

May 26, 2021

The Honorable Patty Murray
Chair
Senate Subcommittee on
Labor, Health and Human Services,
Education, and Related Agencies
154 Russell Senate Office Building

The Honorable Roy Blunt
Ranking Member
Senate Subcommittee on
Labor, Health and Human Services,
Education, and Related Agencies
260 Russell Senate Office Building

Re: Fiscal Year 2022 Funding for National Institute on Disability, Independent Living, and Rehabilitation Research; Interagency Committee on Disability Research; Centers for Disease Control and Prevention

Dear Chairwoman Murray and Ranking Member Blunt:

On behalf of the Disability and Rehabilitation Research Coalition (DRRC)¹, we write to offer our recommendations and requests for program funding in Fiscal Year (FY) 2022 to support federal research impacting people with disabilities, illnesses, injuries, and chronic conditions, especially those suffering from acute or long-term impacts of COVID-19. We are seeking increased funding for the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR), dedicated funding for the Interagency Committee on Disability Research (ICDR), and funding for the Centers for Disease Control and Prevention's (CDC) National Concussion Surveillance System.

COVID-19 has disparately and dramatically impacted the disability community, and the DRRC has already seen an increased number of individuals with new long-term or even permanent disability resulting from COVID-19. Additionally, it is clear that people with disabilities have a greater vulnerability to the COVID-19 virus, including higher risks of exposure, infection, serious complications, and mortality, while also facing preexisting but greatly exacerbated barriers to equitable health care access during the public health emergency (PHE). As the federal government continues to grapple with the impact of COVID-19, it is critical that adequate resources be provided to support the significant research needs accompanying the federal pandemic response for people with disabilities in both the short term and for years to come.

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¹ The DRRC is a coalition of national non-profit organizations committed to improving the science of disability, independent living, and rehabilitation. The DRRC seeks to maximize the return on the federal investment in disability, independent living, and rehabilitation research and development with the goal of improving the ability of Americans with disabilities to live and function as independently as possible, in keeping with the promises of the Americans with Disabilities Act.

FY 2022 Funding at the National Institute on Disability, Independent Living, and Rehabilitation Research

The DRRC recommends that Congress increase funding for NIDILLR by \$10 million for a total of \$122,970,000 in FY 2022 to respond to the COVID-19 pandemic and support existing needs. The COVID-19 pandemic has highlighted and exacerbated the disparities and difficulties faced by persons with disabilities when accessing public assistance, employment and educational opportunities, health care, and independent living services. The Biden Administration and Congress has emphasized the importance of reducing and alleviating these disparities, and NIDILRR has a unique role in advancing these efforts while continuing its established work to promote the wellbeing and advancement of people with disabilities through applied research. NIDILRR is well-positioned to address the dire research needs stemming from the COVID-19 pandemic, but additional resources are needed in order to fulfill its mission.

NIDILRR's mission is to generate new knowledge and promote its effective use to improve the abilities of people with disabilities to perform activities of their choice in the community, and to expand society's capacity to provide full opportunities and accommodations for its citizens with disabilities. NIDILRR's mission includes exploring new and innovative strategies, interventions, and technologies to better achieve the promises of the Americans with Disabilities Act – equality of opportunity, full participation, independent living, and economic self-sufficiency for individuals with disabilities.

From FY 2009 to FY 2019, NIDILRR experienced decreased funding due to sequestration and only reached pre-sequestration funding levels in FY 2019. In FY 2021, NIDILRR received an increase of \$1 million in funding, for a total current budget of \$112,970,000. Given the critical need for applied disability, independent living, and rehabilitation research during the public health emergency and beyond, and the Administration's efforts to establish more equitable data collection practices for underserved populations (including people with disabilities), the DRRC respectfully requests an FY 2022 funding increase of \$10 million for NIDILRR. This increase will allow NIDILRR to continue to support the wide range of applied research that it currently conducts and address the substantial needs of people with disabilities, including newly disabled individuals suffering from post-acute sequelae of SARS-CoV-2 (PASC) or "Long COVID" due to the COVID-19 pandemic.

Some of the future priorities at NIDILRR that would be supported by the requested funding include expanding research into the role of disability in pandemic response initiatives; providing equitable and accessible telehealth, telerehabilitation, and teleworking solutions; examining the intersectionality of racial and ethnic disparities and disability status; and understanding the impact of lockdowns, quarantining, and social isolation on access to services and supports for people with disabilities. A funding increase would also support the continuation and enhancement of current NIDILRR initiatives, such as expansion of the field-initiated research program; the improvement of disability-specific outcomes measures and research infrastructure; increased capacity building for the rehabilitation research field; and impactful knowledge translation efforts to ensure NIDILRR research efforts directly benefit individuals with disabilities, their caregivers, and health care providers across the country.

We urge the Committee to fund the National Institute on Disability, Independent Living, and Rehabilitation Research at \$122,970,000 in FY 2022 to enhance the capacity for applied research directly impacting the lives of people with disabilities during and after the COVID-19 pandemic.

FY 2022 Funding at the Interagency Committee on Disability Research

In order to supplement and effectively enhance the goals of alleviating disparities and inequities faced by people with disabilities, the DRRC also requests a dedicated budget line of \$2 million for the Interagency Committee on Disability Research (ICDR), coupled with specific report language that addresses and emphasizes the integral role that ICDR should play in advancing equity for people with disabilities.

The ICDR was established to promote coordination and collaboration among federal agencies conducting disability, independent living, and rehabilitation research. The DRRC has long advocated for an enhanced role and recognition of ICDR among federal departments to fulfill the ICDR's potential and optimize the impact of federal disability research. The mission of ICDR has become even more critical due to the impact of COVID-19.

Providing dedicated funding for the first time would aid ICDR as it seeks to fulfill the roles and responsibilities prioritized by the Administration, including by allowing for full-time ICDR staff and a recognition by statutorily appointed federal members of the importance of ICDR's work. These roles and responsibilities include disability-specific data collection in collaboration with the newly established Equitable Data Working Group (a partnership which will be critical to the Working Group's success in advancing its mission) and the coordination of disability efforts across all federal agencies.

To fulfill the full potential of ICDR and the goals of the Administration, the DRRC urges the Committee to appropriate \$2 million in funding for ICDR in FY 2022, along with report language directing its use. We respectfully propose the following language:

"In 2014, Congress enacted bipartisan legislation mandating the design and implementation of a Government-Wide Strategic Plan for Disability, Independent Living, and Rehabilitation Research ("the Plan") to maximize the federal return on investment in this crucial area of research. Congress directed the Secretary of Health and Human Services in his capacity as chair of the Interagency Committee on Disability Research to fulfill this mandate. The Committee urges the Secretary to emphasize ICDR's importance to the field of disability research by appointing a dedicated staff of professionals to coordinate federal research priorities across agencies and advance the ICDR's central role in carrying out the Administration's Executive Order on Advancing Racial Equity. The Committee also urges the ICDR to work with the federal Equitable Data Working Group to coordinate the collection of disability-specific data."

FY 2022 Funding for Concussion Research at the Centers for Disease Control and Prevention

Finally, the DRRC strongly supports the request from a large group of disability and rehabilitation stakeholders, led by the National Association of State Head Injury Administrators

and the Brain Injury Association of America, to fund critical concussion research at the Centers for Disease Control and Prevention (CDC). Appropriating \$5 million to fund the National Concussion Surveillance System, authorized by the Traumatic Brain Injury (TBI) Program Reauthorization Act of 2018 (P. L. 115-377), would improve data collection capturing the extent of concussions in the United States. DRRC members also support a variety of other programs administered by the CDC, including the National Center on Birth Defects and Developmental Disabilities' (NCBDDD) efforts on Health and Disability Promotion and the National Center for Chronic Disease Prevention and Health Promotion's (NCCDPHP) work on social determinants of health.

We urge the Committee to fund the National Concussion Surveillance Systems at \$5 million in FY 2022 to improve the knowledge base around concussions in the U.S., support and evaluate prevention activities and efforts, and enhance follow up and treatment activities for concussion-related disabilities.

Thank you for your consideration of our requests. We look forward to continuing to work with you to advance public policy impacting people with disabilities. If you have any questions, please contact the DRRC coordinators at Bobby.Silverstein@PowersLaw.com, Peter. Thomas@PowersLaw.com, and Joseph.Nahra@PowersLaw.com, or call 202-466-6550.

Sincerely,

The Disability and Rehabilitation Research Coalition (DRRC)

American Academy of Orthotists & Prosthetists

American Academy of Physical Medicine & Rehabilitation*

American Association on Health and Disability

American Congress of Rehabilitation Medicine*

American Medical Rehabilitation Providers Association

American Music Therapy Association

American Occupational Therapy Association*

American Physical Therapy Association*

American Speech-Language-Hearing Association

American Therapeutic Recreation Association

Association of Academic Physiatrists*

Association of Rehabilitation Nurses

Association of University Centers on Disabilities

Brain Injury Association of America*

Child Neurology Society

Christopher & Dana Reeve Foundation

National Association for the Advancement of Orthotics & Prosthetics

National Association of Rehabilitation Research and Training Centers*

National Association of State Head Injury Administrators National Neurotrauma Society Paralyzed Veterans of America Rehabilitation Engineering and Assistive Technology Society of North America United Spinal Association

^{*} DRRC Steering Committee Member