

SPECIAL ARTICLE


Making the case for pediatric research: a life-cycle approach and the return on investment

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There is unmistakable evidence of increased NIH funding for pediatric and perinatal research, but there is much work to be done. To further promote NIH-funded pediatric and perinatal research, we advocate for a life-cycle approach in which the return on the investment continues over the lifespan. Although elected policymakers have short-time horizons, pediatric and perinatal researchers must provide novel evidence and theoretical arguments demonstrating the long-term health benefits for the adults of tomorrow by improving the health of our current pediatric populations. Child health researchers must communicate the role of early developmental events on childhood and adult disease, including those that are prenatal and gestational so that its importance is understood by the public and policymakers.

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INTRODUCTION

The National Institutes of Health (NIH) pediatric research portfolio is of significant interest to clinical pediatricians, pediatric researchers, and disease-specific advocacy groups. In a 2018 *Pediatric Research* article, we reported on the uncertain fate of NIH spending on pediatric research.¹ We update the state of the pediatric research portfolio over the past decade and reveal information about contemporary political and biomedical priorities. The news is better to report, for there is unmistakable evidence of increased NIH funding for pediatric research, but we also note that there is much work to be done. Our objective is to avoid framing the allocation of the NIH budget as zero-sum, wherein gains or losses in adult funding result in gains or losses for pediatric funding.

We reject the premise that human health is a distributional problem between age groups at a particular moment in time, and we advocate for a life-cycle approach. Many adult health risks (e.g., obesity, diabetes, cardiovascular diseases, cancer, and immune diseases) are influenced by life events before and throughout pregnancy as well as during childhood. Moreover, prevention in the pediatric age group of adult-onset disorders can reduce health care costs exponentially, more than trying to treat disorders after they clinically appear in adults.^{2,3} To improve the health of future children and adults, it is imperative that the pediatric clinical, research, and advocacy community advocate to prioritize investments in basic and clinical pediatric, perinatal, and pregnancy research.

CONGRESS DEMANDS PEDIATRICS BE A RESEARCH PRIORITY

In the mid-1990s, Congress requested that the NIH establish priorities for pediatric research and establish guidelines that would include children in clinical research and develop performance indicators to measure progress.⁴ NIH defined pediatric research as “studies in all categories of biomedical research (basic,

clinical, epidemiologic, behavioral, prevention, treatment, diagnosis, as well as outcomes and health services) that relate to diseases, conditions, or the health/development of neonates, infants, children, and adolescents up to age 21.”⁵ Despite the promise of such metrics, unsystematic methods led to inconsistent reporting on the state of the pediatric portfolio.

In 1996, NIH released its first report on pediatric research. Performance metrics were not discussed. However, the first report (as well as subsequent reports) highlighted advances in pediatric research and the Pediatric Research Initiative. The latest report to Congress was released in 2020.⁶ In 2008, NIH implemented a process to improve consistency in all reporting through the Research, Condition, and Disease Categorization.⁷ Pediatrics and perinatal spending have been a category since fiscal year (FY) 2008. Since then, pediatric cancer (2014), pediatric cardiomyopathy (2016), pregnancy (2017), and childhood obesity (2018) have been reported as additional sub-categories of special interest.

More recently, the NIH Pediatric Research Consortium was established in 2018,⁸ consisting of representatives from all 27 institutes and centers (ICs)—led by Dr. Diana Bianchi, Director of the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD)—to coordinate the NIH investment in pediatric research and to capitalize on pediatric research expertise and resources across the NIH. It is noteworthy that the increase in NIH pediatric and particularly pregnancy and perinatal research spending over the past half decade has occurred during Dr. Bianchi’s tenure at NICHD.

NIH AND THE PEDIATRIC PORTFOLIO

The NIH pediatric portfolio is defined as the total funds obligated to conduct or support pediatric research in a broad variety of

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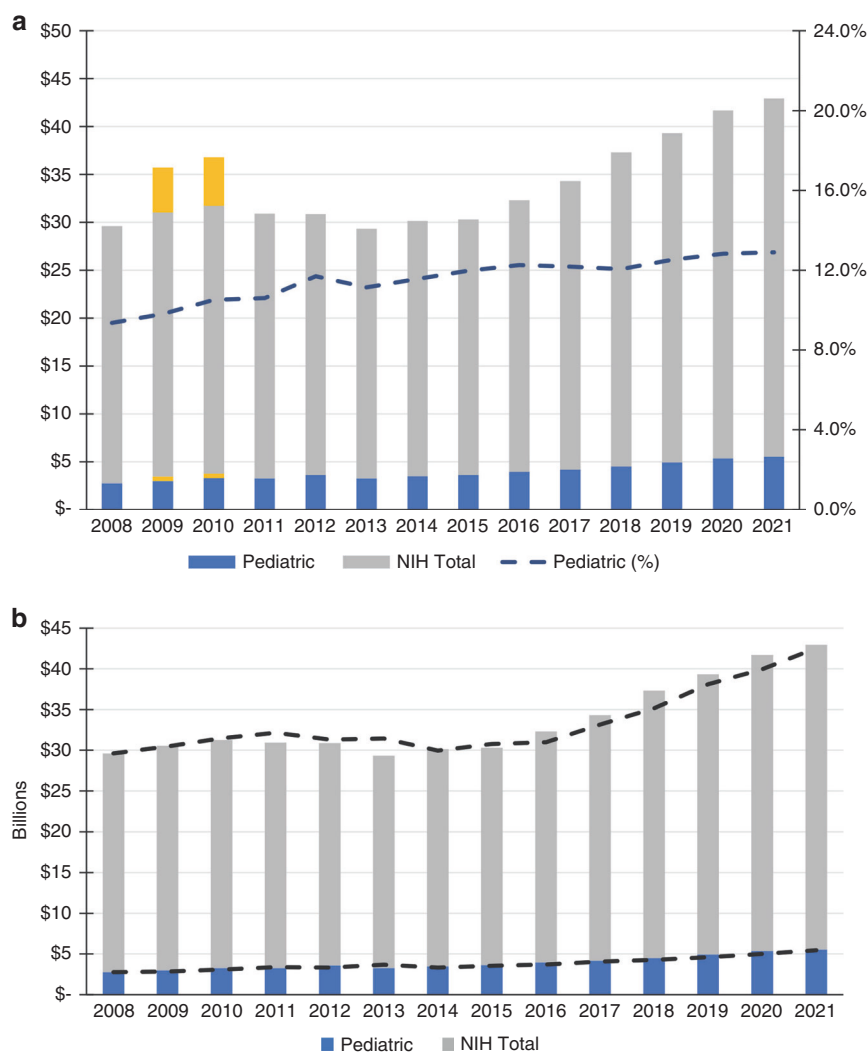


Fig. 1 NIH and the Pediatric Portfolio, 2008–2021. **a** National Institutes of Health (NIH) budget and the pediatric portfolio, fiscal years (FY) 2008–2021 (nominal dollars). Note: the yellow bars represent one-time American Recovery and Reinvestment Act (ARRA) funding. Sources: NIH Office of Budget, NIH RCDC. **b** NIH budget and pediatric portfolio, FY 2008–2021 (nominal dollars) and adjusted for biomedical inflation (BRDPI). Note: the dotted lines represent prior FY spending adjusted for biomedical inflation (BRDPI). Sources: NIH Office of Budget, NIH RCDC.

areas, including neurodevelopment, cardiology, cancer, pharmacology, and behavioral and social sciences. The NIH ICs often take a life course approach on normal health, development, and disease, but research of relevance to children might not always be categorized as pediatric research. Much basic research elucidating the mechanisms of normal development and the origins of disease are important for children’s health.⁹ Given that non-age-specific research might have differential benefits across subpopulations, we argue caution regarding drawing rigid conclusions from increases or decreases in annual pediatric funding.

Figure 1a reports on NIH and pediatric research spending from FY 2008 to FY 2021.

The pediatric portfolio increased from 2.7 in FY 2008 to an estimated 5.5 billion in FY 2021—a doubling of the pediatric budget. In the past decade, pediatric spending increased from 3.9 to 5.5 billion. Pediatric funding increased from a low of 9.4% to an estimated high of 12.9% as a percent of the total NIH budget. During the most recent period (FY 2014–2022), the average annual pediatric research growth rate was 6.8% compared to the NIH average annual growth rate of 4.9%. Figure 1b highlights the status of NIH and pediatric research spending compared to a projected annual change

in the Biomedical Research and Development Price Index (BRDPI), which indicates how much the NIH and pediatric budget should change to maintain purchasing power. The average annual BRDPI between FY 2008 and FY 2021 was 2.4%. In most years, annual spending increases kept pace with biomedical inflation, representing significant catch up in congressional support after the doubling of the NIH budget from FY 1998–2003. These are positive and significant increases in pediatric research funding.

The pediatric research portfolio is well distributed across NIH, with research conducted through 25 ICs. Although NICHD is characterized as the principal institute for the “profession of pediatric research,” NICHD accounted for only 17% of total pediatric funding in 2020. NICHD’s pediatric funding excludes reproductive, behavioral, demographic, and rehabilitation research not specifically aimed at improving the health of pediatric populations. Compared to 2008, notable changes in the distribution of the portfolio occurred: declines in the proportion of pediatric research that NICHD (from 21% to 17%) and National Institute of Mental Health (from 11% to 9%) fund, but an increase in the proportion of pediatric research funded by National Cancer Institute (from 5% to 11%).

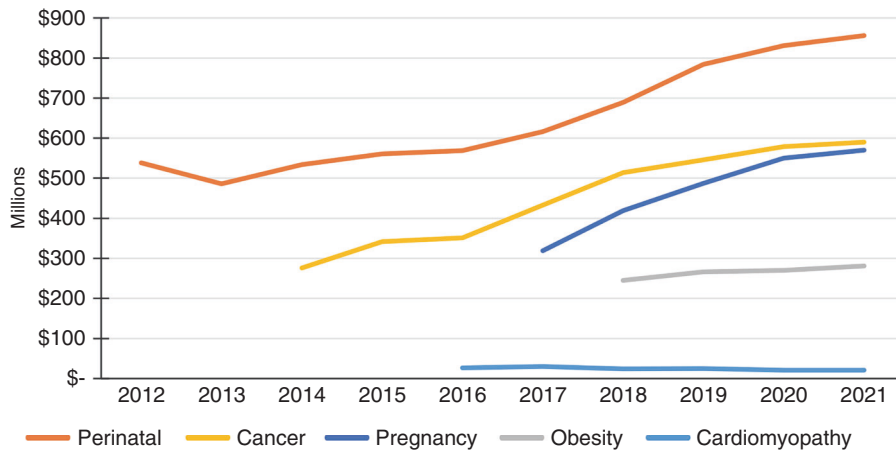


Fig. 2 Pediatric, perinatal, and pregnancy subcategory portfolio, FY 2012–2021 (nominal dollars).

Figure 2 reports annual spending on pediatric sub-categories, including pediatric cancer, pediatric cardiomyopathy, and childhood obesity, as well as annual spending on “conditions originating in the perinatal period” and pregnancy.

Average annual NIH spending on pediatric cancer and obesity increased at 12 and 5%, respectively (2015–2021), while spending on pediatric cardiomyopathy decreased by 4.1% (2017–2021). More notably, NIH spending on conditions originating in the perinatal period increased at 7.4% annual between 2014 and 2021 (from \$534 to \$856 million) and on pregnancy at 16% annually between 2017 and 2021 (from \$319 to \$570 million). These increases are encouraging in meeting the fundamental benefits of pregnancy research that have provided overwhelming evidence that many later-life adverse health outcomes begin in fetal life.^{10,11}

This portfolio of essential research priorities, however, should be evaluated at regular intervals and adjusted to meet new needs and rebalance the current substantial overfunding and underfunding of certain conditions to represent better current health conditions.¹² For example, a review of 19 different meta-analyses noted that “childhood adversity (CA) accounted for approximately 15% of the total U.S. mortality in 2019 (2,854,838 deaths) through associations with leading causes of death (including heart disease, cancer, and suicide).”¹³ CA was associated with millions of cases of unhealthy behaviors and disease markers, including >22 million cases of sexually transmitted infections, 21 million cases of illicit drug use, 19 million cases of elevated inflammation, and >10 million cases each of smoking and physical inactivity. The greatest proportion of outcomes attributable to CA were for suicide attempts (28%) and sexually transmitted infections (33%). Mental health disorders continue to grow at alarming rates in the pediatric population, fueled by increasing exposure to a large variety of adverse experiences, including child abuse and neglect, which continue into adulthood.^{14,15}

Such data points to several areas of concern that can inform future research, clinical care, policy decision making, and programmatic investments to improve the health and well-being of children and their families. We specifically note that it would be futile to substitute research funding of any one childhood adverse event or disease or condition for another. Instead, increased funding is needed for all basic and clinical pediatric childhood adverse events, diseases, and conditions. This should apply to much needed increases in research training support as well as direct research project funding—both are fundamental to enhancing health outcomes in children.¹⁶

MAKING THE CASE: A LIFE-CYCLE APPROACH AND THE RETURN ON INVESTMENT

We advocate for a life-cycle approach: the return on the investment continues over the lifespan. An emerging economics literature documents the importance of the early years in determining adult capacities related to improved cognition and motivation, key determinants of productivity of many kinds, particularly economic.¹⁷ As a society that values children, we need to “champion ongoing research into all aspects of their growth and development.”¹⁸ Although elected policymakers have short-time horizons, pediatric and perinatal researchers will need to offer novel pieces of evidence and theoretical arguments demonstrating the long-term health benefits for the adults of tomorrow by improving the health of our current pediatric populations. Child health researchers must communicate the role of early developmental events on childhood and adult disease, including those that are prenatal and gestational so that its importance is understood by the public and policymakers.

DATA AVAILABILITY

NIH budget: <https://report.nih.gov/nihdatabook/category/1>; RCDC: <https://report.nih.gov/funding/categorical-spending/#/>.

REFERENCES

- Gitterman, D. P., Langford, W. S. & Hay, W. W. Jr. The uncertain fate of the National Institutes of Health (NIH) pediatric research portfolio. *Pediatr. Res.* **84**, 328–332 (2018).
- Zerhouni, E. A. *Testimony on the Fiscal Year 2008 Budget Request Before the Senate Committee* (National Institutes of Health, 2007).
- Hay, W. W. Jr., et al. Child health research funding and policy: imperatives and investments for a healthier world. *Pediatrics* **125**, 1259–1265 (2010).
- U.S. House of Representatives. in *Report No 209. 104th Congress, 1st Session* 80–81 (U.S. House of Representatives, 1995).
- NICHHD. NICHHD internal memo on definition of research on children. (1997).
- Department of Health and Human Services. *National Institutes of Health Report to Congress: Pediatric Research in Fiscal Year 2019* (Department of Health and Human Services, 2020).
- National Institutes of Health. *Estimates of Funding for Various Research, Condition, and Disease Categories (RCDC)*. [Table] (NIH, 2021).
- Hazra, R. & Bianchi, D. W. National Institutes of Health funding priorities. *JAMA Pediatr.* **176**, 324–325 (2022).
- Shurin, S. B. & Castle, V. P. Pediatric research impacts and benefits from all of biomedical science. *J. Pediatr.* **165**, 4–5 (2014).
- Stevenson, D. K., Shaw, G. M. & Katz, M. The uncertain fate of the National Institutes of Health (NIH) pediatric research portfolio: in support of an investment strategy to improve the public health of the nation through perinatal research. *Pediatr. Res.* **84**, 321–322 (2018).
- Barker, D. J. The developmental origins of adult disease. *J. Am. Coll. Nutr.* **23**, 588S–595S (2004). 6 Suppl.

12. Rees, C. A., Monuteaux, M. D., Herdell, V., Fleegler, E. W. & Fourgeois, Fl. T. Correlation between National Institutes of Health funding for pediatric research and pediatric disease burden in the US. *JAMA Pediatr.* **175**, 1236–1243 (2021).
13. Grummitt, L. R. et al. Association of childhood adversity with morbidity and mortality in US adults: a systematic review. *JAMA Pediatr.* **175**, 1269–1278 (2021).
14. Krugman, R. D. Ending gaze aversion toward child abuse and neglect. *Health Aff.* **38**, 1762–1765 (2019).
15. Parnes, M. F. & Schwartz, S. E. O. Adverse childhood experiences: examining latent classes and associations with physical, psychological, and risk-related outcomes in adulthood. *Child Abus. Negl.* **127**, 105562 (2022).
16. Boat, T. F. & Whitsett, J. A. How can the pediatric community enhance funding for child health research? *JAMA Pediatr.* **175**, 1212–1214 (2021).
17. Heckman, J. J. The economics, technology, and neuroscience of human capability formation. *Proc. Natl Acad. Sci. USA* **104**, 13250–13255 (2007).
18. Bearer, C. F., Roland, D., & Molloy, E. J. Value of children in our world. *Pediatr. Res.* <https://doi.org/10.1038/s41390-021-01609-0> (2022).

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COMPETING INTERESTS

The authors declare no competing interests.

ADDITIONAL INFORMATION

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