

# DISABILITY AND REHABILITATION RESEARCH COALITION

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

November 16, 2020

*Submitted Electronically* via [Rehabilitation@nih.gov](mailto:Rehabilitation@nih.gov)

Theresa Hayes Cruz, PhD, Director  
National Center for Medical Rehabilitation Research (NCMRR)  
*Eunice Kennedy Shriver* National Institute on Child Health and Human Development (NICHD)  
National Institutes of Health  
Bethesda, MD 20814

**RE: DRRC Response to Request for Information: Response to Proposed NIH  
Rehabilitation Research Plan Objectives (NOT-HD-20-033)**

Dear Director Cruz:

On behalf of the Disability and Rehabilitation Research Coalition (DRRC), we appreciate the opportunity to provide comments on the National Center for Medical Rehabilitation Research's (NCMRR) Request for Information on the development of the National Institutes of Health (NIH) Rehabilitation Research Plan.

The DRRC is a coalition of more than 20 national research, clinical, and consumer non-profit organizations committed to improving the science of rehabilitation, disability, and independent living. The DRRC seeks to maximize the return on the federal research investment in these areas with the goal of improving the ability of Americans with disabilities to live and function as independently as possible following an injury, illness, disability, or chronic condition. The coalition plays a leadership role in coordinating the activities of stakeholders to increase and leverage federal resources devoted to research and development in these domains.

We would like to thank NCMRR and the entire NIH for the progress so far in achieving the goals set out in the 2016 Rehabilitation Research Plan. As stated in previous comments, there has been substantial progress at NIH in the field of medical rehabilitation research, and we have recognized a significant increase in the coordination and intensity of rehabilitation research conducted across the Institutes and Centers. We believe the proposed themes and objectives outline a clear vision for the future of rehabilitation research at NIH and offer the following comments regarding additional areas of focus to consider. Additionally, we include below suggested language revisions to the proposed themes and objectives, notated in red and underlined.

## *COVID Rehabilitation and Disability Research*

Across the federal government, strategic planning is being redesigned to moderate the ongoing impacts of the COVID-19 pandemic, and the NIH Rehabilitation Research Plan can and should do the same. As the DRRC has noted in previous communications with NIH, the pandemic has had disproportionate impact on people with disabilities and chronic conditions, including a

higher risk of infection and barriers to accessing needed medical care and other services. It is essential that the federal research agenda include work to develop a broader understanding of the specific interactions of the COVID virus with pre-existing disabilities and the disparities in complications and outcomes faced by people with disabilities. This issue is further complicated by the fact that racial and ethnic minority populations with disabilities may be even more adversely impacted by COVID. Additionally, research into the effectiveness of rehabilitation interventions for COVID treatment and access to rehabilitation services during the pandemic and beyond should be a priority for NIH Institutes and Centers conducting rehabilitation-focused research.

We appreciate the work NIH has done so far to emphasize COVID disability and rehabilitation research, including the recently issued Notice of Special Interest on Rehabilitation Needs Associated with the COVID-19 Pandemic (NOT-HD-20-031). However, we urge NIH and NCMRR in particular to continue to prioritize these critical issues and include them explicitly in the research plan. While the public health emergency is a temporary designation, the impacts of the pandemic will continue to reverberate long after the virus is contained, and we believe COVID will remain relevant for at least the term of the 2021-2025 Research Plan. We have included as an attachment the DRRC's September 2020 letter on key research topics and needs for COVID research on disability, independent living, and rehabilitation.

#### *Patient-Centered Care*

We urge the NIH to continue emphasizing research on enhancing patient-centered rehabilitation care across the lifespan. In particular, research should prioritize function, independence, and quality of life as key outcomes for rehabilitation services. Including these as themes in the overarching mission of the NIH rehabilitation research agenda will extend the impact of federal research further into the daily lives of people living with long-term disabilities or chronic conditions. We believe it is essential not to focus exclusively on the underlying causes of disability, but to include research goals addressing the challenges faced by the approximately 54 million Americans currently living with disability as well.

In addition, an increased focus on patient-reported outcomes measures would ensure that research is attuned to the needs of consumers. To facilitate this goal, we suggest that the plan include further details regarding the standardization of such measures across the NIH, to increase interoperability and magnify the reach of NIH-supported research. Rehabilitation researchers and health care providers have long noted the challenges involved with the multiple measures and reporting systems currently utilized across the spectrum of rehabilitation care, and the NIH can and should play a leadership role in developing and encouraging the use of standardized metrics, as is currently supported through NIH-developed comment data elements in certain areas, including neurological disorders such as stroke and traumatic brain injury (TBI).

Finally, the COVID pandemic has dramatically increased the utilization of telehealth and virtual care across nearly all areas, including rehabilitation. This service has been demonstrated to increase access to rehabilitation services to persons in remote and underserved areas and to prevent unnecessary delays in receiving care. Providers have also noted that telehealth has made

certain modalities more accessible to people with disabilities, including those who have difficulty transporting themselves to physical appointments. We believe that understanding the effectiveness of telerehabilitation and other innovative care delivery models should be a primary focus of the Rehabilitation Research Plan.

#### *Patient and Researcher Diversity*

We appreciate that the NIH and NCMRR have included a significant focus on expanding diversity among both subjects and researchers involved in rehabilitation research. As we have stated in past comments, 21<sup>st</sup> century research practice increasingly recognizes the importance of breaking down the divisions between researchers and their subjects, in order to create more equitable and meaningful research. NIH and the updated research plan should adopt the community engagement requirements used by the National Institute for Disability, Independent Living, and Rehabilitation Research (NIDILRR) and the Patient-Centered Outcomes Research Institute (PCORI). It is now time that many or most rehabilitation studies sponsored by NIH should include relevant stakeholders in research development, data collection, analysis and interpretation, and the dissemination and utilization of research findings.

Additionally, we recognize the importance of research that specifically examines subpopulations of people with disabilities, including racial and ethnic minorities and other socio-demographic populations. We have long understood that different populations face health disparities that are compounded by disability status, racial/ethnic minority status, and other social determinants of health. NIH-funded rehabilitation research should always be cognizant of these factors and the Plan should encourage specifically targeted research to better understand their impact.

Another important component of patient-centered research is the involvement of people receiving rehabilitation services in the research process. We applaud the NIH for noting the inclusion of consumers of rehabilitation services in the research enterprise as a proposed objective and encourage the NIH to expand this goal and incorporate it throughout the plan.

It is also critical that the NIH Rehabilitation Research Plan encourage diversity among those conducting rehabilitation research, as well as among subjects and consumers. The NIH should develop and adequately fund pre-doctoral and post-doctoral training programs for researchers with disabilities (analogous to existing programs for racial and ethnic minorities) and encourage grant applicants to disclose the disability status of team members. Supporting disability research by researchers with disabilities will lead to more responsive research and dissemination strategies.

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Thank you for the opportunity to comment on the development of the updated NIH Rehabilitation Research Plan. We look forward to continuing to engage with NIH as this plan takes shape, and we hope that our collective comments will help to guide the publication of the final plan in 2021. If you have any questions, please contact the DRRC coordinators at [Peter.Thomas@powerslaw.com](mailto:Peter.Thomas@powerslaw.com), [Bobby.Silverstein@powerslaw.com](mailto:Bobby.Silverstein@powerslaw.com), and [Joseph.Nahra@powerslaw.com](mailto:Joseph.Nahra@powerslaw.com), or call 202-466-6550.

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\**  
American Medical Rehabilitation Providers Association  
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American Speech-Language-Hearing Association  
American Therapeutic Recreation Association  
Amputee Coalition  
*Association of Academic Physiatrists\**  
Association of Rehabilitation Nurses  
*Brain Injury Association of America\**  
Child Neurology Society  
Christopher & 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  
National Neurotrauma Society  
Paralyzed Veterans of America  
Rehabilitation Engineering and Assistive Technology Society of North America  
United Spinal Association

*\* DRRC Steering Committee Member*

## Suggested Revisions to Proposed Research Themes and Objectives

### THEME A: REHABILITATION ACROSS THE LIFESPAN

- Increase the quality of evidence for multi-disciplinary rehabilitation interventions in populations of people with disabilities across the lifespan (pediatrics through geriatrics) including both aging with a disability and aging into disability, as well as people of various socio-demographic and racial/ethnic backgrounds who have disabilities.
- Determine the mechanisms by which lifestyle and wellness interventions for physical activity, participation in meaningful daily activities, nutrition, mental health, and sleep interact with developmental and aging processes and how these factors can promote overall health and prevent comorbidities to improve health-related quality of life.
- Investigate health disparities and intervene to reduce their impact on the effectiveness, implementation, and uptake of rehabilitation interventions, common medical interventions, and preventive services for people with disabilities.
- Improve transitions through the lifespan (e.g., from infancy to childhood to adolescence, from adolescence to adulthood, from adulthood to late life) as well as the provider information exchange to enable the highest level of function from health interventions and prevention of secondary conditions causing further disability.
- Capitalize on programs like *All of Us* and other large data sets to study the natural history of conditions that cause disability and common secondary conditions associated with disability, and ensure that people with disabilities are actively recruited and included in data sets like the All of Us research program.

### THEME B: COMMUNITY AND FAMILY

- Develop self-management strategies and interventions to promote and maintain independence, function, and participation for people with disabilities in the community of their choice.
- Evaluate the stressors, challenges, gender inequity, and benefits experienced by caregivers of individuals with disabilities, and formulate approaches to address the impact of these on the health and quality of life of both the caregiver and the care recipient.
- Examine interventions to reduce the impact of sociodemographic influences on the outcomes of rehabilitation interventions designed to promote independence and community integration.
- Include consumers of formal and informal rehabilitation services as partners in the research enterprise.
- Identify the characteristics contextual factors and strategies that enable families and communities to provide independence, participate in and perform daily activities, and enhance resiliency and quality of life, while reducing barriers for persons with disability, particularly with respect to current US demographics and family structure.

## THEME C: TECHNOLOGY USE AND DEVELOPMENT

- Develop systems to facilitate the rapid development of effective and affordable user-centric technologies. This includes providing a framework for sharing user preferences and feedback on experience with existing devices, promotion of open-source standards for sharing common rehabilitation technologies, and generation of open-source computational models for designing new rehabilitation technologies and predicting their functional outcomes.
- Increase access to rehabilitation services through telehealth assessment evaluation, delivery of care, and adherence monitoring. This includes combining both novel sensors and technology with the science of behavior change and motivation research.
- Define new and innovative metrics and outcomes measures that link functional outcomes with the physiological and psychosocial processes driving them for application in the use and development of various technologies for rehabilitation, including remote biometric monitoring.
- Apply augmented intelligence systems for processing and interpreting data from individuals and populations. This may include development of intelligent systems for processing the multi-modal data available from existing and new sensing systems applicable to laboratory and community settings.

## THEME D: RESEARCH DESIGN AND METHODOLOGY

- Expand the evidence base for new and existing treatment interventions, emphasizing validated outcome measures and protocols associated with improved functioning outcomes and the understanding of underlying mechanisms for treatment effects.
- Conduct clinical trials based on an integrated translational model that considers all stages of rehabilitation science development including intervention development and refinement, efficacy, cost-effectiveness, and implementation and dissemination. Incorporate randomized, controlled clinical trials, trials with novel statistical designs such as adaptive and pragmatic designs and disease-specific statistical analyses to optimize power where applicable.
- Use innovative health services research and epidemiological methods within existing databases and clinical registries to evaluate relationships between rehabilitation interventions, technologies, devices, health care utilization, and patient-centered outcomes in a real-world context.
- Encourage dissemination and implementation research to achieve more efficient and successful translation of evidence-based approaches and best practices.
- Use economic methodologies to measure the impact of rehabilitation interventions, technologies, and devices on health-related behaviors, healthcare utilization, and health outcomes.
- Improve the quality and quantity of data sharing from clinical trials where appropriate, including promotion of common data elements.

## THEME E: TRANSLATIONAL SCIENCE

- Leverage existing interventions and knowledge to develop rapid solutions that are responsive to the needs of the rehabilitation community.
- Integrate cell-, tissue-, and model organism-based research to identify the principal physiological mechanisms and key interventional targets in the adaptive and maladaptive changes associated with disabling conditions.
- Support “bench-to-bedside-to-bench” translation to better understand mechanisms of disease and recovery, promoting the use of animal models informed by clinical conditions.
- Use a staged intervention development and refinement process to generate mechanism-based, rehabilitation strategies for the clinic that exploit the beneficial biological and physiological adaptations discovered in the laboratory.
- In advancement of precision medicine for rehabilitation, support the development and use of biomarkers associated with specific injuries, illnesses, or disorders that are prognostic or guide prescription of rehabilitation interventions (e.g. biotypes to identify responders and non-responders); as well as biomarkers to assess target-engagement and other biological and physiological changes expected to predict clinical efficacy; and biomarkers of treatment efficacy to validate treatment mechanisms, monitor for recovery and improvement, and provide intermediate outcome measures for treatment interventions.
- Determine the effectiveness of integrative, multimodal interventions that target multiple synergistic mechanisms to enhance and accelerate recovery following injury or disease.

## THEME F: BUILDING RESEARCH CAPACITY AND INFRASTRUCTURE

- Develop training programs that equitably recruit trainees and provide diverse researchers and clinician-scientists who are of diverse professional and sociodemographic backgrounds at all career stages access to cutting edge, diverse approaches/methodologies and the insight needed to understand how they can be used to advance rehabilitation science.
- Support individual training and career development awards from rehabilitation researchers as well as early-career awards and pilot funding through infrastructure granting mechanisms.
- Develop an infrastructure that connects rehabilitation researchers across domains of expertise and career stages to create a robust, self-sustaining network.
- Continue to expand the network of rehabilitation researchers by promoting rehabilitation and disability research in trans-NIH and Common Fund programs.
- Develop ways to incentivize interdisciplinary collaboration in rehabilitation research. Develop metrics that can be used to evaluate and encourage interdisciplinary science that accurately reflect the contributions of scientists who work to drive rehabilitation research.

- Provide a strategy for recruiting individuals with disabilities and underrepresented minority groups into the field of rehabilitation research; consider enhanced diversity supplements and partnerships with other federal agencies (e.g., National Science Foundation; National Institute on Disability, Independent Living, and Rehabilitation Research).
- Develop metrics that can be used to evaluate and encourage rehabilitation research that accurately reflects the contributions of individuals with disabilities and underrepresented minority groups.



# 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](mailto:Peter.Thomas@PowersLaw.com), [Joseph.Nahra@PowersLaw.com](mailto:Joseph.Nahra@PowersLaw.com), and [Bobby.Silverstein@PowersLaw.com](mailto:Bobby.Silverstein@PowersLaw.com).

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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

# DISABILITY AND REHABILITATION RESEARCH COALITION

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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.