

THE 29TH ANNUAL

# AGING

with Developmental  
Disabilities Conference

May 20-21, 2019  
St. Charles Convention Center  
[www.agingwithdd.org](http://www.agingwithdd.org)



4 TRACKS, 3 KEYNOTE PRESENTERS, 2 DAYS,  
FOCUSED ON 1 GOAL:

**DEVELOPING THE BEST SUPPORT PRACTICES**  
FOR AGING WITH DEVELOPMENTAL DISABILITIES.



DR. BENJAMIN L. HANDEN



DR. JOHN E. MORLEY



DR. LIEKE VON HEUMEN



DR. PETER BULOVA



ASSOCIATION ON AGING WITH  
DEVELOPMENTAL DISABILITIES



Intellectual and Developmental Disabilities Research Center



SAINT LOUIS  
UNIVERSITY  
— EST. 1818 —

# AGING

with Developmental Disabilities Conference

May 20-21, 2019



## Conference Location

St. Charles Convention Center

#1 Convention Center Plaza, St. Charles, Missouri 63303

## For More Information

Contact AADD at (314) 647-8100

agingwithdd@msn.com

## Monday, May 20

8:30 Registration/Exhibitors

## 9:30 KEYNOTE ADDRESS: Psychosocial Therapy for Cognition in Individuals Aging with a Developmental Disability



Dr. John E. Morley

JOHN E. MORLEY, MB, BCH, SAINT LOUIS UNIVERSITY SCHOOL OF MEDICINE

Psychosocial Therapy for Cognition has been developed for those with developmental disabilities to stimulate them to talk about their memories. Using familiar items from sports and common events, people with memory problems are encouraged to share their past experiences. This approach enhances mood and communication skills and may even improve intellectual ability. Similarly, loneliness groups (Circle of Friends) can stimulate interactive behavior.

10:30 Break

10:45 Breakout Session I

DIRECT SERVICE TRACK A	PROFESSIONAL TRACK B	NURSING TRACK C	POTPOURRI TRACK D
<b>AGING 101</b> Andrea Frazier EdD, Lindenwood University Identify normal changes of body and mind during aging. Examine common deviations from physical and emotional/cognitive health in aging adults, especially those with developmental/intellectual disabilities.	<b>ADDRESSING SOCIAL ISOLATION THROUGH A CIRCLE OF FRIENDS</b> Marla Berg-Weger, PhD, LCSW, Professor, Saint Louis University School of Social Work Social isolation is a significant concern of older adults and their families. Improve the quality of care provided to all older adults by integrating assessment and intervention of social isolation and loneliness. One such intervention is the evidence-based group intervention, Circle of Friends.	<b>WHY DOES RALPH COUGH?</b> Archie B. Harmon, PhD, Washington University School of Medicine Different types of coughs that an aging person can develop and the appropriate treatment for each type of cough will be discussed in this session.	<b>CANNABIS DERIVED THERAPIES IN EPILEPSY: THE GOOD, THE BAD, AND THE UGLY</b> John Ingram, MD, University of Mississippi Medical Center Dr. Ingram will provide an overview of epilepsy and seizures, focusing on the remote history of cannabis in the treatment of epilepsy and the more recent history of cannabis and CBD's role in epilepsy. Research opportunities in using cannabis in the treatment of epilepsy, including a new trial at UMMC, will also be discussed.

We gratefully acknowledge our sponsors:



Intellectual and Developmental Disabilities Research Center



# The 29th Annual **AGING** with Developmental Disabilities Conference



## Monday, May 20 (continued)

11:45 Lunch

1:00 Breakout Session II

DIRECT SERVICE TRACK A	PROFESSIONAL TRACK B	NURSING TRACK C	POTPOURRI TRACK D
<b>NUTRITION SUPPORTS FOR THE AGING INDIVIDUAL</b> Katharine Rug, MS, RD, LD, St. Louis Arc Explore the relationship between disease, nutrition, and aging with a lens focused on supporting individuals with intellectual and developmental disabilities. This presentation aims to provide caregivers with a better understanding of the etiology of food related challenges that occur within this population, as well as tools to identify when these challenges are on the horizon.	<b>END OF LIFE ISSUES FOR PEOPLE WITH INTELLECTUAL DISABILITIES</b> Martha C. Brown, JD, CELA, Martha C. Brown & Associates, LLC, and Barbara Helm, Arcare, Inc. Learn about legal, ethical, and psycho-social aspects of end of life issues for people with intellectual disabilities.	<b>DELEGATION, DOCUMENTATION, AND THE MISSOURI NURSING PRACTICE ACT</b> Debra Funk, RN, Missouri State Board of Nursing In this interactive session, many topics will be discussed including the responsibilities of the Board of Nursing as well as the general responsibilities that nurses have relating to education, experience, and their relationship with the Board of Nursing.	<b>IMPLICIT BIAS</b> Cynthia L. Mueller, PhD, Licensed Psychologist Implicit bias is all around us. We are even part of the issue. Research on implicit bias and how it may affect the way we support people will be discussed.

2:00 Break

2:15 Breakout Session III

DIRECT SERVICE TRACK A	PROFESSIONAL TRACK B	NURSING TRACK C	POTPOURRI TRACK D
<b>WHAT DO PEOPLE KNOW ABOUT PROMOTING DESIRABLE BEHAVIOR FOR THEMSELVES AND OTHERS AND WHAT IS ACTUALLY MOST EFFECTIVE?</b> Teresa A. Rodgers, PhD, BCBA-D, LBA, Missouri Department of Mental Health Division of Developmental Disabilities Explore beliefs and practices in self-management and the management of the behavior of others through a series of interactive exercises. Common understanding and practices will be compared to best practices identified by science for self-management and the management of the behavior of others.	<b>MANAGING CANCER-RELATED DISTRESS</b> Renata Sledge, MSW, PhD Student This presentation will describe cancer-related distress, the impact of distress on patients and their families, and a framework for everyone on the treatment team, including patients and their families, to manage symptoms of distress.	<b>USE OF VITALSTIM (NMES) FOR THE TREATMENT OF DYSPHAGIA IN INDIVIDUALS WITH IDD</b> Tyyna Bailey, MS, CCC-SL, SSM Health St. Mary's Jefferson City, and Jacqueline Fernald, RN, CDDN, Finck Supported Living Services In this presentation, participants will learn from the presenters' firsthand experience with VitaLStim, a little-known treatment of dysphagia. Awareness of the symptoms of dysphagia and aspiration will be increased.	<b>RETT SYNDROME ACROSS THE AGES</b> Robin C. Ryther, MD, PhD, Washington University School of Medicine Rett Syndrome is a rare genetic disorder primarily affecting females who are born typically developing before regressing and then losing skills. In this session, learn about the numerous medical concerns affecting their entire body as a result of Rett Syndrome and how their needs change throughout their lifespan.

3:15 Break

## 3:30 Postnote: ST. LOUIS ARC HOLISTIC AGING COMMITTEE: A PANEL DISCUSSION

Mary Anne Tolliver, MPA, St. Louis Arc; Jessica Gantner, St. Louis Arc; Katharine Rug, MS, RD, LD, St. Louis Arc; John Kelly, St. Louis Arc; Craig Sever, BS, RPh, Everspring Pharmacy; Kelli Barton, PhD, University of Missouri at Kansas City Institute of Human Development

The St. Louis Arc continues as a leader in serving the aging population with intellectual and developmental disabilities in the best and most holistic way possible. In early 2018, it was determined that a need for a targeted due process review was present, and the Holistic Aging Committee was created. This committee is overseen by the St. Louis Arc and is comprised of community experts in the field of aging. The group meets monthly to not only review any due process issues (behavior modifying medications/supports and/or rights restrictions) but to also review the individual's current strengths and challenges and provide recommendations regarding supports, the environment, the need to seek the assistance of additional professionals, educational opportunities, etc. to support the individual as well as the team that is providing supports to that individual as they age. This session will include a panel discussion with some of the committee members who will discuss how the committee was formed, how it is maintained, and what lessons have been learned in its first year.

4:30 Conference concludes for the day





**Tuesday, May 21**

**8:00 Registration/Exhibitors**

**8:30 KEYNOTE ADDRESS: DOWN SYNDROME AND DEMENTIA**

**BENJAMIN L. HANDEN, PhD, UNIVERSITY OF PITTSBURGH AND PETER BULOVA, MD, UNIVERSITY OF PITTSBURGH MEDICAL CENTER**

Adults with Down syndrome are at extremely high risk for developing Alzheimer's disease. Drs. Handen and Bulova, investigators in a dementia and Down syndrome study, will share findings related to providing appropriate services and support for individuals with Down syndrome and their caregivers.



Dr. Benjamin L. Handen



Dr. Peter Bulova

**9:30 Break**

**9:45 Breakout Session I**

DIRECT CARE TRACK A	PROFESSIONAL TRACK B	NURSING TRACK C	POTPOURRI TRACK D
<b>FALL PREVENTION</b> <i>Jackie Rand, PT, BJC Homecare</i> Falling is a common cause of injuries and reduced quality of life. As the number of elderly persons with ID is growing rapidly, it is imperative to gain insight into the circumstances that precipitate falls and how to prevent these falls.	<b>BEST PRACTICES FOR CREATING LGBT-WELCOMING AGING PROGRAMS</b> <i>Sherrill Wayland, MSW, SAGE</i> This session will look at the intersections of aging, sexual orientation, gender identity and intellectual disabilities. Join this interactive session as we discuss the needs of serving people with intellectual disabilities who identify as LGBT, best practices for creating LGBT-welcoming organizations, and programming ideas.	<b>REDUCING MEDICATIONS-WHEN, WHAT, AND HOW TO MINIMIZE ADVERSE OUTCOMES</b> <i>Craig Sever, BS, RPh, EverSpring Pharmacy</i> Learn about the multiple intricacies of when a medication should be reduced, what medications we should target, how to go about the actual reduction process to enhance the opportunity for a successful reduction, and strategies for reductions and ideas to prevent excessive medication use in the future.	<b>DOWN SYNDROME AND DEMENTIA: A CLOSER LOOK</b> <i>Benjamin L. Handen, PhD, University of Pittsburgh, and Peter Bulova, MD, University of Pittsburgh Medical Center</i> Join this more in-depth follow-up to the keynote presentation on adults with Down syndrome and Alzheimer's disease.

**10:45 Break**

**11:00 Breakout Session II**

DIRECT CARE TRACK A	PROFESSIONAL TRACK B	NURSING TRACK C	POTPOURRI TRACK D
<b>CONCEPTIONAL FRAMEWORK OF REFERENCE: HOW CAN I BETTER SERVE INDIVIDUALS WITH DD?</b> <i>Catherine Goebel, MA, MS Ed, Retired from State of Illinois Guardian and Advocacy Commission</i> Learn to utilize tools you possess to think outside of the box to advocate for others.	<b>INCLUSION INCLUDES HOSPICE</b> <i>Holly Wamser, MSN, RN, BJC Hospice &amp; Home Care Services</i> Explore how to meld two supports to best serve those with developmental and physical disabilities at the end of life. How can new technology assist in bringing inclusion to palliative and hospice services? The presentation will include small group activities.	<b>DIABETES/COMORBIDITY</b> <i>John E Morley, MB, BCh, Saint Louis University School of Medicine</i> It is vital to recognize the importance of special syndromes in diabetes in persons with developmental disabilities. We will explore how diabetes causes cognitive dysfunction.	<b>SIMPLE SOLUTIONS FOR AGING IN PLACE</b> <i>Emily Martin, MOT, OTR/L, CAPS, eSpecial Needs</i> Learn common sense strategies and simple solutions for aging in the home. Equipment versus home modifications will be discussed as well as a review of safety and sensory considerations.

**12:00 Lunch and Award Presentations**

**1:15 Breakout Session III**

DIRECT CARE TRACK A	PROFESSIONAL TRACK B	NURSING TRACK C	POTPOURRI TRACK D
<b>DEMENTIA VS. DELIRIUM?</b> <i>Janis McGillick, MSW, LHNA, Dolan Memory Care Homes</i> Help caregivers distinguish between symptoms of dementia and delirium and develop approaches to respond appropriately to either one or both of these conditions. Definitions, causes, prevention strategies, and related therapies will all be highlighted in the presentation and discussion of case studies.	<b>JOURNEY AND FUTURE WITH AUTISM</b> <i>Karen Kelly, EdD, RN, NEA-BC, Retired Nurse Administrator and Faculty Member</i> Examine the evolving challenges faced by one family with their son with autism spectrum disorder during their autism journey from 1976 to the present. She will review policy trends, research on autism spectrum disorder, and societal trends that may drive the future for adults with autism spectrum disorder.	<b>SUPPORTING AGING INDIVIDUALS WITH EFFECTIVE COMMUNICATION WITH THEIR MEDICAL PROVIDERS</b> <i>Preston Howerton, DO, Howerton Integrated Medical Clinic</i> Gain insight on how nurses and others who interact with the medical team for aging individuals with DD can develop a rapport with the medical team (the doctor as well as the staff) to ensure that the patient's needs are met, including enhanced treatment.	<b>BEHAVIORAL MANIFESTATIONS OF UNDERLYING MEDICAL CONDITIONS IN PEOPLE WITH IDD</b> <i>Craig Escudé, MD, HRS, Inc.</i> In this session, case studies will be reviewed to illustrate how behaviors can be a way of communicating certain medical problems.

**2:15 Break**

**2:30 POSTNOTE: INTENSIVE RESEARCH WITH OLDER ADULTS WITH IDD: IMPLICATIONS FOR PRACTICE**

**LIEKE VAN HEUMEN, PhD, UNIVERSITY OF ILLINOIS AT CHICAGO**

Findings from recent research strategies that retrieve the experiences of older adults with IDD provide insights into the lives and needs of adults aging with IDD from their own perspectives. These insights inform the supports they need to thrive and be fully included members of their communities.



Dr. Lieke van Heumen

**3:30 Conference concludes**



# 29th Annual AADD Conference Registration Form

**PAYING BY CREDIT CARD? Fees will apply.  
Click here or scan the QR code to REGISTER ONLINE.**



Scan this  
QR Code  
to register  
online.

If paying by check or purchase order, online registration is not available.  
Complete this form for each registrant and mail with check payable to  
AADD, 2385 Hampton Avenue, St. Louis, MO 63139.

Name \_\_\_\_\_ Job Title \_\_\_\_\_

Organization \_\_\_\_\_

Home or Business Address \_\_\_\_\_

Email \_\_\_\_\_ Telephone (\_\_\_\_) \_\_\_\_\_

By May 2, 2019, submit any special needs or accommodation requests (including dietary) by listing here:

## Registration Fee (includes instruction, materials, and lunch)

- ☐ \$225 Conference Fee (early registration)
- ☐ \$ 45 Additional Fee if Requesting CEUs
- ☐ \$250 Conference Fee for registrations received after May 2, 2019.
- ☐ \$215 Conference Fee per person for organizations sending 5 or more participants
- ☐ \$240 Conference Fee per person for organizations sending 5 or more participants for registrations received after May 2, 2019.

Please check the sessions you will attend and circle the breakouts of your choice.

### Day One: Monday, May 20th

- ☐ Keynote
- ☐ Breakout Session I: A B C D
- ☐ Breakout Session II: A B C D
- ☐ Breakout Session III: A B C D
- ☐ Postnote

### Day Two: Tuesday, May 21st

- ☐ Keynote
- ☐ Breakout Session I: A B C D
- ☐ Breakout Session II: A B C D
- ☐ Breakout Session III: A B C D
- ☐ Postnote

No refunds after May 10, 2019. Please visit our website at [www.agingwithdd.org](http://www.agingwithdd.org) for more information.

Amount Enclosed \$ \_\_\_\_\_ Purchase Order # \_\_\_\_\_

## Continuing Education Hours (pending approval)

- 10 CEU Contact Hours for Missouri Nurses.  
*Saint Louis University School of Nursing is an approved provider of continuing nursing education by the Midwest Multistate Division, an accredited approver by the American Nurses Credentialing Center's Commission on Accreditation.*  
Midwest Multistate Division provider #MO221-1. Nursing Contact Hours: pending
  - 10 Social Work Clock Hours for Missouri Social Workers. *Application will be submitted to the NASW-Missouri Chapter and is pending for pre-approval of Social Work clock hours.*
  - 10 CEU Hours for Illinois LNHA, LCPC, LPC, LSW, PT, OT, QIDP, RN. *Application will be submitted for clock hours.*  
*This conference will qualify for continuing education hours as required by many national, state and local licensing boards and professional organizations. Save your course outline, certificate of completion, and contact your specific organization for filing requirements. Please bring your license/certification number to the conference. In the event of late arrival or early departure, amended certificates indicating the actual number of credit hours earned will be provided. This conference contains intermediate level content.*
- For more information regarding contact hours, please call 314-647-8100.  
All attendees will receive a certificate of attendance upon request.

Discounted hotel accommodations are available until April 30, 2019 at the Embassy Suites (attached to the Convention Center). Click here or call 800-560-7782. Refer to the room block for AADD.

Or visit [www.discoverstcharles.com](http://www.discoverstcharles.com) for additional accommodations and area attractions.

Registration includes consent for the Association on Aging with Developmental Disabilities to use your name, picture, likeness, film clip, voice recording, and other media-based material to develop marketing materials to be used by AADD.

You may revoke this authorization by initialling here: \_\_\_\_\_

Registration includes consent for the Association on Aging with Developmental Disabilities to share your name and contact information with other conference attendees and vendors. If you DO NOT consent to this use, you may revoke authorization by initialling here: \_\_\_\_\_

Questions?  
Call (314) 647-8100  
email [agingwithdd@msn.com](mailto:agingwithdd@msn.com)  
or visit [www.agingwithdd.org](http://www.agingwithdd.org)



## IN MEMORY AND GRATITUDE



John Blair Moore (1948-2018) spent his career as an artist, illustrator, graphic designer, cartoonist, and keen political commentator. He had notoriety as being a writer and illustrator for Disney, an internationally known graphic designer, a political cartoonist in newsprint and more recently, through social media. John was a self described “Illustrator, Raconteur, Savant”. Since 2007, those of us at the Association on Aging with Developmental Disabilities (AADD) also had the honor of calling John “Colleague, Friend, and Family”.

John had experience in customer service, but not in social services. He began working with people with developmental disabilities in order to share time and interest with his wife, who works in the field. John quickly came to have his own appreciation and understanding of the people he served. He had curiosity, insight, and perspective that allowed him to form unique and meaningful relationships. Before long, John began capturing his impressions on canvas. AADD commissioned John to illustrate programs that AADD offers, and we were fortunate to receive five pieces over the years, three of which are depicted below. These paintings capture the movement, personality and essence of those we serve, as only could be accomplished by one who knows and cares about this population.



Senior Hot Shots Learning to Retire



Senior Hot Shots with Friends



Mature Mile Walk