

EDITORIAL

How Can the Pediatric Community Enhance Funding for Child Health Research?

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Children (younger than 18 years) in the US represent 22% of the total population. Although this segment of the population is healthier than older populations, the prevalence of children with complex medical conditions is growing rapidly,¹ now



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constitutes an estimated 3% to 5% of the total childhood population,² and represents a

growing contribution to the numbers of children hospitalized on a daily basis in the US. In addition, it is increasingly clear that many of the antecedents of adult chronic disease, including mental disorders³ and obesity and cardiovascular disorders,⁴ reside in the first 18 years of life, often before birth, in infancy, and during the preschool years. Approximately 10% of the National Institutes of Health (NIH) budget (\$4 billion) supports research addressing childhood health.⁵ We raise 3 important questions: (1) Is this proportion of the NIH funding addressing child health in the best interest of child and life span health for the US population? (2) Is NIH funding of child health distributed where most needed to advantage individual and population health of our youth and life span health? (3) What can pediatric programs do to enhance the numbers and success of investigators in pediatric research?

While the subspecialty of pediatrics, the establishment of the independent pediatric hospitals, and the creation of child health research programs began in earnest less than a century ago, major advances in science and medicine have been translated into improvements in child health and are associated with remarkable expansion of hospital services and research related to pediatrics. The application of basic physiology, biochemistry, immunology, and infectious disease research developed in the 20th century has transformed child health, preventing once common infectious diseases, reducing infant mortality, enabling life-changing therapies for common and rare congenital disorders, and providing clear evidence for the value of science in improving child health. The concept that prenatal and postnatal health sets a lifelong trajectory of health and disease, supported by evidence for “the developmental origins of adult health,”⁶ is increasingly compelling and provides a strong rationale to invest in pediatric research to prevent disease or intervene early in its progression. While it is an intuitive conclusion that research and training in pediatrics are of great value to society and a moral obligation, it is challenging to provide metrics regarding appropriate allocation of resources to pediatric research rather than to other areas of bioscience and medicine. Taken together with the fact that 22% of our population is in the pediatric age range, but only 10% of the NIH budget is allocated to child health, these

observations provide incentives to quantify and optimize investments in pediatric research.

We take the position that strengthening federal allocations to pediatric research is an opportunity to improve health of the public. If current funding allocations to child health are relatively underrepresented, it is worthwhile understanding the confluence of factors that may limit NIH funding. If we are neglecting real opportunities, efforts are merited to carefully identify best metrics, outcomes, and underlying causes of funding limitations. The relative allocations of funding for pediatric research by other public and private grantors merit similar inspection.

NIH funding for child health has generally kept pace with overall NIH funding increases. However, NIH funding to pediatric institutions and programs is increasingly concentrated in a few sites. Analysis of the 2020 NIH Reporter data indicates that 30% of NIH’s \$1.96 billion funding to pediatric institutions and programs went to 3 children’s hospitals and 57% to the top 10 NIH grant recipients (Arnold W. Strauss, MD, written communication, July 15, 2021). Between 2013 and 2020, NIH funding of research to the top 10 increased 93% while funding to those in the third and fourth deciles increased approximately 10%. Factors differentiating programs at the top from those less well funded by the NIH undoubtedly include local institutional investments in research training, research leadership, and research faculty. Opportunities for collaborations across and beyond institutional research programs and availability of strong mentoring for junior investigators also are critical factors for success.

Top programs can be distinguished by investments in enabling technologies and their ability to launch and manage large, often multicenter, clinical trials. Thirty-four percent of pediatric departments have no NIH funding and 57% no more than 5 NIH grants. Broader participation in impactful research is essential to advance the child health research agenda and clinical innovation nationally. Since there is always a considerable lag time between basic research discoveries, their translation, and assessment of long-term impact on individual and population health, estimation of the impact of grant allocations to pediatric investigators deserves ongoing attention.

Child health research resides in equal part in pediatric and nonpediatric research settings, the latter including other college of medicine and university departments. Many discoveries relevant to child health are made in the study of adult diseases or by basic scientists. For example, RNA-mediated technologies have allowed rapid development of COVID-19 vaccines and will provide a robust platform for childhood

vaccine development. Enhancing collaboration across these disciplines represents an opportunity to advance high-quality basic and translational research and engage more pediatric faculty in funded research.

To address the second question, we agree that distribution of child health funding by the NIH across specific pediatric disorders and categories of disorders is also important to assess, and ultimately balance, based on immediate and lifetime health needs. In 1998 an Institute of Medicine committee recommended that disease burden be used as a measure for managing NIH funding distribution⁷ and a year later Gross et al⁸ reported that disability-adjusted life-years (DALYs) were the most strongly predictive of NIH funding. The article by Rees et al⁹ in this issue is the first to comprehensively assess alignment among NIH funding for pediatric research and DALYs, hospital days, and hospital costs. The article identifies disorder categories that appear to be substantially over- and underfunded based on burden of disease and related cost. Limitations of these analyses include lack of harmonization for pediatric disorder categories across the 3 databases used for analyses, leading to comparison of funding for comprehensive disease categories, such as combined endocrine, metabolic, blood, and immune disorders, with specific disorders, eg, eosinophilic esophagitis. Greater disorder specificity will be important for future targeting of research funding to areas and disorders in greatest need. Another challenge will be factoring in determinants of cognitive, behavioral, and physical health outcomes for children that are not captured in disorder categories, such as the behavioral and physical health of parents before conception, during pregnancy, and after a child's birth.³ Similarly, it is not clear that DALY estimates capture the lifetime health consequences of fetal or early childhood exposures to toxic substances, an example being maternal cigarette smoking that is a substantial risk for adulthood chronic obstructive lung disease,¹⁰ as well as behavioral consequences.¹¹ A focus on disorder-specific burden of disease may exclude consideration of funding for health promotion and risk prevention efforts. Similarly, these analyses are likely to miss inclusion of T1 research that ultimately elucidates mechanisms of pediatric diseases and opens doors to diagnostic and therapeutic advances.

Nevertheless, the analysis by Rees et al will be helpful for high-level management of grant portfolios. It is encouraging that the NIH Pediatric Research Consortium (N-PERC) was organized in 2018 to capitalize on pediatric research expertise and resources across the NIH's 27 institutes and centers and explore gaps in NIH child health research support. This consortium should be positioned to use data such as those published in this issue of *JAMA Pediatrics* to target research funding where it is most likely to advantage child and lifetime health.

How can the pediatric community including departments, children's hospitals, and pediatric scientific societies

enhance research funding targeting child health? While the NIH allocations in general and those related to disease burden metrics provide initial insight into gaps between research funding and pediatric disease, there are pleiotropic factors that influence the garnering of research support. These include the number of pediatric investigators, the strength of training pipelines for pediatric scientists, and the priorities of many children's hospitals that invest preferentially in clinical programs. Many pediatric training programs within freestanding pediatric hospitals lack opportunity for frequent interactions with basic and quantitative scientists. Pediatric programs embedded within university settings are advantaged by relative ease of interaction with diverse scientific faculty and trainees, but often suffer from insufficient research resources. Likewise, the frequent isolation of pediatric personnel in children's hospitals limits opportunities to share their clinical experience with the broader scientific community.

Strengthening and extending the duration of pediatric research training, enhancing immersion in multidisciplinary clinical and scientific teams, and improving access to core infrastructures for advancing technologies in genetics, transcriptomics, and informatics will enhance opportunities for pediatric trainees to establish independent research careers. Since most pediatric care occurs in ambulatory settings, strengthening training and infrastructure for well-organized research related to epidemiology, public health, health services and outcomes, and psychosocial determinants of health, represent some of many opportunities. The pediatric community should also ensure diversity and equity in research training and program development. Seventy percent or more of pediatric trainees are women. They, as well as trainees in underrepresented racial and ethnic minority groups, are not as yet sufficiently represented in pediatric research training and leadership. Support of diversity within the pediatric research workforce promises to extend the reach and impact of child health innovation.

It is incumbent on leadership of pediatric departments, children's hospitals, and pediatric training programs to prioritize research program planning and implementation, including the highest possible level of advice, encouragement, and support for trainees to engage in research that will lead to independently funded careers. Pediatric societies can make this agenda a greater part of their mission. We suggest that the Children's Hospital Association could be an effective venue for promoting more productive child health research and innovation in their sites. All organizations can also contribute to creating a compelling narrative linking research efforts in pediatric settings to a healthier and more productive society.

Raising the level of research qualitatively and quantitatively is a high-priority goal for the entire pediatric community. The pediatric community can also take the lead in crafting messages that convince the public, as well as funders, of the value of pediatric research for the future health of all.

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REFERENCES:

1. Committee to Evaluate the Supplemental Security Income Disability Program for Children with Mental Disorders; Board on the Health of Select Populations; Board on Children, Youth, and Families; Institute of Medicine; Division of Behavioral and Social Sciences and Education; The National Academies of Sciences, Engineering, and Medicine. Mental disorders and disabilities among low-income children. Boat TF, Wu JT, eds. The National Academies Press; 2015:73.
2. Boat TF, Filigno S, Amin RS. Wellness for families of children with chronic health disorders. *JAMA Pediatr*. 2017;171(9):825-826. doi:10.1001/jamapediatrics.2017.1682
3. National Academies of Sciences, Engineering, and Medicine. Fostering healthy mental, emotional and behavioral development in children and youth. The National Academies Press; 2019.
4. Campbell F, Conti G, Heckman JJ, et al. Early childhood investments substantially boost adult health. *Science*. 2014;343(6178):1478-1485. doi:10.1126/science.1248429
5. NIH Pediatric Research Consortium (N-PeRC). Accessed July 14, 2021. <https://www.nichd.nih.gov/research/supported/nperc>
6. Barker DJ, Eriksson JG, Forsén T, Osmond C. Fetal origins of adult disease: strength of effects and biological basis. *Int J Epidemiol*. 2002;31(6):1235-1239. doi:10.1093/ije/31.6.1235
7. Institute of Medicine. *Scientific Opportunities and Public Needs: Improving Priority Setting and Public Input at the NIH*. The National Academies Press; 1998.
8. Gross CP, Anderson GF, Powe NR. The relation between funding by the National Institutes of Health and the burden of disease. *N Engl J Med*. 1999;340(24):1881-1887. doi:10.1056/NEJM199906173402406
9. Rees CA, Monuteaux MC, Herdell V, Flegler EW, Bourgeois FT. Correlation between National Institutes of Health funding for pediatric research and pediatric disease burden in the US. *JAMA Pediatr*. Published online September 13, 2021 doi:10.1001/jamapediatrics.2021.3360
10. Bush A. Lung development and aging. *Ann Am Thorac Soc*. 2016;13(suppl 5):S438-S446. doi:10.1513/AnnalsATS.201602-112AW
11. Brion MJ, Victora C, Matijasevich A, et al. Maternal smoking and child psychological problems: disentangling causal and noncausal effects. *Pediatrics*. 2010;126(1):e57-e65. doi:10.1542/peds.2009-2754