

# Health Disparities in the Medical Record and Disability Determinations: A Workshop

## Committee

### Amy Houtrow

#### Co-Chair

Dr. Houtrow is a professor and Vice Chair in the Department of Physical Medicine and Rehabilitation for Pediatric Rehabilitation Medicine at the University of Pittsburgh School of Medicine. She is also the Vice Chair for Quality and Outcomes. She is the Chief of Pediatric Rehabilitation Medicine Services at the UPMC Children's Hospital of Pittsburgh (CHP). Complementing her clinical focus, Dr. Houtrow's research focus is recognizing the impact raising children with disabilities has on families and developing channels to improve service delivery. She works closely with leaders in health services research around the country. Dr. Houtrow is a collaborator on the DIVERSE Collective that is investigating health equity related to children with disabilities.

### Karrie Shogren

#### Co-Chair

Karrie A. Shogren, Ph.D. is the Director of the Kansas University Center on Developmental Disabilities (a University Center for Excellence in Developmental Disabilities), Senior Scientist at the Schiefelbusch Life Span Institute, and Ross and Marianna Beach Distinguished Professor in the Department of Special Education all at the University of Kansas. Dr. Shogren's research focuses on assessment and intervention in self-determination and supported decision making for people with disabilities. Dr. Shogren has led multiple grant-funded projects, including assessment validation and efficacy trials of self-determination interventions in school and community contexts. Dr. Shogren has published over 225 articles in peer-reviewed journals, is the author or co-author of 25 books, and is the lead author of the Self-Determination Inventory, a recently validated assessment of self-determination and the Supported Decision-Making Inventory System, an assessment of the supports needed to involve people with intellectual and developmental disabilities in decisions about their lives. Dr. Shogren has received grant funding from several sources, including the Institute of Education Sciences (IES) and National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR). Dr. Shogren is co-Editor of Remedial and Special Education and a Fellow of the American Association on Intellectual and Developmental Disabilities and the American Psychological Association.

## **Kenrick Cato**

### **Member**

Kenrick Cato, PhD, RN, CPHIMS, FAAN, is a clinical informatician whose research focuses on mining electronic patient data to support decision-making for clinicians, patients, and caregivers. Operationally, he spends his time mining and modeling Nursing data to optimize Nursing value in Healthcare. He is also involved in several national-level informatics organizations, including as a board member of the American Medical Informatics Association (AMIA), Chair of the Nursing Informatics Working Group (NIWG) of AMIA, as well as a convening member of the AMIA-sponsored 25 x 5 initiative to reduce documentation burden. Dr. Cato received his BSN, MS, and Ph.D. in Clinical informatics at Columbia University.

## **Kensaku Kawamoto**

### **Member**

Dr. Kensaku Kawamoto, MD, PhD, MHS, FACMI, FAMIA, is a Professor of Biomedical Informatics and the Associate Chief Medical Information Officer at the University of Utah. He is also the Founding Director of ReImagine EHR, a multi-stakeholder initiative to improve patient care and the provider experience through interoperable electronic health record (EHR) innovations that convert data to actionable insight. An expert on the practical and scalable use of digital technologies to improve health and healthcare, Dr. Kawamoto co-chairs the Clinical Decision Support (CDS) Work Group of HL7, the primary standards development organization for health IT. He also served as co-Initiative Coordinator for the Clinical Quality Framework (CQF), a public-private partnership sponsored by the Office of the National Coordinator for Health IT and the Centers for Medicare and Medicaid Services that developed and validated a harmonized set of standards for CDS and electronic clinical quality measurement. He also served two terms on the U.S. Health IT Advisory Committee. Dr. Kawamoto is a Fellow of the American College of Medical Informatics and was recognized by Modern Healthcare as a Top Innovator. His formal training includes a BA in Biochemical Sciences from Harvard and an MD, PhD in Biomedical Engineering, and MHS in Clinical Research from Duke.

## **Elham Mahmoudi**

### **Member**

Elham Mahmoudi, PhD, is an Associate Professor of Health Economics at the University of Michigan Department of Family Medicine. She is a mixed methods researcher, with expertise in using administrative claims data. Her research focuses on evaluating healthcare policies aimed at reducing racial/ethnic disparities in access to care and quality of care, and it extends to examining healthcare use, cost, and efficiency of care for older adults with Alzheimer's disease and related dementias.

# Jonathan Platt

## Member

Dr. Jonathan Platt is a social and psychiatric epidemiologist whose research focuses on the identification of social causes of suicide, psychiatric disorders, and harmful substance use, in order to identify key targets to improve public health and reduce group disparities. He has expertise in the measurement of social structures, causal inference methods, and longitudinal data analysis to identify the health consequences of social inequities across the life course. He also has growing expertise in the use of machine learning methods to identify novel health risk patterns and satisfy causal inference assumptions. Dr. Platt has published >40 articles and book chapters (h-index: 24), in leading public health and psychiatry journals, including *The New England Journal of Medicine*, *JAMA Psychiatry*, *American Journal of Epidemiology*, and *Social Science & Medicine*. He is an active member in the broader public health research community, participating in major conferences in the fields of population science, epidemiologic methods, and psychiatry and serving as an ad-hoc reviewer for numerous journals and as a review editor for the journal *Frontiers in Global Women's Health*. He is an early-stage academic researcher (tenure-track) in the department of epidemiology at the University of Iowa College of Public Health.

# **Amanda Alise Price**

## **Member**

Amanda Alise Price, Ph.D., became the director of the Office of Health Equity as well as NICHD's chief scientific diversity officer in April 2023. In these roles, she leads the effort to shape the institute's vision for diversity, equity, inclusion, and accessibility. As part of her duties, she leads NICHD's STrategies to enRich Inclusion and achieve Equity (STRIVE) initiative, guiding it into implementation following finalization of the STRIVE Action Plan. She also provides guidance and serves as a technical authority on health disparities and health equity research across NICHD's extramural and intramural programs. Dr. Price joined NIH in 2020 as a health scientist administrator/program director. She most recently directed the preventive medicine portfolio and served as a team lead of the Division of Extramural Science Programs at the National Institute of Nursing Research. She previously worked at the National Cancer Institute's Center for Reducing Cancer Health Disparities. Throughout her NIH career, she has served on several NIH-wide committees and co-authored concepts and funding opportunities to stimulate health disparity and health equity research, increase inclusion for underrepresented populations in research, and promote scientific workforce diversity.

Prior to joining NIH, Dr. Price was a tenured associate professor in the School of Health Sciences at Winston-Salem State University, both a minority-serving and Historically Black Colleges and Universities-designated institution. She taught, trained, and mentored underrepresented scholars in research and the biomedical sciences. She also successfully competed for NIH funding as a principal investigator and generated publications and presentations from her work, which centered on preventing and managing chronic diseases through promotion of healthy lifestyle behaviors, with an emphasis on addressing health disparities and promoting health equity.

Dr. Price earned both a Ph.D. and B.S.Ed. in exercise physiology, with a doctoral concentration in statistics and undergraduate minors in chemistry and sports medicine from the University of Miami in Coral Gables, Florida.

## **Michael Stanton**

### **Member**

Dr. Stanton is a licensed Clinical Health Psychologist and Associate Professor of Public Health at California State University, East Bay, a diverse Minority-Serving Institution in Northern California. Dr. Stanton's research has been cited over 3700 times and examines how stress, including discrimination and stigma, affect health, with a particular focus on eating behavior. His clinical work integrates mindfulness with cognitive behavioral therapy to treat mental and physical health concerns. Dr. Stanton has held multiple leadership positions, including at the Society of Behavioral Medicine and the American Psychosomatic Society (APS) and he currently serves on the Leadership Council at APS. He contributes his expertise to the field as a Consulting Editor and Editorial Fellow at the American Psychological Association journal, "Health Psychology" and to the general public as a guest contributor to several news stations including ABC, NBC, CBS, NPR, the SF Chronicle and other media, where he adds psychology and public health expertise to the analysis of current events. He is a former NHLBI-sponsored UCSF-RISE Fellow and Fulbright Fellow. He earned his Ph.D. in Clinical Psychology with a focus in Behavioral Medicine from Duke University, completed his postdoctoral training at Stanford University School of Medicine, and received his B.A. from Brown University.

## **Rupa Valdez**

### **Member**

Dr. Rupa Valdez is an Associate Professor at the University of Virginia with joint appointments in the School of Engineering and Applied Sciences and the School of Medicine and serves as president of the Blue Trunk Foundation. Dr. Valdez merges the disciplines of human factors engineering, health informatics, and cultural anthropology to understand and support the ways in which people manage health at home and in the community. Her work draws heavily on community engagement with community organizations and individuals from multiple health disparity populations, and has been supported by the NIH, AHRQ, NSF, and the USDA, among others. She has testified before Congress on the topic of health equity for the disability community and received the Jack A. Kraft Innovator Award from the Human Factors and Ergonomics Society (HFES). Among other appointments, she serves as associate editor for the Journal of American Medical Informatics Association Open, on the Board of Directors for the American Association of People with Disabilities, and as an advisor for PCORI's Patient Engagement Advisory Panel and for NCQA's Health Equity Expert Work Group. Dr. Valdez received her PhD at the University of Wisconsin-Madison.

# **Ruqaiijah Yearby**

## **Member**

Ruqaiijah Yearby is the inaugural Kara J. Trott Professor in Health Law at the Moritz College of Law, Professor in the Department of Health Services Management and Policy at the College of Public Health, and a faculty affiliate of the Kirwan Institute for the Study of Race and Ethnicity at The Ohio State University.

An expert in health policy and civil rights, Professor Yearby has received over \$5 million from the National Institutes of Health (NIH) to study structural racism and discrimination in vaccine allocation and from the Robert Wood Johnson Foundation to study the equitable enforcement of housing laws and structural racism in the health care system.

She was one of the keynote speakers for the 5th Annual Conference of the ELSI Congress and has served as a reviewer for NIH, the Swiss National Science Foundation, and the Wellcome Trust. She is on the editorial board of the American Journal of Bioethics.

She is a Committee Member for the U.S. Department of Health and Human Services, Secretary's Advisory Committee on Human Research Protections. Her work has been published in the American Journal of Bioethics, American Journal of Public Health, Health Affairs, and the Oxford Journal of Law and the Biosciences.