FY 2020 House Appropriations Committee Public Testimony, Submitted by the Friends of NICHD, for the Subcommittee on Labor, Health and Human Services, Education, and Related Agencies (LHHS). Addressing the NIH and NICHD

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 through research funded by the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD) and the National Institutes of Health (NIH). We urge the Subcommittee to provide NICHD with $1.6 billion in Fiscal Year (FY) 2020, an increase of $94 million over FY 2019. We also respectfully ask the subcommittee to maintain its commitment to increasing funding for the National Institutes of Health (NIH) by providing $41.6 billion in FY 2020, a $2.5 billion increase over FY 2019.

We are pleased to support the extraordinary achievements of NICHD 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 these necessary resources, NICHD can build upon the initiatives listed below to produce new insights and solutions to benefit women, children, and families in your districts and states.

Behavioral Health Research: NICHD supports a range of research on child development and behavior and has made great progress developing sophisticated tools to measure children's cognitive, emotional, and social functioning. To build on these successes, we encourage more integrated 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 the impact of behavioral interventions on mental health, physical health, and quality of life. Child health would also benefit from additional work on the role of technology to support optimal development in children, including those with disabilities, and increased access to and engagement with effective psychological and behavioral interventions for childhood conditions.

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: NIH requires investigators to submit deidentified demographic data on study participants, including age at enrollment. It is important for NIH to 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.

Infant and Childhood Health: Through the Best Pharmaceuticals for Children Act (BPCA), NICHD funds 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. We also strongly support NICHD's ongoing research into the causes and prevention strategies for the major causes of death in infancy and childhood, including sudden unexpected infant death, accidents, and suicide.

Reproductive Sciences: Research on the basic biological mechanisms of reproduction is a crucial foundation for all of the work of NICHD. Understanding reproductive biology and associated biological phenomena provides the foundation for innovative medical therapies and technologies and improves existing treatment options for gynecologic conditions. Often, this research focuses on serious conditions that are overlooked and underfunded, despite the fact that they impact many women. Future work could address infertility and the need for treatments for endometriosis, polycystic ovarian syndrome (PCOS) and uterine fibroids.

Pelvic Floor Disorders Network (PFDN): Female pelvic floor disorders represent a major public health burden with high prevalence, impaired quality of life and substantial economic costs affecting 25% of American women. The PFDN conducts research to improve treatment of these painful gynecological conditions. Current research aims to improve female urinary incontinence outcome measures and ensure high quality outcomes.

PregSource: NICHD's PregSource™ initiative allows pregnant women to track their health data from gestation to early infancy and access evidence-based information about healthy pregnancies. It will also 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 Research in Pregnant Women and Lactating Women (PRGLAC): We urge Congress to continue its strong support of the NICHD-led PRGLAC Task Force, and to support the recommendations contained in the report to achieve broader inclusion of pregnant

and lactating women in research and expansion of the workforce of clinicians and researchers with expertise in obstetric and lactation pharmacology and therapeutics, so that lifesaving treatments for this population are known to be safe and effective.

Human development, infancy through adulthood: NICHD supports research on infant through adult development including 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 critical 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 contributing to the development and implementation of evidence-based practices by evaluating the effectiveness of biological, biochemical, and behavioral interventions. These centers have contributed to new treatments for genetic disorders through the study of intellectual and developmental disabilities, such as Everolimus for epilepsy in TSC. We must build on progress in the understanding and treating this class of disorders that affect so many. We urge resources and support for 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, through networks including the Maternal-Fetal Medicine Units (MFMU) Network, 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 MFMU 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. Longitudinal surveys, such as the Fragile Families and Child Wellbeing Study, have demonstrated the role that family stability and parental involvement play in the long-term health and development of children, facilitating 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.