

PHILADELPHIA

COMMUNITY HEALTH SUPPORTS:  
Facing the Challenge

**AAMR 128th Annual Meeting  
and Exhibit Show**

Philadelphia Marriott Downtown  
June 1-4, 2004  
Philadelphia, Pennsylvania

**American Association  
on Mental Retardation**

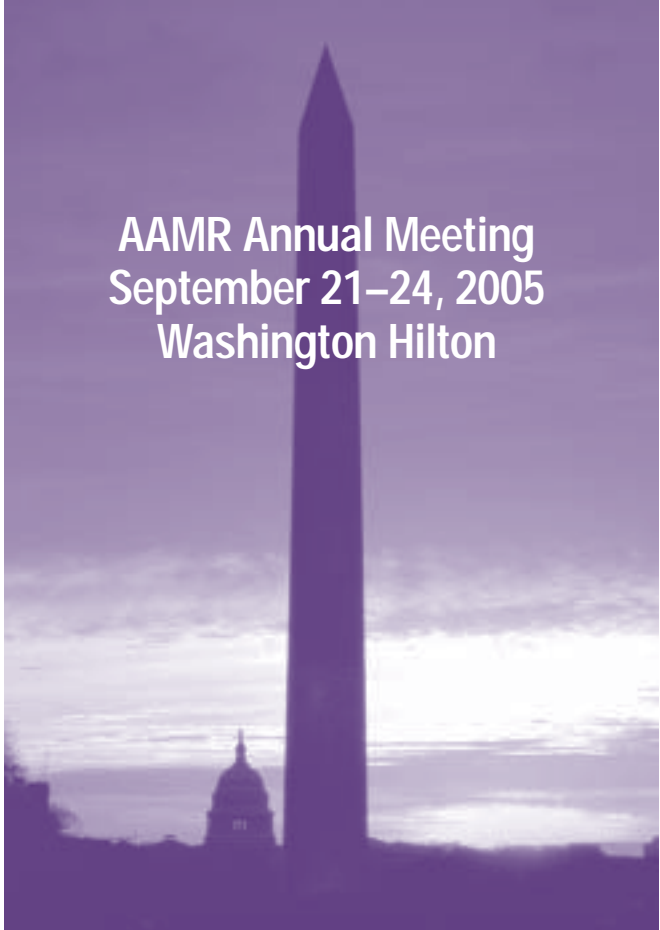
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# Join AAMR in Washington, DC in 2005!

Join us next year in Washington, DC as we hold the **AAMR Annual Meeting** in conjunction with 11 other national disability organizations!

**On September 21–24, 2005**, the Alliance for Full Participation will hold a seminal developmental disabilities Summit with the theme of “Many Voices, One Vision.” This summit is an unprecedented opportunity to create a spirit of partnership and collaboration that can be embraced by all stakeholders—self-advocates, family members, providers, professionals, researchers, educators, and public officials at the federal, state, and local levels to achieve the goal of inclusive communities for all.

***Don't miss this very special exciting event!***



**AAMR Annual Meeting  
September 21–24, 2005  
Washington Hilton**

#### **ALLIANCE FOR FULL PARTICIPATION PARTNERS**

American Association on Mental Retardation  
American Network of Community Options and Resources  
Association of University Centers on Disabilities  
National Association of Councils on Developmental Disabilities  
National Alliance of Direct Support Professionals  
National Association of Protection and Advocacy Systems  
Self-Advocates Becoming Empowered  
The Arc of the United States  
The National Association of State  
Directors of Developmental Disabilities Services  
United Cerebral Palsy  
The Council on Quality and Leadership

The **Alliance for Full Participation, LLC** is composed of 11 national disability organizations whose objective is to work together as partners to achieve our collective vision—a world where people with developmental disabilities and their families realize the promise of integration, productivity, independence, and quality of life choices.

# WELCOME FROM THE AAMR PRESIDENT

## AAMR



Welcome to AAMR's 128th Annual Meeting in the historic city of Philadelphia. Can you imagine what the agenda of AAMR's first meeting must have been 128 years ago? What will AAMR be contemplating 128 years from now—in the year 2232? Clearly, our field has made incredible progress, but we “have miles to go.” The purpose of this meeting is to keep moving forward in a progressive direction.

The Board of Directors has given careful attention this year to AAMR's strategic plan and to its three primary niche goals:

- Promoting the use of AAMR's widely-accepted definition of mental retardation
- Advancing the supports paradigm
- Advancing *physical, emotional, spiritual, and environmental* health for the benefit of individuals with intellectual and developmental disabilities

This year's program focuses primarily on our health priority, and continues to promote the Community Health Supports Model which provides supports to individuals in managing limitations, performing priority activities, and participating in valued relationships within their communities of choice. I especially want to extend my heartfelt gratitude to Dr. David Coulter, President-Elect, for planning the conference. David has done a very commendable job of organizing a coherent and comprehensive program focusing on the four domains of optimal health.

In addition to the substantive and stimulating sessions, you will have the chance to meet new people and expand your own professional and personal networks. I encourage you to “get out of your safety zone of familiarity” and meet new people and learn about their professional experiences and personal perspectives. Just as we seek to create inclusive communities for individuals with disabilities, I hope that we will similarly commit to creating inclusive communities within AAMR where we have opportunities to expand our horizons through personal relationships.

I hope very much that I will have a chance to visit with you during the conference. Please let me know if I can do anything to enhance the quality of this conference experience for you. Thank you for participating in AAMR and especially thank you for enhancing the likelihood that individuals with intellectual and developmental disabilities and their families will have personally satisfying lives.

A handwritten signature in cursive script that reads "Ann P. Turnbull".

Ann P. Turnbull  
AAMR President

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# WELCOME FROM THE LOCAL ARRANGEMENTS COMMITTEE

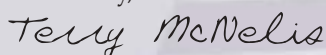
Welcome to Philadelphia where the blend of history and modern innovation is foremost. Philadelphia is the birthplace of the United States of America and the host of the Independence National Historical Park. The City welcomes all visitors from all nations to share our history and charm. In it's most historic mile, you can visit **Independence Hall**, the **Liberty Bell** and the newly opened **National Constitution Center**. Additional sites include **Christ Church**, "the Nation's Church," **Elfreth's Alley**, and the celebrated **Philadelphia Zoo**. The **Philadelphia Museum of Art**, majestically located at the river-end of the **Benjamin Franklin Parkway**, encourages many visitors to run up the famous steps climbed by Sylvester Stallone in *Rocky*. In addition Philadelphia is a culinary attraction with hundreds of exciting restaurants—many within walking distance of the Marriott Hotel. World-renowned **Chefs Morimoto, Bobby Flay and Jacques Pepin** can all be found in Philadelphia. The exciting areas of **Chinatown, South Street, Olde City**, the

**Italian Market, Reading Terminal** and historic **Manyunk** offer many artistic, ethnic and unique shops, restaurants and attractions.

The Local Arrangement Committee members Albert Brown, Celia Feinstein, Dina McFalls, Grace Dempster, Karen Claiborne Pride, Kathy Brown McHale, Kathy Miller, Kathy Sykes, Melissa Evers, Robin Levine, Sharon Kauffman, and Paul Spangler have worked very hard to make this a memorable visit to the city.

We invite you to enjoy the conference and our wonderful host city of "Brotherly Love" and use this opportunity to re-acquaint yourselves with old colleagues as well as make new ones who are interested in advancing the mission of AAMR.

Yours truly,



Terrence McNelis

Local Activities Committee Chairperson



## WELCOME FROM THE AAMR PRESIDENT-ELECT AND PROGRAM CHAIR

Health represents the composite of  
*physical, mental, social and spiritual* wellbeing.

Welcome to AAMR's 128th Annual Meeting and Exhibit Show! This conference was designed to explore the broad meaning of health for persons with intellectual disabilities. Health represents the composite of *physical, mental, social and spiritual* wellbeing. Health is not the absence of disability, and disability is part of the human condition. In this sense, all of us are more or less healthy, and all of us aspire to optimal health in these four areas. The challenge we face as professionals is how to promote and assure optimal health for all persons with intellectual disabilities. The Community Health Supports model, which is based on the World Health Organization's models of health and functioning, provides a way to address this challenge. This new approach envisions health activities that promote wellbeing by helping the individual manage personal impairments in order to perform self-chosen activities that promote participation in desired social roles within the community of choice. Health activities include medical, behavioral, therapeutic, social and spiritual supports, as well as provision of needed environmental adaptations and technological assistance.

During these next few days you will participate in an exceptionally vigorous, diverse, field-initiated, and peer-reviewed discussions of health and intellectual disability.

- **Plenary Sessions** present key topics in spiritual, physical, mental, and environmental health.
- **Special Theme Sessions** expand on these areas of health with presentations that explore what is being done around the country to address the challenges we face.
- **Interactive Sessions** provide an opportunity to meet and interact with speakers who are working to realize the vision of Community Health Supports.
- **Emerging Issues Sessions** present a number of critical issues we will face in the coming years.

So dig deep in this rich mine of knowledge, engage the presenters in discussion, think hard about what you have learned, and determine how you can improve the health of persons with intellectual disabilities. Enjoy your time here in Philadelphia. Meet and make friends, establish new contacts, and leave with the skills you need for the future. Join us in AAMR as we face these challenges together. Your participation is essential for our success. Thank you for coming and being a part of this stimulating program.



David L. Coulter, MD  
Program Chair and President-Elect

# Don't Miss These Exciting Sessions!

Attend these exciting workshops and satellite programs for the opportunity to gain more in-depth knowledge about critical areas of health.

**NEW!**

**Emerging Issues**—A new session track on Emerging Issues explores the topics that will be confronting the field in the future.

**NEW!**

**Direct Support & Advocacy Track**—A new session track especially geared to Direct Support Staff and Self-Advocates is offered for the first time ever!

**NEW!**

**Supports Intensity Scale Workshop**—Hear the authors introduce this revolutionary new standardized assessment tool that measures the individualized support needs of people with cognitive disabilities. This distinguished team will teach you how to use SIS to evaluate support needs, develop plans to address support needs, and monitor outcomes.

**NEW!**

**PBSTC Workshop**—A special professional workshop on how to implement the new Positive Behavior Support Training Curriculum for supervisors and direct support staff will tell you everything you need to know about this exciting new turn-key curriculum (curriculum, overheads, tests, role playing, on-the-job-training assessments, etc.).

**NEW!**

**Special Symposium on Health**—Come hear experts discuss scientific evidence about people with intellectual disabilities and physical activity, mobility, nutrition, hypertension, risk assessment, safety, reproductive health, and health care access, etc., in this all-day symposium.

**NEW!**

**Plenary Session on Environmental Health**—This new session on **Pollution, Toxic Chemicals, Disability, and Our Health** explores the exciting new

research and policy developments in exploring how environmental contaminants may cause or impact people with developmental disabilities.

**They Fought for the Life of Earl Washington, Jr. and Won**—Hear the lawyers and advocates tell how they freed a man from death row—and hear Earl Washington, Jr.'s impressions of the ordeal.

**Plenary Session on Mental Health**—Four national experts discuss the state of **Alzheimer's Disease in adults with Down Syndrome** at this mental health plenary.

**Plenary Session on Spiritual Health**—Rev. Bill Gaventa will discuss the role of spirituality in holistic care in this Opening Session.

**Plenary Session on Physical Health**—Hear the conclusions from the all-day special symposium on health.

**Emerging Technologies and State of the States**—Take a look at state funding, emerging technologies, and barriers to using technologies.

**Professional Workshops**—Attend one of the many morning and afternoon Professional Workshops to find out the latest from those who conduct the research, make the policy, and deliver the services. Workshops include Promoting Good Health, Working for a Living, Leadership, and Transitioning.

**NADD/AAMR Symposia**—When NADD and AAMR team up, the results are impressive. Don't miss these two symposia on Criminal Offenders Risk Assessment and Treatment Options, and Critical Issues in Psychotropic Agents.

COMMUNITY HEALTH SUPPORTS: FACING THE CHALLENGE

# Program-At-A-Glance

	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY
<b>MORNING</b>	<b>Special Symposium on Health</b> 9:00 am–5:00 pm	<b>Business Meetings</b> 7:00 am–8:00 am <b>First Time Attendee Orientation</b> 7:30 am–8:00 am <b>Exhibit Hall Opening</b> 8:00 am–9:00 am <b>Video Theater View-on-Demand</b> 8:00 am–5:00 pm <b>Opening Session Plenary Session on Spiritual Health</b> 9:00 am–10:30 am <b>Direct Support &amp; Self-Advocacy Track</b> 9:00 am–4:30 pm <b>The Academy Program</b> 10:45 am–9:00 pm <b>Special Theme Sessions</b> 10:45 am–12:15 pm	<b>Business Meetings</b> 7:00 am–8:00 am <b>Exclusive Exhibit Time</b> 8:00 am–9:00 am <b>The Academy Program</b> 8:00 am–4:15 pm <b>Video Theater View-on-Demand</b> 8:00 am–5:00 pm <b>Plenary Session on Mental Health</b> 9:00 am–10:15 am <b>Direct Support &amp; Self-Advocacy Track</b> 9:00 am–4:30 pm <b>Exhibit Hall Open and Poster Presentations</b> 10:00 am–1:15 pm <b>Special Theme Sessions</b> 10:45 am–12:00 noon	<b>Business Meetings</b> 7:00 am–8:00 am <b>AAMR Board of Directors Open Forum</b> 8:00 am–9:00 am <b>Half-day Morning Workshops</b> 9:00 am–12:00 noon <b>NADD/AAMR Symposium I</b> 9:00 am–12:30 pm <b>Religion &amp; Spirituality Division Program</b> 9:30 am–7:00 pm
<b>AFTERNOON/ EVENING</b>	<b>AAMR Joint Leadership Meeting</b> 1:00 pm–1:45 pm <b>AAMR Leadership Meetings</b> 2:00 pm–5:00 pm  <b>Welcome Reception</b> 5:30 pm–7:00 pm	<b>Exhibit Hall Open and Poster Presentations</b> 12:15 pm–1:45 pm <b>Plenary Session on Physical Health</b> 1:45 pm–3:00 pm <b>Special Theme Sessions</b> 3:15 pm–4:45 pm <b>Emerging Issues Presentations</b> 3:15 pm–4:45 pm <b>Exhibit Hall Reception &amp; Poster Presentations</b> 5:00 pm–7:30 pm	<b>Plenary Session on Environmental Health</b> 1:45 pm–2:30 pm <b>Special Theme Sessions</b> 3:15 pm–4:45 pm <b>Presidential Address</b> 4:30 pm–5:30 pm <b>Awards Ceremony</b> 5:30 pm  <b>Cocktail Reception</b> 6:30 pm–7:30 pm	<b>Luncheon Meetings</b> 12:00 noon–1:30 pm <b>Half-day Afternoon Workshops</b> 1:00 pm–4:00 pm <b>NADD/AAMR Symposium II</b> 1:30 pm–5:00 pm <b>2004–2005 AAMR Board of Directors' Meeting</b> 1:30 pm–5:00 pm

## Sponsors

AAMR says "Thank You" to Our Generous Sponsors for Contributing to the Success of Our 128th Annual Meeting

**AAMR Pennsylvania State Chapter**

**Coleman Institute for Cognitive Disabilities**  
 University of Colorado  
[www.cu.edu/ColemanInstitute](http://www.cu.edu/ColemanInstitute)

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[www.communityinclusion.org](http://www.communityinclusion.org)

**Irwin Siegel Agency**  
[www.siegelagency.com](http://www.siegelagency.com)

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[www.libertyhealthcare.com](http://www.libertyhealthcare.com)

**The MENTOR Network**  
[www.thementornetwork.com](http://www.thementornetwork.com)

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 215-707-0580

**Pennsylvania Department of Public Welfare**  
 Office of Mental Retardation  
[www.dpw.state.pa.us/omr/dpwmr.asp](http://www.dpw.state.pa.us/omr/dpwmr.asp)

**PMHCC**  
[www.PMHCC.org](http://www.PMHCC.org)

**Sigma-Tau Pharmaceuticals, Inc.**  
[www.sigmatapharma.com](http://www.sigmatapharma.com)

**Community Access Unlimited**  
[www.caunj.org](http://www.caunj.org)

**PCHC**  
[www.PCHC.org](http://www.PCHC.org)

**Philadelphia Office of Behavioral Health/Mental Retardation Services**  
[www.mycitymyplace.org](http://www.mycitymyplace.org)

**Northwestern Human Service**  
[www.NHSONLINE.org](http://www.NHSONLINE.org)

**Ken-Crest Services**  
[www.KenCrest.org](http://www.KenCrest.org)

**Resources for Human Development**  
[www.RHD.org](http://www.RHD.org)

# 2004 Annual Meeting Program

**TUESDAY • 6.1.04**

## Registration

7:00 am–5:00 pm

1:00 pm–1:45 pm

**AAMR Joint Assembly and Conference Leadership Meeting**

Room: Salon A

2:00 pm–5:00 pm

**AAMR Conference of Professional Interests Meeting**

Rooms: 401 & 402

**AAMR Assembly of Geographic Interests Meeting**

Rooms: 414 & 415

2:00 pm–9:00 pm

**Business Meetings**

See page 32 for list of Business Meetings

5:30 pm–7:00 pm

**Welcome Reception**  
**AAMR Leaders Welcome**  
**You to Philadelphia.**

Everyone Welcome!

Sponsored by  
**The Mentor Network**

Room: Salon CD

**Tuesday Night at the Movies**

7:30 pm

Room: Salon KL

## SPECIAL SYMPOSIUM ON HEALTH

9:00 am–5:00 pm

### **Health Promotion for Persons With Intellectual and Developmental Disabilities: The State of Scientific Evidence**

*Moderator: Wendy Nehring, RN, PhD, Rutgers, The State University of New Jersey*

*Welcome and Introductions:*

*Doreen Croser, AAMR Executive Director;*

*José Cordero MD, MPH, National Center on Birth Defects and DD;*

*Lee Barks RN, ARNP, PhD(c)*

*James Rimmer, PhD, University of Illinois at Chicago; Linda Bandini, PhD, RD, Eunice Kennedy Shriver Center; Sheryl Larson, PhD, University of Minnesota; Betsey Benson, PhD, Nisonger Center, Ohio State University; Edward Hurvitz, MD, Pediatric Physical Medicine and Rehabilitation; Christopher Draheim, PhD University of Minnesota; Ruth Northway, PhD, MSc, RNLD, University of Glamorgan at Wales; Tom Seekins, PhD, University of Montana Rural Institute; David Coulter, MD, Harvard Medical School; Children's Hospital-Neurology Division; Richard Sobsey, PhD, University of Alberta, Canada; Sheryl White-Scott, MD, St. Charles Devpl Disabilities Program, SVCMC; J. Joan Sheppard, PhD, CCC; Maureen Lefton-Greif, PhD, CCC/SLP, Johns Hopkins Children's Center; Paula Minnihan, MSN, MPH, PhD, Tufts University SOM; Mary Cerreto, PhD, Center on Self-Determination and Health Dept of Family Medicine; Teresa Moore, Self Advocate*

This all day national conference addresses the state of the scientific evidence on health promotion as it relates to persons with intellectual and developmental disabilities (I/DD). The topics to be presented include physical activity and mobility, obesity and overweight/nutrition, access to health care, hypertension, alternative and complementary medicine, case management/care coordination, mental health, health risk assessment tools, epilepsy, safety/injury and violence, reproductive

health, respiratory health, tobacco use/substance abuse, and conceptual health promotion models. For each topic, nationally recognized speakers will present the current scientific evidence and make recommendations for future research and health care practice. With this conference, AAMR takes the next step in addressing some of the concerns and recommendations made in the Surgeon General's report, "Closing the Gap" (2002).

**COST: \$100**

**Room: Salon B**

**Registration**  
7:00 am–6:00 pm

**Exhibit Hall and Interactive Poster Presentations**

See page 27 for list of Interactive Poster Presentations.

8:00 am–9:00 am—Continental Breakfast  
12:15 pm–1:45 pm—Lunches Available at Noon  
5:00 pm–7:30 pm—Reception

Room: Exhibit Hall/Franklin Hall

7:00 am–8:00 am

**Business Meetings**

See page 32 for list of Business Meetings.

7:30 am–8:00 am

**1st Time Attendees Orientation**

*Presiding: David Coulter, MD*

If this is your first time AAMR Annual Meeting, please join AAMR Mentors for an orientation

Room: Salon D

7:30 am–8:00 am

**Called to Spirituality: A Time for Reflection, Meditation, Worship, and Prayer**

*Presiding: Rev. Earl Bleke*

Room: 403

8:00 am–9:00 am

**Exhibit Hall Opening and Interactive Poster Presentations**

Complimentary Continental Breakfast

See page 27 for list of Interactive Presentations.

Room: Exhibit Hall/Franklin Hall

8:00 am–5:00 pm

**Video Theater**—View-on-Demand

Room: 406

8:00 am–5:00 pm

**Speaker Ready Room**

Room: 404

9:00 am–10:15 am

DIRECT SUPPORT & SELF-ADVOCACY TRACK

**How Waiting List Legislation Has Changed Services**

*Celia Feinstein, Jim Lemanowicz, Temple University Institute on Disabilities*

Celia and Jim will discuss how legislation that requires a state waiting list has expanded and changed services for individuals with disabilities in other states.

Room: 407

**OPENING SESSION**

9:00 am–10:30 am

*Presiding: Ann Turnbull, AAMR President*

*Introductions: David Coulter, Program Chairperson and President-Elect*



Ann Turnbull



David Coulter

**PLENARY SESSION ON SPIRITUAL HEALTH**



Bill Gaventa

**A Place for All of Me and All of Us: Rekindling the Spirit in Services and Supports**

*Bill Gaventa, MDiv, Director, Community and Congregational Supports, The Elizabeth M. Boggs Center on Developmental Disabilities, Department of Pediatrics, Robert Wood Johnson Medical School, University of Medicine and Dentistry of New Jersey*

The role of spirituality in holistic care is receiving increasing attention in healthcare as scientific researchers and clinicians in many disciplines work with pastoral caregivers, religious communities, alternative medicines and therapies, and culturally competent supports—all of which tap the power of spirituality to impact health and healing. How might that research and practice enhance services and supports for people with developmental disabilities and their families? What are the implications for professional caregivers, providers, advocates, families, and communities?

Room: Salon EF

9:00 am–10:15 am

DIRECT SUPPORT & SELF-ADVOCACY TRACK

**“Married With Children:” An Advocate’s Point of View**

*Lee Bongiovi; Mildred Alexander; Vailene Fields, Advocates*

First comes love, then comes marriage, then comes the baby carriage...well, maybe not always in that order! Intimacy and family are key elements of quality of life. Advocates share their insights about the extraordinary experience of being a partner and a parent while living with the ‘disability’ label.

Room: 410

10:45 am–12:15 pm

SPECIAL THEME SESSION

**Peace-Making Is the Answer to Death-Making**

*Wolf Wolfensberger, PhD, Syracuse University; David Coulter, MD, Harvard Medical School; Children’s Hospital Neurology Division; Stephen Drake, Not Dead Yet*

Come hear world-renowned leader Wolf Wolfensberger and incoming AAMR President David Coulter in a lively discussion of the philosophies, realities, and ethics of the field of MR/DD, and a healthy and moral direction and vision of the future.

Room: Salon B



10:45 am–12:15 pm

SPECIAL THEME SESSION

### Personal Wellbeing Includes Health and More: An International Quality of Life Perspective



Robert Schalock

Robert Schalock, PhD, Schalock & Associates; Miguel Verdugo, PhD, University of Salamanca; Mian Wang, PhD, University of Kansas

Internationally recognized experts summarize cross-cultural studies that demonstrate eight core quality of life domains, including discussions of physical well-being, quality of life assessments, and statistical methods in cross-cultural research.

Room: Salon C

10:45 am–12:15 pm

INTERNATIONAL SYMPOSIUM

### What Is Mental Retardation: An International Perspective

Yves LaChapelle, PhD, (Canada); Wil Buntinx, Drs (The Netherlands); Marie-Claire Haelewyck (Belgium); Leslie Rubin, MD (USA)

Speakers from four countries present current definitions and nomenclatures of mental retardation as used in policy and practice, and identify trends and perspectives for the future.

Rooms: 411 & 412

10:45 am–12:15 pm

SPECIAL THEME SESSION

### Risk Management

#### A New Vision of Risk Management: One Organization's Story

Suzanne Thomas, PhD, The Columbus Organization; Denise Micheletti, MS, RN, The Columbus Organization

This presentation chronicles one organization's adoption of a comprehensive risk management system including efforts to assess risk and establish proactive risk prevention strategies.

#### Promoting Health Through Risk Management

Barry Schwartz, EdD, Vinfen Corporation; Madeline Becker, EdD, Vinfen Corporation; Maureen Malin, MD, Vinfen Corporation

Members of Vinfen's Risk Management Committee review its process, and share data and the improvement directions it has undertaken to develop systems to identify areas of risk and take steps to promote more positive outcomes.

#### Managing Risk Through an Outcome-Oriented Investigative Process

Aimee Wilson, Philadelphia County MR Services/Risk Management Unit (RMU); Lynne Opsasnick, MSW, Philadelphia County MR Services/RMU; Clifford Isaac, Philadelphia County MR Services/RMU; Howard Staneruck, Philadelphia County MR Services/RMU; Rodney Acker, Philadelphia County MR Services/RMU

This session presents a three-pronged approach whereby serious and potentially harmful incidents involving individuals with intellectual disabilities are investigated and remediated.

Room: Salon D

10:45 am–12:15 pm

SPECIAL THEME SESSION

### Medical Care in the Community

#### Clinical Supports in the Community

Amy Goldman, MS-CCC, SLP, Community Services Network of West TN

CSN, a non-profit waiver provider serving recently de-institutionalized adults with MR/DD, describe their three-year-old program providing case management, clinical network development, medical management support, and claims paying.

#### Access to Primary and Specialty Care for Persons With MR/DD Living in Florida

David Wood, MD, MPH, Division Community Pediatrics, University of Florida; Allyson Hall, PhD, University of Florida

Wood and Hall present analyses of Medicaid claims data on 30,000 persons with MR/DD in Florida to guide public state and local policy in the improvement of the quality of outpatient health services.

#### Obstacles and Opportunities in Providing Medical Care to Adults With DD

Marc Emmerich, MD, Liberty Healthcare and Boston Community Medical Group

This presentation reviews obstacles to optimal medical care that adults with significant developmental disabilities commonly encounter that can cause actual life-threatening situations, and opportunities for all types of providers to overcome these obstacles.

Rooms: 414 & 415

10:45 am–12:15 pm

SPECIAL SESSION

### Environmental Risks to Health

Allison Davis, RN, The Arc of Anne Arundel County; Barbara Sattler, DrPH, RN, University of Maryland, School of Nursing; Ted Schettler, MD, Science and Environmental Health Network, Greater Boston Physicians for Social Responsibility

Brain development, beginning very early in human gestation and continuing through adolescence, depends on a tightly orchestrated cascade of sequential and concurrent events. Some environmental exposures can create risks for brain and neurological development. This session will discuss the current state of our scientific understanding of the special "windows of vulnerability" and susceptibility to environmental contaminants in our everyday lives—in our air, water, food, and communities, and the practical steps of minimizing environmental health risks.

Room: 413

**10:45 am–12:00 noon**

DIRECT SUPPORT & SELF-ADVOCACY TRACK

**Making Service Coordination Work for You**

*Joanna Pierson, PhD, Michael Planz, The Arc of Frederick County Service Coordination; Tracey Wright, Judy Volkman, Wallbusters*

Your Service Coordinator/Case Manager works for *you*. This session will explain what you have a right to expect from your Service Coordinator, questions to ask your Service Coordinator, and how to complain if your Service Coordinator is not doing what you see as important.

**Room: 403**

**10:45 am–12:00 noon**

DIRECT SUPPORT & SELF-ADVOCACY TRACK

**Working in Partnership With Families to Enhance Quality of Life**

*Ann Turnbull, EdD, Denise Poston, PhD, Kansas University Beach Center*

This session provides strategies for developing partnerships between families and service providers that foster quality of life for individuals and families. We will focus on developing action plans for families around family interaction, parenting, physical wellbeing, emotional wellbeing, and support for the family member with a disability.

**Room: 407**

**10:45 am–12:00 noon**

DIRECT SUPPORT & SELF-ADVOCACY TRACK

**Looking for a Place to Go? How to Get Connected to Community Resources!**

*Ira Geller, Advocate*

During this presentation people will learn that they don't have to stay bored inside their home all day! The presenter discusses social events, different places that people can go to get information, and ways they can get out and enjoy themselves in the community. Community resources include: the public library, social service agencies, colleges and universities, advocacy groups, and recreation departments.

**Don't Let Your Disability Control You**

*Myrta Rosa; Mark Straka; Kathy Marcus; Larry Marcus, Advocates*

This workshop includes a frank discussion about how people's perceptions and bias about "disabilities" could hold you back. We'll share experiences and role-play self-esteem, assertiveness and self-advocacy.

**Room: 410**

**10:45 am–12:15 pm**

ACADEMY SYMPOSIUM

**The Future of Newborn Screening for Genetic Disorders that Cause Intellectual Disabilities**

*Chair: Steven Warren, PhD, Schiefelbusch Institute for Life Span Studies, University of KS*

**Rapid Evolution of Newborn Screening.**

*Rodney Howell, MD, National Institute of Child Health and Human Development.*

**Will Disorders Causing Mental Retardation Meet Criteria for Newborn Screening?**

*Don Bailey, PhD, Frank Porter Graham Child Development Institute, University of North Carolina at Chapel Hill.*

**Treatment Efficacy as a Standard for Newborn Screening of Disorders Associated with Intellectual Disabilities.**

*Steven Warren, PhD, Schiefelbusch Institute for Life Span Studies, University of KS*

**Room: Salon A**

**12:15 pm–1:45 pm**

**Exhibit Hall Open and Interactive Poster Presentations**

**Lunches Available**

See page 27 for a list of Interactive Poster Presentations.

**Room: Exhibit Hall/Franklin Hall**

**12:15 pm–1:45 pm**

**Pennsylvania Chapter Meeting**

**Room: 405**

**PLENARY SESSION ON PHYSICAL HEALTH**

**1:45 pm–3:00 pm**

**Where Are We in Providing Evidence-Based Health Promotion?**

*Moderator: Wendy Nehring, RN, PhD, Rutgers, The State University of New Jersey*

*Speakers: Members Health Promotion and Prevention Committee—Lelia Barks; Robert Arendt, PhD; Susan Haverkamp, PhD; Donna Lehr, PhD; Debbie Lord; Thomas Osinowo, MD*



Wendy Nehring

This session presents the conclusions of the AAMR pre-conference on the state of the science concerning health promotion research for persons with intellectual and developmental disabilities. Experts in the field surveyed the available published scientific research literature to identify knowledge and practice concerning health promotion. Presenters emphasize the significance and usefulness of these conclusions for future research and practice, as well as their application for persons with intellectual and developmental disabilities and their families.

**Room: Salon EF**

1:45 pm–3:00 pm

SPECIAL SESSION

### Working for a Living: The Role of Work in the Healthy Lives of People With Disabilities

*Susan Foley, PhD, Institute for Community Inclusion*

This presentation argues that work is a vital aspect of health. People with disabilities clearly express the desire to work, and its importance to their well-being. Data from several qualitative research projects highlight how people with disabilities define the role of work in their lives.

Room: 403

1:45 pm–3:00 pm

DIRECT SUPPORT & SELF-ADVOCACY TRACK

### What Are People Telling Us About the Quality of Their Service

*Valerie Bradley, Sharon Taub, Human Services Research Institute*

This session reviews results from state surveys of people who receive service and supports. It describes how they feel about their lives, the choices that they make, their health and other important issues.

Room: 407

1:45 pm–3:00 pm

DIRECT SUPPORT & SELF-ADVOCACY TRACK

### People First... Label Second

*Samuel Jenkins, New Jersey Self-Advocacy Project, Jump Start Self-Advocacy, Inc.; Sidney Katz, AAMR Legislative and Social Issues Committee, Jump Start Self-Advocacy, Inc.*

This session explains “labeling”—identifying people by names or descriptions that make them feel like less of a person. Advocates will 1) share their experiences of being labeled and how it made them feel, 2) discuss why it is important to let others know about People First language, 3) discuss their responsibility to educate their peers, families, service providers and the community, 4) view a video.

Room: 410

3:15 pm–4:30 pm

DIRECT SUPPORT & SELF-ADVOCACY TRACK

### Consent Issues

*Cathy Ficker Terrill, Ray Graham Association*

Come hear about consent issues for self advocates. Topics include writing your own will, serving in a jury, informed choice, reversing guardianship, and durable power of attorney.

Room: 407

3:15 pm–4:30 pm

DIRECT SUPPORT & SELF-ADVOCACY TRACK

### Planning for Life: The Role of Direct Support Professionals in Self-Directed Supports

*Michael Steinbruck; Deborah Spitalnik, PhD, UMDNJ—The Boggs Center; Samuel Jenkins*

A twenty-minute video featuring people who both use and provide supports will help direct support professionals better understand their role in providing supports that adhere to the principles of self-determination and self-direction. Plus a panel discussion.

Room 410

3:15 pm–4:45 pm

SPECIAL THEME SESSION

### Quality Assurance and Exercise Programs for People With Disabilities

#### Independent Monitoring for Quality—A Consumer-Focused Quality Assurance and Enhancement System

*Celia Feinstein, MA, Temple University Institute on Disabilities; James Lemanowicz, Temple University Institute on Disabilities*

This presentation explains the Pennsylvania system of monitoring services to people with MR performed by people with disabilities, families, and others—independent of the service delivery system—including developing local projects, uniform data collection instruments, recruiting and training monitors, and analyzing and reporting collected data.

#### Short- and Long-Term Outcomes of an Exercise and Health Education Program for Adults With Down Syndrome

*Tamar Heller, PhD, University of Illinois at Chicago; Kelly Hsieh, PhD, University of Illinois at Chicago; Beth Marks, RN, PhD, University of Illinois at Chicago; James Rimmer, PhD, University of Illinois at Chicago*

Short- and long-term outcomes of an exercise and health education program designed for adults with Down syndrome will be presented.

#### The National Center on Physical Activity and Disability (NCPAD): Providing Web-Based Resources on Physical Activity for People With Disabilities

*James Rimmer, PhD, University of Illinois at Chicago*

An overview of NCPAD’s physical activity resources to help people with disabilities become more active, including an interactive website, searchable databases, fact sheets, monographs, and exercise modules

Rooms: 411 & 412

3:15 pm–4:45 pm

SPECIAL THEME SESSION

### The Death Penalty and People With MR/DD: Virginia as a Case Study

#### Death Penalty and Mental Retardation

*Richard Garnett, PhD, Garnett and Associates*

The Supreme Court’s Atkins decision exempting people with MR from the death penalty has intensified the debate over how mental retardation is determined and explained to the legal community.

**Assessment of Mental Retardation Post-Atkins**

*Jay Bamburg, PhD, Resource Center on Psychiatric & Behavioral Supports; Stephen Anderson, PhD, Resource Center on Psychiatric & Behavioral Supports*

Accurate assessment of mental retardation, historically used for diagnosis, school placement, and supports identification, can now mean the difference between life and death. Come hear how systems can safeguard the rights of people with MR.

**After Atkins: NOW What?**

*Denis Keyes, PhD, College of Charleston/School of Edu-EDFS; Patton James, University of Texas-Austin*

A presentation that considers the legal, psychological, and educational nuances of the Atkins decision.

Room: Salon D

3:15 pm–4:45 pm

SPECIAL THEME SESSION

**Self Determination: Theory and Practice**

**Self-Determination**

*James Conroy, PhD, Center for Outcome Analysis (COA); Mary Cerreto, Center on Self-Determination and Health Department of Family Medicine*

Compelling evidence is now available to show that the “theory” of self-determination is borne out by scientific evidence.

**Individual Outcomes From the National Study of Self-Determination**

*James Conroy, PhD, Center for Outcome Analysis (COA); Fullerton Amanda, MS, COA; Marge Brown, MS, COA; James Garrow, COA*

Data is presented on The Robert Wood Johnson Foundation’s 4-year National Initiative on Self-Determination for Persons with Developmental Disabilities.

**A Study in Contrasting Implementation of Self-Determination: New Jersey and North Carolina, and California**

*James Conroy, PhD, Center for Outcome Analysis, Marge Brown, MS, Center for Outcome Analysis*

This presentation explores the different methods used in North Carolina and in New Jersey to enhance self-determination for people receiving community support.

Room: Salon B

3:15 pm–4:45 pm

SPECIAL THEME SESSION

**Spiritual Communities, Worship Styles, and Religious Participation**

**Healing Through Inclusive Spiritual Communities**

*Roger Peters, DMin, Commonwealth of Pennsylvania Department of Public Welfare; Donna DiCasimirro, MA, Commonwealth of Pennsylvania Department of Public Welfare*

This presentation focuses on the mutuality of spiritual support and healing found through inclusive spiritual communities, reviewing the spiritual connection with healing and rehabilitation.

**Styles of Worship in a Community Setting for People With Developmental Disabilities**

*Judith Broeker, Mdiv, DMin, First Reformed Church of Ridgewood*

This presentation highlights inclusive contemporary liturgy and one congregation’s journey to full inclusion in which 95% of the congregants are people with developmental disabilities.

**Religious Participation by Persons With ID**

*Rev. Dennis Schurter, Denton State School; Gerry Hendershot*

As a measure of population health, estimates of the number of adults with intellectual disability who participate in prayer and corporate worship are presented based on the National Health Interview Survey.

Room: 414 & 415

3:15 pm–4:45 pm

SPECIAL THEME SESSION

**Making Information Technology Work for People With ID**

**Information Technology: Its Potential to Benefit People With Intellectual Disabilities**

*Mark Friedman, PhD, Temple University; Debbie Robinson, Temple University; Allison Carey, PhD, Temple University; Diane Bryen, PhD, Temple University*

This presentation discusses accessible web pages, talking web browsers, accessible e-mail, status of the updated Web Accessibility Guidelines slated to be released in 2004, and initial research results of specialized software for PDAs.

**Web Access for People With Intellectual Disabilities**

*James Conroy, PhD, Center for Outcome Analysis; Benjamin Slotznick, PhD, Point-and-Read, Inc.; Michael Rogers, Center for Outcome Analysis*

A newly developed web browser interface for people with MR/DD is designed to read web content out loud, one sentence at a time. Come hear about this new clickless approach to web accessibility from its creators.

**Information and Wellness**

*Elbert Johns, MDiv, TheArcLink, Inc.; Sue Swenson, The Arc of the United States; Rud Turnbull, LIB, LIM, Beach Center on Disability; Nancy Ward, Oklahoma People First*

Accessing and understanding one’s own health, diagnosis, treatment, and services information improves perceived quality of life, and aids in the planning for one’s own services. Come see how it is done.

Room: Salon C

3:15 pm–4:45 pm

SPECIAL SESSION

### Employment and the Americans with Disabilities Act: Rights and Responsibilities

*Christopher Lage, Assistant General Counsel, EEOC; Judith O'Boyle, Esq., Supervisory Trial Attorney, Philadelphia District Office, EEOC; Mildred Rivera, Esq., Special Assistant EEOC Office of the Chair*

Overview of the employment provisions of the ADA as they relate to individuals with intellectual disabilities. You will learn when to file a charge of employment discrimination with the Equal Employment Opportunity Commission as well as the process after a charge has been filed. Panelists will review the EEOC's recent litigation and investigation of employment discrimination claims filed by, or on behalf of, individuals with intellectual disabilities—including claims of job harassment and denials of reasonable accommodation.

Rooms: 401 & 402

3:15 pm–4:45 pm

SPECIAL SESSION

### Enhancing Supports for People With Co-Occurring Mental Illness and Mental Retardation: A Diagnostically Driven Evaluation Tool

*Amy Nemirow, Philadelphia Coordinated Health Care; Carol Persons, Philadelphia Coordinated Health Care*

Philadelphia County has developed a tool to evaluate supports and assess individual risk of people with co-occurring mental retardation and serious mental illness in order to enhance their community services and supports. Hear their recommendations on clinical intervention, documentation, training, and accessing community resources.

Room: 413

3:15 pm–5:00 pm

ACADEMY CAREER SCIENTIST PRESENTATION

### How Language and Executive Systems Interact in Cognitive Development

*Martha Bridge Denckla, M.D., The Kennedy Krieger Institute, The Johns Hopkins University Medical School*

Room: Salon A

5:00 pm–6:00 pm

SPECIAL SESSION

### Healing and Wholeness: Exploring Relationships Between Health, Spirituality and Community

*Bill Gaventa, MDiv, Community and Congregational Supports, The Boggs Center; Mark Pettus, University of Massachusetts Medical School*

This session explores dimensions of health in relationship to spirituality and community, the themes that arise out of defining disability in a supports paradigm, and the processes of working to include people with intellectual disabilities in all aspects of community life.

### Living Life Fully: Holistic Aging

*Genevieve Pugh, MA, Black Mountain Center; William Gaventa, MDiv, The Elizabeth M. Boggs Center; Richard Rhea, DMin, Black Mountain Center*

This session reviews the gifts and challenges of longer lives for people with intellectual disabilities. Health care, quality of life, spiritual needs, and end-of-life issues are key themes.

Room: Salon D

5:00 pm–6:00 pm

EMERGING ISSUES

### Emerging Trends in Policy: Special Education and Human Rights

#### Federal Changes and Trends in Special Education Law

*Rud Turnbull, LIB, LIM; Beach Center on Disability, Kansas University; Matthew Stowe, JD, Beach Center on Disability, Kansas University*

Congress has introduced legislation to reauthorize the Individuals with Disabilities Education Act (IDEA) which proposes profound changes that will affect the special education rights and services of children with disabilities and their families.

#### Human Rights and Health: Impact and Implications for People With Intellectual Disabilities/Mental Retardation

*Celine Mercier, PhD, West-Montreal and Lisette-Dupras; Jocelin Lecomte, West-Montreal and Lisette-Dupras*

The United Nations' work on a Disability Rights Convention, the result of a decade of international declarations on disability, offers the ID/MR community a unique forum from which to voice our concerns.

Room: Salon B

5:00 pm–6:00 pm

EMERGING ISSUES

### Emerging Issues in Adult Life Satisfaction

#### Direct Video Measure of Practical Intelligence

*Shira Yalon-Chamovitz, PhD, Israeli Institute for Academic Studies; Stephen Greenspan, PhD*

This video-based instrument measures an innate cognitive ability and thus has great potential as a measure of practical intelligence in adults with mild and moderate mental retardation.

#### Post-Secondary Success: The Options and the Outcomes of Learning in a Postsecondary Environment

*Meg Grigal, PhD, University of Maryland; Debra Neubert, PhD, University of Maryland*

See how model school systems are providing students with significant disabilities access to community and four-year colleges that offer self-determination skills, personal goal achievement.

Rooms: 401 & 402

5:00 pm–6:00 pm

EMERGING ISSUES

**Emerging Issues in ID: Parents With Cognitive Limitations, and Psychotropic Meds Use for Autism Spectrum Disorders**

**Parents With Cognitive Limitations: An Unseen Population**

*Joanne Goldblum, MSW, Yale University; Janice Currier-Ezepchick, Yale University; Wendy Kwalwasser, Connecticut Department of Families and Children*

A generation ago, the idea of people with cognitive limitations parenting children was virtually unheard of. Now, things are different. Learn to recognize their unique needs.

**Prevalence, Patterns of Use, and Quality of Psychotropic Medication Service**

*Carol Schall, PhD, Virginia Autism Resource Center*

This study describes the prevalence and patterns of psychotropic medication use, compares monitoring methods, and discusses recommended medication use in this population.

Rooms: 411 & 412

5:00 pm–6:00 pm

EMERGING ISSUES

**Emerging Ethical Issues: Not Dead Yet?**

*Diane Coleman, Not Dead Yet*

This session will explore recent developments in both medical and non-medical killing of people with cognitive disabilities. Topics will include surrogate decision making, the right to food and water, futile care policies, and societal responses to homicides by family members and health care workers.

Rooms: 414 & 415

5:00 pm–6:00 pm

**The Academy Business Meeting**

*Presiding: Marsha Mailick Seltzer, Ph.D., Waisman Center, University of Wisconsin*

Room: Salon A

5:00 pm–7:30 pm

**Exhibit Hall Reception**

**Exhibit Hall and Interactive Poster Presentations**

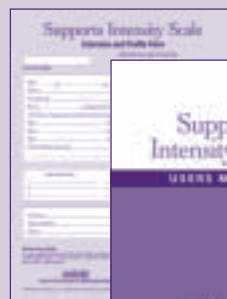
See page 27 for a list of Interactive Poster Presentations.

Room: Exhibit Hall/Franklin Hall

5:00 pm–6:00 pm

EMERGING ISSUES

**Emerging Tools for Professionals: Measuring Support Needs, and Training Staff in Positive Behavior Supports**



**The SIS: A Tool to Measure Support Needs**

*James Thompson, PhD, Illinois State University; Robert Schalock, PhD, Schalock & Associates; Marc Tassé, PhD, University of North Carolina; Wayne Silverman, PhD, Institute of Basic Research; Michael Wehmeyer, PhD, University of Kansas–Beach Center; David*

*Rotholz, PhD, University of South Carolina; Carolyn Hughes, PhD, Vanderbilt University–Peabody College; Ellis (Pat) Craig, PhD, Texas Department of MH/MR; Edward Campbell, PhD, E=Mc2 Consulting, Inc.; Brian Bryant, PhD, Psycho-Educational Services*

A brief overview of the *Supports Intensity Scale*, an exciting new tool that provides a standardized measure of an individual’s support needs.

**Positive Behavior Support Training Curriculum: Overview and Guide for Successful Implementation**

*David Rotholz, PhD, University of South Carolina; Dennis Reid, PhD, Habilitative Management Associates*

The senior author and senior editor of the new AAMR PBSTC will discuss this exciting new curriculum and answer questions about its successful implementation.



Room: Salon C

7:00 pm–9:00 pm

**Academy Dinner**

**Location: Maggiano’s Little Italy**  
(across the street from the Marriott)

Cost: \$50 per person; \$25 students

**Registration**  
7:00 am–4:00 pm

**Exhibit Hall and Interactive Poster Presentations**

See page 27 for list of Interactive Poster Presentations.  
**8:00 am–9:00 am**—Complimentary Continental Breakfast  
**10:00 am–1:00 pm**—Lunches Available at Noon  
**10:15 am–10:30 am**—Coffee Break  
**12:45 pm**—Grand Prize Drawing  
 Room: Exhibit Hall/Franklin Hall

7:00 am–8:00 am

**Business Meetings**  
(See pages 32 for list of Business Meetings)

7:00 am–8:00 am

SPONSORED BY THE MULTICULTURAL SIG

**Partnerships Between Parents—  
Professionals and Family Quality of Life  
Among Families Receiving Services Under  
Part B and Part C of IDEA**

*Presiding: Josephine Calder  
Speaker: Hasheem Mannan*

Room: 402

7:30 am–8:30 am

**Called to Spirituality**  
**A Time for Reflection, Meditation, Worship, and Prayer**  
*Presiding: Rev. Vanessa Ervin*

Room: 403

8:00 am–9:00 am

**Exclusive Exhibit Time and  
Interactive Poster Presentations**  
**Complimentary Continental Breakfast**  
Room: Exhibit Hall/Franklin Hall

8:00 am–9:00 am

ACADEMY DISSERTATION AWARDS SYMPOSIUM

**Increasing Levels of Interpersonal Negotiation  
Strategies in Adults With Mental Retardation**  
*Nektaria Glinou, Teachers College, Columbia University*

**Depression in Individuals with Mental Retar-  
dation: An Evaluation of Cognitive Theories**  
*Anna Esbensen, Nisonger Center, Ohio State University*

Room: Salon A

8:00 am–5:00 pm

**Video Theater**—View-on-Demand

Room: 406

**PLENARY SESSION ON MENTAL HEALTH**

9:00 am–10:15 am

**Alzheimer's Disease (AD) in Adults With Down Syndrome**



Wayne Silverman

*Wayne Silverman, PhD, NYS Institute for Basic Research; Warren Zigman, PhD, NYS Institute for Basic Research; Nicole Schupf Taub, PhD, Institute of Columbia University, Taub Institute of Columbia University; Tiina Urv, PhD, Shriver Center, University of Massachusetts Medical School*

**AD in Adults With Down Syndrome: Homeostatic Risk Factors**  
**Biomarkers of Risk for AD in Adults With Down Syndrome**  
**Patterns of Maladaptive Behavior in Adults With Down Syndrome and Dementia**  
**Variation in Rates of Progression of AD in Adults With Down Syndrome**



Warren Zigman

Virtually all adults with Down syndrome develop some of the key neuropathological features of Alzheimer's disease by their late 30s, yet only a minority experience frank dementia. Even among those affected individuals, age at onset (or age at diagnosis) varies widely, as does rate of progression. Obviously, factors in addition to the presence of an extra copy of chromosome 21 (the underlying cause of Down syndrome) and its associated triplication of the gene coding for amyloid precursor protein must be responsible for these individual differences. Four presentations will describe the results of our current research, focusing on selected aspects of clinical progression of Alzheimer's disease and biological factors that modify individual risk.



Nicole Schupf Taub



Tiina Urv

Room: Salon EF

8:00 am–5:00 pm

**Speaker Ready Room**

Room: 404

9:00 am–10:15 am

SPECIAL SESSION

**The Role and Function of an Agency-Based Medical Ethics Committee**

*John Nicely, MSW, Resources for Human Development; Mary Gregorio, Resources for Human Development; Kilby Sheldon, Resources for Human Development; Dolores Delaney, Resources for Human Development*

This session discusses how one agency developed a medical ethics committee to review cases in order to provide advice to decision-makers on critical care and end-of-life decisions for those without immediate family.

Room: 413

9:00 am–10:15 am

DIRECT SUPPORT & SELF-ADVOCACY TRACK

**Assistive Technology and Self-Determination**

*Hank Bersani, Jr., PhD, Western Oregon University*

Use your advocacy skills to get assistive technology for mobility and communication. Learn how to use your assistive technology to support self-advocacy. Everything you wanted to know about assistive technology and self-advocacy but never knew whom to ask. What is AT and AAC and how can it make me a better self-advocate? Using technology to support self-determination.

Room: 407

9:00 am–10:15 am

DIRECT SUPPORT & SELF-ADVOCACY TRACK

**Couples and Relationships**

*Vailene Fields, Jump Start Self-Advocacy, Inc.; Leslie Walker-Hirsch, Moonstone Group*

This session is for those who are, have been, or wish to be in a relationship. The audience will have a chance to “check themselves out” and think about how their behavior might affect their ability to maintain their relationships. They will view video examples of how to react positively in difficult situations and role-play. The session will explore ways to keep relationships stable and healthy.

Room: 410

10:00 am–1:00 pm

**Exhibit Hall Open and Interactive Poster Presentations**

See page 27 for a list of Interactive Poster Presentations

Coffee Break 10:15 am–10:30 am

Lunches available at 12:00 noon.

Grand Prize Drawing at 12:45 pm.

Room: Exhibit Hall/Franklin Hall

10:30 am–11:45 am

DIRECT SUPPORT & SELF-ADVOCACY TRACK

**VESPA: Very Efficient Scale of Personal Autonomy**

*Julie Silver, MMHS, HSRI; Greg Roberts, PhD, Center for Disability Studies; Sarah Taub, MMHS, HSRI*

Self-determination derives from a complex theory and is hard to measure. The Very Efficient Scale of Personal Autonomy (VESPA) offers program managers, evaluators, consumers, and others an efficient and viable personal autonomy measured, an important component of self-determination.

Room: 407

10:30 am–11:45 am

DIRECT SUPPORT & SELF-ADVOCACY TRACK

**How I Deal With Everyday Challenges**

*Steven Agolia, Advocate*

Steven Agolia will inspire and motivate you as he tells how he enters every day with a positive outlook. You will have the opportunity to practice relaxation exercises, and be uplifted as you hear Steve’s personal story about facing illness, abuse, and prejudices, and how he has found the inner strength to overcome these challenges.

**Spiritual Integration for People With Different Abilities**

*Reverend Aleyah Lacey, Community Access Unlimited; Ed Kurnos; Vailene Fields; Lucious Cox; Steve Agolia*

Come explore identifying spiritual needs and building connections for people with disabilities, congregations and places of worship. Advocates will share the successes and obstacles from the viewpoints of the Catholic, Jewish, Protestant and AME faiths.

Room: 401 & 402

10:30 am–12:00 noon

SPECIAL THEME SESSION

**Mental Health Issues and Intellectual Disabilities: Urban Living, Depression, and Sex Offenders**

**Identifying the Mental Health Needs of Urban Adults With ID Living in Community Residences**

*Joel Levy, DSW, YAI/National Institute for People with Disabilities; Shelly Botuck, PhD, YAI/National Institute for People with Disabilities*

This presentation describes mental health and psychiatric treatment for 145 individuals with ID living in a variety of non-familial community living situations in New York City. Demographic characteristics, employment status, living situation, health status and behavioral strengths and excesses are examined.

**Promoting Health Through Understanding Depression**

*Anna Esbensen, MA, The Ohio State University; Yona Lunskey, PhD, University of Toronto; Sarah Ailey, PhD, RN, Rush University, College of Nursing*



This presentation addresses variables in the environment and the individual that can be targeted to prevent and ameliorate symptoms of depression among individuals with mental retardation.

**Facing Sex Offending Behavior in the Community**

*Leonard Hedges-Goett, PsyD*

This presentation considers clinical issues, legal concerns, and obstacles to safe and respectful service to persons with MR/DD with sex offending behavior in the community. An intervention strategy informed by literature from the social service, psychological and legal communities will be offered.

**Room: Salon B**

**10:30 am–12:00 noon**

SPECIAL THEME SESSION

**A New Look at Prevention: Genetic Advances and Fetal Alcohol Spectrum**

**Fetal Alcohol Spectrum Disorder: The Major Known Cause of Cognitive Disabilities**

*Stanley Handmaker, MD, University of New Mexico; Nancy Handmaker, University of New Mexico, PhD.*

Prenatal alcohol exposure causes brain damage—fetal alcohol spectrum disorder (FASD)—and is the major known cause of developmental disabilities. Learn prevention review strategies.

**Genetic Advances in Diagnosis and Treatment of Developmental Disorders**

*R. Dwain Blackston, MD, Department of Human Genetics*

Genetic diagnosis advances for many developmental disorders are now available (fluorescence in situ hybridization [FISH] and molecular DNA analysis). New treatments for genetic metabolic conditions (lysosomal storage disorders, metabolic diseases, gene therapy) are outlined with a discussion of availability, costs, insurance, ethics, and complications.

**Communication Between Siblings of Persons With Genetic Disorders and Their Family Members**

*J. Carolyn Graff, PhD, University of Tennessee Health Science*

This session reviews research exploring communication between siblings of individuals with a genetic disorder and other family members.

**Room: Salon C**

**10:30 am–12:00 noon**

SPECIAL THEME SESSION

**21st Century Quality Health Care for People With Intellectual Disabilities: How Do We Recognize Quality in Health Care When We See It?**



James Gardner

*James Gardner, PhD, The Council on Quality and Leadership in Supports for People with Disabilities; Danette Castle, MPA Lubbock Regional MHMR Center; Tim Freeman, MD, University Hospital and*

*Alliance Primary Care; Jill Morrow, MD, Office of Mental Retardation Pennsylvania Department of Public Welfare*

See how the characteristics and responsibilities of quality health care can be applied to people with intellectual disabilities who have significant health care concerns.

**Room: Salon D**

**10:30 am–12:00 noon**

SPECIAL THEME SESSION

**Changing the Paradigm: Community Action, Community Inclusion, and Professional Attitudes Toward Treatment**

**The Forgotten Exposés**

*Steven Taylor, PhD, Syracuse University*

This session reviews the forgotten history of exposés of state institutions by 3,000 conscientious observers (COs) in 22 states during World War II. What they found shocked them: overcrowding, understaffing, neglect, abuse, and brutality.

**Strategies for Empowering Community Members to Build Fully Inclusive Communities**

*Angela Amado, PhD, University of Minnesota*

Four approaches used in different communities to strengthen community-wide commitment and action for inclusion are summarized. Final results from a five-year Minnesota research project will be presented.

**Personal Paradigm Shifts and Treatment Acceptability in Positive Behavior Supports**

*Fredda Brown, PhD, Queens College, City University of Educational and Community Programs*

This presentation describes the results of a survey of national experts in the area of Positive Behavior Supports including behavioral strategies used and personal paradigm shifts.

**Rooms: 411 & 412**

**10:30 am–12:00 noon**

SPECIAL THEME SESSION

**Medical Issues: The Medical Home Model and Hospital Admissions Advocacy**

**The Concept of the “Medical Home” in Providing Integrated Coordinated Health Care for People With Developmental Disabilities**

*Leslie Rubin, MD, Emory University School of Medicine*

The elements involved in providing health care for people with DD involve personal lifestyles, environmental adaptations, skilled personnel, and the accessibility of an array of services.

**An Advocacy Program for People With Disabilities Who Are Being Admitted to the Hospital**

*Chris Andry, PhD, Boston Medical Center; Marc Emmerich, PhD, Boston’s Community Medical Group; Mary Cerreto, PhD, Boston Medical Center-Family Medicine*

An advocacy program, based on a patient safeguarding model piloted at Boston Medical Center, Support is provided for people with cognitive disabilities and/or communication limitations that have been hospitalized. A patient advocate, assigned during hospitalization, monitors the care people enrolled in the program receive. The Here to Help: Disability Advocacy Program's goal is to optimize the quality of acute inpatient healthcare for people with disabilities and ensure a coordinated, safe transition home.

**Rooms: 414 & 415**

**10:30 am–12:00 pm**

THE ACADEMY LECTURE

**Processes in the Development of Behavior Problems in Children With Developmental Delays**

*Keith Crnic, PhD, Child Study Center, Department of Psychology, Pennsylvania State University*

**Room: Salon A**

**10:30 am–12:00 noon**

SPECIAL SESSION TO HONOR ROBERT PERSKE

**The Pastoral Voice of Robert Perske: Spiritual Life in Institution and Community**

*Moderator: William Gaventa, MDiv, Community and Congregational Supports, The Elizabeth M. Boggs Center on Developmental Disabilities*

*Speakers: Rev. Earl Bleke, Bethesda Lutheran Homes and Services; Steven Eidelman, The Arc US; Quincy Abbot; Tom Klassen, Eastern Christian Children's Retreat*

Bob Perske began his career with ten years as a chaplain of a residential center in Kansas, during which he published some of the first articles dealing with religion and ministry with people with mental retardation and their families. These articles have recently been collected and published as a book, *The Pastoral Voice of Robert Perske*. This session will explore how themes in pastoral ministry and spiritual supports with people with mental retardation/intellectual disabilities have changed from the 1960's to the present. Bob Perske will be part of the dialogue with the presenters.

**Rooms: 413**

**10:45 am–12:00 pm**

OPEN FORUM

**Adaptive Behavior: What Is It and How Should It Be Measured?**

*Marc Tassé, PhD, University of North Carolina at Chapel Hill*

This Open Forum provides an opportunity to discuss the construct and measurement of adaptive behavior with the AAMR Committee charged with developing a new adaptive behavior assessment instrument. Input

and comments will be sought from participants, and comments and suggestions from attendees will be recorded to aid the committee in its work.

**Room: 403**

**PLENARY SESSION ON ENVIRONMENTAL HEALTH**

**1:15 pm– 2:30 pm**

**Pollution, Toxic Chemicals, Disability, and Our Health**

There is widespread concern about the increasing amounts of chemicals and pollutants in our environment and the impact they may be having on our overall health and quality of life. Mothers-to-be, infants and young children are especially vulnerable, while there is a growing suspicion that adults with developmental disabilities may be at unnecessary risk in their homes and in the workplace because of the lack of information and education about these health promotion and disability prevention issues. The results of the national Wingspread Conference on toxicants and developmental disabilities will be reviewed including what the research shows, what we suspect, and what we can do to improve the quality of our environment and that of the disability service system.

**Why Should We Be Concerned About Environmental Health? What Can We Do as Advocates, Parents, Researchers, Service Providers, and Policy-makers?**

*Moderator: Doreen Croser, AAMR Executive Director*

**Windows of Vulnerability: Brain Development and Susceptibility to Environmental Contaminants**

*Ted Schettler, MD, Science and Environmental Health Network*

**An Advocate's Point of View**

*Tia Nelis, Institute on Disability & Human Development*

**Environmental Policies That Work for People With Disabilities and Their Families**

*Sue Swenson, The Arc of the United States*

**Practical Solutions and Issues Related to Environmental Toxins**

*Cathy Ficker Terrill, MS, Ray Graham Associates*

**Room: Salon EF**

**1:15 pm–2:30 pm**

DIRECT SUPPORT & SELF-ADVOCACY TRACK

**The Voice of Change**

*Sue Swiss; Sharon Weekly; Amber Schneider, Sussex County ARC*

The Voice of Change is an interactive abuse and neglect prevention training. The different types of abuse—physical,

verbal, and sexual abuse, neglect and exploitation—will be explored. The training includes discussion, review, question-and-answer session, and a workbook.

**Room: 407**

**1:15 pm–2:30 pm**

DIRECT SUPPORT & SELF-ADVOCACY TRACK

**SPEAK UP! STAND OUT! New Jersey’s Successes in the Self-Advocacy Movement!**

*Officers of Helping Hands Self-Advocacy and New Jersey United Self-Advocates*

Come network with some of New Jersey’s leading self-advocates and learn what has worked for them! Helping Hands Self Advocacy (HHSA), a statewide Self-Advocacy group, New Jersey United Self Advocates (NJUSA), and Self Advocates Becoming Empowered (SABE) will be discussed.

**Jump Start Your Own Business! An Advocates “How-To”**

*Sid Katz; Adelaide Daskam; Sam Jenkins, Jump Start Self-Advocacy, Inc.*

The presenters walk you through some of the planning and preparation steps that they have taken and will provide tips on how you, too, can start your own business. Come learn some of the perks and challenges they are facing in their new endeavor, and find out how you can benefit from their services.

**Rooms: 401 & 402**

**1:15 pm–2:30 pm**

STUDENT SESSION

**Student Chapters in AAMR: The West Virginia AAMR Student Chapter Shares a Longevity Success Perspective**

*Gabriel Nardi, PhD, Faculty Advisor; Shannon Boswell; Tracey Thomas; Carrie Smith; Tara Johnson; Allison Carpenter, Students*

The West Virginia University AAMR Student Chapter has been active for more than 30 years—something no other student chapter can match! Come hear student and faculty advisors share their experiences and see how the chapter has provided opportunities for students to serve persons with mental retardation and participate in regional and national professional meetings.

**Room: 410**

**2:45 pm–4:00 pm**

DIRECT SUPPORT & SELF-ADVOCACY TRACK

**Everyday Kids, Everyday Lives: A Holistic Vision of Children’s Wellbeing**

*Julie Silver, HSRI; Celia Feinstein, MA, Temple University—Institute on Disabilities*

The project facilitators discuss the development and practical applications of Everyday Kids, Everyday Lives: A Vision for Pennsylvania’s Children. Developed by parents,

advocates, and professionals, and funded by the Pennsylvania Developmental Disabilities Council, Everyday Kids, Everyday Lives explores a holistic vision of child and family life and ten themes inextricably linked to the day-to-day well being of all children, their families, and their full participation in community life.

**Room: 407**

**2:45 pm–4:15 pm**

SPECIAL THEME SESSION

**Emerging Technologies and the State of the States**

**Developmental Disabilities, Emerging Technology and the State of the States**

*David Braddock, PhD, Coleman Institute, University of Colorado*

Developmental Disabilities, Emerging Technology, and the State of the States, a new study funded by the Administration on Developmental Disabilities, found that public spending for MR/DD community services in the states grew rapidly in FY 2000-02, and decreased significantly in FY 2002-04. Quantitative study results for the past four years will be summarized. An overview of emerging assisted care systems and personal support technologies in developmental disabilities long-term care, health, and related areas will be discussed.

**Technology Use and Intellectual Disabilities**

*Michael Wehmeyer, PhD, University of Kansas; Susan Palmer, PhD, University of Kansas, Beach Center; Yves LaChapelle, PhD, Université du Québec-Psychoéducation*

This session presents information about technology use for people with ID, including a brief review of recent studies on ID and technology.

**Augmentative and Alternative Communication (AAC) for Children With Autism: Preliminary Results of a Meta-analysis**

*Oliver Wendt, MA, Purdue University*

This session reports the result of a meta-analysis concerning the effectiveness of augmentative and alternative communication (AAC) for children with autism. Results will be discussed relative to EBP and their implications for AAC interventions in autism.

**Room: Salon B**

**2:45 pm–4:15 pm**

SPECIAL THEME SESSION

**New Directions in Direct Support**

**Gaining Ground, Improving Lives: Direct Support Today and Tomorrow**

*Don Carrick, Nodaway County Services*

Participants will learn about growing direct support groups in Missouri and New Jersey, what these groups stand for, and the changes they are trying to make. There will also be discussion on advocacy groups in other states and how starting advocacy groups.

**An Educational Path to Develop a Direct Support Professional Behavioral Health Specialist**

*Debra Matthai, Special People In Northeast, Inc.; Kathleen Brown-McHale, Special People In Northeast, Inc.; Jennifer Davis-Fenton, Special People In Northeast, Inc.; Amy Nemirow, Philadelphia Coordinated Health Care; Terry Tang, Agnews Developmental Center*

This presentation proposes a model to enhance the image of Direct Support Professionals through the creation of a specialization in behavioral health that has both an educational and career path. The model outlines a comprehensive Behavioral Health training curriculum that includes classroom instruction, independent learning and research, with point of service and on the job evaluation.

**Fun & Functional Replacement Skills Training**

*Terry Tang, PhD, Agnes Developmental Center*

Trainer/trainee evaluations with non-verbal indicators, i.e., smiles, exploration, task completion, when applied to Self-Actualization Theory, can indicate existential commonalities for interpersonal rapport that facilitates fun and functional skills development for all.

Rooms: 411 & 412

2:45 pm–4:15 pm

SPECIAL THEME SESSION

**What Do Surveys Tell Us About the Health and Well-Being of Adults With Dual Diagnosis Compared to Individuals With Developmental Disabilities Who Do Not Have Psychiatric Disabilities?**

**Introduction: Overview of National Core Indicators**

*Valerie Bradley, MA, Human Services Research Institute*

**How Do Health Outcomes Compare in Adults With Developmental Disabilities With and Without Mental Health Problems?**

*Susan Havercamp, PhD; Karen Luken, TRS/CTRS*

Adults with dual diagnoses present unique challenges to the DD service system as well as to the community healthcare system. Research demonstrates that individuals with MR receive little medical care, compared with the general population.

**Health, Social, and Emotional Well-Being of Adults With Intellectual and Psychiatric Disabilities**

*Ruth Freedman, PhD, Boston University; Sarah Taub, Human Services Research Institute*

National Core Indicators (NCI), sponsored by the National Association of State Directors of Developmental Disabilities Services (NASDDDS) and the Human Services Research Institute (HSRI), is a national effort aimed at supporting state DD authorities to develop performance/outcome indicators and to implement data collection strategies for measuring service delivery system performance. This presentation examines the first round of data from Fiscal Year 2002-2003.

**Age, Gender and Disability Type Differences in Service Use and Needs for Adults: Analyses From the National Health Interview Survey on Disability**

*Sheryl Larson, PhD, University of Minnesota*

This presentation describes personal supports and health, mental health, long-term care, transportation, and preventative health services needed or used by adults in the NHIS-D. It uses logistic regression to examine differences by age (18 to 35 years versus 36 years and older), gender, and disability group (persons with intellectual or developmental disabilities versus others with one or more functional limitations) while controlling for overall health status, race and economic status.

Rooms: 414 & 415

2:45 pm–4:15 pm

SPECIAL THEME SESSION

**Racial Disparities in Health: Issues Confronting Individuals With Intellectual Disabilities**

*Sheryl White-Scott, MD, New York Medical College; Vincent Campbell, National Center on Birth Defects and Developmental Disabilities; Center for Disease Control and Prevention; Deborah Spitalnik, PhD, The Elizabeth M. Boggs Center on Developmental Disabilities; Geronimo Robinson, Alexandria Community Services Board*

Evaluation of health disparities among racial groups with I/DD has been relatively limited; this panel will discuss the historical issues related to racial disparities, current data available by race/ethnic groups and future interventions to address these disparities.

Room: Salon C

2:45 pm–4:15 pm

THE ACADEMY SYMPOSIUM

**Advances In Research On Brain Function and the Implications for Better Understanding of Developmental Disabilities**

*Chair: Michael F. Cataldo, PhD, Kennedy Krieger Institute, Johns Hopkins University School of Medicine*

**Cognitive Neuroscience Research With Individuals With Limited Language: Behavioral Methods and Illustrative Data.**

*William McIlvane, PhD, William Dube, PhD, Teresa Mitchell, PhD, Ann Skoczenski, PhD, University of Massachusetts Medical School and Shriver Center*

**NeuroImaging of Learning Processes**

*Michael Cataldo, PhD, Michael Schlund, PhD, Kennedy Krieger Institute, Johns Hopkins University School of Medicine*

**Does Impaired Procedural Learning Contribute To Autism?**

*Stewart Mostofsky, MD, Kennedy Krieger Institute, Johns Hopkins University School of Medicine*

**Cognitive and Neural Correlates of Reading Disabilities.**

*Laura Cutting, PhD, Kennedy Krieger Institute, Johns Hopkins University School of Medicine*

Room: Salon A

**2:45 pm–4:15 pm**

SPECIAL SESSION

**They Fought for the Life of Earl Washington, Jr. and Won—Recollections of Ten People Who Made It Happen**



Earl Washington, Jr.

Moderator: Robert Perske, Perske & Associates  
Guest: Earl Washington, Jr.

Speakers: Joe Giarrantano (Former death row inmate); Marie Deans (Advocate); Marty Geer (Attorney); Eric Freedman (Attorney); Robert Hall (Attorney); Barry Weinstein (Attorney); Gerald Zerkin (Attorney); Ofra Bikel (Journalist); Kay Mirick (Human Services Worker); Margaret Edds (Journalist)

For 16 years, advocates fought tenaciously to keep Mr. Washington, a man with mental retardation, from being executed for a murder he did not commit. Hear how they did it.

**Room: Salon D**

**2:45 pm–4:15 pm**

SPECIAL SESSION

**Chasing Dragons**

Mark Yeager, PhD, MS Dept of Mental Health

How to Be a Black Belt Leader parallels the levels of martial arts training to the levels required to become an effective leader so staff can learn to use their leadership skills to effect change.

**Room: 413**

**2:45 pm–4:15 pm**

**Guthrie Award Winner Lecture  
Can We Treat Diseases of the Nervous System? The Next Generation of Therapy**

Edward Kaye, MD, Genzyme Corporation

**Room: 403**

**2:45 pm–4:15 pm**

**Full Community Inclusion Award Winner Presentation  
Thinking and Acting “Out of the Box”: The Community Access Unlimited Experience**

Sidney Blanchard, Community Access Unlimited

The presentation details how one agency began with one person, a car, and a one year grant of \$90,000 to become an agency serving over 1,500 people with disabilities in a progressive continuum of community supports.

**Room: 410**

**3:00 pm–4:00 pm**

**International Members Informal Reception**

Special welcome for international attendees of the Annual Meeting. Share your thoughts on how AAMR can better serve your research and information needs.

**Room: 405**

**PRESIDENTIAL ADDRESS**

**4:30 pm–5:30 pm**

**Wearing Two Hats:  
“Perspectives  
on Family  
Quality of Life”**



Ann Turnbull, EdD, FAAMR,  
AAMR President

Introductions:  
Michael Wehmeyer, PhD,  
University of Kansas–Beach Center

**Room: Salon EF**

**AWARDS CEREMONY**

**5:30 pm–6:30 pm**

**2004 AAMR Awards Ceremony**

- |                                                                            |                                                                                                                                                                                                                                                                                                                                                 |
|----------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Education Award</b><br>Martha E. Snell, PhD                             | <b>Special Award</b><br>Cathy Ficker Terrill                                                                                                                                                                                                                                                                                                    |
| <b>Full Community Inclusion Award</b><br>Community Access Unlimited        | <b>Student Award</b><br>Paul T. Shattuck                                                                                                                                                                                                                                                                                                        |
| <b>Hervey B. Wilbur Historic Preservation Award</b><br>J. David Smith, EdD | <b>Dybwad Humanitarian Award</b><br>Joe Giarrantano (Former death row inmate)<br>Marie Deans (Advocate)<br>Marty Geer (Attorney)<br>Eric Freedman (Attorney)<br>Robert Hall (Attorney)<br>Barry Weinstein (Attorney)<br>Gerald Zerkin (Attorney)<br>Ofra Bikel (Journalist)<br>Kay Mirick (Human Services Worker)<br>Margaret Edds (Journalist) |
| <b>International Award</b><br>Jean Vanier                                  | <b>Henri Nouwen Award</b><br>Charles Lucen                                                                                                                                                                                                                                                                                                      |
| <b>Leadership Award</b><br>James F. Gardner, PhD                           | <b>Guthrie Award</b><br>Edward Kaye, MD                                                                                                                                                                                                                                                                                                         |
| <b>Media Award</b><br>Chris Dickon                                         |                                                                                                                                                                                                                                                                                                                                                 |
| <b>Research Award</b><br>Carl J. Dunst, PhD                                |                                                                                                                                                                                                                                                                                                                                                 |
| <b>Service Award</b><br>Elizabeth Mount, PhD                               |                                                                                                                                                                                                                                                                                                                                                 |

**Cocktail Reception 6:30 pm–7:30 pm**

**Room: Salon EF**

**Registration**  
8:00 am–2:30 pm

7:00 am–8:00 am

**Business Meetings**

See page 32 for list of Business Meeting.

8:00 am–9:00 am

OPEN FORUM

**AAMR Board of Directors Open Forum**

*Presiding: Ann Turnbull, EdD; David Coulter, MD*

**Room: 411**

8:15 am–4:30 pm

**Religion and Spirituality Division Program**

See page 24 for complete program.

**Location: Vision for Equality,  
718 Arch, Philadelphia, PA**

8:30 am–2:00 pm

**Video Theater**—View-on-demand

**Room: 406**

8:00 am–2:00 pm

**Speaker Ready Room**

**Room: 404**

12:00–1:30 pm

**Luncheon Meetings**

See page 33 for list of Luncheon Meetings

1:30 pm–5:00 pm

**2004-05 AAMR Board of Directors Meeting**

*Presiding: David Coulter, MD*

**Room: Salon A**

**NADD/AAMR SYMPOSIUM I**

9:00 am–12:30 pm

**Criminal Offenders: Assessment of Risk and Treatment Options**

*Edwin J. Mikkelsen, MD, Associate Professor of Psychiatry, Harvard Medical School, Medical Director, The MENTOR Network; Ms. Kate Novak, Director of Quality Assurance, The MENTOR Network; Jennifer B. Fuglestad, Quality Assurance Analyst, The MENTOR Network; Michael Pasinski, MSW, Director of Clinical Services, REM Connecticut Community Services; Robin Keller, BSW, Executive Director, REM Connecticut Community Services*

The symposium examines studies of clinically meaningful subtypes of individuals with developmental disabilities who have a history of criminal offenses in three groups: a) those who commit sexual offenses only, b) those who commit physical offenses only, and c) those who commit sexual *and* physical offenses.

It also discusses contemporary ongoing research supporting this classification, operational and treatment issues by individuals who are actively involved in the management of a community-based program, and concludes with a panel discussion and questions from attendees.

Participants will be able to identify different subtypes of criminal offenders with mental retardation, acquire skills to construct a treatment plan based on historical risk factors, and develop the skills to construct a risk assessment profile.

This three-hour pre-conference symposium consists of two sections, with a short break in the middle.

**COST:** \$79—AAMR/NADD members; \$99—Non-members

**Room: Salon B**

**NADD/AAMR SYMPOSIUM II**

1:30 pm–5:00 pm

**Psychotropic Agents: Critical Issues**

*Leo McKenna, PharPharmD, Clinical Pharmacist, McKesson Medication Management, Massachusetts Department of Mental Retardation; Edwin J. Mikkelsen, MD, Associate Professor of Psychiatry, Harvard Medical School, Medical Director, The MENTOR Network; Kate Novak, Director of Quality Assurance, The MENTOR Network; Jennifer B. Fuglestad, Quality Assurance Analyst, The MENTOR Network*

This symposium consists of three sections. “The Construction of Pharmacological Algorithms” reviews the decision-making process in choosing a particular psychotropic medication, including the ability to clearly establish a psychiatric diagnosis. Factors discussed include: a) the severity and frequency of the behavioral symptoms produced by the psychiatric disorder, b) the side effect profile of the proposed medication, c) the probability of effectiveness. A diagnostic-specific pharmacological algorithm for the more common psychiatric disorders encountered in people with dual diagnosis will then be discussed.

“The Evolution of Knowledge With Regard to the Side Effect Profile of Newer Psychotropic Agents” focuses on the recognition of side effects of psychotropic agents frequently used in individuals with dual diagnosis.

“Strategies for the Reduction of Medication Errors in Community Programs” reviews the most common types of medication errors and strategies for preventing them. Educational materials will be distributed. This symposium concludes with a panel discussion and questions from attendees.

Attendees will be able to recognize the most common side effects of the atypical antipsychotic agents, identify the most significant side effects of the SSRI antidepressants, and identify the most common subtypes of medication administration errors and strategies for preventing them.

**COST:** \$79—AAMR or NADD members; \$99—Non-members

**Room: Salon B**

# The **Academy Program**

**WEDNESDAY • 6.2.2004**

10:45 am–12:15 pm

ACADEMY SYMPOSIUM

## The Future of Newborn Screening for Genetic Disorders That Cause Intellectual Disabilities

*Chair: Steven Warren, Schiefelbusch Institute for Life Span Studies, University of Kansas*

### Rapid Evolution of Newborn Screening

*Rodney Howell, MD, National Institute of Child Health and Human Development*

### Will Disorders Causing Mental Retardation Meet Criteria for Newborn Screening?

*Don Bailey, PhD, Frank Porter Graham Child Development Institute, University of North Carolina at Chapel Hill*

### Treatment Efficacy as a Standard for Newborn Screening of Disorders Associated with Intellectual Disabilities

*Steven Warren, PhD, Schiefelbusch Institute for Life Span Studies, University of Kansas, Lawrence, KS*

Room: Salon A–5th Floor

12:25 pm–1:30 pm

## AAMR and the Academy Student Lunch and Conversation Hour

An opportunity for informal and “student-friendly” collegial interactions. All students welcome!

Room: 401

3:15 pm–5:00 pm

ACADEMY CAREER SCIENTIST PRESENTATION

## How Language and Executive Systems Interact in Cognitive Development

*Martha Bridge Denckla, The Kennedy Krieger Institute, The Johns Hopkins University Medical School*

Room: Salon A–5th Floor

5:00 pm–6:00 pm

## Academy Business Meeting

*Chair: Marsha Seltzer, Waisman Center, University of Wisconsin*

Room: Salon A–5th Floor

7:00 pm–9:00 pm

## Academy Dinner

**Location: Maggiano's Little Italy**  
(across the street from the Marriott)

**Cost:** \$50.00 per person (\$25.00 for students)

**THURSDAY • 6.3.2004**

8:00 am–9:00 am • 10:00 am–1:00 pm

THE ACADEMY POSTER PRESENTATION BOARD #27

## Wellbeing Among Parents With Down Syndrome or Fragile X Syndrome

*Melissa Murphy; Loredana Bruno; Leonard Abbeduto; Nancy Giles; Erica Richmond; Gael Osmond*

Room: Franklin Hall B

8:00 am–9:00 am

ACADEMY DISSERTATION AWARDS SYMPOSIUM

## Increasing Levels of Interpersonal Negotiation Strategies in Adults With Mental Retardation

*Nektaria Glinou, Teachers College, Columbia University, NY*

## Depression in Individuals With Mental Retardation: An Evaluation of Cognitive Theories

*Anna Esbensen, Nisonger Center, Ohio State University*

Room: Salon A–5th Floor

10:30 am–12:00 noon

ACADEMY LECTURE

## Processes in the Development of Behavior Problems in Children With Developmental Delays

*Keith Crnic, Child Study Center, Department of Psychology, Pennsylvania State University*

Room: Salon A–5th Floor

2:45 pm–4:15 pm

ACADEMY SYMPOSIUM

## Advances in Research on Brain Function and the Implications for Better Understanding of Developmental Disabilities

*Michael Cataldo, Kennedy Krieger Institute, Johns Hopkins University School of Medicine*

## Cognitive Neuroscience Research With Individuals With Limited Language: Behavioral Methods and Illustrative Data

*William McLane; William Dube; Teresa Mitchell; Ann Skoczenski, University of MA, Medical School and Shriver Center*

## Neuroimaging of Learning Process

*Michael Cataldo; Michael Schlund, Kennedy Krieger Institute, Johns Hopkins University School of Medicine*

## Does Impaired Procedural Learning Contribute to Autism?

*Stewart Mostofsky, M.D., Kennedy Krieger Institute, Johns Hopkins University School of Medicine*

## Cognitive and Neural Correlates of Reading Disabilities

*Laura Cutting, Ph.D., Kennedy Krieger Institute, Johns Hopkins University School of Medicine*

Room: Salon A–5th Floor

# Direct Support & Self-Advocacy Track

WEDNESDAY • 6.2.2004

9:00 am–10:15 am

## How Waiting List Legislation Has Changed Services

*Celia Feinstein, Temple University, Institute on Disability; Jim Lemanowicz, Temple University, Institute on Disability*

Celia and Jim will discuss how legislation that requires a state waiting list has expanded and changed services for individuals with disabilities in other states.

Room: 407

9:00 am– 10:15 am

## “Married With Children:” An Advocates Point of View

*Lee Bongiovi; Mildred Alexander; Vailene Fields, Advocates*

First comes love, then comes marriage, then comes the baby carriage...well, maybe not always in that order! Intimacy and family are key elements of quality of life. Advocates share their insights about the extraordinary experience of being a partner and a parent while living with the ‘disability’ label.

Room: 410

10:45 am–12:00 noon

## Making Service Coordination Work for You

*Joanna Pierson; Michael Planz, The Arc of Frederick County Service Coordination; Tracey Wright; Judy Volkman, Wallbusters*

Your Service Coordinator / Case Manager works for *you*. This session will explain what you have a right to expect from your Service Coordinator, questions to ask your Service Coordinator, and how to complain if your Service Coordinator is not doing what you see as important.

Room: 403

10:45 am–12:00 noon

## Working in Partnership With Families to Enhance Quality of Life

*Ann Turnbull, University of Kansas-Beach Center; Denise Poston, University of Kansas-Beach Center*

This session provides strategies for developing partnerships between families and service providers that foster quality of life for individuals and families. We will focus on developing action plans for families around family interaction, parenting, physical wellbeing, emotional wellbeing, and support for the family member with a disability.

Room: 407

10:45 am–12:00 noon

## Looking for a Place to Go? How to Get Connected to Community Resources!

*Ira Geller, Advocate*

During this presentation people will learn that they don't have to stay bored inside their home all day! The presenter discusses social events, different places that people can go to get information, and ways they can get out and enjoy themselves in the community. Community resources include: the public library, social service agencies, colleges and universities, advocacy groups, and recreation departments.

## Don't Let Your Disability Control You

*Myrta Rosa; Mark Straka; Kathy Marcus; Larry Marcus, Advocates*

This workshop includes a frank discussion about how people's perceptions and bias about “disabilities” could hold you back. We'll share experiences and role-play self-esteem, assertiveness and self-advocacy.

Room: 410

1:45 pm–3:00 pm

## What Are People Telling Us About the Quality of Their Service

*Valerie Bradley, HSRI; Sharon Taub, HSRI*

This session reviews results from state surveys of people who receive service and supports. It describes how they feel about their lives, the choices that they make, their health and other important issues.

Room: 407

1:45 pm–3:00 pm

## People First...Label Second

*Samuel Jenkins, New Jersey Self-Advocacy Project, Jump Start Self-Advocacy, Inc.; Sidney Katz, AAMR Legislative and Social Issues Committee, Jump Start Self-Advocacy, Inc.*

This session explains, “labeling”—identifying people by names or descriptions that make them feel like less of a person. Advocates will 1) share their experiences of being labeled and how it made them feel, 2) discuss why it is important to let others know about People First language, 3) discuss their responsibility to educate their peers, families, service providers and the community, 4) view a video.

Room: 410

3:15 pm–4:30 pm

## Consent Issues

*Cathy Ficker Terrill, Ray Graham Association*

Come hear about consent issues for self advocates. Topics include writing your own will, serving in a jury, informed choice, reversing guardianship, and durable power of attorney.

Room: 407



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3:15 pm–4:30 pm

### Planning for Life: The Role of Direct Support Professionals in Self-Directed Supports

Michael Steinbruck, *The Boggs Center*; Deborah Spitalnik, *The Boggs Center*; Samuel Jenkins, *NJ Self-Advocacy Project*

A twenty-minute video featuring people who both use and provide supports will help direct support professionals better understand their role in providing supports that adhere to the principles of self-determination and self-direction. Plus a panel discussion.

Room 410

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**THURSDAY • 6.3.2004**

9:00 am–10:15 am

### Assistive Technology and Self-Determination

Hank Bersani, Jr., PhD, *Western Oregon University*

Use your advocacy skills to get assistive technology for mobility and communication. Learn how to use your assistive technology to support self-advocacy. Everything you wanted to know about assistive technology and self-advocacy but never knew whom to ask. What is AT and AAC and how can it make me a better self-advocate? Using technology to support self-determination.

Room: 407

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9:00 am–10:15 am

### Couples and Relationships

Vailene Fields, *Jump Start Self-Advocacy, Inc.*; Leslie Walker-Hirsch, *Moonstone Group*

This workshop is for those who are, have been, or wish to be in a relationship. The audience will have a chance to 'check themselves out' and think about how their behavior might affect their ability to maintain their relationships. They will view video examples of how to react positively in difficult situations and role-play. The workshop will explore ways to keep relationships stable and healthy.

Room: 410

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10:30 am–11:45 am

### VESPA: Very Efficient Scale of Personal Autonomy

Julie Silver, *HSRI*; Greg Roberts, *Center for Disability Studies*; Sarah Taub, *HSRI*

Self-determination derives from a complex theory and is hard to measure. The Very Efficient Scale of Personal Autonomy (VESPA) offers program managers, evaluators, consumers, and others an efficient and viable measured personal autonomy, an important component of self-determination.

Room: 407

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10:30 am–11:45 am

### How I Deal With Everyday Challenges

Steven Agolia, *Advocate*

Steven Agolia will inspire and motivate you as he tells how he enters every day with a positive outlook. You will have

the opportunity to practice relaxation exercises, and be uplifted as you hear Steve's personal story about facing illness, abuse, and prejudices, and how he has found the inner strength to overcome these challenges.

### Spiritual Integration for People With Different Abilities

Rev. Aleyah Lacey; Ed Kurnos; Vailene Fields; Lucious Cox; Steve Agolia

Come explore identifying spiritual needs and building connections for people with disabilities, congregations and places of worship. Advocates will share the successes and obstacles from the viewpoints of the Catholic, Jewish, Protestant and AME faiths.

Room: 401 & 402

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1:15 pm–2:30 pm

### The Voice of Change

Sue Swiss; Sharon Weekly; Amber Schneider, *Sussex County ARC*

The Voice of Change is an interactive abuse and neglect prevention training. The different types of abuse—physical, verbal, and sexual abuse, neglect and exploitation—will be explored. The training includes discussion, review, question-and-answer session, and a workbook.

Room: 407

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1:15 pm–2:30 pm

### SPEAK UP! STAND OUT! New Jersey's Successes in the Self-Advocacy Movement!

Officers of *Helping Hands Self-Advocacy and New Jersey United Self-Advocates*

Come network with some of New Jersey's leading self-advocates and learn what has worked for them! Helping Hands Self Advocacy (HHSA), a statewide Self-Advocacy group, New Jersey United Self Advocates (NJUSA), and Self Advocates Becoming Empowered (SABE) will be discussed.

### Jump Start Your Own Business! An Advocates "How-To"

Sid Katz; Adelaide Daskam; Sam Jenkins, *Jump Start Self-Advocacy, Inc.*

The presenters walk you through some of the planning and preparation steps that they have taken and will provide tips on how you, too, can start your own business. Come learn some of the perks and challenges they are facing in their new endeavor, and find out how you can benefit from their services.

Rooms: 401 & 402

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1:15 pm–2:30 pm

STUDENT SESSION

### Student Chapters in AAMR: The West Virginia AAMR Student Chapter Shares a Longevity Success Perspective

Gabriel Nardi, PhD, *Faculty Advisor*; Shannon Boswell; Tracey Thomas; Carrie Smith; Tara Johnson; Allison Carpenter, *Students*

The West Virginia University AAMR Student Chapter has been active for more than 30 years—something no other student chapter can match! Come hear student and faculty

advisors share their experiences and see how the chapter has provided opportunities for students to serve persons with mental retardation and participate in regional and national professional meetings.

Room: 410

2:45 pm–4:00 pm

### Everyday Kids, Everyday Lives: A Holistic Vision of Children's Wellbeing

*Julie Silver, HSRI; Celia Feinstein, Temple University, Institute on Disabilities*

The project facilitators discuss the development and practical applications of Everyday Kids, Everyday Lives: A Vision for Pennsylvania's Children. Developed by parents, advocates, and professionals, and funded by the Pennsylvania Developmental Disabilities Council, Everyday Kids, Everyday Lives explores a holistic vision of child and family life and ten themes inextricably linked to the day-to-day well being of all children, their families, and their full participation in community life.

Room: 407



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# Religion & Spirituality Division **Program**

**FRIDAY, JUNE 4, 2004**

**Location:** Vision for Equality, 718 Arch, Philadelphia, PA 19106

**Full Day Registration Fee:** \$30–AAMR Members; \$40–Non-Members

8:15 am–9:15 am

### Business Meeting

9:30 am–12:00 noon

### RETREAT: The Good News of Access and Inclusion

*Sister Kathleen Schipani, Lori Brew, Kathy Kienlen, Mary Bevolock*

Presentation, reflection time, and discussion facilitated by Archdiocese of Philadelphia staff. Two adults with mental retardation will share their perspective and spirituality.



Lori Brew and Sister Kathleen Schipani

12:00– 1:00 pm

Lunch provided

1:00 pm–4:30 pm

### Workshops

#### Reflection on Theology and Spirituality

*Rev. Barbara Hedges-Goettl; Dr. Donald Healy, Jr.*

#### Reflection on Application

*Jim and Lorrie Lewis, Institute of Abundant Living; Joe Landis, Peaceful Living; Chuck Luce, Conversation with Henri Nouwen Award Winner*

5:30 pm

### Spirituality Division Dinner

Entertainment provided by the "Magical Movement Dancers" of Mercy Special Learning Center, Allentown, PA

**Cost:** \$30.00

**Location:** Project H.O.M.E.,  
1515 Fairmount Ave., Philadelphia, PA

# Professional Workshops

**COST:** Onsite Registration Fee \$60—AAMR members; \$90—non-members

## MORNING WORKSHOPS

**8:00 am–12:00 noon**

### #1 An Overview of Social Role Valorization

*Wolf Wolfensberger, PhD; Jo Massarelli*

Social Role Valorization posits that people who are devalued by others are likely to be treated better if they are seen as holding positively valued social roles. This workshop will explain the “wounds” that typically get inflicted on people of low intellect, and the power of valued roles to address these. Competency enhancement and image enhancement as main avenues towards valued roles, and suggest an implementations sequence of role-valorizaing measures will also be discussed.

**Room: 414**

**9:00 am–12:00 noon**

### #2 Evidence-Based Practices in Education

*Susan Palmer, PhD, Susan Copeland, PhD, Michael Wehmeyer, PhD, Jim Thompson, PhD*

Members of the Education Division will present applications derived from research-based projects and applications that can be used to educate students with disabilities. A number of educators will be on hand to discuss the very practical outcomes and methods that are the products of evidence-based research. A discussion of evidence-based practice and the implications for students with intellectual disabilities will also be held.

**Room: 401**

**9:00 am–12:00 noon**

### #3 Exceptional Staff and a Focus on Wholistic Health: One Person’s Journey to a Quality of Life

*John Sauer MSW, MEd; Nathan Perry; Amy Hewitt, PhD*

The current transition from provider-driven services in the community to consumer-directed community supports has provided many individuals with disabilities, their families, and support networks to focus on recruiting, selecting, and working with quality direct support staff and to embrace more fully the creation of person-centered plans and the implementation of these plans for a wholistic healthy live. Listen to and interact with one person’s story about the success of this transitional process as well as the role and support of his guardian and the facilitation of his support team coordinator.

**Room: 402**

**9:00 am–12:00 noon**

### #4 NISH and Ticket-to-Work

*Brian DeAtley, NISH*

The Ticket-to-Work Program has now been fully implemented in several states. Find out how this program is providing opportunities for people with disabilities who want to work. You will learn how Ticket-to-Work is really operating, including both challenges and opportunities, and how to make this new Social Security Administration (SSA) initiative a good fit for your organization. The session will include an overview of the mechanics of the program, as well as examples from the first states that have begun implementation. The Ticket-to-Work Program has now been fully implemented in several states. Find out how this program is providing opportunities for people with disabilities who want to work. You will learn how Ticket-to-Work is really operating, including both challenges and opportunities, and how to make this new Social Security Administration (SSA) initiative a good fit for your organization. The session will include an overview of the mechanics of the program, as well as examples from the first states that have begun implementation.

**Room: 403**

**9:00 am–12:00 noon**

### #5 Positive Behavior Support Training Curriculum: Overview and Guide for Successful Implementation

*David Rotholz, PhD; Dennis Reid, PhD*

This workshop will be provided by the senior author and senior editor of the new AAMR Positive Behavior Support Training Curriculum. The presenters, both of whom were key participants in developing and implementing this training curriculum, will provide information from the source on what the curriculum includes and how to plan for its successful implementation. Participants will have the opportunity to get answers to questions about implementing this important training curriculum at their own agencies.

**Room: 413**

**9:00 am–12:00 noon**

### #6 The Rewards of Social Capital: Health, Happiness and Relationships

*Sheri Keith; Margaret Dominguez*

Social capital refers to the connection among individuals through social networks. In the first section of this workshop, we will explore the research and its conclusions regarding the connections between social capital and mental and physical health. In the second section we will discover ways in which social capital can be increased, not only for the people we support, but also for ourselves.

**Room: 405**

## AFTERNOON WORKSHOPS

1:00 pm–4:00 pm

### #7 Working for a Living: The Role of Work in the Healthy Lives of People With Disabilities

*Susan Foley, PhD*

This presentation will argue that work is a vital aspect of health. People with disabilities clearly express the desire to work, connect it to functioning, and describe its importance to their well-being. Data from several qualitative research projects will highlight how people with disabilities define the role of work in their lives. Efforts to define health should include employment as a key component.

Room: 401

1:00 pm–4:00 pm

### #8 Leadership: A Quest for Quality

*John Rose; Margaret (Peggy) Gould*

Effective leadership enhances the capabilities of employees, provides assurances to stakeholders, and sets high expectations for performance and quality improvement. It builds loyalty and teamwork, and encourages appropriate risk taking. Effective leadership includes mechanisms for leaders to conduct self-assessment and personal growth. An organization's senior leaders need to set direction and create a customer focus, clear and visible values and high expectations. The leader needs to ensure the creation of strategies, systems and methods for achieving excellence, stimulating innovation and building knowledge and capabilities. This session is designed to facilitate communication between agency leaders and to focus on how leaders develop quality within their agencies, in order to meet today's service delivery demands.

Room: 402

1:00 pm–4:00 pm

### #9 Preference and Reinforcer Assessment in Individuals With Special Needs

*Richard Graff*

The topic of identifying preferences in individuals with special needs has received much attention recently. Although there is empirical evidence that systematic preference assessments identify reinforcers more effectively than other methods, few parents and professionals are familiar with these techniques. This workshop presents a practitioner's guide to conducting systematic preference assessments. Participants will be taught several different methods to accurately assess preferences; assessment protocols, data sheets, and scoring instructions have been included for each assessment.

Room: 403

1:00 pm–4:00 pm

### #10 Promoting Good Health

*Ginny Focht-New; Patty Graves, RN, CDDN; Jack Toomey, RN; Aimee Grev, RN*

This workshop focuses on developing a plan for good health that can be used by caregivers on a day-to-day basis. Health Promotion Plan is used to increase positive health

outcomes by addressing individual diagnoses. It is easily integrated into an annual plan. This workshop requires active participation by those in attendance.

Room: 405

1:00 pm–4:00 pm

### #11 The Supports Intensity Scale

*James Thompson, PhD; Carolyn Hughes, PhD; Marc Tassé, PhD; Michael Weymeyer, PhD; Robert Schalock, PhD; Brian Bryant, PhD; David Rotholz, PhD; Edward Campbell, PhD; Wayne Silverman, PhD; Ellis (Pat) Craig, PhD*

The *Supports Intensity Scale (SIS)* is a new assessment tool published by AAMR that provides a means to obtain a standardized measure an individual's support needs. The *SIS* and its accompanying manual will be in print and on sale at the convention. One of the main goals of this workshop is to introduce this product to the AAMR membership and the field. In this pre-conference workshop we will teach people how to use the *SIS* writing a process that involves determining support needs, developing plans that address support needs, and monitoring outcomes.

Room: 413

1:00 pm–4:00 pm

### #12 Transitioning: Individual and Community

*Claus Sproll; David Schwartz, PhD; Sabine Otto*

Sharing experiences in transitioning will be done on real life situations by looking at various life transitions in Camphill community settings—both educational and life sharing—with children, youth and adults. The approach to transitioning in a Camphill community is guided by the assumption that each individual goes through transitions and in those needs support and guidance.

Room: 414

# AAMR 2004

## AAMR Fellows

Wil H. E. Buntinx

Edward G. Carr, PhD

Robert J. Fletcher, DSW

Sheryl A. Larson, PhD

Richard A. Rader, MD

## AAMR New Leaders

### Board of Directors

Henry A. Bersani, Jr., PhD

*Vice President*

Joanna L. Pierson, PhD

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### Members-at-Large:

Susan M. Havercamp, PhD

Wayne P. Silverman, PhD

# Interactive Poster Presentations

Exhibit Hall/Franklin Hall

WEDNESDAY • 6.2.2004

8:00 am–9:00 am

12:15 pm–1:45 pm

5:00 pm–7:30 pm

Presenters will be available at the boards  
at 8:00 am and 5:00 pm

## BOARD #1

### A Case Study in Webinar Production: Individualized Health Support for People With Developmental Disabilities

*Marianne Taylor; Elizabeth Pell, MSW; Sheryl White-Scott, MD*

## BOARD #2

### A Comparative Study of Sleep/wake Processes in People With Learning Disabilities With and Without Autism

*Dougal Hare, MSc; Steve Jones, MSc, PhD; Kate Evershed*

## BOARD #3

### A Holistic Approach to Transitioning Adolescents With Disabilities to Adult Health Care Services

*Judith Levy, MSW, MA; Eric Levey, MD; Joan Carney; Jackie Stone*

## BOARD #4

### A Program of Supported Employment for People With Intellectual Disabilities in Israel: A Qualitative and Quantitative Analysis on Quality of Life

*Anat Ben-Zvi*

## BOARD #5

### Abuse and Neglect of Children and Adults With DD: A Web-Based Course for Health Professionals

*Bernice Allen, MS, RN; Ann Cox, PhD, RN*

## BOARD #6

### Adaptive Behavior Factor Structure in Children With and Without Mental Retardation

*Giulia Balboni, PhD*

## BOARD #7

### Anxiety and Mood Disorders: Is There Any Evidence of Problem Behavior Specificity?

*Sophie Methot; Diane Morin, PhD; Marie-France Giard*

## BOARD #8

### Assessing and Treating Feeding Problems in Children With Developmental Disabilities

*William Ahearn, PhD, BCBA*

## BOARD #9

### Assessing the Impact of a Class Action Lawsuit: Can Change Be Mandated

*Joan Nicoll-Senft, PhD*

## BOARD #10

### Attitudes of Optometrists Towards Persons With Mental Retardation

*Sandra Block, OD, MEd*

## BOARD #11

### Barriers to Including Nutrition Services on IEPs

*Donna Lockner, PhD; Cynthia Chall-Silva; Ruth Luckasson, JD*

## BOARD #12

### Behavioral Service Models for Persons With Mental Retardation at the Kennedy Krieger Institute

*David Kuhn, PhD; John Huete, PhD; Steven Lindauer, PhD; Peter Girolami*

## BOARD #13

### Building Bridges: Understanding the Challenges and Policy Implications for the Aging and Mental Retardation Community

*Barbara Mazzella, MS*

## BOARD #14

### Building Partnerships With Community Service Organization in a Teacher Preparation Program

*Thomas Sinclair, EdD*

## BOARD #15

### Changing Attitudes of Professionals in Training

*Peter Smith, MD*

## BOARD #16

### Changing Lives: Down Syndrome and the Health Care Professional

*Andrea Lack, MSW*

## BOARD #17

### Children With Developmental Disorders: Adoptive Family Health and Wellness

*Barbara Hanley, PhD*

## BOARD #18

### Children's Inclusive Pathways Through Education

*Susan Palmer, PhD*

## BOARD #19

### Communicating With Medical Professionals

*Frances Elliott Ulrich, EdD; Carl Tyler, Jr., MD; David Pfriend, MA*

## BOARD #21

### Community-Based Treatment for Patients With Intellectual Disability and Psychiatric Illness

*Gerard Gallucci, MD, MHS; Florence Hackerman*

## BOARD #22

### Connecting People With Severe Disabilities to Technology Resources

*Lori Peters; Tim Alberts; Angela Bergman*

## BOARD #23

### Coordinated Healthcare for Persons With Mental Retardation and Developmental Disabilities: A Community Based Multidisciplinary Approach

*David Ervin, MA; MaryEllen Curran, MA, CRC, LCPC; Melonie Jessen; Marina Demos, MA*

## BOARD #24

### Creative Arts Therapy's Impact in Expressive Domains in Adults With Disabilities: Dance Therapy's Impact on Developmental Disabilities

*Miranda D'Amico, PhD; Snow Stephen, PhD; Denise Tanguay, MA; Barbara Welburn, MA*

BOARD #25

**Cultural Influence on Teachers and Parents' Practice in Fostering Elementary Students' Self-Determination: Results From an International Study**

*Dalun Zhang, PhD*

BOARD #26

**Cultural Perceptions of Disability: Service Implications**

*David Helm, PhD*

BOARD #27

**Development of a Health Risk Assessment Instrument for People With Mental Retardation**

*Nancy Klimon; Jill Morrow, MD*

BOARD #28

**Communication Services and Supports for Persons With Severe Disabilities**

*MaryAnn Ronski, PhD; Rose Sevcik, PhD; Martha Snell, PhD*

BOARD #29

**Empowering People With Disabilities to Access Managed Care: Implications for Self-Advocates, Families, Direct Support Professionals, and Developmental Disabilities Services**

*Deborah Spitalnik, PhD; Robyn Carroll, MSW*

BOARD #30

**Enhancing Health Supports in Massachusetts**

*Alexandra Bonardi OTR/L, MHA; Emily Saunders; Gail Grossman*

BOARD #31

**Enhancing Inclusion and Access Through Assistive Technology**

*Sandra Alper, PhD; Stephen Noyes, MAE; Lech Wisniewski, PhD*

BOARD #32

**Enhancing the Social Well Being of Individuals With Intellectual Disabilities Through Peer Mentoring**

*Stewart Shear, PhD; Elizabeth DelPizzo-Cheng, PhD; Dorothy Carter*

BOARD #33

**Evaluating the Acquiescence Response Set in Persons With and Without Mental Retardation**

*Sylvia Ramirez, PhD; Astrid Bonilla*

BOARD #34

**Evaluation of the Special Olympics International Health Promotion Pilot Projects**

*Tamar Heller, PhD; Beth Marks, PhD, RN; Courtney Pastorfield; Mark Wagner, DDS*

BOARD #35

**Facial Recognition of Emotions in Children With and Without Autism**

*Maria Hopkins*

BOARD #36

**Family Quality of Life**

*Denise Poston, PhD; Hasheem Mannan; Mian Wang, PhD*

BOARD #37

**Frequency of Saliva Swallowing in Typically Developing and Developmentally Delayed Children Before and After Eating**

*Justine Joan Sheppard, PhD; Andrea Leone, MS; Loni Burke; Andrea Guglielmo*

BOARD #38

**From Myth to Method to Meaning: The Unfolding Gnosis of Disabilities and Spirituality**

*Donald Healy, Jr., PhD*

BOARD #39

**Growth of Caregiver-Infant Interactions During Early Intervention**

*Angela Howell*

BOARD #40

**Health Care Quality Units: Pennsylvania's Initiative: The SE Regional HCQU Experience**

*Dina McFalls*

BOARD #41

**Help People With Mental Retardation Understand Grief and Loss: Guiding Principles for Care Givers**

*Billie Friedland, EdD; David Friedland*

BOARD #42

**Hope Without S.O.A.P: Pain Management in People With Severe and Profound Retardation**

*Kathryn Thomson*

BOARD #43

**How Readily Is the Internet Explorer for Use by People With Mental Retardation**

*Alex Wong; Chetwyn Chan, PhD; Cecilia Tsang, PhD; Chow Lam, PhD*

BOARD #44

**Implementation of a Community Peer Mentoring Program to Facilitate Social Integration of Young Adults**

*Francine Julien-Gauthier; Colette Jourdan-Ionescu*

BOARD #45

**Involvement in Special Olympics and Its Relations to Maternal and Paternal Stress**

*Jonathan Weiss; Terry Diamond*

BOARD #46

**Foster care: Are there Differences in the Cognitive and Psychiatric Characteristics of Young Children with Developmental Disabilities in Kinship vs Non Kinship Homes?**

*Maria del Rosario Valicenti, MD; Howard Demb, MD*

BOARD #47

**Kansans Mobilizing for Change: Creating Systems Change in the Direct Support Workforce**

*Amy Hewitt, PhD; Sheryl Larson, PhD; John Sauer, MSW; Kathy Olson, PhD*

BOARD #48

**Last Passages: End of Life Care for People With Developmental Disabilities**

*Angela King, MSSW; Anne Botsford, PhD*

BOARD #49

**Launching a Collaborative Mental Retardation and Severe Disabilities Teacher Preparation Program: Lessons Learned**

*Kelley Peters, PhD; Ruth Luckasson, JD; Lou Rena Cash, MA*

BOARD #50

**Leisure/Recreation Access and Lifestyle Satisfaction**

*Diane Ciccarelli*

BOARD #51

**Multi-Disciplinary Family Support in an Outpatient Pediatric Hospital Setting: Mental Health Services, Case Management, and Nursing Support**

*Stephanie Marcy, PhD; Eileen Schmidt, RN; Rosemary Flores, RN*

BOARD #52

**The Multi-Sensory Intervention as an Additional Environment for Physical Therapy: Two Case Studies**

*Meir Lotan, MSc, PT*

BOARD #53

**The Resource Center on Medical and Dental Supports: A Louisiana Initiative to Build Community Capacity**

*Kathy Kliebert; Angela Shockley, MS, RN*

BOARD #54

**Access to the General Education Curriculum for Students With Mental Retardation**

*Susan Bashinski, PhD; Michael Wehmeyer, PhD*

**THURSDAY • 6.3.2004**

8:00 am–9:00 am

10:00 am–1:00 pm

Presenters will be available at the Boards 8:00 am and 12:00 pm

BOARD #1

**Collaborative Community Services: Improving Adult Services and Supports via a Consultative Approach**

*Cynthia Epstein, MA, OTR, FAOTA; Patricia Deotte, DPT, PT, GCS; Catherine Gardner, MPA; Ralph Lollar, MSW*

BOARD #2

**Complementary Therapies**

*Cindy Holland, MS; Sonia Erhard*

BOARD #3

**Components of the Sibling Dyad: Disability Versus Nondisability**

*Kameron Partridge; Stephanie Chopko*

BOARD #4

**Differentiating the Behaviors of Children With Intellectual Disabilities From Those With ADHD**

*Laura Murphy, EdD; Amy Balentine, PhD*

BOARD #5

**Divalproex in Patients With Pervasive Developmental Disorders and Intermittent Explosive Disorder: Effectiveness as Reviewed in Medical Records of 300 Inpatients During a Two-Year Pilot of Specialized Care**

*Ronald Hardrict, MD*

BOARD #6

**French Translation and Cross-Cultural Adaptation of the Anxiety, Depression and Mood Screen**

*Sophie Methot; Diane Morin, PhD; Marie-France Giard*

BOARD #7

**Improving Staff and Residents Wellbeing Using the Multi-Sensory Treatment: Four Case Studies With Washout Periods**

*Meir Lotan, MSc, PT*

BOARD #8

**Life Experiences of Older Women With Intellectual Disabilities: A Global View**

*Barbara LeRoy, PhD; Patricia Noonan Walsh, PhD*

BOARD #9

**Lifestyles Management: An Education and Support Group for Individuals Seeking Healthy Change**

*Susan Wilson, PhD; Kaydee Sullivan; Marie Beauvais; Hope Laurie*

BOARD #10

**Living Well With CMS Funding: Study of Mortality of Wyoming**

*Christine Newman; Ken Heinlein, PhD; Jon Fortune, EdD; David Heath*

BOARD #11

**Low Bone Mineral Density Among Persons With Mental Retardation**

*Courtney Pastorfield; Sigfried Pueschel, MD; Alice Lenihan; Joan Medlen*

BOARD #12

**Meeting the Needs of Persons With Intellectual Disabilities Within a 12-Step Program of Recovery**

*Thomas Sinclair, EdD*

BOARD #13

**National Homeownership Research: The Impact on Social Well-Being**

*Celia Feinstein, MA; Robin Levine, MSW; David Hagner, PhD*

BOARD #14

**Navigating the Heart During Stormy Weather: Can the Concept of Quality of Life Make a Difference in the Lives of Persons With Disabilities With Severe Behavioral Difficulties?**

*Anthony Michael McCroovitz, PhD*

BOARD #15

**Oral Hygiene Support for People With Special Dental Needs**

*Donna McMonagle, MSW; Melissa Evers*

BOARD #16

**Outcomes of Deinstitutionalization in Oklahoma: Ten Years of Community Living and Working**

*James Conroy, PhD; Amanda Fullerton*

BOARD #17

**Parental Stress Evaluation**

*Diane Morin, PhD; Marie-France Giard, DEC*

BOARD #18

**Physical and Mental Disorders in People With Down Syndrome**

*Maju Mathews, MD, MRCPsych, Dip Ps; Anton Canagasabay, MD, MRCPsych*

BOARD #19

**Perspectives on Mental Retardation: Comparison of Assessment Team Members and Group Home/Day Program Staff**

*Stephanie Chopko, MA; Richard Rector; Kameron Partridge; Fred Biasini, PhD*

BOARD #21

**Predictors of Expenditures in Western States**

*Edward Campbell, PhD; Don Severance; Jon Fortune, EdD; Janice Frisch*

BOARD #22

**Preparing Special Education and Disability Services Personnel Online: Distance Education Across the United States and Around the World**

*Barbara Ludlow, EdD; Michael Duff; Joshua Schechter*

BOARD #23

**Prevalence of Aggressive Behavior Among Persons With Mental Retardation in Quebec**

*Yves Lachapelle, PhD*

BOARD #24

**Primary Health Care for Adults With Intellectual Disability**

*Dalice Hertzberg, RN, FNP-C; Barry Martin, MD*

BOARD #25

**Putting the Pieces Together: Arizona's Consultation Assessment Team**

*Laura Nelson, MD; James Kerwin, MD*

BOARD #26

**Religion and People With Mental Retardation: A Study of Self-Reported Perspectives**

*Karrie Shogren; Mark Rye, PhD*

BOARD #27

The Academy Poster Presentation

**Well-being Among Parents With Down Syndrome or Fragile X Syndrome**

*Melissa Murphy; Loredana Bruno; Leonard Abbeduto; Nancy Giles; Erica Richmond; Gael Osmond*

BOARD #28

**The Environment and Intellectual and Developmental Disabilities: Need for Education in the Health Professions**

*Wendy Nehring, RN, PhD, FAAN*

BOARD #29

**Relationships between Siblings' Perceptions of their Brother or Sister's Developmental Disability and Parent-Sibling Qualities**

*Carolyn Graff, PhD, RN*

BOARD #30

**In their Own Words**

*Timothy Freeman, MD*

BOARD #31

**Residential Decision Profile: Planning Institutional Discharge Using Olmstead Criteria**

*Paul Kolstoe, PhD; Susan Foerster, MEd; Keith Vavrovsky, BSW*

BOARD #32

**Sleep Disorders: An Often-Missed, Readily Treatable Condition in People With Developmental Disabilities**

*Ann Poindexter, MD*

BOARD #33

**So You Want to go to College? The Community College of Philadelphia and Holy Family University Experience**

*Teresa Myers-Thompson, BSW; Lillian Smith; Christina Achler; Troy Davidson*

BOARD #34

**Special Education and Healthcare Utilization Among Children With Attention Deficit Hyperactivity Disability**

*Yevgeniya Sorokin; Patricia Pastor, PhD; Cynthia Reuben, MA*

BOARD #35

**Survey of Special Olympics Coaches on Athlete Health Promotion**

*Stephen Corbin, DDS, MPH; Dawn Munson; Courtney Pastorfield*

BOARD #36

**The Implementation of Family-Centered Practice in Childhood Disability Services in Manitoba, Canada**

*Diane Hiebert-Murphy, PhD; Barry Trute, PhD; Alexandra Wright, PhD*

BOARD #37

**The Medical Safeguards Project: Lessons Learned**

*Andre Blanchet, MD; Conrad O'Donnell, MS*

BOARD #38

**The Mexican School of Art by Persons with Down Syndrome**

*Sylvia Escamilla*

BOARD #39

**The Midewin Institute: Preventing Abuse and Neglect of People With Developmental Disabilities**

*Mary Mercer; Bryce Fifield, PhD; Cindy Haworth, MS*

BOARD #40

**Thinking Theologically About PWDs in Faith Communities**

*Barbara Hedges-Goettl, MS*

BOARD #41

**Understanding Dysphagia in People With Developmental Disabilities**

*Pamela Smith, MS*

BOARD #42

**Unpacking the Complex Issue of Disproportionate Representation of Minority Students in Special Education**

*Julia Scherba de Valenzuela, PhD; Cathy Qi, PhD; Susan Copeland, PhD*

BOARD #43

**Use of Divalproex Sodium ER in Persons With Mental Retardation**

*Nanette Wrobel, RPh*

BOARD #44

**Using Assistive Technology to Support Web Access**

*Molly Vitale, DEd*

BOARD #45

**Using Data and Information to Reduce Risk and Improve Health Care Quality: A Focus on Mortality Review**

*June Rowe, CAGS; Steven Staugaitis, PhD; Sharon Oxx, RN*

BOARD #46

**Using the Person/Family Directed Support Waiver**

*Carol Frangicetto, MEd; Helen Falguera, MSW; William Schoppe, MEd*

BOARD #47

**WALLBUSTERS: A Peer Mentoring Program**

*Michael Planz, MS*

BOARD #48

**We Get by With a Little Help From our Friends**

*Harold Kleinert, EdD; Elizabeth Harrison, MRC*

BOARD #49

**Bringing the Family Together—A Field Day for Children With Developmental Delay and Their Siblings**

*Yaara Haspel, BEd*

BOARD #50

**The Need for Best Practice Information Related to Therapeutic Intervention for People With Intellectual Disability**

*Donna Bainbridge, PT, EdD, ATC*

BOARD #51

**Therapeutic Approaches for People With Intellectual Disability**

*James Gleason, MS*

BOARD #52

**A Comparison of the Vineland and ICAP Adaptive Behavior Measures**

*Charlotte Kimmel, PhD; Nedra Francis, MA*





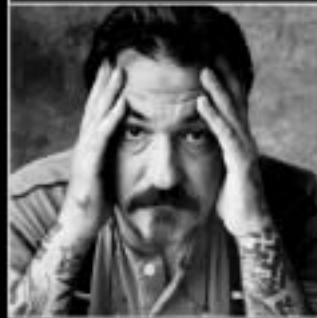
**mania**  
associated  
with  
**bipolar  
disorder**

## MAKING A DIFFERENCE



**epilepsy**

**migraine**  
headaches



 **Abbott Laboratories**  
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# Business Meetings

## TUESDAY • 6.1.04

**1:00 pm–1:45 pm**  
**Joint Assembly and Conference Leadership Meeting**  
*Presiding: Doreen Croser*  
 Room: Salon A

**2:00 pm–5:00 pm**  
**Religion and Spirituality Division Certification Committee Meeting**  
*Presiding: Rev Dennis Schurter*  
 Room: 411

**2:00 pm–5:00 pm**  
**Conference of Professional Interests Meeting**  
*Presiding: David Rotholz, PhD; David Coulter, MD*  
 Rooms: 401 & 402

**2:00 pm–5:00 pm**  
**The Assembly of Geographic Interests**  
*Presiding: Suzie Lassiter, PhD; Valerie Bradley, MA*  
 Rooms: 414 & 415

**5:00 pm–9:00 pm**  
**ABAI Committee Meeting**  
*Presiding: Marc Tassé, PhD*  
 Room: 403

## WEDNESDAY • 6.2.04

**7:00 am–8:00 am**  
**Education Division Business Meeting**  
*Presiding: Susan Palmer, PhD*  
 Room: 401

**7:00 am–8:00 am**  
**Psychology Division Business Meeting**  
*Presiding: Victoria Swanson, PhD*  
 Room: 402

**7:00 am–8:00 am**  
**ABAI Committee Meeting**  
*Presiding: Marc Tassé, PhD*  
 Room: 405

**7:00 am–8:00 am**  
**Awards and Fellowship Committee Business Meeting**  
*Presiding: Warren Zigman, PhD*  
 Room: 407

**7:00 am–8:00 am**  
**Families SIG Business Meeting**  
*Presiding: Richard Garnett, PhD*  
 Room: 410

**7:00 am–8:00 am**  
**Gerontology Division Business Meeting**  
*Presiding: Jenny Overeynder, MSW*  
 Room: 411

**7:00 am–8:00 am**  
**Nursing Division Business Meeting**  
*Presiding: Sally Colatarci, MSN*  
 Room: 412

**7:00 am–8:00 am**  
**Ad Hoc Committee on Implementation of the 2002 Definition Meeting**  
*Presiding: Robert Schalock, PhD*  
 Room: 413

**7:00 am–8:00 am**  
**Journal Editors Meeting**  
*Presiding: Bruce Appelgren*  
 Room: 415

**8:00 am–9:00 am**  
**Region VIII Business Meeting**  
*Presiding: Carl Edwards, MED*  
 Room 413

**12:15 pm–1:45 pm**  
**Pennsylvania Chapter Meeting**  
*Presiding: Paul Spangler, PhD*  
 Room: 405

## THURSDAY • 6.3.04

**7:00 am–8:00 am**  
**Technology SIG Business Meeting**  
*Presiding: Michael Wehmeyer, PhD*  
 Room: 401

**7:00 am–8:00 am**  
**Multicultural SIG Meeting**  
**Partnerships Between Parents-Professionals and Family Quality of Life Among Families Receiving Services Under Part B and Part C of IDEA**  
*Presiding: Josephine Calder, MBA; Speaker: Hasheem Mannan*  
 Room: 402

**7:00 am–8:00 am**  
**ABAI Committee Meeting**  
*Presiding: Marc Tassé, PhD*  
 Room: 405

**7:00 am–8:00 am**  
**Ad Hoc Committee on the Implementation of the Supports Intensity Scale**  
*Presiding: Val Bradley, MA*  
 Room: 407

**7:00 am–8:00 am**  
**Nominations and Elections Committee Meeting**  
*Presiding: Ann Turnbull, EdD*  
 Room: 410

7:00 am–8:00 am  
**Direct Support Professionals Division**  
*Presiding: Gina Farrer*  
Room: 411

7:00 am–8:00 am  
**Finance Committee Business Meeting**  
*Presiding: Joanna Pierson, PhD*  
Room: 412

7:00 am–8:00 am  
**Region IX Business Meeting**  
*Presiding: Sidney Blanchard, MA*  
Room: 413

7:00 am–8:00 am  
**Medicine Division Business Meeting**  
*Presiding: Stan Handmaker, MD*  
Room: 414

7:00 am–8:00 am  
**Social/Sexual Concerns SIG Business Meeting**  
*Presiding: Sharon Kauffman, MS*  
Room: 415

8:00 am–9:00 am  
**Joint Meeting of the Health Promotion Coordinating Committee and the Health Issues SIG**  
*Presiding: Leslie Rubin, MD*  
Room: 403

8:15 am–9:15 am  
**Editorial Advisory Committee**  
*Presiding: Bruce Appलगren*  
Room: 405

10:45 am–12:00 pm  
**Adaptive Behavior Open Forum: What Is it and How Should it be Measured?**  
*Presiding: Marc Tassé, PhD*  
Room: 413

**FRIDAY 6.4.04**

7:00 am–8:00 am  
**Mental Health SIG Business Meeting**  
*Presiding: Ann Poindexter, MD*  
Room: 401

7:00 am–8:00 am  
**Down Syndrome SIG Business Meeting**  
*Presiding: Myra Madnick, MEd*  
Room: 402

7:00 am–8:00 am  
**ABAI Committee Meeting**  
*Presiding: Marc Tassé, PhD*  
Room: 405

7:00 am–8:00 am  
**Genetics SIG Business Meeting**  
*Presiding: Nina Scribanu, MD*  
Room: 410

7:00 am–8:00 am  
**Region IV Business Meeting**  
*Presiding: Kathleen Biersdorff, PhD*  
Room: 412

7:00 am–8:00 am  
**International Activities Committee**  
*Presiding: Diego González Castañon, MD*  
Room: 413

7:00 am–8:00 am  
**Joint Administration Division and Community Services Division Meeting**  
*Presiding: Sharon Coutryer, PhD; Richard Jacobs, MPA*  
Room: 415

8:00 am–9:00 am  
**AAMR Board of Directors Annual Open Forum**  
*Presiding: Ann Turnbull, EdD, David Coulter, MD*  
Room: 411

8:15 am–9:15 am  
**Religion & Spirituality Division Business Meeting**  
*Presiding: Sr. Gabrielle Kowalski*  
Location: Vision for Equality  
718 Arch, Philadelphia, PA

12:00 noon–1:30 pm  
**Joint Nursing and Medicine Divisions Luncheon**  
Room: 412  
Cost: \$30.00

1:30 pm–5:00 pm  
**2004-05 AAMR Board of Directors Meeting**  
*Presiding: David Coulter, MD*  
Room: Salon A

5:30 pm  
**Religion and Spirituality Division Dinner**  
Cost: \$30.00  
Location: Project H.O.M.E.  
1515 Fairmount Ave., Philadelphia, PA

**SATURDAY • 6.5.04**

8:00 am–11:00 am  
**Religion and Spirituality Division Strategic Planning Meeting**  
*Presiding: Sr. Gabrielle Kowalski*  
Room: Conference Suite I  
3rd Floor

# General Information

## Registration Schedule

Registration will take place on the 5th Floor of the Philadelphia Marriott Downtown. The Registration area will be open as follows:

Tuesday, June 1 .....	7:00 am–5:00 pm
Wednesday, June 2 .....	7:00 am–6:00 pm
Thursday, June 3 .....	7:00 am–4:00 pm
Friday, June 4 .....	8:00 am–2:30 pm

## Refund Policy

All refunds will be made after the Annual Meeting. There will be a \$75 processing fee deducted from each individual refund request. All refund requests must be in writing. No phone or e-mail cancellations will be accepted. Please include a copy of your canceled check and registration form. Individuals canceling workshops only will be charged a \$25 processing fee. Individuals requesting refunds on or before May 1, 2004, will receive a full refund on all registration fees, workshops fees and special events less the \$75 processing fee. No refund requests will be honored after May 3, 2004.

## AAMR Market Place

Information on AAMR membership, insurance programs, and publications will be on display in the Exhibit Area during regular exhibit hours. Booth personnel will be available to answer questions.

## Silent Auction

A silent Auction will be held at the AAMR Market Place in the Exhibit Area during regular exhibit hours. Be sure to bid on items of your choice! Biddings closes at 12:00 noon on Thursday, 6/3/04. All items must be picked up by 1:00 pm on Thursday.

## Prize Drawings

There will be drawings daily in the Exhibit Area. Remember to drop your name in the drum at the AAMR Market Place.

## 50/50 Raffle

There will be a 50/50 raffle ongoing throughout the week. The lucky winner will share half the proceeds. The drawing will be held at the Awards Ceremony on Thursday, June 3 at 5:30 pm.

## Exciting Grand Prize Drawing

AAMR will be giving away two plane tickets to anywhere in the Continental United States. To qualify for the Grand Prize Drawing you must visit all the exhibit booths in the Exhibit Area and have each exhibitor sign the **Grand Prize Drawing Card**. Contest entry forms will be included in your registration materials. **To be eligible to win, your completed**

**entry form must be dropped in the Grand Prize Drawing drum in the Exhibit Area by 12:30 pm on Thursday, June 3, 2004.** Drawing will be held on Thursday at 12:45 pm in the Exhibit Area.

You must be present to win!

## Presidential Address, International Awards Ceremony and Reception

**Thursday, June 3 at 4:30 pm**

AAMR is hosting an International Awards Ceremony and Reception for all attendees. Please join us for a special tribute to AAMR's 2004 Awardees, and a delicious complimentary buffet.

**Room: Salon EF–5th Floor**

## Admittance to the Annual Meeting Activities

Registrants are required to wear their badges for all meetings, exhibits, and other events. Admittance to all professional meetings as well as other Annual Meeting activities will be with a badge only. Door monitors will be instructed not to admit non-registered attendees.

## Speaker Preparation Room

A Speaker preparation room will be available for all speakers throughout the Annual Meeting.

**Room: 404**

## Barrier Free Meeting



Plans have been made to make the 2004 meeting site and program in Philadelphia as barrier free as possible.

## Message Center

The Message Center will be in the Hall by the Registration Area on the 5th Floor. Volunteers will assist you in locating friends and colleagues.

## Lost Tickets

There will be NO replacements for lost social events tickets. Anyone losing a ticket will have to purchase a new one.

## Breakfasts and Luncheons

Several divisions have luncheons or breakfasts during the meeting. Please check the business meetings calendar to determine which require pre-registration and have a fee.

## The Exhibit Show Hours

**Wednesday, June 2, 2004**

8:00 am–9:00 am

12:15 pm–1:45 pm

5:00 pm–7:30 pm

**Thursday, June 3, 2004**

8:00 am–9:00 am

10:00 am–1:00 pm

For more than three decades...

## The Council on Quality and Leadership

has set standards...

changed society's vision...

improved the lives of thousands.



Our focus on the innovative concepts of social capital, community quality and person-centered service has enhanced not only the lives of those we serve, but our own lives as well.



As quiet leaders, we continue to move forward, enabling those we serve to live healthier, more fulfilled lives, in turn creating healthier, inclusive communities.



The Council and Jim Gardner, president and CEO of The Council and this year's recipient of the AAMR Leadership Award, invite you to join us in making a difference one life at a time.



**The Council's Fall 2004 Leadership Conference** will be held October 19-20, 2004 in Atlantic City, New Jersey.



100 West Road  
Suite 406  
Towson, MD 21204

410.583.0060  
[www.thecouncil.org](http://www.thecouncil.org)

Create change...

one life, one community, many visions.

# Guide to Exhibitors

## 128th Annual Meeting and Exhibit Show

We invite you to visit our exhibitors in the Exhibit Hall  
and contact those companies whose products or services interest you.  
The exhibits are located in the Exhibit Hall in Franklin Hall.

### **AAMR wishes to thank all of our exhibitors.**

- |                                                            |                                                             |
|------------------------------------------------------------|-------------------------------------------------------------|
| 100 Health Care Software, Inc. (HCS)                       | 301 The Center for Outcome Analysis                         |
| 101 Fantagraph                                             | 302 Synchrony Solutions LLC                                 |
| 102 COMHAR, Inc.                                           | 303 Centers for Disease Control/NCBDDD                      |
| 103 St John's Community Services                           | 304 ResCare, Inc.                                           |
| 104 DynaVox Systems, Inc.                                  | 305 Therapeutic Health & Equipment                          |
| 105 YAI/National Institute for People<br>With Disabilities | 306 The Council on Quality & Leadership                     |
| 106 Quarter Turn Software                                  | 307 Melmark, Inc.                                           |
| 107 CARF                                                   | 308 Mass Mutual Financial Group                             |
| 108 Abilitations                                           | 309 The MENTOR Network                                      |
| 109 T F H (USA) Ltd                                        | 310 Crotched Mountain Foundation                            |
| 110 Martha Lloyd Community Services                        | 311 Heartspring School                                      |
| 111 The Columbus Organization                              | 312 Bancroft NeuroHealth                                    |
| 112 The National Fragile X Foundation                      | 313 The Center for Discovery                                |
| 113 Kennedy Krieger Institute                              | 314 Evergreen Center                                        |
| 114 Mutual of America                                      | 317 UIC—Dept. of Disability & Human<br>Development          |
| 115 Exceptional Parent                                     | 400 Brookes Publishing Company                              |
| 200 Liberty Healthcare Corporation                         | 401 Elwyn Inc                                               |
| 201 Philadelphia Insurance Companies                       | 403 Crisis Prevention Institute (CPI)                       |
| 202 FlagHouse                                              | 404 Irwin Siegel Agency, Inc.                               |
| 203 Abbott Laboratories                                    | 405 Computer Consulting Group                               |
| 204 The Echo Group                                         | 406 John Langdon Down Foundation                            |
| 205 T & M Ranch                                            | 407 Blockhouse Company, Inc.                                |
| 206 AdvoServe                                              | 408 ANCOR                                                   |
| 207 CNSI—Client Network Services, Inc.                     | 409 Municipal Capital Markets Group, Inc.                   |
| 208 Program Development Associates                         | 410 Ken Crest Consultants                                   |
| 209 Esteam                                                 | 411 KLM Skill Builders                                      |
| 210 Blackwell Publishing                                   | 412 Bethesda Lutheran Homes & Services, Inc.                |
| 211 AAMR Religion & Spirituality Division                  | 413 Abledata                                                |
| 212 Association Book Exhibit                               | 414 The Guided Tour, Inc.                                   |
| 213 NISH                                                   | 415 Devereaux                                               |
| 214 Delta-T Group Inc.                                     | 500 Ilderton Conversion Co.                                 |
| 215 Habilitation Software                                  | 601 National Association For The Dually<br>Diagnosed (NADD) |
| 300 Shepherds Baptist Ministries                           |                                                             |

# AAMR's **Exhibit Show** & **Interactive Poster Presentations**

**Exhibit Hall, Franklin Hall, 4th Floor  
Philadelphia Marriott Downtown**

This year for the first time, you can attend Interactive Poster Presentations and visit the Exhibits all in one convenient location. Interactive Poster Presentations will be located around the Exhibit Hall on a variety of topics. (See page 27 for a complete list of Interactive Poster Presentations.) Here you will have a chance to talk one-on-one with the researchers, policy leaders, and service providers as they present their new and important issues.

AAMR's Exhibit Show is simply the most exciting and comprehensive exhibit show in the field of mental retardation. Exhibitors include publishing houses, vehicle manufacturers, travel agencies, testing and diagnostic service companies, teaching aids, computer software, and residential facilities, pharmaceutical companies, and technology companies all offering the latest products and services of interest to professionals in the field.

Come support AAMR's Exhibitors and see the newest and the best products and services in the field! And don't forget the Grand Prize Drawing.

The Exhibit Hall will include a Silent Auction, a 50/50 Raffle, the AAMR Marketplace, a Hospitality Desk, and Daily Door Prizes!

**Admission to the Exhibit Hall is free to all registered attendees. The AAMR Exhibit Show is located on the 4th floor in Franklin Hall of the Philadelphia Marriott Downtown.**

## **WEDNESDAY • 6/2/04**

8:00 am—9:00 am  
12:15 pm—1:45 pm  
3:00 pm—7:30 pm

8:00 am—9:00 am

### **Exhibit Hall Opening and Interactive Poster Presentations**

- Complimentary Continental Breakfast
- Exclusive Exhibit Time—Take Time to Visit the 2004 Exhibits
- Have Your Grand Prize Drawing Card Signed by all the Exhibitors to be Eligible for the Grand Prize
- Don't Miss the Daily Door Prizes
- Visit the Hospitality Area and AAMR Marketplace

12:15 pm—1:45 pm

### **Exhibit Hall Open and Interactive Poster Presentations**

Lunches Available at Noon

3:00 pm—7:30 pm

### **Exhibit Hall Reception**

**Exhibit Hall Open and Interactive Poster Presentations**  
Join the AAMR Leadership, Local Arrangements Committee and Exhibitors for a lively reception in the Exhibit Hall.

## **THURSDAY • 6/3/04**

8:00 am—9:00 am  
10:00 am—1:00 pm  
12:45 pm Grand Prize Drawing

8:00 am—9:00 am

### **Exhibit Hall Open and Interactive Poster Presentations**

- Complimentary Continental Breakfast
- Join your colleagues in the Exhibit Hall to see the latest products and services

10:00 am—1:00 pm

### **Exhibit Hall Open and Interactive Poster Presentations**

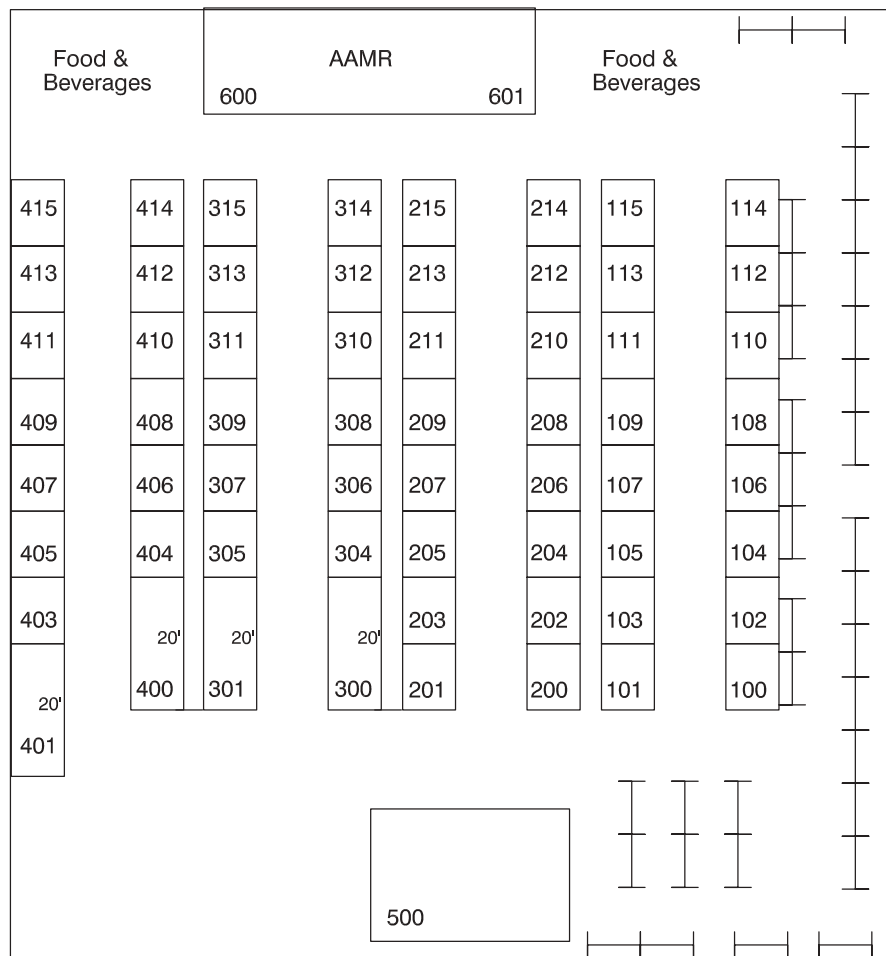
- Coffee Break
- Lunches Available at Noon
- Grand Prize Drawing at 12:45 pm (You must be present to win.)
- Visit the Exhibits
- Meet Your Colleagues and Friends
- Participate in the Silent Auction
- Enjoy A Continental Breakfast

**PLUS**

Daily Prize Drawings and AAMR Marketplace

# AAMR Exhibit Hall

Franklin Hall



ENTRANCE

## Guide to Exhibitors

Booth Exhibitor

- 211 AAMR Religion & Spirituality Division**  
 Boggs Center, PO Box 2688, New Brunswick, NJ 08903  
 Phone: 732-235-9304, Fax: 732-235-9330  
 e-mail: [bill.gavent@umdnj.edu](mailto:bill.gavent@umdnj.edu)  
 Contact: Rev Bill Gaventa—Religion Division  
 A cooperative resource exhibit with books, videos, curricula and other material on inclusive ministries and spiritual supports for people with developmental disabilities and their families, and resources on community building. Resources for clergy, providers, families, professionals, and self advocates.
- 203 Abbott Laboratories**  
 200 Abbott Park Rd, D-304, AP30-4, Abbott Park, IL 60064-6182  
 Phone: 847-937-6100  
 Web: <http://www.abbott.com>  
 You are invited to visit Abbott Laboratories exhibit where representatives will be on hand to answer your questions regarding our products.
- 108 Abilitations**  
 One Sportime Way, Atlanta, GA 30340  
 Phone: 770-449-5700, Fax: 800-333-0712

Booth Exhibitor

- e-mail: [esiegel@sportime.com](mailto:esiegel@sportime.com)  
 Contact: Evan Siegel—National Sales Manager  
 Abilitations® is a catalog brand devoted to improving the lives of children with special needs and learning differences. Abilitations features: on site professionals in therapy and education selecting and designing product; easy to understand product descriptions, tips and educational catalog information; on line resources and ordering; innovative product design; on site consultation; friendly reliable customer care; and an unconditional guarantee.
- 413 Abledata**  
 8630 Fenton St—Ste 930, Silver Spring, MD 20910  
 Phone: 301-608-8998, Fax: 301-608-8958  
 e-mail: [katherine.a.belknap@orcmacro.com](mailto:katherine.a.belknap@orcmacro.com)  
 Contact: Janice Benton—Information Services Manager  
 Abledata is funded by the National Institute on Disability and Rehabilitation Research, US Department of Education, to provide information on assistive devices and rehabilitation equipment for the purpose of aiding people in finding needed items. Resources include a product information database listing more than 30,000 products and a fully-accessible web site.



**206 AdvoServ**

4185 Kirkwood - St Georges Rd, Bear, DE 19701  
 Phone: 302-834-7018, Fax: 302-836-2516  
 e-mail: [mdusseau@advoserv.com](mailto:mdusseau@advoserv.com)  
 Web: [www.advoserv.com](http://www.advoserv.com)  
 Contact: Dennis Reardon

AdvoServ is a provider of residential services for children, adolescents and adults with developmental disabilities and exceptional behavioral challenges. Programs are located in Delaware, Florida and New Jersey and referrals are accepted nationwide. AdvoServ utilizes state of the art behavioral treatment methods and has had success in addressing serious behavioral problems.

**408 ANCOR**

1101 King St–Ste 380, Alexandria, VA 22314  
 Phone: 703-535-7850, Fax: 703-535-7860  
 e-mail: [jmccandless@ancor.org](mailto:jmccandless@ancor.org)  
 Web: [www.ancor.org](http://www.ancor.org)  
 Contact: Jerri Mc Candles

ANCOR is a nonprofit trade association representing private providers who provide supports and services to people with disabilities. ANCOR is distinguished by its balance of leading practices resources and advocacy for member agencies and the people and families they serve and support.

**212 Association Book Exhibit**

8727-A Cooper Rd, Alexandria, VA 22309  
 Phone: 703-619-5030, Fax: 703-619-5035  
 e-mail: [info@bookexhibit.com](mailto:info@bookexhibit.com)  
 Web: [www.bookexhibit.com](http://www.bookexhibit.com)  
 Contact: James Powell–Exhibit Manager

New and current books of professional interest from leading publishers. Free catalog available.

**312 Bancroft NeuroHealth**

Hopkins Lane, PO Box 20, Haddonfield, NJ 08033  
 Phone: 856-429-5637, Fax: 856-429-4755  
 e-mail: [cmartella@bnh.org](mailto:cmartella@bnh.org)  
 Web: [www.bnh.org](http://www.bnh.org)

Bancroft NeuroHealth, a New Jersey Non-Profit Corporation, has been serving people with disabilities since 1883. Based in Haddonfield, New Jersey, Bancroft neuroHealth serves more than 1,000 individuals with developmental disabilities and acquired brain injuries. With more than 140 sites throughout Southern New Jersey, Maine, Delaware and Louisiana, Bancroft NeuroHealth is internationally recognized as a leader in special education, rehabilitation, evaluation and research.

**412 Bethesda Lutheran Homes & Services, Inc.**

600 Hoffmann Dr, Watertown, WI 53094  
 Phone: 920-261-3050, Fax: 920-262-6513  
 e-mail: [mhagen@blhs.org](mailto:mhagen@blhs.org)  
 Web: [www.blhs.org](http://www.blhs.org)

Contact: Mark Hagen–Director Public Relations

Since 1904, Bethesda has been a leader in providing Christian supports to people with developmental disabilities. Along with this, Bethesda produces staff development materials and holds workshops on staff development. Additionally, Bethesda works to promote advocacy and awareness of disability issues.

**210 Blackwell Publishing**

350 Main St, Malden, MA 02148  
 Phone: 781-388-8440, Fax: 781-338-8440

e-mail: [sfagan@blackwellpublishing.com](mailto:sfagan@blackwellpublishing.com)  
 Web: [www.blackwellpublishing.com](http://www.blackwellpublishing.com)

Blackwell Publishing is a leading international publisher in the area of science and medicine. Please stop by our booth for complimentary copies of our journals and visit our website [www.blackwellpublishing.com](http://www.blackwellpublishing.com) for information on all our publications.

**407 Blockhouse Company, Inc.**

3285 Farmtrail Rd, York, PA 17402  
 Phone: 717-764-5555, Fax: 717-767-8939  
 e-mail: [lmitchell@blockhouse.com](mailto:lmitchell@blockhouse.com)  
 Web: [www.blockhouse.com](http://www.blockhouse.com)  
 Contact: Jim McCauley–Sales Representative

Manufacturer of “high use” lounge seating and casegoods to provide value by improving the living and common area environments in your facility. Blockhouse is the right choice when superior performance and low maintenance are essential requirements.

**400 Brookes Publishing Company**

PO Box 10624, Baltimore, MD 21285-0624  
 Phone: 410-337-9580, Fax: 410-337-8539  
 e-mail: [ccreight@brookespublishing.com](mailto:ccreight@brookespublishing.com)  
 Web: [www.brookespublishing.com](http://www.brookespublishing.com)

Stop by our booth and receive 20% off of our titles on developmental disabilities, inclusion, education and more!

**107 CARF**

4891 E Grant Rd, Tucson, AZ 85704  
 Phone: 520-325-1044, Fax: 520-318-1129  
 e-mail: [pandrew@carf.org](mailto:pandrew@carf.org)  
 Web: [www.carf.org](http://www.carf.org)

Contact: Margaret McHenry–Account Development

The mission of CARF is to promote the quality, value and optimal outcomes of services through a consultative accreditation process that centers on enhancing the lives of the person served.

**313 The Center for Discovery**

PO Box 840, Harris, NY 12742-0840  
 Phone: 845-794-1400, Fax: 845-791-2022  
 e-mail: [draymond@sdtc.org](mailto:draymond@sdtc.org)  
 Contact: Dennis Raymond–Admissions

The Center for Discovery is a private, nonprofit program just 90 miles northwest of New York City near Monticello, NY. We offer children and adults with significant disabilities educational, clinical, medical and residential services designed to meet each individual's needs; and the needs of their family. We utilize an interdisciplinary approach to enrich the individual's life and to encourage more independence, while always expecting positive outcomes. Our specialties include: medical fragility, autism, visual impairment, and rare syndromes.

**301 The Center for Outcome Analysis**

201 Sabine Ave #NARBSCHL, Narbert, PA 19072-1611  
 Phone: 610-668-9001, Fax: 610-668-9002  
 e-mail: [jconroycoa@aol.com](mailto:jconroycoa@aol.com)

The Consortium for Quality Living Designs has been formed to assist government agencies and organizations to track the quality of people's lives, in order to learn how to improve quality. CQLD is partners with like-minded groups including self-advocates, advocates, researchers, public interest attorneys, and innovators.

Booth	Exhibitor
303	<p><b>Centers for Disease Control/NCBDDD</b> 1600 Clifton Rd—MS E87, Atlanta, GA 30333 Phone: 404-498-3974, Fax: 404-498-3060 e-mail: cbolen@cdc.gov</p> <p>CDC's National Center on Birth Defects and Developmental Disabilities. We promote the health of babies, children, and adults, and enhance the potential for full, productive living. Our work includes identifying the causes of birth defects, developmental disabilities, helping children to develop and reach their full potential, and promoting health and well-being among people of all ages with disabilities.</p>
207	<p><b>CNSI—Client Network Services, Inc.</b> 702 King Farm Blvd—2nd Fl, Rockville, MD 21117 Phone: 301-634-4600, Fax: 301-634-4666 e-mail: jeff.gottlieb@cns-inc.com Web: www.cns-inc.com Contact: Jeff Gottlieb—Director Healthcare Solutions</p> <p>An award-winning employee owned systems integrator, CNSI is a Maryland business that provides innovative technology solutions for clients worldwide. CNSI is currently developing a one-of-a-kind web-centric Claims Management system for Maine. Other efforts include web-based Mental Retardation / Developmental Disabilities / Vital Records applications developed for healthcare agencies in Maryland, Maine, and New Hampshire.</p>
111	<p><b>The Columbus Organization</b> 1012 W 9th Ave, King of Prussia, PA 19406-1093 Phone: 610-592-0292, Fax: 610-592-0362 e-mail: dmooney@columbusorg.com Contact: Suzanne Thomas</p>
102	<p><b>COMHAR, Inc.</b> 100 W Lehigh, Philadelphia, PA 19133 Phone: 215-203-3059, Fax: 215-203-3011 Contact: Cathy Gray—Board Liaison</p> <p>For over twenty-five years, COMHAR has helped people of all ages and cultures who have developmental disabilities, mental health concerns, physical limitations and other challenges. We provide assistance at home and a broad array of services at COMHAR locations throughout Greater Philadelphia, and suburban communities.</p>
405	<p><b>Computer Consulting Group, Inc</b> 7904 E Chaparral PMB 185, Scottsdale, AZ 85250 Phone: 480-970-1615, Fax: 928-395-4594 e-mail: rdenen@ccpartners.com Web: www.ccpartners.com Contact: Jeff Rutledge—Manager Business Development</p> <p>Computer Consulting Group's Integrated Software Series for MR/DD is a suite of integrated software solutions for developmental disability agencies that simplifies financial overview, minimizes administration, and improves communication.</p>
306	<p><b>The Council on Quality &amp; Leadership</b> 100 West Rd—Ste 406, Towson, MD 21204 Phone: 410-583-0060, Fax: 410-583-0063 e-mail: slhcouncil@aol.com Contact: Shelly McLaughlin—Marketing Manager</p> <p>The Council on Quality and Leadership offers person-centered solutions for organizations and systems supporting individuals with disabilities and mental illness by providing accreditation, monitoring, evaluation, training and consultation services.</p>

Booth	Exhibitor
403	<p><b>Crisis Prevention Institute (CPI)</b> 3315 N 124th St, Brookfield, WI 53005 Fax: 262-783-5906 e-mail: sritter@crisisprevention.com Web: www.crisisprevention.com</p> <p>The Crisis Prevention Institute (CPI) trains professionals to safely manage disruptive and assaultive behavior. Over 4.5 million individuals have participated in CPI's Nonviolent Crisis Intervention™ training program. Training options include scheduled programs in over 139 US cities, customized training, videotapes, posters, and books. For more information, see us at booth #403, visit our website at www.crisisprevention.com or call us toll-free at 1-800-558-8976.</p>
310	<p><b>Crotched Mountain Foundation</b> One Verney Dr, Greenfield, NH 03047 Phone: 603-547-3311, Fax: 603-547-6212 e-mail: barbara.summers@crotchedmountain.org Web: www.crotchedmountain.org Contact: Barbara Summers—Marketing Manager</p> <p>Crotched Mountain School is co-educational, serving children and young adults with one or more disabilities in grades K-12. We provide both residential and day programs. Crotched Mountain offers children the chance to learn and grow at their own level, from mastery of daily living skills through a high school diploma. Each child's educational program is individualized, and support is available from multiple therapy and medical professionals. We have a skilled nursing facility that can address the needs of medically complex children.</p>
214	<p><b>Delta-T Group Inc.</b> 950 Hazerford Rd—Ste 200, Bryn Mawr, PA 19010 Phone: 610-527-0830, Fax: 610-527-7908 e-mail: mvonrohr@deltatg.com Contact: Christopher McAndrew—Vice President</p> <p>Committed to caring professionals, Delta-T Group focuses on temporary and contractual placements for Behavioral Healthcare professionals. To our clients we represent a trusted partner for both long and short-term placements. In business for more than 13 years, Delta-T Group provides exceptional customer service.</p>
415	<p><b>Devereux</b> 444 Devereux Drive, Villanova, PA 19085 Phone: 610-542-3030, toll free 800-345-1212, Fax: 610-542-3141 e-mail: knash@devereux.org Web: www.devereux.org Contact: Deborah Sulli—Director of Marketing and Admission</p> <p>Devereux is the nation's largest independent, nonprofit provider of treatment services for children, adolescents, and adults who have a wide range of emotional, behavioral, and developmental challenges and neurological impairments. Devereux's residential, day, and community-based programs are located in 12 states the District of Columbia. For more information contact our National Referral Office at 800/345/1212 or visit our website.</p>
104	<p><b>DynaVox Systems, Inc.</b> 2100 Wharton St—#400, Pittsburgh, PA 15203 Fax: 412-381-5241 e-mail: susan.mackowiak@dynavoxsys.com Contact: James Warren</p> <p>DynaVox Systems LLC, the world's leading manufacturer of advanced augmentative communication solutions, will</p>

**Booth Exhibitor**

display their full line of products, including the new DV4 and the Enkidu Impact line.

**204 The Echo Group**

PO Box 2150, Conway, NH 03818  
Phone: 603-447-8600, Fax: 603-447-8680  
e-mail: info@echoman.com  
Web: www.echoman.com  
Contact: Michael Hill—Senior Account Manager

The Echo Group's innovative software applications developed for behavioral healthcare are unsurpassed in their ability to provide agencies with the decision support and executive analysis tools necessary to manage more efficient agencies. Our fully integrated Windows and Browser-based products include Clinical, Revenue Management, Managed Care, Accounting and Analytical solutions.

**401 Elwyn Inc**

111 Elwyn Rd, Elwyn, PA 19063-4699  
Phone: 610-891-2525, Fax: 610-891-2662  
e-mail: yelvertonh@elwyn.org

Elwyn Inc. is a human services organization serving adults and children. Since 1852, Elwyn grew to a multisite, full-service provider for people with all types of challenges in life. Programs are offered to local schools, community sites, workplaces, and individual homes.

**209 Esteem**

2611 Stayton St., Pittsburgh, PA 15212  
Phone: 412-322-0629, Fax: 412-321-5313  
e-mail: drumberger@esteem.net  
Contact: David Rumberger—Director of Sales & Marketing

The Total: impact system of products and services was created by Esteem, an organization of human service professionals, dedicated to providing the best in administrative and managerial support to our industry. The Esteem partners are able to provide invaluable insights, coupled with the navigation tools for the challenges you face.

**314 Evergreen Center**

345 Fortune Blvd, Milford, MA 01757  
Phone: 508-478-2631, Fax: 508-634-3251  
e-mail: nmanske@evergreenctr.org  
Web: www.evergreenctr.org  
Contact: Nancy Manske—Director of Family Services & Admissions

For over 20 years, the Evergreen Center continues to provide two school programs with a range of community based residential options. Both programs utilize applied behavior analysis to implement a philosophy which values the acquisition of social competency. The Center for Basic Skills serves students with Mental Retardation, Autism, Physical Disability, Sensory Impairments, and Medical fragility, ages 6–22. The Center for Behavior Development serves students with Dual Diagnosis of Mental Illness/Mental Retardation, Severe Maladaptive Behaviors, Traumatic Brain Injury, and Post traumatic Stress Disorder ages 6–22.

**115 Exceptional Parent**

65 E Rt 4, River Edge, NJ 07661  
Phone: 201-489-4111, Fax: 201-489-0074  
e-mail: dorisd@eparent.com  
Web: www.eparent.com

*Exceptional Parent* is a 33 year-old magazine that has won numerous awards for excellence for its editorial content relating to special needs persons. It is the "go to" source for the latest information on a range of disabilities

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including epilepsy, autism, mental retardation, and many other neurological disorders. We would encourage you to go to our website at www.eparent.com for insight into the multitude of informational offerings that it contains.

**101 Fantagraph**

One Knollcrest Dr, Cincinnati, OH 45237  
Phone: 513-761-9256, Fax: 513-679-6922  
e-mail: volsen@standardtextile.com  
Contact: Virginia Olsen

Fantagraph decorative products by Standard Textile bring cutting edge fabrics and products, for the appropriate use in health care coupled with reliable on time service.

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e-mail: ggarcia@flaghouse.com  
Web: www.flaghouse.com  
Contact: Carrie Aspen—Account Representative

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**414 The Guided Tour, Inc.**

7900 Old York Rd—#111-B, Elkins Park, PA 19027-2339  
Phone: 215-782-1370, Fax: 215-635-2637  
e-mail: gtour400@aol.com  
Contact: Doron Segal—Tour Coordinator

The Guided Tour, Inc. founded in 1972, was the first professionally supervised travel and vacation program for adults with developmental and physical challenges. Our staff are paid professionals with most of them working, or having worked in the field of MR/DD. We do not seek volunteers and have virtually no staff turnover. A nurse accompanies most trips and we have a staff to traveler ratio of 1:3 and offer a ratio of 1:1 for slow pacers, persons in wheelchairs, or persons with visual challenges. In our 32nd year, we continue to pioneer in this field!

**215 Habilitation Software, Inc.**

204 N Sterling St, Morganton, NC 28655  
Phone: 828-438-9455, Fax: 828-438-9488  
e-mail: mike@habsoft.com  
Web: www.habsoft.com

The PPS is software designed to help QMRPs cut down on the amount of time it takes to complete their many daily tasks. The PPS comes with a complete modifiable program library, assists with Person-Centered Planning, helps with objective writing, offers a computer generated Progress note, and QMRP review.

**100 Health Care Software, Inc. (HCS)**

PO Box 2430, Farmingdale, NJ 07727  
Phone: 732-938-5600, Fax: 732-938-5380  
e-mail: marketing@hcsinteractant.com  
Web: www.hcsinteractant.com  
Contact: Tom Fahey—Vice President of Sales & Marketing

Health Care Software, Inc. (HCS) has been dedicated to the development, installation, and support of clinical and financial applications for over 34 years. Our product, INTERACTANT, is designed specifically for sub-acute

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	care and human service organizations. HCS specializes in multi-site organizations providing inpatient, outpatient, and residential type services.
<b>311</b>	<p><b>Heartspring School</b>            8700 E 29th St N, Wichita, KS 67226            Fax: 316-634-0555            e-mail: kbaker@heartspring.org            Web: www.heartspring.org            Contact: Kristina Baker—Admissions Specialist</p> <p>Heartspring is a private, not-for-profit, residential school that serves special needs children, ages 5-21, from across the country.</p>
<b>500</b>	<p><b>Ilderton Conversion Co.</b>            701 S Main St, High Point, NC 27261            Phone: 336-841-2020, Fax: 336-887-2342            e-mail: bpj@northstate.net            Contact: Brian Johnson—Operations Manager</p> <p>Ilderton Conversion Company of High Point, NC was established in 1972 as a division of Ilderton Dodge Chrysler Jeep Sprinter Inc. We participate in a national dealer network that provides accessible vans to the physically challenged. Our highly experienced sales and service staff can assist you with financing, leasing or third party payment programs.</p>
<b>404</b>	<p><b>Irwin Siegel Agency, Inc.</b>            25 Lake Louise Marie Rd, Rock Hill, NY 12775            Fax: 845-796-3400            e-mail: 2johnrose@excite.com</p> <p>Providing quality insurance services and customized risk management for human service organizations.</p>
<b>406</b>	<p><b>John Langdon Down Foundation</b>            Selva 4 - Ingurgentes Cuicuico, Mexico City,            Phone: 011-52-55-56-66-85-80, Fax: 011- 52- 55-56-06-38-09            e-mail: contacio@fjldown.org.mx            Web: www.fjldown.org.mx            Contact: Juan Bribiesca Ruiz</p> <p>Products done by people with Down Syndrome or to help them such as: calendars, postcards, posters, coffee mugs, t-shirts, key rings, pins, engravings, pens and pencils.</p>
<b>410</b>	<p><b>Ken Crest Consultants</b>            502 W Germantown Pk—Ste 200, Plymouth Meeting, PA 19462            Phone: 610-825-9360, Fax: 610-825-7406            e-mail: dlord@kencrest.org            Web: www.kencrest.org            Contact: Debbie Lord—Director of Clinical &amp; Healthcare Services</p> <p>Ken-Crest Consultants provides specialized therapy / consultative services in the Philadelphia, New Jersey and Delaware area. We provide community based consultative and education services to individuals, work and schools.</p>
<b>113</b>	<p><b>Kennedy Krieger Institute</b>            707 N Broadway, Baltimore, MD 21205            Phone: 443-923-2792, Fax: 443-923-9317            e-mail: stone@kennedykrieger.org            Contact: Joan Carney</p> <p>Kennedy Krieger Institute is dedicated to helping children and adolescents with disabilities resulting from disorders of the brain achieve their potential and participate as fully as possible in family, community and school life. For more information about Kennedy Krieger Institute, visit www.kennedykrieger.org.</p>

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<b>411</b>	<p><b>KLM Skill Builders</b>            PO Box 408, Lynn, MA 01903            Phone: 781-599-4240, Fax: 781-596-4135            e-mail: tmccormack@glmh.org            Web: www.glmrh.org            Contact: Jeri Kroll—Director of Training</p> <p>KLM Skill Builders have developed training modules to assist your managers to deliver high impact trainings directly at the worksite. These laminated, easy to read colorful skill cards make our materials unique and effective. Topics include nutrition, fire safety, human rights, professionalism, food safety, documentation, diversity, teaching skills and more.</p>
<b>200</b>	<p><b>Liberty Healthcare Corporation</b>            401 City Ave—Ste 820, Bala-Cynwyd, PA 19004            Phone: 610-668-8800, Fax: 610-668-7689            e-mail: loris@libertyhealth.com            Contact: Lori Schulze—Administrator</p> <p>Liberty Healthcare is a contract medical management organization. We have over 25 years of experience staffing and managing a wide variety of healthcare and treatment programs throughout the United States with a proven record of providing customized services to public and private sector clients. Liberty Healthcare maintains contracts in twenty (20) states through a network of hundreds of physicians, nurses, psychiatrists, therapists, and other health care professionals.</p>
<b>110</b>	<p><b>Martha Lloyd Community Services</b>            190 W Main St, Troy, PA 16947            Phone: 570-297-2185, Fax: 570-297-1019            e-mail: information@marthalloyd.org            Web: www.marthalloyd.org            Contact: Todd Boyles—Public Relations</p> <p>Over 75 years offering a continuum of care and services for individuals 15 and older with mental retardation and developmental disabilities: Community residential programs; adult day care; respite care; vocational work center work experience; school to work; sensory integration, health, recreation, exercise, and dietary programs—in a safe, secure setting.</p>
<b>308</b>	<p><b>Mass Mutual Financial Group</b>            410 Pebble Hill Rd, Doylestown, PA 18901            Phone: 215-489-7450, Fax: 215-489-7451            e-mail: w.cosgriff@finsvcs.com            Contact: Wesley Cosgriff—Special Care Planner</p> <p>Comprehensive special care planning services for persons with disabilities and their family.</p>
<b>307</b>	<p><b>Melmark, Inc.</b>            2600 Wayland Rd, Berwyn, PA 19312            Phone: 610-325-4969, Fax: 610-353-4956            e-mail: pjm@melmark.org            Web: www.melmark.org            Contact: Peter McGuinness</p> <p>Melmark's approved private school and adult programs provides residential, educational, therapeutic and recreational services for children and adults with developmental disabilities, which include Down syndrome, autism and neurological impairments. Residential options accommodate varying needs, both within a campus setting and in our community homes. The Meadows at Melmark adult program provides meaningful work, small community residential living options and a full life of social, and recreational activities.</p>

**309 The MENTOR Network**

313 Congress St, Boston, MA 02210  
 Phone: 617-790-4800, Fax: 617-790-4258  
 e-mail: tracey.antaya@thementornetwork.com  
 Web: www.thementornetwork.com  
 Contact: Tracey Antaya—Director of Marketing

Providing services in over 30 states, The MENTOR Network offers community-based residential; and nonresidential services to adults with mental retardation and/or developmental disabilities through its national network of local providers. Some member providers in The Network have been operating for over 30 years. Services and support options include host home, in-home support, supported living, small group care, day programming, and employment services and can range in intensity, duration and frequency depending on the needs of the individuals we serve.

**409 Municipal Capital Markets Group, Inc.**

5429 LBJ Frwy, Dallas, TX 75240  
 Phone: 972-386-0200, Fax: 972-386-6636  
 e-mail: kcornwall@municipal.com  
 Web: www.municipal.com  
 Contact: Fred Cornwall—President

MCM provides long term financing through the issuance of tax-exempt municipal bonds for MR/DD Service Providers that are 501(c)3 corporations. Typically the use of municipal bonds provides the borrower with significant interest savings. The savings generated can be put back into the essential services you provide.

**114 Mutual of America**

320 Park Ave, New York, NY 10022  
 Phone: 212-224-1707 Fax: 212-224-2527  
 e-mail: thomas.macmurray@mutualofamerica.com  
 Web: www.mutualofamerica.com  
 Contact: Thomas MacMurray—Senior Field Vice President

Mutual of America provides group and individual annuities and related services for the pension, retirement and long-term savings needs of organizations and their employees as well as individuals. We also offer investment products for institutional funds. Stop by our booth and find out how Mutual of America can assist you and your organization.

**601 National Association For The Dually Diagnosed (NADD)**

132 Fair St, Kingston, NY 12401-4802  
 Phone: 845-331-4336, Fax: 845-331-4569  
 e-mail: info@thenadd.org  
 Web: www.thenadd.org

Contact: Robert Fletcher—Executive Director & Founder

NADD is a membership association designed to promote appropriate supports and treatment for persons who have developmental disabilities and mental health needs. Membership is open to professionals, parents, concerned citizens and organizations. The NADD mission is to advance mental wellness for persons with developmental disabilities through the promotion of excellence in mental health care. NADD offers a wide selection of training and educational materials including audio tapes, compact disks, videotapes and books, as well as web cast online training. Additionally, NADD provides expert consultation services.

**112 The National Fragile X Foundation**

1615 Bonanza St—Ste 320, Walnut Creek, CA 94596  
 Phone: 925-938-9300, Fax: 925-938-9315  
 e-mail: teddy@fragilex.org

The National Fragile X Foundation unites the fragile X community to enrich lives through educational and emotional support, promote public awareness, advance research toward improved treatments and a cure for fragile X syndrome.

**213 NISH**

8401 Old Courthouse Rd, Vienna, VA 22182  
 Phone: 571-226-4523, Fax: 703-288-9146  
 e-mail: swalton@nish.org  
 Web: www.nish.org  
 Contact: Brian DeAtley

NISH is a national Non-Profit agency that provides employment opportunities for people with severe disabilities by securing federal contracts for Community Rehabilitation Programs under the Javits-Wagner-O'Day Program. Additionally, NISH is the subcontractor for the Ticket to Work Program. This program increases choices of SSI/SSDI beneficiaries for obtaining employment, occasional rehabilitation, and other support services.

**201 Philadelphia Insurance Companies**

One Bala Plaza—Ste 100, Bala-Cynwyd, PA 19004  
 Phone: 610-617-7646, Fax: 610-227-2212  
 e-mail: mburke@phlyins.com  
 Web: www.phlyins.com

Philadelphia Insurance Companies is rated A+ by AM Best Company and is committed to providing non-profit organizations with a quality insurance program. Our underwriting flexibility enables us to address the unique exposures that confront non-profits while understanding your budgetary constraints. For more information, contact our marketing department at 800-873-4552 or visit us on line at www.phly.com

**208 Program Development Associates**

PO Box 2038, Syracuse, NY 13220  
 Phone: 315-452-0643, Fax: 315-452-0710  
 e-mail: pcomo@pdassoc.com  
 Web: www.disabilitytraining.com  
 Contact: Perry Como—President

We provide disability-related staff training and educational videos, DVDs, CD-ROMs and resources for residential and vocational agencies, organizations, schools, and colleges. Leading professionals produce many of our resources. Subjects include employment, self-determination, sex education, assistive technology, autism, mental retardation, advocacy, inclusion, and history. Free previews available. Visit our web site at www.disabilitytraining.com.

**106 Quarter Turn Software**

116 Morehead St, Morganton, NC 28655  
 Phone: 785-633-9933  
 e-mail: vanonc2@bellsouth.net  
 Web: www.quarterturnsoftware.com  
 Contact: Tom Van Ordstrand

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- 304 ResCare, Inc.**  
10140 Linn Station Rd, Louisville, KY 40223  
Phone: 502-394-2135, Fax: 502-394-2181  
e-mail: lweishaar@rescare.com  
Web: www.rescare.com  
Contact: Larry Weishaar—Vice President Support Services  
ResCare—a local provider with national resources. We are a provider of residential, training, educational and support services for persons with developmental and neurological disabilities. Our local agencies are involved in developing, operating and/or managing group homes, supported living, in-home supports, supported employment, vocational and day program services.
- 300 Shepherds Baptist Ministries**  
1805 15th Ave, Union Grove, WI 53182  
Phone: 262-878-5620, Fax: 262-878-3402  
e-mail: drendall@shepherdsministries.org  
Shepherds Ministries helps people with mental disabilities reach their potential by providing residential, spiritual, medical, and recreational services. We offer respite services to people throughout the country. Employment services are provided through SERVE Enterprises.  
We offer inkjet and toner cartridges through our subsidiary, SERVE Ink.
- 103 St John's Community Services**  
5151 Wisconsin Ave NW, Washington, DC 20016-4124  
Phone: 202-274-3409, Fax: 202-237-6352  
e-mail: vtaylor@sjcs.org  
Contact: Albert Brown—Pennsylvania State Director  
Founded in 1868, St. John's Community services is a non-profit provider for adults and children with disabilities in the District of Columbia, Virginia, New Jersey, Tennessee and Pennsylvania. Services include community living / supported, employment, community participation, special education in D.C. schools and Saturday recreation program for children in Newark.
- 302 Synchrony Solutions LLC**  
185 Hillside Ave, East Williston, NY 11049  
Phone: 860-916-9279, Fax: 860-571-8906  
e-mail: aspencer@bnkst.edu  
Synchrony Solutions, LLC, designs and produces CD-ROM and Web-based training programs designed to provide human service workers with essential skills and competencies for high quality care, treatment and training. Staff development modules include assessment and documentation of performance for personnel records to demonstrate compliance with regulatory requirements.
- 109 T F H (USA) Ltd**  
4537 Gibsonia Rd, Gibsonia, PA 15044  
Phone: 724-444-6400, Fax: 724-444-6411

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Contact: Tom Marshall—Multi-Sensory Consultant  
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- 205 T & M Ranch**  
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Phone: 561-842-5814, Fax: 561-881-3554  
e-mail: fred@seagull.org  
Contact: Fred Eisinger—Executive Director  
Residential service, adult day training service, supported employment / supported living services for developmentally challenged adults.
- 305 Therapeutic Health & Equipment**  
14000 NW 1st Ave, Miami, FL 33168  
Phone: 305-681-9900, Fax: 305-681-9179  
e-mail: therequip@aol.com  
Contact: Ann English—General Manager  
Therapeutic Health & Equipment Specialists, Inc. is a manufacturer of foam positioning rolls, wedges, and blocks since 1985. Our products are made of high density foam, preventing our equipment from "bottoming out" and have no stitched seams making them completely waterproof. Equipment is available in infant, child, and adult sizes.
- 317 UIC—Dept. of Disability & Human Development**  
1640 W Roosevelt Rd, Chicago, IL 60608  
Phone: 312-413-1647, Fax: 312-413-1630  
e-mail: maitha@uic.edu  
The Department of Disability and Human Development (DHD) is dedicated to the scholarly, interdisciplinary study of disability, and related aspects of human development. DHD is the home of a number of interdisciplinary centers and projects conducting research across the spectrum of disability. The Institute on Disability and Human Development serves as a public service arm of DHD and as the federally chartered UCEDD for Illinois.
- 105 YAI/National Institute for People With Disabilities**  
460 W 34th St - 11th Fl, New York, NY 10001  
Phone: 212-273-6289, Fax: 212-273-6590  
e-mail: jennifer.shaoul@yai.org  
Web: www.yai.org  
Contact: Jennifer Shaoul—Senior Coordinator of Intake  
Provides full range of services to people with developmental disabilities and their families in the New York Metropolitan region, New Jersey and Puerto Rico. Produces and sells a wide variety of training videotapes and curricula for staff working with people with DD and for people with disabilities themselves.



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1895–1896 Samuel J. Fort, MD	1937–1938 Harry C. Storrs, MD	1980–1981 H. Carl Haywood, PhD
1896–1897 Martin W. Barr, MD	1938–1939 Neil A. Dayton, MD	1981–1982 Frank A. Borreca, EdD
1897–1898 George A. Brown, MD	1939–1940 Frederick Kuhlmann, PhD	1982–1983 A. Gail O'Connor, PhD
1898–1899 Mary J. Dunlap, MD	1940–1941 Meta L. Anderson, PhD	1983–1984 Herbert J. Grossman, MD
1899–1900 Alexander Johnson	1941–1942 Fred O. Butler, MD	1984–1985 B.R. (Bill) Walker, PhD
1900–1901 W.A. Polglase, MD	1942–1943 Horatio M. Pollock, PhD	1985–1986 H. Rutherford Turnbull III, LLB, LLM
1901–1902 F.W. Keating, MD	1943–1944 C. Stanley Raymond, MD	1986–1987 Harold Michal-Smith, PhD
1902–1903 J.M. Murdoch, MD	1944–1945 E. Arthur Witney, MD	1987–1988 Valaida S. Walker, EdD
1903–1904 Edward R. Johnstone	1945–1946 Mabel A. Matthews	1988–1989 Robert G. Griffith, EdD
1904–1905 A.H. Beaton, MD	1946–1947 Warren G. Murray, MD	1989–1990 James W. Ellis, JD
1905–1906 George Mogridge, MD	1947–1948 Lloyd N. Yepsen, PhD	1990–1991 Robert R. Bruininks, PhD
1906–1907 W.H.C. Smith, MD	1948–1949 Edward J. Humphreys, MD	1991–1992 Jack A. Stark, PhD
1907–1908 Charles Bernstein, MD	1949–1950 Mildred Thomson	1992–1993 Michael R. Dillon, EdD
1908–1909 W.N. Bullard, MD	1950–1951 Richard H. Hungerford	1993–1994 David L. Braddock, PhD
1909–1910 Miss Mattie Gundry	1951–1952 Edward J. Engberg, MD	1994–1995 Karen L. Middendorf
1910–1911 Arthur R.T. Wylie, MD	1952–1953 Bertha M. Luckey, PhD	1995–1996 William E. Kiernan, PhD
1911–1912 H.G. Hardt, MD	1953–1954 Arthur T. Hopwood, MD	1996–1997 Pamela C. Baker, PhD
1912–1913 Allan E. Carrol, MD	1954–1955 Gale H. Walker, MD	1997–1998 Robert L. Schalock, PhD
1913–1914 J.K. Kutnewsky, MD	1955–1956 Arthur E. Westwell, DMD	1998–1999 Stanley S. Herr, J.D., PhD
1914–1915 H.H. Goddard, PhD	1956–1957 Thomas L. McCulloch, PhD	1999–2000 Bernard R. Wagner, PhD
1915–1916 Charles Bernstein, MD	1957–1958 Chris J. DeProspero, EdD	2000–2001 Cathy Ficker Terrill
1916–1917 E.J. Emerick, MD	1958–1959 George Tarjan, MD	2001–2002 Steven F. Warren, PhD
1917–1918 George L. Wallace, MD	1959–1960 Frances M. Coakley	2002–2003 Ruth A. Luckasson, JD
1918–1919 Charles S. Little, MD	1960–1961 Edward L. Johnstone	2003–2004 Ann P. Turnbull, EdD
	1961–1962 Herschel W. Nisonger	