



February 15, 2019

**NICHD Strategic Planning Group**

*Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD)

1 Center Drive

Bethesda, MD 20892

RE: NOT-HD-18-031 **Request for information (RFI): NICHD Strategic Plan Fiscal Years 2020-2024**

To Whom It May Concern:

Child Trends is a nonpartisan research organization focused exclusively on improving the lives and prospects of children, youth, and their families. For 40 years, decision makers have relied on our rigorous research, unbiased analyses, and clear communications to improve public policies and interventions that serve children and families. Child Trends is an interdisciplinary research organization, utilizing theoretical and analytic frameworks from the fields of psychology, sociology, public health, demography, education, and public policy, among others.

As an institution dedicated to promoting research-based, data-driven solutions to the challenges facing children and their families, we are grateful for this opportunity to respond to the *Eunice Kennedy Shriver* National Institutes of Child Health and Human Development's (NICHD) request for comment on the scientific themes, goals, and opportunities identified as part of the NICHD strategic planning process that will guide the institute's work for the next five years. Rather than focusing our comments on each of the six scientific themes noted in the NICHD Strategic Plan, our comments reflect an approach to conducting innovative research that we hope NICHD will apply *across* these themes.

We hope that the following recommendations regarding this multifaceted approach will permeate across the NICHD Strategic Plan. Throughout our comments, we provide examples of how these approaches could be applied to multiple themes.

## 1. Maintain and support population-level research across the six themes.

NICHD funds research efforts to inform the field, along with policies and practices, in ways that will “address health disparities and improve prevention efforts among the populations we serve.” Population is a critical word in this statement. While the six themes each identify exciting and important goals, the opportunities noted under each goal—while detailing clinical and evaluation research—only indirectly reference the importance of population-level studies (e.g., social determinants of health in Theme 4). **We recommend that the opportunities put forth under each of these goals explicitly highlight the importance of various types of data collection efforts and studies, including population-based efforts, in making progress toward any one goal.** The success of many of NICHD’s funded research studies will be assessed, in part, by their impact on the general population, not just on a clinical or program population from which it may be hard to generalize findings. This impact cannot be determined without having population-based data and studies.

For example, Theme 2 describes using “new and/or existing datasets to better understand the course and complications of pregnancy...” Making sure there are longitudinal data bases that will support population-based research efforts will allow for a richer examination of these questions, helping to determine the burden of maternal and infant health outcomes or exposures at the national level, as well as assess variation in this burden across geography and other important social determinants of health (e.g., race, ethnicity, gender, and socioeconomic status [SES]). Population-based research efforts are essential to maximizing interventions.

In meeting its goal, Theme 5 notes that “NICHD aims to identify the behavioral, cognitive, social, environmental, hormonal, endocrine, and genetic factors that contribute to adolescent development...” The ability to better understand this developmental period requires studying a population-based sample of adolescents—ideally with longitudinal data on the wide range of developmental indicators listed above. Additionally, social science research has established that the pathways through adolescence are varied and changing. Population-level data are needed to adequately measure this variation across critical sociodemographic characteristics and to keep up with changes over time. **We recommend that NICHD fund new longitudinal data collection efforts to enable future research on child and adolescent development (particularly in support of Research Themes 2, 4, and 5).** These data collection efforts should incorporate large samples of underserved and racial or ethnic minority populations (see # 5 below); include socio-demographic factors, contextual data, and bio-markers; and follow participants from early childhood into adolescence, and from early adolescence through the transition to adulthood.

## 2. **Highlight positive youth development, especially in Research Theme 5.**

NICHD's strategic plan includes several themes highlighting child and adolescent development. **We recommend incorporating positive youth development approaches across themes.** Healthy People 2020 identifies positive youth development (PYD) interventions as "intentional processes that provide all youth with the support, relationships, experiences, resources, and opportunities needed to become competent, thriving adults."<sup>1</sup> Accumulating research indicates that PYD is an effective strategy to both enhance positive outcomes and reduce negative and risky behaviors among youth. Although PYD arose from research and evaluation efforts in youth development programs, growing research has demonstrated that PYD is effective in diverse contexts, including workforce development programs, teen pregnancy prevention programs, and juvenile justice systems. Research incorporating a PYD approach encompasses both the development of strengths-based, supportive, promotive programs and the measurement of positive outcomes.

Consequently, we recommend integrating eight key elements of PYD into the NICHD Strategic Plan: physical and psychological safety; supportive relationships; opportunities to belong; support for efficacy and mattering; positive social norms; opportunities for skill-building; appropriate structure; and integration of family, school, and community efforts.<sup>2</sup> This approach is particularly relevant for Theme 5 (Improving Health During the Transition From Adolescence to Adulthood), and broadens the approach to include factors that contribute to adolescent resilience and positive health behaviors. For instance, Theme 5 is currently focused on identifying the factors that "...may give rise to specific health behaviors that place the adolescent at higher risk for specific disorders in adulthood." We encourage NICHD to also focus on protective or promotive factors to support the positive development of adolescents as they transition to adulthood. For example, one could design and fund studies that do not only include negative outcomes (such as school dropout, substance misuse, adolescent childbearing, delinquent behaviors, or mental health problems), but also include positive outcomes such as the attainment of post-secondary credentials and degrees; employment and economic self-sufficiency; community and civic engagement; development of healthy peer, family, and romantic relationships; physical health; and social and emotional competence. In addition to focusing on positive outcomes, NICHD can incorporate a PYD approach by supporting studies of programs focused on reducing risks or promoting positive development through the incorporation of such practices as identifying young people's assets, building their skills, and helping to foster positive relationships.

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<sup>1</sup> Office of Disease Prevention and Health Promotion (no date). Adolescent Health. Available at <https://www.healthypeople.gov/2020/topics-objectives/topic/Adolescent-Health>

<sup>2</sup> Eccles, J., & Gootman, J.A. (Eds.). (2002). Community programs to promote youth development. Washington DC: National Academy Press.

3. **Consider determinants of health and well-being from a bioecological perspective, considering multiple levels of influence, in Research Themes 1, 4, and 5.**

The research themes identified in the NICHD Strategic Plan emphasize the importance of considering the social determinants of typical and atypical development from preconception, conception, and gestation (Theme 1) through early childhood development (Theme 4), and into adolescence and the transition to adulthood (Theme 5). However, as indicated in the description of these opportunities, the social determinants are not represented at all levels of contextual influence. For example, Theme 1 (Understanding Early Human Development) calls out the role of environmental exposures that might affect early development but does not describe other contextual or interactive factors (such as social and economic inequities and family factors) that likely also affect early development. **We recommend that NICHD encourage investigators to consider the full range of contexts at multiple levels of the complex human developmental system (as specified in Bronfenbrenner’s bioecological model<sup>3</sup> of development) in the design and execution of their studies to understand the nature of human development (Theme 1), identify critical periods for intervention (Theme 4), and improve outcomes from the transition from adolescence to adulthood (Theme 5).**

The bioecological model posits that gene-environment interactions that can affect the course of human development occur within five systems: (1) the most proximal developmental environments such as the home or child care setting (i.e., the microsystem); (2) interactions among these microsystems (i.e., the mesosystem); (3) environments that are a bit more removed from immediate contact with the individual, such as the neighborhood (i.e., exosystem); (4) even more distal environments and contexts, such as state and federal policies (i.e., the macrosystem), which are often the root of structural inequalities that lead to disparities; and (5) environments experienced over time (i.e., the chronosystem). A consideration of the full range of bioecological systems affecting development is applicable across Themes 1, 4, and 5. As just one example, Theme 4 (Identifying Sensitive Time Periods to Optimize Health Interventions) suggests that research examine nutritional interventions introduced during sensitive developmental periods. Participants in a nutritional study may be receiving—in addition to a specific nutritional supplement as part of the study—nutrition assistance through federal programs such as WIC or SNAP, or may be experiencing food deserts in their neighborhoods; in addition, they will be exposed to and influenced by the nutritional practices of their home and school environments over time. In sum, a bioecological perspective is important to understanding child and adolescent

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<sup>3</sup> Bronfenbrenner, U. & Ceci, S.J. (1994). Nature-Nurture Reconceptualized in Developmental Perspective: A Bioecological Model. *Psychological Review*, 101(4), 568-586.

development and should be embedded within the NICHD Strategic Plan, especially when considering the range of determinants of health and well-being.

**4. Relatedly, adopt a whole child approach, considering all aspects of child development, in Research Themes 4 and 5.**

The NICHD Strategic Plan primarily measures child development outcomes with biomedical or behavioral markers and does not yet emphasize key outcomes in other important domains of development that are also essential to young children's and adolescents' optimal growth and well-being. We know that the social and cognitive domains of development are closely linked. For example, the quality of an infant's emotional attachment to a primary caregiver not only contributes to the infant's social-emotional development,<sup>4</sup> but is also a strong contributor to the infant's ability to engage in physical exploration of his or her environment; this, in turn, contributes to the development of children's motor and cognitive development.<sup>5</sup> We also know that the social-emotional context of development can have long-ranging effects on health, social and economic achievement, and well-being throughout adolescence and into adulthood. Similarly, we know that the number and variety of words children hear in their first years of life can influence their own vocabulary growth, and that disparities in children's language skills can contribute to disparities in academic trajectories.<sup>6</sup> **We therefore encourage NICHD to include social-emotional and language outcomes—along with cognitive, behavioral, and physiological outcomes—as areas of targeted inquiry for the health and well-being of children and adolescents as part of Research Themes 4 and 5.** The Theme 4 discussion of critical periods mentions plasticity in the motor, cognitive, and behavioral systems, but there is no mention of plasticity in the social-emotional domain. In addition, in Theme 5, the social domain is mentioned only as a "factor contributing to" adolescent development and not as a targeted area of investigation for either child or adolescent development. Research supported by NICHD should explore the role of biological, environmental, social, and cultural factors on the physiological, social-emotional, cognitive, language, and behavioral outcomes for young children and adolescents.

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<sup>4</sup> Ainsworth, M. D. S., Bell, S. M., & Stayton, D. (1974). Infant-mother attachment and social development. In M. P. Richards (Ed.), *The introduction of the child into a social world* (pp. 99-135). London: Cambridge University Press.

<sup>5</sup> Bell, S. M. (1970). The development of the concept of the object as related to infant-mother attachment. *Child Development*, 41, 291- 311.

<sup>6</sup> Hart, B., & Risley, T. R. (1995). *Meaningful differences in the everyday experience of young American children*. Baltimore, MD: Paul H. Brookes Publishing Company.

5. **Emphasize variability in risks, protection, and outcomes by race/ethnicity, socioeconomic status, gender, and sexual orientation in all six research themes.**

As noted in the RFI, NICHD has been a national and international leader in research involving children, pregnant women, and people with disabilities. **We encourage the NICHD to prioritize generating research that 1) underscores the heterogeneity in experiences and outcomes across individuals from different racial and ethnic groups, socioeconomic statuses, genders, sexual orientations, and other subgroups; 2) does not perpetuate inequities; 3) acknowledges structural root causes of disparities (e.g., policy); and 4) incorporates the voice of the communities being studied.** Disparities in the various outcomes of interest specified in the strategic plan (e.g., birth defects, maternal health) have been documented. One-size-fits-all solutions that do not consider the variability in risks, assets, and outcomes across groups are not likely to be effective at reducing or eliminating disparities. We have seen how interventions that are, on average, effective do not always have the same effects across subpopulations. For instance, trends in Sudden Unexpected Infant Death (SUID) rates following the *Back to Sleep!* Campaign were distinct, with varying significance in declines for different racial and ethnic subgroups.<sup>7</sup> Well-established conceptual models can also be flawed if they do not consider unique risks among specific populations. For example, a recent study showed that the negative relationship between effective parenting and children’s antisocial behaviors—a widely documented relationship that has served as the foundation for many parenting interventions—was not as strong when children were experiencing cultural and minority-related stressors in the United States (e.g., discrimination, tension navigating the demands of two cultures).<sup>8</sup> Similar arguments can be made across other important stratifiers such as sex, gender, socioeconomic status, and sexual orientation.

**We recommend that research across the six themes should examine common and unique predictors and outcomes across different segments of the population.** This approach is essential to developing tailored and effective interventions. At minimum, this requires gathering adequate data with sample sizes large enough to allow for such examinations between and within groups (also see #1 above). Hard-to-reach and non-white populations have often been underrepresented in studies, creating a gap in knowledge about specific populations. Efforts to include these groups in research is a necessary first step, but an intentional effort to examine variability across groups also requires an

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<sup>7</sup> Parks, S. E., Erck Lambert, A. B., & Shapiro-Mendoza, C. K. (2017). Racial and Ethnic Trends in Sudden Unexpected Infant Deaths: United States, 1995–2013. *Pediatrics*, 139(6). doi:10.1542/peds.2016-3844

<sup>8</sup> Wei, C., Eisenberg, R. E., Ramos-Olazagasti, M. A., Wall, M., Bird, H. R., Canino, G., Duarte, C. S. (2017). Developmental psychopathology in minority youth: A longitudinal study of parental risks and behavior, cultural stress, and antisocial behaviors among Puerto Rican youth. *Journal of the American Academy of Child and Adolescent Psychiatry*, 56(12), 1081-1088. PMC5846190

investigation of the underlying causes of disparities and a commitment to conducting research in a culturally appropriate way (see #6 below). For example, pregnancy and postpartum outcomes such as low birthweight and preterm delivery vary widely among racial/ethnic subgroups. For Theme 2, which aims to “improve pregnancy outcomes to maximize the lifelong health of the woman and her child(ren),” we recommend that research examine the structural factors (e.g., access to health care, housing insecurity) that contribute to variability in pregnancy outcomes across subgroups (see #3 above) and identify group-specific protective factors on which to build interventions. Studies of the placenta (Theme 2) can examine early exposures and risks to illuminate the prenatal conditions that might set certain groups of children on a negative trajectory. The adequate timing of interventions (Theme 4) may also vary depending on the population of study. Those who have been exposed to risks for generations may need multi-generational interventions for more extended periods of time. All in all, research that is sensitive to the heterogeneity of risks and outcomes across groups will lead to better science and better outcomes.

#### 6. **Embed an equity lens in research approaches.**

NICHD’s strategic plan recognizes “a great need for innovative and transformative work to harness new technologies and methods that address health disparities and improve prevention efforts among the populations we serve.” NICHD’s research initiatives within and outside the United States serve diverse populations, including across race and ethnicity, gender, sexual orientation, and geography (among other distinctions). This context presents an opportunity to harness the benefits of diverse perspectives and cultural strengths, and to minimize the potential that research advances might unintentionally contribute to further disparities among the many subpopulations mentioned above (see #5 above). **Therefore, we recommend that opportunities put forth for all research themes under consideration by NICHD call for an equity approach in the design, conduct, and dissemination of research.** Culture—including one’s race and ethnicity—shapes values, beliefs, and behaviors. Incorporation of cultural assumptions and norms, the group’s history and context, and the reality of structural inequities in the experiences of diverse populations can foster innovation and relevance of research by informing the types of questions asked, methods used, and interpretation and communication of results. Moreover, research grounded in equity approaches that acknowledge power, privilege, and intersectionality will often include the groups that are frequently marginalized in research and ultimately promote equity in exploring persistent disparities. Mandating an equity approach in NICHD’s strategic plan must involve an acknowledgment of the additional resources, capacity, and time needed to conduct this research.

We recommend that NICHD embed an equity lens across the six research themes outlined in the proposed strategic plan. For example, to achieve the goals for Theme 2 (Setting the Foundation for a Healthy Pregnancy and Lifelong Wellness) and Theme 6 (Ensuring Safe and Effective Therapeutics and Devices), we recommend the following: that researchers acknowledge that, to address the decades of disparities in pregnancy and child health outcomes faced by certain racial and ethnic subgroups, these groups should be engaged in research that aims to unpack their structural root causes. Equity approaches emphasize inclusion of these subgroups at the beginning of the research process and may require accommodations for group preferences within research protocols (e.g., to address cultural differences in the appropriateness of sharing placental tissue or other biospecimens). Studies designed and conducted with an equity lens can facilitate recruitment of the groups that may benefit the most from research advances, and the prevention and intervention strategies based on that research will be more likely to align with the cultural belief systems and contexts of these subgroups to produce practical recommendations and sustainable improvements. Finally, Theme 4 (Identifying Sensitive Time Periods to Optimize Health Interventions) presents an opportunity to draw on diversity as a strength. For instance, cultures across the globe have rituals, ceremonies, and rites of passage tied to developmental milestones; if explored with an equity lens, such cultural factors could provide insights for health promotion and disease prevention.

Again, we thank you for this opportunity to comment on NICHD's proposed Strategic Plan for Fiscal Years 2020-2024. For any questions regarding these comments, please contact Jennifer Manlove ([jmanlove@childtrends.org](mailto:jmanlove@childtrends.org), 240-223-9262) or Tamara Halle ([thalle@childtrends.org](mailto:thalle@childtrends.org), 240-223-9234).

Sincerely,

/s/

Carol Emig

President