

Building a Diverse Community for Down Syndrome Research

September 2021, 2022
NIH-Sponsored Virtual Workshop

EXECUTIVE SUMMARY

5 7 0 On September 20-21, 2022, the National Institutes of Health (NIH) sponsored a virtual workshop on "Building a Diverse Community for Down Syndrome Research". The workshop was held on the NIH campus in Bethesda, Maryland, and was open to all researchers and community members interested in Down Syndrome research.

The workshop was divided into three sessions. The first session, "Overview of Diversity in DS Research", focused on the current state of research in Down Syndrome and the challenges of conducting research in a diverse population. The second session, "Health Disparities and Research", discussed the impact of social and economic factors on health outcomes and the role of research in addressing these disparities. The third session, "Community Engagement and Research", explored ways to engage diverse communities in research and the importance of building trust and rapport. The workshop concluded with a panel discussion and a closing presentation.

Overview of Diversity in DS Research

This session focused on the current state of research in Down Syndrome and the challenges of conducting research in a diverse population.

¹ All presentations from [Day 1](#) and [Day 2](#) can be viewed via the [NIH VideoCast](#) site.

NIH's Community Engagement Alliance Consultative Resource (CEACR) provides consultations and resources to help researchers improve their community engagement and inclusive participation efforts. CEACR leverages assets gathered through the Community Engagement Alliance (CEAL) Against COVID-19 Disparities.

Stakeholders' Perspectives: Panel Discussion

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Ensuring Representation in the DS Scientific Workforce—Investigators and Trainees

Day 2 opened with a focus on ensuring diversity in the DS scientific workforce. Dr. Bardhan summarized INCLUDE activities to support diversity, equity, inclusion, and accessibility (DEIA). These include organizing a session on outreach and participant engagement at a DS cohort planning workshop, submitting a statement on outreach and engagement in DS research, and hosting a summer course for students from underrepresented groups. INCLUDE funding opportunities aim to promote diversity by prioritizing digital technologies, broadening the geographic distribution of funding, and encouraging community-based participatory research.

Christy Ley, Ph.D., a social science analyst in the NIH Chief Officer for Scientific Workforce Diversity (COSWD) office, reviewed COSWD activities to address disparities in the scientific workforce. To build evidence, the COSWD establishes metrics, conducts assessments, and advises NIH Institutes and Centers (ICs) and others in the biomedical research community on programs' effectiveness. The COSWD has piloted the use of diversity catalysts, individuals in each IC who disseminate DEIA best practices, and a program to build mentoring support for extramural researchers. It also trains and deploys recruitment strategists across NIH to identify diverse candidates, supports DEIA mentorship supplements, and sponsors a prize competition for DEIA excellence.

Michelle Jones-London, Ph.D., chief of the Office of Programs to Enhance Neuroscience Workforce Diversity (OPEN) at the National Institute of Neurological Disorders and Stroke (NINDS), discussed efforts to expand workforce diversity. They include fellowships, supplements, other forms of individual support, and institutional programs. One key to growing a diverse scientific workforce is to ensure that all individuals have the opportunity to contribute to the field.

participate in research. It offers primary and specialty care in one location and aims to serve the individual and their family, addressing physical, psychosocial, and behavioral health; dealing with insurance and other financial aspects of the transition from pe