

DEPARTMENT OF HEALTH AND HUMAN SERVICES

NATIONAL INSTITUTES OF HEALTH

EUNICE KENNEDY SHRIVER NATIONAL INSTITUTE OF CHILD HEALTH AND HUMAN DEVELOPMENT (NICHD)

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General Notes

- 1. FY 2024 funding levels cited in this document are based on the Continuing Resolution in effect at the time of the budget preparation (Public Law 118-35) and do not include the HIV/AIDS transfers.
- 2. Detail in this document may not sum to the subtotals and totals due to rounding.

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Director's Overview

The Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD) has been a global leader in improving the health of women, children, and people with disabilities. The NICHD makes consistent progress every day towards its mission to "lead research and training to understand human development, improve reproductive health, enhance the lives of children and adolescents, and optimize abilities for all."



Director, Dr. Diana W. Bianchi, M.D.

For NICHD, precision medicine is providing opportunities to confront understudied, poorly understood, but critically important problems and tailoring solutions to the populations that need them most – including children, pregnant and lactating people, and individuals with disabilities. Led by NICHD, NIH has expanded research funding in reproductive health, where precision medicine is playing a key role in identifying new treatment opportunities for conditions that have traditionally been underrecognized and undertreated. New research centers focusing on the role of genetics and genomics in uterine fibroids are working towards better understanding of fibroid pathogenesis. Ten percent of all women in the U.S. have endometriosis, a condition that is associated with debilitating pain. Modern, less invasive methods for early detection and treatment of endometriosis and uterine fibroids are on the horizon. For example, results from a recent study of mice and human tissue cultures by NICHDfunded researchers suggest that oleuropein, a compound found in olive oil and olive leaves, may have the potential to treat endometriosis with fewer side effects. After many years of effort, new methods of male contraception are within sight, and new targets continue to be identified. Scientists have discovered a gene that controls the last step in sperm maturation. Deactivating this gene results in lower sperm counts and sperm with impaired movement that are incapable of fertilizing an egg—without any apparent ill effects elsewhere in the body. A range of safe, effective, and reversible contraceptive options are envisioned for both men and women on an equal basis. Researchers are working towards a future in which fertility treatments may no longer be invasive and could have fewer serious side effects.

New technologies in imaging and in the development of biomarkers allow scientists to take a precision medicine approach to maternal and child health. For example, a magnetic resonance imaging technique administered as early as the 14th week of pregnancy may predict the chances of impaired fetal growth. The method measures the ability of the placenta to supply blood to the fetus and appears to allow earlier diagnosis than the current standard technique, sonographic examination of the placenta. Another new imaging tool, called electromyometrial imaging, can create real-time, three-dimensional images and maps of contractions during labor. This technique can help quantify contraction patterns, providing knowledge to improve labor management.

A worldwide movement is underway to integrate the lived experiences of individuals with disabilities into medical treatment because of targeted and inclusive research. For example, recently funded projects are helping scientists develop a national registry of individuals with limb loss, and researchers are also gathering feedback from lower-limb prosthesis wearers to better assess mobility challenges and inform treatments. Precision rehabilitation is advancing closer to becoming a reality, with advanced technologies being developed and tested to treat

spinal cord and traumatic brain injuries more precisely. New research opportunities in studying limb regeneration, a long-time focus of research in developmental biology, may help move regenerative medicine towards realistic treatment options.

More precisely tailored medical and educational approaches and technologies are being developed for students with learning and intellectual disabilities. For example, researchers developed a computer app that can monitor many early signs of autism spectrum disorders (ASD). By tracking differences in social attention, facial expressions, head movements, response to name, blink rates and motor skills, the app correctly identified most of the children who ultimately were determined to have ASD. Early screening tools like this one can help healthcare providers ensure that children and families receive the support and interventions they need. Other areas under development include a gene editing strategy recently tested in a mouse model of spinal muscular atrophy. The gene editing treatment helped protect the neurological system from damage and significantly extended the mice's lifespan. Such innovations demonstrate how R&D can advance critical and emerging technology areas to support and enhance applied research.

The development of new treatments using precision medicine is the key initial step, to be followed by implementing, applying, and rigorously testing new therapies. New treatments must be tested today in the same populations in which these interventions will be used tomorrow. In the past, medical treatment for infants and children was often extrapolated from methods used to treat similar conditions in adults, despite the physiological differences between children and adults that made this a potentially harmful practice.

At medical centers across the country, NICHD supports networks that are specifically designed for larger-scale clinical research in specific populations. For example, the Pediatric Research Network studies the formulation, dosing, efficacy, and safety of drugs, as well as the development of medical devices, used in children. Studies from the Neonatal Research Network, a collaborative network of 15 neonatal intensive care units across the United States, have changed clinical practice by developing and refining treatments for neonatal encephalopathy, enhancing phototherapy for extremely low gestational age neonates, and describing neonatal outcomes following congenital heart disease, antenatal corticosteroid use, fetal growth restriction, and other conditions. The Collaborative Pediatric Critical Care Network seeks to accelerate pediatric critical care research, leading to evaluation of promising new approaches to life support and critical decision-making in complex childhood illnesses and trauma. For each of NICHD's clinical research networks, rigorous patient evaluation using common protocols enable scientists to study the required numbers of patients and provide answers more rapidly than individual centers acting alone.

NICHD's Maternal and Pediatric Precision in Therapeutics (MPRINT) program serves as a national resource to aggregate, present, and expand the available knowledge, tools, and expertise in maternal and pediatric therapeutics to the broader research, regulatory science, and drug development communities. It also conducts therapeutics-focused research in obstetrics, lactation, and pediatrics while enhancing inclusion of people with disabilities. The Maternal and Fetal Medicine Units (MFMU) conduct clinical trials to assess interventions to prevent preterm birth, treat pregnancy complications, and improve maternal and infant health. Due to their access to network infrastructure, MFMU and MPRINT scientists were able to work rapidly to

assess the impact of SARS-CoV-2 infection during pregnancy and lactation on mothers and infants. MPRINT researchers observed that lactating women passed maternal antibodies to the viral infection in their breast milk, but the immunological profiles of these antibodies were distinct in each woman. MFMU clinical researchers found that among pregnant and postpartum individuals at 17 U.S. hospitals, SARS-CoV-2 infection was associated with an increased risk for maternal morbidity and mortality. However, there were no changes in preterm birth rates in these hospitals during the COVID-19 pandemic.

To modernize these networks and prepare for tomorrow's challenges while supporting innovation and workforce development, NICHD has expanded the availability of network resources and infrastructure to a wider range of researchers, including scientists from institutions outside the network. Opening network resources to a greater number of well-qualified, clinically trained scientists with innovative ideas and access to diverse populations will expand the number of studies that can be done on a scale large enough to support changes in clinical practice. The Institute has also accelerated efforts to facilitate data sharing and access to biospecimens from network studies. This effort will maximize NICHD's infrastructure investment by promoting secondary analysis, rigor and reproducibility of results, and enhanced data/specimen aggregation and sharing. As health disparities and inclusion in clinical trials are significant concerns for the populations and conditions that are priorities for NICHD, the Institute emphasizes that infrastructure for multisite trials needs to encompass racially and geographically diverse populations. Together these efforts will take steps to ameliorate inequities and create opportunity in ways that strengthen our values.

Collaborations, especially with other NIH Institutes, Centers, and Offices (ICOs), have helped NICHD extend the impact of our research, including research conducted in clinical research networks. For example, NICHD-supported scientists worked with colleagues in a network supported by NIH's National Center for Advancing Translational Sciences to assess a commonly used medication often given to infants undergoing surgery with cardiopulmonary bypass. The clinical trial discovered that the use of a specific corticosteroid before the operation did not significantly reduce the likelihood of a worse outcome; in fact, infants receiving the medication were more likely to develop hyperglycemia and require insulin. Scientists in two network programs – the NIH's Environmental influences on Child Health Outcomes and NICHD's Neonatal Research Network – worked to improve the treatment of opioid-exposed infants. The researchers demonstrated that the "Eat, Sleep, and Console" approach was more effective than standard care to help manage symptoms in opioid-exposed newborns. Newborns cared for with this non-pharmacologic method were medically ready for discharge nearly 1 week earlier and were 63 percent less likely to receive medication as part of their treatment, compared with newborns under usual care. The findings are generating evidence about how well different approaches can help us reach national goals more equitable and expeditiously. In this case they are already changing medical practice, with infants receiving less exposure to narcotics and parents having more opportunities to bond with their child.

Unfortunately, the U.S. maternal mortality rate today is still unacceptably high and exceeds that of most high-income countries.¹ Disparities in maternal health persist. Women in underserved areas, known as maternity care deserts, may not have access to approved and lifesaving

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¹ who.int/news-room/fact-sheets/detail/maternal-mortality. Accessed December 20, 2023.

treatments for ectopic pregnancy, postpartum hemorrhage, sepsis, and other severe maternal conditions. In 2023, the NIH Implementing a Maternal health and PRegnancy Outcomes Vision for Everyone (IMPROVE) initiative launched the IMPROVE Centers of Excellence to bolster community-based maternal health research at 10 sites with a focus on implementation science. The newly funded network of IMPROVE Centers of Excellence will develop and evaluate innovative approaches to reduce pregnancy-related complications and deaths and promote maternal health equity. To complement the network, the Rapid Acceleration of Diagnostics Technology (RADx® Tech) for Maternal Health Challenge—an \$8 million Challenge prize competition—is accelerating development of home-based or point-of-care diagnostic technologies to improve postpartum healthcare in underserved areas, both urban and rural, across the United States.

The NIH-wide INCLUDE (INvestigation of Co-occurring conditions across the Lifespan to Understand Down syndromE) project, with co-leadership from NICHD, continues to address the need for research on Down syndrome and co-occurring conditions. Applying the expertise and resources from multiple NIH ICOs, the INCLUDE program conducts targeted, high-risk, high-reward basic science studies on chromosome 21; assembles populations of individuals with Down syndrome (DS); and supports clinical research inclusive of individuals with DS. Because INCLUDE investigates conditions that affect individuals with DS and the general population, such as Alzheimer's disease/dementia, autism, cataracts, celiac disease, congenital heart disease and diabetes, the program has demonstrated the value of studying the same conditions across diverse populations to yield important clues about both pathological mechanisms and responses to treatment.

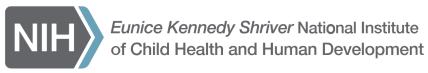
NICHD was able to fund several new initiatives between fiscal years 2019 and 2023. These efforts included:

- Support for the NIH-wide IMPROVE initiative, developed in response to high rates of pregnancy-related complications and deaths in the United States, especially in disparity populations such as racial and ethnic minorities, very young women, women of advanced maternal age, and people with disabilities;
- Expansion of NICHD's research portfolio on gynecology—particularly as it relates to uterine fibroids and endometriosis. Already, promising results are being tested to improve treatment. These include a prototype genetic test with the potential to predict the development and eventual severity of uterine fibroids; potential pharmaceutical options to treat fibroids; and new treatment targets for endometriosis;
- Implementation of the MPRINT program to expand the available knowledge, tools, and expertise in maternal and pediatric therapeutics to the broader research, regulatory science, and drug development communities; and
- Performing essential research on how technology and digital media affect child and adolescent development and the mental and physical health of the family.

From these efforts, we can envision a future in which safe and effective treatments are widely available for reproductive health, maternal, and pediatric conditions. Community-based research, designed to help reduce disparities in maternal and child health, can be expected to advance. Through research investments, the causes of stillbirth may become better understood, and safe and effective interventions to prevent this devastating outcome can potentially be developed. Taking advantage of scientific opportunities created by developments in genomics,

artificial intelligence, developmental biology, critical care medicine, and pharmacology, researchers are studying how to develop and test new approaches to caring for the youngest and most vulnerable patients. With the evidence base to describe how drugs are metabolized specifically in lactating persons and in children, precision medicine approaches will be available from the very start of life.

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Healthy pregnancies. Healthy children. Healthy and optimal lives.

NICHD's mission is to lead research and training to understand human development, improve reproductive health, enhance the lives of children and adolescents, and optimize abilities for all. http://nichd.nih.gov

Key populations: Children, Pregnant and Lactating Women, People with Disabilities



Director: Diana W. Bianchi, M.D.

HISTORY I	National Center for Medical Rehabilitation Research (NCMRR)	Best Pharmaceuticals for Children Act (BPCA)	Renamed: Eunice Kennedy Shriver NICHD	New Mission and Vision	NICHD YEARS OF INNOVATION
1962	1990	2002	2007	2020	2022

IMPROVE MATERNAL HEALTH

Maternal Health Centers of Excellence:

National network to develop communitytailored interventions, with focus on populations that experience health disparities

 Centers will develop and evaluate innovative approaches to reduce pregnancy-related complications and deaths and promote maternal health equity

 Includes 10 research centers, a data innovation and coordinating hub and an implementation science hub

 Centers also support training and professional development of maternal health researchers

• Awarded \$24 million in first-year funding

2 HBCUs among 10 awarded centers







WOMEN'S HEALTH RESEARCH

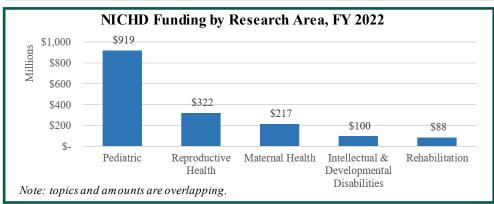


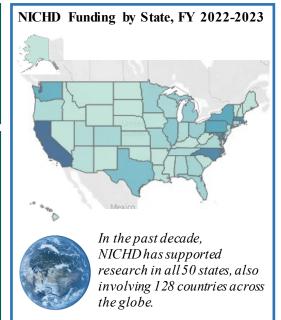




- Investigational drug reduces the size of fibroid tumors in mice
- Green tea compound may inhibit processes promoting uterine fibroid growth
- Prototype genetic test demonstrates potential to predict the development and eventual severity of uterine fibroids
- Higher ambient temperature associated with pregnancy complications
- Compound in olive oil and olive leaves may provide endometriosis treatment with fewer side effects
- Differences in endometriosis-related gene expression may identify links to other chronic pain conditions
- Cancer treatment technique—using heat to remove disease-causing tissue—adapted to treat endometriosis in animal studies

















Healthy pregnancies. Healthy children. Healthy and optimal lives.

RECENT ACCOMPLISHMENTS

Prenatal testing and newborn screening can identify issues and allow treatment to begin early, preventing or alleviating developmental problems. Now, a same-day, less expensive test can identify abnormal fetal chromosomes.

Human Development



CURRENT ACTIVITIES

NICHD leads the birth defects portion of the Gabriella Miller Kids First Pediatric Research Program at NIH, to help researchers uncover new insights into the biology of structural birth defects and share these data.

In a mouse study, researchers have identified compounds that temporarily inhibit sperm mobility, which could lead to an on-demand, non-hormonal, short-term contraceptive for men.

Reproductive Health



The Centers to Advance Research in Endometriosis support basic, translational, and clinical studies of endometriosis, a chronic painful condition affecting 1 in 10 women of reproductive age.

New, non-invasive imaging tool maps uterine contractions during labor. Tool has the potential to assist with preterm birth, labor management and clinical decision-making.

Maternal Health



The Global Network for Women's and Children's Health Research is dedicated to improving maternal and child health outcomes worldwide and building health research capacity in resource-poor settings.

With data from studies conducted under the Best Pharmaceuticals for Children Act, FDA labels for diazepam and clindamycin now include better information on recommended usage and dosage in pediatric populations.

Child Health



The Maternal and Pediatric Precision in Therapeutics (MPRINT) Program supports therapeutics-focused research in obstetrics, lactation, and pediatrics while enhancing inclusion of people with disabilities.

Early diagnosis and intervention can help children with autism spectrum disorder (ASD). A new app-based method could improve the accuracy of autism screening in primary care settings.

Optimizing Abilities for All



Supported by NICHD's National Center for Medical Rehabilitation Research (NCMRR), the Medical Rehabilitation Research Resource (MR3) Network builds infrastructure, focusing on tissue engineering, pediatric rehabilitation, technology development, and neuromodulation.

RESEARCH HIGHLIGHTS

NEW AND FUTURE INITIATIVES



















- "Eat, Sleep, Console" reduces hospital stay and need for medication among opioid-exposed infants.
- A second brain receptor abnormality was identified in tissue from sudden infant death syndrome (SIDS) cases.
- Commonly-used drug in infants undergoing cardiac surgery does not improve outcomes, and has side effects
- "Prosthetic Limb Users Survey of Mobility" taps prosthesis users' perspectives to understand mobility challenges and guide care.
- Noninvasive treatment safely enables upright posture in children with spinal cord injury.
- Placental examinations can improve researchers' and providers' efforts to identify cause of death in stillbirth.
- An MRI technique administered as early as the 14th week of pregnancy may predict impaired fetal growth.
- Fortified human milk may promote preterm infant growth.

- Reconvening the Task Force on Research Specific to Pregnant Women and Lactating Women (PRGLAC) to monitor and report on the implementation of its recommendations to promote inclusion of pregnant and lactating people in clinical trials
- Continuing the Stillbirth Working Group of Council to examine data collection/epidemiology, prevention, and psychological impact of stillbirth
- Establishing new specialized centers for research on health disparities in uterine fibroids
- Understanding and mitigating health disparities experienced by people with disabilities caused by ableism
- Advancing our knowledge of human milk and lactation
- Addressing the impact of climate change on health and well-being over the life course

Major Changes in the Budget Request

Major changes by budget mechanism and/or budget activity detail are briefly described below. Note that there may be overlap between budget mechanisms and activity detail and these highlights will not sum to the total change for the FY 2025 President's Budget for the National Institute of Child Health and Human Development (NICHD), which is an increase of \$18.6 million or 1.1 percent above the FY 2023 Final level, for a total of \$1,766.4 million. The FY 2025 President's Budget reflects the Administration's fiscal policy goals for the Federal Government. Within that framework, NICHD will pursue its highest research priorities through strategic investments and careful stewardship of appropriated funds.

Research Project Grants (RPGs) (+\$14.2 million, total \$1,031.3 million):

NICHD will support a total of 1,859 Research Project Grant (RPG) awards in FY 2025, including Small Business Innovation Research/Small Business Technology Transfer (SBIR/STTR) awards. Non-competing RPGs will decrease by 66 awards to an estimated level of 1,253 awards, while the amount to support the costs associated with the commitments of these prior year competing awards will increase by \$12.5 million compared to the FY 2023 Final level. Competing RPGs will increase by 17 grants compared to the FY 2023 Final level of 500 awards, and the amount to support the costs associated with new competing awards will increase by \$14.3 million compared to the FY 2023 Final level.

Research Centers (+\$12.4 million, total \$106.2 million):

NICHD will support a total of 66 Research Centers awards in FY 2025, an increase of 6 Research Centers compared with the FY 2023 Final level. The increases are due to higher funding to current grant programs, as well as a grant program for over \$5.0 million that is moving from Other Research to Centers in FY 2025.

Other Research (-\$12.9 million, total \$109.6 million):

NICHD will support a total of 411 awards in the Other Research areas in FY 2025, a decrease of 19 awards compared with the FY 2023 Final level of 430 awards. This is a result of the restructuring of Network Data Coordinating Centers and a grant program converting to Centers. NICHD will continue to support Career awards and clinical trial networks within these funding amounts.

Ruth L. Kirschstein Training Awards (+\$1.8 million, total \$41.2 million):

NICHD will support a total of 708 training awards in FY 2025, an increase of 13 awards compared to the FY 2023 Final level. The increased funding is due to additional trainees and increases in stipends for fellows.

Research and Development Contracts (-\$8.0 million, total \$150.4 million):

NICHD will support a total of 130 contract awards in FY 2025, the same as in the FY 2023 Final level. The decreased funding reflects one-time contract support in FY 2023.

Research Management and Support (+\$11.4 million, total \$97.9 million):

NICHD will increase support for Research Management and Support functions by \$11.4 million compared to the FY 2023 Final level, supporting increased inflationary costs for both centrally funded services and staff, as well as increased federal staffing levels, cybersecurity efforts, clinical trials management, and automating business practices.

Budget Mechanism* (Dollars in Thousands)

Mechanism	FY 20	23 Final	FY 2	024 CR	CR FY 2025 President's Budget			5 +/- FY 123
Mechanism	Number	Amount	Number	Amount	Number	Amount	Number	Amount
Research Projects:	Tumber	Milount	Tumber	rimount	Tumber	Amount	Tumber	Amount
Noncompeting	1,319	\$698,731	1,289	\$714,050	1,253	\$711,212	-66	\$12,481
Administrative Supplements	(92)	\$22,107	(40)	\$10,051	(40)	\$10,100	-(52)	-\$12,007
Competing:	()	4,,	(, ,	4-0,00-	(,	4,	(=)	4-2,007
Renewal	33	\$22,515	33	\$22,564	35	\$23,711	2	\$1,196
New	466	\$221,295	458	\$223,025	481	\$234,404	15	\$13,109
Supplements	1	\$747	1	\$750	1	\$750	0	\$3
Subtotal, Competing	500	\$244,557	492	\$246,339	517	\$258,865	17	\$14,308
Subtotal, RPGs	1,819	\$965,395	1,781	\$970,440	1,770	\$980,177	-49	\$14,782
SBIR/STTR	90	\$51,696	88	\$50,698	89	\$51,136	-1	-\$560
Research Project Grants	1,909	\$1,017,090	1,869	\$1,021,138	1,859	\$1,031,313	-50	\$14,223
Research Centers								
Specialized/Comprehensive	57	\$88,002	59	\$92,652	63	\$100,358	6	\$12,356
Clinical Research	0	\$0	0	\$0	0	\$0	0	\$0
Biotechnology	3	\$5,271	3	\$5,590	3	\$5,590	0	\$319
Comparative Medicine	0	\$513	0	\$450	0	\$250	0	-\$263
Research Centers in Minority	0	\$0	0	\$0	0	\$0	0	\$0
Institutions		* *		* .		* -	_	
Research Centers	60	\$93,786	62	\$98,692	66	\$106,198	6	\$12,412
Other Research:	2.52	0.42.250	254	A 4 7 60 1	242	044.207	10	#1 020
Research Careers	253	\$43,359	254	\$45,681	243	\$44,397	-10	\$1,038
Cancer Education	0	\$0	0	\$0	0	\$0	0	\$0
Cooperative Clinical Research	52 0	\$22,394 \$0	52 0	\$23,275 \$0	48 0	\$21,588 \$0	-4 0	-\$806
Biomedical Research Support Minority Biomedical Research	U	\$0	U	\$0	0	\$0	U	\$0
Support Support	0	\$0	0	\$0	0	\$0	0	\$0
Other	125	\$56,752	123	\$49,437	120	\$43,656	-5	-\$13,096
Other Research	430	\$122,506	429	\$118,393	411	\$109,641	-19	-\$12,865
Total Research Grants	2,399	\$1,233,382	2,360	\$1,238,223	2,336	\$1,247,152	-63	\$13,770
Ruth L Kirschstein Training Awards:	FTTPs	\$1,233,362	FTTPs	\$1,236,223	FTTPs	\$1,247,132	FTTPs	\$13,770
Individual Awards	285	\$13,901	289	\$14,279	299	\$15,002	14	\$1,101
Institutional Awards	410	\$25,527	422	\$26,646	409	\$26,181	-1	\$654
Total Research Training	695	\$39,428	711	\$40,925	708	\$41,183	13	\$1,755
g		407,120		410,720		412,200		4-,
Research & Develop. Contracts	130	\$158,391	130	\$147,160	130	\$150,398	0	-\$7,993
SBIR/STTR (non-add)	(3)	(\$644)	(4)	(\$971)	(4)	(\$981)	(1)	(\$338)
Intramural Research	279	\$230,058	297	\$229,770	302	\$229,770	23	-\$288
Res. Management & Support	282	\$86,526	305	\$93,000	322	\$97,912	40	\$11,387
SBIR Admin. (non-add)		(\$271)		(\$283)		(\$291)		(\$21)
Construction		\$0		\$0		\$0		\$0
Buildings and Facilities		\$0 \$0		\$0 \$0		\$0		\$0
Total, NICHD	561	\$1,747,784	602	\$1,749,078	624	\$1,766,415	63	\$18,631

^{*} All items in italics and brackets are non-add entries.

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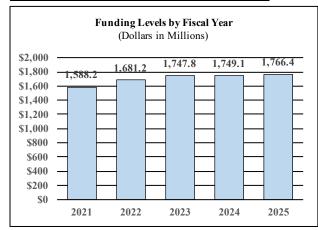
EUNICE KENNEDY SHRIVER NATIONAL INSTITUTE OF CHILD HEALTH AND HUMAN DEVELOPMENT

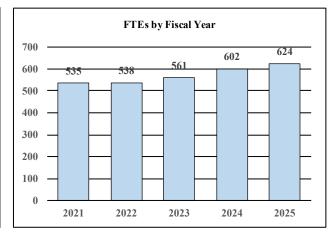
For carrying out section 301 and title IV of the PHS Act with respect to child health and human development, \$1,766,415,000.

Summary of Changes (Dollars in Thousands)

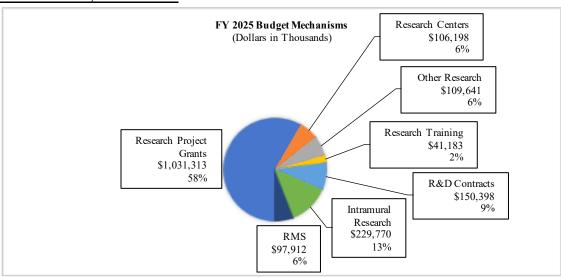
	FY 2	2023 Final		5 President's Judget		Change from 023 Final
CHANGES	FTEs	Budget Authority	FTEs	Budget Authority	FTEs	Budget Authority
1. Intramural Research:		rathonty		rathority		rumonty
A. Built-in cost changes:		\$75.002		#96.503		\$00.4
a. FY 2024 effect of FY 2023 pay & benefits increase b. FY 2024 effect of FY 2024 pay & benefits increase		\$75,903 \$75,903		\$86,503 \$86,503		\$894 \$2,954
c. FY 2024 paid days adjustment		\$75,903		\$86,503		\$2,934
d. Differences attributable to FY 2024 change in FTE		\$75,903		\$86,503		\$3,247
e. FY 2025 effect of FY 2024 pay & benefits increase		\$75,903		\$86,503		\$1,044
f. FY 2025 effect of FY 2025 pay & benefits increase g. FY 2025 paid days adjustment		\$75,903 \$75,903		\$86,503 \$86,503		\$1,392 \$0
h. Differences attributable to FY 2025 change in FTE		\$75,903		\$86,503		\$760
i. Payment for centrally furnished services		\$36,210		\$38,826		\$2,616
 j. Cost of laboratory supplies, materials, other expenses, and non-recurring costs 		\$117,929		\$104,441		\$9,114
Subtotal, IR built-in cost changes						\$22,314
2. Research Management and Support:						
A. Built-in cost changes:						
a. FY 2024 effect of FY 2023 pay & benefits increase		\$50,200 \$50,200		\$61,087 \$61,087		\$594 \$1,953
b. FY 2024 effect of FY 2024 pay & benefits increase c. FY 2024 paid days adjustment		\$50,200 \$50,200		\$61,087		\$1,933 \$193
d. Differences attributable to FY 2024 change in FTE		\$50,200		\$61,087		\$3,586
e. FY 2025 effect of FY 2024 pay & benefits increase		\$50,200		\$61,087		\$704
f. FY 2025 effect of FY 2025 pay & benefits increase		\$50,200		\$61,087		\$975
g. FY 2025 paid days adjustment h. Differences attributable to FY 2025 change in FTE		\$50,200 \$50,200		\$61,087 \$61,087		\$0 \$2,871
i. Payment for centrally furnished services		\$7,767		\$8,328		\$561
j. Cost of laboratory supplies, materials, other expenses, and		\$28,523		\$28,497		\$2,330
non-recurring costs						A12 50
Subtotal, RMS built-in cost changes	FV 2	2023 Final	FV 2024	5 President's	Program	\$13,768 Change from
	1112	2025 Finai	Budget			023 Final
CHANGES	No.	Amount	No.	Amount	No.	Amount
B. Program: 1. Research Project Grants:						
a. Noncompeting	1,319	\$720,838	1,253	\$721,312	-66	\$474
b. Competing	500	\$244,557	517	\$258,865		\$14,308
c. SBIR/STTR Subtotal. RPGs	90 1,909	\$51,696 \$1,017,090	89 1,859	\$51,136 \$1,031,313		-\$560 \$14,223
2. Research Centers	60	\$93,786	1,839	\$1,031,313		\$14,223
3. Other Research	430	\$122,506	411	\$109,641		-\$12,865
4. Research Training	695	\$39,428	708	\$41,183	13	\$1,755
5. Research and development contracts	130	\$158,391	130	\$150,398	0	-\$7,993
Subtotal, Extramural		\$1,431,201		\$1,438,733		\$7,532
6. Intramural Research	279	\$230,058	302	\$229,770	23	-\$22,602
7. Research Management and Support	282	\$86,526	322	\$97,912	40	-\$2,381
8. Construction		\$0		\$0		\$0
Buildings and Facilities		\$0		\$0		\$0
Subtotal, program changes		**				-\$17,451
Total built-in and program changes	561	\$1,747,784	624	\$1,766,415	63	\$18,631

History of Budget Authority and FTEs:

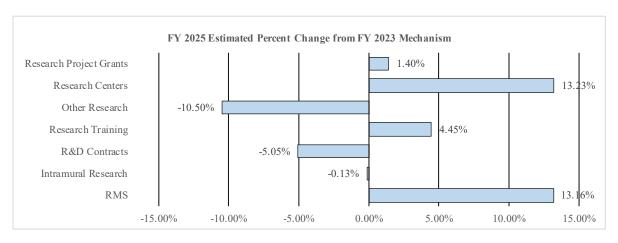


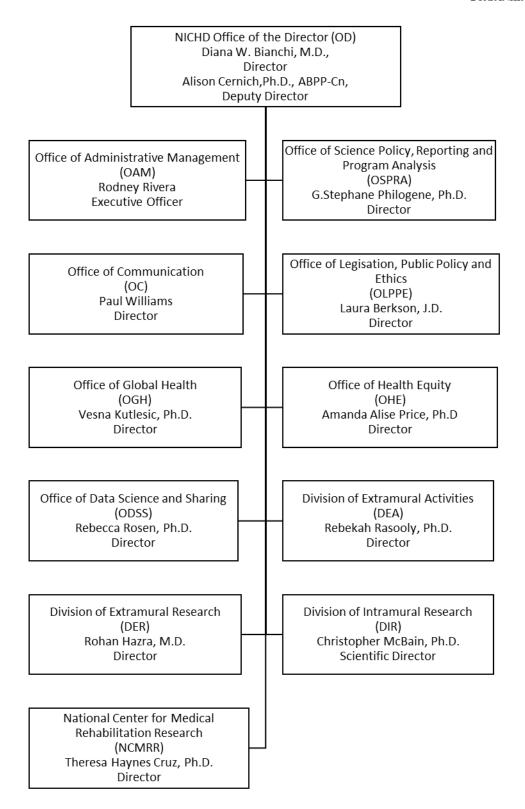


Distribution by Mechanism



Changes by Selected Mechanism





Budget Authority by Activity* (Dollars in Thousands)

	FY 2023 Final		FY 2024 CR		FY 2025 President's Budget		FY 2025 +/- FY 2023 Final	
Extramural Research	FTE	Amount	FTE	Amount	<u>FTE</u>	<u>Amount</u>	FTE	Amount
Detail Reproductive Health, Pregnancy, and								
Perinatology		\$487,568		\$485,901		\$499,301		\$11,733
Child Health		\$457,039		\$455,476		\$455,003		-\$2,036
Demography and Behavior		\$242,681		\$241,851		\$241,601		-\$1,080
Intellectual and Developmental Disabilities		\$141,312		\$140,829		\$140,683		-\$629
Rehabilitation		\$102,601		\$102,250		\$102,144		-\$457
Subtotal, Extramural		\$1,431,201		\$1,426,308		\$1,438,733		\$7,532
Intramural Research	279	\$230,058	297	\$229,770	302	\$229,770	23	-\$288
Research Management & Support	282	\$86,526	305	\$93,000	322	\$97,912	40	\$11,387
TOTAL	561	\$1,747,784	602	\$1,749,078	624	\$1,766,415	63	\$18,631

^{*} Includes FTEs whose payroll obligations are supported by the NIH Common Fund.

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

Authorizing Legislation: Section 301 and Title IV of the Public Health Service Act, as amended Budget Authority (BA):

			FY 2025	
		FY 2024 CR	President's	FY 2025 +/- FY
	FY 2023 Final	Level	Budget	2023
BA	\$1,747,784,000	\$1,749,078,000	\$1,766,415,000	+\$18,631,000
FTE	561	602	624	+63

Program funds are allocated as follows: Competitive Grants/Cooperative Agreements; Contracts; Direct Federal/Intramural and Other.

Overall Budget Policy: The FY 2025 President's Budget request for NICHD is \$1,766.4 million, an increase of \$18.6 million or 1.1 percent compared to the FY 2023 Final level. Within this level, NICHD will allocate \$43.4 million for the Implementing a Maternal health and PRegnancy Outcomes Vision for Everyone (IMPROVE) initiative, one component of NIH's substantial annual commitment to maternal morbidity and mortality research funding. NICHD will also support other high priority research in its portfolio, including sustaining the \$3.0 million investment in research on the effects of COVID-19 on pregnant and lactating individuals, and \$10.0M supporting research on the effects of COVID-19 on children provided in FY 2023.

Program Descriptions and Accomplishments

Reproductive Health, Pregnancy, and Perinatology: The NICHD program in reproductive health, pregnancy, and perinatology supports basic, clinical, and translational research on gynecologic and andrologic disorders; contraception; fertility and infertility; pregnancy; and newborn care. Most U.S. women will be affected by one or more gynecological disorders during their lifetime. NICHD manages a broad research portfolio to better understand, treat, and prevent these common, painful, and costly conditions, including endometriosis, uterine fibroids, Polycystic Ovary Syndrome, chronic pelvic pain, and pelvic floor disorders.

Uterine fibroids are the most common non-cancerous tumors in women and can cause pain and abnormal bleeding. Sometimes fibroids can make it difficult for a woman to become pregnant or maintain a pregnancy. NICHD-supported scientists are working to develop new prevention and treatment approaches. For example, researchers found that a treatment featuring the drug relugolix could help reduce heavy menstrual bleeding and pain associated with fibroids, without loss in bone mineral density. Another research team is looking at a different drug, an anti-inflammatory medication, which reduced the size of fibroid tumors in mice without side effects.

Endometriosis is another gynecologic health condition that can cause severe pain, irregular periods, and infertility. Although the condition runs in families, known genes explain less than two percent of cases. To identify more genes that can account for the condition, researchers recently combined the data from two dozen studies that looked at the whole genomes of almost 61,000 women who had endometriosis, as well as another 702,000 who did not. The scientists found 42 locations within the women's DNA that were linked to endometriosis. A closer look revealed genetic connections to 11 pain conditions, such as migraine, headache, back and spinal pain, and multisite chronic pain. Future studies that reveal more about the shared biology between the pain and inflammatory conditions and endometriosis could lead to new therapies.

There is an urgent need for safe, effective, and less invasive infertility treatments, as well as contraception options for both men and women. With support from NICHD, male contraceptive agents are already being tested in humans, and even more promising approaches are being developed in animal models. In a mouse study, researchers identified a potential non-hormonal contraceptive compound that could be taken shortly before sexual activity, with fertility restored the very next day. A recently discovered gene expressed only in the reproductive organs is another promising target for male contraception, because deactivating this gene does not appear to interfere with testosterone production and would not block the hormone's other functions, such as regulating sex drive, building bone mass, and muscle strength.



As NIH's leader in pregnancy and maternal health research, NICHD supports studies on clinical treatments to reduce the risk of pregnancy complications for both pregnant women and their offspring. Through NIH's IMPROVE initiative, NICHD established Maternal Health Research Centers of Excellence to develop and evaluate innovative approaches to reduce pregnancy-related complications and deaths and promote maternal health equity across the country. These

Centers, comprising 10 research centers, a data innovation and coordinating hub and an implementation science hub. Together, these institutions will work to design and implement research projects to address the biological, behavioral, environmental, sociocultural, and structural factors that affect pregnancy-related complications and deaths. They will focus on populations that experience health disparities, including racial and ethnic minorities, socioeconomically disadvantaged populations, those living in underserved rural areas, sexual and gender minority populations and people with disabilities. The IMPROVE initiative also includes two Challenge prize competition initiatives, in addition to traditional grant funding, that provide innovative approaches to well defined barriers in maternal health care and research engagement. The Rapid Acceleration of Diagnostics (RADx® Tech) for Maternal Health Challenge leverages an innovation funnel approach to accelerate the development of maternal health diagnostic or other remote-sensing technologies (e.g., wearable devices, smartphone-enabled tools) to improve access to care in the postpartum period and complement the use of telehealth in areas without sufficient maternity care. The Connecting the Community for Maternal Health Challenge aims to address the structural barriers faced by community and advocacy organizations to conduct maternal health research by helping them build effective research infrastructure and capacity. In addition to cash prize awards to incentivize participation and reward successful outcomes, the Challenge program provides expert guidance and consultation on maternal health research

project design, implementation, and evaluation. The goal is to support successful organizations to compete for federal grant funding and sustain their research capabilities.

NICHD also continues to improve understanding of the effects of COVID-19 infection and disease during pregnancy, in the postpartum, during lactation, and in newborns, as well as its long term impact, and continues to work toward inclusion of pregnant and lactating people in SARS-CoV-2 vaccine research. A recent study found that by late 2022, widespread COVID-19 vaccination of pregnant people likely halted a spike in the preterm birth rate that began at the start of the pandemic. Another study found that preterm infants receive similar levels of maternal antibody protection as term infants after maternal COVID-19 vaccination.

NICHD's research networks play a leading role in clinical research advances for maternal and neonatal health. For example, in a large, multi-country clinical trial, researchers showed that a single dose of the antibiotic azithromycin can reduce the risk of postpartum sepsis and death by one third among women who deliver vaginally. For vulnerable infants, scientists found that extremely preterm infants who were fed fortified human milk grew longer and more rapidly and had larger head circumferences

STILLBIRTH RESEARCH

Stillbirth affects roughly 1 in 175 births, and each year over 20,000 babies are stillborn in the United States. Recognizing the need to better understand stillbirth, Congress directed the Secretary of Health and Human Services (HHS) to form a task force to examine stillbirth in the United States. This task force, led by NICHD, was formed as subgroup of the National Advisory Child Health and Human Development Advisory Council. In its 2023 report, the Stillbirth Working Group recommended 12 priority areas to help guide HHS agencies together with families, state and federal public health agencies, researchers, providers, professional societies, and advocacy organizations in alleviating the tragedy of stillbirth. The task force continues its work to identify and address data collection, scientific research, and resources for families affected by stillbirth.

NICHD continues to support research specifically on stillbirth, as well as studies aimed at preventing preterm birth and other pregnancy complications that can lead to stillbirth. For example, many couples want to conceive again after stillbirth, but the optimal timing is unclear. Scientists assessed the association between interpregnancy intervals and birth outcomes, in a group of about 5,600 individuals with a stillbirth and subsequent birth. Preterm birth was common in the group, but interpregnancy interval was not associated with any adverse outcomes. Although the study size is relatively small, the findings provide some reassurance to families who conceive shortly after stillbirth.

compared with extremely preterm infants fed unfortified human milk. The findings provide support for future studies on the potential benefits of human milk fortification in preventing malnutrition among infants born at 28 weeks or younger.

NICHD is represented on the executive and steering committees of the NIH-wide Climate Change and Health Initiative aiming to reduce the health threats posed by climate change across the lifespan. The health effects of climate and environmental changes can affect many stages of a women's reproductive life, impacting the health of future generations. Growing evidence suggests that heat stress negatively influences fetal growth and pregnancy outcomes, as two recent studies from NICHD's Global Network for Women's and Children's Health illustrate. One study, which evaluated more than 120,000 pregnant women in India and Pakistan, found a higher incidence of pregnancy-related high blood pressure, severe preeclampsia, preterm birth, and low birth weight with greater temperatures. Another study, conducted in Pakistan, found

that exposure to excessive heat in early pregnancy was linked to lower infant lengths and head circumferences at birth. The findings also suggest that nutritional supplementation early in pregnancy may help offset some of the effects of heat stress.

Budget Policy: The FY 2025 President's Budget request for Reproductive Health, Pregnancy, and Perinatology is \$499.3 million, an increase of \$11.7 million or 2.4 percent compared with the FY 2023 Final level. This increase allows NICHD to fund the IMPROVE initiative at a total level of \$43.4 million without requiring one-time contributions from other NIH Institutes, Centers, and Offices (ICOs) to supplement NICHD base funding. NICHD will also continue the \$3.0 million investment in research on mitigating the effects of COVID-19 on pregnancies, lactation and postpartum health, particularly focusing on racial and ethnic minority groups. NICHD plans to continue research emphasizing maternal health, eliminating disparities in maternal morbidity and mortality, addressing gynecologic and andrologic conditions, preventing preterm birth, and advancing newborn health. NICHD will continue to support clinical research networks in maternal-fetal medicine and neonatal intensive care, providing opportunities for researchers from a wide geographic range and encouraging participation of diverse populations in clinical research.

<u>Child Health</u>: Research on child and adolescent health encompasses biological and behavioral processes that control development, including development of social-emotional health, cognitive development, learning, and physical growth. This research program also supports the evidence base for pediatric medicine, through clinical studies in pharmacology, infectious diseases, endocrinology, trauma and critical illness, and other aspects of health throughout infancy, childhood, and adolescence.

Although children have distinct medical needs, and their physiology is not the same as adults, medical practices are often extrapolated from adult research without adequate study specifically in children. The Collaborative Pediatric Critical Care Research Network is funded by NICHD to conduct large-scale, multicenter randomized controlled trials to provide the research needed to make the best medical decisions for children in real-time while they are in the pediatric intensive care unit. Recent research supported through NICHD uncovered links between severe sepsis—a factor in 60 percent of child deaths worldwide—and certain genes related to the child's immune system. These findings are opening the way for genetic screening to tailor sepsis treatment according to a child's specific immune system functioning. NICHD also administers eight grants to refine technologies for early diagnosis of severe illnesses resulting from SARS-CoV-2 infection in children, including Multisystem Inflammatory Syndrome in Children (MIS-C). NICHD-supported researchers recently found that children with COVID-19 who develop MIS-C have unique biochemical indicators of cell injury and cell death, providing a pathway to develop tests that can identify children with MIS-C. Other researchers identified the mechanism by which MIS-C appears to cause shock in children. Inflammation of the blood vessels prevents the vessels from constricting, resulting in low blood pressure and circulation. This finding indicates that medications that constrict the blood vessels may be a preferred treatment option.

NICHD supports a broad spectrum of research that seeks to prevent and treat pediatric injuries. To minimize the impact of head injury in youth football, researchers compared the magnitude, frequency, and location of head impacts among youth and college football players to inform the development of age-appropriate guidelines for helmet design and other



prevention measures. Motor vehicle accidents and firearms are also leading causes of injury and death in children in the United States. NICHD-funded researchers recently developed a driving simulation program to reduce crash risk in teens with attention deficit hyperactivity disorder. According to the Centers for Disease Control and Prevention, suicides involving firearms increased substantially among children aged 10-14 years from 2010 to 2020, and firearms are the most common method of suicide for teens aged 14-18 years.² Recent NICHD-funded studies underscore the urgent need to reduce firearm access among children. For example, one research team found that teens with recent depression or a history of suicidality were *more* likely than their peers to report access to firearms.

Unfortunately, child maltreatment is another common cause of injury and long-term harm. The effects of maltreatment are far-reaching. Researchers at NICHD recently analyzed the long-term effects of adverse childhood events on mortality through middle adulthood. Those who experienced parental harshness and neglect had a 16 percent higher risk of premature death. Through the CAPSTONE Centers for Multidisciplinary Research in Child Abuse and Neglect and other projects, NICHD supports research to better understand the risk factors for, impact of, and prevention of child maltreatment. Scientists developed a clinical protocol to identify potential cases of physical child abuse based on bruising patterns. The protocol is now available via a smartphone app-based screening tool, helping providers identify early abuse and prevent subsequent injury. Experiencing maltreatment in childhood is also associated with higher incidences of teen pregnancy. NICHD-funded researchers tracked families that had Child Protective Services involvement and found that children placed in foster care were significantly less likely to become pregnant or to give birth during adolescence than those not placed in foster care. Being adopted from foster care led to even greater benefits, including significant reductions in the percentage of children who were diagnosed with a sexually transmitted infection in adolescence.

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² cdc.gov/nchs/fastats/suicide.htm

Adolescents and young adults comprise 20 percent of new cases in 2020 of HIV in the United States,³ and NICHD has a strong portfolio dedicated to treating and reducing the spread of HIV among young people. For example, the Adolescent Medicine Trials Network for HIV/AIDS Interventions is the only multicenter research network in the country devoted to the health and well-being of adolescents and young adults with or at risk for HIV. NICHD collaborates with other NIH ICOs on domestic and international HIV research in adolescents and pregnant persons, through several clinical networks. Recent NICHD-supported work has led to the development of a digital tool to encourage HIV testing in youth. Among participants aged 19 and younger who previously declined HIV testing, those who used the digital tool were 1.7 times more likely to agree to an HIV test compared to those who received a faceto-face offer.

<u>Budget Policy</u>: The FY 2025 President's Budget request for Child Health is \$455.0 million, a decrease of \$2.0 million or 0.4

DIGITAL MEDIA AND CHILD DEVELOPMENT

The use of technology and digital media by children and adolescents reached levels much higher than the recommended amount prepandemic and has only increased since then. It is therefore critical to understand how this increased use affects child and adolescent development and behavior, as well as mental well-being and substance use. With support from NICHD and other NIH ICOs, scientists have developed strong evidence that children's screen time is associated with development of mental and behavioral disorders, including obsessivecompulsive disorder. Other studies highlighted that more screen time typically led to less interaction with peers for toddlers, increased risk of cognitive and behavioral issues for children born prematurely, and less physical activity for adolescents. In addition to funding research that reveals the potential risks of over-exposure to digital media, NICHD also supports research on the ways digital technology can be used to improve health outcomes for children and adolescents. For example, one group of researchers used a mobile app to teach motor skills interventions to parents with preschoolers at risk for motor development delays, effectively boosting the children's motor skills.

percent compared with the FY 2023 Final level. NICHD places a high priority on pediatric pharmacology, adolescent health promotion, pediatric critical care research, and childhood injury through the implementation of the NICHD Strategic Plan 2020.⁴ Within this level, NICHD will maintain the \$10.0 million supporting research on the effects of COVID-19 on children, including MIS-C.

<u>Demography and Behavior</u>: The program in demography and behavior incorporates NICHD's comprehensive portfolio on behavioral and social influences on health. Key priorities for this research area include childhood obesity; studies of family and population dynamics; neurobiology underlying child learning and learning disabilities; and adolescent health behaviors, including the transition to adulthood. A significant component of NICHD's programs in this research area is to support large survey and longitudinal cohort studies of children and families, often in collaboration with other NIH ICOs and other federal agencies such as the Centers for Disease Control and Prevention. These large-scale efforts, such as the Fragile Families and Child Well-Being Study, the National Survey of Family Growth, and the Pregnancy Risk Assessment Monitoring System, provide the underlying data used by many researchers to analyze behavioral and social risk factors. To support and sustain research capacity, NICHD continues to support the long-standing Population Dynamics Research Infrastructure Program,

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³ cdc.gov/healthyyouth/youth hiv/hiv-information-and-youth.htm

⁴ nichd.nih.gov/about/org/strategicplan

which supports population research centers across the county. These centers support junior researchers; provide access to shared data and resources; and disseminate data, methods, and materials to a broad array of scientists across the field of population dynamics research. Much of the research supported by these centers has served to broaden understanding of health disparities. For example, demographic researchers explored the impact of the COVID-19 pandemic within Asian-American subgroups. The scientists estimated life expectancy at birth before and during the pandemic, with a set of demographic, health, and socioeconomic risk factors for the four largest subgroups: Asian Indians, Chinese, Filipinos, and Vietnamese. The results showed that despite high pre-pandemic life expectancies, Asian Americans suffered a large increase in mortality during the pandemic, with substantial differences across subgroups and between women and men.

Unfortunately, violence is another large public health threat, and NICHD's portfolio in behavioral research is documenting this problem and assessing potential interventions. Homicide is a leading cause of death with women during pregnancy and within one year postpartum in the United States. Most of these crimes are committed by an intimate partner, and most involve firearms. Researchers evaluated the impact of state laws that prohibit the possession of firearms by people convicted of domestic violence misdemeanors or under domestic violence restraining orders, with and without a mandated firearm relinquishment. The results showed that firearm prohibition laws could be effective in preventing homicide of pregnant and postpartum women, but only when the laws also included a firearm relinquishment provision. Another research team assessed the changes in pregnancy-associated deaths in the United States during the pandemic in 2020. During 2020, the rate of overall pregnancy-associated death increased by 35 percent from 2019. Analyses of the cause of death revealed that those caused by drug overdoses increased by 55 percent from 2019 to 2020, and those from homicides increased by 41 percent. Both represented larger increases compared with changes from 2018 to 2019.

<u>Budget Policy</u>: The FY 2025 President's Budget request for Demography and Behavior is \$241.6 million, a decrease of \$1.1 million or 0.4 percent compared with the FY 2023 Final level. NICHD will capitalize on the advances made possible by the population research centers and expand population health research related to health disparities, particularly social determinants of health related to maternal and child health and development. Additional research on the impact of digital media on child development, especially in view of pandemic-related changes, is also planned.

Intellectual and Developmental Disabilities: Research on intellectual and developmental disabilities (IDDs) has been fundamental to NICHD since the founding of the Institute in the early 1960s. Over the past several decades, scientific advances have demonstrated the importance of early intervention and the potential for even more effective ways to improve the lives of individuals with intellectual and developmental disabilities. Now, to maintain this progress scientists need to include diverse groups of people with IDDs in research studies, especially research conducted over a long period of time. Researchers looked at retention of diverse families with children with developmental disabilities in a nine-year research study. They found that retention rates for participants with IDDs were higher than expected. Moreover,

contrary to expectations, parents of children with developmental disabilities who were from diverse racial and ethnic backgrounds were most likely to continue participation in the study.

NICHD's IDD research program is designed to discover new ways to ameliorate both common and rare disorders, including Down syndrome (DS), Fragile X syndrome, Rett syndrome, and muscular dystrophy; inborn errors of metabolism; autism spectrum disorders (ASD); congenital conditions currently or potentially detectable through newborn screening; and IDDs that have no identified cause or are not associated with a specific syndrome. NICHD's Eunice Kennedy Shriver Intellectual and Developmental Disabilities Research Centers offer a wide range of research services to scientists, including informatics and biostatistics; genomic, proteomic, and metabolomics facilities; cellular neuroimaging and optogenetic services; and animal and human behavioral testing. The Autism Centers of Excellence program, sponsored by multiple NIH ICOs, supports large-scale multidisciplinary studies to identify causes and potential treatments for ASDs. Another cooperative effort, the Centers for Collaborative Research in Fragile X and FMR1-Associated Conditions, stimulates multidisciplinary research to facilitate the translation of basic science research findings to the clinical and community settings. A broad array of investigator-initiated projects complements these programs to support rigorous research in detection and screening, early intervention, and supporting child development for individuals with IDDs.



ASDs affect as many as 1 in 68 U.S. children, and the differences in neurodevelopment for children with ASD range from very minor to profound. NICHD-funded research related to ASD emphasizes efforts to improve understanding of how ASD manifests in very young children, and how to identify at risk-children at the earliest possible age to facilitate interventions. Healthcare

providers typically screen toddlers for ASD using a parent questionnaire. However, studies have found that the accuracy of such questionnaires tends to be lower in primary care settings compared to research settings, particularly among girls and children of color. This can widen disparities in early diagnosis and intervention. To address the need for more accurate ASD screening tools, researchers developed a computer app that can track many early signs of ASD, including differences in social attention, facial expressions, head movements, response to name, blink rates and motor skills, and was consistently effective for toddlers of different sex, race and ethnicity. By accurately identifying toddlers who warrant further investigation for ASD, the app may help providers ensure that children and families receive the support they need.

DOWN SYNDROME: TAILORED INTERVENTIONS NEEDED

Down syndrome is a set of cognitive and physical symptoms that result from having an extra chromosome 21 or an extra piece of that chromosome, commonly causing mild to moderate intellectual disability. Within the past 25 years, the average lifespan for a person with Down syndrome has doubled, from 30 to 60 years. Despite this increase in lifespan, individuals with Down syndrome and their families face significant and changing health challenges, and the interventions to address these conditions are frequently developed without their participation and without consideration for their unique needs. For example, Down syndrome, and other IDDs, often co-exist with cardiovascular, metabolic, and other disorders that can be at least partially addressed with lifestyle interventions. However, exercise, diet, and other lifestyle programs are often designed exclusively for a typically developing population. Researchers conducted a smallscale clinical trial of a tailored telehealth exercise program that addressed visual/vestibular deficits and hip muscle weakness often found in individuals with Down syndrome. They found that this program significantly improved balance in low-active adults with Down syndrome, potentially helping to prevent falls as well as improving overall health. Another research team reported that youth with Down syndrome were more engaged in light physical activity, but participated less often in more intensive physical activity, when compared to typically developing youth. This group suggested developing frequent, but lighter, physical activity interventions for youth with Down syndrome.

NICHD continues to lead research on DS and associated conditions, in conjunction with the NIH-wide INCLUDE (INvestigation of Cooccurring conditions across the Lifespan to Understand Down syndromE) project. Researchers recently studied adaptive socialization, daily living, and communication skills in young children with DS. They found that there were a variety of patterns of skill levels among the children, underscoring the importance of individualizing interventions. INCLUDE is also committed to expanding and diversifying the pool of clinical research participants and the DS scientific workforce and will be launching a webinar series to foster communication and collaborations with underrepresented groups and promote diversity.

Budget Policy: The FY 2025 President's Budget request for Intellectual and Developmental Disabilities is \$140.7 million, a decrease of \$0.6 million or 0.4 percent compared with the FY 2023 Final level. NICHD plans to continue to highlight the inclusion of IDD populations in broader clinical research, including the development of tailored interventions specific to IDD population groups. NICHD will also prioritize transition to adult medical care for the IDD population. Finally, NICHD plans to continue emphasizing research on genetic and environmental risk factors for IDDs and ways to address these risk factors through early intervention.

Rehabilitation: NICHD includes the National Center for Medical Rehabilitation Research (NCMRR), which fosters the development of scientific knowledge to enhance the health, productivity, independence, and quality of life of people with physical disabilities. This is achieved through supporting a large research portfolio, building research infrastructure, and guiding NIH's priorities for rehabilitation research. The results of NCMRR's research are felt in the daily clinical practice of rehabilitation. For example, scientists recently found that a program with intervals of high-intensity walking promotes greater gains in fitness for stroke patients than the currently recommended program of moderate-intensity walking. The study was especially significant because the participants were chronic stroke patients—those at least six months past their stroke—for whom rehabilitation is often considered more difficult.

NCMRR's research portfolio includes investigations on the causes and management of injuries, including stroke, traumatic brain injury, spinal cord injury, and orthopedic conditions; repair and recovery of motor and cognitive function; and rehabilitative strategies involving pharmaceutical, stimulation, prosthetics, and other assistive technologies and devices. For instance, to support the more than two million people in the United States who are living with limb injury or disease induced amputations, NICHD recently issued a call for research on limb regeneration. Scientists will focus on understanding how lower-level vertebrates (such as newts and salamanders) are able to regenerate limbs, with the ultimate hope of replicating that process or developing similar capabilities for human use. A recent NICHD-supported advance in this area has outlined a key mechanism in the development of a blastema (a mass of cells capable of growth and regeneration in salamanders), finding that active inhibition of protein synthesis is critical during blastema formation and growth.

Other examples of recent research have focused on the development of neural stimulation and feedback technologies to improve recovery and prostheses. NICHD-funded researchers found that non-invasive spinal stimulation safely enabled upright posture in children with spinal cord injury. Other work found that connecting muscles via electrodes to computers within a limb prosthesis allowed patients to sense the movement of the prosthetic device, leading to improved motor control and range of motion with less pain and fewer phantom limb sensations. While brain-controlled prosthetics typically require time-intensive daily retraining, through NICHD's support, researchers were able to shorten this time by adding machine learning to their retraining algorithms, reducing the need for any recalibration or retraining for more than 40 days.

In addition to supporting researchers directly, NCMRR drives the development of medical rehabilitation research infrastructure through the Medical Rehabilitation Research Resource (MR3) Network. MR3 comprises six resource centers across the country that provide expertise, technologies, and resources to promote multidisciplinary collaborations, develop research opportunities, and expand the nation's capability for medical rehabilitation research.

NICHD also plays a primary role in developing NIH's overall priorities for rehabilitation research. NCMRR led development of NIH's current Research Plan on Rehabilitation 2021,⁵ released in 2021, which guides NIH's efforts to advance the science of rehabilitation through 2026. A major crosscutting theme of this Plan is the need to address inequities for individuals with disabilities. To that end, NICHD released a funding opportunity requesting research to better understand and mitigate health disparities experienced by people with disabilities caused by ableism.

<u>Budget Policy</u>: The FY 2025 President's Budget request for Rehabilitation is \$102.1 million, a decrease of \$0.5 million or 0.4 percent compared with the FY 2023 Final level. NICHD plans to continue to focus on technology development, translational research, and building research capacity within the rehabilitation research community.

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⁵ nichd.nih.gov/publications/product/505

<u>Intramural Research</u>: 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 through basic, clinical, and population-based research.

DIR supported studies lead to discoveries that answer fundamental biomedical research questions and can be used to create novel innovations and therapeutics for various medical conditions. DIR scientists worked with collaborators to develop a potential gene therapy for hereditary spastic paraplegia 50, a rare childhood-onset neurodegenerative disorder that leads to developmental delays, cognitive impairment, and eventual paralysis. The condition is caused by mutations in a single gene, and the team designed an investigational therapy to deliver a functioning copy of this gene to the cells of the central nervous system. Another group of DIR scientists discovered that mutations in the gene SPIN4 cause a rare overgrowth disorder in people—marked by very tall height, large organs, and a large head. Other work developed new



Zebra fish help scientists understand growth and development, the nervous system, genetics, and human health. This microscopy image created by NICHD DIR researchers is part of the "Life Magnified" stamp panel issued by the United States Postal Service.

methods of detecting brain activity. Water molecules are both passively and actively exchanging between the inside and outside of brain cells. This water exchange indicates brain activity, but it occurs too rapidly to be observed by current techniques. However, DIR researchers and their colleagues recently reported the development of a nuclear magnetic resonance method able to detect these rapidly exchanging water molecules.

Researchers in NICHD's Division of Population Health Research (DIPHR) examined how classes of diabetes-specific parenting behaviors are associated with disease management and well-being for youth with type 1 diabetes. They found that differences in parenting behaviors were associated with adherence to dietary guidelines and psychological well-being, but that the families benefitted similarly from a behavioral intervention to improve diabetes management. A long-term study supported by DIPHR examined associations between cognitive performance in adolescence and early adulthood and the risk of suicide death throughout adulthood. The results showed that childhood neurocognitive performance is associated with vulnerability to suicide through middle-adulthood, even after other factors related to suicide risk are taken into account. These data are particularly important with the post-COVID-19 pandemic rise in mental health issues and support the growing need for behavioral and mental health interventions for all Americans, including at-risk communities such as youth.

<u>Budget Policy</u>: The FY 2025 President's Budget request for Intramural Research is \$229.8 million, a decrease of \$0.3 million or 0.1 percent compared to the 2023 Final level. NICHD's intramural research efforts will continue to support studies with implications across the NICHD mission areas.

Research Management and Support: Research and Management Support (RMS) activities include administrative and technical functions that support and enhance the effectiveness of NICHD's research investments. Included among these functions are public communications; budget, contracts, and grants management; peer review; reporting; program evaluation; public policy; and information technology. NICHD anticipates increased investment in information

technology development to support sophisticated data analysis for research, to take advantage of advanced technologies to support administration and reporting, and to modernize program monitoring systems. To support responsible stewardship of valuable resources, NICHD will continue to support systematic evaluations of NICHD's scientific and administrative programs, helping to identify ways to ensure program effectiveness.

<u>Budget Policy</u>: The FY 2025 President's Budget request for Research Management and Support is \$97.9 million, an increase of \$11.4 million or 13.2 percent compared with the FY 2023 Final level. This increase will support increased inflationary costs for both centrally funded services and staff, as well as increasing federal staffing levels to support the implementation of the NICHD Strategic Plan, while reducing contract support. Priorities for RMS will emphasize information technology development and cybersecurity, along with efforts to maintain excellent stewardship of federal resources.

Appropriations History

Fiscal Year	Budget Estimate to Congress	House Allowance	Senate Allowance	Appropriation
2016	\$1,318,061,000	\$1,305,586,000	\$1,345,355,000	\$1,339,802,000
Rescission				\$0
2017 1	\$1,338,348,000	\$1,373,408,000	\$1,395,811,000	\$1,380,295,000
Rescission	\$1,550,540,000	\$1,575,400,000	\$1,373,611,000	\$1,380,233,000
resonstan				Ψ0
2018	\$1,032,029,000	\$1,401,727,000	\$1,426,092,000	\$1,452,006,000
Rescission				\$0
2019	¢1 220 502 000	\$1,469,346,000	\$1,507,251,000	\$1,506,458,000
Rescission	\$1,339,592,000	\$1,409,340,000	\$1,307,231,000	\$1,300,438,000
reseission				ΨΨ
2020	\$1,296,732,000	\$1,580,084,000	\$1,587,278,000	\$1,556,879,000
Rescission				\$0
2021	\$1,416,366,000	\$1,582,269,000	\$1,657,606,000	\$1,590,337,000
Rescission	\$1,410,300,000	\$1,382,209,000	\$1,037,000,000	\$1,390,337,000
resonstan				Ψ0
2022	\$1,942,117,000	\$1,689,786,000	\$1,678,970,000	\$1,683,009,000
Rescission				\$0
2023	\$1,674,941,000	\$1,756,630,000	\$1,745,682,000	\$1,749,078,000
Rescission	\$1,074,941,000	\$1,730,030,000	\$1,745,082,000	\$1,749,078,000
resonstan				Ψ0
2024	\$1,747,784,000	\$1,749,078,000	\$1,759,078,000	\$1,749,078,000
Rescission				\$0
2025	\$1,766,415,000			

¹ Budget Estimate to Congress includes mandatory financing.

Authorizing Legislation

	PHS Act/ Other Citation	U.S. Code Citation	2024 Amount Authorized	FY 2024 CR	2025 Amount Authorized		FY 2025 President's Budget
Research and Investigation	Section 301	42§241	Indefinite	\$1,749,078,000	Indefinite		\$1,766,415,000
National Institute of Child Health and Human Development	Section 401(a)	42§281	Indefinite	}	Indefinite	\int	
Total, Budget Authority				\$1,749,078,000			\$1,766,415,000

Amounts Available for Obligation¹

(Dollars in Thousands)

Source of Funding	FY 2023 Final	FY 2024 CR	FY 2025 President's Budget
Appropriation	\$1,749,078	\$1,749,078	\$1,766,415
Mandatory Appropriation: (non-add)			
Type 1 Diabetes	(\$0)	(\$0)	(\$0)
Other Mandatory financing	(\$0)	(\$0)	(\$0)
Subtotal, adjusted appropriation	\$1,749,078	\$1,749,078	\$1,766,415
OAR HIV/AIDS Transfers	-\$1,294	\$0	\$0
Subtotal, adjusted budget authority	\$1,747,784	\$1,749,078	\$1,766,415
Unobligated balance, start of year	\$0	\$0	\$0
Unobligated balance, end of year (carryover)	\$0	\$0	\$0
Subtotal, adjusted budget authority	\$1,747,784	\$1,749,078	\$1,766,415
Unobligated balance lapsing	-\$65	\$0	\$0
Total obligations	\$1,747,719	\$1,749,078	\$1,766,415

¹ Excludes the following amounts (in thousands) for reimbursable activities carried out by this account: FY 2023 - \$37,259 FY 2024 - \$38,000 FY 2025 - \$39,000

Budget Authority by Object Class¹ (Dollars in Thousands)

		FY 2024 CR	FY 2025 President's
		F1 2024 CK	Budget
Total com	pensable workyears:		
	Full-time equivalent	602	624
	Full-time equivalent of overtime and holiday hours	3	3
	Average ES salary	\$222	\$228
	Average GM/GS grade	12.8	12.8
	Average GM/GS salary	\$145	\$149
	Average salary, Commissioned Corps (42 U.S.C. 207)	\$106	\$111
	Average salary of ungraded positions	\$168	\$173
	OBJECT CLASSES	FY 2024 CR	FY 2025 President's Budget
	Personnel Compensation		
11.1	Full-Time Permanent	\$55,412	\$59,710
11.3	Other Than Full-Time Permanent	\$27,246	\$28,009
11.5	Other Personnel Compensation	\$3,086	\$3,172
11.7	Military Personnel	\$572	\$599
11.8	Special Personnel Services Payments	\$19,267	\$19,887
11.9	Subtotal Personnel Compensation	\$105,584	\$111,377
12.1	Civilian Personnel Benefits	\$34,131	\$36,078
12.2	Military Personnel Benefits	\$128	\$134
13.0	Benefits to Former Personnel	\$0	\$0
	Subtotal Pay Costs	\$139,842	\$147,590
21.0	Travel & Transportation of Persons	\$1,896	\$1,968
22.0	Transportation of Things	\$340	\$347
23.1	Rental Payments to GSA	\$59	\$60
23.2	Rental Payments to Others	\$0	\$0
23.3	Communications, Utilities & Misc. Charges	\$125	\$127
24.0	Printing & Reproduction	\$2	\$2
25.1	Consulting Services	\$52,395	\$54,050
25.2	Other Services	\$64,999	\$63,280
25.3	Purchase of Goods and Services from Government Accounts	\$128,469	\$131,217
25.4	Operation & Maintenance of Facilities	\$58	\$59
25.5	R&D Contracts	\$78,523	\$79,091
25.6	Medical Care	\$1,752	\$1,320
25.7	Operation & Maintenance of Equipment	\$3,928	\$4,014
25.8	Subsistence & Support of Persons	\$0	\$0
25.0	Subtotal Other Contractual Services	\$330,124	\$333,031
26.0	Supplies & Materials	\$10,955	\$10,036
31.0	Equipment	\$4,522	\$3,036
32.0	Land and Structures	\$1,600	\$1,635
33.0	Investments & Loans	\$0	\$0
41.0	Grants, Subsidies & Contributions	\$1,259,593	\$1,268,562
42.0	Insurance Claims & Indemnities	\$0	\$0
43.0 44.0	Interest & Dividends Refunds	\$20 \$0	\$20 \$0
44.0		* -	
	Subtotal Non-Pay Costs	\$1,609,236	\$1,618,825
	Total Budget Authority by Object Class	\$1,749,078	\$1,766,415

¹ Includes FTEs whose payroll obligations are supported by the NIH Common Fund

Salaries and Expenses (Dollars in Thousands)

Object Classes	FY 2024 CR	FY 2025 President's Budget
Personnel Compensation	-	
Full-Time Permanent (11.1)	\$55,412	\$59,710
Other Than Full-Time Permanent (11.3)	\$27,246	\$28,009
Other Personnel Compensation (11.5)	\$3,086	\$3,172
Military Personnel (11.7)	\$572	\$599
Special Personnel Services Payments (11.8)	\$19,267	\$19,887
Subtotal, Personnel Compensation (11.9)	\$105,584	\$111,377
Civilian Personnel Benefits (12.1)	\$34,131	\$36,078
Military Personnel Benefits (12.2)	\$128	\$134
Benefits to Former Personnel (13.0)	\$0	\$0
Subtotal Pay Costs	\$139,842	\$147,590
Travel & Transportation of Persons (21.0)	\$1,896	\$1,968
Transportation of Things (22.0)	\$340	\$347
Rental Payments to Others (23.2)	\$0	\$0
Communications, Utilities & Misc. Charges (23.3)	\$125	\$127
Printing & Reproduction (24.0)	\$2	\$2
Other Contractual Services	_	-
Consultant Services (25.1)	\$48,189	\$49,751
Other Services (25.2)	\$64,999	\$63,280
Purchase of Goods and Services from Government Accounts (25.3)	\$79,688	\$81,859
Operation & Maintenance of Facilities (25.4)	\$58	\$59
Operation & Maintenance of Equipment (25.7)	\$3,928	\$4,014
Subsistence & Support of Persons (25.8)	\$0	\$0
Subtotal Other Contractual Services	\$196,862	\$198,963
Supplies & Materials (26.0)	\$10,955	\$10,036
Subtotal Non-Pay Costs	\$210,179	\$211,444
Total Administrative Costs	\$350,022	\$359,033

Detail of Full-Time Equivalent Employment (FTE)

	FV	FY 2023 Final			FY 2024 CR			FY 2025 President's		
Office							Budget			
	Civilian	Military	Total	Civilian	Military	Total	Civilian	Military	Total	
Office of the Director				104		104	121		101	
Direct:	111	-	111	124	-	124	131	-	131	
Reimbursable:	13	-	13	13	-	13	13	-	13	
Total:	124	-	124	137	-	137	144	-	144	
Division of Extramural										
Research										
Direct:	110	3	113	118	3	121	124	3	127	
Total:	110	3	113	118	3	121	124	3	127	
Total.	110	3	113	110	3	121	127	3	12/	
Division of Extramural										
Activities										
Direct:	28	1	29	38	1	39	42	1	43	
Total:	28	1	29	38	1	39	42	1	43	
1 9 442.1		-		50	•			•		
National Center for Medical										
Rehabilitation Research										
Direct:	8	_	8	8	_	8	8	_	8	
Total:	8	_	8	8	_	8	8	_	8	
1 9 442.1			Ü	Ü			Ü		Ŭ	
Division of Intramural										
Programs										
Direct:	281	_	281	291	_	291	296	_	296	
Reimbursable:	6	-	6	6	_	6	6	-	6	
Total:	287	_	287	297	_	297	302	_	302	
Total	557	4	561	598	4	602	620	4	624	
Includes FTEs whose payroll of	bligations a	are supporte	ed by the	NIH Com	non Fund.					
FTEs supported by funds										
from Cooperative Research	0	0	0	0	0	0	0	0	0	
and Development	U	U	U	U	U	U	U	U	U	
Agreements.										
FISCAL YEAR				Avera	age GS Gra	ıde				
2021					12.6					
2022					12.7					
2023					12.8					
2024					12.8					
2025					12.8					

Detail of Positions¹

GRADE	FY 2023 Final	FY 2024 CR	FY 2025 President's Budget
Total, ES Positions	1	1	1
Total, ES Salary	\$212,100	\$221,900	\$228,113
General Schedule			
GM/GS-15	71	75	76
GM/GS-14	80	83	84
GM/GS-13	117	120	123
GS-12	74	76	79
GS-11	21	23	27
GS-10	0	0	0
GS-9	19	26	27
GS-8	12	12	12
GS-7	8	9	9
GS-6	5	5	5
GS-5	3	3	3
GS-4	0	0	0
GS-3	1	1	1
GS-2	0	0	0
GS-1	0	0	0
Subtotal	411	433	446
Commissioned Corps (42 U.S.C. 207)			
Assistant Surgeon General	0	0	0
Director Grade	2	2	2
Senior Grade	2	2	2
Full Grade	0	0	0
Senior Assistant Grade	0	0	0
Assistant Grade	0	0	0
Junior Assistant	0	0	0
Subtotal	4	4	4
Ungraded	174	180	181
Total permanent positions	412	441	453
Total positions, end of year	590	618	632
- Total full-time equivalent (FTE)	=	-	-
employment, end of year	561	602	624
	\$212,100	\$221,900	\$220 112
Average ES salary		\$221,900 12.8	\$228,113
Average GM/GS grade	12.8		12.8
Average GM/GS salary	\$138,025	\$145,202	\$149,268

¹ Includes FTEs whose payroll obligations are supported by the NIH Common Fund.