

Invited Conference March 23-24 at Rush University

People with disabilities receive primary, acute and transitional health care services at lower rates and with poorer outcomes than the non-disabled population. Barriers to equitable care include physical access to care (accessible transportation), space and equipment to accommodate specific disability conditions, communication barriers, lack of knowledge of health care providers in adapting health services for disability conditions and poor coordination of care. The unequal treatment of people with disabilities leads to increased health care costs, decreased quality of life, and increased morbidity and mortality for individuals with disabilities. The Partnering to Transform Health care with People with Disabilities (PATH-PWD) conference will bring together advocates across disability communities (intellectual, physical, sensory and mental) with health care stakeholders (providers and policy makers, executives. insurers, regulators and others). Participants will review and synthesize best practices and innovations in health care for people with disabilities, develop partnerships between stakeholders to implement best practices and innovations and improve quality and access, propose needed research, and recommend policies for improved health and health care.

RUSH UNIVERSITY



PATH-PWD@rush.edu

Funding for this conference was made possible [in part] by grant HS24842-01 from the Agency for Healthcare Research and Quality (AHRQ). The views expressed in written conference materials or publications and by speakers and moderators do not necessarily reflect the official policies of the Department of Health and Human Services; nor does mention of trade names, commercial practices, or organizations imply endorsement by the U.S. Government.

Support for this conference was also made possible by The Special Hope Foundation, an organization that advocates for accessible healthcare delivery designed to meet the needs of adults with intellectual and developmental disabilities.

Conference Hosts







Sarah Ailey, PhD, RN, CDDN, APHN-BC, is a nurse researcher and clinician who works to improve the health and health care of people with disabilities, concentrating on intellectual disabilities. Her research and scholarly practice are concentrated on translating research to community and inpatient hospital settings to improve the lives of individuals with intellectual disabilities. She is investigating the effect of the Steps to Effective Problem-solving (STEPS) program in group homes, funded by an R01 grant from the Eunice Kennedy Shriver Institute. Ailey has been a member of the Americans with Disabilities Act Task Force at Rush University Medical Center since 2003. She also co-chairs (with Robyn Hart) the Adults with Intellectual and Developmental Disabilities Committee at Rush since 2007; the collective work at Rush to improve patient care for this population has been described as the "gold standard" in *The Hospitalist*, a publication of the American College of Physicians.

Molly Bathje, PhD, OTR/L, is an assistant professor and the academic coordinator in the Department of Occupational Therapy at Rush University. She has been an occupational therapist for 18 years, with experience in inpatient and outpatient mental health, pediatrics, acute care medicine, long term care and academics. Her scholarship focuses on young adults with intellectual and developmental disabilities.

Tamar Heller, PhD, is a distinguished professor and heads the Department of Disability and Human Development and its University Center of Excellence in Developmental Disabilities at the University of Illinois at Chicago. She also directs the Rehabilitation Research and Training Center (RRTC) on Developmental Disabilities and Health and is Co-PI of two other national centers concerned with disability policies: the RRTC on Community Living Disability Policy and the Family Support RTC. Heller is past president of the board of the Association of University Centers on Disabilities (AUCD) and served as President Obama's delegate to the 2005 White House Conference on Aging. A few of her awards include the 2009 Autism Ally for Public Policy Award of The Arc and the 2008 Lifetime Research Achievement Award, International Association for the Scientific Study of Intellectual Disabilities, Special Interest Group on Aging and Intellectual Disabilities. Heller's research focuses on health and long term services and the impact of family support and health promotion interventions on adults with disabilities and their families across the lifespan.

Keynote Speaker



Lisa I. Iezzoni, MD, MSc, is professor of medicine at Harvard Medical School and a director at the Mongan Institute Health Policy Center at Massachusetts General Hospital. Her research focuses on health care quality and delivery system concerns relating to persons with disability. Iezzoni is a member of the National Academy of Medicine.

Guest Speakers



Amy Eisenstein, PhD, is the director of the Leonard Schanfield Research Institute at CJE Senior Life in Chicago and an adjunct assistant professor at Northwestern University in the Feinberg School of Medicine. She completed her PhD at the University of Illinois at Chicago, in the School of Public Health, with a focus on aging in 2011. Eisenstein has presented her work at local, national and international venues. Her research interests include issues related to aging, health and disease with a focus on measuring outcomes associated with long term care and community-based living.



David Fray, DDS, MBA, is an associate professor in the Department of General Practice and Dental Public Health at the University of Texas School of Dentistry at Houston. As past chief of the Developmental Disabilities Division in the Hawaii Department of Health, he administered statewide comprehensive health and community support services to persons with disabilities, including developmental medicine outreach clinics, and administered the Hospital and Community Dentistry Branch, including the five dental clinics on Oahu. He is board certified in long term care from the National Association of Boards and is a licensed nursing facility administrator with more than 25 years of experience working as a special needs and geriatric dentist. Fray is the president of the American Academy of Developmental Medicine and Dentistry.



Merrill A. Friedman is the senior director of the disability policy engagement team and stakeholder advocacy strategy for Anthem, a leading health benefits company serving nearly 71 million people nationwide through its affiliates. She leads strategic partnerships with national and local organizations to advance the development of inclusive public policy. Friedman serves on the board of directors for the Long-Term Quality Alliance (LTQA), Family Voices and TASH and is a council member for the Americans with Disabilities Act Legacy Project.



Andrés J. Gallegos, Esq., is a shareholder with the law firm of Robbins, Salomon and Patt, Ltd., in Chicago, Illinois, where he focuses his practice on disability rights and health care law. He founded and spearheads the law firm's initiative to improve access to health care and wellness programs for persons across all types of disabilities. Gallegos is the 2015 recipient of the Paul G. Hearne Leadership Award from the American Association of People with Disabilities. He has written numerous articles for national and state professional health care and legal organizations on matters relating to the Americans with Disabilities Act's application to health care providers and is a frequent lecturer on that subject.



Nancy A. Hodgson, PhD, RN, FAAN, is associate professor in the Department of Biobehavioral Health and the Anthony Buividas Endowed Term Chair in Gerontology at the University of Pennsylvania School of Nursing. Hodgson is involved in developing, evaluating, disseminating and implementing innovative programs to improve the lives of cognitively and physically disabled adults and their families. As a well-funded researcher, she has received continuous funding from federal agencies and private foundations to test and translate nonpharmacological interventions to promote an individual's dignity, function and quality of life and to reduce symptoms that pose the greatest burden to older adults and their family caregivers. She is a Fellow in the American Academy of Nursing and the Gerontological Society of America.









Kristi L. Kirschner, MD, is a Clinical Professor in the University of Illinois College of Medicine (UICOM) Department of Medical Education, with a secondary appointment in the Department of Disability and Human Development, University of Illinois at Chicago. She is currently the subtheme leader for Health Humanities for the UICOM curriculum taskforce and overseeing the development and enhancement of Health Humanities Programs within the University of Illinois College of Medicine. Kirschner's academic interests include medical humanities and bioethics with a particular focus on disability issues and marginalized populations; the training of health care professionals about health humanities, bioethics and disability; and health care access for people with disabilities including reproductive health services. She is a specialist in Physical Medicine and Rehabilitation and has a clinical practice at Schwab Rehabilitation Hospital, a safety net hospital on the westside of Chicago, where she care for patients with complex neurological disabilities, including adults with spina bifida, neuromuscular diseases and cerebral palsy.

Sherri L. LaVela, PhD, MPH, MBA, is a senior research health scientist at the Department of Veterans Affairs Health Services Research and Development Service (HSR&D) and Spinal Cord Injury Quality Enhancement Research Initiative (SCI QUERI). Her research spans several areas, including: rehabilitation, disability studies, health promotion/disease prevention, chronic disease prevalence and multiple-morbidity in persons with disabilities, gerontology/aging, aging with a disability, patient-reported outcomes, functional health outcomes, health disparities and informal caregiving/family support. LaVela has conducted research across several fields and believes that the most desirable and sustainable outcomes are accomplished through research and interventions across multiple levels (patient/person, informal caregiver/family, health care provider/staff, facility/organization and community) and multiple disciplines.

Karen McCulloh, BS, RN, is considered a pioneer in her field as an RN that has worked for the last 26 years in the workforce development arena promoting the full inclusion of people with disabilities in integrated competitive employment across the United States workforce. She is the Co-Founder (2003) and the Director of the National Organization of Nurses with Disabilities (NOND), www.nond.org. McCulloh was not able to find a job in healthcare when she first became disabled which has driven her passion to keep opening the doors to opportunities in healthcare careers for people with disabilities. McCulloh has worked to influence national disability employment policy and is NOND's liaison to the National Disability Leadership Alliance Steering Committee, a coalition of 15 national cross-disability consumer-driven organizations that work in collaboration to influence federal policy directed to people with disabilities in all aspects of community life. She has written policy and made recommendations to enhance opportunities for qualified people with disabilities to enter nursing and other healthcare professions.

Lisa Meeks, PhD, is an assistant professor of medicine and the director of medical student disability services at the University of California San Francisco School of Medicine. She is the cofounder and president elect of the Coalition for Disability Access in Health Science and Medical Education and co-chair of the Graduate and Professional School Special Interest Group for the Association on Higher Education and Disability (AHEAD). Meeks has co-authored two books and several articles on ASD. She is associate editor of *Good Autism Practice* and a reviewer for the *Journal of Autism and Developmental Disorders*. She served as co-editor and author of the seminal text on disability in health science *The Guide to Assisting Students With Disabilities: Equal Access in Health Science and Professional Education*.

Travel Information

Airports - Attendees can fly into either of the Chicago airports, O'Hare International or Midway

Public Transportation - Attendees can take the Metra Commuter rail into Chicago from the surrounding suburbs.

Train stations are less than 2 miles from Rush's campus. Attendees can also utilize the Chicago Transit Authority

(CTA) bus and "L" trains. Several bus lines, the Blue line "L" train and the Pink Line "L" train all stop on or near Rush's campus. Service from the O'Hare International Airport is available on a continuous basis with Blue line trains. Service from Midway is available a continuous basis using the Orange line train and transferring to the Blue or Pink lines to reach Rush's campus.

Taxi Service - Taxis are readily available at the airport. The airport is about 30 miles from downtown and taxi fare from the airport is around \$60-70.

Lyft and Uber - Download the Lyft and Uber apps to get around Chicago.

Parking - Daily parking is available at Rush for \$20 (8-24 hours) and valet parking is available for \$25 (5-10 hours).

Accessible Travel Information - Accessible transportation is available through the CTA and Metra. A discounted parking rate of \$10 for valet parking is available to people with disabilities. Wheelchair assistance is available at the valet parking entrances. Designated parking for people with disabilities is available on the fourth and fifth floor levels of Section A in Rush's parking garage.

Lodging

Discounted lodging for conference participants has been arranged. Please use the links below to make your lodging reservations and receive the discounted rates.

Chicago Marriott at Medical District/UIC
625 South Ashland Avenue at Harrison Street

Main Phone: (312) 491-1234

Start Date: March 22 End Date: March 25 Rate: \$169/night plus tax Reservation Website

The Hotel Chicago 1622 W Jackson Blvd

Main Phone: (312) 243-2900

Start Date: March 22 End Date: March 24 Rate: \$119/night plus tax

Reservations: Please Contact Melissa Bisch at 312-702-1712 or mbisch@hotelchicago1622.com

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