy, MAEd; Institute for Human Development; Kansas City, MO

This poster session features the contributions of graduates of the Institute for Human Development's Leadership in Disability Studies certificate program. Graduates describe how participation in the disability studies program influenced their career and how they are currently making contributions which have a positive impact on the lives of people with disabilities.

Poster 19

#### Using Electronic Portfolios to Showcase MCH/LEND Trainee Leadership Skills

> Lori Risk, MOT; Center for Excellence in Disabilities; Morgantown, WV

This poster will describe the development and use of electronic leadership portfolios by MCH/LEND trainees. It will include the purpose of creating the portfolios, the portfolio template, how current and former trainees have used their portfolios, and how they have benefited from them.

### PAR Parkway

Poster 20

#### Parent Perceptions and Needs-A Telephone Survey of 300 Parents Actively Participating in Mississippi's Title V CYSHCN Program

> Alma Ellis; Institute for Disability Studies; Hattiesburg, MS

The Institute for Disability Studies, University of Southern Mississippi, received 2006 HRSA funding to implement a Family to Family Health Education and Information Center. This poster will present data collected through telephone survey of 300 parents receiving Title V services and contrast findings with 2005-2006 National Survey of Children with Special Health Care Needs Programs.

Poster 21

#### **Disability Culture: Global & Diverse**

> Steven Brown, PhD; Center on Disability Studies; Honolulu, HI

A multi-medial exploration of historical contexts of disability culture, from US and international perspectives.

Poster 22

#### Get Better Results for Family Involvement: Evidence-Based Practices

- > Lizette Flammer-Rivera, MEd; Louisiana State University Human Development Center; New Orleans, LA
- > Holly Paczak, EdS; Louisiana State University Human Development Center; New Orleans, LA
- > Lauren Giovingo; Louisiana State University Human Development Center; New Orleans, LA

This poster provides an overview of the Parent Involvement Indicator (B-8) of the state performance plan required by OSEP and IDEA. Participants will become familiar with concrete strategies and interventions that will improve their performance on this Indicator, and recognize methods to evaluate the effectiveness of these techniques.

Poster 23

#### Using a Participatory Action Research Model to Develop Program Evaluation Measures



- > Stephen Leff, PhD; Children's Seashore House; Philadelphia, PA
- > Michael Cassano, MA, LEND Fellow; Children's Seashore House; Philadelphia, PA

Our LEND Program Evaluation Committee has used participatory research to design three measures to evaluate fellows' perception of their knowledge/skills related to the core competency domains of LEND. Analyses from six cohorts of fellows (n=90) will be presented to illustrate the validity and usefulness of these new measures.

Poster 24

#### PicPlan: A Journey in Research and Development

> Cathy Haarstad, MS; North Dakota Center for Persons with Disabilities; Minot, ND

This poster session describes the journey a research associate takes in bringing a project from design to full development. Content describes how to find and work with a for-profit business as a UCEDD and how to navigate the landscape of business models, intellectual property rights and grant development.

Poster 25

#### Norwegian and Midwestern US Citizens' Perspectives on Institutional and Community Living

- > Brent Askvig, PhD; North Dakota Center for Persons with Disabilities; Minot, ND
- > Jan Meyer, PhD; Harstad University College; Harstad, Norway

As part of an international collaboration, participatory research has been conducted with citizens in rural Norwegian communities and in rural North Dakota communities. Individual and focus group perceptions of various living environments are described and compared with the Norwegian and US disability service systems.

Poster 26

#### My Voice, My Choice

- > Nathan Say; Center on Disability Studies; Honolulu, HI
- > Jean Johnson, DrPH; Center on Disability Studies; Honolulu, HI

My Voice, My choice is a Youth Information and Training Center funded by the Administration on Developmental Disabilities created to train and mentor youth and emerging leaders in self advocacy, employment, and educational opportunities.

Poster 27

#### Participatory Research in Obesity Prevention: The Disability Community Partners with the Academy

- > Mary Segal, PhD; Institute on Disabilities; Philadelphia, PA
- > Jeffrey Cooper, MBA; United Cerebral Palsy of Central Pennsylvania; Harrisburg, PA
- > Bre Metoxen, MS; United Cerebral Palsy of Central Pennsylvania; Harrisburg, PA

We present a new participatory model funded by the NIH Partners in Research program, to test methods to address practical questions in development of true academic/disability community partnerships. We use a wellness/prevention framework to work through issues of research design, methodology, and ownership of protocol development and analysis of results.

#### Transition Hill

Poster 28

#### One Community's Commitment to Improving Adolescent Transition

- > Martha Mock, PhD; Strong Center for Developmental Disabilities; Rochester, NY
- > Susan Hetherington, MS; Strong Center for Developmental Disabilities; Rochester, NY

This poster focuses on how our UCEDD, the School of Education, and a local foundation, launched the Institute for Innovative Transition. Attendees will discover the unique way in which the Institute was developed and the programs that are offered to address transition for youth with developmental disabilities and their families.

Poster 29

#### Web-based Resources for Inclusive Career and Technical Education Programs that Support Transition to Employment

- > Deborah Amsden, MS; Center for Disabilities Studies; Newark, DE
- > Debby Boyer, MA; Center for Disabilities Studies; Newark, DE
- > Megan Pell, MA; Center for Disabilities Studies; Newark, DE

Delaware's Center for Disabilities Studies has created a website which has compiled resources for students, teachers, and families regarding career exploration, strategies for creating inclusive career and technical education courses, and the transition of students with special needs into post-secondary opportunities and to work. This website will be demonstrated.

Poster 30

### Transition Assessment and Youth with Intellectual and Developmental Disabilities: Educator, Parent, and Youth Perspectives

- > Erik Carter, PhD; Waisman Center; Madison, WI
- > Beth Swedeen, Parent; Waisman Center; Madison, WI

Meaningful assessment is considered central to effective transition planning efforts. Presenters will present findings from a research study utilizing the Transition Planning Inventory and AIR Self-Determination Scale with youth with intellectual and developmental disabilities. Similarities and differences in the perceptions of teachers, parents, and youth themselves will be shared, along with recommendations for incorporating assessment findings into transition plans.



#### Poster 31

#### The Experience of University Students with Disabilities: Issues Related to the Transition and Adaptation Process

- > Annie Alonso, PsyD, MSW; Puerto Rico Institute on Developmental Disabilities; San Juan, PR
- > Mario Rodríguez, PhD; Graduate School of Public Health, University of Puerto Rico; San Juan, PR
- > Ilia Torres, MS; Puerto Rico Institute on Developmental Disabilities; San Juan, PR
- > Aimar Cajigas, MS; Puerto Rico Institute on Developmental Disabilities; San Juan, PR
- > Maria Reyes, MSW; Puerto Rico Institute on Developmental Disabilities; San Juan, PR

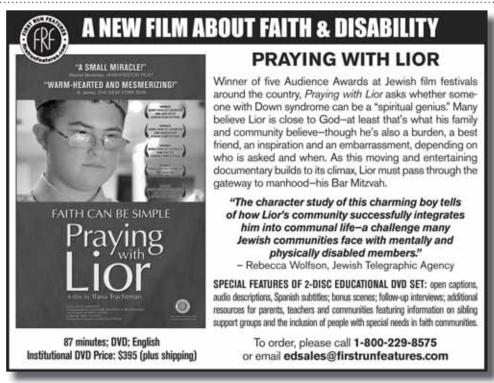
Transitions from high school to university represent a personal and academic threat to students. This transition requires personal and organizational adjustments to deal with the changes. This project aims to examine the personal and organizational needs related to the transition process of university students with disabilities.

#### Poster 1

## Arthrogyposis Multiplex Congenita: Occupational and Physical Therapy Making Changes from Limited Movement to Functional Participation

- > Timothy Conly, MSOT; Rose F. Kennedy Center; Bronx, NY
- > Carol Terilli, DPT; Rose F. Kennedy Center; Bronx, NY

Children affected by arthrogryposis show delays in achieving developmental milestones of rolling, crawling, sitting, walking, prehension, and reaching. These limitations affect performance of activities of daily living including feeding, dressing, and development of play skills. Physical therapy and occupational therapy interventions can have an immense impact on age appropriate function.



### **Employment Autobahn**

Poster 32

#### Cultural Adaptation of the Maine Employment Curriculum for Employment Support Personnel in Puerto Rico

- > Annie Alonso, PsyD, MSW; Puerto Rico Institute on Developmental Disabilities; San Juan, PR
- > Lucille A. Zeph, EdD; Center for Community Inclusion and Disability Studies; Orono, ME
- > Ilia Torres, MS; Puerto Rico Institute on Developmental Disabilities; San Juan, PR
- > Mario Rodriguez, PhD; Graduate School of Public Health, University of Puerto Rico; San Juan, PR
- > Carmen Landrón, MA; Medical Sciences Campus, University of Puerto Rico; San Juan, PR

Job coaching services are useful to promote the employment of people with disabilities. This study aimed to validate job coach competencies across cultures through a partnership between the Maine and Puerto Rico UCEDDs.

Poster 33

#### Louisiana's Supported Employment Continuous Improvement Project (LA SECIP): Building Trust and Commitment

- > Patricia Ghiossi; Louisiana State University Human Development Center; New Orleans, LA
- > Philip Wilson, PhD; Louisiana State University Human Development Center; New Orleans, LA

Building trust, shifting attitudes and practices, and influencing policy are all outcomes of this project. Instead of focusing on a standard's driven approach to technical assistance this project looks at 'what will it take' to achieve the provider's desired employment outcome and builds its technical assistance around that effort.

Poster 34

## Achieving Successful Employment for Young Adults with Disabilities by Bridging the Gap between Schools and Adult Service Providers

- > Emily Obremski, MEd; Kansas University Center on Developmental Disabilities; Lawrence, KS
- > Wendy Parent, PhD; Kansas University Center on Developmental Disabilities; Lawrence, KS

This poster will present a pilot program developed to provide job coach training and information about supported and customized employment to school related personnel and their local adult service provider to achieve competitive employment for young adults with disabilities.

Poster 35

#### US Neoliberal Workfare Policies and the UN Convention on the Rights of Persons with Disabilities

This paper examines the extent to which neoliberal workfare policies and programs in the US facilitate full and equal participation for disabled people. It will assess the effectiveness of these policies (e.g. PRWORA and TWWII) against the right-based framework of the UN Convention on the Rights of Persons with Disabilities.

#### **Health Professions Terrace**

Poster 36

#### The Impact of Medicaid Drug Policies on People with Intellectual and Developmental Disabilities

> Amie Lulinski Norris; Institute on Disability and Human Development; Chicago, IL

Increases in Medicaid enrollment and medication spending, notably psychotropic medication, have led states to enact prescription medication cost-saving legislation. As people with intellectual and developmental disabilities (I/DD) have a higher prevalence of mental illness as compared to their non-disabled peers, they use a disproportionate share of psychotropic medications. This study sought to determine the effects of such legislation on people with I/DD.

Poster 37

## Rethinking Disability: Designing a Half-Day Interprofessional Seminar for Medical, Nursing, Pharmacy, Public Health, Social Work and Law Students

- > Lynne Tomasa, PhD; Sonoran UCEDD; Tucson, AZ
- > Leslie Cohen, JD; Sonoran UCEDD; Tucson, AZ
- > Jim Kerwin, MD; Sonoran UCEDD; Tucson, AZ

The poster explains the implementation and evaluation of a half-day class activity for medical, nursing, pharmacy, public health, social work and law students. The goal of the activity was to teach students how to collaborate respectfully with other professionals as an interdisciplinary team to address the often-complex needs of individuals with disabilities.

Poster 38

### A Call to Action: An Electronic Tool Kit for Medical, Dental, and Nursing Schools in Caring for Patients with Disabilities



- > Harold Kleinert, EdD; Interdisciplinary Human Development Institute; Lexington, KY
- > Lann E. Thompson, EdD; Riley Child Development Center; Indianapolis, IN
- > Diane N. Bryen , PhD; Institute on Disabilities; Philadelphia, PA
- > Keysha Hammons, MA, Trainee; Interdisciplinary Human Development Institute; Lexington, KY
- > Sara Boyd, MA, Trainee; Interdisciplinary Human Development Institute; Lexington, KY

The creation of an Electronic Tool Kit of validated curricular tools for medical, dental, and nursing students will be described. The purpose of this tool kit is to provide medical, dental, and nursing schools with evidence-based examples for training their students to care for their future patients with disabilities.



Poster listings continued on next page

Poster 39

#### Implementing Follow-Up Programs: A Necessity for Effective Interdisciplinary Practice

- > Carol Rabideau, MSSW; Vanderbilt Kennedy Center; Nashville, TN
- > Belinda Tate Hardy, MPA, LCSW; Boling Center for Developmental Disabilities; Memphis, TN

This poster will examine two UCEDD patient follow-up programs. Both the University of Tennessee Boling Center for Developmental Disabilities and the Vanderbilt Kennedy Center implemented qualitative follow-up programs for individuals receiving diagnostic evaluations within a designated 6 month period, using a structured follow-up form developed collaboratively by the UCEDDs.

### **Data Alley**

Poster 40

#### Kicking it up a Notch: Using the LAQI to Guide Systematic Team Training, TA, and Program Evaluation

> Maria Blanco, MEd; Louisiana State University Human Development Center; New Orleans, LA

The Human Development Center developed a program evaluation tool to guide training, technical assistance, and continuous improvement efforts for schools serving students with autism and related disabilities. A description of the protocol used for training and TA as well video samples of school implementation will be shared. Outcome data will be used to discuss successes and challenges of the model.

Poster 41

#### Oklahoma's Self-Directed Services Pilot Program Evaluation 2008

- > Angela Harnden, PhD; Center for Interdisciplinary Learning and Leadership; Oklahoma City, OK
- > Valerie N. Williams, MPA, PhD; Center for Interdisciplinary Learning and Leadership; Oklahoma City, OK
- > Vyonda G. Martin, MA; Center for Interdisciplinary Learning and Leadership; Oklahoma City, OK

The Center for Learning and Leadership (Oklahoma UCEDD) conducted an evaluation of Oklahoma's Self-Directed Services Pilot Program. The program was mandated by the Oklahoma Legislature and implemented by the Oklahoma Department of Human Services. This poster will provide information about the program and results of the evaluation.

Poster 42

### Behavioral Risk Factor Surveillance System: A Flexible Tool for Monitoring Health Status among People with Disabilities

- > Ilka K. Riddle, PhD; Center for Disabilities Studies; Newark, DE
- > Eileen Sparling, EdM; Center for Disabilities Studies; Newark, DE
- > Monika Mitra, PhD; Massachusetts Department of Health, Office of Statistics and Evaluation; Boston, MA
- > Pialee Roy, MA; Massachusetts Department of Health, Office on Health and Disability; Boston, MA

The Behavioral Risk Factor Surveillance System (BRFSS) is an on-going telephone health survey system, tracking health conditions and risk behaviors in the United States since 1984. Data from the BRFSS can be used to monitor the health status of people with disabilities at national, state, and local levels.

Poster 43

#### Beyond Race and Ethnicity: Measuring Diversity in the Vermont LEND

- > Jean Beatson, EdD, RN; VT Interdisciplinary Leadership Education for Health Professionals; Burlington, VT
- > Stephen Contompasis, MD; VT Interdisciplinary Leadership Education for Health Professionals; Burlington, VT

The Vermont LEND program developed a Diversity Survey to measure the range of diversity among their faculty, staff, trainees, and fellows. Diversity elements include SES, religion, sexual orientation, and disability, in addition to others.

Poster 44

#### Emerging trends in the AUCD network: A multi-year analysis of NIRS data system

- > Margaret Nygren, EdD; Association of University Centers on Disabilities; Silver Spring, MD
- > Elizabeth Bishop, MSSW; Boling Center for Developmental Disabilities; Memphis, TN

This poster presents a multi-year analysis of national data elements in the NIRS data system.

### Caregiver Circle

Poster 45

#### Conversations about Cultural Competence and Family-Centered Care: Beginning the Journey

> Barbara Leach; Center for Development and Learning; Chapel Hill, NC

Participants will engage in a dialog about cultural awareness and culturally responsive family-centered care.

Poster 46

#### Family Centered Care in Practice: Experiences of LEND Graduates

- > Geri M. Lotze, MS, MT; Partnership for People with Disabilities; Richmond, VA
- > Mel Bellin, PhD, MSW, LCSW; University of Maryland; College Park, MD

LEND graduates receive specialized training in the importance and practice of family centered care for children with special health care needs, yet they still experience barriers to family centered care in the field. Issues related to institutional culture, absence of care coordination, insufficient training, policy factors, and family factors are shared.

Poster 47

#### Oklahoma Families Caring for Children with Special Health Care Needs

> Rob C. Wild, MS; Center for Interdisciplinary Learning and Leadership; Oklahoma City, OK

An interdisciplinary research based investigation into the relationships between characteristics of Oklahoma families caring for children with special health care needs and the impact the care process has on the family.

## POSTERS

Poster 48

#### Meeting the Needs of Parents of Children with Severe Disabilities

> Rita Walters, MSW; Michigan State University; Holt, MI

This presentation will critically examine what has been discovered about parents of children with severe disabilities; how is severe disability defined; what factors influence parents' ability to adequately care for their disabled child; and how severely disabled children are viewed in education, political, and cultural systems.

Poster 49

#### Giving Parents a Voice: A Qualitative Study on the Stress and Challenges Parents of Children with Disabilities Experience

- > Aaron Resch; Center on Disability and Development; College Station, TX
- > Gerardo Mireles, MA; Center on Disability and Development; College Station, TX
- > Michael Benz, PhD; Center on Disability and Development; College Station, TX

Parent caregivers of children with disabilities have a significant amount of responsibility placed upon them. As a result of these responsibilities the parent caregiver is likely to experience substantial stress and burden. The purpose of this presentation is to highlight the specific sources of caregiver stress as expressed by caregivers.

Poster 50

#### Problem Solving and Maternal Distress at the Time of Child's Cancer Diagnosis: English versus Spanish-Speaking Mothers



> Alison Pilsner, Former Trainee; Current Fellow with National Cancer Institute, National Institutes of Health; Washington, DC

This proposal is an ongoing research project and the data originates from a larger data set of a randomized clinical trial funded by the National Cancer Institute (NCI). A portion of this project was completed while I served as a LEND Fellow at the University of Pittsburgh over the past year. Currently as a fellow with NCI, I continue to collaborate with the research team in

Pittsburgh on this project as it moves toward publication.



### Health Promotion Boulevard

Poster 51

#### Implementing Healthy Nutrition Choices for Obesity Prevention in Persons with Intellectual Disabilities

- > Mary Segal, PhD; Institute on Disabilities; Philadelphia, PA
- > Beverly Frantz, EdD; Institute on Disabilities; Philadelphia, PA

Presenters asked adults with mild intellectual disabilities and support staff about facilitators and barriers regarding healthy nutrition. Respondents understood established guidelines for wholesome diets, but significant obstacles remained in translating the guidelines into behavior. The data analysis provides a decision-making framework for developing programs to accomplish this important health goal.

Poster 52

### Nutrition Health Promotion Program for Adults with Intellectual or Developmental Disabilities Residing in Group Homes: MENU-AIDDs

- > Kathleen Humphries, PhD; University of Montana Rural Institute; Missoula, MT
- > Alison C. Pepper, MA; University of Montana Rural Institute; Missoula, MT
- > Meg A. Traci, PhD; University of Montana Rural Institute; Missoula, MT
- > Julianna Olsen; University of Montana Rural Institute; Missoula, MT
- > Tom Seekins, PhD; University of Montana Rural Institute; Missoula, MT

This poster will a) describe the MENU-AIDDs nutrition intervention for adults with intellectual or developmental disabilities and display the materials, b) report on the Montana dissemination and training of MENU-AIDDs, and c) show results of the evaluation of the trainings and outcomes to implementation in community group homes for dietary intake, weight, and gastrointestinal health.

Poster 53

#### Small Changes Make Big Impacts: An Inclusive Fitness and Nutrition Program



- > Alexis Petri, MA; Institute for Human Development; Kansas City, MO
- > Terri Glenn, Trainee; Institute for Human Development; Kansas City, MO

This poster session shares information about fitness and nutrition programming for youth with developmental disabilities in inclusive settings. An inclusion guide to an existing curriculum, Jump into Foods and Fitness, promotes health and exercise by providing teachers and staff at youth organizations with training, lesson plans, and resources.

#### Poster 54

### Relationship between the Number of Foster Homes Placements and the Mental and Physical Wellbeing of Foster Children with Developmental Disabilities

- > Ethel Teichberg, LCSW; Rose F. Kennedy University Center; Bronx, NY
- > Howard Demb, MD; Rose F. Kennedy University Center; Bronx, NY
- > Rosario Maria Valicenti, MD; Rose F. Kennedy University Center; Bronx, NY

The study provides information about the relationship between the number of foster home placements of a sample of foster children with developmental disabilities and the psychiatric and health related disorders of these children.

#### Poster 55

#### Developmental Disabilities in Foster Care: Meeting Children's Needs in Out of Home Care

> Robert Basler, MSW; Kennedy Krieger Institute; Baltimore, MD

Recent research suggests that youth in foster care have developmental disabilities at significantly higher rates than the general population; however, the child welfare system does not always respond well to meet these children's needs. This poster will look at ways that providers can better meet these needs.



Poster listings continued on next page

Poster 56

#### LEND Community Project: The Homeless Health Initiative Developmental Screening Training

> Melissa Berrios, MSW; Children's Seashore House; Philadelphia, PA

An interdisciplinary team partnered with the Homeless Health Initiative to train shelter staff to perform developmental screenings for children living in the shelter. The team modified the Ages & Stages curriculum to create activities that stimulate mother-child interaction and healthy development within the limits of a homeless shelter environment.

Poster 57

#### Assessment of Consumer Awareness and Understanding of Newborn Screening

- > Caroline Lieber, MS; Westchester Institute for Human Development; Valhalla, NY
- > Patricia Patrick, MPH; Westchester Institute for Human Development; Valhalla, NY
- > Aieya Jean-Francois, OT; Westchester Institute for Human Development; Valhalla, NY
- > Ejiro Agboro-Idahosa, MD; Westchester Institute for Human Development; Valhalla, NY
- > Jessica Hutter, MS; Westchester Institute for Human Development; Valhalla, NY
- > Rosetta Malvese, MSEd; Westchester Institute for Human Development; Valhalla, NY

Every state screens newborns for certain harmful or potentially fatal disorders at birth; however, the public possesses limited awareness and understanding of the newborn screening process. Improved educational programs are needed to increase knowledge of newborn screening among healthcare professionals and consumers.

Poster 58

#### Emergency Preparedness for All Utahns: Preparing Yourself, Your Family, or Your Agency

> Jefferson Sheen, MSW; Center for Persons with Disabilities; Logan, UT

This poster highlights the 'Emergency Preparedness for All Utahns' project and the train-the-trainer and participant materials that were developed utilizing existing materials from around the country. Training materials were produced for three specific groups: individuals with developmental disabilities, families of children with special health care needs, and state/community service providers.

Poster 59

#### North Dakota (ND) Disability Health Project

- > Kari Arrayan, MS; North Dakota Center for Persons with Disabilities; Minot, ND
- > Kylene Kraft; North Dakota Center for Persons with Disabilities; Minot, ND
- > Brent Askvig, PhD; North Dakota Center for Persons with Disabilities; Minot, ND

The ND Disability Health Project promotes the health and wellness of ND citizens with disabilities. The project has developed a strategic plan, based upon state data sources and focus group sessions, that includes health promotion strategies, technical assistance, and other techniques to promote awareness of health disparities and to address health related issues for people with disabilities.

## POSTERS

Poster 60

## Patterns of Mental Health Service Utilization in Children and Adolescents with Chronic Health Conditions or Physical Disabilities



> Sara Hunt, Trainee; Center for Persons with Disabilities; Logan, UT

Results from a larger mixed-method study exploring the psychosocial functioning of youth with special health care needs and their need for and use of mental health services are presented. Findings on patterns of service use as well as barriers to receiving needed mental health services are discussed.



### **Bus Stop**

Poster 61

## Public versus Private Transportation: What is Being Utilized by People with Disabilities in the Greater Richmond Metropolitan Area



- > Michelle Battle, Trainee; Partnership for People with Disabilities; Richmond, VA
- > Ken Thompson, Easter Seals Project ACTION; Washington, DC

As a trainee funded under the 2008 ESPA-AUCD Sponsored Project, I examined the transportation options of people with disabilities in the Greater Richmond Metropolitan Area. Findings include reasons why a person with a disability chooses certain modes of transportation, and what barriers they face in using that mode. The most common barriers reported by consumers were the time constraints, the cost, and the primary locations accessible.

### **Advocacy Highway**

Poster 62

#### OurSABE.org: An Online Self-Advocacy Community

- > Laura Walker; Institute for Human Development; Kansas City, MO
- > Ronda Jenson, PhD; Institute for Human Development; Kansas City, MO
- > Tia Nelis; Institute in Disability and Human Development; Chicago, IL

Through a grant from the NEC Foundation, SABE and the University of Missouri-Kansas City

Institute for Human Development are developing a fully accessible online learning community to connect self-advocates and inform professionals and the general public about self-advocacy in the U.S. This poster session will introduce a pilot version of the site www.ourSABE.org.



Poster 63

#### PhotoVoice: Using Photos in Research to Communicate and Influence Constituents and Policymakers

- > Cathy Haarstad, MS; North Dakota Center for Persons with Disabilities; Minot, ND
- > Dawn Olson; North Dakota Center for Persons with Disabilities; Minot, ND
- > Cynthia Salazar; North Dakota Center for Persons with Disabilities; Minot, ND
- > Shannon Simonson; North Dakota Center for Persons with Disabilities; Minot, ND

This poster describes the results of a participatory action research project using PhotoVoice. The purpose was: a) to assess the use of PhotoVoice as a tool for conducting a community needs assessment and; b) to increase the North Dakota Center for Persons with Disabilities's Consumer Advisory Council member experience with participatory action research to develop leadership skills.

Poster 65

#### Strengthening Family Partnerships: Building the Capacity of Family Organizations

> Molly Cole; A.J. Pappanikou Center; Farmington, CT

This poster will focus on three ways to build capacity in state and local family organizations through technical assistance and support. These include strategic planning and organizational development, grant writing and reviewing, and mentoring/leadership development.

#### Poster 66

#### **Disabilities and Law Enforcement**

- > Marc J. Tasse, PhD; Florida Center for Inclusive Communities; Tampa, FL
- > Nila Benito; Florida Center for Inclusive Communities; Tampa, FL
- > Bobbie Vaughn, PhD; Florida Center for Inclusive Communities; Tampa, FL

Brian Sterner is a 32 year-old Tampa man who was dumped out of his wheelchair by a Hillsborough County Sherriff Office (HCSO) Deputy. The Deputy dumped Mr. Sterner out of his wheel chair to search his pockets and clothing. This poster presents the results from a Needs Assessment and the results from Focus Groups of HCSO deputies.

#### Poster 67

#### Taking Charge of Your Health & Safety: Activating Senior Networks in Rural Appalachia

- > Tammy Hare, MS; Center for Excellence in Disabilities; Morgantown, WV
- > Mary Slabinski, MSW; Center for Excellence in Disabilities; Morgantown, WV

Choosing to age-in-place or live independently are increasingly popular alternatives to traditional senior care. Innovative in its service delivery, 'Taking Charge' disseminates health education materials by incorporating culturally sensitive chronic health messages with a community based approach and flexible program design that can be customized to individual needs.

#### Poster 68

#### An Innovative LEND Curriculum Module on Advocacy and Policy

- > Karen Edwards, MD, MPH; Westchester Institute for Human Development; Valhalla, NY
- > Ansley Bacon, PhD; Westchester Institute for Human Development; Valhalla, NY
- > Barbara Levitz, MS; Westchester Institute for Human Development; Valhalla, NY
- > KimLori Devine, MSEd; Westchester Institute for Human Development; Valhalla, NY

MCH leaders must possess the knowledge and skills required to defend and advocate for resources in competitive economic and political environments. The LEND Program at WIHD has expanded its advocacy and policy curriculum module to provide hands-on, active learning and teaching experiences for trainees. Feedback has been positive.

#### Poster 69

## Creating Community Leaders with Leadership and Advocacy Training: Texas Youth Leadership Forum (YLF)-A New and Improved YLF Model

- > Cheryl Grenwelge, MEd; Center on Disability and Development; College Station, TX
- > Jackie Pacha; Center on Disability and Development; College Station, TX
- > Leena Landmark, MEd; Center on Disability and Development; College Station, TX

This poster provides an overview of a new leadership training model. Under this new model three regional YLF projects and one statewide YLF project have been funded to provide progressive leadership training to youth with disabilities. Participants also receive extended information on the statewide YLF implementation structure.

## <u>Posters</u>

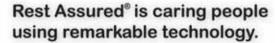
#### Low Incidence Street

Poster 70

### Communication/Educational Programs for Children with Angelman Syndrome in Inclusive Classrooms: A Look at Best Practices

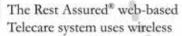
> Tibbany Black, MS; New Hampshire LEND Program; Lebanon, NH

This poster will report on the development and results of a survey of evidence-based AAC best practices for students with significant disabilities, all of which were validated by an expert panel and then socially validated by the parents of 36 children with Angelman Syndrome. Results were compared for students in self-contained and partial-full inclusion programs. Factors fostering and impeding best practices will be identified and discussed.





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Poster 71

### An Ethnographic Study of Professional Care Approaches and Roles When Dealing with Severe and Profound Disorders

- > Gaetano Lotrecchiano, PhD; Children's National Medical Center; Washington, DC
- > Sheela Stuart, PhD; Children's National Medical Center; Washington, DC

This project focuses on the relationships and roles of professionals as they strive to work in interdisciplinary teams. The nature and definition of interdisciplinary service and collaboration is explored.

Poster 72

## Current Treatment Practices of Pediatric Oncologists Management of Depression and Anxiety Disorders in 9 Institutions across the United States



- > Robert Noll, PhD; UCLID Center; Pittsburgh, PA
- > Lalymar Fernandez, MS, Trainee; UCLID Center; Pittsburgh, PA

While many children/adolescents receive treatment with antidepressant medication, specifically selective serotonin reuptake inhibitors known as SSRIs, this practice has been questioned in the pediatric population due to lack of data on safety and efficacy issues. Although it seems feasible that children receiving treatment for cancer experience more depression, especially during intensive phases of care, numerous studies examining this find a low prevalence of depression in comparison to the general population.

Poster 73

## Parental Report on Coordination of Care with the Education and Medical System of Children with Cornelia de Lange Syndrome

- > Mary Beth Bruder, PhD; A.J. Pappanikou Center; Farmington, CT
- > Cristina Mogro-Wilson, PhD; A.J. Pappanikou Center; Farmington, CT

The Cornelia de Lange Syndrome (CdLS) population has different educational and medical needs. Results from a research study to increase the amount of knowledge on children affected by CdLS, their development, and their experience with the educational and medical system will be presented.

Poster 74

#### What is Happening at the National Spina Bifida Program?

- > Ann Alriksson-Schmidt, PhD, MSPH; Centers for Disease Control and Prevention; Atlanta, GA
- > Judy Thibadeau, RN, MN; Centers for Disease Control and Prevention; Atlanta, GA
- > Caresse Campbell, MPH; Centers for Disease Control and Prevention; Atlanta, GA
- > Mark Swanson, MD, MPH; Centers for Disease Control and Prevention; Atlanta, GA
- > Vince Campbell, PhD; Centers for Disease Control and Prevention; Atlanta, GA

This poster will outline the National Spina Bifida Program as a model which could be replicated with other conditions of childhood, or disability in general, which result in life-long challenges to health, quality of life, and participation.

Poster listings continued on next page

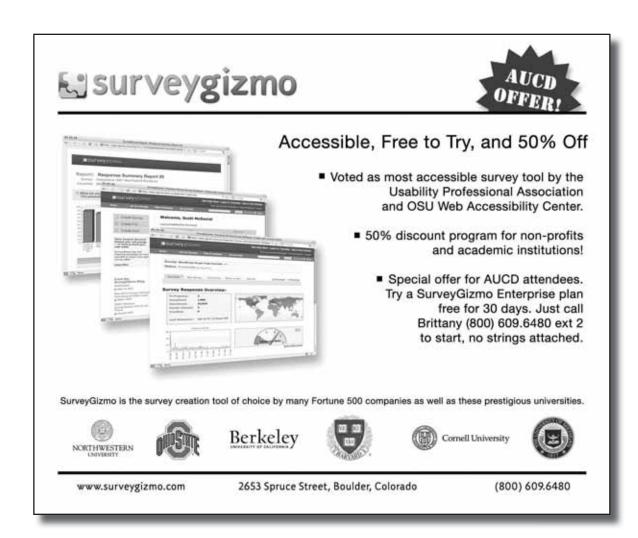
#### **Autism Avenue**

Poster 75

#### New Hampshire's Commission on Autism Spectrum Disorders: A Public Policy Report

- > Amy H. Frechette; Institute on Disability; Durham, NH
- > Rae M. Sonnenmeier, PhD; New Hampshire LEND Program; Lebanon, NH

In 2007 the governor appointed the NH Commission on ASD to study gaps in services for individual and their families. The final report addresses six areas of need: infrastructure; early identification and intervention; transition to adulthood; safety; professional development; and funding. Progress on implementation of the recommendations will be presented.



#### Poster 76

#### Autism Outcome Data in Nevada

- > Debra Vigil, PhD; Research and Educational Planning Center; Reno, NV
- > Candace Ganz; Center for Children and Youth with Special Needs; Portland, OR
- > Kate Green; Research and Educational Planning Center; Reno, NV
- > George McKinlay, MS; Research and Educational Planning Center; Reno, NV
- > Scott Harrington, PhD; Research and Educational Planning Center; Reno, NV



#### Poster 77

#### Follow-up of Young Children with Autism Spectrum Disorders: Continuity of Diagnosis

- > Patricia Towle, PhD; Westchester Institute for Human Development; Valhalla, NY
- > Lisa DeDomenico, PhD; Westchester Institute for Human Development; Valhalla, NY
- > Elizabeth Gonsalves, MS; Westchester Institute for Human Development; Valhalla, NY
- > Marie Pennacchio, RN, MBA; Westchester Institute for Human Development; Valhalla, NY
- > Julie Reichling, MS; Westchester Institute for Human Development; Valhalla, NY
- > Karyn Vacanti, MS; Westchester Institute for Human Development; Valhalla, NY

This study investigated the retention of an ASD diagnosis from preschool to 7-12 years of age. In addition, the outcome variables of educational setting and parent-rated autism symptoms were examined, in conjunction with the role of early intervention and the use of alternative and private therapies.

#### Poster 78

#### Feeding Behaviors of Children and Adolescents with Autism Spectrum Disorders

- > Keith Ayoob, EdD, RD; Rose F. Kennedy Center; Bronx, NY
- > Colleen Lennon, Trainee; Rose F. Kennedy Center; Bronx, NY

Presenters performed a retrospective chart review of 20 children with prior diagnosis of Autism Spectrum

Disorder who had formal nutrition assessment. They examined the feeding behaviors of subjects on antipsychotic medication at time of the evaluation with those who were not on medication and compared the findings.

#### Poster 79

#### Medical Home Service System Guidelines for Autism Spectrum Disorders

- > Daniel Bier, MPA, MSW; Waisman Center; Madison, WI
- > Linda Tuchman, PhD; Waisman Center; Madison, WI
- > Christine Breunig, MS; Children's Hospital of Wisconsin-Fox Valley; Neenah, WI

Review of ASD Service System Guidelines that have been developed and how they can be utilized to promote development of state plans to address ASD.



Poster listings continued on next page

Poster 80

#### A Social/Vocational Program for Transition Age Youth with High Functioning Autism

- > Tom Fish, PhD; Nisonger Center; Columbus, OH
- > Angela Suell Denny, PhD; Nisonger Center; Columbus, OH

This poster will describe a social vocational support program for young adults with high functioning autism and their families. In existence for six years, Aspirations has served over 100 individuals. Information will be provided regarding treatment interventions, curriculum, and research outcomes.

Poster 81

#### Training in Autism Spectrum Disorders: Impact and Implications Classroom Practice

- > Ann Mastergeorge, PhD; UC Davis M.I.N.D. Institute; Sacramento, CA
- > Lisa Sullivan, MS; UC Davis School of Education; Sacramento, CA
- > Patty Schetter, MA; UC Davis M.I.N.D. Institute; Sacramento, CA
- > Robin Hansen, MD; UC Davis M.I.N.D. Institute; Sacramento, CA

The focus of this poster is an autism training program that provides best practice information about strategies, techniques, and theories related to autism interventions. Training in a classroom and on-line format will be highlighted. General competency areas, specific course components, and examples of the training materials will be presented.

Poster 82

#### The New Jersey Autism and Faith Task Force: Collaboration on Resources, Training, and Technical Assistance

- > William Gaventa, MDiv; Elizabeth M. Boggs Center on Developmental Disabilities; New Brunswick, NJ
- > Robyn Carroll, MSW; Elizabeth M. Boggs Center on Developmental Disabilities; New Brunswick, NJ

A New Jersey Autism and Faith Task Force, a collaboration between the Boggs Center and COSAC, the statewide autism network, and a number of faith networks has developed resources for training and technical assistance for families and congregations.

Poster 83

#### Mile Markers, Signposts, and Intersections: the 'Act Early' Initiative of the 'Learn the Signs. Act Early.' Campaign

> Tracy Mann, MA; AUCD CDC Fellow, Centers for Disease Control and Prevention; Atlanta, GA

CDC's 'Learn the Signs. Act Early' campaign seeks to increase the awareness of parents about the importance of early identification and intervention for children with signs of autism and related disabilities. This presentation will provide an overview of the 'Act Early' initiatives, including activities to build partnerships among early intervention systems.

### **Neighborhood Entrance**

Poster 84

#### **Association of University Centers on Disabilities**

The Association of University Centers on Disabilities is a membership network of interdisciplinary centers advancing policy and practice for and with individuals with developmental and other disabilities, their families, and communities.

#### About the Media Room...From the Program Chair

New this year to the AUCD Annual Meeting is the Media Room, a place for AUCD members, filmmakers and other artisans to share their efforts with you. As the ways we communicate our research, teaching, and service evolve, the use of multiple forms of media become increasingly important. Film and video are powerful mechanisms for conveying experiences. Our Media Room presents films that give voice to the love of two young adults with Down syndrome; reveals a sister's reflections and rediscovery of her relationship with her brother, a man with autism; and provides a platform for a treatise about the "R" word by a theater group composed of persons with disabilities. Part of paving the way toward a world that is inclusive and empowering is the use of the tools available to us to communicate. These films provide an opportunity to view the world through the eyes of young adults with disabilities, siblings, family members, parents and advocates. I encourage you to take the time to view some of these offerings; in combination with our research, instruction and service, they are another tool to pave the way to a better future.

Michael Gamel-McCormick, PhD President-Elect, AUCD Board of Directors

### Monday, November 10, 2008

11:30 am - 12:30 pm

### **Strong Love**

"Strong Love" is the story of world-class weight lifter Jon Shapiro and his childhood sweetheart Holly James, both of whom were born with Down syndrome. This documentary follows the couple over the course of three years, starting with their decision to get married. Their challenges, their triumphs, and their complex, sometimes surprising relationships with family and friends are at the heart of this inspiring film.

Filmmaker: Bonnie Burt of Bonnie Burt Productions



1:30 pm - 2:53 pm

### Without Apology

"Without Apology" is a highly personal account of a family's and sibling's struggles to cope with the responses, realities and decisions posed by a family member with disabilities. The film travels an historical sweep, including the now unbelievable theories of refridgerator mothers causing their children's autism, the prescription of vast, walled-in institutions, the scandals uncovered by Geraldo Rivera and later the home and program options which replaced the institution.

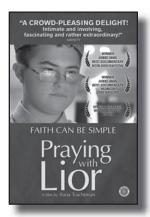
Filmmaker Susan Hamovitch of one~eyedCat Productions will be available for questions following the screening.



2:55 pm - 4:35 pm

#### Praying with Lior

"Praying with Lior" introduces Lior Liebling, also called "the little rebbe." Lior has Down syndrome, and has spent his entire life praying with utter abandon. Is he a "spiritual genius" as many around him say? Or simply the vessel that contains everyone's unfulfilled wishes and expectations? Lior—whose name means "my light"—lost his mother at age six, and her words and spirit hover over the film. While everyone agrees Lior is closer to God, he's also a burden, a best friend, an inspiration, and an embarrassment, depending on which family member is speaking. As Lior approaches Bar Mitzvah, the Jewish coming-of-age ceremony, different characters provide a window into life spent "praying with Lior." The movie poses difficult questions such as what is "disability" and who really talks to God?



Told with intimacy and humor, Praying with Lior is a family story, a triumph story, a grief story, a divinely-inspired story. Filmmaker Ilana Trachtman of Ruby Pictures will be available for questions following the screening.

4:35 pm - 5:05 pm

### Offense Taken: A Documentary About How One Community

#### Responded to the R Word

In the spring of 2007, when a Minneapolis theater company put on a show titled "Rise of the Celebretards," people with disabilities and their allies took action. "Offense Taken" documents this community's organized response to the play title and to the public use of the "R" word. By lifting up the voices of a broad range of citizens—people with disabilities, allies, educators, artists, and neutral theatergoers—the documentary also serves as a springboard for discussion about language: "Does artistic freedom trump human rights?" Filmmaker: Jerry Smith of RTC Media, Institute on Community Integration, University of Minnesota



The Media Room is located in MR 16

The Media Room is located in MR 16

### Tuesday, November 11, 2008

10:15 am - 11:30 am

#### The Teachings of Jon

This soul-touching and funny documentary about Jon, a 40 year old man who is severely affected by Down syndrome, ponders the serious questions of how we value each other and what is truly important in life. Although Jon has an IQ of 20, doesn't talk, and earns less than \$13.00 a year, he has an important purpose here, not necessarily to learn, but to teach.

Filmmaker: Jennifer Owensby, Waking Heart Films

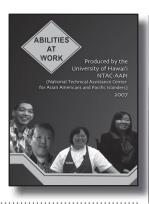


11:45 am – 12:45 pm

#### **Abilities at Work**

This film shows four compelling stories of Asian Americans and Pacific Islanders with disabilities who share their successful stories as workers in a variety of non-traditional settings for persons with disabilities.

Jean Johnson of the Center on Disability Studies, University of Hawaii, will be available for questions following the screening.



The Media Room is located in MR 16

## MEDIA

1:00 pm - 1:27 pm

#### Direct Support: A Realistic Job Preview

This video is focused on a recruitment strategy used to give potential employees detailed and balanced information about direct support job expectations, the employer, and the worksite, so they can make an informed decision about accepting a job offer. This professionally produced 22-minute video illustrates the real, every day work of direct support professionals.

Filmmaker: Jerry Smith, RTC Media, Institute on Community Integration, University of Minnesota

Amy Hewitt, Training Director; Institute on Community Integration, University of Minnesota will be available for questions following the screening.

1:27 pm - 1:45 pm

### **Direct Support Professionals**

The University of Delaware Center for Disabilities Studies presents an award winning video, which highlights the voices and careers of direct support professionals, and the people they support. The twelve-minute video provides a realistic snapshot depicting the rewards and the challenges of the profession.

Filmmaker Renee Settles Bean of the Center for Disability Studies, University of Delaware will be available for questions following the screening.

Direct Support Professionals Videos

To promos a more positive image of the direct suggest and included and professional deal for time-applicants by the field of disabilities, the Workforce Recruitment and Retention (Direction of the Control of t

Direct

Support

A Realistic Job Preview

1:45 pm - 2:15 pm

#### Beyond Disability: the Fe Fe Stories

The Empowered Fe Fes (slang for female), a group of young women with disabilities, hit the streets of Chicago on a quest to discover the difference between how they see themselves and how others see them.

Submitted by Salome Chasnoff, Beyondmedia Education



2:30 pm - 3:35 pm

#### Autism Spectrum Disorder Risk Alert (ASDRA)

"Detecting Autism at an Early Age", a video documentary CME, compares behaviors of children 18 months to three years old at risk for autism, to behaviors of age-matched children who are typically developing. Children are photographed in natural settings (at home, school, etc.) and also while being assessed by examiners.

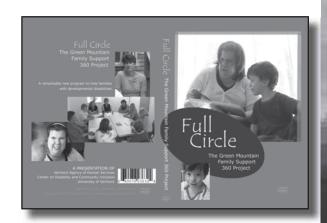




3:35 pm - 3:45 pm

#### Full Circle: Green Mountain FS360 Project

This DVD features the story of a mother and son, both with developmental disabilities, and the efforts of the Green Mountain Family Support 360 Project and the Vermont Agency of Human Services to reunite them in an innovative supportive living situation. Submitted by Susan Yuan, Center on Disability and Community Inclusion, University of Vermont



The Media Room is located in MR 16

# Notes





### AUCD Vision, Mission, and Values

#### Vision

The Association of University Centers on Disabilities (AUCD) envisions a future where all persons, including those living with developmental and other disabilities, are fully integrated and participating members of their communities. We envision a future where culturally appropriate supports are available across the life span to individuals and families: supports that lead to independence, productivity, and a satisfying quality of life.

#### Mission

The mission of AUCD is to advance policy and practice for and with people living with developmental and other disabilities, their families, and communities by supporting our members as they engage in research, education, and service that further independence, productivity, and a satisfying quality of life.

#### **Values**

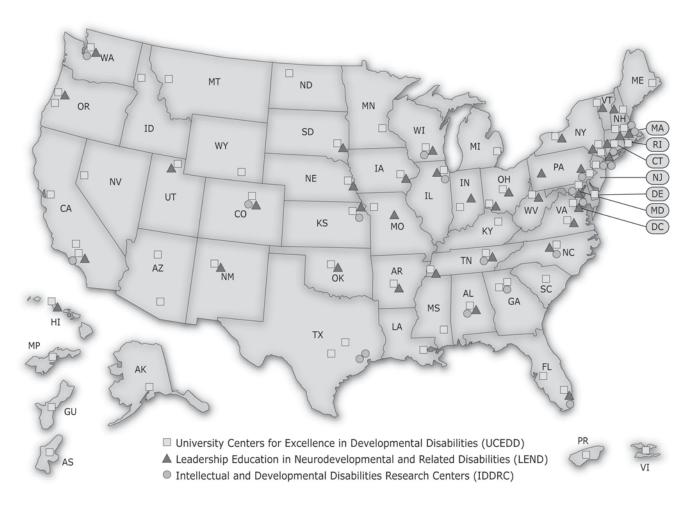
AUCD values the participation of people living with disabilities, family members and a culturally diverse membership in its governance and its programs. The network promotes the principles of self-determination, family-centered care, and cultural competence in disability services and supports throughout the life span.

### **About AUCD**

AUCD members—more than 200 universities and medical schools—represent every US state and territory. Through its members, AUCD is a resource for local, state, national, and international agencies, organizations, and policy-makers concerned about people living with developmental and other disabilities and their families. Its members engage in a range of interdisciplinary activities, including:

- · Exemplary services for children, adults, and families;
- Academic training;
- Basic and applied research;
- · Training and technical assistance to schools, communities, and state and local government;
- Policy advocacy;
- Program evaluation; and
- Dissemination of best practices and new information.

AUCD members train and educate the next generation of leaders in disability-related research, training, service delivery, and policy advocacy.



AUCD members also serve as a bridge between the university and the community, bringing together the resources of both to achieve meaningful change. Member organizations have unique strengths training professional leaders, individuals living with disabilities, and family members. in fields such as early intervention and education, primary health care, and special education, and in innovative housing and employment programs. Other members excel in basic and applied research, model demonstration, systemic reform and policy analysis. Because members are part of a national network, innovations emerging from one Center can be rapidly deployed and implemented in communities across the country. The network engages in nationally significant research that can inform national policy and understanding of evidence-based best practices, as well as guide broad implementation of innovations.

AUCD serves its members by promoting and supporting this national network. The network emphasizes national implementation of innovations in education, health care, prevention, and supports and services for people living with disabilities and special health needs. It offers national leadership on major social problems affecting children and adults living with developmental and other disabilities or special health needs. It accomplishes this through advocacy with Congress and executive branch agencies that fund and regulate disability and related programs, and through networking and partnering with other national organizations. AUCD promotes communication within its network and with other groups by collecting, organizing, and disseminating data on network accomplishments.

AUCD is a membership organization comprised of university-based entities. Membership in AUCD is open to University Centers for Excellence funded by the Administration on Developmental Disabilities, Leadership Education in Neurodevelopmental and related Disabilities Programs funded by the Health Resources and Services Administration's Maternal and Child Health Bureau, the Eunice Kennedy Shriver Intellectual and Developmental Disabilities Research Centers funded by the Eunice Kennedy Shriver National Institute for Child Health & Human Development, and related centers and entities in universities with similar missions and values. An elected Board of Directors that includes professionals, individuals with disabilities, and family members governs AUCD.

AUCD's organizational and program priorities are guided by a long-range plan that is regularly developed and updated by its Board of Directors.

### **AUCD Councils and Committees**

The AUCD Board of Directors has established a number of councils, committees, work groups, and task forces that are made up of experts in the field to help the Board address emerging trends and issues, and to facilitate communication across and beyond the AUCD network.

#### Councils of the Board

#### **Council on Community Advocacy**

The Council on Community Advocacy (COCA) advises and assists AUCD in enhancing the quality of life for persons with developmental disabilities and their families. The COCA accomplishes this through its member representation on the AUCD Board of Directors and other pertinent AUCD Committees. By providing the consumer's perspective on issues of concern, including cultural diversity issues, to all Committees, the COCA helps to build AUCD's capacity to better meet the needs of individuals with disabilities and their families.

#### **Council for Interdisciplinary Service**

The Council for Interdisciplinary Service (CIS) works with issues of concern to the core disciplines within the network and acts as a conduit for information to go to and from the Board of Directors and the various disciplines. Each core discipline in the Centers is represented on the CIS. The members of the core disciplines elect representatives to the CIS.

#### Council on Research and Evaluation

The mission of the Council on Research and Evaluation (CORE) is to encourage quality research and evaluation, promote collaborative studies across the AUCD network, advocate for broad acceptance of the many research and evaluation methodologies utilized across both the disciplines and the network Centers, support enhanced training to perform quality research and evaluation activities, advance the involvement of individuals with disabilities in all aspects of research, and to recognize quality research and evaluation across the AUCD network. The CORE serves as a focus for the identification and discussion of issues regarding research and evaluation; serves as a representative voice of the research and evaluation activities within the Association's network; and influences the development and implementation of initiatives relevant to achieving and sustaining appropriate research and evaluation activities to guide the development of national policies.

#### **Multicultural Council**

The Multicultural Council (MCC) advocates on behalf of the cultural diversity and cultural competence mandates of the Developmental Disabilities Assistance and Bill of Rights Act by providing support, technical assistance and policy input to AUCD. The MCC recruits and develops new leadership committed to the multicultural mission of the AUCD. The MCC incorporates considerations of cultural diversity and cultural competence into the deliberations of all standing AUCD Committees. The MCC has also established a formal initiative to serve in the multicultural assistance needs of the AUCD and member programs.

#### **National Community Education Directors Council**

The National Community Education Directors Council (NCEDC) is comprised of the Outreach Training Director/Coordinator (or a designee who best represents the overall outreach training interests) of each member program of AUCD. The purpose of the NCEDC is to serve as a focus and forum for the identification, discussion, and resolution of problems and issues regarding outreach training; function as a representative voice of the outreach training interests and concerns within the AUCD network; and influence the development and implementation of national outreach training policies and initiatives.

#### **National Training Directors Council**

The National Training Directors Council (NTDC) serves as a forum for the identification, discussion, and resolution of issues affecting interdisciplinary training. It represents training concerns within the AUCD network and influences overall policies and procedures that affect training. In addition, the NTDC acts as a communication vehicle for the implementation of national training policies through liaison with other groups.

#### Committees of the Board

#### **Communications Committee**

The Communications Committee serves to enhance and strengthen AUCD's internal and external communications to help ensure the greatest impact and fullest utilization of the network's capacity and resources.

#### **Finance Committee**

The purpose of the Finance Committee is to monitor, maintain, and build the financial health and stability of AUCD.

#### **Legislative Affairs Committee**

The Legislative Affairs Committee works to build AUCD's capacity for legislative advocacy, promote collaboration with the disability community to advance public policy, and develop new opportunities for member programs to promote the independence, productivity, and full participation of people with developmental and other disabilities.

#### **Program Committee**

The Program Committee serves to strengthen the AUCD network by developing strategic partnerships and collaborative programmatic opportunities for the membership and the Association.

#### Committees of the Association

#### **Health Care Policy Committee**

The Health Care Policy Committee has evolved into a national forum and network-based resource for promoting and protecting the consumer interests of people with developmental disabilities with regard to the health care delivery system, public policy, and the transition to managed care. The Committee, on occasion, will generate position papers related to current concerns and policy issues about access, quality of services, and accommodations for people with disabilities. It will create an inventory of knowledgeable network members regarding health care policy who can offer consultation to individual member programs, as needed. Finally, it will seek to create partnerships with similar associations, state and federal agencies, and community-based programs to achieve accessible and affordable health care for all Americans.

#### International Committee

The International Committee serves as an information collection and exchange mechanism for UCEDDs and programs throughout the world that serve persons with developmental disabilities. The International Committee determines the feasibility of pre-service and in-service training exchange programs and coordinates, arranges, and provides technical assistance and consultation on program development or program modification to any country or program making such a request. The International Committee also facilitates the development and planning of international presentations, workshops, and other activities appropriate for international conferences.

### **AUCD Past Presidents**

AUCD is pleased to recognize the following individuals for their outstanding contributions to the network and for their leadership as President of the AUCD Board of Directors:

Robert W. Deisher, MD	Jack H. Rubinstein, MD	Terrence R. Dolan, PhD	Penny Seay, PhD
1967-1969	1978-1979	1988-1989	1998-1999
William M. Gibson, MD	Victor D. Menashe, MD	Gerald Golden, MD	David M. Mank, PhD
1969-1970	1979-1980	1989-1990	1999-2000
Margaret P. Giannini, MD	Herbert J. Cohen, MD	Robert Stempfel, MD	Gloria L. Krahn, PhD, MPH
1970-1971	1980-1981	1990-1991	2000-2001
Charles L. Davis	James F. Budde, EdD	Deborah Spitalnik, PhD	Robert A. Stodden, PhD
1971-1972	1981-1982	1991-1992	2001-2002
Robert G. Jordan, MD	Allen C. Crocker, MD	Gary Goldstein, MD	Robert Bacon, MA
1972-1973	1982-1983	1992-1993	2002-2003
John H. Meier, PhD	Alfred Healy, MD	Carl F. Calkins, PhD	David R. Johnson, PhD
1973-1974	1983-1984	1993-1994	2003-2004
Harvey A. Stevens	Marvin Fifield, EdD	Bruce A. Buehler, MD	Fred Palmer, MD
1974-1975	1984-1985	1994-1995	2004-2005
Paul H. Pearson, MD	Hugo W. Moser, MD	Valerie N. Williams, MPA	Lucille A. Zeph, EdD
1975-1976	1985-1986	1995-1996	2005-2006
Charles V. Keeran, MS, MSW	Michael J. Guralnick, PhD	Fred P. Orelove, PhD	Royal P. Walker, Jr., JD
1976-1977	1986-1987	1996-1997	2006-2007
Phyllis R. Magrab, PhD	Ansley Bacon, PhD	Sheryl White-Scott, MD	William E. Kiernan, PhD
1977-1978	1987-1988	1997-1998	2007-2008

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Laura Martin, Director of Operations

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Development
Danielle Onunkwo, Technical Assistance Specialist

Crystal Pariseau, MSSW, MCH Technical Assistance and Materials

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Tammie Picklesimer, MEd, Disability Policy Leadership Fellow

George S. Jesien, PhD, Executive Director



## SAVE THE DATE

# 2009 Disability Policy Seminar April 27-29, 2009

AUCD is again joining the Arc, UCP, AAIDD, and NACDD to host the 2009 Disability Policy Seminar. It is critical that the disability community and other interested participants from around the country participate in this three-day seminar. Preserving and strengthening the federal policies and programs important to people with disabilities and their families is our top priority.

The Disability Policy Seminar is an opportunity for UCEDD, LEND, and IDDRC directors, staff, and trainees to gain intensive knowledge on these federal policies and programs to enhance your state and community work. The seminar is also an opportunity to network



with colleagues throughout your field and engage national experts on current and future trends in fiscal policy, employment, healthcare, education, housing, transportation, and other important issues in the lives of people with disabilities.

Check <u>www.aucd.org</u> for updates on the 2009 Disability Policy Seminar

## SAVE THE DATE



ASSOCIATION OF UNIVERSITY CENTERS ON DISABILITIES

RESEARCH, EDUCATION, SERVICE

### AUCD 2009

# Annual Meeting & Conference

November 7-11, 2009

Renaissance Washington Hotel Washington, DC

Join AUCD at its 2009 Annual Meeting & Conference.

We will explore all that has changed in the disability community and in our network.

With exciting plenary sessions, engaging concurrent sessions, and enticing posters,

AUCD's 2009 meeting promises to be one event you don't want to miss.

Mark your calendars now!

Watch your email and the homepage of www.aucd.org for updates on the 2009 AUCD Annual Meeting & Conference

# Notes

