

SPAN & Family Voices-New Jersey comments on the Request for Information (RFI): NICHD Strategic Plan Fiscal Years 2020-2024

January 10, 2019

Thank you for the opportunity to comment to the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD) on the proposed Request for Information (RFI): NICHD Strategic Plan Fiscal Years 2020-2024. The SPAN Parent Advocacy Network (SPAN) is New Jersey's one-stop for families of children birth to 26 across systems; our special priority are children and families at greatest risk due to poverty, disability and special healthcare needs, discrimination based on race, ethnicity, immigrant or language status, or other special circumstances. Family Voices-NJ is the New Jersey affiliate for Family Voices, dedicated to supporting the family voice in children's healthcare. SPAN also serves as the Parent to Parent USA affiliate for NJ; the NJ Parent Training and Information Center and Family to Family Health Information Center; and a chapter of the National Federation of Families for Children's Mental Health. Our comments today are based on our extensive experience providing support to families around these issues.

Purpose

We understand that the “*Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD) is updating its strategic plan to help guide the research.”

Background

Although we acknowledge that “the United States and the global community face an array of challenges, such as the opioid crisis and high rates of maternal mortality, that threaten to erode gains in public health,” we disagree that there have been [significant](#) gains in black infant/maternal mortality and other topics and our concerns appear under the research themes below.

Information Requested

We understand that “NICHD seeks comments and suggestions on the following research themes, goals, and opportunities:”

Research Theme #1: Understanding Early Human Development

Goal: *Enhance knowledge of genes and regulatory networks at the single- and multi-cell levels during preconception, conception, and gestation to understand human development, improve fertility, and reduce pregnancy loss.*

Opportunities:

We **support** analyzing “novel platforms, tools, and techniques to characterize the early stages of development.” We also **support** helping to “identify potential targets for prevention. We **agree** that this will provide “opportunities to understand at a cellular level what developmental factors contribute not only to typical development but also to infertility, miscarriage, stillbirth, birth defects, and other congenital conditions.” We would caution however that this needs to be used to help families prepare, and not misused such as abortion of all babies with Down syndrome.

Research Theme #2: Setting the Foundation for a Healthy Pregnancy and Lifelong Wellness

Goal: *Improve pregnancy outcomes to maximize the lifelong health of the woman and her child (ren).*

Opportunities:

We **support** this goal which is “focused on the developmental origins of health, including the development of early indicators of risk for threats to maternal health during pregnancy...” We **agree** that this would also help address the opioid epidemic by informing “prevention strategies by considering lifestyle factors (e.g., maternal weight, substance misuse, etc.)...” We **strongly support** understanding “the contributors to morbidity and mortality will help to identify and validate targets for preventing preterm birth and related adverse events” as this will help address black infant and maternal mortality.

Research Theme #3: Promoting Gynecological, Andrological, and Reproductive Health

Goal: *Enable men and women to manage fertility and minimize the impact of gynecological and andrological conditions.*

Opportunities:

We **agree** with this goal as an opportunity to increase “knowledge that may lead to treatments.” We **support** research on conditions that are often not diagnosed for years for women or misdiagnosed in minority populations (e.g. pelvic inflammatory disease) such as endometriosis (see <https://www.webmd.com/women/news/20180607/why-women-are-getting-misdiagnosed.>)

Research Theme #4: Identifying Sensitive Time Periods to Optimize Health Interventions

Goal: *Understand sensitive time periods during development and rehabilitation when prevention and treatment strategies may have the greatest impact.*

Opportunities:

We **support** determination of when “the use of a particular intervention—will have the greatest impact.” We **agree** with investigating “mechanisms of plasticity in early developmental stages.” In addition, we **support** examining “the initiation and termination of these sensitive time periods... [to] inform the timing of prevention and management, including early interventions for intellectual, developmental, and learning disabilities and therapeutic approaches in critical care and rehabilitation settings.” However, we caution that this should not be used by insurance companies to deny treatment after a certain age if it is not the “optimal time”, particularly if the individual received a late diagnosis. We **agree** with “looking at social determinants, in conjunction with biological factors, that influence these sensitive time periods will enhance our ability to target interventions.”

Research Theme #5: Improving Health During the Transition From Adolescence to Adulthood

Goal: *Improve the transition from adolescence to adulthood by identifying behavioral, social, environmental, and biological factors that enhance health, especially for adolescents with disabilities or other chronic conditions.*

Opportunities:

We **strongly agree** with looking at adolescent health in terms of preventive care such as immunizations, risky behavior, and particularly “the impact of the medical transition from pediatric to adult care, especially for children with disabilities or other chronic diseases.” However, we **disagree** that it has been “understudied” as transition to adult care is one of the Maternal/Child Health 6 core outcomes (see <https://mchb.hrsa.gov/cshcn0910/core/co.html>; see also <https://www.gottransition.org/researchpolicy/index.cfm>, Got Transition’s resources for [researcher and policymakers](#)).— Much is known about transition to adult care for children with special health care needs and research needs to build on implementation strategies for better outcomes. Children with medical complexity are particularly at risk, and those with organ transplants have often gone into rejection during inappropriate handoff between pediatric and adult providers (see <https://optn.transplant.hrsa.gov/governance/public-comment/pediatric-transition-and-transfer-guidance-document/>.)

Research Theme #6: Ensuring Safe and Effective Therapeutics and Devices

Goal: *Develop, test, and validate safe and effective therapeutics and devices specifically for pregnant and lactating women, children, and individuals with disabilities.*

Opportunities:

We **strongly support**, with consent, the inclusion of pregnant “and lactating women, children, and individuals with disabilities have specific needs that can only be addressed through their inclusion in the development, testing, and validation of therapeutics and devices.” We would caution however that this must be done with informed consent as historically individuals with disabilities have been inappropriately used in research and experimentation, even recently. Women react different to diseases, interventions, and drug treatments than men. In fact, it wasn’t until 1993 that Congress required clinical trials to include women. Conditions also affect children differently than adults. For example, physical and cognitive growth can be affected in children with kidney disease but not adults. People with disabilities may react differently to common conditions. For example, the CDC found the individuals with neurological factors such as developmental disability or seizure disorder were more at risk of hospitalization or death from the flu.

We would suggest combining themes 1-3 on early human development; healthy pregnancy; and gynecological, andrological, and reproductive health. We would then add a separate theme on addressing health disparities. Health disparities affect underserved populations in various ways. The NJ Hospital Association found that uninsured families (Black followed by Hispanic families) were diagnosed on average age 2-4 years after their covered peers, when disease is harder to treat, increasing morbidity and mortality. NECTACS (National Early Childhood Technical Assistance CenterSystem) found that in NJ Hispanic followed by Asian families were diagnosed later than peers, even though early intervention is key to best outcomes. Indeed current research in autism spectrum disorders (see <https://www.npr.org/sections/health-shots/2018/03/19/587249339/black-and-latino-children-are-often-overlooked-when-it-comes-to-autism>) shows again that minority children are diagnosed later which worsens lifelong outcomes. Black infant mortality has been stagnant in our state for over a decade. New initiatives will finally address the fact that black babies are at a 3 times higher risk of death and their mothers are at a 4 times higher risk. SPAN has~~We had~~ a pilot doula project which demonstrated that just by having support, new mothers could avoid unnecessary C-sections and other pregnancy complications (see <https://www.njspotlight.com/stories/18/04/24/black-mamas-highlight-racial-maternal-health-disparities/>.) The National Association of City and County Health Officials now has a separate initiative on people with disabilities as an underserved population which results in health disparities (see <https://www.naccho.org/programs/community-health/disability/>.) People with disabilities are also discriminated against when considering organ transplants (see <https://autisticadvocacy.org/policy/toolkits/organs/>.) Health literacy is the single largest barrier to health care access. In summary, health disparities must be addressed in underserved populations throughout the lifespan with consideration of health literacy as well as cultural and linguistic competency.

Thank you for the opportunity to comment on the proposed NICHD Strategic Plan.

Sincerely,

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To empower families and inform and involve professionals and other individuals interested in the healthy development and education of children, to enable all children to become fully participating and contributing members of our communities and society.