# NICHD Strategic Planning: Background and Context

# Introduction

For more than 50 years, the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD) has supported and conducted research on the processes of human development and how they affect health, from preconception through adulthood. NICHD's research has saved lives, prevented disabilities, and improved quality of life for many Americans. The NICHD portfolio encompasses research on areas as diverse as cellular biology; fetal, infant, and child growth and development; learning and intellectual and developmental disabilities; early education; infectious diseases; contraception; gynecology; male and female infertility; pregnancy; population sciences, biotechnology; behavioral and social sciences; injury and trauma; medical rehabilitation; pediatric and obstetric pharmacology; and many others. Today, new challenges and opportunities are emerging rapidly, and the institute must examine approaches to advancing the science in its broad mandate.

In January 2018, NICHD initiated a data-driven process to develop a new strategic plan and guide the institute's activities for the next several years. This included a review of NICHD's research portfolio across its intramural and extramural programs and of the impact of the science supported by NICHD. Portions of these preliminary analyses are summarized here to provide contextual information to inform the deliberations of the NICHD Strategic Planning Working Group.

# Background

NICHD is the ninth largest of the 27 Institutes and Centers (ICs) that constitute the National Institutes of Health (NIH), within the U.S. Department of Health and Human Services (HHS). Most of NICHD's research dollars are distributed through the extramural program<sup>1</sup> to academic and other research institutions. NICHD also supports a vibrant intramural program<sup>2</sup> of research on the NIH campus in Bethesda, Maryland, and at other facilities. Table 1 uses data from fiscal year 2017 to provide an overview on the type and extent of support NICHD provides to the extramural and intramural community.

NICHD's Division of Extramural Research (DER) coordinates and funds research and training programs across the United States and internationally through grants and contracts. DER is comprised of 12 extramural branches, covering wide-ranging topics including developmental biology, contraception, intellectual disabilities, pediatric trauma, pregnancy, and population

<sup>&</sup>lt;sup>1</sup> The Extramural Research Program funds research and training opportunities at universities, medical centers, and other institutions throughout the United States and abroad through research grants, career development awards, and other mechanisms.

<sup>&</sup>lt;sup>2</sup> The Intramural Research Program supports the research projects that are conducted on the NIH campus or other satellite laboratories by scientists who are employed by the Federal government.

sciences. The National Center for Medical Rehabilitation Research (NCMRR) also supports research extramurally and serves a coordinating function for medical rehabilitation research across NIH and the federal government.

NICHD's Division of Intramural Research (DIR) conducts laboratory and clinical research programs to seek fundamental knowledge about the nature and behavior of living systems. DIR research is conducted in a multidisciplinary environment that investigates the physics, chemistry, and biology of cells; the processes that govern and regulate cellular function; and the effects when these processes fail. DIR includes 74 tenured and tenure-track investigators, organized into 13 affinity groups, and 335 postbaccalaureate, clinical, and postdoctoral fellows and graduate students.

NICHD	FY 2017	
Total appropriations	\$1,380,295	
Percent of extramural/intramural funding	Extramural: 81%;	
	Intramural: 14%;	
	Research Management &	
	Support 5%	
Number of new competing applications received	4,874	
Number of funded extramural grants		
(new & non-competing; no subprojects)	2,578	
Number of extramural PIs	2,783	
Number of extramural funded institutions	442	
Number of funded early-stage extramural PIs 321		
Number of Intramural Research Staff	1,030	
Number of intramural PIs	74	
Number of intramural Trainees	335	
Number of intramural clinical protocols	77	

#### Table 1: Key Statistics About the NICHD, FY 2017

The institute's Division of Intramural Population Health Research (DIPHR) designs and conducts innovative etiologic and interventional research on preconception through adulthood. Key areas of focus within DIPHR include bioinformatics at a population level, including biomarker and genetic analysis; reproductive, perinatal, and pediatric epidemiology; and behavioral sciences research focused on children, adolescents, and families. DIPHR scientists collaborate extensively with extramural scientists, including providing support through contracts, to further population research.

NICHD has benefited from a steady increase in funding support since 1990. Although the unadjusted funding shows a general upward trend, NICHD's 2017 appropriation is below year 2000 levels after adjustment for inflation using the Biomedical Research and Development Price Index (Figure 1).<sup>3</sup>

<sup>&</sup>lt;sup>3</sup> For more information about the Biomedical Research and Development Price Index, see <u>https://officeofbudget.od.nih.gov/gbiPriceIndexes.html</u>.



*Figure 1: NICHD Appropriations, Adjusted and Unadjusted for Biomedical Cost Inflation, FY 1990-2017* 

#### **NICHD's Strategic Planning Process**

Research topics and technologies that fit the NICHD mission are evolving rapidly and drive the need to update the NICHD strategic plan from 2000. In January 2018, NICHD began a new strategic planning process based on three core principles: (1) a transparent process that focuses on the science, (2) guided by evidence, and (3) informed by our communities. The overarching goal of this process is to provide a focus and strategy for the research NICHD supports to improve the health of the populations we serve.

The Strategic Planning Process entails 5 primary phases: (1) pre-planning, (2) data gathering and analyses, (3) outreach to seek input from internal and external stakeholders, (4) review and refinement of the collected information and plan generation, and (5) development of a communication strategy and implementation plan. NICHD is embarking on Phase 3 to seek input from our internal and external stakeholders. This includes the NICHD Strategic Planning Working Group (Working Group), comprised of both internal and external stakeholders (27 NICHD staff-members, 53 external researchers).

The Working Group is charged with providing input on the following key points: defining the scientific foci for NICHD and identifying priorities within them, identifying opportunities in training and partnerships to advance these foci, and identifying key areas of technical innovation NICHD should be poised to address. After the working group and other opportunities for public input, NICHD will synthesize the information gathered to identify the elements of its new strategic plan.

# NICHD's Portfolio: Scientific and Public Health Domains

NICHD's wide-ranging mission demands a variety of scientific tools and approaches. For example, research to promote healthy child development requires a range of expertise in pediatric physiology, psychology, social and emotional development, population sciences, childhood diseases, and clinical practice. NICHD's portfolio, both intramural and extramural, incorporates basic biomedical and behavioral sciences, population sciences, screening and diagnostics, and behavioral and biomedical interventions to prevent and treat diseases and conditions (Figure 2). These categories, which are not mutually exclusive, are defined as follows:

- Basic sciences refers to research designed to describe or elucidate underlying biological and/or behavioral processes and mechanisms necessary for understanding disease and health. At NICHD, this includes fundamental studies of disease mechanisms using animal models or human tissue, but does not include studies of interventions. A portion of this research includes basic behavioral sciences, with a focus on understanding fundamental behavioral mechanisms.
- Population sciences and epidemiology studies refers to research aimed at describing health and disease, as well as health-related behavioral and biomedical risk factors, at the population level.
- Screening and diagnosis refers to research efforts designed to develop and/or assess new or existing methods for screening and diagnosis of diseases or conditions.
- Biomedical interventions refers to research designed to develop and/or assess new biomedically based interventions to prevent or treat diseases or conditions. Research in this category includes pharmaceuticals, vaccines, therapies, medical devices, and others.
- Behavioral interventions refers to research intended to develop and/or assess behaviorally based interventions to prevent or treat diseases or conditions. Research in this area includes lifestyle interventions, diet, exercise, and other health behaviors.



#### Figure 2: NICHD Portfolio by Scientific Domains, FY 2017

Source: NIH Research, Condition, and Disease Categories (RCDC) system<sup>4</sup>; NICHD Child Health Information Retrieval Program (CHIRP)<sup>5</sup>

Because of NICHD's broad mission, a wide range of public health concerns fall within the institute's purview. Public health domains of key importance to NICHD can be classified into four broad, overlapping groups: Pediatrics and Child Development; Gynecology and Reproductive Health; Pregnancy and Maternal Health; Intellectual, Developmental, Learning, and Physical Disabilities. The distribution of NICHD's 2017 funding, combining intramural and extramural research, is demonstrated in Figure 3. Together, the four groups cover 93 percent of the NICHD research portfolio. Although pediatrics and child development represents the largest share of funding, each group accounts for a significant share of the institute's research dollars.

Figure 3: NICHD Portfolio by Public Health Domains, FY 2017



Source: NIH Research, Condition, and Disease Categories (RCDC) system; NICHD Child Health Information Retrieval Program (CHIRP). Data for the Disabilities category are unofficial; they have not been validated through the RCDC process.

# Pediatrics and Child Development

NICHD accounts for 18 percent of pediatric and child development research spending across NIH. Pediatric research plays a significant role at other NIH ICs, including pediatric cardiology and asthma (NHLBI), pediatric cancer (NCI), mental health in children and adolescents (NIMH), and others. However, NICHD supports more pediatric research than any other single NIH IC, and pediatrics accounts for over half of the NICHD budget. The pediatric research portfolio at NICHD is broad, with typical child development, infectious disease, and preterm birth representing the largest concentrations of funding (Figure 4). Categories with lower funding levels include depression, maltreatment, and sudden infant death syndrome. The bulk of research funding in

<sup>&</sup>lt;sup>4</sup> The NIH's Research, Condition, and Disease Categorization (RCDC) system is used to estimate the annual support level for various research, condition, and disease categories based on grants, contracts, intramural projects, and other funding mechanisms. RCDC combines sophisticated text mining methods with scientific expert input and review to provide a consistent method for categorizing and reporting NIH support for more than 280 topics.

<sup>&</sup>lt;sup>5</sup> NICHD's Child Health Information Retrieval Program (CHIRP) is an internal scientific coding and reporting system that is used to code, track and monitor NICHD's research portfolio (grants, contracts, and intramural projects); CHIRP complements RCDC and provides more detailed information on specific topics of key interest to the NICHD.

pediatrics and child development is in basic sciences, followed by behavioral interventions; population science or epidemiology receives the lowest amount of funding in this category.





Note: Categories are overlapping and should not be added. Intramural is not broken out by public health domain as much of the portfolio focuses on basic science and is not specifically targeting diseases or health conditions.



Figure 5: NICHD Pediatric Research Portfolio by Broad Scientific Domain, FY 2017

Note: NIH Research, Condition, and Disease Categories (RCDC) system and NICHD Child Health Information Retrieval Program (CHIRP). Categories are overlapping and should not be added.

### **Gynecology and Reproductive Health**

NICHD accounts for nearly half (47%) of NIH spending on reproductive health and supports more reproductive health research than any other single NIH IC. NICHD's reproductive health portfolio emphasizes contraception and infertility, and includes gynecologic conditions (Figure 6). Much of this portfolio focuses on basic sciences, although support for biomedical intervention studies is also significant (Figure 7). However, the distribution of scientific domains differs across diseases and conditions. In infertility, a higher proportion of the research is within the basic sciences category; however, in gynecology, intervention research (particularly biomedical interventions) are disproportionally represented. NICHD's Pelvic Floor Disorders Network has focused on intervention studies, with a particular emphasis on comparative effectiveness research.



Figure 6: NICHD Gynecology and Reproductive Health Research Portfolio by Condition, FY 2017

Note: NIH Research, Condition, and Disease Categories (RCDC) system and (\*) NICHD Child Health Information Retrieval Program (CHIRP). Categories are overlapping and should not be added. Intramural is not broken out by public health domain as much of the portfolio focuses on basic science and is not specifically targeting diseases or health conditions.

Figure 7: NICHD Gynecology and Reproductive Health Research Portfolio by Broad Scientific Domain, FY 2017



Note: NIH Research, Condition, and Disease Categories (RCDC) system and NICHD Child Health Information Retrieval Program (CHIRP). Categories are overlapping and should not be added.

### Pregnancy and Maternal Health

Pregnancy and maternal health are a key focus for NICHD. As the NIH leader in this area, NICHD research accounts for 46 percent of NIH spending on pregnancy, lactation, and maternal health. NICHD's portfolio in this area emphasizes preeclampsia, gestational diabetes, the effects of obesity on pregnancy, and perinatal and postpartum depression (Figure 8). NICHD-supported research on pregnancy and maternal health often includes multiple components emphasizing both interventions and basic sciences (Figure 9). For example, a recent early-stage clinical trial evaluated the safety of administering the drug pravastatin to pregnant women at high-risk of developing preeclampsia. The study was designed to determine the safety profile of the drug, but also incorporated research on the role of genetic variation affects preeclampsia risk and response to treatment.



Figure 8: NICHD Pregnancy and Maternal Health Research Portfolio by Condition, FY 2017

Note: Categories are overlapping and should not be added. Intramural is not broken out by public health domain as much of the portfolio focuses on basic science and is not specifically targeting diseases or health conditions.





Note: Categories are overlapping and should not be added.

# Intellectual, Developmental, Learning, and Physical Disabilities

Research on intellectual, developmental, learning, and physical disabilities is widely dispersed across NIH. NICHD's portfolio centers around intellectual disabilities, learning disabilities, and medical rehabilitation. The two largest portfolios are in intellectual and developmental

disabilities and medical rehabilitation (Figure 10). The funds expended in this category were concentrated in the basic sciences (Figure 11) in FY 2017.



Figure 10: NICHD Intellectual, Developmental, Learning, and Physical Disabilities Research Portfolio by Condition, FY 2017

Note: Categories are overlapping and should not be added. Intramural is not broken out by public health domain as much of the portfolio focuses on basic science and is not specifically targeting diseases or health conditions.





Note: Categories are overlapping and should not be added.

# **Impact of NICHD Research**

The impact of NICHD research can be measured by scientific productivity and the impact of publications that incrementally advance the field. NICHD is engaged in analyzing measures of short-term scientific productivity by examining publication data, subsequent funding, patent data, and impact of research on guidelines that inform clinical practice. For example, the general influence of publications from NICHD-funded R01 grants, as measured by the median relative citation ratio<sup>6</sup> is above the NIH average of 1.0 and generally on par with other NIH ICs (Figure 12).

*Figure 12: Median Relative Citation Ratio for R01 Grants Across NIH Institutes and Centers:* 2006-2015



#### Source: NIH Library

Technical innovation can be partially captured by patents linked to publications from NICHDsupported R01 grants. An analysis of this data shows a substantial number of patents associated with fertility and infertility research (Figure 13).

<sup>&</sup>lt;sup>6</sup>The Relative Citation Ratio (or RCR) is a field-normalized metric that shows the scientific influence of one or more articles relative to the average NIH-funded paper (Hutchins et al. PLoS Biol. 2016 Sep 6;14(9)).

# *Figure 13: Number of patents that cited publications supported by NICHD R01 grants, by extramural branch, 2006-2015*



#### Source: NIH Library

Publications from NICHD clinical research networks are highly cited in practice guidelines and point-of-care tools, with two networks having nearly 26 percent of their publications included (Table 2). Although no comparable reference groups are available to precisely measure the full effect of the research, NICHD research is informing the provider community.

Program	Number of Publications Cited in Guidelines	Percent (%) of Publications Cited in Guidelines	Percent (%) of Publications Cited in >1 Guideline
Maternal Fetal Medicine Units Network	90	25.6	13.4
Pediatric HIV/AIDS Cohort Study	9	6.9	1.5
Collaborative Pediatric Critical Care Research Network	14	11.6	4.1
<b>Neonatal Research Network</b>	77	16.1	7.9
Pelvic Floor Disorders Network	33	25.8	14.8
Reproductive Medicine Network	15	18.1	12.0

Table 2: NICHD Large Extramural Programs: Impact on Practice Guidelines

## Summary

NICHD has a wide-ranging portfolio that broadly covers the far-reaching mission of the institute and incorporates, in substantial proportions, the breadth of scientific methods and domains. The impact of NICHD research is difficult to assess precisely, especially given the broad range topics and methods covered by the institute. However, publication analyses and citations of NICHD research in guidelines indicate that the institute's research is broadly published and disseminated. With guidance from scientific experts, the NICHD Advisory Council, and NICHD staff, the institute's task will be to further focus its efforts to advance its mission through the strategic planning process.