

Mary Jo Hoeksema, Chair, Friends of the National Institute of Child Health and Human Development (NICHD), Subcommittee on Labor, Health and Human Services, Education

I am writing on behalf of the Friends of NICHD, a coalition of over 100 organizations representing patients, providers, scientists, and caregivers who are united in our support for ensuring the health and welfare of women, children, families, and people with disabilities. We are pleased to communicate our support for funding both the National Institute of Child Health and Human Development (NICHD) and the National Institutes of Health (NIH) in Fiscal Year (FY) 2019. Our coalition urges the Labor, Health and Human Services, Education Appropriations Subcommittee to provide NICHD with \$1.531 billion in Fiscal Year (FY) 2019, an increase of \$79 million over FY 2018. The Friends of NICHD also respectfully ask the subcommittee to maintain its commitment to increasing funding for the National Institutes of Health (NIH) and to provide that agency with \$39.3 billion in FY 2019, a \$2.2 billion increase over FY 2018.

We are pleased to support the extraordinary work of NICHD. NICHD has achieved great success in meeting the objectives of its biomedical, social, and behavioral research mission, including research on child development before and after birth; women's health throughout the life cycle; maternal, child, and family health; learning and language development; reproductive biology; population health; and medical rehabilitation. With sufficient resources, NICHD can build upon the initiatives listed below to produce new insights and solutions to benefit the women, children, and families in your districts and states.

Behavioral health research: NICHD supports a range of research on child development and behavior. We now have a wide range of sophisticated methodological and statistical tools to

delineate children's cognitive and socioemotional functioning at a grain level that can be articulated with brain data. We therefore encourage more longitudinal behavioral and biobehavioral work on child developmental trajectories, across infancy, childhood, and adolescence, in both normative and at-risk environments, across diverse contexts (school, home, and community) and including underrepresented and vulnerable groups. More research is also needed on integrated behavioral health in primary care settings, including cost effectiveness comparisons, and impact of behavioral interventions on mental health, physical health, and quality of life. More work on the role of technology to support optimal development in children and increase access to and engagement with effective psychological and behavioral interventions for childhood conditions would also be helpful.

Poverty and Child Health: Poverty can be especially detrimental in childhood and adolescence, leading to adverse impacts on physical health, mental health, social well-being, cognitive and emotional development, and the acquisition of motor and language skills. NICHD is in the unique position to examine the biological, psychological, social, cultural, and environmental factors that impact the developing child in high-poverty environments -- including challenges due to chronic stress, neighborhood safety, school environments, family health status, education, job instability, unstable family structures, and substandard living conditions -- and to evaluate interventions aimed at improving the developmental trajectories of these children.

Data on Pediatric Enrollment in NIH Trials: New NIH policy will soon require investigators to submit to NIH deidentified demographic data on study participants, including age at enrollment. It is important that NIH appropriately analyze and report on this data to ensure

that all populations, including children, benefit from research. NICHD should play a leading role in the implementation of this policy vis-à-vis age.

Best Pharmaceuticals for Children Act (BPCA): NICHD funds, through BCPA, the study of old, off-patent drugs important to children but inadequately studied in pediatric populations. We urge continued funding for this research and for training the next generation of pediatric clinical investigators.

Environmental Influences on Child Health Outcomes (ECHO) Program: The ECHO program has the potential to be an important tool for assessing the impact of a child's environment on health outcomes. We encourage continued support for this important program.

PregSource: We urge Congress to continue its support of NICHD's PregSource™ initiative, which recently launched. This crowd-sourcing project allows pregnant women to track their health data from gestation to early infancy and access evidence-based information about healthy pregnancies, as well as will allow researchers to utilize aggregated data and potentially recruit participants for clinical trials so that knowledge gaps can be eliminated and care for pregnant and post-partum women can be improved.

Task Force Specific to Pregnant Women and Lactating Women (PRGLAC): We urge Congress to continue its strong support of the PRGLAC Task Force, led by the NICHD. We expect PRGLAC's required report to the Secretary and Congress in the fall, and we urge Congress to support appropriate recommendations contained in the report that lead to broader inclusion of pregnant and lactating women in research, and so that lifesaving treatments that this population may take are known to be safe and effective.

Human development, infancy through adulthood: NICHD supports research on infant through adult development including investigating how father-child relationships and co-parenting positively impacts children's socio-emotional development and decreases behavior problems; children's adjustment after the birth of a sibling; pathways and outcomes associated with mothers' postseparation co-parenting relationships, with a particular focus on experiences of intimate partner violence and negative health outcomes; and the health and well-being across three generations of lesbians, gay men, and bisexuals.

Intellectual and Developmental Disabilities Research Centers (IDDRC): The IDDRCs are a national resource for basic research into the genetic and biological basis of human brain development, greatly improving our understanding of the causes of developmental disabilities and contribute to the development and implementation of evidence-based practices by evaluating the effectiveness of biological, biochemical, and behavioral interventions. We urge NICHD to provide additional resources to the IDDRCs for research infrastructure and expansion of cores to conduct basic and translational research to develop effective prevention, treatment, and intervention strategies for children and adults with developmental disabilities.

Maternal Mortality: The Pregnancy and Perinatology Branch supports research to improve the health of women before, during and after pregnancy. Maternal mortality rates are at an unprecedented high in the United States and significant racial and ethnic disparities persist. Research to better understand the mechanisms of disparities, to include social determinants of health and genetic factors that adversely affect pregnancy outcomes, are vitally needed.

Preterm Birth: NICHD supports a comprehensive research program on the causes, prevention, and treatment of preterm birth, the leading cause of infant mortality and intellectual and physical disabilities. Research shows the survival rate and neurological outcomes may be improving for very early preterm infants, but continued prioritization is needed through extramural preterm birth prevention research, the Maternal-Fetal Medicine Units Network, the Neonatal Research Network, and intramural research program. Robust funding is needed for research to determine the complex interaction of behavioral, social, environmental, genetic, and biological influences on preterm birth with the goal of developing the interventions necessary to decrease prematurity.

Population Dynamics: The NICHD Population Dynamics Branch supports research on how population change affects the health, development, and wellbeing of children and their families. The branch's support of longitudinal surveys, such as the Fragile Families and Child Wellbeing Study, which has demonstrated the role that family stability (e.g., chronic stress) and parental involvement (e.g., paternal engagement) play in the long-term health and development of children, has facilitated tremendous progress in the population sciences.

NICHD also supports the Population Dynamics Centers Research Infrastructure Program, which supports research and research training in demographic or population research. These centers focus on research areas such as family demography and intergenerational relationships; education, work, and inequality; population health; and reproductive health.

Thank you for considering our request to fund the NIH and NICHD in FY 2019. We look forward to working with you to meet the needs of these agencies and advance their scientific research missions.