Diversity, Equity, Inclusion, and Health Inequities Training in Neurologic Disorders and Stroke

Analysis and Recommendations From the NINDS Advisory Council Working Group

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Abstract

Background and Objectives
In 2020, the National Institute of Neurological Disorders and Stroke (NINDS) leadership asked its Advisory Council to review NINDS efforts in the domains of diversity, equity, inclusion, and health inequities. Part of these efforts involved a focus on health equity training and health equity research workforce diversification activities. The objective of this article was to summarize the findings and make recommendations regarding these training activities.

Methods
A subgroup of the National Advisory Neurological Disorders and Stroke Council Working Group for Health Disparities and Inequities in Neurological Disorders was engaged to advise NINDS leadership in the domain of diversity in health equity training. Activities included video teleconference meetings, multiple consultations with experienced leaders in the field, independent writing assignments, and an open public discussion as part of the NINDS HEADWAY workshop held on September 22–24, 2021.

Results
The working group recommends support for 2 distinct types of training activities: one designed for scientists from historically under-represented backgrounds and the second designed for scientists of all backgrounds performing health inequities research. Support for grant writing workshops and establishment of multi-institutional mentorship networks are recommended as potentially especially high-yield activities. The working group recommends that all NINDS-supported investigators should have sufficient diversity, equity, and inclusion training to be prepared and qualified to mentor trainees from under-represented backgrounds and mentor trainees engaged in health disparities research; there should be no “diversity tax” placed on established investigators from under-represented backgrounds to shoulder all the mentorship responsibilities. Among other recommendations, training in health disparities research should include a focus on interventional studies to alleviate inequities as well as social science and qualitative methods.

Discussion
There is a great deal of work to do in the field of diversity, equity, inclusion, and health inequities training, but we are optimistic that the activities outlined here, if fully implemented, will set us on the right track.
Introduction

In 2020, the NINDS Director charged an expert working group of the National Advisory Neurological Disorders and Stroke Council to develop a comprehensive set of actionable recommendations to guide NINDS efforts and research investments in health disparities (HDs) and health equity (HE) over the next 5–10 years. Part of these efforts involved a focus on training programs devoted to issues of diversity, equity, inclusion, and health inequities. Because of the vastness of this topic, 2 subgroups were created to focus on these specific areas. Both training groups worked independently. This report summarizes the findings of the subgroup engaged to advise NINDS leadership in the domain of diversity in HE diversity training.

The activities of the subgroup consisted of several video teleconference meetings, multiple consultations with experienced leaders in the field, consultation with NINDS staff from the Office of Programs to Enhance Neuroscience Diversity (OPEN), independent writing assignments, and an open public discussion as part of the NINDS HEADWAY workshop held on September 22–24, 2021. The subgroup consisted of experts in the field of neuroscience, neurology, research, and/or diversity training.

The primary goal of the working group of the National Advisory Neurological Disorders and Stroke Council was to generate recommendations to not only improve training for all NINDS-funded investigators in areas of diversity, equity, and inclusion but also to support specific training of investigators for whom study of HDs would be a major career focus. Furthermore, the work group focused on improving research training for individuals from historically under-represented groups to increase the representativeness of the workforce. As part of work group discussions and the open public discussion at the HEADWAY workshop, the emphasis was not only on recommendations that could be practically implemented but ones that could have measurable outcomes.

According to the Association of American Medical Colleges 2020 medical school report, the proportion of faculty from under-represented groups decreases with more senior rank. In US neurology departments, typically the academic home for physician-scientists in the field, among 6,334 faculty, only 149 were Black and only 151 were Hispanic/Latino (the term Hispanic/Latino, while gendered, refers to people of all sexes in this context) (each under 2.5%), although another 199 were self-reported multiple races (Hispanic/Latino) and 142 self-reported multiple races (non-Hispanic/Latino).

The research workforce does not accurately represent the US population, and the rate of funding by NIH grants is similarly low for under-represented groups. In 2011, it was published that Black applicants are 10 percentage points less likely to receive NIH research funding. However, ongoing efforts have led to some improvements, particularly with the establishment of the Chief Office of Scientific Workforce Diversity at the NIH and the work of the NINDS OPEN. The number of R01 grants awarded to Black candidates increased from 52 to 166, from 2013 to 2020, yet still representing only 2% of awarded NIH R01 grants. Grants to Hispanic/Latino applicants increased from 183 to 428 over the same time period and represent 5% of awarded R01 grants. Training grants in particular show improving numbers, with an increase from 22% (in 2013) to 34% (in 2018) of K-awardees being of Black race and increasing numbers of fellowship awards and PhD recipients in historically under-represented group over the past 5–10 years.

As stated above, a major purpose of this working group is not only to improve the diversity of the workforce but also to increase training in areas of diversity, equity, and inclusion, along with research on HDs. In an evaluation of grant review by the NIH Center for Scientific Review, however, research related to HDs was less likely to be funded than other types of research. Although White applicants conducting HDs research were less likely to have their research funded than were White applicants conducting research in other areas, by nearly a 2-fold difference, a difference of a similar magnitude was found based on the race of the applicant: White applicants had a 1.87 times higher odds of getting disparities research funded than Black applicants conducting disparities research. Furthermore, Black researchers are more likely than White researchers to conduct disparities research.

Training in HDs tends to be limited to those investigators with specific interest in this field: Most investigators do not have specific requirements to learn more about the existence or evaluation of HDs as part of their institutional requirements or training grant plans. Although grant submissions require discussion of “Inclusion of Women and Minorities” and clinical trial applications now require analyses to be conducted by sex and race/ethnicity, no specific training in social determinants of health or HDs is required. Even Responsible Conduct of Research requirements do not focus on recruitment and retention of diverse populations, although applicants are required to comment on “Recruitment and Retention Plan to Enhance Diversity.”

Definitions and Conceptual Models

We adopted the Association of American Medical Colleges’ definition of under-represented in medicine (UIM), which

Glossary

DoD = Department of Defense; HD = health disparity; HE = health equity; NINDS = National Institute of Neurological Disorders and Stroke; OPEN = Office of Programs to Enhance Neuroscience Diversity; UIM = underrepresented in medicine.
defines UIM as individuals from “those racial and ethnic populations that are underrepresented in the medical profession relative to their numbers in the general population.” The scope and definition of HE, HD, and HD research for the purposes of this study is based on the Healthy People 2030 definition.10

We developed recommendations that aim to direct the development and expansion of training programs for NINDS researchers to promote diversity among the research workforce and to encourage and amplify research in HDs in neurologic diseases. Distinct needs and goals were identified for researchers based on their backgrounds and their research interest. We created a conceptual model to help the NINDS in targeting training to specific populations of researchers (Figure).

We believe that our approach can inform NINDS priorities and help the NINDS be more precise in the types, content, and organization of training programs to offer investigators from diverse backgrounds and with diverse research interests. This model is based on the premise that all research in the areas covered by NINDS are influenced by structural racism, unconscious bias, social/academic position, and inequitable treatment in its design, implementation, and interpretation. We contend that all NINDS-funded researchers merit appropriate training related to health inequities, but that more extensive and detailed training programs should be developed and made available for those researchers from underrepresented backgrounds and those researchers specifically performing investigations in HDs/HEs. Those who fall in the latter 2 categories deserve special consideration to minimize the burden often placed on UIM researchers to solve the problems facing diverse communities. Furthermore, we recommend that all major NINDS-supported research endeavors include training opportunities for UIM trainees as an explicit part of their operations.

To provide structure to our approach, the working group performed an analysis following a process used by the Department of Defense (DoD) Joint Capabilities Integration and Development System that systematically addresses doctrine, organization, training, material, leadership, personnel, facilities, and policies. Although the work of this subgroup was not performed by DoD staff, coordinated with the DoD, or meant in any way to reflect DoD activities, the structure was felt by working group members to be helpful for organizational purposes. While this process was used to develop recommendations, for ease and consistency of reporting, our recommendations are presented based on the organization of our conceptual model, which aims to focus training resources based on an investigator’s background and research interests.

Subgroup Findings and Results

The subgroup recommends a multifaceted portfolio of training and mentoring programs, with periodic evaluations of programs at appropriate intervals. The portfolio of training programs should include both early-phase trainees (e.g., student, fellows, junior faculty) and later-phase programs to promote retention and career advancement. Overall, the working group recommends sustained long-term support for training programs in 3 categories, each with a distinct rationale (Table).
Foundational Diversity, Equity, and Inclusion Training for All Scientists Supported by NINDS

The purpose of this training should be to ensure that all scientists have an understanding of issues related to diversity, equity, and inclusion with a special emphasis on racism and its effects on the design, conduct, and interpretation of research. HDs are universal, and the design of any clinical interventions requires knowledge of how disparities negatively affect all patient experiences and outcomes. It is imperative that the NINDS standardizes and implements training for all NINDS-funded scientists in the domains of diversity, equity, and inclusion with 2 specific goals: (1) to enable researchers to better design and implement studies with health inequity in mind and (2) to give researchers the knowledge and skills to better support and understand UIM trainees and colleagues. We recommend developing both online and in-person training programs in these domains. Online training programs have the advantage of easily reaching a wide geographic audience. However, it is important to have in-person or virtual experiences to improve individual comfort and fluency with difficult topics. The content of such training programs should include education on the history of racism in research and health care, discussion of implicit and explicit bias, and recognition of the benefits of diversity in organizations. Trainings that teach individuals how to approach systemic inequities and how to solve problems with an equity framework could help researchers in developing antiracist identities and lead to important structural changes within their institutions and research programs. Finally, the education must build an awareness of the direct effect of racism today on patients, trainees, and colleagues. From a practical perspective, these training programs could be analogous to those focused on scientific ethics, human studies protection, preventing toxic workplace environment, information security, laboratory safety, radiation safety, and other essential aspects of the modern scientific enterprise. To implement in-person or virtual components, we recommend that the NINDS works in collaboration with universities, research institutes, companies, and other organizations that conduct NINDS-sponsored research and assist them in developing these capabilities. Input from communities and from diverse patients is critical to inform training and to ensure accurate and fair representation of the issues discussed.

Research and Career Development Training for Scientists From Under-represented Backgrounds

We recommend development and expansion of training programs that aim to recruit, support, engage, and retain UIM scientists within the research areas supported by NINDS and to promote their success within the field. We recommend that the NINDS continues to expand fully funded undergraduate, graduate school, and postdoctoral training programs (including activities

Table Recommendations for Training Programs in Health Disparities

<table>
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<th>Type of investigator</th>
<th>Recommendations</th>
<th>Questions to address when developing outcome measures</th>
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<tr>
<td>All NINDS-funded investigators at all career stages</td>
<td>1. Foundational training in Diversity, Equity, and Inclusion with special emphasis on antiracism a. Online, virtual, and in-person formats</td>
<td>Is the training effective? Does it influence the research practices of individuals who complete the training?</td>
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<td>UIM investigators seeking funding and developing research careers across the NINDS portfolio (focused on early-career investigators)</td>
<td>2. Expand existing training programs across research areas focused on UIM investigators a. Address skills such as research methodology and grant writing b. Training programs should also focus on career development for UIM researchers 3. Develop mentorship networks of established and funded investigators a. UIM researchers should have privileged access to these networks b. Mentors should not be limited to UIM mentors</td>
<td>Do the training programs attract more UIM individuals into researcher careers? Do the training programs enhance the success of individuals in their careers? Do the training programs compensate for the burden of the diversity tax?</td>
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<tr>
<td>All investigators seeking funding for investigations in health disparities research (includes early-career investigators and established investigators who are newly interested in health disparities research)</td>
<td>4. Expand existing training programs focused on health disparities research a. Increase emphasis on interventional studies to reduce and eliminate health inequities b. Continue training in health outcomes research methods and grant writing c. Include social science and qualitative methods 5. Develop mentorship networks of investigators focused on health disparities research</td>
<td>Do the training programs engage more individuals into health disparities research? Do the training programs elevate the interest, quality, and status of health disparities research?</td>
</tr>
<tr>
<td>Investigators from UIM backgrounds working in health disparities research</td>
<td>6. In addition to training programs mentioned above, dedicated tracking of individuals in this group to ensure adequate funding levels, publication record, and promotions in academia</td>
<td>Do the training programs compensate for the burden of the diversity tax (e.g., by offering protected time, financial incentives, leadership opportunities, or other tangible benefits)?</td>
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Abbreviations: NINDS = National Institute of Neurological Disorders and Stroke; UIM = under-represented in medicine.
such as the R25 Program: ninds.nih.gov/funding/training-career-development/diversity-awards/nih-neuroscience-development-advancing-careers-diverse-research-force) for scientists from under-represented backgrounds. These programs are critical for recruiting and developing a diverse workforce in neuroscience research. The NINDS should set the aspiration that the proportion of UIM researchers in neuroscience reflect and mirror (or exceed) the national population. To overcome undermentoring of individuals who are UIM, we recommend the funding and development of multi-institutional, nationwide mentoring networks for UIM trainees. UIM trainees and early-career faculty lack access to the same mentoring networks as their counterparts. Given the critical importance of mentorship in scientific success, establishment of mentorship networks may be an especially high-yield activity. It is important that these networks improve access to mentors with expertise and funding records and that these not be limited to mentors from UIM backgrounds. The historic dependence on mentors from UIM backgrounds is detrimental in 2 ways. It places an excessive burden on UIM faculty and mentors to have to promote and sponsor the careers of UIM mentees, and it limits the pool and breadth of mentor expertise because UIM researchers represent a smaller pool of researchers. Independent of the above programs, the NINDS should provide funding and create resources for logistic support for grant writing workshops for UIM researchers in early career. These grant writing workshops, if designed correctly, should identify key gaps in an individual’s access to resources, mentors, and career development opportunities, and infrastructure should be provided to proactively fill these gaps. Given that many of the definitions of “success” in research involve obtaining grant funding, grant writing workshops may be especially fruitful, high-yield activities. For UIM researchers who work at institutions that are community-based and that often take care of diverse communities, these workshops can help offset the disparity in training and career development resources available at community-based institutions compared with academic institutions. Finally, we recommend that the NINDS funds and proactively develops resources to promote these programs and proactively invites UIM researchers who have not yet secured competitive funding.

Methodologic Training and Development of Mentorship Networks Focused on HDs Research

The purpose of these training programs is to better engage researchers at all career stages and from all backgrounds in developing investigations in health disparities, as well as adapting existing lines of inquiry to focus on health inequity. Ultimately, the goal of these programs is to strengthen the caliber of health inequity research in neurologic diseases across the United States and to elevate the status of this research to be equivalent—in funding, reputation, and publication potential and for an individual’s academic promotions—to basic science research or experimental therapeutics research. We recommend that the NINDS continues and expands fully funded undergraduate, graduate school, and postdoctoral training programs for scientists of all backgrounds focused on HDs research. We believe that these programs should emphasize interventional research focused on directly addressing HDs. Many institutions, including established academic institutions, lack experience in conducting peer-reviewed, externally funded health inequity investigations, and therefore, we recommend that the NINDS funds and establishes national mentoring networks for trainees focused on HDs research. These mentoring networks should be expanded beyond traditional networks in academic institutions to include individuals in community-based health centers, patient advocacy groups, and social justice organizations. These efforts are to ensure that research initiatives are genuinely aimed to address the needs of communities and incorporate the perspective of diverse patients. To complement these efforts, the NINDS should provide funding and logistic support for grant writing workshops for researchers who are either early in their career or newly focusing on HDs research. We believe that training programs and resources that are traditionally reserved for early-career researchers should also be available and encouraged for established researchers, for whom work in HDs is a new direction. Training programs and grant writing workshops should include qualitative and social science research methods that are traditionally used in HDs research, but we also want to re-emphasize the importance of interventional research methods focused specifically on actively reducing HDs. Education and training across these recommended mechanisms should additionally include best practices in partnering with community organizations. We recommend embedding substantial portions of the programs for health inequity research training in the communities that are affected by these disparities, and thereby, the NINDS would also be directly funding resources within these communities in addition to providing trainees with “real-world” understanding of the challenges faced by patients in diverse communities.

Directly Addressing the Diversity Tax

Our subgroup developed these recommendations to actively counter the “diversity tax” that places a burden on UIM researchers to take it on themselves to do the work on addressing diversity issues and HDs. This work is often less compensated, less respected, less likely to help with promotions, and less likely to be published than other activities. Taking on excessive burdens of mentorship can actively impede an individual investigator’s career development. While quantitative data are not available to our knowledge, it is important to recognize that UIM researchers may be more likely to contribute to HDs research than others and that the researchers in HDs are disproportionately from UIM backgrounds. Our recommendations aim to provide broad-based mentoring and career development resources for those who are UIM along with another layer of support and resources for those individuals who are UIM and doing HDs research. This group of individuals would benefit from training programs designed for UIM individuals and programs designed for those engaging in HDs research. It is important that the NINDS pays particular attention to this group and tracks their professional outcomes and progress. As stated above, the aspiration by the NINDS should be that UIM researchers funded by the NINDS mirror (or exceed) the population. However, the aspiration by the NINDS should also be that UIM researchers performing HDs research not be expected...
automatically to exceed representation in the population. To be clear, we would not recommend policies that prevent or interfere with representation of UIM researchers performing HDs research, even if their representation in HDs research exceeds representation in the population, but only that this should not be automatically expected. HDs research should not be the work of only UIM physicians: Researchers of all backgrounds should be trained to excel in this field.

Outcomes and Metrics of Success

Training is a long-term effort and requires sustainment for many decades before results can be fully evaluated. However, shorter term evaluations are required to flexibly adjust activities and priorities based on available data. NINDS leadership will be responsible for selecting and implementing metrics for evaluating training programs with input from external advisors and in coordination with other NIH institute and center leaders. We recommend developing specific metrics that measure (1) the engagement of individuals in these training programs, (2) the effect of training programs on their individual success (promotions, publications, grant awards), (3) incremental changes to the percentage of UIM investigators who apply for and receive grants from the NINDS, and (4) incremental changes to the percentage of NINDS-funded researchers engaged in HDs research. On a periodic basis, NINDS leadership may need to modify offerings based on success metrics.

To be effective, funding, staff, and leadership allocations need to be commensurate with these priorities. Our recommendations will require investment in key infrastructure items. The NINDS will need to develop online, in-person, and virtual training programs with the input of funded experts, community leaders, and community organizations. The NINDS will need the infrastructure to engage in widespread communication efforts to promote NINDS training programs, including bi-directional community outreach, social media, video presentations, and in-person presence at conferences. We recommend that NINDS explicitly evaluates the efficacy of communication efforts on a regular basis. In particular, the NINDS should be proactive in trying to engage researchers eligible for these opportunities who have not yet secured funding. Expansion of both website and social media presence will be necessary to disseminate these opportunities beyond traditional academic institutions to include researchers in community-based health centers and community organizations. Finally, we believe the NINDS can meaningfully help researchers by developing and publishing guidance documents with best practices to mentor UIM researchers, to develop community base partnerships, and to conduct HDs research outside academia.

The development of specific training, mentoring, and career development programs can leverage NINDS resources to actively improve representation of UIM in relevant research domains, reduce racial bias across all lines of inquiry, elevate the quality and effect of investigation in HDs, and reduce the burden of the diversity tax on those from under-represented groups. As a subgroup, we believe that ultimate success of these programs would result in the following:

1. A large number of well-qualified students from under-represented backgrounds apply to and are accepted into MD, PhD, and MD/PhD programs with a focus on neuroscience research.
2. A large number of well-qualified students interested in studying neurologic HDs apply to and are accepted into MD, PhD and MD/PhD programs with a focus on neuroscience research.
3. Researchers from under-represented backgrounds and researchers studying HDs understand their career paths and have appropriate opportunities at all academic centers engaging in research supported by the NINDS.
4. Researchers from under-represented backgrounds and researchers studying HDs can publish their work in high-quality journals without concerns of bias or “second class” status.
5. Training in the domains of diversity, equity, and inclusion and antiracism will be an accepted part of scientific ethics training that is routinely implemented at all NINDS-funded institutions.

Future Directions

It became clear in the course of the discussions that training scientists from under-represented backgrounds and training scientists (of all backgrounds) to perform high-quality health inequity research are 2 related, but distinct topics and may be optimally addressed by separate working groups in the future and evaluated separately by NINDS leadership. This subgroup recommends that future endeavors in this domain be conducted by 2 distinct work groups, as was conducted during this planning process. One focused on training scientists from under-represented backgrounds and the other focused on training scientists (of all backgrounds) to perform high-quality health inequity research. These work groups should be in close communication with each other, but not be necessarily required to provide the same recommendations. Similarly, while we have grouped neuroscience training activities together for the purposes of this report, it may be that some parts of the neuroscience training ecosystem are doing better than others. We recommend additional deep dives into specific subpopulations and more granular interventions targeted to specific subspecialty areas.

It also became clear that while the NINDS has substantial leverage, the NINDS cannot do everything. Synergistic partnerships between NIH Institutes, Centers, and Offices and other organizations involved in training activities will further advance the mission: Examples include cooperating with K-12 neuroscience education efforts, providing information about scientific careers to guidance counselors and academic advisors, and providing logistic support to groups focused on future neuroscientists from under-represented backgrounds (e.g., Black in Neuro,
TAKE-HOME POINTS

- The NINDS Advisory Council’s diversity, equity, inclusion, and HD training subgroup recommends sustained long-term support for training programs in 2 distinct domains: (1) research training for scientists from historically under-represented backgrounds in domains relevant to the mission of the NINSD and (2) training scientists of all backgrounds to perform high-quality health inequities research relevant to the mission of the NINDS.

- The portfolio of training programs should include both early-phase trainees (e.g., students, fellows, junior faculty) and later-phase programs to promote retention and career advancement.

- Mentorship roles should not involve a “diversity tax” on investigators from historically under-represented backgrounds. All NINDS-supported investigators should have sufficient diversity, equity, and inclusion training to be prepared and qualified to mentor trainees from under-represented backgrounds and trainees engaged in HDs research.

- Grantsmanship workshops for trainees at multiple levels and organization of multi-institutional mentorship networks may be especially fruitful activities.

Women in Neuroscience, Women in Neurotrauma Research, etc.). Furthermore, support for public statements from peer-review process leaders (study section chairs, scientific review officers, etc.) articulating their approach to reviewing applications for training program awards from scientists from under-represented backgrounds and applications from scientists (of all backgrounds) involving health inequities research would be a great benefit to trainees seeking clarity in their career paths. Similarly, support for public statements from academic publishing leaders (editors-in-chief, associate editors, marketing team leaders, publishers, etc) denoting their policies regarding the handling of submissions from scientists from under-represented backgrounds and scientists (of all backgrounds) performing health inequities research would improve understanding of the academic publishing system. Finally, support for public statements from academic leaders (Deans, Department Chairs, Program Directors, etc) articulating their policies regarding training scientists from under-represented backgrounds and training scientists (of all backgrounds) to perform high-quality health inequities research would allow potential trainees to make informed choices about their careers.

Conclusion

Training for scientists from historically under-represented backgrounds in domains relevant to the mission of the NINDS and training scientists of all backgrounds to perform high-quality HDs/HEs research relevant to the mission of the NINDS should be top priorities. There is a great deal of work to do in the field of diversity, equity, inclusion, and HD/HD training, but we are optimistic that the activities outlined here, if fully implemented, will set us on the right track. To paraphrase President Barack Obama, “To restore America’s completeness, we must recruit and train a new generation of science and technology leaders by investing in diversity.”

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### References


### Appendix Authors

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