

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

APRIL 4, 2024: 9:00 AM – 4:00 PM EDT

9:00 AM

Welcome and Goals for the Workshop Day 1

Amy J. Houtrow, Planning Committee Co-Chair

Karrie Shogren, Planning Committee Co-Chair

9:10 AM

Sponsor Opening Remarks

Michael Goldstein, U.S. Social Security Administration

9:15 AM

SESSION I: OVERVIEW, CONCEPTS, AND FRAMING

Moderator: Karrie Shogren, Planning Committee Co-Chair

Definition of Disability

- **Amy J. Houtrow**, Planning Committee Co-Chair

Social Security Administration Disability Determinations Process Overview

- **Vincent Nibali**, U.S. Social Security Administration (Confirmed)

Basics of Health Disparities

- **Jonathan Platt**, Planning Committee Member

The Purpose and Function of the Medical Record

- **Kensaku Kawamoto**, Planning Committee Member

9:55 AM

SESSION II: SOCIAL DETERMINANTS OF HEALTH AND IMPACT ON CARE

Moderator: Ruqaiijah Yearby, Planning Committee Member

Panelist Remarks

- **Monika Mitra**, Brandeis University
- **Joy Johnson**, Charlottesville Public Housing Association of Residents/Disability Advocate
- **Benjamin Miller**, Stanford School of Medicine

- **Jennifer Hudson**, Williamson Health and Wellness Center

Q&A with Panelists

11:00 AM

BREAK

11:15 AM

SESSION III: DISPARITIES AND BIAS IN EVALUATIVE TESTING AND RECORDING OF MEDICAL INFORMATION

Rupa Valdez, Planning Committee Member

Panelist Remarks

- **Marshall Chin**, University of Chicago
- **Gloria Thornton**, Amplified Disabled Voices/Disability Advocate
- **Tara Lagu**, Northwestern University Feinberg School of Medicine
- **A.J. Link**, Autistic Self Advocacy Network/Disability Advocate

Q&A with Panelists

12:30 PM

BREAK FOR LUNCH

1:30 PM

SESSION IV: HEALTH DISPARITIES AND THE DISABILITY APPLICATION PROCESS

Moderator: Amanda Alise Price, Planning Committee Member

Panelist Remarks

- **Bonnielin Swenor**, Johns Hopkins Medicine
- **D'Sena' Warren**, Disability Advocate
- **Yvonne Perret**, Advocacy and Training Center

Q&A with Panelists

2:45 PM

BREAK

3:00 PM

SESSION V: MODERATED DISCUSSION ON MITIGATING THE IMPACT OF HEALTH DISPARITIES IN THE SSA DISABILITY DETERMINATION PROCESS

Moderator: Michael Stanton, Planning Committee Member

Panel discussion will comprise of selected speakers from previous sessions

- **Marshall Chin**, University of Chicago

- **Yvonne Perret**, Advocacy and Training Center
- **D'Sena' Warren**, Disability Advocate
- **Monika Mitra**, Brandeis University

3:45 PM

Closing Reflections

Amy J. Houtrow, Planning Committee Co-Chair

Karrie Shogren, Planning Committee Co-Chair

4:00 PM

ADJOURN DAY 1

9:00 AM **Welcome and Goals for the Workshop Day 2**
Karrie Shogren, Planning Committee Co-Chair

9:10 AM **Day 1 Recap**
Amy J. Houtrow, Planning Committee Co-Chair

9:20 AM **SESSION VI: THE HEALTH RECORD IN-DEPTH**
Moderator: Ken Kawamoto, Planning Committee Member

Panelist Remarks

- **Trent Rosenbloom**, Vanderbilt University Medical Center
- **Guilherme Del Fiol**, University of Utah Medical School
- **Julia Adler-Milstein**, University of California San Francisco
- **Vinod Vydiswaran**, University of Michigan

Q&A with Panelists

10:30 AM **BREAK**

10:45 AM **SESSION VII: THE RELATIONSHIP BETWEEN THE MEDICAL RECORD AND HEALTH DISPARITIES**
Moderator: Kenrick Cato, Planning Committee Member

Panelist Remarks

- **Megan Morris**, University of Colorado Anschutz Medical Center
- **Carolyn Petersen**, Mayo Clinic
- **Prerana Laddha**, Epic Systems
- **Julia Skapik**, National Association of Community Health Centers

Q&A with Panelists

12:00 PM **BREAK FOR LUNCH**

1:00 PM **SESSION VIII: MODERATED DISCUSSION ON APPROACHES TO ADVANCING MEDICAL RECORDS TO ADDRESS DISPARITIES IN DISABILITY DETERMINATIONS**
Moderator: Elham Mahmoudi, Planning Committee Member

Panel discussion will comprise of selected speakers from previous sessions

- **Megan Morris**, University of Colorado Anschutz Medical Center
- **Julia Adler-Milstein**, University of California San Francisco
- **Bonnielin Swenor**, Johns Hopkins Medicine
- **Vinod Vydiswaran**, University of Michigan
- **D'Sena' Warren**, Disability Advocate
- **Prerana Laddha**, Epic Systems
- **Tara Lagu**, Northwestern University Feinberg School of Medicine

2:15 PM

Closing Reflections

Amy J. Houtrow, Planning Committee Co-Chair

Karrie Shogren, Planning Committee Co-Chair

2:30 PM

ADJOURN DAY 2

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

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.

Health Disparities in the Medical Record and Disabilities Determination Workshop Planning Committee and Speaker BioSketches

PLANNING COMMITTEE



Amy J. Houtrow, MD, PhD, MPH (Co-Chair)

University of Pittsburgh School of Medicine

Amy J. Houtrow, MD, PhD, MPH (Co-Chair), 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

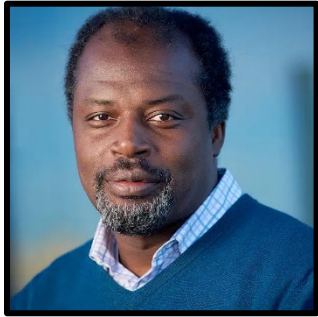
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Kansas University Center on Developmental Disabilities

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Ruqaiijah Yearby, JD, MPH
The Ohio State University

Ruqaiijah Yearby, JD, MPH, 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.

SPEAKERS BIOSKETCHES



Julia Adler-Milstein, PhD
University of California, San Francisco

Dr. Julia Adler-Milstein is a Professor of Medicine, Chief of the Division of Clinical Informatics & Digital Transformation, and Director of the Center for Clinical Informatics & Improvement Research (CLIIR). Dr. Adler-Milstein is a leading researcher in health IT policy, with a specific focus on electronic health records and interoperability. She has examined policies and organizational strategies that enable effective use of electronic health records and promote interoperability. She is also an expert in EHR audit log data and its application to studying clinician behavior. Her research – used by researchers, health systems, and policymakers – identifies obstacles to progress and ways to overcome them.

She has published over 200 influential papers, testified before the US Senate Health, Education, Labor and Pensions Committee, is a member of the National Academy of Medicine, been named one of the top 10 influential women in health IT, and won numerous awards, including the New Investigator Award from the American Medical Informatics Association and the Alice S. Hersh New Investigator Award from AcademyHealth. She has served on an array of influential committees and boards, including the NHS National Advisory Group on Health Information Technology, the Health Care Advisory Board for Politico, and the Interoperability Committee of the National Quality Forum. Dr. Adler-Milstein holds a PhD in Health Policy from Harvard and spent six years on the faculty at University of Michigan prior to joining UCSF as a Professor in the Department of Medicine and the inaugural director of the Center for Clinical Informatics and Improvement Research in 2017. She became the inaugural Chief of the Division of Clinical Informatics and Digital Transformation in 2023.



Marshall Chin, MD, MPH
University of Chicago

Marshall H. Chin, M.D., M.P.H., Richard Parrillo Family Distinguished Service Professor of Healthcare Ethics at the University of Chicago, is a practicing general internist and health services researcher who has dedicated his career to advancing health equity through interventions at individual, organizational, community, and policy levels. Through the Robert Wood Johnson Foundation Advancing Health Equity: Leading Care, Payment, and Systems Transformation program, Dr. Chin collaborates with teams of state Medicaid agencies, Medicaid managed care organizations, frontline healthcare delivery organizations, and community-based organizations to implement payment reforms to support and incentivize care transformations that advance health equity within an anti-racist framework. He also co-chairs the Centers for Medicare & Medicaid Services Health Care Payment Learning and Action Network Health Equity Advisory Team.

Dr. Chin evaluates the value of the federally qualified health center program, improves diabetes outcomes in Chicago's South Side through healthcare and community interventions, and improves shared decision making among clinicians and LGBTQ persons of color. He also applies ethical principles to reforms to advance health equity, discussions about a culture of equity, and what it means for health professionals to care and advocate for their patients. Dr. Chin uses improv and standup comedy, storytelling, and theater to improve training of students in caring for diverse patients and engaging in constructive discussions around systemic racism and social privilege. Dr. Chin is a graduate of Harvard College and the University of California at San Francisco School of Medicine, and he completed residency and fellowship training in general internal medicine at Brigham and Women's Hospital, Harvard Medical School. He has received mentoring awards from the Society of General Internal Medicine and University of Chicago. He is a former President of the Society of General Internal Medicine. Dr. Chin was elected to the National Academy of Medicine in 2017, and is on the Steering Committee for the NAM paper series on structural racism and health.



Guilherme Del Fiol, MD PhD
University of Utah School of Medicine

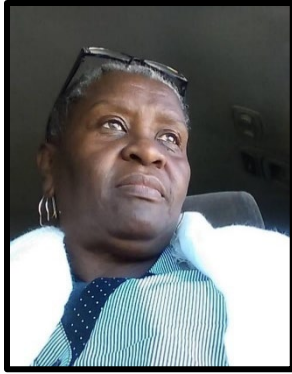
Dr. Guilherme Del Fiol earned his MD from the University of Sao Paulo, Brazil; his MS in Information Systems from the Catholic University of Parana, Brazil; and his PhD in Biomedical Informatics from the University of Utah. He is currently Professor and Vice-Chair for Research in the University of Utah's Department of Biomedical Informatics. Prior to the University of Utah, Dr. Del Fiol held positions in Clinical Knowledge Management at Intermountain Healthcare and as faculty at the Duke Community and Family Medicine Department. Since 2008, he has served as an elected co-chair of the Clinical Decision Support Work Group at Health Level International (HL7). He is also an elected Fellow of the American College of Medical Informatics (ACMI) and a member of the Comprehensive Cancer Center at Huntsman Cancer Institute.

Dr. Del Fiol's research interests are in the design, development, evaluation, and dissemination of standards-based clinical decision support and digital health interventions. He has been focusing particularly on interventions to improve cancer prevention and reduce health disparities. He is the lead author of the HL7 Infobutton Standard and the project lead for OpenInfobutton, an open source suite of infobutton tools and Web services, which is in production use at several healthcare organizations throughout the United States, including Intermountain Healthcare, Duke University, and the Veterans Health Administration (VHA). His research has been funded by various sources including the National Library of Medicine (NLM), National Cancer Institute (NCI), AHRQ, CDC, CMS, and PCORI.



Jennifer Hudson
Williamson Health & Wellness Center, Inc.

Jennifer Hudson is Development Director for a federally qualified health center in southern West Virginia. She brings together resources behind efforts including the reopening of a rural hospital and growing a commercial kitchen and clothing store. Jenny believes in systems of care that invest in building community infrastructure and support to serve individuals and their families.

**Joy Johnson**

Charlottesville Redevelopment and Housing Authority

My name is Joy Amaryllis Johnson. I am 67 years old. I am a Public Housing Resident. I have four children and four granddaughters, two grandsons and one great grandson. I am a native of Kingston, Jamaica and I became an American citizen in 2000.

I currently work for Charlottesville Redevelopment and Housing Authority as their resident services/Section 3 coordinator. I assisted residents to connect with a variety of resources and work with contractors to set up interviews with residents. I previously worked as an Outreach Coordinator for the Westhaven

Nursing Clinic in Charlottesville, Virginia for over 20 plus years. I have been a long-time community activist and organizer working to address low-income housing issues at the local and national levels. I have volunteered countless hours as an advocate for Charlottesville's low-income residents, speaking out on their behalf to demand safe and clean affordable housing, adequate representation on city boards and commissions, living wage employment, and voter education. In 1998, I helped found the Public Housing Association of Residents (PHAR), a nationally recognized citywide resident association, which is responsible for our city's outstanding level of resident representation on its Housing Authority Board of Commissioners.

I am a former member of the Charlottesville Redevelopment and Housing Authority Board of Commissioners. I have also previously served on the Head Start Policy Council, University of Virginia Employee Council, Virginia Association of Neighborhoods, Offender Aid and Restoration Board, Westhaven Tenant Association, Everywhere and Now Public Housing Residents Organizing Nationally Together (ENPHRONT), National Low Income Housing Coalition (NLIHC), Monticello Area Agency Community Action (MACAA), Connecting People to Jobs, Charlottesville CBDG Task Force, Charlottesville Housing Advisory Committee, and Charlottesville Social Services Advisory Board. Currently, I serve as Chair for the Public Housing Association of Residents (PHAR), Vice-President of the Board of Legal Aid Justice Center, Chair for Charlottesville Housing Advisory Committee and UVA housing Committee.

I have received training with a certificate from Nan McKay as a Public Housing Specialist. I have also received training with HUD on Public Housing Assessment Scores, Section 3, Train the Trainer I and II as well as with the National Low Income Housing Coalition on the Quality Housing and Work Responsibility Act and Section 3. I have also received training and attended workshops with LAOSHAC, Babcock Foundation, and the Legal Aid Justice Center. I am the recipient of the 2020 Cushing Niles Dolbeare lifetime service award and 2023 Reflector Award. Since childhood, I have been a member of Mt. Zion First African Baptist Church. In my spare time I enjoy gardening, dancing, spending time with friends who are supportive, but most of all, I love spending time with my grandchildren and great grand.

**Prerana Laddha**

Epic Systems

Prerana Laddha serves as the Director of Social Care and Behavioral Health at Epic Systems. In this role, she leads global product development in the areas of continuing care and population health. With over a decade of experience in healthcare and a master's degree in computer science, Prerana is driven by a commitment to leveraging technology and research to foster the well-being of individuals and communities across the globe.

Prerana was instrumental in leading Epic's development projects to advance the integration of social drivers of health into Electronic Medical Records, connect patients with community resources and close loop on community referrals. Prerana's influence extends beyond national boundaries; she has collaborated with Finland, Norway, Northern Ireland, and Australia to deeply understand and address social needs on a global scale. Notably, she led the development project to implement the world's first integrated health and social record in Finland. She has represented Epic at the White House and is part of the White House Challenge to end hunger and build healthy communities across the nation. Additionally, as a member of the Alignment of Progress, she advises on national strategies for mental health and substance abuse disorders, aiming to inform policymakers and advocate for standardized, measurement-based care.

Prerana's global experience has equipped her with valuable insights, which she leverages to guide Epic's client community towards best practices in governance, implementation, interoperability, and outcome measurement within social and behavioral health workflows. Her blend of computer science expertise and a passionate commitment to social and behavioral health challenges empowers her to champion innovative technology solutions that address complex social and mental health issues.



Tara Lagu, MD, MPH

Northwestern University Feinberg School of Medicine

Tara Lagu, MD, MPH, is Professor of Medicine and Medical Social Sciences and the Director of the Center for Health Services and Outcomes Research in the Institute for Public Health and Medicine at Northwestern University Feinberg School of Medicine. She is a pharmacist, hospitalist, and health services researcher with expertise in application of mixed methods to measure quality of health care, observational comparative effectiveness, and implementation science. She is passionate about influencing policy and improving care and for vulnerable and marginalized patients, including patients with heart failure (HF) and disability. After completing a degree in Pharmacy from Purdue University, an MD/MPH at the Yale University School of Medicine, and General Internal Medicine Residency at Rhode Island Hospital/Warren Alpert Medical

School/Brown University, Dr. Lagu was a Robert Wood Johnson Clinical Scholar at the University of Pennsylvania from 2005-2008. She has published about 150 original peer-reviewed manuscripts in high-impact journals, including the New England Journal of Medicine (NEJM), JAMA, the Annals of Internal Medicine, and Health Affairs.

In 2013, Dr. Lagu was inspired by her clinical work as a hospitalist to focus a portion of her research on gaps in access to care for patients with disabilities. Using a “secret shopper” approach, she found that 20% of outpatient physicians nationwide would refuse to see a patient who uses a wheelchair. In 2022, Dr. Lagu, with senior author Dr. Lisa Iezzoni, led on a study that identified that physicians make strategic decisions to refuse to care for patients with disabilities. This work was published in Health Affairs, profiled in The New York Times, and featured on NPR’s Science Friday. Dr. Lagu is using this work to launch efforts to improve care delivery for patients with disabilities and to rethink and redesign medical education around people with disabilities. Dr. Lagu also serves as a standing member of the NIH Health Services: Quality, and Effectiveness study section and on the editorial board for the Journal of Hospital Medicine. She was the winner of the 2019 Society of Hospital Medicine Award for Excellence in Research, and was named one of the American College of Physicians “Top Hospitalists” in 2019.



A.J. Link, JD
Autistic Self Advocacy Network

AJ Link (he/him) is openly autistic. He received his JD from The George Washington University Law School and his LL.M in Space Law at the University of Mississippi School of Law. He is the inaugural director of The Center for Air and Space Law Task Force on Inclusion, Diversity, and Equity in Aerospace and an adjunct professor of space law at Howard University School of Law. AJ works as a research director for the Jus Ad Astra project and previously served as the Communications Director for AstroAccess. He is the Space Law and Policy Chair for Black in Astro and was the founding

president of the National Disabled Law Students Association. He also helped found the National Disabled Legal Professionals Association and is a commissioner on the American Bar Association Commission on Disability Rights.

AJ is a policy analyst for the Autistic Self Advocacy Network. He has been actively involved with disability advocacy in the Washington, DC area and nationally within the United States. He serves on several advisory boards and steering committees that focus on disability advocacy and broader social justice movements.



Benjamin Miller, PsyD
Well Being Trust

Dr. Benjamin F. Miller, PsyD, a clinical psychologist by training, is an academic, executive, and policy expert. Over the last two decades, Dr. Miller has worked tirelessly to prioritize mental health in our policies, programs, and investments. He works at the intersection of policy and practice, ensuring that mental health and substance misuse solutions are a focus across the world.

Dr. Miller's expertise in the mental health space largely stems from the early days of his career. Beginning as an educator, teaching special education, he saw firsthand how our systems fail those who are in the most need. After receiving his doctorate in clinical psychology from Spalding University in Louisville, he began his years-long professional relationship with the University of Colorado School of Medicine, beginning with his predoctoral internship at Colorado in 2006. He subsequently trained at the University of Massachusetts Medical School, focusing on how we can better integrate mental health into primary care.

After returning to Colorado from Massachusetts, he joined the Department of Family Medicine where he worked for over 8 years, ultimately achieving the academic rank of Associate Professor. During his tenure at Colorado, he helped establish the Eugene S. Farley, Jr. Health Policy Center as its founding director. The Farley Center positioned Miller as a national thought leader on mental health and policy and led to the creation of several seminal documents and publications. From Colorado, he transitioned to help start Well Being Trust, a national foundation that focused on advancing the mental, social, and spiritual health of the nation. Under his leadership as president of the foundation, Well Being Trust helped invest in the creation of several movement building organizations, reports that influenced policy change, and tools that could be used by communities to advance mental health.

With over 100 publications and hundreds of invited keynote speaking engagements, Miller has fought relentlessly to change the national narrative around mental health.



Monica Mitra, PhD
Brandeis University

Dr. Monica Mitra is the Nancy Lurie Marks Professor of Disability Policy and Director of the Lurie Institute for Disability Policy at Brandeis University. Her research broadly focuses on disparities in health outcomes and health care access among people with disabilities. She leads several federally funded projects including the National Research Center for Parents with Disabilities which is focused on addressing knowledge gaps regarding the needs of parents with diverse disabilities and their families, and the Community Living Policy Center which is aimed at improving policies and practices that advance community living outcomes for people with disabilities. Dr. Mitra is also the co-PI of the recently launched Center for Disability and Pregnancy Research and is co-Editor-in-Chief of the Disability and Health Journal.



Megan Morris, PhD, MPH, CCC-SLP
University of Colorado Anschutz Medical Campus

Megan Morris, PhD, MPH, CCC-SLP is an Associate Professor in the Division of General Internal Medicine at the University of Colorado Anschutz Medical Campus. Her research aims to identify and address the multi-level conditions that contribute to the provision of equitable care for people with disabilities. She is a leading expert on the documentation of patients' disability status in the Electronic Health Record and healthcare disparities experienced by patients with communication disabilities. Dr. Morris is founder and director of the Disability Equity Collaborative, a community aimed at advancing equitable care for patients with disabilities through practice, policy and research. Dr. Morris's research and advocacy has been shaped by both her personal and professional experiences of ableism in the healthcare setting.



Yvonne M. Perret, MA, MSW, LCSW-C,
Advocacy and Training Center

Yvonne M. Perret, MA, MSW, LCSW-C, is a psychiatric clinical social worker with over 45 years of experience. She is the Executive Director of the Advocacy and Training Center in Cumberland, MD and has a Master's degree in journalism. She is the co-author of a book on children with disabilities (three editions) as well as two book chapters and several articles on SSI/SSDI and related mental health topics. She has written curricula on Mental Illness, Homelessness and Recovery, on co-occurring disorders, on self-compassion, on identifying and working with shelter residents' strengths, and on brain injury and homelessness for the New York State Office of Temporary Disability Assistance. She trains these curricula to NYC and NYS shelter and Department of Social Services staff.

Ms. Perret is the primary founder of SOAR (SSI/SSDI Outreach, Access and Recovery), a national program that includes a SOAR TA Center based in Albany, New York, which is funded by SAMHSA. SOAR focuses on assisting adults who are homeless with accessing SSI/SSDI in an expedited way and beginning their recovery both from homelessness and mental illness and/or co-occurring disorders. In 2001, the Baltimore SSI Outreach Project, the program on which SOAR is based and which Ms. Perret directed, was named a Best Practice Program by the National Alliance to End Homelessness and, in 2005, an Exemplary Practice Program by SAMHSA. As part of SOAR, she is the lead author of Stepping Stones to Recovery (funded by SAMHSA) and Stepping Stones to SSI/SSDI (funded by HUD HOPWA), two

curricula that focus on assisting individuals with accessing SSI/SSDI and beginning recovery. The emphasis in both curricula is on using benefits as tools in recovery. Ms. Perret has worked in 47 states promoting SOAR and working with community teams, including SSA and DDS, to promote collaboration, training, and planning.

Ms. Perret has also trained and worked extensively in co-occurring disorders, mental illness, and other mental health-related topics. She has presented at numerous mental health and other national conferences and is the recipient of several awards for mental health advocacy. Most recently, she was named one of Maryland's Top 100 Women by the Daily Record, the Maryland publication for government, business and legal news.



Carolyn Petersen, MS, MBI, FAMIA
Mayo Clinic

Ms. Petersen is an Assistant Professor in the Department of Artificial Intelligence and Informatics at Mayo Clinic and Senior Editor of the consumer health information website MayoClinic.org. She holds a Master of Science in Exercise and Movement Science from the University of Oregon and a Master of Biomedical Informatics from Oregon Health & Science University. She previously co-chaired the Office of the National Coordinator for Health IT's Health Information Technology Advisory Committee and has served on FDA medical device advisory panels and the Patient-Centered Outcomes Research Institute's Advisory Panel on Healthcare Delivery and Disparities Research. A long-term pediatric cancer survivor, Ms. Petersen's work focuses on patient engagement and experience, person-generated health data and data governance, health equity, and ethics and technology.



S. Trent Rosenbloom, MD MPH FACMI FAAP FAMIA
Vanderbilt University Medical Center

Dr. Rosenbloom is the Vice Chair for Faculty Affairs and a Professor of Biomedical Informatics with secondary appointments in Medicine, Pediatrics, and the School of Nursing at Vanderbilt University. He is a board certified Internist and Pediatrician who earned his M.D., completed a residency in Internal Medicine and Pediatrics, a fellowship in Biomedical Informatics, and earned an MPH all at Vanderbilt. Dr. Rosenbloom is a nationally recognized investigator in the field of health information technology evaluation. His research has focused on studying how healthcare providers, patients and caregivers interact with health information technologies when documenting medical and health-related activities, and when making clinical decisions. Dr. Rosenbloom is the Director for My Health at Vanderbilt, one of the nation's oldest and best adopted patient portals that now has over one million users.

Dr. Rosenbloom has successfully competed for extramural funding from the National Library of Medicine, the Agency for Healthcare Research and Quality, and the Patient-Centered Outcomes Research Institute. Dr. Rosenbloom's work has resulted in lead and collaborating authorship on over 100 peer reviewed manuscripts, which have been published in Journal of the American Medical Informatics Association, Pediatrics, Annals of Internal Medicine, and Academic Medicine, among others. In addition, Dr. Rosenbloom has authored and coauthored 6 book chapters and numerous posters, white papers and invited papers. He has been a committed member of the principal professional organization in his field, the American Medical Informatics Association (AMIA). He has served AMIA in leadership roles, including participating in: the Board of Directors, the Journal and Publications Committee, Scientific Program Committees, the Journal of the American Medical Informatics Association (JAMIA) Editorial Board,

several national Health Policy Meetings, the JAMIA Editor in Chief search committee, and a Working Group on Unintended Consequences. As a result of his research success and service to AMIA, Dr. Rosenbloom was the annual recipient of the competitive AMIA New Investigator Award in 2009, was elected to the American College of Medical Informatics (ACMI) in 2011 and as a Fellow of the American Medical Informatics Association (FAMIA) in 2020, and granted an AMIA Leadership Award in 2023. In addition, Dr. Rosenbloom has participated in study sections for the National Library of Medicine, the Agency for Healthcare Research and Quality in Healthcare, the National Science Foundation and the Patient Centered Outcomes Research Institute.

Dr. Rosenbloom has participated as a mentor for numerous students, including PhD candidates from Biomedical Informatics, medical students performing research projects. He has been an advisor to medical students, and is a Faculty Affiliate Advisor for the School of Medicine's Chapman Advisory College. He is an Associate Director for the Vanderbilt Medical Innovators Development Program (MIDP), a four-year MD training program tailored to engineers and applied scientists that teaches them to solve clinical problems by translating discoveries in engineering into valuable innovation.



Julia Skapik MD, MPH
Medical Director, Informatics, NACHC

Julia Skapik is the Medical Director for Informatics at NACHC and a board-certified Internist and Clinical Informaticist. She came to NACHC after a stint as the Chief Health Information Officer for Cognitive Medical Systems after 5 years as a Senior Medical Informatics Officer at ONC. Dr. Skapik is also an ongoing leader in HIT interoperability, governance and clinical content as the Chief Medical Informatics Officer for Logica Health and in standards development as a member of the HL7 Board of Directors. In her role at

NACHC, Dr. Skapik is focused on broad HIT stakeholder coordination and engagement, common data definitions and measure harmonization, and HIT-enabled clinical quality improvement, care coordination, and patient engagement.



Bonnielin Swenor, PhD, MPH
Johns Hopkins Disability Health Research Center

Bonnielin Swenor is an epidemiologist and the Endowed Professor of Disability Health and Justice at The Johns Hopkins School of Nursing and joint appointments at the Johns Hopkins School of Medicine and the Johns Hopkins Bloomberg School of Public Health. She is the founder and director of the Johns Hopkins Disability Health Research Center, which uses data-driven approaches to shift the paradigm from 'living with a disability' to 'thriving with a disability'. Motivated by her personal experience with

disability, her work is focused on advancing equity for people with disabilities, promoting disability inclusion and accessibility, and developing evidence-based and disability-inclusive policies. Dr. Swenor has provided advice and expertise to multiple organizations and agencies, including speaking at the White House Office of Science and Technology Policy (OSTP) Summit on Equity and Excellence in STEM, chairing the National Academy of Science, Engineering, and Medicine (NASEM) planning committee for the Disrupting Ableism and Advancing STEM series, co-chairing the NIH Advisory Committee to the Director (ACD) Subgroup on Individuals with Disabilities, and serving as a member of the Centers for Disease Control and Prevention (CDC) ACD Health Equity Workgroup. Her work has been published in leading academic journals, such as the New England Journal of Medicine (NEJM), The Journal of the American Medical Association (JAMA), and the Lancet, and has been featured in multiple news outlets,

including the New York Times, the Washington Post, and TIME magazine. Dr. Swenor has a track record of translating research into policy change, as she played a pivotal role in national advocacy that led the NIH to designate people with disabilities as a health disparity population and recently co-led efforts outlining limitations with proposed changes to the US Census Bureau disability questions.



Gloria Thornton
Amplified Disabled Voices LLC

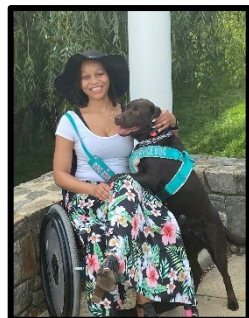
Gloria Thornton, founder of Amplified Disabled Voices LLC is an ombudsman deeply committed to disability advocacy. As a person with disabilities Gloria is well versed on medical discrepancies fueled by personal and professional drive. Gloria Thornton obtained a Master's Degree in Human Services and a Bachelors in Psychology. She is currently working toward obtaining her Doctor of Human Services with a specialty in Prevention, Intervention, and advocacy.

As a woman and a minority, she has had an abundance of lived experience which consist of barriers directly related to cultural incompetence thus resulting in medical discrepancies. Once finding a doctor who listened she received multiple different health diagnoses which sparked the love for advocacy. When she is not advocating for herself or others Gloria enjoys watching movies with friends, spending time with her family and dog, reading, and Dancing as a Lil Sis for the Rollettes , a Los Angeles based wheelchair dance team. Gloria believes that accessibility should be a universal design.



V.G Vinod Vydiwaran, PhD
University of Michigan

Prof. V.G.VInod Vydiswaran is an Associate Professor of Learning Health Sciences in the Medical School, and Associate Professor of Information in the School of Information, University of Michigan. His research is on natural language processing (NLP) algorithms, tools, and resources for medical informatics. His current research focuses on developing computable phenotypes, extracting clinically-relevant information from electronic health record text, and federated network-based approaches to better train deep neural network models over health data.



D'Sena' Warren

D'Sena' Warren is from VA by way of FL. She is a mother of two boys ages 14 & 10; and has lived with migraine attacks since a child. Only after sustaining a TBI due to a MVA in 2010, did she become chronic. She suffers daily from them along with a host of other comorbidities that impact her daily living. D'Sena' works heavily to advocate for persons of color in a space that tends to push them off. When she's not working or advocating, she enjoys trying to new foods with her boys.

PREVENTING DISCRIMINATION, HARASSMENT, AND BULLYING EXPECTATIONS FOR PARTICIPANTS IN NASEM ACTIVITIES

The National Academies of Sciences, Engineering, and Medicine (NASEM) are committed to the principles of diversity, integrity, civility, and respect in all of our activities. We look to you to be a partner in this commitment by helping us to maintain a professional and cordial environment. All forms of discrimination, harassment, and bullying are prohibited in any NASEM activity. This commitment applies to all participants in all settings and locations in which NASEM work and activities are conducted, including committee meetings, workshops, conferences, and other work and social functions where employees, volunteers, sponsors, vendors, or guests are present.

Discrimination is prejudicial treatment of individuals or groups of people based on their race, ethnicity, color, national origin, sex, sexual orientation, gender identity, age, religion, disability, veteran status, or any other characteristic protected by applicable laws.

Sexual harassment is unwelcome sexual advances, requests for sexual favors, and other verbal or physical conduct of a sexual nature that creates an intimidating, hostile, or offensive environment.

Other types of harassment include any verbal or physical conduct directed at individuals or groups of people because of their race, ethnicity, color, national origin, sex, sexual orientation, gender identity, age, religion, disability, veteran status, or any other characteristic protected by applicable laws, that creates an intimidating, hostile, or offensive environment.

Bullying is unwelcome, aggressive behavior involving the use of influence, threat, intimidation, or coercion to dominate others in the professional environment.

REPORTING AND RESOLUTION

Any violation of this policy should be reported. If you experience or witness discrimination, harassment, or bullying, you are encouraged to make your unease or disapproval known to the individual, if you are comfortable doing so. You are also urged to report any incident by:

- Filing a complaint with the Office of Human Resources at 202-334-3400, or
- Reporting the incident to an employee involved in the activity in which the member or volunteer is participating, who will then file a complaint with the Office of Human Resources.

Complaints should be filed as soon as possible after an incident. To ensure the prompt and thorough investigation of the complaint, the complainant should provide as much information as is possible, such as names, dates, locations, and steps taken. The Office of Human Resources will investigate the alleged violation in consultation with the Office of the General Counsel.

If an investigation results in a finding that an individual has committed a violation, NASEM will take the actions necessary to protect those involved in its activities from any future discrimination, harassment, or bullying, including in appropriate circumstances the removal of an individual from current NASEM activities and a ban on participation in future activities.

CONFIDENTIALITY

Information contained in a complaint is kept confidential, and information is revealed only on a need-to-know basis. NASEM will not retaliate or tolerate retaliation against anyone who makes a good faith report of discrimination, harassment, or bullying.

Updated June 7, 2018

National Academy of Sciences

500 5th St. NW

1. Sweet Green – 624 E St. NW
2. Luke Lobster – 624 E St. NW
3. Soul Spice – 439 7th St. NW
4. Chick-fil-A – 707 G St. NW
5. Dos Toros Taqueria 700 7th St

