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Applying a Health Equity Lens to Pediatric Neurology Research: Lessons Learned From an Educational Workshop.

Permalink

<https://escholarship.org/uc/item/55w9201p>

Journal

Journal of Child Neurology

ISSN

0883-0738

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Publication Date

2026-09-16

DOI

10.1177/08830738261467844

Peer reviewed

Applying a Health Equity Lens to Pediatric Neurology Research: Lessons Learned from an Educational Workshop

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Abstract

Health disparities are increasingly important considerations in clinical practice and public health initiatives. Health disparities and health equity research methods are under-utilized in research design, analysis, and dissemination in pediatric neurology. This paper highlights our collective experience in organizing a one-hour workshop on “Applying a Health Equity Lens to Pediatric Neurology Research” at the 54th Annual Child Neurology Society Meeting. The topics covered included: 1) use of theories, models, and frameworks from dissemination and implementation science for health equity, 2) community engagement and qualitative research methods in health equity research, 3) recruitment of representative populations in research studies, 4) social determinants of health, data collection tools and indices used in research, and 5) integrating health equity research into a research career. In this manuscript, we describe session content and summarize participant survey data. We also provide future directions and recommendations for integrating health equity into pediatric neurology research.

Keywords: health equity, health equity research, research methods

Introduction

Health disparities, defined as health outcome differences due to social, demographic, economic, geographic, and environmental factors, have been identified in

pediatric neurology, including the care of children with epilepsy, autism spectrum disorder, cerebral palsy, headache, and many other neurological conditions of childhood.¹ To ensure that all children can achieve their greatest potential neurologic health, we must develop a better understanding of the root causes and drivers of these health disparities so that we can mitigate disparities through interventions and promote health equity. Health equity research involves using research methodologies to analyze health disparities including causal factors, developing interventions or strategies to resolve disparities, and rigorously evaluating the effectiveness of equity interventions.¹ Health equity research can therefore inform public policy and public health initiatives in a data-driven manner.

To increase knowledge and awareness of methodologies used in health equity research and foster health equity research in pediatric neurology, our group led a workshop session at the 54th Annual Child Neurology Society Meeting held in Charlotte, North Carolina on October 8, 2025 entitled “Applying a Health Equity Lens to Child Neurology Research.” In this workshop, each speaker sat at a small round table to address a distinct topic. Attendees were able to rotate among the tables at scheduled 15-minute intervals. The topics included: 1) use of theories, models, and frameworks from dissemination and implementation science for health equity, 2) community engagement and qualitative research methods in health equity research 3) recruitment of diverse populations in research studies, 4) social determinants of health, examples of data collection tools and indices used in research and 5) integrating health equity research into a research career. We selected these topics to cover the continuum of health equity research. At the end of the workshop, the participants were given a link

with additional resources and detailed handouts that expounded on topics that may have not been covered during the workshop.

In this manuscript, we present an overview of the content of our workshop. We also present workshop evaluation findings as pilot data supporting our approach to health equity research education. Our intent is to provide more child neurologists with the tools that they need to engage in impactful health equity research and ultimately, promote optimal neurologic health for children across all demographic groups.

Theories, Models and Frameworks from Dissemination & Implementation Science for Health Equity

Theories, models, and frameworks can be helpful in designing a study to characterize, understand and/or mitigate health disparities as well as interpret findings. In particular, theories, models, and frameworks from dissemination and implementation science (D&I) can be used to plan, implement, and disseminate evidence-based interventions to mitigate disparities. The goal of dissemination and implementation science (D&I) is to understand processes and factors that are associated with successful uptake of evidence-based interventions in real-world settings.² D&I includes consideration of systems/structural, organizational, and individual-level factors to study whether and how innovations are successful in marginalized versus privileged populations. The basis of D&I methodology involves the application of theories, models, and frameworks to approach research questions about whether, how, and why a particular evidence-based intervention is or could be integrated in practice in a particular context. Generally, theories include detailed *explanations* for how or why something

occurs, whereas models and frameworks are theory-based *descriptions* of processes/factors.³

There are over 100 discrete theories, models, and frameworks within the field of D&I.⁴ A small number of D&I theories, models, and frameworks were originally explicitly designed to focus on health equity.⁵⁻⁹ In recent years, there have been published articles discussing ways in which other theories, models, and frameworks not originally designed for equity research can be applied to this field.¹⁰⁻¹⁵ In Table 1, we have provided a few examples of appropriate ways to use D&I theories, models, and frameworks for equity considerations. An exhaustive discussion is beyond the scope of this article; readers are encouraged to review references cited and to explore freely-available online webtools¹⁶⁻²² for additional guidance. In the workshop, we reviewed select theories, models, and frameworks from D&I science, particularly addressing potential applications to health equity research.

Community Engagement and Qualitative Methods in Health Equity Research

Engagement with communities affected by health disparities is critical to optimally understand and mitigate those disparities to promote health equity. Community engagement in research is a continuum spanning a traditional academic-centered model of research – in which academics perform research *on* communities – to participatory models in which academics perform research *with* communities (i.e. community-based participatory research) or support research *by* communities (i.e. community-driven research).³⁰⁻³² Meaningful community engagement should include more than support from a community on recruitment. Ideally, communities should also

be engaged in developing the research question, determining research methods, analyzing and interpreting data, and/or disseminating results.³⁰⁻³² Community engagement, however, can be challenging given the need for the academic team to cultivate sustained relationships with communities despite academics and community members having both limited time and resources. Importantly, academics must demonstrate trustworthiness, particularly when working with communities that have experienced unethical or frankly abusive treatment from academic institutions in the past. Despite the importance of community engagement, a recent scoping review identified that only 0.4% percent of publications in high-impact neurology journals reported community engagement, and of those, only 18% included pediatric patients.³³

Qualitative research methods are particularly suitable for community engaged research. Qualitative methods can allow meaningful engagement with the perspectives of people with lived experience of health disparities.^{34,35} For instance, in-depth semi-structured interviews can be a method of elicitation and exploration of the experiences and viewpoints of such individuals.³⁶ Focus groups can allow different people from a community to exchange ideas, brainstorm, and provide mutual input. A focus group can sometimes be a more comfortable environment for sharing than an individual interview given the presence of others with a similar lived experience.³⁶ Notably, it is important for academics involved in qualitative research to perform reflexivity: to consider how their own background and experiences may influence their data collection practices and analysis.³⁶ Reflexivity is particularly important in health equity research. In addition to collecting information from people affected by disparities through qualitative methods, it

is also possible to engage people from affected communities in collaborative data analysis and interpretation of results using community engaged methods.³⁷

In the workshop, we introduced the concept of community engaged and qualitative research, and considered how these methods could be used to support and enhance ideas for future health equity research studies in pediatric neurology. An example would be co-design and co-leadership of a research study by an advisory board of parents of children with autism spectrum disorder who identify as Hispanic or Latino to interview similar families about experiences of discrimination in healthcare.

Recruitment of Representative Populations in Research Studies

Recruitment decisions are a critical determinant of equity in research, as early sampling shapes downstream discovery, generalizability, and implementation.³⁸ These considerations affect both clinical studies and preclinical research, in which models and biospecimens may not reflect the populations most affected by neurologic disease. Underrepresentation of rural populations, non–English-speaking participants, individuals with lower socioeconomic status, and racial, ethnic, and ancestrally minoritized groups leads to missed biological insights and an inequitable distribution of research benefits.³⁹⁻

⁴⁶ Early recruitment decisions shape both study outcomes and broader scientific impact.

During this session, representative recruitment was emphasized as being foundational to rigorous research. Participants discussed examples from their own fields, including genomic datasets dominated by European ancestry, clinical trials underrepresenting individuals with lower socioeconomic status or from rural regions, and natural history studies excluding families with languages other than English.

Additional examples included research conducted at academic referral institutions, rare disease registries skewed toward higher-resourced families, and induced pluripotent stem cells and fibroblast biobanks derived largely from individuals of European ancestry.⁴⁷ Similar gaps were noted in studies of environmental exposures and neurologic outcomes, where cohorts often underrepresent communities facing higher exposure burdens.

Participants were introduced to the National Institute on Minority Health and Health Disparities Research Framework and the National Institute of Neurological Disorders and Stroke Social Determinants of Health (SDOH) Framework as practical tools for examining recruitment through multilevel biological, behavioral, social, environmental, and healthcare system lenses.^{48,49} These frameworks were used to help investigators identify who is currently represented in their studies, which populations are systematically excluded, and where barriers to participation arise, recognizing that overlapping identities and local context often impact recruitment. A key message of the workshop was that health equity is not a standalone methodology but can be embedded within existing research approaches across the research lifecycle (Figure 1).

Participants applied these frameworks by mapping current recruitment practices, identifying gaps in representation, discussing strategies to expand access, and determining actionable steps. Guided discussion focused on who is recruited, which populations are underrepresented, potential sources of selection bias, and commonly used recruitment models (Table 2). Strategies generated by the group included community partnerships, culturally and linguistically tailored materials, interpreter services, flexible scheduling, reduction of logistical barriers, and equity-informed

eligibility criteria. Collectively, this session emphasized recruitment as an early and modifiable leverage point for advancing equity in pediatric neurology research.

Social Determinants of Health, Examples of Data Collection Tools and Indices Used in Research

SDOH are “the conditions in the environments where people are born, live, work, play, worship, and age that affect a wide range of health functioning and quality-of-life outcomes and risks.”⁵⁰ These are grouped across 5 domains: 1) education access and quality, 2) health care access and quality, 3) economic stability, 4) neighborhood and built environment, and 5) social and community context.⁵⁰ In neurology, there is increasing evidence that differences in SDOH affect neurological disease and outcomes and it is important to include SDOH factors not only in neurology research but also in thinking about health care outcomes for all children that we see as child neurologists.⁵¹ In the workshop, we highlighted examples of SDOH research in neurology (Table 3).

Several validated screening tools and resources are available for collecting SDOH data. Determining which one(s) to utilize would depend on various factors including study objectives and questions and study population. The National Institute on Minority Health and Health Disparities has created the PhenX Toolkit, which is a consensus toolbox of measures on SDOH across disciplines.⁵² The Protocol for Responding to and Assessing Patient’s Assets, Risks, and Experiences (PRAPARE) is another validated tool and is available in multiple languages. Although there is a licensing fee associated with the use of the tool, it may already be integrated and built into existing electronic health record systems.⁵³ Large publicly available datasets may

also be available to understand the association between SDOH and health outcomes. The Agency for Healthcare Research and Quality include datasets such as the Healthcare Cost and Utilization Project (HCUP) and the Medical Expenditure Panel Survey (MEPS).⁵⁴

There are also several examples of indices used in research that were discussed during the workshop that include the social vulnerability index (SVI), area deprivation index (ADI), social deprivation index (SDI), and childhood opportunity index (COI). The utilization of the different indices would depend on the overall study objectives, questions, study population, and data available for analysis.⁵⁵⁻⁶³

Lastly, we asked workshop participants to map out SDOH research resources at their respective institutions, with the goal of identifying at least 3 local resources. Questions asked were: 1) What institutional centers or departments at your hospital/university focus on health services research or population health? 2) Does your electronic health record system or central data warehouse capture social determinants of health? What other data sources might be available (e.g., research patient data registry, i2b2) 3) Are there partnerships with public health departments, community organizations, or local government that you could leverage? 4) Where could you find mentorship or collaborators for SDOH research at your institution?

Integrating health equity research into a research career

Conducting clinical research requires resources, which oftentimes can be challenging for individuals at the trainee and junior faculty level. Shifting funding priorities pose additional pressure points that may deter investigators from pursuing

research related to health equity. However, given the importance of understanding health disparities in the context of pediatric health outcomes, we identified three main strategies to pragmatically integrate health equity into clinical research particularly for early-stage investigators. These strategies include: 1) identifying institutional resources to minimize time and financial burdens, 2) diversifying research portfolios to build resilience in shifting funding climates, and 3) building robust support systems for academic advancement and expand research collaborations.

In our pilot education session, we outlined three exercises for the participants to consider that address each strategic focus (Table 4). The session was designed to include participants from different levels of training to provide various perspectives on the challenges and strategies to overcome those challenges. The first exercise asked participants to identify resources available at the individual's institutions that can integrate health equity concepts and methodologies into the research aims. Participants were asked to access their institutional websites and search for resources that would alleviate funding burdens and provide experience in research writing for individual investigators. These resources include grant writing courses, biostatistical support, early investigator career development programs, formal coursework or didactics on research methodologies geared toward post-doctoral audiences and clinicians, and community participatory research groups.

The second exercise asked the participants to list their current research projects and gauge whether there are opportunities to diversify and expand their existing work, including ways to collaborate with other researchers within or outside of the institution. Suggestions we asked the participants to consider were diversifying outside of

traditional clinical research, leveraging translational platforms or clinical trials, working with industry and patient advocacy groups on projects focused on patient-oriented outcomes, and minimizing individual research costs by leveraging existing research networks with infrastructural support, including longitudinal studies for age-matched controls.

As a group, we discussed the importance of maintaining funding to continue health equity work and considering various funding sources for different aspects of health equity. This includes developing patient-oriented, real-world pragmatic designs appropriate for Patient-Centered Outcomes Research (PCORI) and leveraging rare disease clinical research networks or disease-specific foundations that conduct multi-institutional clinical research. Lastly, we discussed the importance of developing resilience to adapt to changing research and geopolitical landscapes. In our third exercise, participants were asked to evaluate their overall support system, including work environment and mentorship. Participants were asked to write down peer, research, and career mentors who would provide guidance to support their research and academic careers. We recognize that identifying mentors can be challenging, especially in pediatric neurology health equity research and for those specializing in very niche fields. Participants were encouraged to think about individuals outside of their local institutions who could help ensure that their careers thrive. If they were unsure about how to approach individuals outside their institutions, we discussed strategies to build multi-institutional partnerships and attend national workshops and networking events to build cross-disciplinary collaborations.

When considering personal resilience, trainee, junior and late-career faculty level participants in the group discussed shifting and reframing pediatric health equity research to appeal to broader audiences. Early-stage investigators were encouraged to consider their unique positions as pediatric neurologists to emphasize the importance of investing in pediatric health to support the growth and development of children, and appeal to the commonality of improving health outcomes for all.

Evaluation of the Workshop

All five topics above were provided in a workshop format. The workshop was attended by 46 individuals. The University of North Carolina Institutional Review Board determined our survey-based evaluation of the workshop to be Not Human Subjects research.

Twenty-three individuals completed a survey evaluating the workshop. Participant training level ranged from medical school to late career, and the level of prior proficiency and exposure to health equity research varied, although no participants reported having significant prior experience (Table 5). A majority of participants were 'Interested but didn't have a lot of experience' at 65% of attendees. This indicates that the workshop goals aligned with that of the attendees, which was the aim of the session.

Prior to the start of the workshop, participants completed a pre-survey, rating their confidence, knowledge, and proficiency in specific topics of health equity research. Topics were based on dissemination and implementation (D&I) science, health equity frameworks, SDOH variables, qualitative and mixed methods approaches, recruitment

and representation, current challenges, and local institutional and peer resources. All eight questions had larger percentages of ratings with lower confidence or knowledge in each of the topic areas on the pre-survey (ratings of 1 or 2 on a 5-point Likert scale, Figure 2).

Sessions on applying D&I frameworks, data analysis and interpretation, methods, and recruitment were rated in the post-survey as “extremely helpful” or “somewhat helpful” by 58-63% of participants. The session on Integrating Health Equity Research into a Research Career was rated “extremely helpful” or “somewhat helpful” by 50% of participants. Quotes were sampled regarding the most valuable learning from the session: participants commented on appreciating the provision of resources (such as handouts, the shared google drive, and the SDOH indexes); others commented on the change in perspective provided “opening my mind to new perspectives.” Participants commented on the possible application of this into their research, stating they might consider “questions before generating data and approaches” and “Ideas for implementing this in my basic science research to enhance care for DEI communities.” One participant appreciated the sense of community - “that I’m not alone!” The most common suggestion for improvement was that one hour was insufficient time to sufficiently address the complex topic of health equity research in pediatric neurology.

Discussion

Herein we describe the development, implementation, and preliminary evaluation of a structured educational workshop designed to equip child neurologists with tools to integrate health equity into research. There is a critical gap in formal training on equity-

focused research design, recruitment, and implementation strategies within neurology.⁴⁹

The workshop sought to address that gap by introducing practical frameworks, community-engaged approaches, recruitment strategies, data evaluation methods, and career-development considerations applicable across a broad range of research contexts.

Importantly, the relevance of these concepts extends beyond academic referral centers. Advancing health equity in pediatric neurology requires deliberate dissemination of research principles and findings to community-based practices and under-resourced settings, where many children receive care and where disparities are often most pronounced.^{49,64} Broadening the dissemination of equity-informed research methods is essential to ensure that scientific advances translate into meaningful outcomes for all children, regardless of geography or access to specialty centers.

Evaluation data from this pilot session suggest that participants found the content valuable, particularly given limited prior exposure to health equity research methodologies. Feedback underscored the need for accessible, cross-disciplinary educational opportunities in pediatric neurology. Participant feedback also highlighted the importance of practical tools, concrete examples, and peer discussion in fostering confidence and reducing isolation among investigators interested in equity-focused work. These findings align with prior studies focusing on incorporating health equity domains into neurological research.⁶⁴⁻⁶⁶ Results suggest that targeted training increases investigators' understanding of and confidence in nontraditional research methods, including qualitative, implementation, equity-informed, and community-engaged approaches.

A key message of the workshop was that health equity research is not a siloed discipline. Rather, equity principles can be intentionally integrated into both qualitative and quantitative research across the research lifecycle. Participants were encouraged to move beyond traditional, often implicit assumptions in pediatric neurology research by mapping their own studies onto established frameworks and identifying overlooked domains. This approach emphasized reflexivity and adaptability rather than traditional solutions, highlighting factors such as geography, language, social context, and structural barriers that meaningfully shape health outcomes. This reframing is particularly relevant in pediatric neurology, where disease rarity, developmental considerations, and caregiver burden can amplify inequities in research participation.

Several limitations should be acknowledged. This was a single-session workshop conducted at a national meeting with a modest number of participants, and evaluation relied on self-reported measures rather than objective changes in research practices. Additionally, participants self-selected to attend a health equity-focused session, which may limit generalizability. The limitation of a one-hour session did not allow in-depth discussions within each topic, which limited the dissemination of information. Nonetheless, these findings provide early evidence that targeted, framework-based education is both feasible and well-received within the pediatric neurology community.

Future directions include scaling this content beyond a single workshop. The workshop model could be adapted into a modular educational resource or virtual curriculum that investigators can reference when designing studies or initiatives, enabling equity considerations to be incorporated from the outset rather than retrospectively. Integration into pediatric neurology training programs, research

curricula, and national platforms may standardize equity-informed approaches as foundational components of rigorous research. Cross-disciplinary collaboration will be essential to this effort, drawing on expertise from implementation science, qualitative research, public health, and community engagement.

In response to the need for sustained mentorship and peer support in this area, we have initiated a national working group, QUICKER (Qualitative, Implementation, Community-engaged, and Knowledge translation Research), comprising pediatric neurology faculty from multiple institutions. This group aims to provide a collaborative forum for researchers interested in nontraditional and equity-focused methodologies, supporting skill development, mentorship, and shared learning. Such efforts may help build durable expertise and research capacity in health equity within pediatric neurology.

In conclusion, this workshop demonstrates a practical and scalable approach to advancing health equity education in pediatric neurology. We provide a foundation for developing a durable research workforce equipped to address inequities and improve neurologic outcomes for all children.

Declaration of conflicting interest: The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding statement: The author(s) received no financial support for the research, authorship, and/or publication of this article.

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