

Discussion Paper

Why the United States Needs a National Birth Cohort Study

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About This Paper

This paper is part of the National Academy of Medicine Perspectives series, *Lifelong Impact: Why the United States Needs a National Birth Cohort Study*. To download both papers in the series, visit www.nam.edu/lifelonghealth.

Background: With funding from the Robert Wood Johnson Foundation, the National Academy of Medicine (NAM) and the Division of Behavioral and Social Sciences and Education of the National Academies of Sciences, Engineering, and Medicine held two expert meetings to identify the reason why the U.S. needs a longitudinal birth cohort study and the methods that can be used to make its implementation successful. The meetings drew on the National Research Council/Institute of Medicine report *The National Children's Study 2014: An Assessment*. In addition to engaging a diverse array of stakeholders from academia, philanthropy, local communities, industry, and government, the meetings included discussions about how to design a national longitudinal cohort study that is multidisciplinary, focuses on the main drivers of health, engages communities, employs a diverse set of data sources, and includes innovative techniques in data analysis. Discussions included how to use the findings from such a study to improve and direct resources toward improvements in the drivers of health.

The final product of this effort is *Lifelong Impact: Why the United States Needs a National Birth Cohort Study*, a two-paper NAM Perspectives series. The goal of the series is to provide input into and catalyze action toward improvements in the design of future longitudinal birth cohort studies.

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Why the United States Needs a National Birth Cohort Study

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In a list of 17 high-income countries, the United States ranks last in terms of life expectancy for males and second-to-last for females. The U.S. population also experiences worse outcomes compared with its peers in nine key areas: infant mortality and low birth weight; injuries and homicides; adolescent pregnancy and sexually transmitted infections; HIV and AIDS; drug-related deaths; obesity and diabetes; heart disease; chronic lung disease; and disability (NRC/IOM, 2013). In addition, the United States sees persistent racial, ethnic, socioeconomic, and geographic disparities in health (IOM, 2012).

Why does the United States fare so poorly compared with its peers? There are many possible reasons, ranging from adverse economic and social conditions to individual behaviors and environmental factors. For example, we know that people often have difficulty accessing or affording care in the United States; and the U.S. population has higher rates of risky health-related behaviors, such as alcohol use, injuries, and unprotected sex. The United States also sees greater income inequality, less social mobility, fewer family supports, and higher rates of poverty—especially child poverty—than its peers. Finally, elements of the built environment, such as inadequate public transportation infrastructure, may discourage physical activity and contribute to high obesity levels (NRC/IOM, 2013).

Each of these factors helps to explain the relatively poor health of the U.S. population, but none presents a complete picture. Many questions remain. For instance, why do nonsmoking Americans who maintain a healthy weight still experience higher rates of some diseases than their peers in other high-income countries? (NRC/IOM, 2013). This question is difficult to answer, because we don't know how individual behaviors combine with the vast multitude of social, economic, and environmental influences to affect health across a person's life span. Most existing population health studies are narrow in focus—examining a single population group, a limited number of environmental factors, or a single stage of human development. There is only one way to get a more complete picture: a nationally representative birth cohort study that begins prenatally and lasts throughout adulthood.

Without the comprehensive, longitudinal data provided by such a study, it will be difficult to identify and make wise investments in policies that will promote health at the individual, community, and societal levels. In short, a national birth cohort study is essential for developing evidence-based policies that are capable of improving the United States' international health standing—and ensuring that every member of the U.S. population has an equal opportunity to thrive.

In this paper, we explain the unique benefits of such a study and outline three elements that are essential to produce the kind of comprehensive, cross-cutting data we need to build sound policies: (1) that the study is nationally representative; (2) that it begins before birth and continues through adulthood; and (3) that it explores a range of environmental influences on health and well-being, both harmful and protective.

THE CHILDREN'S HEALTH ACT OF 2000 AND CURRENT RESEARCH INITIATIVES

In 1999, the President's Task Force on Environmental Health Risks and Safety Risks to Children concluded that a large study to understand the association between environmental

exposures and children's health was essential (NICHD, 2016). Following the task force, the U.S. Congress recognized the need for a national study to examine environmental influences on children's health and development. In a bipartisan effort, Congress passed the Children's Health Act of 2000, mandating a national study of children's health, well-being, and development until age 21. This act authorized the National Children's Study (NCS). The NCS was intended to be a birth cohort study that would follow a nationally representative cohort until the age of 21. The study was led by the National Institutes of Health (NIH) with a program office run out of the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD). A pilot study began in 2009 in seven locations and was later expanded to include 33 additional locations.

In 2013, Congress mandated that the National Research Council (NRC) and the Institute of Medicine (IOM) review the design of the NCS Main Study. The NRC/IOM report stated that the NCS had great potential to add to our knowledge about the impact of environment on health, but criticized its scientific oversight and leadership (NRC/IOM, 2014). Following the release of this report in 2014, Francis Collins, director of the NIH, formed an advisory committee that further reviewed the NCS. Following recommendations of this advisory committee, the NCS was shut down (NIH, 2014).

Given the unfortunate outcome of the NCS, it is important to note that both the NRC/IOM report and the report of the NIH advisory committee state that the NCS had laudable and important goals. The NRC/IOM report also supported two design features: the NCS's proposed use of a probability sample¹ and the recruitment of women prenatally (NRC/IOM, 2014).

Although the NCS was halted, numerous other pediatric research efforts continue. The National Institute of Environmental Health Sciences and the Environmental Protection Agency (EPA) have been studying children's health through the Children's Environmental Health and Disease Prevention Research Centers since 1998. Research from these centers has increased our understanding of the impact of the physical chemical environment on child health and development. In addition, the NIH has formed several children's health efforts, such as the Nulliparous Pregnancy Outcomes Study (NuMom2B) (begun in 2010), the Centers of Excellence on Environmental Health Disparities Research (grants awarded in 2014), and two major efforts in 2015 and 2016: CHEAR (Children's Health Exposure Analysis Resource) and ECHO (Environmental Influences on Child Health Outcomes).

CHEAR is designed to provide extramural researchers access to a laboratory and data resources to expand knowledge on environmental exposures through a National Exposure Assessment Laboratory Network; a Data Repository, Analysis and Science Center (a data and analytics support resource serving as a repository for all data and providing support for statistical analysis and interpretation); and a Coordinating Center (a center for administrative management). The goal of ECHO is essentially to create a synthetic cohort out of existing cohorts already being studied in the United States. The focus of ECHO is on key outcomes associated with early life exposures, where early life is defined as the period from preconception to age 5. The synthetic cohort created by ECHO will contain early life exposure data and include information on key outcomes such as upper- and/or lower-airway function (e.g., asthma, allergies, and sleep-disordered breathing); obesity (e.g., nutrition, metabolic risk factors, and activity level); pre-, peri, and post-natal outcomes (e.g., birth defects, prematurity, and neonatal/infant mortality); and neurodevelopment (e.g., attention, cognition, emotion, and social/language/behavioral development).

¹ A probability sample selects a random sample of individuals to represent a larger number of individuals, such as the U.S. population. In probability sampling, every individual has a known, non-zero chance of selection in that sample. Therefore, the results of a national probability sample can be extrapolated to the entire population from which the sample was selected. Confidence intervals for estimates generated from the national probability sampling can be computed.

CHEAR and ECHO have great potential for addressing scientific questions about factors associated with increases in chronic diseases in children. However, because ECHO will be built around existing cohorts, it will not address social, physical, nutritional, and chemical exposures in ways that reflect the different experiences and exposures of families and children in diverse cultures across the nation. As a consequence, inferences based on the study will not generalize as readily as those that would be generated by a study with a national probability sample frame.

Only a nationally representative birth cohort study that begins prenatally and continues into adulthood will provide a data infrastructure capable of identifying the “drivers” of health and development and informing solutions, or “levers,” that can be activated to support better health and development, not only during the early years, but throughout the life course. Moreover, in order to calculate representative rates of exposures and levels of health and disease, and to understand the distribution of certain environments, this study should start from a national probability sample that properly represents cultural, racial, and ethnic subgroups in the United States.

A well-designed probability sample will not only support the estimation of descriptive statistics, but will also support inferences about drivers of children’s health and well-being (Michael and O’Muircheartaigh, 2008), thereby shedding light on the causes of current disparities. Only a probability sample can provide nationally representative depictions of the environments in which children grow and develop across our nation’s geographic regions and cultures. This broad sample of environments will add to our understanding of inequities in access to environments that support health and well-being and allow investigation into potential pathways to support positive health and development.

THREE ESSENTIAL QUESTIONS THAT CAN BE ANSWERED BY A NATIONAL BIRTH COHORT STUDY

Research that seeks to understand only one outcome—for example, how children develop medical conditions or why they fail in school—will not provide a comprehensive evidence base to develop policies that support a healthy, safe, and thriving U.S. population. Moreover, to inform investment and policy decisions, it is necessary to move beyond an incomplete understanding of health as simply the absence of disease to include outcomes that encompass positive development and well-being.

Answers to the following three cross-cutting questions are critical to understanding factors that affect health, development, and well-being through the life course. To help answer them, we must have a diverse, nationally representative birth cohort study starting prenatally.

1. What explains the disparities in health and well-being in the United States?
2. What are the drivers of health and well-being from the prenatal, infancy, and early childhood periods of development through adolescence and early adulthood?
3. How do the social, family, physical, nutritional, chemical, and digital environments together influence health and well-being across the life course?

What Explains the Disparities in Health and Well-Being in the United States?

Because many health outcomes vary by socioeconomic status, ethnicity, race, and geography, it is imperative to study a full range of individuals across this increasingly diverse nation. Although health disparities by race, ethnicity, and income have been well characterized by past research, our nation has been changing in terms of its ethnic and racial make-up, as well as

trends in family configuration. For example, the proportion of Non-Hispanic Whites in the U.S. population has declined substantially, from 84 percent in 1970 to 62 percent in 2015 (NASEM, 2015). This is in part due to the fast-growing representation of immigrants; today, one out of four people in the United States is either a first- or a second-generation immigrant. As of 2009, Asian immigrants have surpassed Latinos as the largest group emigrating to the United States, and both groups are growing faster than the Non-Hispanic White population (NASEM, 2015). These rapid changes mean existing research may no longer represent the current U.S. population.

The socially organized systems into which children are born and develop are also important contributors to disparities in health and well-being. These systems drive options for where and how families live, the work parents can do, and the schools children attend. Past studies of these social forces may be less relevant today, as shifts in sociocultural forces have led to more nuanced practices and markers of identity, especially among younger generations, while sociopolitical forces have reconfigured processes of power and marginalization. Rapid sociodemographic shifts, such as a reduction in marriage rates, even among couples with children, and the legalization of same-sex marriage, have already and will continue to create changes in families and their access to benefits associated with marriage. A nationally representative cohort study would allow us to examine in more nuanced and innovative ways the forces and processes of marginalization that lead to social inequities in health and development. This is particularly important to account for processes and forces that produce inequalities associated with race, gender, immigration, class, sexuality, and dis/ability (e.g., Dixon-Román, in press; Suarez-Orozco, et al., 2015).

Finally, it has recently become clear that health disparities encompass far more than access to care and health-promoting environments. Recent epigenetic studies showing differing amounts of DNA methylation and haplotypes by race, economic status, and stressful life events provide evidence that environmental factors actually impact how genes are expressed (Olden et al., 2014). This provides biological evidence for “embodiment” theories that argue that adverse events, including experiences of marginalization, “get under the skin” via neurochemical and physiological processes (Bourdieu, 1977; Gravlee, 2009; Krieger, 2005; Wynter, 2001). Growing research has demonstrated empirically the myriad ways in which negative social experiences—such as child abuse; domestic violence; racism and discrimination; sexism; unemployment; financial stress; lack of health insurance; and residing in communities that are segregated by race or class or lack supermarkets, have a high incidence of gun violence, or have high levels of environmental contaminants—materialize in neurobiological processes of the body. Only through a longitudinal study can we fully understand the ways in which social forces like these become incorporated into a person’s health over time.

What Are the Drivers of Health and Well-Being from the Prenatal, Infancy, and Early Childhood Periods of Development Through Adolescence and Early Adulthood?

Health and development each builds on themselves; each period of development lays the foundation for the next (Halfon and Hochstein, 2002). This is important when it comes to understanding the drivers of health within a population. Even though the impacts of early exposures may not be evident for years or decades, they have consequences—not just in terms of life expectancy, disease, and disability but also for cognition, self-concept, emotional functioning, behavior, and school and work performance. Thus, early life growth and development creates the basis for lifelong health. But health is not static. As children move through the life course, they engage, make choices about, and potentially influence their environments as well as being influenced by them.

Although family, peers, and school influences are the most powerful shapers of development (Bronfenbrenner and Morris, 2006), these influences are themselves shaped by

social forces, including experiences of discrimination and marginalization over time. This interplay influences not only the development of physical health, but also behavioral and mental health, which are particularly important given that disorders across these dimensions are the leading causes of disease burden in the United States (Kyu et al., 2016). The effects of cumulative positive and negative exposures across the life course, as well as how certain types of exposures cascade to produce novel outcomes, can only be captured in a birth cohort study. Psychological assessments that can be generalized to real-life settings will reflect health and well-being in terms of a dynamic, emergent, continually changing set of indicators of adaptive functioning and development that is profoundly shaped by interactions within families in their proximal environments—which, in turn, expand as children mature to include schools and neighborhoods, all of which are further shaped by sociocultural, economic, and policy environments.

The United States continues to have one of the highest rates of infant mortality among developed nations; it is ranked number 32 out of 41 countries monitored by the World Bank (OECD, 2013). Much infant mortality is accounted for by preterm birth, which increased by 11 percent in the United States from 1990 to 2011 (OECD, 2013). Premature birth and infant mortality can only be understood fully by studying a diverse sample of women during, and even before, pregnancy. Moreover, neurodevelopmental disorders, such as autism spectrum disorder and attention deficit hyperactivity disorder, as well as asthma and obesity, are likely to be best understood by studying the prenatal period of development. This is because the foundation for all regulatory systems—neural, cognitive, cardiovascular, and immune—has its basis during gestation and the first years of life (Etzel and Landrigan, 2014). An in-depth study of these fundamental regulatory processes will not be possible in studies that begin after, rather than before, birth.

In order to identify health drivers across the life course, it is essential to measure development across different life stages with appropriate psychosocial measurements of health and well-being, relationships, and other aspects of the environment. Although the validity of any particular measure may be limited to a specific age range, there are key age-limited indicators that are known to be associated with health and well-being (e.g., quality of attachment relationships with caregivers; quality of early childcare settings and housing; residential and school mobility; maternal post-partum depression; and pubertal timing). All layers of the social environment—from the family to the community and the society in which we live—have impact on health and development across the life course (Bronfenbrenner, 1979; Bronfenbrenner and Morris, 2006; Elder et al., 2003).

These observations underscore our assertion that to understand the drivers of health and development we must have early and ongoing ecologically valid² assessments that characterize the timing, intensity, and duration of exposures across the life course. Many environmental exposures are episodic, occurring during particular times in life, in certain places, or with specific people. The most accurate way to collect data on life events and exposures is to do so as close in time to the event as possible, rather than months or years afterward. Beginning assessments after the birth of a child jeopardizes the accuracy of critically important information about pregnancy supports or social stressors, traumatic experiences, or fetal exposures to toxic chemicals in the air, water, food, or soil.

How Do the Social, Family, Physical, Nutritional, Chemical, and Digital Environments Together Influence Health and Well-Being Across the Life Course?

Simply identifying individual factors as drivers of health will not yield a full understanding of

² Able to be generalized in real-life settings

the dramatic increases in obesity, asthma, neurodevelopmental problems, and other health burdens now prevalent in the United States, such as behavioral and mental health disorders. An analysis of how different factors in the environment interact to disrupt or enhance health and well-being is urgently needed. For example, neighborhood poverty may be a driver of increased asthma in populations, but, without accounting for increased air pollution, we may be mistaken as to which exposure is most important. Many other exposures are either protective of insults from another exposure or exposures or can increase the effects of another exposure. In addition, chronic psychological stress might enhance a child's vulnerability to air pollution and contribute to the development of asthma (Chiu et al., 2014; Wright et al., 1998). Social support from families is associated with better adolescent nutrition (Larson et al., 2013); and some nutritional exposures can protect against negative environmental factors. Examples include iodine intake and perchlorate exposure or iron intake and lead exposure (Hennig et al., 2012). Thus, if we only look at one or two factors that influence health, rather than the whole picture, we might misidentify the chief drivers of health and disease.

Moreover, just as patterns of disease differ by income, so do chemical exposure patterns. Lower-income individuals have increased exposures to lead, cadmium, antimony, and bisphenol A, but higher-income individuals have increased exposures to mercury, arsenic, cesium, and thallium (Tyrrell et al., 2013). Without evaluating these differences in exposures, one could mistakenly conclude that the cause of a disease is a factor associated with lower income, such a decreased access to health care.

It is also critical to understand the developmental patterns and timing of nutritional environments for children, especially in the context of other aspects of the environment. Over the past several decades, nutritional influences from families, neighborhoods, the media, and the food industry have changed substantially. The health influences of dietary supplements; fortification of cereals and grains; dietary options and habits; and the role of advertising on food choices are poorly understood at the population level. It unknown how the nutritional environment interacts with the physical and chemical environments; or how these various factors worsen or ameliorate the dramatic increases in obesity, asthma, and other noncommunicable diseases in the United States. The developmental timing and patterns of such influences are also not well understood (e.g., we cannot yet identify predictors of overweight and obesity in the prenatal period, first 1,000 days, or early and middle childhood).

Another important change in the social environment is the rapid rise of digital technologies. As a sociotechnical force, digital technologies have become ubiquitous in the lives of the majority of Americans. As these technologies and methods advance and evolve, we continue to know little about how they affect child health and development—let alone how they might enable, mediate, and/or reconfigure the social dynamics and processes of health, health care, learning, and development. The social spaces and practices of the Internet have produced traumas, anxieties, and mental health concerns that need to be better understood. Thus, capturing the use of digital technologies and spaces, particularly in relation to disparities in quality of digital experiences and information, and how these experiences interact with other environmental exposures, will be necessary to have a full picture of how variations in environmental exposures influence health and well-being.

For a national longitudinal birth cohort study to be successful, we will need to break down scientific siloes across disciplines that typically assess only a small portion of environmental exposures. Currently, our understanding of health drivers and levers is unbalanced and incomplete. A nationally representative study that collects data on a cross-section of environmental exposures over time has the potential to inform resource allocation, service delivery, urban planning, and other policies that can improve the health and well-being of the nation. This requires repeated assessments that can account for the timing of environmental influences and characterize outcomes that may themselves become causes of shifts in trajectories of development. Health problems arise not only from negative environmental exposures but also from missing or weak promotive and protective influences. Research on drivers and levers of health and well-being must include promotive/protective factors as well as risk factors, and must be embedded in a developmental perspective to expand our perspective on what drives health and well-being.

CONCLUSION

A nationally representative birth cohort study that begins prenatally will generate foundational data that can be analyzed to understand what drives health and well-being across the life course. There is a consensus among leading scientific and political organizations (NRC/IOM, 2014) that a national longitudinal study of a representative birth cohort, particularly one beginning in pregnancy and designed to examine disparities in health outcomes related to inequality of health care and sociodemographic diversity, has unique value for major advancements in our understanding of how children in this nation grow into healthy, successful, and happy adults. This goal cannot be accomplished through efforts currently under way in the U.S., because these studies are not nationally representative or sufficiently comprehensive in their focus, particularly with respect to assessing cross-cutting environmental factors. Moreover, existing cross-sectional studies, smaller cohort studies, and health surveillance efforts will be substantially enriched by the ability to compare to these nationally representative data. A new, nationally representative longitudinal birth cohort study focused on the processes by which individuals and their environments interact to impact lifelong health and well-being has tremendous and unique potential to inform and transform evidence-based policies and practices to improve the health and well-being of the nation.

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