

DISABILITY AND REHABILITATION RESEARCH COALITION

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MEMORANDUM

To: DRRC

From: Bobby Silverstein, Peter Thomas, Joe Nahra, and Fernando Montoya

Date: August 4, 2020

Subject: Summary and Excerpts from FY 2021 House Labor, Health and Human Services, Education, and Related Agencies Appropriations Bill

On July 31, the House of Representatives passed its Fiscal Year (FY) 2021 Appropriations [bill](#) for the Departments of Labor, Health and Human Services (HHS), Education, and related agencies. The bill is accompanied by a written [report](#) that includes statements of Congressional intent and charts documenting appropriated levels for specific programs. A press release from the majority staff can be found [here](#). While the House bill has been passed, the Senate's negotiations have stalled, and it currently seems more likely that Congress will eventually advance a Continuing Resolution (CR) to fund the government into FY 2021 rather than a traditional, full-fledged appropriations process (at least until after the 2020 elections).

The FY 2021 House Labor-HHS-Education appropriations bill provides a total of \$196.5 billion in base discretionary funding for the three Departments and their related agencies. In total, the proposed funding level for those departments is \$2.4 billion over the 2020 enacted level and \$20.8 billion over the President's 2021 budget request.

Several programs, including the National Institutes of Health (NIH), would receive significant increases in funding over FY 2020. In particular, the NIH receives an increase of \$500 million for a total of \$42 billion in FY 2021 funding. Overall, this represents an increase of \$3.6 billion over the President's FY 2021 budget request. The National Institute of Child Health and Human Development (NICHD), which houses the National Center for Medical Rehabilitation Research (NCMRR), would receive an increase of \$13.4 million over FY 2020 enacted levels, with total funding set at \$1.57 billion for FY 2021.

We also note that the House included language directing the HHS Office of the Secretary to establish and operate a health disparities education program, including collaboration with public, private, and nonprofit stakeholders on awareness campaigns targeting the general public and medical communities. The language specifically encourages this program to include information about the "importance and legality of data collection and analysis" according to disability status and other demographic factors. The full language is excerpted below on p. 41.

Other significant funding decisions within the House legislation include:

- The Centers for Disease Control & Prevention (CDC) would receive \$8 billion for FY 2021, an increase of \$232 million over the FY 2020 enacted level.
 - The National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP) would receive an increase of \$66.5 million, for a total of \$1.306 billion in funding.
 - The National Center for Injury Prevention and Control (NCIPC) would receive an increase of \$22.5 million, for a total of \$700 million in funding.
- The National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) would receive level funding over the FY 2020 enactment, for a total of \$111,970,000.
- The Agency for Healthcare Research and Quality (AHRQ) would receive \$343 million for its research on health costs, quality, and outcomes, an increase of \$5 million over the FY 2020 enactment.

Program-Specific COVID-19 Emergency Funding

In addition to appropriated amounts for FY 2021, the House-passed bill includes nearly \$25 billion in emergency funding for the current fiscal year to respond to the COVID-19 pandemic. The inclusion of FY 2020 emergency funding, which is allocated outside of the bipartisan budget caps agreed to last year, has been especially controversial during this year's negotiations, and the Senate's process has stalled due to disagreement over whether to include such additional appropriations in the Senate bill. It is unclear how these allocations will fare if and when Congress proceeds to a bicameral conference process. **As such, we have included the House's emergency funding decisions as a separate section and have NOT included these amounts in the attached funding chart.**

The following disability and rehabilitation-related programs would receive emergency funding for FY 2020:

- The CDC would receive \$9 billion in emergency appropriations (more than the total recommended level for FY 2021) to “enhance public health and emergency preparedness and response capacities to better prepare for future public health emergencies.” This allocation includes \$400 million for a Public Health Data Modernization Initiative as well as \$200 million to support public health workforce and infrastructure.
- The NIH Office of the Director would receive \$5 billion in emergency funding to support biomedical research, including support for current grantees to cover costs related to shutdown, startup, and delays due to the pandemic. Approximately half of this would be spread among all 27 Institutes and Centers, ensuring that each IC receives at least a 7% boost in emergency funding. The remaining funds would be available for the NIH Director to allocate as needed to support the research costs outlined above.
 - NICHD would receive \$100.2 million, for an overall level of \$1.67 billion.
 - The National Institute of Deafness and Communication Disorders (NIDCD) would receive \$31.6 million in emergency funds, for an overall level of \$526.5 million.
 - The National Institute of Neurological Diseases and Stroke (NINDS) would receive \$157.3 million in emergency funds, for an overall level of \$2.622 billion.

- The National Institute of Arthritis and Musculoskeletal Disease (NIAMS) would receive \$40.2 million in emergency funds, for an overall level of \$670.5 million.
- The National Eye Institute (NEI) would receive \$53 million in emergency funds, for an overall level of \$884.2 million.
- The National Institute of Mental Health (NIMH) would receive \$131.2 million in emergency funds, for an overall level of \$2.186 billion.
- The National Institute on Aging (NIA) would receive \$228 million in emergency funds, for an overall level of \$3.84 billion.
- The National Cancer Institute (NCI) would receive \$414.5 million in emergency funds, for an overall level of \$6.9 billion.
- The National Institute on Drug Abuse (NIDA) would receive \$94.1 million in emergency funds, for an overall level of \$1.57 billion.
- The National Institute of Nursing Research (NINR) would receive \$10.9 million in emergency funds, for an overall level of \$181.45 million.
- The National Institute on Dental and Craniofacial Research (NIDCR) would receive \$30.7 million in emergency funds, for an overall level of \$512.26 million.
- The National Center for Complementary and Integrative Health (NCCIH) would receive \$9.77 million in emergency funds, for an overall level of \$162.2 million.
- The National Institute of Biomedical Imaging and Bioengineering (NIBIB) would receive \$26 million in emergency funds, for an overall level of \$433 million.
- The National Institute on Minority Health and Health Disparities (NIMHD) would receive \$21.6 million, for an overall level of \$365.3 million.

Additional Materials

Our accompanying chart, included as a separate attachment and provided below, describes the difference between the House FY 2021 Appropriations Committee bill and the previous year's funding. The far right column compares the current House appropriations legislation with the FY 2020 Further Consolidated Appropriations Act, the final legislation enacting funding for the current fiscal year, showing whether an increase, decrease, or level funding (\$0) was provided for in the current House legislation. We have also included numbers from the President's 2021 budget proposal and the FY 2019 and 2018 omnibus.

Additionally, we have included, as an appendix to this document and as a separate attachment, a summary of important sections of the House report language (with verbatim excerpts from the report). "Report language" instructs the federal agencies how Congress intends to spend the appropriated amounts in the actual bill. We have included a number of statements for relevant agencies, with a focus on policies that may impact people with disabilities in general and disability, independent living, and rehabilitation research in particular. **We ONLY included excerpts that specify statements of Congressional intent and did not include references to report language that simply described a particular program.** Additionally, within the report, we included page numbers that reference the original Committee report language via hyperlink. We encourage you to use the accompanying table of contents to quickly access relevant sections.

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TITLE I – DEPARTMENT OF LABOR

([p.12](#))

1. OFFICE OF FEDERAL CONTRACT COMPLIANCE PROGRAMS ([p.27](#))

In the fiscal year 2022 Congressional Budget Justification, OFCCP is directed to detail the agency's compliance and enforcement efforts with regard to promoting equal opportunities for employment by contractors and subcontractors to the Federal government, including technology contractors and subcontractors. The Committee strongly opposes OFCCP's proposed rule on Implementing Legal Requirements Regarding the Equal Opportunity Clause's Religious Exemption, (RIN 1250-AA09), which would give taxpayer funded contractors, including for-profit corporations, the extraordinary power to hire and fire employees based on religion and the employer's understanding of religious tenets and beliefs. In response to these concerns, new bill language is included to prohibit funds from being used to implement, enforce, or give effect to this proposed rule.

2. OFFICE OF DISABILITY EMPLOYMENT POLICY ([p.33](#))

Given the high number of young adults with disabilities who experience significant challenges to live independently and achieve gainful employment, the Committee encourages ODEP to quantify and evaluate the efficacy of experiential learning work-life programs that serve young adults with developmental disabilities, including those with Autism Spectrum Disorder (ASD), which is the fastest growing developmental disability in the U.S. with approximately 1 in 59 children diagnosed each year, and more than 50,000 young adults with ASD turning 18 in the next fiscal year. Further, the Committee encourages ODEP to evaluate barriers to both attaining and sustaining employment and career development within this population, and the financial impact that long-term gainful employment will have on increasing the number of young adults with developmental disabilities who are able to achieve economic self-sufficiency.

TITLE II: DEPARTMENT OF HEALTH AND HUMAN SERVICES ([p.40](#))

1. HEALTH RESOURCES AND SERVICES ADMINISTRATION (HRSA) ([p.40](#))

A. HEALTH WORKFORCE ([p.43](#))

Health Professionals ([p.43](#))—Within the total for Health Professions, the Committee recommends the following amounts:

Budget Activity	FY 2021 Committee
National Health Service Corps	\$120,000,000
Health Professions Training for Diversity	
<i>Centers of Excellence</i>	23,711,000
<i>Health Careers Opportunity Program</i>	15,000,000
<i>Faculty Loan Repayment</i>	1,190,000
<i>Scholarships for Disadvantaged Students</i>	51,470,000
Primary Care Training and Enhancement	48,924,000
Oral Health Training Programs	40,673,000
Interdisciplinary, Community-Based Linkages	
<i>Area Health Education Centers</i>	43,249,000
<i>Geriatric Programs</i>	42,737,000
<i>Mental and Behavioral Health</i>	38,916,000
<i>Behavioral Health Workforce Education and Training</i>	127,000,000
Workforce Information and Analysis	5,663,000
Public Health and Preventive Medicine Programs	19,000,000
Nursing Programs	10,000,000
<i>Advanced Education Nursing</i>	78,581,000
<i>Nurse Education, Practice, and Retention</i>	45,913,000
<i>Nurse Practitioner Optional Fellowship Program</i>	5,000,000
<i>Nursing Workforce Diversity</i>	20,343,000
<i>NURSE Corps Scholarship and Loan Repayment</i>	96,635,000
<i>Nursing Faculty Loan Program</i>	28,500,000

Health Professionals Staffing Shortages Report ([p.44](#)) - The Committee recognizes the current and growing shortage of primary care physicians, psychiatrists, behavioral health specialists, and geriatric medical professionals. The Committee looks forward to receiving the Health Professional Staffing Shortages report requested in House Report 116–62, which was due by June 20, 2020.

HRSA Diversity Programs ([p.44](#)) - The Committee requests a report within 180 days of enactment of this Act on how these programs can be further strengthened to address mental health disparities.

National Health Service Corps ([p.44](#)) - The Committee directs HRSA to examine the application processes and eligibility requirements for both NHSC recruits and provider locations, including the HPSA qualification and scoring. The Committee looks forward to receiving the report, as directed in House Report 116–62, with recommendations on how the NHSC program, including the HPSA application and scoring process, may be modified to increase recruitment and field strength as well as diversify provider sites on the roles of Department agencies in addressing gaps in maternal mental health, within 60 days of enactment of this Act.

Scholarships for Disadvantaged Students ([p.45](#)) - Within the total funding for Scholarships for Disadvantaged Students, the Committee directs \$2,500,000, the same as the fiscal year 2020 enacted level, to be set aside to educate midwives to address the national shortage of maternity care providers and the lack of diversity in the maternity care workforce.

Mental and Behavioral Health Education Training (MBHET) Programs Graduate Psychology Education ([p.46](#)) - In addressing the opioid epidemic, the Committee recognizes the growing need for highly trained mental and behavioral health professionals to deliver evidence-based behavioral interventions for pain management. The Committee encourages HRSA to help integrate health service psychology trainees at FQHCs.

Mental and Substance Use Disorder Workforce Training Demonstration ([p.47](#)) - Within the total, the Committee includes an additional \$15,000,000 for new grants to expand the number of nurse practitioners, physician assistants, health service psychologists, and social workers trained to provide mental and substance use disorder services in underserved community- based settings that integrate primary care and mental and substance use disorder services, which may include establishing, maintaining, or improving academic units or programs to support those activities, as authorized under section 760 of the PHS Act.

The Committee remains concerned by the lack of pediatric and adolescent addiction medicine and addiction psychiatry expertise. Currently, there are insufficient opportunities to effectively train a robust mental health and substance use disorder workforce. Only 75 of the nation’s 179 accredited medical schools offer addiction medicine fellowships, and only one program focuses on fellowship opportunities for pediatric and adolescent addiction medicine and addiction psychiatry. This gap is even more troubling given that the onset of mental health disorders and substance use disorders are most likely to occur at a young age. Substance use disorders prevent children and adolescents from reaching their full potential and are antecedent to addiction in adulthood, and it is evident that our nation is not equipped to support this population. Therefore, the Committee strongly encourages HRSA to include an adequate number of funding awards to fellowship programs focused on increasing the number of board-certified pediatric and adolescent addiction medicine and addiction psychiatry subspecialists.

Nurse Practitioner Optional Fellowship Program ([p.47](#)) - The Committee directs HRSA to give preference to FQHCs, as defined by section 1861(aa)(4) of the Social Security Act. The Committee is concerned the nation is unprepared for healthcare provider shortages and recognizes that optional postgraduate programs with this focus, integrating primary care and behavioral health, will help to address this problem. Patients need expert primary care and behavioral health providers prepared to manage the social and clinical complexities experienced in FQHCs. A key focus of the program will be training and professional development in the integration of primary care and behavioral health. The program will provide original fellowships for transitioning to an integrated model of care consistent with the current high standards of NP education and practice meeting the needs of our nation's most vulnerable populations.

Nursing Education, Practice, Quality, and Retention Experiential Learning Opportunities ([p.48](#)) – The Committee encourages HRSA to support qualifying nurse education training programs at community colleges throughout the country. The Committee directs HRSA to ensure that these grants include as an allowable use the purchase of simulation training equipment. The Committee also directs HRSA to give priority to grantees located in a health professional shortage area in a State with an age-adjusted high burden of stroke, heart disease, and obesity, and to prioritize submissions that support high poverty rate communities.

B. MATERNAL AND CHILD HEALTH ([p.49](#))

Special Projects of Regional and National Significance ([p.49](#)) – The Committee provides the following within SPRANS:

Budget Activity	FY 2021 Committee
Set -aside for Oral Health	\$5,250,000
Set-aside for Epilepsy	3,642,000
Set-aside for Sickle Cell Disease	5,000,000
Set-aside for Fetal Alcohol Syndrome	1,000,000

Maternal and Child Health Programs ([p.51](#)) - Within the total for Maternal and Child Health Programs, the Committee recommends the following amounts:

Budget Activity	FY 2021 Committee
Sickle Cell Anemia Program	\$7,205,000
Autism and Other Developmental Disorders	53,344,000
Heritable Disorders	21,883,000
Healthy Start	130,500,000
Universal Newborn Hearing	17,818,000
Emergency Medical Services for Children	22,334,000

Screening and Treatment for Maternal Depression	5,000,000
Pediatric Mental Health Access	10,000,000

Maternal Mental Health Hotline ([p.51](#)) – To help address these issues, the Committee includes \$3,000,000 to contract with a qualified entity to establish and maintain a maternal mental health hotline to be staffed by qualified counselors, 24 hours a day. Funding may also be used for outreach to raise awareness about maternal mental health issues and the hotline. (**NOTE:** Amended to include an additional \$500,000 for the hotline)

Severe Combined Immune Deficiency (SCID) ([p.53](#)) - The Committee applauds HRSA’s ongoing work to ensure screening of all newborns for Severe Combined Immune Deficiency (SCID), including through initiatives that help parents of newborns diagnosed with SCID understand the disease and treatment options and to navigate the path forward. The Committee encourages HRSA to support efforts to develop telehealth approaches to link families in rural and underserved communities with support and resources, engage providers in education or training related to SCID, and establish mechanisms to obtain long-term outcomes information on infants with SCID through newborn screening.

Maternal Mortality ([p.53](#)) - The Committee recognizes the rising maternal mortality rate in the U.S. as a pressing public health issue. Analysis of maternal mortality review committee data indicates that over 60 percent of pregnancy-related deaths are preventable. The Committee continues to provide no less than \$15,000,000, the same as the fiscal year 2020 enacted level and the fiscal year 2021 budget request, for Healthy Start grantees to support nurse practitioners, certified nurse midwives, physician assistants, and other maternal-child advance practice health professionals within all program sites nationwide. Clinical staff will provide direct access to well-woman care and maternity care services to reduce barriers in access to maternity care and help address maternal health disparities among high-risk and underserved women. Clinical staff will also support health educators by conducting training on maternal early warning signs.

D. RYAN WHITE HIV/AIDS PROGRAM ([p.54](#))

Within the total for the Ryan White HIV/AIDS program, the Committee provides the following amounts:

Budget Activity	FY 2021 Committee
Emergency Assistance	\$655,876,000
Comprehensive Care Programs	1,315,005,000
<i>AIDS Drug Assistance Program</i>	900,313,000
Early Intervention Program	201,079,000
Children, Youth, Women, and Families	75,088,000
AIDS Dental Services	13,122,000

Education and Training Centers	33,611,000
Special Projects of National Significance	25,000,000
Domestic HIV Initiative	90,000,000

E. HEALTH CARE SYSTEMS ([p.54](#))

Within the total for Health Care Systems, the Committee provides the following amounts:

Budget Activity	FY 2021 Committee
Organ Transplantation	\$33,049,000
National Cord Blood Inventory	17,266,000
C.W. Bill Young Cell Transplantation Program	30,009,000
Office of Pharmacy Affairs	10,238,000
Poison Control Centers	24,846,000
Hansen's Disease Program	13,706,000
Hansen's Disease Buildings and Facilities	122,000
Hansen's Payment to Hawaii	1,857,000

Office of Pharmacy Affairs ([p.56](#)) - The Committee recognizes 340B remains important and allows providers to stretch scarce Federal resources to reach more eligible patients and provide comprehensive services.

The Committee acknowledges the request for additional regulatory authority and notes that HRSA already has existing oversight authority that allows the agency to conduct audits of stakeholders who participate in the program to ensure compliance. The Committee recognizes that HRSA has used this authority to conduct 1,300 audits of covered entities, but only 20 audits of manufacturers. The Committee is concerned that HRSA is not using their existing oversight authority to pursue balanced oversight of both providers and drug manufacturers. We encourage HRSA to use its existing oversight authority to pursue more balanced oversight of both providers and manufacturers to ensure compliance and integrity of the 340B program.

F. RURAL HEALTH ([p.56](#))

Rural Telehealth Projects ([p.58](#)) - The Committee strongly supports expanded use of effective and secure telemedicine platforms and remote capabilities to provide expanded health care and related behavior health monitoring and surveillance services in areas that have been hard hit by the opioid epidemic and related substance use disorders. Such technology is needed to augment care and provide access to high quality medical services and monitoring capabilities that decrease geographic barriers and reduce the cost of care, especially for individuals at risk for incarceration and recidivism. To bolster current efforts and address current and anticipated needs surrounding infectious disease outbreaks such as the novel coronavirus of 2019, as well as other

medication-assisted treatments and related mental health monitoring services, the Committee supports efforts that use telemedicine platforms to expand access to rural regions and communities disproportionately impacted by the lack of much needed health care delivery services.

2. CENTERS FOR DISEASE CONTROL AND PREVENTION ([p.61](#))

In addition, the Committee includes \$9,000,000,000 in emergency appropriations for CDC programs and activities, including emergency appropriations for State and local health departments, State and local public health laboratories, global health and global disease detection, vaccination campaigns, public health data modernization, public health workforce development, and the Infectious Diseases Rapid Response Reserve Fund. The emergency appropriation is further described under Title VI of this committee report.

A. CHRONIC DISEASE PREVENTION AND HEALTH PROMOTION (CDPHP) ([p.70](#))

The recommendation for CDPHP maintains the existing program line items as they were funded in fiscal year 2020 and does not provide funding for the America's Health Block Grant proposed again in the fiscal year 2021 budget request. The Committee supports evidence-based strategies to address public health priorities through proven State-based grant programs, utilizing related national organizations for technical assistance, and encourages CDC to continue and expand these successful approaches. Within the total provided, the Committee recommends the following amounts:

Budget Activity	FY 2021 Committee
Health Promotion	\$36,600,000
<i>Glaucoma</i>	4,000,000
<i>Vision and Eye Health</i>	1,000,000
<i>Alzheimer's Disease</i>	20,000,000
<i>Inflammatory Bowel Diseases</i>	1,000,000
<i>Interstitial Cystitis</i>	1,100,000
<i>Excessive Alcohol Use</i>	4,000,000
<i>Chronic Kidney Disease</i>	2,500,000
<i>Chronic Disease Education & Awareness</i>	3,000,000
Prevention Research Centers	26,461,000
Heart Disease and Stroke	145,105,000
Diabetes	148,129,000
National Diabetes Prevention Program	30,300,000
Cancer Prevention and Control	386,049,000
Oral Health	19,500,000
Safe Motherhood/Infant Health	68,000,000

Maternal Mortality Review Committees	22,000,000
Preterm Birth	2,000,000
Other Chronic Diseases	30,000,000
Arthritis	11,000,000
Epilepsy	10,500,000
National Lupus Patient Registry	8,500,000
Social Determinants of Health	10,000,000
Healthy Aging	10,000,000

Arthritis ([p.72](#)) - The Committee recognizes the serious issue of arthritis in communities across the country, which affects one in four Americans and is the number one cause of disability in the U.S. The Committee commends the ongoing work of the CDC Arthritis Program to provide existing investments in data and intervention and prevention research. The Committee urges CDC to support robust investment to expand the number of state-based arthritis programs, provide access to proven arthritis self-management and physical activity programs, and improve data collection and surveillance. The Committee requests a report on the resources necessary to fully scale the Arthritis Program and identify gaps in arthritis public health research and data collection in the fiscal year 2022 Congressional Justification.

Chronic Disease Education and Awareness ([p.72](#)) - The Committee recognizes CDC's work with stakeholders to expand public health education and awareness activities that help to improve surveillance, diagnosis, and proper treatment for chronic diseases. The Committee includes \$3,000,000 to establish a Chronic Disease Education and Awareness competitive grant program to expand and advance CDC's work with stakeholders on education, outreach, and public awareness activities for a variety of chronic diseases for which there is a clear disparity in public and professional awareness that are not already specified under CDC in this report. This approach would utilize a competitive grant process to strengthen the science base for prevention, education, and public health awareness for a variety of chronic diseases, such as lymphatic diseases, that do not currently have dedicated resources that would lead to meaningful patient outcomes.

Chronic Obstructive Pulmonary Disease ([p.72](#)) - The Committee urges CDC to do more to address Chronic Obstructive Pulmonary Disease (COPD), the nation's fourth leading cause of death, including fully engaging with the timely implementation of the COPD National Action Plan, developed by the National Heart, Lung, Blood Institute in coordination with CDC, such as fully integrating COPD surveillance, research, prevention, and management strategies into existing chronic disease efforts. The Committee requests a written report on the updates to the COPD Action Plan no later than 180 days after enactment of this Act.

Chronic Pain ([p.73](#)) - The Committee previously encouraged CDC to analyze data collected from the chronic pain questions included in the 2017 National Health Interview Survey and to clarify the incidence and prevalence of various pain syndromes differentiated by patient age, comorbidities, socioeconomic status, race and gender. The Committee also encouraged CDC to collect data on direct and indirect costs of pain treatment and the effectiveness of evidence-based

treatment approaches (S. Rept. 115–150—Departments of Labor, Health and Human Services, and Education, and Related Agencies Appropriation Bill, 2018). In light of the issuance of the HHS Pain Management Best Practices Task Force report identifying gaps in access to care, and the importance of utilizing interventional procedures such as nerve blocks, injections and surgical devices; behavioral health approaches such as cognitive behavioral therapy; and complementary and integrative health therapies such as massage therapy and acupuncture to address pain, the Committee again encourages CDC to collect this needed data and publish it annually. Furthermore, the Committee directs CDC to provide an update on pain statistics in the fiscal year 2022 Congressional Justification.

Diabetes ([p.73](#)) – The Committee encourages CDC to support diabetes screening programs located in hospital settings.

Food and Health ([p.74](#)) – The Committee understands that many chronic medical conditions, such as diabetes, asthma, arthritis and inflammatory diseases, and maternal health and child development, can be managed cost effectively by improved nutrition. The Committee supports efforts to provide information on how culturally appropriate, food-based solutions integrated into the healthcare system, using the latest knowledge in nutrition, can improve medical effectiveness resulting in cost savings.

Healthy Aging ([p.74](#)) - The Committee recognizes the role of public health in promoting healthy aging. As the nation’s population rapidly ages, the U.S. public health system must adapt accordingly. Isolation and loneliness, financial struggles, multiple chronic conditions, including loss of bone density, hearing, decline in vision, and access to transportation, healthy food, and affordable housing are challenges many older people face. Social isolation alone increases the risk of heart disease, infections, depression, cognitive decline and death among older people. The impact of social isolation is particularly important to consider as the U.S. responds to the outbreak of COVID–19. Age-friendly public health interventions can optimize the health and well-being of adults 65 and over, prolong their independence, and reduce their use of expensive healthcare services.

Inflammatory Bowel Diseases ([p.74](#)) - The Committee commends CDC for continuing to support research on the incidence and prevalence of inflammatory bowel diseases (IBD) in the U.S., including on disparities in patterns of care within minority populations. The Committee encourages CDC to begin planning an educational campaign to increase awareness among healthcare providers and patients in order to reduce disparate health outcomes among minority populations with IBD.

Interstitial Cystitis ([p.74](#)) - The Committee requests an update on education, outreach, and public awareness activities in the fiscal year 2022 Congressional Justification.

Kidney Disease ([p.75](#)) - The Committee is deeply troubled by the significant and growing burden of chronic kidney disease (CKD), which affects an estimated 37 million Americans. Unfortunately, 90 percent of individuals with CKD are unaware they have the illness, only learning of it when there is a need for dialysis or kidney transplantation. With timely awareness, diagnosis, and treatment, the progression of kidney disease and its comorbidities can be slowed.

Social Determinants of Health Pilot Program ([p.76](#)) - The Committee recognizes the role of public health in working across sectors on social determinants of health. The Committee includes \$10,000,000 for CDC to establish a Social Determinants of Health pilot program to award competitive grants to State, local, Territorial, or Tribal jurisdictions to support the development of Social Determinants of Health Accelerator Plans. Such plans should include a description of the health and social outcome objectives of the Social Determinants Accelerator Plan; identify target populations that would benefit from implementation of the plan; and identify non-governmental public health organizations and community organizations that would participate in the development of the plan. Grantees may use a portion of grant funding to convene government entities and stakeholders and to engage qualified research experts in developing Social Determinants Accelerator Plans. The Committee directs CDC to submit a report within 120 days of enactment of this Act on how such grants will be administered.

Vision and Eye Health ([p.77](#)) - The Committee includes funding to enhance programs that prevent blindness and preserve sight. The Committee is aware that vision impairments and eye disease contribute to or complicate many other serious and costly chronic health conditions, including diabetes, cardiovascular disease, injuries and death related to falling, depression, and cognitive decline. State and community-level intervention are vital, as 75 percent of incidents of vision loss are preventable through early detection and treatment.

B. BIRTH DEFECTS, DEVELOPMENTAL DISABILITIES, DISABILITIES AND HEALTH ([p.78](#))

Within this total, the Committee recommends the following amounts:

Budget Activity	FY 2020 Committee
Child Health and Human Development	\$65,800,000
<i>Birth Defects</i>	19,000,000
<i>Fetal Death</i>	900,000
<i>Fetal Alcohol Syndrome</i>	11,000,000
<i>Folic Acid</i>	3,150,000
<i>Infant Health</i>	8,650,000
<i>Autism</i>	23,100,000
Health and Development for People with Disabilities	69,660,000
<i>Disability & Health incl. Child Development</i>	35,000,000
<i>Tourette Syndrome</i>	2,000,000
<i>Early Hearing Detection and Intervention</i>	10,760,000
<i>Muscular Dystrophy</i>	6,000,000
<i>Attention Deficit Hyperactivity Disorder</i>	1,900,000
<i>Fragile X</i>	2,000,000
<i>Spina Bifida</i>	6,000,000

<i>Congenital Heart</i>	6,000,000
Public Health Approach to Blood Disorders	4,400,000
Hemophilia Activities	3,500,000
Hemophilia Treatment Centers	5,100,000
Thalassemia	2,100,000
Neonatal Abstinence Syndrome	2,250,000
Surveillance for Emerging Threats to Mothers and Babies	10,000,000

Duchenne Muscular Dystrophy ([p.78](#)) - The Committee is aware of the development and dissemination of the Duchenne Muscular Dystrophy Care Considerations. In order to understand their impact, the Committee urges CDC to consider how widely the Care Considerations have been adopted across the country and whether this has led to changes in practice or an improvement in patient outcomes, particularly in rural and underserved areas, and the presence of a Certified Duchenne Care Center.

Sickle Cell Disease ([p.79](#)) - The Committee urges the Division of Blood Disorders plan to establish a population-based surveillance system to collect and analyze longitudinal data on people living in the U.S. with sickle cell disease and established a separate budget account for sickle cell disease.

Spina Bifida ([p.79](#)) - The Committee is aware of a growing incidence of sudden death in the adult spina bifida population, and understands that there is a significant need to study this issue and to develop medical interventions that lead to optimal outcomes and to address the transitional and adult care needs of the growing, aging Spina Bifida community. Therefore, the Committee encourages CDC to use funding for the National Spina Bifida Program (NSBP) to be used to support the continuation of the Spina Bifida Clinical Care Monitoring and Tracking Program which works with the National Spina Bifida Registry to guide the health care community in best treatment options for people living with Spina Bifida.

C. PUBLIC HEALTH SCIENTIFIC SERVICES ([p.80](#))

Public Health Data Modernization Initiative ([p.81](#)) - The Coronavirus Pandemic and the outbreak of lung injury associated with the use of e-cigarette, or vaping, products brought to national attention that more needs to be done to ensure that CDC can develop and deploy world-class data and analytics that scale rapidly in emergencies, provide predictive capacity to identify emerging threats, reduce burden on public health partners who are reporting data and ensure bidirectional information flows. In addition, public health professionals are faced with rapid advances in data science and evolving cybersecurity threats that require the necessary skills to securely integrate health data. The Committee initiated the funding for this effort in fiscal year 2020 and provided significant, multi-year resources in the CARES Act (P.L. 116–136); the Committee directs these funds to be thoughtfully planned and invested for a comprehensive, crosscutting effort to advance CDC’s capabilities to respond to all public health threats not limited to COVID– 19. This is the opportunity for there to be significant improvement in public health data and analytics. The Committee includes \$50,000,000 to continue to modernize

systems, and recruit and retain skilled data scientists to improve public health data including at the National Center for Health Statistics, and State, local, tribal and territorial partners. Furthermore, the Committee encourages CDC to consider the acceleration of predictive modeling and use of artificial intelligence to more rapidly transform how CDC collects and uses data to understand various situations in real time.

D. ENVIRONMENTAL HEALTH ([p.81](#))

Newborn Screening ([p.82](#)) - The Committee is aware that State laboratories need specialized support to begin screening for additional newborn conditions and recognizes CDC's expertise in working with laboratories to implement accurate newborn screening tests. The Committee supports the Newborn Screening Quality Assurance Program to support State laboratories as they implement screening for new disorders. This funding will support evaluation of testing methods for new conditions, expansion of CDC's quality assurance materials, and critical infrastructure and development of tests for rare conditions.

E. INJURY PREVENTION AND CONTROL ([p.83](#))

Within this total, the Committee recommends the following amounts:

Budget Activity	FY 2021 Committee
Traumatic Brain Injury	\$6,750,000
Elderly Falls	2,050,000
Injury Prevention Activities	28,950,000

Adverse Childhood Experiences ([p.83](#)) - The Committee encourages CDC to prioritize the collection and reporting of data on adverse childhood experiences (ACEs), including exposure to violence, neglect, and living in a home with mental health or substance use problems, and to use these data to support the implementation of comprehensive ACEs prevention strategies at the State, territorial, tribal and local levels. The Committee also encourages CDC to report on the prevalence of adverse childhood experiences across geography, race and ethnicity, disability and socioeconomic status.

Prevention and Public Health Fund ([p.91](#)) - The Committee encourages the Prevention and Public Health fund be used for programs it was intended to assist, such as cardiovascular/stroke prevention through Million Hearts.

3. National Institutes of Health ([p.92](#))

In addition, Title VI of this Act includes \$5,000,000,000 in emergency appropriations to NIH, of which not less than \$2,500,000,000 must be transferred to Institutes and Centers in proportion to their share of appropriations in fiscal year 2020.

A. NATIONAL CANCER INSTITUTE (NCI) ([p.93](#))

Cancer Immunotherapy ([p.93](#)) - The Committee recognizes that cancer immunotherapies hold enormous promise to cure a number of cancers. Patients with certain hematologic malignancies have already benefited from the development of chimeric antigen receptor T-cell (CAR-T), an immunotherapy. Additional innovative and life-saving therapies for different types of cancers, some with few treatment options, will only be available from additional research in this field. The Committee is encouraged by the research NCI has already supported in this field, but urges the Institute to continue to prioritize research on new immunotherapies. The Committee requests that NCI provide an update in the fiscal year 2022 Congressional Justification on progress being made in this area and the gaps in research that remain.

Heart Disease ([p.99](#)) - The Committee is concerned that this largely preventable disease disproportionately affects racial and ethnic minorities and those living in rural communities and supports ongoing population studies that seek to address these disparities. The Committee is concerned that heart disease is the leading cause of death of pregnant women and that one in five American women experience some type of cardiovascular complication during pregnancy. The Committee supports the NHLBI's Strategic Vision Objective to address maternal health and reduce the risk of cardiovascular disease for women before, during, and after pregnancy. The Committee also supports continued research addressing congenital heart disease, the acceleration of research in regenerative medicine, further investments in data science that will help facilitate precision medicine, and continued genetic research related to heart disease, including heart failure and atrial fibrillation (AFib). The Committee also commends the Institute for initiating research that seeks to address the health-related effects of e-cigarette use and vaping.

National Chronic Obstructive Pulmonary Disease (COPD) Action Plan ([p.100](#)) - The Committee notes NHLBI's role in crafting the National COPD Action Plan and encourages NHLBI to continue this important work by supporting additional research activities and collaborating with other Public Health Service agencies to facilitate implementation of the plan's recommendations.

Postural Orthostatic Tachycardia Syndrome (POTS) ([p.100](#)) - The Committee is disappointed in NIH's disregard for Congressional direction in the recent NIH report Postural Orthostatic Tachycardia Syndrome (POTS): State of the Science, Clinical Care, and Research, which was requested in Senate Report 115-289 and submitted to the Committee on January 31, 2020. NIH appears to have ignored the symposium participants' recommendations and failed to provide the requested estimate of the level of funding needed annually to achieve the objectives specified in Senate Report 115-289. The Committee directs NIH to: (1) update the January 31, 2020 report with recommendations from the POTS experts and submit a revised report to the Committee within 30 days of enactment of this Act, (2) implement the research priorities described in the January 31, 2020 report supplemented with recommendations from the POTS experts, including a funding estimate, and (3) provide a progress update to the Committee within 90 days of enactment of this Act documenting progress towards identifying priority areas of focus for future POTS research.

Pulmonary Fibrosis (PF) ([p.100](#)) - The Committee recognizes that PF is a family of more than 200 different lung diseases that all look very much alike despite having a variety of causes. This

heterogeneity presents significant challenges for diagnosis and treatment. The Committee commends NHLBI for its recent efforts to apply the principles of precision medicine to PF research, especially by funding a major new study that will evaluate a promising treatment for a subset of patients with a particular gene variant. This study, known as PRECISIONS, also aims to identify genetic variants that play a role in certain forms of PF. The Committee urges NHLBI to prioritize basic research on PF, particularly to better understand the causes and process of scarring and the varying impacts on patients.

Sickle Cell Disease (SCD) ([p.100](#)) - The Committee commends NIH for its ongoing support of clinical research for SCD, which imposes major morbidity on an estimated 90,000 to 100,000 individuals in the U.S., with three million Americans carrying the sickle cell trait. The Committee encourages NIH to support clinical trials for prenatal and postnatal treatment of SCD, which includes multiple promising approaches to eradicate this disease, save lives, and dramatically reduce the substantial health care costs associated with SCD for children and adults. The Committee encourages NIH to consider programs both domestically and globally to evaluate the effectiveness of screening technologies for infants and children with the sickle cell trait and disease. Further, while the Committee is aware that NHLBI is funding very promising areas of innovation related to curative gene therapies, the Committee strongly encourages NHLBI to increase its focus as well on disease-modifying therapies that could improve day-to-day care for the vast majority of patients and address issues such as organ damage and pain management. Lastly, the Committee encourages NHLBI to fund the training of more sickle cell disease clinicians and researchers in order to maintain this essential workforce pipeline and to make advances on the transition from childhood medical care to adult.

Thalassemia ([p.101](#)) - The Committee urges NHLBI to review the scientific literature on this issue and provide an update in the fiscal year 2022 Congressional Justification on the best way to address this public health issue.

Regenerative Medicine ([p.101](#)) - The Committee appreciates NIDCR's contributions to the field of regenerative medicine and recognizes the promise this field holds for people across the country, including but not limited to members of the military. The Committee urges NIDCR to continue supporting its already robust regenerative medicine research portfolio and dedicate resources into promising research in this space, including autotherapies research.

End-Stage Renal Disease (ESRD) ([p.102](#)) - The Committee notes the work in supporting critical kidney research that NIDDK has accomplished, including research on ESRD. This research has led to new developments for possible treatments and the Committee continues to encourage NIDDK to work with stakeholders to facilitate new opportunities for research.

B. NATIONAL INSTITUTE OF NEUROLOGICAL DISORDERS AND STROKE (NINDS) ([p.103](#))

Amyotrophic Lateral Sclerosis (ALS) ([p.103](#)) - To leverage the work done thus far in a meaningful way and make measurable progress towards a cure for ALS patients, the Committee encourages NIH to bring together researchers to capitalize on recent advancements, augment existing efforts by bringing into the fight against ALS leading researchers from other, more developed disciplines, and expedite the drive towards a cure for ALS. The Committee

encourages NIH to incentivize the continued exploration of novel therapeutic pathways and support additional clinical trials, increasing the likelihood that the progress of the last decade can germinate into cures with the next decade.

Brain Aneurysm ([p.103](#)) - The Committee continues to be concerned that an estimated one out of 50 individuals in the U.S. has a brain aneurysm, and an estimated 30,000 Americans suffer from a brain aneurysm rupture each year. The Committee is concerned that not enough research is focused on prevention of brain aneurysm ruptures and urges NINDS to increase research on preventing brain aneurysm ruptures.

BRAIN Initiative ([p.104](#)) - The Committee directs NIH to transfer \$50,000,000 from the NIH Innovation Account to NINDS to support the BRAIN Initiative. These funds were authorized in the 21st Century Cures Act (P.L. 114–255). This collaborative effort is revolutionizing the understanding of how neural components and their dynamic interactions result in complex behaviors, cognition, and disease, while accelerating the development of transformative tools to explore the brain in unprecedented ways, making information previously beyond reach accessible. To achieve this goal, two specific projects outlined in a recent BRAIN 2.0 Initiative Advisory Committee report stand out for their importance to human health and technical viability: the Human Brain Cell Atlas and the Human Brain Projectome. Both projects are separate transformative projects that will culminate in a body of data that will provide the clearest view possible of the human brain. To be successful, these projects will require a focused, large-scale effort with multidisciplinary teams with open platforms for dissemination of the tools and knowledge realized. The Committee requests an update on this effort in the fiscal year 2022 Congressional Justification.

Chronic Fatigue Syndrome (ME/CFS) ([p.104](#)) - The Committee commends NIH on its ongoing ME/CFS efforts, including the unanimous adoption of the National Advisory Neurological Disorders and Stroke (NANDS) Council Working Group by the full NANDS Council, the Thinking the Future: A Workshop for Young/Early Career ME/CFS Investigators workshop, and the continued investment in the Collaborative Research Centers (CRC) Consortium. The Committee remains concerned that these initiatives are not making progress fast enough to meet the urgent needs of millions of American adults and children suffering with ME/CFS today. The Committee encourages NIH to accelerate and expand efforts for ME/CFS; such as: (1) accelerating the progress of the NIH ME/CFS Intramural Study by publishing and sharing data, (2) issuing new ME/CFS disease specific funding announcements, (3) coordinating an initiative to develop an interagency consensus on the selection criteria for study participants involved in ME/CFS research, and (4) implementing mechanisms to incentivize new and early career researchers to enter and contribute data to the ME/CFS scientific field.

Duchenne Muscular Dystrophy ([p.104](#)) - The Committee strongly encourages NIH to significantly expand its support for research on Duchenne muscular dystrophy, particularly accelerating and optimizing the clinical trial process through novel and innovative trial designs, such as platform trials, which might serve as a model for other rare diseases communities. The Committee also urges NIH to support methodological research on challenges, such as redosing, manufacturing supply, and potential immune response, associated with the advent of gene therapies for rare diseases such as Duchenne.

***Dystonia* (p.105)** - The Committee notes the recommendations from the conference on dystonia held by NINDS to revitalize the dystonia research portfolio were recently released. The Committee requests an update in the fiscal year 2022 Congressional Justification on the release of the recommendations and new research and therapeutic needs that the conference identified. The Committee encourages NINDS to work with other dystonia research related Institutes such as the National Institute on Deafness and Other Communication Disorders (NIDCD) and the National Eye Institute (NEI) on research that will lead to a better understanding of dystonia etiology and evaluation of the current status of translational research that may lead to more treatment options for those affected by dystonia.

***Expanded Access for ALS Treatment* (p.105)** - The Committee supports efforts to expand access for neurodegenerative diseases with no disease modifying treatments. The Committee encourages NINDS to collaborate with stakeholders to expand access for patients through clinical trials.

***Headache Disorders* (p.105)** - The Committee strongly urges NINDS to consider funding applications on fundamental, translational, and clinical research on headache disorders, including migraine, posttraumatic headache, the trigeminal autonomic cephalalgias, and intracranial hypo/hypertension, that align with the HEAL Initiative's goal to achieve rapid and long-lasting solutions to the opioid crisis.

***Multiple Sclerosis (MS)* (p.105)** - The Committee encourages NINDS to prioritize studies that develop the medical understanding of the progression of MS and advance research on prevention strategies, treatments, and cures for MS.

***Muscular Dystrophy* (p.105)** - The Committee is aware of the Eunice Kennedy Shriver National Institute of Child Health and Human Development's (NICHD's) Data and Specimen Hub (DASH) project to create a centralized resource to store and access de-identified data from NICHD-supported studies. The Committee encourages NINDS to work with NICHD to explore utilizing the DASH site for NINDS studies.

***Myotonic Dystrophy* (p.105)** - The Committee recognizes there are significant opportunities to advance the science regarding the causes of myotonic dystrophy, a serious degenerative genetic condition, and support current efforts to develop the first ever FDA-approved treatment for this inherited genetic disorder. The Committee directs NIH to prioritize the recruitment of young researchers to this field to grow the number of high-quality research proposals submitted for peer review as these efforts hold significant promise for major advances across many neurodegenerative diseases, particularly other triplet repeat expansion diseases. The Committee requests an update on these activities in the fiscal year 2022 Congressional Justification.

***Peripheral Neuropathies* (p.106)** - The Committee notes the continued progress of ongoing research into Guillain-Barre syndrome (GBS), chronic inflammatory demyelinating polyneuropathy (CIDP), and related conditions. The Committee encourages NINDS to continue its work with NIAID and stakeholders on a state of the science conference on evolving research and scientific mechanisms.

***Stroke* (p.106)** - Despite remarkable progress to reduce the stroke mortality rate, it is still the most common cause of severe long-term disability. The Committee supports continued research to improve the scientific understanding of stroke and clinical trials that are developing new treatments and improved approaches to stroke recovery and rehabilitation through the NIH-funded clinical trials network StrokeNet. The Committee supports continued stroke-related research conducted through the BRAIN Initiative that seeks to discover how brain circuits rewire themselves to repair damage that occurs during a stroke and that may lead to effective treatments to mitigate this damage in the future. Understanding that stroke is a largely preventable disorder, the Committee supports ongoing population studies that seek to reveal the reasons for stroke disparities found in communities, especially in rural States in the stroke belt. The Committee further supports additional research exploring how, and the extent to which, the accumulation of white matter lesions in the brain are related to stroke and dementia and urges continued collaborative research among NIH Institutes related to vascular dementia.

***Traumatic Brain Injury (TBI) Mitigation* (p.106)** - The Committee understands that research on regenerative medicine and neuroplasticity, including the use of adult stem cells and neuroplasticity, may play an important role in developing treatments and identifying therapeutic targets for neuroprotection pre/ post TBI. The Committee urges NINDS to work with all relevant Institutes and Centers, including NIA, to support a robust and coordinated portfolio of TBI research that explores all promising avenues to facilitate functional repair of damaged circuitry in TBI. Such analysis should include research on regenerative medicine and neuroplasticity, inclusive to preventative approaches in reducing risk or to eliminate vulnerabilities from a TBI. A potential mitigation approach is to develop interventions that protect from the delayed effects of TBI and associated pathology before they occur. The Committee directs NINDS to provide an update regarding these specific areas of TBI research in the fiscal year 2022 Congressional Justification.

C. EUNICE KENNEDY SHRIVER NATIONAL INSTITUTE OF CHILD HEALTH AND HUMAN DEVELOPMENT (NICHD) (p.110)

***Addressing Maternal Mortality Disparities* (p.110)** - The Committee encourages NICHD to continue its support of research into the leading causes of maternal morbidity and mortality. As Black women experience maternal mortality at nearly four times the rate of white women, the Committee strongly urges NICHD to support research that investigates factors contributing to this disparity, and test evidence-based interventions to address this disparity. The Committee also encourages NICHD to collaborate with the National Institute for Minority Health and Health Disparities (NIMHD) as appropriate to develop targeted funding opportunities.

***Congenital Syphilis (CS)* (p.111)** - The Committee continues to be concerned about the rise of congenital syphilis and the lifelong health effects the disease can have on children. The Committee encourages NICHD to prioritize research in this area and to work with NIAID on new testing, diagnosis, and treatment efforts.

***Endometriosis* (p.111)** - The Committee strongly encourages NICHD to significantly increase funding to expand basic, clinical, and translational research into the mechanics of endometriosis, identify early diagnostic markers, and develop new treatment methods.

Learning Disabilities Research ([p.111](#)) - The Committee is concerned with the decline in achievement for students with disabilities and recognizes the need for continued research and improved interventions. The Committee recognizes the importance of NICHD's funding of Learning Disabilities Research Centers and Learning Disabilities Innovation Hubs, which are the only source of Federal funding available to researchers interested in exploring child development and learning disabilities to conduct randomized control trials and explore the relationships between different variables at work. While learning disabilities affect an individual's education and academic achievement, these disorders are brain-based, and clinical research using the latest technology and advances in neuroscience is essential. The Committee encourages NICHD to continue its robust research into language, reading development, learning disabilities, and disorders that adversely affect the development of listening, speaking, reading, writing, and mathematics abilities. The Committee also encourages NICHD to increase its investment in its Learning Disabilities Research Centers and Learning Disabilities Innovation Hubs.

Maternal Mortality Research ([p.112](#)) - The Committee supports NIH efforts to establish the Implementing a Maternal Health and Pregnancy Outcomes Vision for Everyone (IMPROVE) Initiative. The initiative will use an integrated approach to understand biological, behavioral, sociocultural, and structural factors that affect severe maternal mortality and maternal mortality (SMM/MM) by building an evidence base for improved care and outcomes in specific regions of the country. IMPROVE will target health disparities associated with SMM/MM by (1) implementing and evaluating community-based interventions for disproportionately affected women (e.g., African American, American Indian/Alaska Native, advanced maternal age, low socioeconomic status, and rural populations), and (2) identifying risk factors and the underlying biological mechanisms associated with leading causes of SMM/MM, including cardiovascular disease, infection and immunity, and mental health.

Polycystic Ovary Syndrome (PCOS) ([p.113](#)) - The Committee encourages NICHD to partner with NHLBI to promote research in PCOS, particularly with a focus on comorbidities associated with PCOS that impact heart, blood, lung, sleep, and maternal/ fetal health as they contribute to negative health outcomes. The Committee also encourages NHLBI to report on research that has been conducted on PCOS and its impact on cardiovascular health to date in the fiscal year 2022 Congressional Justification.

Strategic Plan ([p.114](#)) - The Committee has reviewed NICHD's 2020 Strategic Plan and believes that there is insufficient focus on behavioral health, cognition, development of young children, language, learning differences, and school readiness. NICHD has long history of funding critical and meritorious work in these areas. The Committee encourages NICHD to consider otherwise qualified grants in these areas on the same basis as any other areas of focus as it works to implement its strategic plan.

D. NATIONAL EYE INSTITUTE (NEI) ([p.114](#))

Macular Degeneration ([p.115](#)) - The Committee is concerned with advanced age-related macular degeneration as the leading cause of irreversible blindness and vision impairment globally. At least 11 million people in the U.S. have some form of macular degeneration and that

number is expected to double to 22 million by 2050. The Committee encourages NIH to fund research that will stem the growth of macular degeneration and requests an update on current research and future initiatives in the fiscal year 2022 Congressional Justification.

Vision Research ([p.115](#)) - The number of Americans with visual impairment or blindness is expected to double to more than 8 million by 2050. The Committee recognizes NEI's research to advance the understanding of the causes of these afflictions and potential treatments and encourages NEI to expand these research activities.

E. NATIONAL INSTITUTE ON AGING (NIA) ([p.116](#))

Alzheimer's Disease ([p.116](#)) – The Committee encourages NIA to continue to address the research goals set forth in the National Plan to Address Alzheimer's disease, as well as the recommendations from the Alzheimer's Disease Research Summits in 2015 and 2018, the Alzheimer's Disease Related Dementias Research Summits in 2017 and 2020, and the Dementia Care and Services Research Summit in 2017. In addition, the Committee is concerned about the racial and ethnic disparities that exist in Alzheimer's disease diagnoses and encourages NIA to support research exploring the disproportionate impact Alzheimer's disease has on people of color, particularly African-Americans, who are two times more likely to develop late-onset Alzheimer's disease than whites.

Thalassemia ([p.117](#)) - Thanks to significant advances in medical science, thalassemia patients and others dealing with chronic diseases are now living well into adulthood, some even into their 60s. While this is a tremendous victory for research, it has opened new questions. Among these are female and male reproductive issues, the impact of non-disease related medicines, the relationship to diseases of aging such as Alzheimer's disease and other dementias, Parkinson's, arthritis, osteoporosis, and more. The Committee requests that NIA review these issues and report back on the steps that will be taken to address them in the fiscal year 2022 Congressional Justification.

Update NIH Alzheimer's Disease and Dementia Screening Tools ([p.117](#)) - The Committee remains very interested in opportunities to detect cognitive impairment that may be caused by Alzheimer's disease and related dementias as early as possible. The Committee directs NIH to update its analysis of validated screening tools, including digital screening tools, that are able to reliably detect mild cognitive impairment (MCI). This review should focus on identifying tools that have been developed in the time since the last assessment was conducted and on providing information to assist healthcare providers in regularly using such tools to assess the cognitive health of their patients.

E. NATIONAL INSTITUTE OF ARTHRITIS AND MUSCULOSKELETAL AND SKIN DISEASES (NIAMS) ([p.117](#))

Musculoskeletal Research ([p.117](#)) - The NIH has made significant progress in terms of diversity in musculoskeletal research and has included it as a priority in its 2020–2024 strategic plan. The Committee encourages NIAMS to support additional focused research into sexual dimorphism, race/ethnicity, and socio-economic status and how these factors relate to injury prevention, levels of disease activity and functional status, access, and quality of care across the lifespan.

Specifically, we recommend that NIAMS issue Request for Applications (RFA) or Participatory Action Research (PAR) grant programs on disparities similar to those of the NIMHD or NCI. In addition, the Committee encourages NIAMS to support further research on rural inequities in musculoskeletal care in terms of addressing occupational injury types and resulting complications due to limited specialty care access.

F. NATIONAL INSTITUTE ON DEAFNESS AND OTHER COMMUNICATION DISORDERS (NIDCD) [\(p.118\)](#)

Spasmodic Dysphonia [\(p.118\)](#) - The Committee notes the work that NIDCD has done in conducting research on spasmodic dysphonia and encourages NIDCD to work with stakeholders to advance critical research resulting from the 2018 dystonia conference.

G. NATIONAL INSTITUTE OF MENTAL HEALTH (NIMH) [\(p.122\)](#)

Addressing Youth Mental Health Disparities [\(p.122\)](#) - The Committee is encouraged by the work of NIMH to support research on issues related to youth mental health, including suicide among youth. The Committee is further encouraged by NIMH efforts to address mental health disparities among underrepresented and undeserved youth. To guide this continuing work, the Committee requests within 180 days of enactment of this Act, a 10-year strategic plan with long-term plan with short-term goals from NIMH with a goal of eliminating racial mental health disparities in youth by 2030.

This plan should include, but is not limited to: (1) convening a consensus conference, which could be used to guide strategic plan development; (2) identifying and/or creating funding mechanisms that actively support the development of evidence-based practices for racial mental health disparities populations; (3) developing targeted funding opportunities for projects in communities with disparities starting in fiscal year 2021; and (4) developing structures to solicit wide-ranging community input on barriers to addressing mental health disparities. This may include quarterly workshops to solicit community input. The Committee requests an update in the fiscal year 2022 Congressional Justification on progress towards achieving goals in this strategic plan.

The Committee further encourages the Institute to convene a consensus conference that includes: leading extramural experts on health disparities; representatives from other relevant NIH Institutes and Centers like the HHS Office of Minority Health, NICHD, NIMHD; and public stakeholders to discuss research opportunities and gaps, as well as evidence-based solutions and therapeutic interventions. At the conclusion of the conference, the Committee requests a report which should include priority areas for additional study to advance research in addressing mental health disparities in youth.

Autism [\(p.122\)](#) - The Committee encourages NIH to support greater investment in research and collaborations focused on addressing gaps in the Strategic Plan developed by the Interagency Autism Coordinating Committee, including efforts to understand the intersection of biology, behavior, and the environment.

Pediatric Lyme Disease [\(p.123\)](#) - The Committee is concerned about reports that Lyme disease poses special risks for children in terms of neurodevelopmental disorders and psychiatric

comorbidities and encourages NIMH to conduct studies on the neuropsychiatric manifestations of pediatric Lyme disease.

H. NATIONAL INSTITUTE ON MINORITY HEALTH AND HEALTH DISPARITIES (NIMHD) (p.124)

Mission (p.124) - The Committee strongly supports the mission of NIMHD to lead scientific research to improve minority health and reduce health disparities. Persistent racial and ethnic health disparities can be largely attributed to poor social and physical determinants of health in communities of color. Advancing health equity requires a multifactorial response to address issues such as high unemployment, unstable housing, lack of quality education, and inability to access health care. Reducing health disparities also requires solutions that are informed by and tailored to the specific racial, ethnic, socioeconomic, and geographic communities at which they are aimed. The Committee urges NIMHD to maximize funding opportunities that emphasize community-based, multidisciplinary research focused on identifying root causes of health disparities while also informing regional health and social policy to strategically reduce health inequity across communities.

I. OFFICE OF THE DIRECTOR (OD) (p.128)

Adult Cellular Therapies/Regenerative Medicine (p.129) - The Committee encourages NIH, in coordination with FDA and HRSA, to explore the feasibility and utility of an outcomes database for adult cellular therapies that are either FDA-approved or are being administered under FDA Investigational New Drug or Investigational Device Exemption protocols. The Committee also encourages engagement of experts and stakeholders to define data types and standards necessary for such a database.

Amyloidosis (p.129) - The Committee encourages NIH to continue its expansion of research efforts in amyloidosis, a group of rare diseases characterized by abnormally folded protein deposits in tissues. The Committee directs NIH to inform the Committee on the steps NIH has taken to understand the causes of amyloidosis and the measures taken to improve the diagnosis and treatment of this devastating group of diseases in the fiscal year 2022 Congressional Justification.

Amyotrophic Lateral Sclerosis (ALS) (p.129) - The Committee strongly supports the Transformative Research Award program for ALS and directs the Director to continue to fund this critical initiative in fiscal year 2021.

Behavioral Research (p.130) - The Committee believes that a more robust and focused NIH commitment to behavioral science research and training would yield significant improvements to the nation's health due to the important connections between behavior and health. The Committee directs the Director to convene a special advisory panel of behavioral scientists and other community experts to complete an assessment providing recommendations on how to better integrate and realize the benefits to overall health from behavioral research at NIH. The Committee requests that this assessment be finalized before the end of fiscal year 2021 and that a report be submitted to the Committee at that time.

Brain and Body Health ([p.131](#)) - The Committee encourages partnership and collaboration with entities able to explore the similarities in the brains and comorbid conditions of those with Alzheimer’s disease, dementia, and autism, to facilitate studies related to brain and body health, including studies designed to improve and empirically validate a variety of supports for complex conditions.

Clinical Trials During the COVID–19 Pandemic ([p.131](#)) - The Committee appreciates the accommodations NIH has made for clinical trial sites so that institutions can continue to safely conduct clinical trials during the COVID–19 pandemic. The Committee encourages the Director to make investments in research at trial sites to study the impacts of these flexibilities on trial participants, providers, and the overall integrity of the research, and to determine similar adaptations that could be made to improve accessibility of trials, especially for those with historically low participation rates (e.g., racial and ethnic minorities, rural residents, adolescent and young adults, and older adults).

Diversity at NIH Working Group and Strategic Plan ([p.132](#)) - While the Committee is encouraged by the NIH’s demonstrated commitment to diversity, the Committee remains concerned about the continued lack of diversity at NIH among staff and grantees. Accordingly, the Committee requests, within 180 days of enactment of this Act, a strategic plan with long-term and short-term goals to address the racial, ethnic, and gender disparities at NIH. Given recent research in funding gaps at NIH, the Committee requests that this strategic plan identifies barriers in access to NIH funding by investigators researching health disparities, as well as corrective solutions that can be implemented at NIH. The Committee encourages NIH to establish a working group to support development and implementation of this plan, which should be comprised of, but is not limited to, the NIH Office of Equity, Diversity, and Inclusion; Institute and Center Directors and their designees; extramural grantees; experts working in diversity and inclusion; and other community stakeholders.

The Committee requests a report from the NIH within 90 days of enactment of this Act that includes detailed information about the composition of the NIH workforce, advisory committees, and grantees over the last five fiscal years. The data should include disaggregated race and ethnicity data, gender, disability status, and veteran status. For grantees and advisory committee members, the data should also include data on the institution of terminal degree and undergraduate institution.

Duchenne Muscular Dystrophy Research Models ([p.133](#)) - In recent years, more Duchenne drug trials have failed than succeeded despite promising results from pre-clinical animal models. These results lead to years of inefficient drug development and few approved treatments. The Committee urges NIH to convene a multi-stakeholder workshop to evaluate pre-clinical animal models used frequently in muscular dystrophy treatment research, including Duchenne muscular dystrophy, and to consider whether alternative models or strategies may improve therapy development outcomes.

Ehlers-Danlos Syndrome ([p.133](#)) - The Committee encourages NIH to support research and activities with respect to Ehlers-Danlos Syndrome and related connective tissue disorders.

Fragile X (FX) ([p.134](#)) - The Committee encourages NIH to expand the base of researchers and clinicians who are familiar with and trained in the Fragile X-associated disorders and promoting collaboration between basic scientists and clinicians to enable researchers to better understand phenotypes, document variations in how the disorder presents itself, identify potential biomarkers and outcome measures, and develop new interventions.

Lyme and Other Tick-Borne Diseases ([p.137](#)) - The Committee strongly encourages NIH to hold, within one year of enactment of this Act, a workshop on the numerous molecular and functional mechanisms that *Borrelia burgdorferi* (Bb) employs to evade and subvert the immune system of the human host and the immune responses and consequences and also how these mechanisms and responses can subvert the effectiveness of antibiotics. The Committee supports inclusion of other TBD pathogens to consider shared and unique characteristics of the pathogens as NIH determines practical for the workshop, with participation by researchers who have published peer-reviewed articles describing such mechanisms and immune cell responses, particularly for Bb. Multiple, well-documented, defense mechanisms of Bb should be evaluated and recognized as understanding these mechanisms and their significance underpins the ability to develop effective diagnostics and treatments. The Committee encourages NIH to continue research on early diagnosis and treatment of Lyme and other TBD to prevent the development of late stage disease and more serious and longer-term disability, but also intensify research on diagnosis and treatment of late stage and chronic disease. Priority should be based on disease burden and should be given to Lyme disease, which has a high public health burden in the U.S. and has a significant patient population who are not diagnosed until late stage when treatment is more difficult.

Neurofibromatosis (NF) ([p.139](#)) - The Committee supports efforts to increase funding and resources for NF research and treatment at multiple Institutes, including NCI, NINDS, NIDCD, NHLBI, NICHD, NIMH, NCATS, and NEI. Children and adults with NF are at elevated risk for the development of many forms of cancer, as well as deafness, blindness, developmental delays and autism; the Committee encourages NCI to increase its NF research portfolio in fundamental laboratory science, patient-directed research, and clinical trials focused on NF-associated benign and malignant cancers. The Committee also encourages NCI to support clinical and preclinical trials consortia. Because NF can cause blindness, pain, and hearing loss, the Committee urges NINDS, NEI, and NIDCD to continue to aggressively fund fundamental basic science research on NF relevant to restoring normal nerve function. Based on emerging findings from numerous researchers worldwide demonstrating that children with NF are at significant risk for autism, learning disabilities, motor delays, and attention deficits, the Committee encourages NINDS, NIMH, and NICHD to increase their investments in laboratory-based and patient-directed research investigations in these areas. Since NF2 accounts for approximately 5 percent of genetic forms of deafness, the Committee encourages NIDCD to expand its investment in NF2-related research. NF can cause vision loss due to optic gliomas. The Committee encourages NEI to expand its investment in NF1-focused research on optic gliomas and vision restoration.

Polycystic Ovary Syndrome (PCOS) ([p.141](#)) - The Committee recognizes the significant health burden of PCOS, the most common cause of female infertility. About 10 million women have PCOS, which has affected their reproductive, mental, and metabolic health and wellness. The Committee commends NICHD for its continued leadership in PCOS research. Over 70 percent of

NIH's investment in PCOS research has focused on symptoms and comorbidities that impact women's reproductive health. Pregnant women with PCOS are more likely to develop preeclampsia (pregnancy-related hypertension) and have emergency C-sections. Given that the majority of NIH research on PCOS has focused on reproductive implications of the syndrome, critical gaps still exist in understanding the connections between these severe comorbidities and PCOS. The Committee encourages NIH to expand its PCOS research activities and programs to include research on comorbidities associated with PCOS, including liver disease, uterine cancer, heart disease, stroke, diabetes, anxiety, depression, sleep disorders, and suicide. Therefore, the Committee requests an update in the fiscal year 2022 Congressional Justification on current PCOS research activities on related comorbidities and existing research gaps, as well as opportunities for trans-NIH research efforts to address PCOS and related diseases. The Committee urges NIH to prioritize PCOS research funding for New and Early Stage Investigator Awards, and to encourage experienced biomedical and public health researchers to study PCOS and collaborate with patients to identify more effective treatments and a possible cure for PCOS.

Prematurity and Maternal Mortality ([p.142](#)) - Preterm birth and its complications continue to be the leading cause of death for infants in the U.S. and around the world. The Committee is aware that the PREEMIE Reauthorization Act of 2018 (P.L. 115–328) enables the Secretary to establish an interagency working group to improve coordination of programs and activities within the Department to prevent preterm birth, infant mortality, and related adverse birth outcomes. The Committee requests a report within 60 days of enactment of this Act regarding NIH's activities to create the interagency workgroup and its activities to-date to accomplish the duties outlined in the PREEMIE Act. In addition, the Committee recognizes the disparities in outcomes by race, ethnicity, geography and income related to maternal mortality and prematurity and appreciates the work of many agencies in addressing these disparities. The Committee directs the Interagency Workgroup to develop a coordinated Department-wide strategy and implementation plan to share learnings and identify and address factors that lead to maternal mortality and prematurity, including those socio-economic and racial-ethnic factors contributing to disparities in outcomes and inequities in health care. Within one year of the enactment of this Act, the Committee directs NIH to submit a report to the Committee on the aforementioned strategy and a plan for implementation.

Spina Bifida ([p.143](#)) - The Committee encourages NIA, NIDDK, NICHD, and NINDS to study the causes and care of neurogenic bladder and kidney disease to improve the quality of life of children and adults with spina bifida; to support research to address issues related to the treatment and management of spina bifida and associated secondary conditions, such as hydrocephalus and sudden death in the adult spina bifida population; and to invest in understanding the myriad co-morbid conditions experienced by individuals with spina bifida, including those associated with both paralysis and developmental delay; and to provide an update on research findings related to spina bifida in the fiscal year 2022 Congressional Justification. The Committee supports the specific efforts of NICHD to understand early human development; set the foundation for healthy pregnancy, and lifelong wellness of women and children; and promote the gynecological, andrological and reproductive health for people with spina bifida. In addition, the Committee encourages NICHD to identify sensitive time periods to optimize health interventions; improve health during transition from adolescence to adulthood; and ensure safe and effective therapeutics and devices for adults as well as children.

Strengthening Maternal Health Coordination ([p.144](#)) - The Committee is concerned with the rising rate of maternal mortality and morbidity in the U.S., especially in communities of color. The Committee supports the activities of the trans-NIH Maternal Health Working Group, and its new Implementing a Maternal Health and Pregnancy Outcomes Vision for Everyone (IMPROVE) Initiative. The Committee urges the working group to share results from IMPROVE, including the research, knowledge, and best practices to State and local governments, health organizations, and private entities, to assist with efforts to combat the growing trend. The Committee directs the working group to submit a report outlining actions taken within one year of enactment of this Act.

Women's Health Research Priorities ([p.145](#)) - The Committee is concerned that funding for women's health research specifically related to gynecology and obstetrics remains disproportionately lower than other areas of research at NIH. The Committee believes that more focus on this research would help to address the rising maternal morbidity and mortality rates; rising rates of chronic debilitating conditions in women; and stagnant cervical cancer survival rates. The Committee encourages NIH to convene a consensus conference within six months of enactment of this Act to include representatives from the Office of Research on Women's Health, NICHD, NCI, NHLBI, and NIDDK, as well as any other relevant NIH Institutes and Centers, and researchers, clinicians, women's health advocates and other relevant public stakeholders, to evaluate research currently underway related to women's health. As part of the consensus conference, the Committee directs NIH to provide an update in the fiscal year 2022 Congressional Justification that identifies priority areas for additional study to advance women's health research, including reproductive sciences.

4. CENTERS FOR MEDICARE AND MEDICAID SERVICES (CMS) ([p.159](#))

A. PROGRAM MANAGEMENT ([p.160](#))

Access to Rare Disease Treatments ([p.160](#)) - The Committee understands that 1 in 10 Americans is impacted by a rare disease and that the Orphan Drug Act incentivizes the discovery of diagnostics and treatments that confirm prognosis, prolong life, and realize health system savings. Despite progress, treatments exist for only five percent of rare diseases. The Committee urges CMS to support access to biologic and gene therapies to address rare diseases.

Breast Prosthetics ([p.162](#)) - The Committee is encouraged by the deployment of new technologies related to prosthesis. The Committee urges CMS to ensure Medicare recipients recovering from breast cancer are given the opportunity, under the care of a medical professional, to select custom breast prosthetics.

CMMI Strong Start Initiative ([p.162](#)) - The Committee continues to be concerned that the U.S. spends significantly more per capita on childbirth than any other industrialized nation—with costs estimated over \$50 billion annually—but continues to rank behind almost all other developed countries in birth outcomes for both mothers and babies, including high rates of preterm birth, low birth weight, and high maternal and infant mortality. The Committee is aware that the CMMI Strong Start Initiative, as well as other research studies, have shown that models

of care utilizing Certified Nurse Midwives, birth centers and licensed doulas are associated with higher patient satisfaction and improved outcomes for mothers and infants. The Committee looks forward to the report, requested in House Report 116–62, that would build on the CMMI Strong Start Initiative to develop a proposal for CMS to increase access to birth centers and midwives in all state Medicaid programs, and incentivize this model of care for low-risk women.

Diabetic Retinopathy (p.163) - The Committee notes that diabetic retinopathy remains a major national health challenge. According to the National Eye Institute, early detection and treatment of diabetic retinopathy can reduce the risk of blindness by 95 percent. The Committee urges CMS to update its policy to promote earlier diagnosis of diabetic retinopathy.

Health Data Dashboard (p.165) - In order to improve health outcomes of Medicaid beneficiaries and improve efficiency of Medicaid payment models, the Committee encourages CMS, in coordination with CDC, to establish a pilot program to facilitate the integration of population health and social and economic determinants of health into a health care data platform. Such a platform should be able to create performance indicators for State Medicaid programs.

Health Inequalities (p.165) - The Committee recognizes the importance of understanding and addressing the needs of health inequalities amongst minority populations. To ensure these populations are better served by programs and offices within HHS, the Committee directs the Secretary to maintain the collection of data pertaining to health inequalities, as defined by Healthy People 2020, on surveys administered with funding from this Act.

Home Health Payment Systems (p.166) - The Committee urges CMS to avoid home health payment systems that would risk patient access to home health providers in rural areas. The Committee requests a report within 90 days of enactment of this Act regarding the impact of implementation of home health payment systems on the delivery of home health services.

Measuring Incidence and Prevalence of Mild Cognitive Impairment and Alzheimer's Disease (p.167) - The Committee remains interested in better understanding the impact of Mild Cognitive Impairment (MCI), Alzheimer's disease, and other related dementias on Medicare beneficiaries to ensure the Medicare program is able to address current and future needs. To gather such information, the Committee directs CMS to develop and incorporate within the Medicare Current Beneficiary Survey a module of questions pertaining to MCI, Alzheimer's disease, and other related dementias including if beneficiaries have received a diagnosis of either condition and how long it took for them to receive such a diagnosis; if their providers have used the cognitive detection component of the Annual Wellness Visit; and if the beneficiaries have been advised about Alzheimer's and dementia care planning services that are covered under Medicare.

Social Determinants of Health (p.173) - The Committee is aware that social determinants of health are critical drivers of health outcomes and health care costs and that early childhood development is affected by social factors. The Committee encourages CMS to clarify and disseminate the strategies that States can implement under current Medicaid and CHIP authority, or through waivers, to address social determinants of health in the provision of health care, including strategies specifically targeting the pediatric population. This should include guidance on how States can encourage and incentivize managed care organizations to address social determinants of health through contracts. In addition, academic medical centers can be leaders in addressing social determinants of health. The Committee encourages CMS to identify

opportunities to partner with academic medical centers to find innovative approaches to addressing social determinants of health, especially at academic medical centers that have expertise in addressing health disparities and are affiliated with Historically Black Colleges and Universities, Hispanic-Serving Institutions, or other Minority-Serving Institutions.

5. ADMINISTRATION FOR CHILDREN AND FAMILIES ([p.176](#))

A. REFUGEE AND ENTRANT ASSISTANCE ([p.177](#))

Protection & Advocacy for Disabled Children ([p.187](#)) - The Committee believes there must be more robust monitoring of care and treatment for unaccompanied alien children with disabilities in ORR funded care provider facilities and encourages ORR to partner with the nationwide network of Protection & Advocacy agencies to ensure adherence to Federal, State and local codes related to the standards of childcare or the well-being of children with disabilities.

6. ADMINISTRATION FOR COMMUNITY LIVING (ACL) ([p.197](#))

A. AGING AND DISABILITY SERVICES PROGRAMS ([p.197](#))

Youth Caregivers ([p.198](#)) - The Committee recognizes the significant barriers and lack of support youth caregivers face, and urges ACL and its Family Caregiving Advisory Council to consider the needs of youth caregivers in the development and execution of its national family caregiving strategy.

Malnutrition ([p.198](#)) - The Committee is concerned that older adults homebound during the COVID-19 pandemic may not have regular access to food, putting them at increased risk of malnutrition. The Committee understands that malnutrition screening was included as a defined disease prevention and health promotion service in the recent Older Americans Act (OAA) reauthorization, and expects programs to ensure that they are using proper nutrition risk screening tools that capture people at risk for, or that have malnutrition, as part of regular nutrition screening.

Care Corps ([p.198](#)) - The Committee recognizes the growing demand for services and supports to help seniors and individuals with disabilities live independently in their homes, and the need to support family caregivers who facilitate that independence. Within 120 days of enactment of this Act, the Committee requests ACL provide a briefing on the status and benefits of the Care Corps grant program, which places volunteers in communities to assist family care-givers and/or assist seniors and individuals with disabilities in maintaining independence by providing non-medical care.

Integrated Wellness in Supportive Housing ([p.202](#)) - The Committee supports the continued collaboration between HHS and the Department of Housing and Urban Development (HUD) on research initiatives to inform the design of the Supportive Services Demonstration for Elderly Households in HUD Assisted Multifamily Housing. The Committee recognizes that ADRCs support efforts to develop more efficient, cost-effective, and consumer-responsive systems, and believes that they can play an important role in evaluating the Integrated Wellness in Supportive Housing (IWISH) demonstration. The Committee strongly urges the ADRCs to continue to

collaborate with HUD to evaluate the effectiveness of the IWISH project, including its potential for expansion and its cost-savings implications for the healthcare system.

Paralysis Resource Center ([p. 202](#)) - The Committee is concerned that PRC State Pilot Programs may be duplicative of similar grantmaking efforts at the federal level. Within 120 days of enactment of this Act, the Committee requests an assessment of the effectiveness of the State Pilot Programs in meeting funding or programmatic needs not already met by the National PRC.

Traumatic Brain Injury ([p.203](#)) - The Committee encourages ACL to expand efforts to better understand the impacts of TBI on young people.

Developmental Disabilities State Councils ([p.203](#)) - The Committee recommends not less than \$700,000 for technical assistance and training for the State Councils on Developmental Disabilities, and requests that ACL report back to the Committee within 90 days of enactment of this Act on implementation of this language.

Developmental Disabilities Protection and Advocacy ([p.203](#)) - The Committee notes that the Supreme Court decision in *Olmstead v. L.C.* (1999) held that the Americans with Disabilities Act (ADA) does not require removing individuals from institutional settings when they are unable to handle or benefit from a community- based setting and that the ADA does not require community-based treatment on patients who do not desire it. The Committee supports efforts that ensure programs properly account for the needs and desires of patients, their families, and caregivers and the importance of affording patients the proper setting for their care.

Assistive Technology ([p.204](#)) - The Committee continues to provide \$2,000,000 for competitive grants to support existing and new alternative financing programs that provide for the purchase of AT devices.

Telehealth Training and Education for Medicare Beneficiaries ([p.205](#)) - The Committee recognizes the potential for telehealth, remote monitoring, and digital health technologies to help meet the needs of patients and families across the country. In response to the COVID–19 pandemic, Congress expanded access to telehealth services by providing the Secretary with the authority to waive longstanding restrictions on Medicare telehealth services for the duration of the public health emergency. The Committee is aware that as healthcare providers have sought to deliver virtual care at scale, some beneficiaries and caregivers are in need of training and education on how to interact with providers prior to a telehealth visit. To address this issue, the Committee directs ACL to work with CMS and other stakeholders to develop education and training resources that account for age-related differences in how beneficiaries interact with technology. The Committee directs ACL to submit a report within 60 days of enactment of this Act, evaluating current telehealth training and education programs, and provide additional recommendations on how to improve beneficiary utilization and access to synchronous and asynchronous Medicare telehealth services.

7. OFFICE OF THE SECRETARY ([p.205](#))

A. MEDICARE HEARINGS AND APPEALS ([p.205](#))

Medicare Appeals Backlog ([p.205](#)) - The Committee continues bill language included in fiscal year 2020 to provide flexibility for the Department to address backlogs of appeals hearings, as well as retain and recruit Administrative Law Judges. HHS to foster interagency and stakeholder collaboration in addressing the crisis in ME/CFS clinical care and accelerating drug development for ME/CFS.

B. GENERAL DEPARTMENTAL MANAGEMENT ([p.205](#))

Chronic Fatigue Syndrome Advisory Committee ([p.206](#)) - The Committee looks forward to reviewing HHS's plan regarding myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) as requested in House Report 116–62. In the interim, the Committee encourages

Chronic Pain ([p.207](#)) - The Committee remains concerned about the public health epidemic of acute and chronic pain, including its interrelationship with the opioid crisis. The Committee is pleased with the release of the HHS Pain Management Best Practices Inter-Agency Task Force Report in May 2019, but remains concerned over delayed dissemination and implementation of the Report's recommendations. A strategic plan to disseminate the report and implement recommendations is needed, and the Committee strongly encourages the Department to widely disseminate the Report to health care providers and other public health stakeholders, and to update relevant pain management policies and educational tools to reflect Task Force recommended best practices across all relevant HHS agencies, including the CDC, CMS, SAMHSA and other relevant agencies. The Committee also urges the Department to coordinate with the Department of Defense and Veterans Affairs to launch a public awareness campaign to educate Americans about acute and chronic pain and the evidence based non-opioid treatment options that are available, including non-opioid medications; interventional procedures such as nerve blocks, injections and surgical devices; behavioral health approaches such as cognitive behavioral therapy; and complementary and integrative health therapies such as massage therapy and acupuncture.

Evidence-based Grants and Policy ([p.208](#)) - The Committee requests an update in the fiscal year 2022 Congressional Budget Justification on implementation of the Foundations for Evidence-based Policymaking Act (P.L. 115–435) and implementation plans for the coming year. The Committee encourages the Secretary to develop guidance to ensure relevant participants and grantees are involved in the Department-wide process of prioritizing evidence needs, including participating in Department-led evaluations. Consistent with program statutes, the Committee encourages the Secretary to ensure that evidence of effectiveness is a consideration in grant opportunities.

Geriatric Centers of Excellence ([p.208](#)) - The Committee is concerned about demographic challenges driven by an aging population. The Committee directs the Secretary to submit a report within 180 days of enactment of this Act about how to create the most effective and efficient models for “geriatric centers of excellence.” which would serve as hubs to provide integrated

and holistic supportive care for the aging population while monitoring and managing performance of the community's eldercare arrangements. The report should address issues of how these centers will engage in clinical care, as well as provide an array of services and supports to make community living a possibility for more elders. The report should address how a cohort of local geriatric centers of excellence could be used to test and disseminate best practices. Moreover, the report should examine the benefits of establishing geriatric centers of excellence in a variety of settings, including urban, suburban, or rural areas.

Grants Policy (p.209) - The Committee understands Departmental grant guidance makes clear that directives contained in a House, Senate, or Conference report or explanatory statement accompanying an appropriations act should be incorporated into funding opportunity announcements as appropriate. However, the Committee is aware of instances of funding announcements in the past fiscal year failing to address language applicable in a fiscal year 2020 report or statement. The Committee requests a briefing from the Office of Grants within 90 days of enactment of this Act on the process for addressing report or statement language.

Health Impact Assessments (p.209) - The Committee believes there is an opportunity to use health impact assessments and other related approaches in the federal government to raise awareness of the potential health consequences of proposed policies outside the health domain. The Committee strongly encourages the Department to study the benefits of incorporating assessments of health effects into the federal policymaking process with the intention to solve fundamental challenges of population health by better addressing the full range of factors that influence overall health and wellbeing (e.g., education, safe environments, housing, transportation, economic development, access to healthy foods).

Maternal Mental Health (p.210) - The Committee looks forward to receiving a report, as directed in House Report 116–62, on the roles of Department agencies in addressing gaps in maternal mental health.

Mental Health Parity (p.210) - The Committee recognizes the important role Mental Health parity laws have in ensuring access to medical care and treatment. The Mental Health Parity and Addiction Equality Act (MHPAEA) requires insurers to cover care for mental health and substance use disorders at the same level as other medical and surgical care services. However, without proper oversight and compliance, patients are left fighting for coverage of benefits. The Committee is concerned there is still a lack of compliance among insurance companies not adequately covering mental and behavioral health services and providers more than 11 years after MHPAEA passed. In FY 2017, the Department of Labor (DOL) conducted 187 investigations and found 92 insurers were noncompliant. Furthermore, in December 2019, the Government Accountability Office reported that this lack of compliance extends beyond the DOL and includes Health and Human Services (HHS) employer- sponsored health plans. The Committee directs the Secretary of HHS to coordinate with the Secretary of Labor and the Secretary of the Treasury to create guidelines, within 90 days of enactment, in which all employer-sponsored health plans are required to submit an annual public compliance report, with the application of nonquantitative treatment limitations while ensuring that any proprietary, personal, or confidential consumer information is protected. The public compliance report shall

be based on the Department of Labor’s Self-Compliance Tool for the MHPAEA. The Secretary of HHS shall also annually report any auditing and enforcement of all plans.

National Health Care Workforce Commission ([p.210](#)) - The Committee includes \$3,000,000 to establish the National Health Care Workforce Commission, as authorized by the Affordable Care Act. The Commission is intended to serve as a resource on health care workforce policy for Congress, the Administration, States, and localities and is tasked with evaluating healthcare workforce needs, assessing education and training activities, identifying barriers to improved coordination at the Federal, State, and local levels and recommending changes to address those barriers.

Social Determinants Council ([p.212](#)) - The Committee directs the Secretary of Health and Human Services to form an interagency-intergovernmental Social Determinants Council, which shall be responsible for drafting and releasing a report on federal cross-agency opportunities to address social determinants of health, including the potential benefits of grants to State, local, or Tribal jurisdictions to address social determinants of health. The Council shall consist of at least one designee from the Office of Management and Budget, the Department of Agriculture, the Department of Education, the Indian Health Service, HUD, the Department of Labor, the Department of Transportation, three designees of the Department of Health and Human Services—including CMS—and others as deemed appropriate. Up to six council designees may be non-federal subject matter experts with experience in areas such as implementing and evaluating transformative initiatives that harness data and conduct evaluations to increase the impact and cost-effectiveness of Federal Government Services and represent State, local, and Tribal health and human service agencies, public housing authorities, budget offices, State Medicaid agencies, or national Consumer organizations. The Council shall provide technical assistance to State, local, and tribal jurisdictions seeking to develop Social Determinants Accelerator Plans through a new pilot program under the CDC.

Health Disparities Education Program ([p.216](#)) - The Committee strongly encourages the Office of Minority Health to establish and coordinate a health and health care disparities education program. The health and health care disparities education program should collaborate with public, private, and nonprofit stakeholder organizations on education, outreach, and public awareness campaigns targeting the general public and the medical community. In addition, the program should disseminate scientific evidence for the existence and extent of racial and ethnic disparities in health care; new research findings to health care providers and patients to assist them in understanding, reducing, and eliminating health and health care disparities; information about the impact of linguistic and cultural barriers on health care quality; and information about the importance and legality of data collection and analysis according to race, ethnicity, disability status, socioeconomic status, sex, gender identity, sexual orientation, and primary language.

Lupus Program ([p.217](#)) - The Committee includes \$2,000,000 to support the first year of a new multiyear grant cycle for the National Lupus Training, Outreach, and Clinical Trial Program (Lupus Program). The purpose of the Lupus Program is to reduce lupus-related health disparities among racial and ethnic minority populations disproportionately affected by lupus and also to increase minority participation in lupus-related clinical trials.

Social Determinants of Health ([p.217](#)) - The Committee is aware that social determinants of health are critical drivers of health outcomes and health care costs. Social determinants of health can have impacts on the health outcomes of specific populations and impact health disparities in the United States. OMH is encouraged to enter into cooperative agreements with academic institutions with HBCU, HSI, or Minority-Serving Institution status that have expertise in addressing social determinants of health to address the impact of social determinants on minority populations.

C. OFFICE FOR CIVIL RIGHTS ([p.221](#))

Assisted Suicide Laws and Disabled Americans ([p.221](#)) - The Committee is aware of a recent National Council on Disability report entitled “The Danger of Assisted Suicide Laws,” which raises concern that such laws could lead to a two-tiered system that results disproportionately in the deaths of people with disabilities. Accordingly, the Committee strongly encourages OCR to clarify that all HHS suicide prevention grants and services must comply with existing disability rights laws, including the ADA, Sections 504 and 508 of the Rehabilitation Act, and Section 1557, including the provisions requiring accessible communications, so that all videos, documents, and other products ensure access to persons with disabilities. The Committee further strongly encourages OCR to clarify that Sections 504 and 508 of the Rehabilitation Act require physicians to provide people with disabilities with information on the full array of available clinical treatments and available long-term services and supports (LTSS) and to require that referrals to such treatments and services be given if requested. Finally, the Committee encourages OCR to recommend that hospitals create a disability ombudsperson position who is authorized to facilitate communication between healthcare providers and patients with disabilities or their proxies and advocate on the patient’s behalf, when required, to ensure that all clinical and LTSS options and choices are made available.

Rehabilitation Act ([p.221](#)) - The Committee directs the Secretary to fully enforce the Rehabilitation Act of 1973 and the Americans with Disabilities Act.

D. PREVENTION AND PUBLIC HEALTH FUND ([p.229](#))

The Committee includes bill language in section 222 of this Act that requires that funds be transferred within 45 days of enactment of this Act to the following accounts, for the following activities, and in the following amounts:

Agency	Budget Activity	FY 2021 Committee
ACL	Alzheimer’s Disease Program	\$14,700,000
ACL	Chronic Disease Self-Management	8,000,000
ACL	Falls Prevention	5,000,000
CDC	Breastfeeding Grants (Hospitals Promoting	9,000,000
CDC	Diabetes	52,275,000
CDC	Epidemiology and Laboratory Capacity Grants	40,000,000
CDC	Healthcare Associated Infections	12,000,000

CDC	Heart Disease and Stroke Prevention Program	57,075,000
CDC	Million Hearts Program	4,000,000
CDC	Preventive Health and Health Services Bloc Grant	160,000,000
CDC	Tobacco	130,500,000
CDC	Section 317 Immunization Grants	370,300,000
CDC	Lead Poisoning Prevention	17,000,000
CDC	Early Care Collaboratives	4,000,000
SAMHSA	Garrett Lee Smith—Youth	12,000,000

III. Title III – Department of Education ([p.231](#))

1. INNOVATION AND IMPROVEMENT ([p.242](#))

Charter Schools Grants ([p.246](#)) - The Committee requests GAO to provide a report to the Committees on Appropriations on the Department's oversight over CSP and whether the program is being implemented effectively among grantees and subgrantees. The report should include an analysis of CSP grant amounts over time that supported charter schools, with a particular focus on schools that eventually closed or received funds but never opened; the relationships between charter schools supported by CSP grants and charter management organizations; and an analysis of enrollment patterns at these schools, especially for students with disabilities. The report should examine ways to improve the Department's oversight of CSP as well as make recommendations on potential legislative changes to the program that would reduce the potential for mismanagement and ineffective operations.

Javits Gifted and Talented Education ([p.248](#)) - The Committee encourages the Department to use funds to increase the number of grants that assist schools in the identification of, and provision of services to, gifted and talented students who may not be identified and served through traditional assessment methods, such as children with disabilities, English learners, children of color, and economically disadvantaged students.

2. SAFE SCHOOLS AND CITIZENSHIP EDUCATION ([p.248](#))

School Safety National Activities ([p.248](#)) – The Committee is concerned about the possible mental, emotional, and behavioral health effects on students and staff resulting from lockdown drills and active shooter drills conducted in elementary and secondary schools. In response, the Committee provides \$1,000,000 for the Department to enter into an agreement with the National Academies of Sciences, Engineering, and Medicine (National Academies) under which the National Academies will conduct a study to assess the science on the potential mental, emotional, and behavioral health effects of firearm violence prevention activities on students and staff in elementary and secondary school settings. The study and subsequent report should include an analysis of the effects of active shooter simulations, full-scale lockdowns, secured-perimeter lockouts, and other school security measures (e.g. metal detectors, visibility of police/policing on campus) and their mental, emotional and behavioral consequences. The assessment should review the potential effects on children and youth of different ages and on students with disabilities. The National Academies report should identify practices and procedures that can minimize any adverse mental, emotional, and behavioral health effects on children, youth, and staff in elementary and secondary schools resulting from the drills and make recommendations where appropriate.

3. SPECIAL EDUCATION ([p.251](#))

The Committee is concerned that the Federal share of the excess cost of educating students with disabilities has declined and notes the critical role increased funding plays in helping to reverse this trend. The Committee encourages the Department to address the unique needs of students

who use American Sign Language (ASL). The Committee directs the Department to assess the needs of, and identify ways to better serve, students who use ASL and to share findings with the Committee in the fiscal year 2022 Congressional Budget Justification.

Grants for Infants and Families ([p.252](#)) – The Committee recommendation includes new bill language to clarify that States may use funds to support subgrants to non-profit and other organizations for State activity work under IDEA Part C.

Educational Technology, Media, and Materials ([p.252](#)) - The Committee continues to recognize the ongoing progress made with the tools and services provided under this program that have allowed more than 620,000 students with disabilities free access to more than 700,000 books in digitally accessible formats. The Committee strongly encourages continued effort to expand this program's reach to K–12 students in underserved areas.

Personnel Preparation ([p.253](#)) - The Committee notes the critical role the Personnel Preparation program plays in helping to address the nation's shortage of teachers for students with disabilities. Given the critical shortage of special education teachers, including the higher education special education faculty who prepare them, the Committee includes no less than \$10,000,000 for doctoral- level personnel preparation in special education.

4. AMERICAN PRINTING HOUSE FOR THE BLIND ([p.256](#))

The Committee commends the Printing House for ensuring that students who are blind and visually impaired are able to benefit from the latest educational technologies. The increase in funding will help provide accessible technologies developed for students who are blind and visually impaired that are comparable to those available to their sighted peers, thus enabling students with vision loss to take advanced class work, achieve academic success, and obtain gainful employment.

5. HIGHER EDUCATION ([p.266](#))

Open Textbook Pilot ([p.275](#)) - The agreement includes \$7,000,000 to continue the Open Textbook Pilot and fund a new grant competition in fiscal year 2021. The Department shall issue a notice inviting applications consistent with notice and comment procedures and allow for a 60-day application period. This funding should support a significant number of grant awards to IHEs as defined by 20 U.S.C. 1001, a group of IHEs, or State higher education agencies that lead the activities of (and serve as fiscal agent for) a consortium. Funding should be used to create new open textbooks and expand the use of open textbooks in courses that are part of a degree granting program, and particularly those with high enrollments. Allowable uses of funds should include professional development for faculty and staff, including relating to the search for and review of open textbooks; the creation or adaptation of open textbooks; development or improvement of tools and informational resources that support the use of open textbooks, including accessible instructional materials for students with disabilities; and research evaluating the efficacy of the use of open textbooks for achieving savings for students and the impact on instruction and student learning outcomes. The Secretary shall require that any open textbooks created with these funds shall be released to the public under a nonexclusive, royalty-free,

perpetual, and irrevocable license to exercise any of the rights under copyright conditioned only on the requirement that attribution be given as directed by the copyright owner. Further, any tools, technologies, or other resources that are created, developed, or improved wholly or in part with these funds for use with any open textbook must be similarly licensed. Any eligible entity receiving a grant through the Open Textbooks Pilot, upon completion of the supported project, shall report to the Secretary regarding the effectiveness of the project in expanding the use of open textbooks and in achieving savings for students; the impact of the project on expanding the use of open textbooks at IHEs outside of the institution receiving the grant; open textbooks created or adapted under the grant, including instructions on where the public can access each open textbook; the impact of the project on instruction and student learning outcomes; and all project costs, including the value of any volunteer labor and institutional capital used for the project. The Secretary shall make such reports publicly available.

6. OFFICE FOR CIVIL RIGHTS ([p.285](#))

Expulsions and Suspensions in Preschool and Primary Education ([p.286](#)) - The Committee continues to request from the Department its overdue report on preschool and primary education expulsions and suspensions. The Committee remains deeply concerned about expulsions and suspensions that occur in preschool settings and K–3 classrooms, particularly given the racial and gender disparities that exist. This is problematic given the research that indicates these practices can adversely affect development, health and education outcomes. The Committee strongly encourages OCR to collect annually, from all elementary and secondary schools receiving Federal financial assistance, data on the number and type of suspension and expulsions of preschool children and K–12 students, disaggregated by race/ethnicity, sex, disability status, and EL status. OCR should also submit to the Committees on Appropriations, the Committee on Education and Labor, and the Committee on Health, Education, Labor, and Pensions, no later than 180 days after the enactment of this Act, and annually thereafter, a report detailing school discipline in all preschool and K–12 classrooms, including the disaggregated data and any disparities by subgroup in disciplinary rates. The report should also include specific recommendations given to schools on expulsions and suspensions, including highlighting evidence-based interventions, providing consumer education specific to each school, and identifying opportunities to improve school climate, including through relevant programs and the provision of technical assistance that helps prevent and severely limit expulsion and suspension practices in preschool settings and K–3 classrooms, eliminate disparities in the provision of discipline, and ensure the safety and well-being of all young children. The Committee requests a briefing within 90 days of enactment of this Act on the progress the Department is making towards these goals.

IV. Title IV – Related Agencies

([p.289](#))

1. COMMITTEE FOR PURCHASE FROM PEOPLE WHO ARE BLIND OR SEVERELY DISABLED ([p.289](#))

To ensure the Committee for Purchase from People Who Are Blind or Severely Disabled (AbilityOne Commission) maintains its oversight capacity, the Committee continues bill language requiring the AbilityOne Commission to establish written agreements with central nonprofit agencies. The written agreements ensure the AbilityOne Commission can conduct appropriate audit, oversight, and reporting functions in accordance with standard Federal procurement policies.

The Committee supports opportunities for the Commission to assert its authority in the oversight of the AbilityOne program. However, it is concerned about language in the cooperative agreements between the Commission and the Central Nonprofit Agencies (“CNAs”) requiring CNAs to report to the Commission any meetings with key stakeholders, including Congressional members and staff. The Committee requests additional information on the justification for and necessity of this language, to be included in the fiscal year 2022 Congressional Justification.

Committee for Purchase from People Who Are Blind or Severely Disabled—Requested Reports

(p.290) - The Committee continues to request the reports listed under this heading in House Report 115– 244.

V. Title VI – Emergency Funding

([p.309](#))

1. CENTERS FOR DISEASE CONTROL AND PREVENTION ([p.309](#))

The Committee includes \$9,000,000,000 in multi-year emergency funding for programs and activities at the Centers for Disease Control and Prevention (CDC) to enhance public health and emergency preparedness and response capacities to better prepare for future public health emergencies.

2. NATIONAL INSTITUTES OF HEALTH ([p.310](#))

A. OFFICE OF THE DIRECTOR ([p.310](#))

The Committee includes \$5,000,000,000 in emergency funding in the Office of the Director to support biomedical research—including support for current grantees to cover the shutdown costs, startup costs, and other costs related to delays in research in 2020. In 2020, most research laboratories ceased to operate out of safety concerns. Institutions incurred the costs of these shutdowns, and will also incur the cost of reopening these labs when doing so is safe and feasible. The resulting delays in ongoing research will also have a financial impact on research institutions. The emergency funds provided to NIH in this bill will help research institutions to address this financial burden and return to conducting lifesaving research as quickly and safely as possible. The Director of the NIH is required to brief the Committees on Appropriations at least one week prior to obligating emergency funding.