NATIONAL ACADEMIES Sciences Engineering Medicine

Health and Medicine Division and Division of Behavioral and Social Sciences and Education
Board on Health Sciences Policy | Board on Children, Youth, and Families

SPEAKER BIOGRAPHIES

Presentation of the Task and Goals of the Study

Alisha Blanks, MPH, RD, CDN, IBCLC is a Public Health Analyst with the Office on Women's Health in the Department of Health and Human Services. Alisha previously led the Supplemental Nutrition Assistance Program, where she provided nutrition care and facilitated access to critical resources for maternal, infant and child populations. For more than ten years, Alisha provided care to thousands of mothers, infants and children, working with communities, local health departments, hospitals and interdisciplinary teams to bridge gaps in care, and increase access to high quality services and resources. Additionally, Alisha served children, educators, and administrators in after school programs in Harlem, NY to facilitate and increase access to nutrition education and healthy foods.

Jeffrey Brosco, MD, PhD is a pediatrician and historian who serves as the Director for the Division of Services for Children with Special Health Needs at the Health Resources and Services Administration's Maternal and Child Health Bureau. Dr. Brosco also continues to teach and practice general pediatrics and developmental-behavioral pediatrics at the University of Miami Miller School of Medicine. He directed the MCHB-funded Leadership Education in Neurodevelopmental Disabilities (LEND) training program at the Mailman Center for Child Development from 2010 to 2022. He has also served as Director, Population Health Ethics, at UM's Institute for Bioethics and Health Policy, and as Associate Chair, Population Health, for UM's Department of Pediatrics. Dr. Brosco's research focuses on the organization of health care services for children with special health care needs, on the education of professionals in family-centered, interprofessional practice, and on public policy regarding public health programs such as newborn screening. For over two decades, Dr. Brosco also has held a series of leadership positions for the Florida Department of Health's Children's Medical Services (CMS). From 2017-19, he was Florida's Deputy Secretary of Health for CMS, and he stepped down in 2022 after 4 years as the state's Title V Director for CSHCN. Dr. Brosco has also been active in national health policy groups, such as the Advisory Committee on Heritable Disorders in Newborns and Children and the National Workgroup on Standards for Systems of Care for Children and Youth with Special Health Care Needs.

Panel on State/Regional Newborn Screening Programs –
Perspectives on the Study Task

Anne Marie Comeau, PhD has been with the New England Newborn Screening Program since 1988 and serves as the Deputy Director. In her role, she directs the scientific program focused on the development and evaluation of emerging technologies applicable to screening newborns for genetic and infectious disorders. She also consults with scientists and clinical specialists in the development and clinical interpretation of new screening assays. Dr. Comeau is a professor in the department of pediatrics at the University of Massachusetts Chan Medical School. She received her Ph.D. from Brandeis University and held a postdoctoral research fellowship with the Harvard School of Public Health. She is a prolific author/co-author in the area of newborn screening and genetics. Dr. Comeau is the Principal Investigator of one of two CDC grant awards to study the feasibility of newborn screening for severe combined immunodeficiency (SCID) detection and has overseen the implementation of the pilot SCID Newborn Screening program for Massachusetts. Dr. Comeau was awarded the 2013 Harry Hannon Laboratory Improvement Award in Newborn Screening by the Association of Public Health Laboratories (APHL), in part due to her research efforts on SCID detection. She is a member of the APHL, the International Society of Newborn Screening, and the Council of State and Laboratory Epidemiologists.

Sylvia Mann, MS, CGC recently retired as the Supervisor of the Hawaii State Department of Health Genomics Section which includes the Newborn Metabolic and Hearing Screening, Birth Defects, and Genetics Programs. She continues in her role as the Project Director for the Western States Regional Genetics Network. She is a board certified genetic counselor who graduated with her Master of Science degree in human genetics and genetic counseling from Sarah Lawrence College. She has over 30 years' experience working in newborn screening locally and within the Western States region. In her Genomics Section position, Ms. Mann had responsibility for assessment, assurance, and policy development in the areas of genetics, newborn screening, birth defects and other related areas such as chronic disease. She has also been the principal investigator on several federally funded projects to assess the genetic service and newborn screening needs of professionals and families and use of needs assessment information to plan activities to address the identified needs. In addition to her state and regional work, Ms. Mann has served on regional and national committees including the Secretary's Advisory Committee on Genetics, Health, and Society.

Jill Simonetti is the Newborn Screening Program Section Manager for the Minnesota Department of Health where she manages and directs the overall operation of the program's analytical testing and follow-up activities. She has been with the program since 2002. As the manager she has also participated in national and regional forums to share laboratory findings and interpretations; conducted seminars and presented findings at appropriate local, regional, and national meetings; and collaborated with medical specialists to partner in developing special projects. Ms. Simonetti has been the principal investigator for several federally funded projects related to improving health outcomes by expanding and enhancing access to screening and follow up.

Panel on Child Health and Rare Disease Organizations –
Perspectives on the Study Task

Natasha Bonhomme is the Founder of Expecting Health and has over 15 years of nonprofit and maternal and child health experience. She launched Expecting Health to bring a range of family, community, and professional stakeholders together to address the need for clearer information, high quality engagement, and scalable solutions in healthcare. Her focus is on centering families' perspectives into policy and program design and implementation. Bonhomme led and managed an extensive study of women (with more than 2,000 expectant and new mothers) to understand their attitudes towards newborn screening and their preferences on how and when to be educated. She created and oversees Baby's First Test, a national resource center that reaches over 600,000 families and health providers annually. She has testified before the US Senate Health, Education, Labor, and Pension Committee's Subcommittee on Children and Families on the importance of public education on screening. She sits on numerous committees on maternal and child health including the Secretary's Advisory Committee on Heritable Disorders in Newborns and Children. Bonhomme has also been involved in numerous community-based initiatives and is a Board Member of Whitman Walker Health, a DC-based federally-qualified health center focused on offering affirming community-based health and wellness services to all with a special expertise in LGBTQ and HIV care.

Allison Herrity, MPH is a Policy Analyst at the National Organization for Rare Disorders (NORD). She became involved with NORD in 2018, shortly after being diagnosed with a rare condition herself. Allison served as a Policy Intern and Policy Fellow before joining NORD's full-time staff in 2020. In her current role, Allison is responsible for covering NORD's newborn screening, genetic testing, and telehealth policy work. Allison earned a B.S. in Public Health and M.P.H. with a Health Policy concentration both from the George Washington University School of Public Health.

Annie Kennedy is chief of policy, advocacy, and patient engagement at EveryLife Foundation for Rare Diseases. Focused on improving health outcomes for people living with rare diseases by advancing the development of treatment and diagnostic opportunities for rare disease patients through science-driven public policy, Kennedy's work includes building strong partnerships with policy makers, federal agencies, industry, and alliances. Kennedy has served within the community for nearly three decades through her roles with Parent Project Muscular Dystrophy and the Muscular Dystrophy Association. In that time, she helped lead legislative efforts around passage and implementation of the MD-CARE Act (2001, 2008, 2014) and the Patient Focused Impact Assessment Act, which became the Patient Experience Data provision within the 21st Century Cures Act. She has engaged with the Food and Drug Administration and industry around regulatory policy and therapeutic pipelines, led access efforts as the first therapies were approved in Duchenne, and engaged with the Institute for Clinical and Economic Review around the development of the modified framework for the valuation of ultra-rare diseases. Kennedy's community roles include service on the board of directors for several organizations including Cure SMA, the PFDD Works coalition, the Patient Driven Values in Healthcare Evaluation (PAVE) Steering Committee, among others, and as a member of the National Institutes of Health's National Center for Advancing Translational Sciences Advisory Council and the Cures Accelerator Network Advisory Board.

Perspective on the Congressional History of the Study Task

Debbie Jessup, CNM, PhD is President and Founder of Sage Femme Strategies and Senior Advisor to Wheat Shroyer Government Relations. For 18 years, Dr. Jessup was a Health Policy Advisor in the office of former Congresswoman Lucille Roybal-Allard (CA-40). In that position, she was actively engaged in health appropriations work as well as helping the Congresswoman develop a robust public health, nursing, and maternal health legislative agenda. She holds the distinction of being the only Midwife to have ever worked in Congress, and the longest tenured Nurse to serve as a staffer in Congress. Bills that she helped write and shepherd through the Congress include the Sober Truth on Preventing (STOP) Underage Drinking Act (passed in 2006 and reauthorized in 2016), the Newborn Screening Saves Lives Act (passed in 2007 and reauthorized in 2014), the MOMS for the 21st Century Act, the Midwives for MOMS Act, the Increasing Care and Access to Nurses (I CAN) Act, and the 113th Congress Health Equity and Accountability (HEAA) Act. She also helped the Congresswoman found and Chair the Public Health Caucus and the Maternity Care Caucus, and staffed her boss as Co-Chair of the Nursing Caucus. Dr. Jessup is a frequent lecturer to health professional groups on the legislative and appropriations processes, and how to be effective at organizational advocacy. In her early career she worked as a childbirth educator, a labor and delivery nurse, and a nurse-midwife. Dr. Jessup is a Fellow of the American College of Nurse Midwives, and completed a PhD in Nursing at George Mason University in 2012.