Starting Early: A Life-Course Perspective on Child Health Disparities—Research Recommendations

AUTHORS: DC Baltimore Research Center on Child Health Disparities Writing Group

ABBREVIATION

IOM—Institute of Medicine

The views and recommendations presented in the articles in this volume are those of the authors and participants and not intended to represent those of the organizations with which they are affiliated, the American Academy of Pediatrics, or the funders of the conference or research.

www.pediatrics.org/cgi/doi/10.1542/peds.2009-11000

doi:10.1542/peds.2009-11000

Accepted for publication Jul 20, 2009

Address correspondence to Ivor B. Horn, MD, MPH. E-mail: ihorn@cnmc.org

PEDIATRICS (ISSN Numbers: Print, 0031-4005; Online, 1098-4275).

FINANCIAL DISCLOSURE: *The authors have indicated they have no financial relationships relevant to this article to disclose.*

The future health and well-being of America is linked to how successfully we manage the health and well-being of today's children. In this report we review recommendations for a research agenda on the disparities that affect the health and opportunities of many children and contribute to suboptimal health in adulthood.

On November 6–7, 2008, a multidisciplinary group of 70 researchers, practitioners, and funders gathered in Washington, DC, to develop this research agenda for eliminating child health disparities. The meeting focused on disparities, defined as "differences in health, health care, and developmental outcomes, particularly among racial and ethnic minority groups." Led by the DC-Baltimore Research Center on Child Health Disparities, a collaboration of Howard University, Johns Hopkins University, and Children's National Medical Center, the conference was sponsored by the National Center on Minority Health and Health Disparities, Eunice Kennedy Shriver National Institute of Child Health and Human Development, American Academy of Pediatrics, Agency for Healthcare Quality and Research, The Commonwealth Fund, Academic Pediatric Association, Lucile Packard Foundation for Children's Health, and Robert Wood Johnson Foundation.

The multidisciplinary conference planning committee reviewed existing health disparities reports and, in consensus building of expert opinion, chose 9 topic areas to be discussed in 2 conference panels on conceptualization of child health disparities and solving child health disparities. Nine articles were commissioned and briefly presented at the conference with time for discussion and development of a research action agenda. The 9 articles, discussant comments, and final conference recommendations make up this supplement to *Pediatrics*.

In this summary article, we discuss our overarching definition and conceptualization of "health disparities," which we believe should inform future research. We also discuss 2 useful models that informed the conference and provide recommendations regarding the scope, content, and methods of child health disparities research. Finally, we present recommendations regarding the infrastructure required to conduct this research, including training and funding.

Demographic Trends in the United States

Much more is understood about the state of child health disparities today than in 2003, when the Institute of Medicine (IOM) released *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*.[1] Nonetheless, significant work remains to be done, particularly when we contrast the knowledge of child health disparities with our knowledge of disparities in adult health. The reasons for this contrast are many, but the consequences of not conducting the research re-

quired to better understand and ameliorate child health disparities do not bode well for our nation.

Throughout this article, we frequently refer to race and ethnicity; therefore, we briefly present here the context in which we use these terms. Growing literature suggests that race and ethnicity are a sociocultural category with little or no inherent biological or physiologic meaning, although people are often sorted into these categories on the basis of vague phenotypic criteria.[1–3] The sociocultural definition of race and ethnicity differs across time and place but is often the basis for differential treatment, including limited access to resources and power, that can have dramatic and adverse effects on health.[4]

Considerable heterogeneity exists both within and between the racial minority groups in the United States. Nonetheless, the data on these groups make apparent the many ways in which socioeconomic adversity is admixed with "minority" racial status in this country. Taken together, minority status and decreased access to socioeconomic resources can create profound social disadvantage that is expressed in health disparities.

Demographic trends in the US population provide a backdrop for our consideration of child health disparities. In 2007, the United States had almost 74 million children, representing ~24% of the population; this number was projected to increase to 80 million by 2020.[5] As the ratio of children to adults has declined since the 1960s, the racial and ethnic diversity of children in the United States has increased significantly. In 2007, 57% of children were non-Hispanic white compared with 74% in the 1980s.[5] By 2050, it is estimated that 62% of America's children will be ethnic minorities compared with 44% currently.[6] Furthermore, 55% of the working-age population (18–64 years) is projected to be minority in 2050 (up from 34% in 2008).[6] A significantly greater portion of minority children than non-Hispanic white children live in poverty. For example, in 2006, whereas only 10% of non-Hispanic white children lived in poverty, 27% of black and 33% of Hispanic children bore this burden.[5] Racial and ethnic minorities are disproportionately represented among the socially and economically disadvantaged.

Previous Disparities Reports

There is growing scientific and popular consensus regarding the existence and importance of racial and ethnic health disparities, as well as diverse efforts to address and ameliorate them. These efforts include publication of the ground-breaking 2003 IOM report on health care disparities[1] and the subsequent IOM roundtable discussions in 2007,[7] national health care disparities reports from the Agency for Healthcare Quality and Research,[8] and the Finding Answers program supported by the Robert Wood Johnson Foundation.

Although this work has been informative, significant limitations exist in understanding and addressing child health disparities. First, fewer discussions have focused on health disparities in children than in adults. Notably, the original IOM report made little mention of pediatric issues. Second, and perhaps more importantly, when child health issues have been raised as part of the discussion of disparities, the approach is usually disease oriented and categorical (focused on disparities in a condition such as asthma or immunization rates). This approach overlooks the fundamental ways in which disparities are created and may be sustained over the life course and transgenerationally. Equally important, it does not incorporate the unique health characteristics of children that differentiate them from adults, and it ignores reciprocal impact of adult and child health disparities,[9] which collectively limit life chances and burden families. For example, high rates of childhood asthma morbidity mean that adult caretakers take time off work, experience sleep disruptions, divert family resources into medical care, and experience additional sources of anxiety. Similarly, when adults carry heavy burdens of chronic disease, such as type 2 diabetes and early stroke, their ability to be effective parents and grandparents becomes constrained by their own health limitations. Finally, the focus on disease and diagnosis (or even on prevention) tends to minimize the importance of broad social forces and socioeconomic disadvantage, factors that are beyond the often-limited biomedical focus. This narrow focus necessarily constrains our consideration of opportunities for intervention.

CONFERENCE RECOMMENDATIONS

First, we discuss our overarching definition and conceptualization of health disparities, which we believe should inform future research. Second, we discuss 2 useful models that informed the conference and our recommendations. Third, on the basis of this understanding of health disparities, we provide recommendations regarding the scope, content, and methods of child health disparities research. Finally, we present conference recommendations regarding the infrastructure required to conduct this research, including training and funding.

Defining and Conceptualizing Health Disparities

Several definitions of health disparities exist in the literature; however, the majority of definitions are adult oriented and approach child health disparities by using a similar framework. However, previous literature has made a cogent argument that child health is unique and

distinct from that of adult health and that research on child health should incorporate this perspective.[9,10] Consequently, adapted from the Eunice Kennedy Shriver National Institute of Child Health and Human Development, the working definition of health disparities for the conference was "significant differences in health, health care, or developmental outcomes, particularly among racial and ethnic groups."[11] However, through the work of the conference, participants proposed broadening the definition to incorporate the issues listed below. We believe that these issues should inform future research:

1. Health disparities should be defined not simply as a difference but an inequitable difference that is potentially systematic and avoidable.
2. Health disparities research should involve consideration of life chances, opportunity and risk, and quality of life in a way that includes psychosocial and socioeconomic perspectives, as well as more traditional attention to health status and the provision of health care.
3. Health disparities should be defined, investigated, and ameliorated on the basis of race and ethnicity, socioeconomic status, generation, and geography, as well as their complex interactions.
4. Health disparities within groups characterized by specific racial, ethnic, and/or socioeconomic characteristics require careful consideration and could be an important tool for identifying resiliency factors.

Appropriate Conceptual Models for Understanding Child Health Disparities

Most existing health disparities frameworks approach inequities with an adult focus and make the assumption that child inequities follow a similar paradigm. However, Horn and Beal[10] have argued that a child-specific framework is needed when investigating child health disparities. A developmental or life-course model and an ecological model provide cogent paradigms for understanding the precursors of health outcomes and disparities that occur in childhood. The conference organizers chose the life-course framework as a source of guidance for the conference to move beyond disease-oriented and cross-sectional approaches to child health disparities. This model emphasizes the development of disparities across the continuum of childhood, adolescence, and adulthood. Although there continues to be debate and discussion regarding the evidence for, and value of, this approach, it provides a method for considering the many transgenerational and developmental processes that produce and sustain social disadvantage and health disparities.

In addition, we recognize the need for an ecological perspective that encompasses the diverse and far-reaching biological and social systems and interactions within which disparities are produced and sustained. Whereas the life-course model draws attention to developmental and transgenerational perspectives, the ecological model focuses on appreciating the complex environmental and extraindividual factors present at every point in time. In this way, these models are complementary. The conceptual model presented in *Children's Health, the Nation's Wealth: Assessing and Improving Child Health*,[12] an IOM report, incorporates these models. Although neither the life-course nor the ecological model should be considered deterministic or preclude the use of other relevant models, we generally recommend that these models inform future investigations of child health disparities.

Future Research on Child Health Disparities: Scope, Content, and Methods

Scope

We call for translational research that addresses the need for new mechanistic insights, interventions, and approaches for making established interventions available to everyone. Disparities research has been regarded too often as the domain of psychosocial and behavioral investigators, who are typically rooted in a public health perspective. It is our view that basic, clinical, health-services, and community research are all needed to adequately understand and eliminate child health disparities. This research will identify:

1. Factors that create and sustain child health disparities: biological, environmental, and psychosocial exposures, as well as their complex interactions, all of which require investigation.
2. Ways in which such disparities affect the health and well-being of children, which includes carefully describing the magnitude of health disparities, identifying naturally occurring differences in response to risk factors, and tracking the effects of health disparities over time and across generations.
3. Optimal methods for preventing, addressing, or eliminating child health disparities, which must include dissemination and implementation research that translates science to health care–delivery systems, practice, and policy; such research should also incorporate quality improvement approaches.

Content

It is not our intention to constrain child health disparities research, and the recommendations below are not meant to be exclusive. Rather, they

identify areas of emphasis that merit special consideration. We recommend that, collectively, child health-disparities research:

1. incorporate multiple disciplines and perspectives;
2. include etiologic, descriptive, and intervention investigations (eg, more intervention research is needed that incorporates community engagement and uses randomized, controlled trials and other designs);
3. document biological, psychosocial, and environmental factors that mediate health outcomes across vulnerable populations;
4. investigate intrapersonal, family, and community factors that moderate or ameliorate the deleterious effects of risk factors on child health (eg, resiliency);
5. investigate critical or sensitive periods for interventions that are specific to particular risks in particular outcomes;
6. study the interrelated effects of disparities in health and education as they affect children's lives;
7. explore the contribution to child health disparities of racial discrimination at the personal, interpersonal, and institutional levels;
8. explore the contribution of self-perception (eg, racial identity and socioeconomic status identity) to child health disparities;
9. investigate the mediating and moderating effects of acculturation and immigration status on child health outcomes; and
10. determine if and how clinician cultural competency and linguistic competency influence health care quality and health disparities.

Methods

Methodologic rigor and innovation are both required to advance health-disparities research generally and child health disparities research specifically. Methodologic issues in research on child health disparities include the need to:

1. ensure greater rigor and consistency in metrics for race and ethnicity, socioeconomic status, education, generation, and geography;
2. create or make available measures that are developed and/or validated in diverse groups and across languages;
3. create developmentally appropriate measures for children, including child self-report measures;
4. disaggregate traditional census categories to include more specific racial and ethnic groups and mixed-race categories as well as data on immigrant status and generation;
5. develop intermediary measures of predictors, mediators, and outcomes;
6. include health information technology and systematic data collection;
7. improve documentation of where vulnerable (at-risk) children receive health services and the care they are receiving;
8. incorporate mixed (qualitative and quantitative) methods into child health disparities research; and
9. make better use of existing health data collections by developing new ways to make sensitive data (eg, geographic location) available for research as much of what is known about the effects of recent expansions of health insurance for children through Medicaid and/or the State Children's Health Insurance Program has been learned because state identifiers in the National Health Interview Survey allow researchers to determine which policies cover children in different states and time periods.

Research Infrastructure

Conference attendees also developed recommendations concerning the infrastructure support required for effective child health disparities research. The critical infrastructure elements they identified were training an effective and diverse scientific workforce and ensuring funding for this underappreciated area of investigation.

Specifically, we recommend the development, implementation, or increased investment in:

1. broad training in child health disparities, which should incorporate the various disciplines of medicine and allied health across the life span, as well as the social sciences (such as sociology, psychology, and political science), public health, education, economics, and policy analysis;
2. funding and technical assistance to support this training, including support through research career-development awards;
3. programs to strengthen child health research and practice workforce diversity;
4. requests for applications from the National Institutes of Health and other agencies and foundations that address these research recommendations (reviewers should recognize the value of child health-disparities research and the developmental and life-course approaches); and
5. methods for incorporating child health disparities research into established infrastructural support for pediatric research (such as the National Children's Study, Intellectual and Developmental Disabilities

Research Centers, and Pediatric Research in Office Settings), including support for efforts to enhance recruitment of practices that serve racial and ethnic minority populations from diverse socioeconomic backgrounds.

CONCLUSIONS

Improving the health of all children is not only a social priority in its own right but is also essential for ensuring the future health of our nation. This conference was designed to shape the research agenda for child health disparities, recognize the importance of child health disparities in the life course, and maximize our opportunities for eliminating health disparities.

CONFERENCE ORGANIZERS

Tina L. Cheng, MD, MPH, FAAP
Renée Jenkins, MD, FAAP

WRITING GROUP

*Ivor B. Horn, MD, MPH, FAAP
Denice Cora-Bramble, MD, MBA, FAAP
Tina L. Cheng, MD, MPH, FAAP
Renée Jenkins, MD, FAAP
Lee Pachter, DO, FAAP
Jill Joseph, MD, PhD

STAFF

Debby Berlyne, PhD
Angela Gaskin, MA
Maura Gaughan
Regina Shaefer, MPH

*Lead author

REFERENCES

1. Smedley B, Stith A, Nelson A. *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*. Washington, DC: National Academies Press; 2003
2. Lewontin R, Rose S, Kamin L. *Not in Our Genes: Biology, Ideology and Human Nature*. New York, NY: Pantheon Books; 1984
3. Senio P, Bhopal R. Ethnicity as a variable in epidemiological research. *BMJ*. 1994; 309(6950):327–330
4. Williams D, Lavizzo-Mourey R, Warren R. The concept of race and health status in America. *Public Health Rep*. 1994;109(1): 26–41
5. Federal Interagency Forum on Child and Family Statistics. *America's Children in Brief: Key National Indicators of Well Being*. Washington, DC: US Government Printing Office; 2008
6. US Census Bureau. 2008 national population projections. Available at: www.census.gov/population/www/projections/2008projections.html. Accessed February 9, 2009
7. Institute of Medicine. *Challenges and Successes in Reducing Health Disparities: Workshop Summary—Roundtable on Health Disparities*. Washington, DC: National Academies Press; 2008
8. Agency for Healthcare Research and Quality. *2007 National Healthcare Disparities Report*. Rockville, MD: Agency for Healthcare and Quality; 2008. AHRQ publication No. 08-0041
9. Forrest C, Simpson L, Clancy C. Child health services research: challenges and opportunities. *JAMA*. 1997;277(22):1787–1793
10. Horn IB, Beal AC. Child health disparities: framing a research agenda. *Ambul Pediatr*. 2004;4(4):269–275
11. National Center for Child Health and Health Development. *From Cells to Selves: Health Disparities—Bridging the Gap*. Washington, DC: US Department of Health and Human Services; 2000
12. Committee on Evaluation of Children's Health; Board on Children, Youth, and Families; Division of Behavioral and Social Sciences and Education; National Research Council and Institute of Medicine. *Children's Health, the Nation's Wealth: Assessing and Improving Child Health*. Washington, DC: National Academies Press; 2004

Starting Early: A Life-Course Perspective on Child Health Disparities—Research Recommendations

DC Baltimore Research Center on Child Health Disparities Writing Group

Pediatrics 2009;124;S257
DOI: 10.1542/peds.2009-1100O

PEDIATRICS®
OFFICIAL JOURNAL OF THE AMERICAN ACADEMY OF PEDIATRICS

Starting Early: A Life-Course Perspective on Child Health Disparities—Research Recommendations

DC Baltimore Research Center on Child Health Disparities Writing Group

Pediatrics 2009;124;S257
DOI: 10.1542/peds.2009-1100O