

Office of Health Equity Review Final Report (Revised)
***Eunice Kennedy Shriver* National Institutes of Child Health and Human Development**
(NICHD)
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Members of the Review Panel

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- Candace Tingen, PhD, NICHD
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The Panel's Charge

An expert review panel was charged to assist the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD) in considering how the NICHD should assist the Division of Extramural Research (DER) and Division of Intramural Research (DIR) in accomplishing their goals as they relate to addressing and eliminating health disparities and improving the number of underrepresented individuals who make up the scientific workforce.

The Panel was asked to consider the following questions:

- What areas should NICHD focus on to address and eliminate health disparities?
- To address these areas of focus, what activities should NICHD consider? How can the OHE assist in promoting or enhancing these activities?
- What opportunities exist for OHE to enhance collaboration within NICHD DER and DIR, and NIH Institutes, Centers, and Offices?
- How can OHE assist the DER/DIR to increase the number of underrepresented individuals participating in the scientific workforce? Are there opportunities to collaborate with other organizations, such as professional societies, nonprofits, universities, or other government agencies?
- In what ways should the OHE inform and educate the public about issues related to health equity?

INTRODUCTION

The current and changing United States demographic has major implications for health, science, and the scientific workforce. A demographic shift coupled with economic inequality results in persistent health disparities. Disparities in health are particularly vexing because they are often complex, lifelong, and intergenerational. Science must meet the needs of a diverse and global population. A vibrant STEM and health workforce will require a diverse STEM pipeline. Given its mission, the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD) is uniquely positioned to be a leader in reducing health disparities, promoting health equity, creating a diverse scientific workforce, and communicating to the public. As the OHE is reestablished, reimagined, and reanimated, it can lead NICHD in bringing issues of diversity, inclusion, and equity to all aspects of the work of NICHD. The committee envisions OHE as a diversity, inclusion, and equity think tank and innovation hub for NICHD, infusing expertise into NICHD's research portfolio, grant making, and daily operations.

Further, NICHD's equity and diversity work will pay special attention not only to those segments of the population that have been excluded historically for reasons such as culture, ethnicity, race, national origin, and sexual orientation, but also to those populations that are at the core of NICHD's mission:

- children
- women
- persons with intellectual, developmental, and physical disabilities.

Too frequently, the populations that NICHD serves have been the unrecognized victims of health inequities, underemployment, and social isolation. The Institute should focus relentlessly on their needs as well as promoting research, training, and clinical approaches that promote equal opportunity and justice for all.

After reviewing data gathered by NICHD and conducting several panel discussions, the panel developed the following recommendations and priority areas.

Global vision, OHE will:

- Serve as a diversity, inclusion, and equity think tank for NICHD, contributing advice on the research domains within the extramural and intramural programs to strategically address health disparities.
- Help to foster greater diversity within NICHD itself and support the Institute and its staff in fostering a positive culture around diversity.
- Create strategies to increase diversity among funded investigators.
- Foster bidirectional communication between NICHD and external stakeholders.
- Identify goals and establish metrics for measuring progress towards diversity, inclusion, and equity goals.

SPECIFIC AREAS

The panel's recommendations focused on three main areas: health disparities research, workforce, and communication.

Health Disparities Research

The US Census Bureau recently reported that half of infants (<1 year) and preschool age children (<5 years) are racial or ethnic minorities, and by 2020, half of the nation's children and adolescents (<18 years) will be racial or ethnic minorities. This demographic shift requires consideration of the changing prevalence and incidence of maternal, neonatal, and pediatric conditions; the constellation of risk and protective factors associated with these conditions; the potential for negative health sequelae in adulthood, and the influences of genetic, cultural, environmental, behavioral, social, structural, and intergenerational exposures.

Role of OHE

- Lead the discussion of health disparities at the NICHD.
- Serve as coordinator of the NICHD health disparities portfolio, including the process to identify needed epidemiological, mechanistic, and intervention studies.
- Reframe the goal from a specific focus on health disparities toward an actualization of health equity, including methodology and criteria to define success. Designate reduction of health disparities/increase in health equity as a cross-cutting theme across NICHD strategic research priorities.
- Train institute staff on health disparities issues (with emphasis on health disparities in NICHD-supported research and research training activities) and interpretation of health disparities data from a culturally-relevant context (e.g. reproductive choice regarding chromosomal defects).
- Identify innovative and transformative ideas for propelling health disparities research forward. Sources might include the extant literature and workshops involving grantees, staff from other NIH ICs and outside stakeholders. Help integrate these ideas into the NICHD operational planning process.
- Lead NICHD in identifying goals and establishing metrics for reducing health disparities and achieving health equity. Ensure that researchers in the DER and DIR are aware of, adopt, and use these goals and measures.
- Deepen NICHD's understanding and expertise in diversity beyond race, ethnicity, gender, and sexuality.

Activities and ideas for NICHD to consider:

- Create health disparities research networks in NICHD mission-relevant areas and ensure that existing networks incorporate research questions relevant to health disparities.
- Integrate the study of health disparities into research along the continuum from basic to translational and clinical science. Areas that should be considered for specific focus include maternal health and pregnancy, fetal and childhood origins of adult-onset disease, perinatal health disparities, violence, disabilities, adolescent health, and reproductive and gynecologic health.
- Prioritize protocols for clinical studies that include a health disparities hypothesis; encourage analysis of data by race/ethnicity and other dimensions of diversity for all clinical studies; encourage secondary data analyses that examine variables relevant to health disparities.
- Encourage disaggregation of research findings within broad population groups (Asian Pacific Islanders, e.g.) when designing studies.
- Encourage health disparities research that considers developmental trajectories, life course approaches, and intergenerational risks. Encourage research that examines mechanisms underlying disparities and the effects of racism and discrimination.

- Consider the relationship between biomedical, social, and structural factors (e.g., research on stress, integrative biology, and social epidemiology).
- Identify the opportunities for health disparities research within the intramural program.

Workforce

The public benefits when health professionals reflect the diversity of the communities they serve; diversity improves access to and the satisfaction of underserved minority groups in the health care delivery system, and the educational experiences of students and trainees. In order to reach this goal, it is essential to promote among minorities an interest in the sciences and health throughout all levels of education, both pre and post baccalaureate. Further, there is a need to recruit and retain minority students and trainees and develop mentors to enrich the experiences of minority scientist and clinician investigators. Recent data indicate that race is a factor in the awarding of NIH funding. This fact should result in efforts to mitigate bias in the award process and boost the number of applications from minority applicants.

Role of OHE

- Lead the discussion on workforce diversity within NICHD.
- Focus on diversity within NICHD; provide training to members of NICHD (e.g., bias, cultural competency, health equity).
- Collaborate more with DIR on workforce recruitment.
- Set goals for workforce diversity and focus on creating the programs and practices to achieve it. Ensure NICHD stays abreast of research on inequities in funding and create appropriate trainings and policies to enhance equity of grant making process.
- Link NICHD to diversity efforts across NIH, in particular the National Institute for Minority Health and Health Disparities.
- Use external collaborations to enhance the diversity of the scientific workforce.
- Create more diversity supplements and reduce hurdles to obtaining them.

Activities and ideas for NICHD to consider:

- Use and perhaps expand intramural opportunities – summer trainees; “developing talent” program for grad students, post-bac levels; PIs to encourage post-doc recruitment.
- Consider additional pipeline development in pre-baccalaureate programs, including programs in elementary, junior and senior high schools in STEM fields. Collaborate with the Science Education Partnership Award program to identify pipeline programs.
- Bring students and junior researchers to NIH to meet with program staff.
- Identify promising scientists and bring them into the NIH system.
- Offer grant writing workshops, online programs, mock study section, especially through NICHD and non-traditional venues; include programs for grant administration and management to increase the capacity of institutions with diverse faculty and students.
- Consider ways to track, engage and encourage unfunded URM investigators who have scored above the payline to revise and resubmit.
- Consider external collaborations with organizations that are doing a good job working with minority investigators (e.g., Robert Wood Johnson, NSF pipeline programs at universities, Leadership Alliance, White House OSTP, Bill and Melinda Gates Foundation, professional societies, etc.).
- Consider creative methods to recruit into and **retain** funded faculty at minority institutions, with packages that include funding for junior or mid-career faculty and trainees and for administrative infrastructure to manage an increased research portfolio; increased capacity attracts trainees; start with a Beta site.

- Consider mandatory period of time for funded investigators at minority serving institution to remain at institution or designated percentage of award due to be repaid.
- Consider partnership grants for minority institutions, not subawards, so that minority institutions are not junior partners. Include needed administrative structure and onsite training.
- Prioritize minority institution membership on Council.
- Solicit suggestions for increasing diversity of workforce from funded minority researchers and researchers from minority institutions at NICHD or NIH-wide professional development workshops.
- Facilitate collaborations with, between and/or among minority serving institutions, minority researchers and health disparity researchers by posting contact information and field of scientific interest for designated faculty at those institutions.

Communication

Health communication can be a powerful tool for addressing and eliminating health disparities. In particular, health communication promotes awareness, facilitates partnerships and shapes social norms as well as individual behaviors. Effective messages that are targeted appropriately and stimulate bidirectional communication with diverse stakeholders create a supportive climate for advancing equity in research, policy, and programmatic efforts across the NICHD. The push for a stronger focus on equity is gathering momentum at the national and international level. Using strategic communications, partnerships, and evidence-based information, the OHE can play a major leadership role within NICHD to distinguish, elevate and prioritize equity in health across the Institute's mission areas.

Role of OHE

- Lead the institution in increasing awareness of how health disparities research is shifting from solely documenting health differences towards understanding the reasons and root causes of these differences and ideas to improve health equity.
- Lend expertise to incorporate health disparities into NICHD communications plans.
- Identify and promote potential partners/collaborators and engage them on behalf of the Institute, where appropriate. Partnerships provide frameworks for shared learning and strengthening the collective impact of NICHD's work.
- Facilitate connections and serve as a NICHD liaison to internal and external partners, as it pertains to health disparities communication activities.
- Assist NICHD intramural and NICHD-supported investigators with dissemination of their research findings relating to health equity beyond the academic community. The NICHD should serve as an amplifier of research on health equity.

Activities and ideas for NICHD to consider:

- Represent NICHD in collaborating with other agencies and private sector partners on health disparities activities and support the Institute by identifying significant opportunities for impact.
- Build upon relationships with advocacy groups and community groups to encourage their involvement in NICHD's health disparities activities.
- Participate in knowledge generation by participating in research collaborations, event sponsorships, and community tie-ins to support and reinforce the NICHD comprehensive communication efforts.
- Establish and maintain effective communication channels specifically between NICHD Communication and OHE.

- Foster accountability by reporting on relevance, impact, effectiveness, efficiency and sustainability of pro-equity interventions and methodologies.
- Create social media activities (e.g. Blog, Twitter, Facebook) to communicate priorities and emerging directions for NICHD health disparities activities.

CONCLUSION

There is a tremendous opportunity to build on NICHD's commitment to promoting health equity. The OHE should be positioned and empowered to lead, serving as a think tank informing NICHD on achieving diversity and equity throughout its daily operations, the research of the DER and DIR, the current and future scientific and health workforce, and health communications. The committee recommends setting goals, creating metrics, and that the leadership of NICHD is held accountable that progress is made.