National Institutes of Health

Vision

Biomedical research is essential for improving child health and too often pediatric research is an afterthought. New frontiers in science, including epigenetics, increasingly show how childhood is the foundation for lifelong health. The National Institutes of Health (NIH), which is the primary funder of biomedical research in the United States, must realign its research portfolios to address the childhood roots of the costly diseases of adulthood. In doing so, NIH must increase its focus on disparities. For instance, since poverty disproportionately impacts children, we need more research on how to reduce the health and educational disparities that lead to the intergenerational transmission of disadvantage. Finally, NIH must also invest in the future of pediatric research by supporting the career development of physician-scientists.

Recommended Administrative Actions

Inclusion of children and adolescents in research. The next administration must immediately take steps to reverse decades of inaction at NIH related to the implementation of its 1998 policy requiring children to be included in NIH-funded studies. NIH refuses to systematically track the numbers and ages of children and adolescents actually enrolled in NIH studies, like it does for women and minorities. Without this data, gaps in pediatric research will remain unidentified. NIH must immediately begin collecting and reporting this important data.

Environmental Influences on Child Health Outcomes Program. The Environmental Influences on Child Health Outcomes (ECHO) Program is an essential program to investigate how prenatal and early childhood environmental influences—including physical, chemical, biological, and psychosocial exposures—affect high-impact pediatric conditions such as prematurity, asthma, autism, and obesity. The maternal and child health community is committed to the success of ECHO, and NIH must make a long-term commitment to this important initiative. NIH must also ensure that the cohorts selected to participate in this project appropriately include data on prenatal environmental influences.

Precision Medicine Initiative. The Precision Medicine Initiative (PMI) and its planned genetic cohort of over one million individuals shows great promise for the development of personalized therapies. It is absolutely essential that children be included in the cohort.

Partnerships with other federal agencies. NIH should pursue research funding partnerships with other federal agencies such as CMS, FDA, and MCHB. To address the urgent issues in child health including population health, genomics, environmental health, behavioral health, and health-systems reform, creative solutions will require action that impacts the major federal agencies that are charged with funding systems of care for children.

Recommended Congressional Actions

Studies of off-patent drugs in children. Congress must reauthorize and expand the NIH program authorized under the Best Pharmaceuticals for Children Act (BPCA), which expires in 2017. This program funds essential research into old off-patent drugs that are commonly used in children but have not been appropriately studied or labeled for pediatric use. It also funds the development of pediatric clinical pharmacology researchers to conduct these needed studies.

Inclusion of children in research. If the administration fails to take quick action to collect the numbers of children enrolled in NIH-funded studies, Congress must require NIH to do so in statute.

Funding Priorities

Sustainable NIH funding. While the Eunice Kennedy Shriver National Institutes of Child Health and Human Development (NICHD) funds more pediatric-focused research than any other institute at the NIH, the majority of NIH’s pediatric research portfolio resides outside of NICHD. Increasing the NIH budget across the board is essential to ensuring that NIH has the resources to fund pediatric research. Many successive years of flat budgets have decreased grant success rates to unacceptably low levels—with NICHD having among the lowest paylines—which threaten the viability of research careers. The NIH budget must be raised in a consistent and sustainable manner that provides meaningful increases over and above biomedical inflation.

Pipeline of the next generation of pediatric researchers. Funding new and emerging scientists is absolutely essential to ensure that important scientific advances will continued to be made in the future. Therefore, robust funding of training grants and training programs is a significant priority. In addition, physician-scientists have unique financial and institutional challenges that deserve special attention from NIH in order to maintain the long-term viability of these researchers who have contributed so much to the medical field.
**ECHO program.** Congress has shown great leadership over the past two decades in supporting funding for large studies to investigate the impact of the environment on child health and development. To continue this important legacy, Congress must make a long-term funding commitment to the ECHO program.

**Zika virus.** The Zika virus is increasingly understood to cause a range of serious health effects, including microcephaly, in infants born to mothers who contracted the virus while pregnant. Microcephaly is a debilitating lifelong condition that has been linked to seizures, developmental delays, intellectual disability, and vision problems. However, even infants who appear healthy at birth may have effects that cannot be detected until later. Medications and early intervention therapies will be needed to protect women of childbearing potential and pregnant women and to help children affected by microcephaly and other health consequences of Zika. The NIH can and must play an important role in better understanding how Zika damages the fetus in utero, developing therapies and vaccines to protect against the virus, and treating children who have been impacted by Zika.

**About this Document**

This document is an excerpt from Blueprint for Children: How the Next President Can Build a Foundation for a Healthy Future (http://aap.org/blueprint), which was produced by the American Academy of Pediatrics in September 2016 and has also been endorsed by the following organizations: the Academic Pediatric Association, the American Pediatric Society, America’s Promise Alliance, the Association of Medical School Pediatric Department Chairs, Family Voices, the National Association of Pediatric Nurse Practitioners, the Pediatric Policy Council, the Society for Adolescent Health and Medicine, the Society for Pediatric Research and ZERO TO THREE.