

Advancing Children's Health & Development: The National Children's Study in Northeast Ohio

Author's Note: *This policy brief is a summary of the National Children's Study (NCS) of the U.S. Department of Health and Human Services, the National Institutes of Health, Centers for Disease Control and Prevention and the U.S. Environmental Protection Agency and its planning and implementation in Cuyahoga and Lorain Counties; please note that unless otherwise referenced, most of the language and information comes directly from the NCS materials cited and credited in the Endnotes.*

While most children born today in the United States are growing up healthy and living longer than ever before, a number of health problems are on the rise.¹ The combined annual cost of the disease burdens of low birth weight, diabetes, obesity, asthma, injury, and neurobehavioral disorders is \$758.7 billion.²

Children are physically and developmentally different from adults with unique life experiences that impact their health and development. Their brains are undergoing rapid and profound neurological growth, with the more complex, executive functioning developing throughout adolescence; they bear an increased vulnerability to various kinds of environmental exposures; and, they do not have the same immune system protection or detoxification capacities as adults. Children also interact with their surroundings differently (i.e. putting objects in mouths, spending more time on the ground, close to dust, pet dander and soil) and have limited control over their environment, especially at very young ages. For instance, children's access to nutritional foods, use of safeguards (i.e. fire alarms, seat belts, helmets), engagement in healthy activities and interactions with caring adults, as well as their exposure to environmental toxins, trauma, neglect or violence are largely dependent on choices made by the adults in their lives. Indeed, many of the childhood health conditions

identified above have suspected environmental connections. Despite the many advances in scientific health research and practice, much remains unknown about preventable diseases, particularly regarding interactions among environmental exposures.

In 2000, in its effort to promote health, prevent disease and eliminate health disparities, the federal government initiated an ambitious research endeavor, undertaking the most extensive and largest long-term study of children's health and development ever conducted in the United States: The National Children's Study (NCS). Relying on a public-private partnership of government, private industry, and community organizations, the NCS is a national response to the need for new knowledge in the area of children's health.³

The potential impact of such a study is sweeping with major treatment and practice implications, access to comprehensive data for further research, and opportunities for significant influence on public policy-making. The prospective economic savings are likewise substantial. In a much less quantifiable way, the NCS will enable a greater number of children to realize their individual potential by helping them grow into healthy and contributing members of society.⁴ Among other positive impacts, healthier children have greater school attendance and learn better, thus strengthening the foundation for continued success into adulthood.⁵

This study will not only assist public health practitioners in developing effective prevention and intervention strategies to improve the health of children and adults, but it will also help doctors and health care professionals better diagnose and treat diseases in the future and policy makers make more informed decisions regarding the health of children.⁶

THE SCHUBERT CENTER FOR CHILD STUDIES in the College of Arts and Sciences at Case Western Reserve University strives to bridge research, practice and policy and to promote educational initiatives across disciplines. Our focus is on children and childhood from infancy through adolescence and in local, national, international and global contexts.

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The National Children's Study: Scope & Goals

The Children's Health Act of 2000 (Public Law 106-310) in Section 1004 authorized the National Institute of Child Health and Human Development (NICHD) with a consortium of representatives from other federal agencies (such as the CDC and EPA) to establish the National Children's Study. It will follow the environmental (using pre- and post-natal natural and man-made environmental, biological, genetic, and psychosocial factors) influences on the health and development of approximately 100,000 children from 105 locations across the United States from birth to age 21. As the largest longitudinal study of U.S. children, their families and their environments, the National Children's Study will be a collaborative effort involving children of diverse ethnicities and socioeconomic backgrounds.

The goal of the study is ultimately to improve the health and well-being of children. The study's key scientific questions address some of the most pressing health and development concerns for today's children, including: diabetes, injuries, asthma, obesity, autism, and learning and behavioral problems. Focusing on pregnancy related outcomes, injury, asthma, obesity, diabetes, physical development, child development, and mental health as priority health outcome themes, the NCS will be large enough to identify the causes of important but less common diseases and conditions⁷ and help us to better understand the long-term health effects of these issues.⁸ The NCS will be the first nationwide children's study to benefit from human genome

mapping and will explore the intersection of genetic and environmental factors in order to examine the affect of gene mutation and variation on the development of disease.⁹ Utilizing both advanced technology to capture data and to track developments as well as critical community based partnerships, this study will provide a national resource for many future studies.

After many years of planning, the pilot phase of the NCS began in January 2009 and currently seven (7) Vanguard sites have begun testing the protocol for the main study. The pilot study will help to ensure a scientifically sound and economically feasible study that will provide the basis for addressing its many hypotheses.

The NCS in Northeast Ohio

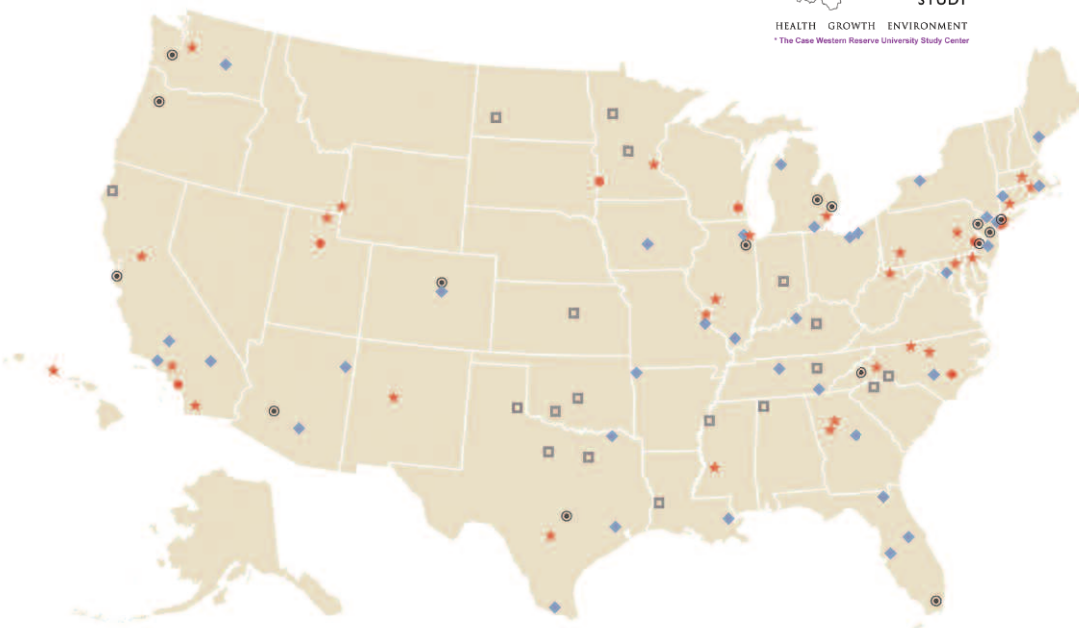
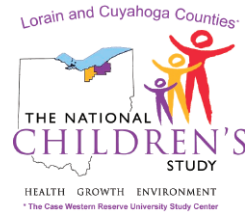
Study Centers are the administrative centers that run the NCS, commonly in more than one study location. The Case Western Reserve University (CWRU) Study Center, with Dorr Dearborn, PhD, MD as the Study Center PI and Lorain County location PI and Michele Walsh, MD, MS as Cuyahoga County PI, administers the Cuyahoga County and Lorain County sites. The project is being carried out by working with the center partners in each county and Battelle from Columbus, Ohio who will be responsible for data collection at both study locations. The Mandel School of Applied Social Sciences (MSASS) is providing support on county characterization of both counties. Battelle will hire local workers, reflecting the make-up of the communities they will work in, thus providing quality employment opportunities within both counties.

NATIONAL CHILDREN'S STUDY LOCATIONS

105 study locations were chosen to recruit a 100,000- child sample, representative of the United States population
<http://www.nationalchildrensstudy.gov/about/overview/Pages/Printable-Study-Locations-Map.pdf>

Map Legend

- ★ Wave 1 Locations
- Vanguard/Wave 1 Locations
- ◆ Wave 2 Locations
- ⊙ Wave 3 Locations
- Locations Not Awarded



Community partners are a vital component of the NCS implementation providing valuable staff and expertise. These partners include University Hospitals and University Hospitals Case Medical Center, MetroHealth System, the Cleveland Clinic Hospital System, Cuyahoga County Board of Health, Cuyahoga County Invest in Children, EMH Regional Medical Center, Lorain County General Health District, Elyria City Health District, and the Public Services Institute of Lorain County Community College, making this study truly a community project.

Part of the responsibility of the CWRU Study Center is to facilitate the process of adding local adjunct studies to the National Children's Study. These studies would add measures/assessments to obtain additional

important information to the study, either for the local populations or on a grander, more multi-site scale. These studies cannot however add a significant burden to the study participants and must be independently funded after being vetted on both a local and national level. The process for adding adjunct studies is not yet finalized, but will be soon, so it is important for researchers to familiarize themselves as much as possible with the study and consider possible adjunct studies and sources of funding in order to be able to turn around an initial application quickly when the process is opened. *For further information about the NCS and the application process, please contact Sarah Fulton at sarah.fulton@case.edu.*

POLICY AND PRACTICE IMPLICATIONS *for Child Health and Well-Being*

The data and findings of the National Children's Study has the potential to influence a multitude of future policy and practice decisions in various fields and to improve the health outcomes for children, particularly with regards to the priority health areas (asthma, pregnancy related outcomes, injury, obesity, diabetes, physical development, child development, and mental health). The NCS is expected to have public data available within 2-3 years of the study launch, enhancing our understanding of some of the most important child health issues of our time, and advancing the development of new prevention strategies, health and safety guidelines, educational approaches, and more.¹⁰ As the NCS will "incorporate behavioral, emotional, educational, and contextual consequences to enable a complete assessment of the physical, chemical, biological and psychosocial environmental influences on children's well-being,"¹¹ the implications are far-reaching.

In addition to the medical and behavioral health fields, environmental policy, city planning, urban and neighborhood development, housing, transportation, food and drug administration, nutrition and dietary policy, public safety, juvenile justice, child care, child welfare, and education are among the range of other public policy areas potentially impacted by the NCS. Researchers, practitioners, policy-makers and advocates will have the chance to develop targeted prevention, early intervention and treatment strategies that build from the NCS

data. While the breadth and depth of possible policy changes in connection with this study, including public and private funding opportunities, are limitless, some of the prospects identified by the NCS include the following:¹²

Prevention & Early Intervention

- Revised standards of care for prenatal screening to address pregnancy-related outcomes (i.e. birth defects, low birth weight, neonatal problems)
- Design of science-based injury prevention programs targeting subgroups of children at greatest risk of injury based on increased understanding of why some children exhibit high risk behaviors
- Food and drug regulatory changes, including targeted use of nutritional supplements and specialized diets within public nutrition and education programs to increase health protective factors and to decrease risk of asthma, obesity and/or diabetes
- Support for monitoring of environmental pollutants, waste control and utilization of home and school-based environmental protections and toxic chemical abatement policies
- Incentives for land use policies and public space design that promotes physical activity (i.e. walkable communities, playgrounds), safety (i.e. well-lit spaces) and access to nutritional resources (i.e. grocery stores, local produce)
- Regulation of identified chemicals (i.e. lead, pesticides, mercury) affecting developing immune systems, neurobehavioral and cognitive functioning

Treatment and Support Services

- Access to health care and development of specific screenings and health care programs, including patient-based interventions
- Medical and community health center practices focused on improved maternal health, prenatal care and infant care
- Enhanced detection and treatment management for those physical and mental health ailments linked to prenatal exposure to certain infections
- Revised behavioral health assessment and treatment standards and services based on reinforcing identified protective factors and eliminating or minimizing linked risk factors
- Public safety and social service policies that incorporate NCS findings regarding children's exposure to stress, trauma and violence, and relationships with family, caregivers and schools
- Enhancement of early care and education interventions

Additionally, the NCS will create a large-scale database capable of responding to new scientific questions and supporting expanded areas of research, such as combined studies of gene-environment interactions and multi-disciplinary studies incorporating the results of the NCS. It will be incumbent on the various stakeholders, including families and children, to be engaged in this impressive public-private venture to promote child health and well-being.

¹ U.S. Department of Health and Human Services. (n.d.) "The National Children's Study and your community: Partners in our children's health." [Brochure].

² U.S. Department of Health and Human Services. (n.d.) "Growing up healthy: An overview of the National Children's Study." p.27.

³ U.S. Department of Health and Human Services (n.d.) "Be part of the National Children's Study" [Brochure].

⁴ U.S. Department of Health and Human Services. (n.d.) "Growing up healthy: An overview of the National Children's Study." p.26.

⁵ Ibid. p.26.

⁶ Ibid. p.15.

⁷ Ibid. p.17.

⁸ Ibid. p.15.

⁹ Ibid. p.16.

¹⁰ Ibid. p.9.

¹¹ National Children's Study Website. "Hypotheses." Accessed 12/15/09. <http://www.nationalchildrensstudy.gov/research/hypotheses/Pages/default.aspx>

¹² U.S. Department of Health and Human Services. (n.d.) "Growing up healthy: An overview of the National Children's Study." pp.39-49.