

DISABILITY AND REHABILITATION RESEARCH COALITION

1501 M STREET, N.W. SUITE 700 WASHINGTON, D.C. 20005

September 8, 2020

Francis S. Collins, M.D., Ph.D.
Director
National Institutes of Health
1 Center Drive
Bethesda, MD 20814

**Re: Support for Federal Investment into COVID-19 Research on Disability,
Independent Living, and Rehabilitation**

Dear Director Collins:

On behalf of the Disability and Rehabilitation Research Coalition (DRRC), we write to express our strong support for the critical research being conducted on the COVID-19 pandemic and urge that this research encompass the pandemic's impact on people with disabilities and chronic conditions. Including this population in COVID-19 research will boost the pandemic response, more efficiently direct federal resources, and inform risk communication development. In addition, it is crucial that federal research develop a broader understanding of the specific interactions of this virus with pre-existing disabilities and the disparities in complications and outcomes faced by people with disabilities, who already tend to have poorer health and health outcomes due to entrenched disparities in the health care system.

It is already clear that people with disabilities have greater vulnerability to the COVID-19 virus, including a higher risk of exposure and infection, especially for those living in congregate settings. Additionally, people with disabilities face barriers to accessing care that have only been exacerbated during the pandemic, making disability-focused research a critical priority for the federal government.

We have included below an appendix outlining research topics, developed by members of the DRRC conducting clinical research across the country, for inclusion in the federal research agenda on COVID-19. These topics cover a wide spectrum and are organized into four thematic categories:

- **Ensuring Inclusion of People with Disabilities in Existing COVID-19 Research** (e.g., collecting and reporting disability status information in all ongoing collections; tracking sequelae of COVID-19 in the context of disability; and studying acute, subacute, and chronic effects of virus on recovering patients)
- **Disability-Specific COVID-19 Research** (e.g., sequelae of COVID-19 that may result in disability; disparities in COVID-19 outcomes and potential heightened risks of infection among people with disabilities; and development of a national database or registry to track outcomes for COVID-positive patients)

- **Rehabilitation Interventions for COVID-19 Treatment and Recovery** (e.g., examination and comparative effectiveness analysis of alternative treatments for COVID-19 patients with complex needs, including ventilation and respiratory support; opportunities to expand and increase access to tele-rehabilitation for COVID-19 treatment; and potential treatments to regain function during the course of recovery)
- **Immediate Impacts of COVID-19 Pandemic on People with Disabilities** (e.g., disparities and patterns in furlough, loss of employment, and return to employment for people with disabilities during the pandemic; impacts of social isolation and quarantine policies on older adults and people with disabilities; and barriers in access to services caused by the pandemic, including prevention, wellness, and fitness programs)

As the Department of Health and Human Services (HHS) and agencies within the Department, including the National Institutes of Health (NIH), the Centers for Disease Control and Prevention (CDC), and the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) draft, revise, and update their respective strategic plans and budget requests in response to the pandemic, it is crucial that there be a recognized and explicit inclusion of research specifically relating to people with disabilities.

We urge the leadership of these agencies to consult with career disability researchers, medical experts, advocacy organizations, and other stakeholders with the necessary expertise and experience within the disability community in order to develop research plans that will appropriately address the needs of these populations. As trusted thought leaders and health care service providers, these individuals and organizations should be used as a resource to develop research toward creating holistic solutions to remedy the inequitable impact of this and future public health crises.

We appreciate your consideration of our recommendations to integrate rehabilitation and disability considerations into the federal research structure for COVID-19. The DRRC stands ready to serve as a resource to answer any questions that may arise and provide technical expertise on behalf of the field. If we can be of any assistance, please do not hesitate to contact the DRRC coordinators, Peter Thomas, Joe Nahra, and Bobby Silverstein, at 202-466-6550 or by email at Peter.Thomas@PowersLaw.com, Joseph.Nahra@PowersLaw.com, and Bobby.Silverstein@PowersLaw.com.

Sincerely,

The Undersigned Members of the Disability and Rehabilitation Research Coalition

Academy of Spinal Cord Injury Professionals
 American Academy of Orthotists and Prosthetists
 American Academy of Physical Medicine and Rehabilitation
 American Association on Health and Disability
 American Congress of Rehabilitation Medicine

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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
Amputee Coalition
Association of Academic Physiatrists
Association of Rehabilitation Nurses
Association of University Centers on Disabilities
Brain Injury Association of America
Christopher and Dana Reeve Foundation
National Association for the Advancement of Orthotics and Prosthetics
National Association of Rehabilitation Research and Training Centers
National Association of State Head Injury Administrators
National Multiple Sclerosis Society
Paralyzed Veterans of America
Rehabilitation Engineering and Assistive Technology Society of North America
United Spinal Association

CC:

Dr. Alison Cernich, Deputy Director, National Institute of Child Health and Human Development

Dr. Theresa Cruz, Director, National Center for Medical Rehabilitation Research

Lisa Kaeser, Chief, Office of Legislation and Public Policy, National Institute of Child Health and Human Development

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COVID-19 Research Topics on Disability, Rehabilitation, and Independent Living

1. Ensuring Inclusion of People with Disabilities in Existing COVID-19 Research

As the federal government has turned its focus to pandemic response, research agencies have embarked on significant and widespread efforts to develop and advance fundamental knowledge of the novel coronavirus, including the viral biology, processes of infection and transmission, and the impact of the disease on COVID-positive patients. These efforts are critical to informing public health actions to combat the virus. However, it is essential that any COVID-19 research include people with disabilities, especially regarding broad data collection and related analyses. Without collecting data associated with COVID-19 disaggregated by disability status and other demographic factors, people with disabilities will remain at greater risk of disease and death. Inclusive research on COVID-19 will boost the pandemic response, more efficiently direct critical resources, and inform risk communication development. Existing research projects should ensure that individuals with disabilities are included in the studied populations and that data collection appropriately identifies and tracks these individuals, in order to properly reflect the wider population that continues to be impacted by COVID-19. Potential research topics under this theme may include:

- Sequelae of COVID-19 in the context of disability, including impact of virus on mobility, cognition, and functional performance.
- Acute, subacute, and chronic effects of virus on recovering patients, including cognitive changes, fatigue, endurance, activity tolerance, quality of life, and psychosocial/mental health functioning.
- Inclusion of people with disabilities and collection of disability status information in all ongoing research on COVID-19.
- Disability status changes by incidence and disparity, including cross-references with demographic and geographic factors.

2. Disability-Specific COVID-19 Research

As researchers and clinicians are beginning to better understand the impact of the COVID-19 virus, it is clear that infection can result in serious, extensive, and potentially long-lasting damage beyond the commonly understood respiratory symptoms. It seems likely that there will be a population of previously nondisabled individuals who will develop short-term or even permanent disabilities as a result of COVID-19. It is also clear that people with pre-existing chronic health conditions and disabilities will be at higher risk for serious complications from the disease. It is essential that the federal government work to understand the specific interactions of this virus with pre-existing disabilities and the disparities in complications and outcomes faced by people with disabilities, who already tend to have poorer health and health outcomes due to entrenched disparities in the health care system. Additionally, research must be conducted to better understand the long-term impacts of the disease and the potentially permanent complications related to COVID-19 infection. Potential research topics under this theme may include:

- Sequelae of COVID-19 that result in disability, among people with and without pre-existing disabling conditions.

- Disparities in COVID-19 outcomes and potential heightened risks of viral infection for people with pre-existing disabilities.
- COVID-related brain and other body organ damage.
 - Extent/permanence of observed neurologic symptoms.
 - Impact of prolonged ventilator treatment.
 - Prevalence/association of additional comorbidities due to COVID (e.g., stroke, deep vein thromboses, myocardial infarctions, etc.)
 - Impact of prolonged isolation during treatment
 - Long-term impact(s) on physical and cognitive function/outcomes.
- Development of a national database or registry to track outcomes (including mortality, function, community integration, daily living, and employment) for people diagnosed with COVID-19, similar to the TBI, SCI, and Burn Model Systems.
- Enhancement of existing Model Systems databases with inclusion of information on the impact of COVID-19 among patients in the databases.
- Systematic evaluation of consumer experiences regarding COVID-19 testing, treatment, and rehabilitation/habilitation among persons with disabilities to inform guidance for improved access and accessibility to health services.

3. Rehabilitation Interventions for COVID-19 Treatment and Recovery

The breadth of the potential complications associated with COVID infections necessitate a broad treatment portfolio to aid in recovery from the virus. In order to assist with treatment of some specific conditions of the virus (e.g., respiratory issues resulting from ventilator support, cognitive “fog,” and general motor function), many patients will need some form of short- or long-term rehabilitation in order to regain lost function. As rehabilitation interventions are used in a variety of settings to enhance COVID-19 recovery, it is important that research into the effectiveness of such treatments be conducted, including best practices, outcomes, and COVID-specific training for rehabilitation providers. Additionally, patients who were in need of rehabilitation prior to contracting COVID-19 will likely still need these services, depending on the severity of their case – the practice of rehabilitation will necessarily shift for these patients and research should examine the impacts of these changes. Potential research topics under this theme may include:

- Potential alternative treatments for COVID-19 patients in need of ventilation, e.g., forced inspiratory training.
- Development of standard outcome and quality measures for individuals with COVID-19 receiving rehabilitation services.
- Evaluation of respiratory support needs and outcomes among persons with disabilities who receive complementary interventions (i.e., music-based and other interventions with therapy support vs. without)
- Best practices for the provision of rehabilitation services such as physical and occupational therapy during acute and post-acute disease management to restore or maintain mobility and function to achieve the highest degree of independence, and methods to measure the results and effectiveness of such treatments.
- Impact of rehabilitation therapy (including physical, occupational, and speech-language pathology) on improving function post-recovery for COVID-19 patients and associated training for family and caregivers.

- Feasibility of validated instruments for assessing persons with disabilities experiencing prolonged disorders of consciousness (PDOC) following COVID-19 ventilator support.
- Opportunities to expand and increase equitable access to and permanent coverage of tele-rehabilitation for COVID-19 treatment and recovery.
- Roles and efficacy of rehabilitation therapy provided via telehealth (including physical, occupational, and speech language pathology) for improving functional capacity and maximizing independent living skills during and following COVID-19 infection.
- Development of best practices for training and implementation of COVID-19 rehabilitation programs.
- Potential treatment(s) and course of recovery of physical, cognitive, and psychosocial functioning post-COVID.
- Use of crisis standards of care to understand the scope of potential biases experienced by people with disabilities when receiving care during a health crisis and inform ethical guidance for service providers and caregivers.
- Recognition by insurers and third-party administrators of the appropriateness of and payment for post-COVID rehabilitation services.
- Importance of reduced cost-sharing and administrative burden in eliminating barriers to care.

4. Immediate Impacts of COVID-19 Pandemic on People with Disabilities

The pandemic has not only impacted the country's health care system but has upended nearly every facet of the nation's infrastructure. The pandemic's quarantining and social distancing requirements, along with the associated economic recession, have already had dire and disproportionate consequences for people with disabilities and other vulnerable populations. People with disabilities already face significant systemic inequities in income, education, employment, housing, transportation, and community participation. These conditions have been exacerbated in many cases by the indirect effects of COVID-19, necessitating an informed, coordinated, and sustained federal response. Applied research into the impact of the pandemic, including on employment, education, and access to services for people with disabilities, is critical to supporting this population during the pandemic and the prolonged aftereffects. Of course, the non-COVID-related health concerns of people with disabilities have not diminished, and it is similarly important for federal research to explore how health care and rehabilitation for these individuals has been impacted by the system's pivot to a COVID-19 focus. Potential research topics under this theme may include:

Employment

- Comparative likelihood of furlough/loss of employment for workers with disabilities.
- Disparities in return-to-work patterns and employment for people with disabilities.
- Use of SSI/SSDI vs. unemployment insurance for workers with disabilities furloughed/terminated due to the pandemic.
- Impact of the pandemic on the transition from school to work for youth with disabilities.
- Impact of the pandemic on access to and effectiveness of supportive services toward the school-to-work transition and career development in young adulthood for people with disabilities.
- Disparities in return-to-work patterns, employment, access to and effectiveness of supportive services for people with disabilities during and post-COVID.

Quarantine/Social Distancing

- Impact of and disparities in social isolation and occupational deprivation on older adults and people with disabilities.
 - Equitable and accessible interventions to reduce social isolation during times of quarantine.
- Metric development for measuring community participation and re-engagement following COVID-19.
- Impact of quarantining/social distancing on individuals with serious mental illness.
 - Shutdown of public transportation systems.
 - Heightened structural risk for individuals in group, residential, or inpatient settings.
 - Loss of income for individuals on SSI/SSDI.
- Psychosocial impact of social distancing on people with disabilities, especially youth with disabilities, and related impact on other areas of function.
- Effectiveness of community-based interventions and innovations in creative arts therapies to address social isolation for people with disabilities, especially those living in congregate care settings.
- Effectiveness of different media and tele-rehabilitation services for teaching students with disabilities during periods of isolation/distancing.
- Impact of social distancing and COVID-19 response on treatment/rehabilitation and associated outcomes for people with pre-existing disabilities, chronic conditions, and injuries.
- Opportunities for existing providers of services for people with disabilities to implement telehealth and mobile health services.
- Opportunities to support people with disabilities, students, and caregivers directly through the use of telehealth and mobile health technology and services.
- Efficacy of in-person, telehealth, and virtual therapy interventions (including physical, occupational, and recreational therapy) focused on mindfulness, physical activity, exercise, and stress management during quarantine, including for people with physical, cognitive, and sensory impairments.
- Effectiveness of the use of prescribed video games, mindfulness/meditation apps (like Headspace), and at-home biofeedback tools to reduce depression, anxiety, and mood issues in adults and behavior and academic difficulties of students with IEPs/behavioral intervention plans during the pandemic.

Access to Essential Services

- Impact on availability and quality of care provided by health care providers including peer specialists/peer providers due to social distancing requirements and limits on in-person visits.
- Impact of COVID-19 on access to non-COVID health care services for people with disabilities.
- Impact of COVID-19 recession on budgets for state and local services provided to people with disabilities.
- Impact of stay-at-home orders and safety of public transportation to accessing COVID-19 testing facilities for people with disabilities.
- Availability of home- and community-based services and supports for adults with disabilities due to the pandemic, especially a ready-trained and reliable workforce of personal care assistants and an affordable supply of essential personal protective equipment (PPE) and products.

- Availability of assistive devices and accessible emergency response technologies. Maintaining an adequate supply chain of assistive devices that can be delivered and/or repaired in a timely manner.
- Opportunity for community health workers to work as social “first responders” for people with disabilities and concomitant health disparities during COVID-related workforce shortages and how to receive payment for these services.
- Opportunities to develop/improve telehealth interventions to address needs of people with disabilities.
- Effectiveness of expanded telehealth services and related treatment guidelines for people with disabilities.
- Access to critical supplies for people with limited mobility, low vision, blindness, and other sensory and/or cognitive disabilities during pandemics.
- Potential protective factors against COVID-19 and related complications of social safety net programs (including SNAP, SSI, and housing supports) for people with disabilities.
- Impact of increased food insecurity on people with disabilities due to quarantines, limited availability of food delivery services, limited food products, especially for those already living in food deserts and/or increased demand on federal, state, and local nutrition assistance programs and reductions in income/resources.
- Impact of increased housing insecurity on people with disabilities.
- Interventions to boost the impact of housing/food assistance programs for people with disabilities during and post-COVID.
- Investigation of disparities faced by people with long-term disabilities pre- and post-COVID.
 - Community living, community participation, work/economic equity.
- Disparities in access to rehabilitation services based on social determinants of health and impact of lack of access to treatment pre- and post-COVID, including economic stability, education, health and health care, neighborhood and built environment, and social and community context.