



Investment, integration, and innovation: Fostering diversity, equity, and inclusion across the HEALTHY Brain and Child Development (HBCD) Study consortium

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ABSTRACT

The HEALTHY Brain and Child Development (HBCD) Study, a multi-site prospective longitudinal cohort study, will examine human brain, cognitive, behavioral, social, and emotional development beginning prenatally and planned through early childhood. From the outset, the HBCD Study integrated diversity, equity, and inclusion (DEI) into its core mission, with key elements like an Associate Director for DEI, a DEI values statement, and establishing a DEI committee to help ensure sustainable progress for the future. The DEI Coordinating Committee supports DEI efforts impacting members of the HBCD consortium, study participants, and the analysis and dissemination of HBCD data. Committee members include representatives from every study site and workgroup which contributes to DEI integration throughout the study. Committee activities include reviewing all measures and protocols, creating accountability metrics, and supporting training opportunities for consortium members. Several successes and lessons have been learned through the Committee's activities like implementing consortium-wide unconscious bias training and changing the DEI leadership and committee structure. This article presents an overview of HBCD's DEI components within HBCD and provides examples of collaborative efforts between the DEI Coordinating Committee and other workgroups. The article concludes with plans for future activities and recommendations for other large consortia considering formal DEI structures.

1. Introduction

Developmental cognitive neuroscience research aims to advance understanding of brain development and its relation to cognition, behavior, and health and can inform intervention and policy approaches to promote health and health equity (Nelson and Luciana, 2008; Munakata et al., 2004). Like many fields, developmental cognitive neuroscience has historically lacked diversity, equity, and inclusion (DEI) in its study participants and research workforce (Nketia et al., 2021; Garcini et al., 2022). This lack of diversity can limit the generalizability of findings and hinder progress toward equitable health outcomes for all populations. In recognition of this issue, the Healthy Brain and Child Development (HBCD) Study established a formal diversity, equity, and inclusion (DEI) structure to promote DEI values throughout the large research consortium. This paper describes the HBCD Study's approach to investing in, integrating, and innovating DEI efforts across

the consortium through its DEI Coordinating Committee. It is important to note that DEI is an overarching term and covers a wide range of topics related to fostering a climate of justice, inclusivity, and equity within HBCD. DEI activities within HBCD address a variety of social identity groups, including those based on career stage, language, gender, race, ethnicity, disability status, sexual orientation, substance use history, and other attributes. The HBCD Study is a major longitudinal study of child development beginning in pregnancy. The study aims to enroll over 7000 families across 27 recruitment sites in the United States. The recruitment sites are spread across the United States, including urban and rural areas, and there is a workgroup dedicated to the topic of data collection in rural and sovereign communities. Most of the pregnant individuals recruited into the cohort will come from the general population, and the study aims to match population distributions for race, ethnicity, and educational attainment among other characteristics. The study utilizes multimodal assessments—including survey assessments,

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biospecimens, biosensors, MRI, and EEG—to develop a deep and nuanced understanding of how children’s development is influenced by their social environments and lived experiences. As a large, multi-site research consortium, HBCD recognized the need to establish formal DEI efforts to ensure its work represents and benefits diverse populations. This paper outlines the HBCD Study’s commitment to DEI through the investment of human and financial resources. It then discusses how the study has integrated DEI values and the DEI Coordinating Committee into its governance structure and collaborative work. Finally, we provide examples of innovation in the committee’s activities, leadership, and processes.

2. Investment

From the outset, the HBCD Study has invested time and human resources toward advancing DEI values in the study. The National Institute on Drug Abuse (NIDA), a major study partner, provides significant support to the DEI efforts through its Scientific Diversity Advisor. This newly created role demonstrates the agency’s commitment to DEI values by actively advising the study on best practices and available resources within the NIH and NIDA. Within the study, there is an Associate Director (AD) with DEI expertise and oversight of related study activities. The AD for DEI serves in a senior leadership role alongside three other ADs as part of the HBCD Consortium Administrative Core (HCAC). In addition to the AD role, the HBCD Study implemented the DEI Coordinating Committee whose main goal is establishing effective approaches to promote DEI across all facets of HBCD.

The DEI Coordinating Committee supports DEI efforts related to Consortium members, research participants, and the analysis and dissemination of data. The committee’s original structure included two co-chairs, the main committee, and three subcommittees focused on measure review, diversity training, and metrics. The co-chair positions were initially held by the AD for DEI and an outside consultant with DEI expertise affiliated with an HBCD Study site. All other DEI Coordinating Committee members are volunteers from across the Consortium who contribute their time and expertise to the committee. Membership is open to all interested HBCD affiliates, including research assistants, investigators, and study navigators (i.e., individuals available to provide material and instrumental support to participating families).

The DEI Coordinating Committee subcommittees managed several important activities. The Measures Review subgroup reviewed all proposed measures and protocols from assessment workgroups and other study-related materials for participants. The review process included a critical assessment of potential bias in six main areas: gender bias, racial bias, cultural bias, ableist assumptions, heteronormative or nuclear family assumptions, and coded language. The Diversity Training subgroup promoted trainings for consortium members and awareness of NIH Diversity Supplements to site PIs to raise attention to and introduce strategies for diversifying the workforce. In conjunction with those efforts, the Metrics subgroup developed and administered a demographic survey to document the diversity of HBCD Study’s Consortium members. This initial survey will serve as a baseline and the DEI Coordinating Committee intends to administer the survey bi-annually.

3. Integration

The HBCD Study has worked intentionally to integrate DEI values throughout the study with its values statement, committee representation, and collaborative activities. The DEI values are prominently placed on the study’s public-facing website and all consortium members are asked to sign an attestation of their understanding of the study’s commitment to DEI. The core values (HBCD Study, 2024) include:

- Participation is open to all people.
- We will monitor diversity, equity, and inclusion.
- We will work with and for our participants and their communities.

- We will promote dignity and respect for all persons.
- We will engage in activities to create a diverse community of scientists and staff.
- Responsible use of study data.

Other examples of intentional integration include having DEI Coordinating Committee members represent every study site and assessment workgroup. On this basis, we have representation from urban and rural sites from across the United States, and the group is comprised of a diverse set of members based on gender, race, ethnicity, primary language, career stage, and project roles. This approach allows committee members to serve as liaisons between the committee and their site as well as between the committee and their respective assessment workgroups. The committee co-chairs routinely review the committee roster for membership changes to ensure each site and assessment workgroup is represented. In addition, members of the DEI Coordinating Committee periodically attend consortium-wide research assistant meetings to provide updates on the Committee’s activities and initiatives. This allows research assistants to provide their own feedback and suggestions, ensuring the voices of individuals who work directly with participating families are represented in diversity efforts.

The DEI Coordinating Committee is regularly approached for collaborative work with other workgroups in the Consortium. Workgroups proactively engaged with the DEI Coordinating Committee to develop resources, such as phone scripts for research assistants who are providing hairstyling guidance to participants with thick or curly hair before an EEG visit. The committee has also been actively involved in efforts to support community advisory board efforts across the Consortium. In the future, the DEI Coordinating Committee will play a role in the review of ancillary study proposals to identify potential biases and offer suggestions.

4. Innovation

The DEI Coordinating Committee exhibits innovation and flexibility in its response to training needs, its leadership and committee structure, and committee activities. While reviewing a proposed measure, it was determined that the Consortium would benefit from unconscious bias training to improve the administration of measures and create a more inclusive Consortium environment. In response to this training need, the DEI Coordinating Committee identified and implemented a five-month online unconscious bias training Consortium-wide for nearly 700 HBCD Study staff at all sites. This course covered topics of unconscious bias, types and effects of microaggressions, strategies to mitigate personal biases, self-awareness of the origins of unconscious bias and how they impact interactions, and bias in healthcare. To increase participation, the committee combined the training’s self-paced modules with group learning activities led by a committee member. Group activities included the circle of trust for affinity bias, identifying microaggressions, and a virtual privilege walk. This highly engaging approach received positive feedback from Consortium members and resulted in a 71 % completion rate for the training.

Innovation within the DEI Coordinating Committee has recently included changes to the leadership and committee structure. As the AD for DEI assumed more responsibility within the study, it was decided that another committee member would take on the AD’s co-chair role. In this new leadership model, the AD for DEI still provided oversight to the committee through regular meetings with the co-chairs who handled the day-to-day committee responsibilities.

As with the AD, committee members began assuming additional responsibilities in the study and at their respective sites. To increase committee participation while avoiding burnout, the three subcommittees were dissolved and all work became part of the full committee’s responsibility. For example, instead of a small group of available people participating in a Measures Review subcommittee, requests for volunteer reviewers went to the entire committee. This has

allowed more people to be involved in the review process and spread the workload across more committee members.

5. Recommendations

As the HBCD Study continues to grow, there will be more opportunities to expand the activities of the DEI Coordinating Committee. Future activities should focus on continued investment, integration, and innovation to ensure DEI values remain a core aspect of the study. Opportunities for additional investment in DEI may include a more sustainable leadership structure with funded roles given the increasing importance and breadth of DEI within the study. It may also include allotted funds for DEI-related training activities or honoraria for guest speakers to share their expertise with the Consortium.

Integrating DEI throughout all aspects of the study remains a top priority. One recommendation would be to compile previous measure review feedback into a resource guide for workgroups to use as they prepare future measures. This empowers workgroups to conduct their own DEI reviews and begin to critically consider whether their measures promote bias. By transferring this DEI knowledge to workgroups, the DEI Coordinating Committee can focus its efforts on other aspects of the study like the analysis and dissemination of data. Finally, the HBCD Study and DEI Coordinating Committee must remain flexible and innovative in their approach to advancing DEI values. The committee should assess the study's climate to better understand how Consortium members and research participants feel the study has made progress toward its DEI goals.

Other large consortia considering formal DEI structures should consider their capacity to invest, integrate, and innovate. While they may look different in each consortium, all three are necessary for promoting DEI as a core component of the research enterprise. Consortium leadership should thoughtfully consider the role of DEI in improving the entire study from consortium member satisfaction to participant recruitment and retention. The HBCD Study serves as an example of progress, not perfection, as the study's DEI activities evolve to meet its changing needs and lessons from peer organizations pursuing comparable objectives. By reviewing best practices elsewhere and soliciting diverse viewpoints, the HBCD Study works to enhance its commitment to diversity, equity, and inclusion.

6. Conclusion

The HBCD Study's DEI Coordinating Committee demonstrates how a large research consortium can make meaningful progress toward promoting DEI through strategic investment, integration, and innovation. As the study continues, further investment in sustainable DEI leadership structures and training opportunities will help ensure these efforts can be maintained and expanded over time. Integrating DEI more fully into the workgroups will help embed these principles throughout the Consortium's scientific work. Flexibility and innovation will also be crucial as the committee evaluates how to best support the evolving needs of Consortium members and study participants. By continuing efforts at all levels of the Consortium's work, the Committee aims to ensure that the HBCD Study is inclusive, equitable, and will produce unbiased science that can advance the health and wellbeing of all children and families.

CRediT authorship contribution statement

Natalie Slopen: Writing – review & editing, Writing – original draft, Project administration, Conceptualization. **Traci Murray:** Writing – review & editing, Writing – original draft, Project administration, Conceptualization.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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