

DISABILITY AND REHABILITATION RESEARCH COALITION

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

November 23, 2020

President-Elect Joseph Biden
Vice President-Elect Kamala Harris
Presidential Transition Team
1401 Constitution Ave. NW
Washington, DC 20230

Summary Recommendations to Develop and Implement a Comprehensive Research Agenda on Disability, Independent Living, and Rehabilitation During the Biden Administration

*Submitted to the Biden-Harris Transition Team
November 2020*

Dear President-Elect Biden and Vice President-Elect Harris:

On behalf of the Disability and Rehabilitation Research Coalition (DRRC), we are pleased to share with you and your colleagues at the Biden-Harris Presidential Transition Team our recommendations for improving the lives of Americans with disabilities by enhancing the federal commitment to disability, independent living, and rehabilitation research.

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 living¹. 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.

The DRRC believes that disability and rehabilitation research plays a critical role in enabling and empowering individuals with disabilities to live the American dream, consistent with the notion that disability, like race and gender, is a natural part of the human experience and the goals of federal disability policy articulated in the Americans with Disabilities Act (ADA) – equality of opportunity, full participation, independent living, and economic self-sufficiency.

We appreciate the focus that the Biden-Harris campaign placed on disability issues and look forward to working with your Administration to enact federal public policy impacting people with disabilities. Significant disability and rehabilitation research, including translational research, is necessary to develop new and more effective approaches to test and evaluate the costs and benefits of current services, supports, treatments, and devices and to use these findings

¹ Please see the first attachment for a complete list of DRRC members.

to affect future programs and maximize benefits to costs. Therefore, the DRRC recommends that the Biden-Harris Administration support the development and implementation of a comprehensive disability and rehabilitation research agenda, including the priorities enumerated below. We also provide as attachments to this letter key documents expounding upon these principles that have been shared with Congress and the Trump Administration over the past year.

Recognize and Conduct Critical COVID-19 Research on Disability, Independent Living, and Rehabilitation Research

As the Biden-Harris Administration implements its effort to combat the COVID-19 pandemic and prepare for future global health crises, we urge the Administration to ensure that the federal research agenda 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 to the specific interactions of this virus with pre-existing disabilities and the disparities in complications and outcomes faced by disabilities, it is also crucial to understand the ripple effects of the pandemic on disability populations, including increased barriers to accessing health care and social services, loss of employment, social isolation, and other disparate impacts on people with disabilities.

Additionally, among all efforts to collect data regarding COVID-19 testing, diagnoses, treatment, and outcomes, we urge your Administration to help ensure that data is disaggregated by disability status, as well as other key demographic factors. Without collecting data disaggregated by disability status associated with COVID-19, people with disabilities will remain at greater risk of disease and death. This is an essential step to supporting the federal pandemic response and addressing the disparate impact of COVID-19 on people with disabilities and other minority populations.

We have included a September 2020 letter from the DRRC outlining the importance of a dedicated disability and rehabilitation-focused federal research effort into COVID-19 and proposing an agenda of key themes and topics for investigation. We have also included a May 2020 letter regarding the collection of disability status data in all COVID-19 related research.

Build on Progress in the Disability and Rehabilitation Research Agenda

The DRRC recognizes that there has been great progress in the field, especially at the National Institutes of Health (NIH) and the National Center for Medical Rehabilitation Research (NCMRR), since the passage of the 21st Century Cures Act and Sec. 2040 of that legislation, which focuses on medical rehabilitation research. There has been a renewed focus on rehabilitation research throughout NIH as well as strong new leadership at NCMRR and its parent agency, the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD). We believe that the disability and rehabilitation community has recognized a significant increase in the coordination and intensity of rehabilitation research and a high level of enthusiasm towards this are within NIH in recent years. We urge the Biden-Harris Administration to continue this emphasis on federal disability and rehabilitation research and to build on the work conducted at NIH, NCMRR, and other federal agencies thus far, especially as

NIH prepares to issue the updated NIH-Wide Strategic Plan on Rehabilitation Research for 2021-2025.

We have included the DRRC's November 2020 comments on the proposed themes and objectives for the NIH Rehabilitation Research Strategic Plan.

Increase Funding for Disability and Rehabilitation Research

DRRC believes that disability and rehabilitation research programs have been chronically underfunded for many years, especially considering the magnitude of the aging population and the current and future veterans' and civilians' need for rehabilitation, independent living, and disability-related services, supports, treatments, and devices. As outlined above, this research has become even more critical to address the additional needs associated with understanding the impact of the COVID-19 pandemic on people with disabilities. DRRC urges the Biden-Harris Administration to support significant increases in funding for the various federal agencies supporting and conducting this research, especially the National Institute for Disability, Independent Living, and Rehabilitation Research (NIDILRR), housed within the Administration for Community Living.

We have included a June 2020 letter from the DRRC and a white paper from the National Association of Rehabilitation Research and Training Centers (NARRTC) detailing the specific need for additional funding at NIDILRR to conduct applied research relating to the COVID-19 pandemic.

Improve Coordination, Cooperation, and Collaboration among Federal Agencies

DRRC has been encouraged by efforts in previous administrations led by the Interagency Committee on Disability Research (ICDR) to develop a government-wide strategic plan for disability, independent living, and rehabilitation research in order to better coordinate and prioritize such research across federal agencies. However, we also note that the ICDR may not have received sufficient commitments of resources and high-level staff to appropriately implement this plan. We also note that NIDILRR, whose director is typically designated as chair of the ICDR by the Secretary of Health and Human Services (HHS), has been without a permanent director since June 2019. In order to appropriately carry out the mission of the ICDR, DRRC recommends that the Biden-Harris Administration support the following policies:

- Provide the necessary infrastructure support to improve the functioning of the ICDR;
- Provide the commitment and resources necessary to develop and fully implement the congressionally mandated comprehensive government-wide strategic plan for disability, independent living, and rehabilitation research; and
- Develop a government wide database of disability, independent living, and rehabilitation research in order to catalogue the existing research portfolio and identify gaps in research.

We have included a July 2019 letter from the DRRC outlining the need for increased commitment from leadership at HHS to carry out the ICDR's strategic plan.

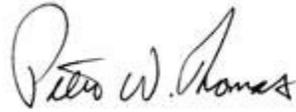
We greatly appreciate your consideration of our recommendations to enhance the federal research agenda regarding disability, independent living, and rehabilitation. The DRRC stands ready to serve as a resource for your Administration to answer any questions that may arise and provide technical expertise 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 Disability and Rehabilitation Research Coalition (DRRC)



Bobby Silverstein, DRRC Coordinator
Bobby.Silverstein@PowersLaw.com



Peter W. Thomas, DRRC Coordinator
Peter.Thomas@PowersLaw.com



Joe Nahra, DRRC Coordinator
Joseph.Nahra@PowersLaw.com

CC:

Chiquita Brooks-LaSure, Team Lead, HHS Agency Review Team
Robert Gordon, Team Lead, HHS Agency Review Team
Henry Claypool, Member, HHS Agency Review Team
Carmel Martin, Senior Policy Advisor, Biden for President

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The DRRC is a coalition of 26 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. The coalition plays a leadership role in increasing and leveraging federal resources devoted to disability, independent living, and rehabilitation research.

DRRC Members

Academy of Spinal Cord Injury Professionals
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
Amputee Coalition of America
Association of Academic Physiatrists*
Association of Rehabilitation Nurses
Association of University Centers on Disabilities
Brain Injury Association of America*
Child Neurology Society
Christopher and Dana Reeve Foundation
National Association for the Advancement of Orthotics & Prosthetics
National Association of Rehabilitation Research 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*

For more information:

Contact the DRRC coordinators at 202-466-6550 or via email at:

Peter Thomas: Peter.Thomas@powerslaw.com

Bobby Silverstein: Bobby.Silverstein@powerslaw.com

Joe Nahra: Joseph.Nahra@powerslaw.com

DISABILITY AND REHABILITATION RESEARCH COALITION

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

September 8, 2020

The Honorable Alex M. Azar, II
Secretary
U.S. Department of Health and Human Services
Hubert H. Humphrey Building
200 Independence Avenue, SW
Washington, DC 20201

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

Dear Secretary Azar:

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
(continued on next page)

American Medical Rehabilitation Providers Association
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Paralyzed Veterans of America
Rehabilitation Engineering and Assistive Technology Society of North America
United Spinal Association

CC:

Eric Hargan, Deputy Secretary, Department of Health and Human Services
Adm. Brett Giroir, Assistant Secretary for Health, Department of Health and Human Services
Seema Verma, Administrator, Centers for Medicare and Medicaid Services
Lance Robertson, Administrator, Administration for Community Living
Mary Lazare, Principal Deputy Administrator, Administration for Community Living
Kristi Hill, Acting Director, National Institute on Disability, Independent Living, and
Rehabilitation Research
Phillip Beatty, Director of Research Sciences, National Institute on Disability, Independent
Living, and Rehabilitation Research

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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.

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May 15, 2020

The Honorable Alex M. Azar, II
Secretary
U.S. Department of Health and Human Services
Hubert H. Humphrey Building
200 Independence Avenue, SW
Washington, DC 20201

**Re: Collection of Disability Status Data in Mandated Reporting Regarding
COVID-19 Testing, Diagnoses, Treatment, and Outcomes**

Dear Secretary Azar:

On behalf of the Disability and Rehabilitation Research Coalition (DRRC)¹ and the undersigned disability and rehabilitation stakeholder organizations, we urge you to ensure that the Centers for Disease Control and Prevention (CDC) and other program operating components (POCs) within the Department of Health and Human Services (HHS) collect and report data on demographic characteristics, de-identified and disaggregated by disability status, to better inform the COVID-19 pandemic response. We strongly support the letter on this issue to your office from Senators Bob Casey and Elizabeth Warren and Representatives James Langevin and Ayanna Pressley, dated May 13, 2020 and included as an attachment to this letter. The data should, among other things, address:

- Testing and diagnoses;
- Treatment (including admissions and denials to hospitals and intensive care units, denials of needed accommodations, virus interactions with chronic disease and disability, and recovery patterns); and
- Outcomes (including morbidities, mortalities, rehabilitation, and recovery).

Without collecting data disaggregated by disability status associated with COVID-19, people with disabilities will remain at greater risk of disease and death. Health data collected regarding disability status will boost the pandemic response, more efficiently direct critical resources, and inform risk communication development.² In the appendix below, we outline some of the ways

¹ The DRRC is a coalition of 25 national non-profit organizations committed to improving the science of disability, independent living, and rehabilitation. The DRRC seeks to maximize the return on investment in these fields with the goal of improving the ability of Americans with disabilities to live and function as independently as possible. The coalition plays a leadership role in increasing and leveraging federal resources devoted to disability, independent living, and rehabilitation research.

² As you know, the recently passed Paycheck Protection Program and Health Care Enhancement Act (P.L. 116-139) includes provisions requiring the regular reporting of demographic data on individuals tested for COVID-19, as well as diagnoses, hospitalizations, and deaths. The legislative text specifically references “race, ethnicity, age, sex,

in which people with disabilities are experiencing additional, disparate impacts of the COVID-19 crisis beyond the infection itself. These only serve to reiterate the importance of widespread and comprehensive data collection to understand these and other burdens faced by the disability community.

We recognize that recently enacted legislation mandates the collection of race and ethnicity data regarding COVID-19 testing and morbidity. This data will be critical to document the disproportionate impact of the pandemic on people of color and to begin to develop measures to mitigate immediate and long-term issues of health disparities and access to treatment. However, we will not be able to understand the intersectionality of race, age, disability, geography, and chronic illness without collecting disability data. Current case reporting forms used by the CDC to track COVID-19 cases do not include disability identifiers, and as such, we do not know the full impact of the virus on people with disabilities. It is essential that the public health response include an understanding of the impact that disability status has on increasing risk and vulnerability for minority populations, older adults, those in high-risk geographic areas, and other populations.

Our request to disaggregate data by disability status reflects the underlying realities faced by people with disabilities. Many people with disabilities already face significant inequities in income, education, employment, housing, transportation, and community participation. Disability status is also correlated with poorer health and health care outcomes.

Populations with physical, cognitive, psychiatric, or communication disabilities have decreased access to preventative care, including wellness, fitness, smoking cessation and weight loss interventions. Deaf populations, for example, are 7 times more likely to have low health literacy compared to hearing populations; people with disabilities are 30% more likely to be obese, are over 2 ½ times more likely to develop diabetes and are around 3 times more likely to develop cardiovascular disease. People with disabilities face negative attitudes and biases; inaccessible environments and equipment; inaccessible written, verbal, and electronic health care communication; and failure to provide accommodations and other modifications to policies, practices, and procedures.

These disparities are likely to lead to decreased access to or denial of COVID-19 treatment. Even before the current public health emergency, cause of death for people with disabilities, including people with intellectual and developmental disabilities, was too often inaccurately attributed. Independent data collection efforts, including the recently released COVID-19 & Disability survey conducted by the American Association on Health and Disability, have shown that people with disabilities are already facing significant disruptions in their ability to access regular health

geographic region, and other relevant factors.” Our request is consistent with the expectations of members of both chambers of Congress, outlined in a [letter to CDC Director Robert Redfield](#) dated April 30, 2020, expecting CDC and other program operating components within HHS to include disability status in the “other relevant characteristics” category of the required reports. Additionally, Section 4302 of the Affordable Care Act requires that federal health care and public health programs collect and report data on demographic factors, explicitly listing disability status. The Office of the Assistant Secretary for Planning and Evaluation (ASPE) issued [implementation guidance](#) on data collection standards under this section in 2011.

care treatment during the outbreak.³ This underscores the importance of a coordinated federal effort to collect and report critical data on COVID-19 and disability.

We also know that data alone are not enough. The federal government has a responsibility to direct support, information, and resources to people with disabilities, who are disproportionately impacted by this pandemic. Disability researchers, medical experts, and advocacy organizations have the necessary expertise to address these issues and are embedded in the disability community. These individuals and organizations are well-positioned, as trusted thought leaders and health care service providers, to collect data and conduct research toward creating holistic solutions to remedy the inequitable impact of this and future public health crises.

They are also well-situated to investigate how various demographic characteristics intersect to influence testing and treatment response. They can be deployed in partnership with public health departments to develop rapid response interventions to target the unmet needs of people with disabilities, such as the need for personal protective equipment (PPE), protections for their direct service workers, adequate medications and medical supplies, access to disability component mobile health units, COVID-19 testing in the community, and telehealth services, particularly for those who lack internet access.

The combination of limited resources and high needs creates a relatively thin “margin of health” and much greater vulnerability to communicable disease for people with disabilities. Additionally, people with disabilities face barriers to accessing care that are only exacerbated during the pandemic, including those outlined above. Consequently, people with disabilities appear to be at significantly higher risk of COVID-19 exposure, infection, serious and life-threatening symptoms, hospitalization, and death.

This grim reality is demonstrated most starkly in the shockingly high rates of COVID-19 deaths reported in nursing homes, psychiatric facilities, and other residential facilities throughout the U.S. It may also account for at least some of the racial and ethnic disparities observed thus far during the pandemic, because disability rates are much higher within African American, American Indian, and Native Alaskan populations. People with disabilities share many of the same risk factors of these populations. Real-time tracking of COVID-19 morbidity and mortality among people with disabilities and chronic conditions will be essential for developing targeted interventions in testing, treatment, economic support, and, ultimately, vaccination.

Thank you for considering our request to collect and report data on COVID-19 testing and diagnoses, treatment, and outcomes (including recovery) disaggregated by disability status. We support the difficult and important work of HHS during this unprecedented public health crisis and stand ready to provide political and technical support for your efforts in disability

³ Drum, C.E., Oberg, A., Cooper, K., & Carlin, R. (2020). “COVID-19 & Adults with Disabilities: Health and Health Care Access Online Survey Summary Report.” Rockville, MD: American Association on Health and Disability. <https://www.aahd.us/initiatives/dissemination/covid-19-disability-survey/>

measurement, needs assessment, program development, and evaluation. If the DRRC can be of any assistance, please do not hesitate to contact the DRRC coordinators, Bobby Silverstein, Peter Thomas, and Joe Nahra , at 202-466-6550 or by email at Peter.Thomas@PowersLaw.com, Bobby.Silverstein@PowersLaw.com, and Joseph.Nahra@PowersLaw.com.

Sincerely,

The Undersigned Members of the Disability and Rehabilitation Research Coalition

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
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
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
United Spinal Association

Supporting Organizations

American Foundation for the Blind
American Psychological Association
Autistic Self Advocacy Network
Center for Public Representation
CommunicationFIRST
Disability Rights Education and Defense Fund
Easterseals
Justice in Aging
Lakeshore Foundation
RespectAbility
National Association of Councils on Developmental Disabilities
National Center for Parent Leadership, Advocacy, and Community Empowerment

CC:

Adm. Brett Giroir, Assistant Secretary for Health, Department of Health and Human Services
Eric Hargan, Deputy Secretary, Department of Health and Human Services
Dr. Robert Redfield, Director, Centers for Disease Control and Prevention
R. Adm. Anne Schuchat, Principal Deputy Director, Centers for Disease Control and Prevention
Seema Verma, Administrator, Centers for Medicare and Medicaid Services
Lance Robertson, Administrator, Administration for Community Living
Mary Lazare, Principal Deputy Administrator, Administration for Community Living
Kristi Hill, Acting Director, National Institute on Disability, Independent Living, and
Rehabilitation Research
Phillip Beatty, Director of Research Sciences, National Institute on Disability, Independent
Living, and Rehabilitation Research
Dr. Francis Collins, Director, National Institutes of Health
Dr. Alison Cernich, Deputy Director, National Institute of Child Health and Human
Development
Lisa Kaeser, Chief, Office of Legislation and Public Policy, National Institute of Child Health
and Human Development
Dr. Theresa Cruz, Acting Director, National Center for Medical Rehabilitation Research

DISABILITY AND REHABILITATION RESEARCH COALITION

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

Appendix: Need for Disability Status Data Collection - Burdens Faced by People with Disabilities

We believe that people with disabilities are experiencing **disproportionate and unique burdens from COVID-19 that are currently under-recognized and, therefore, under-addressed.** Without systematic data collection regarding disability status, we cannot hope to mitigate or address these burdens in any meaningful way. For example:

1. People in congregate living facilities are experiencing exorbitant rates of COVID-19 infections, and in many states about half of the reported COVID-19 deaths occurred in these facilities.⁴ Overwhelmingly, we believe these cases represent people with disabilities who require personal care, supervision, or mobility assistance. People who require intimate personal care from direct service workers are unable to follow social distancing guidelines. Improved data collection would allow us to explore questions such as:
 - a. How many individuals reside in these facilities as their “home” and how many have been placed there temporarily as a result of acute illness and a need for subacute rehabilitation or wound care?
 - b. Which individuals would be able to live in the community if they had adequate accessible housing or personal assistant services?
 - c. How many of these infected individuals have multiple chronic illnesses, and what are they?
2. We are learning from post-acute rehabilitation providers that people who were not disabled before COVID-19 infection are experiencing significant functional problems due to the virus.⁵ We need to be able to track this population of “newly disabled” patients to document their “long tail” of rehabilitation and recovery, and to consider the potential for permanent disability even when the initial infection has passed.
3. Direct service workers who care for people with disabilities in nursing homes and the community have been an “invisible” workforce during the COVID-19 emergency.⁶ Getting access to proper personal protective equipment (PPE) and infection control training has been slow to non-existent, especially for those who are independently contracted by Medicaid waiver programs to care for a single person in their home setting. This critical but low-paid workforce may be the single most important factor that keeps people with disabilities out of emergency rooms, hospitals, and nursing homes. Without proper disability-focused data, interventions to improve the availability and safety of these workers are less likely.

⁴ Chidambaram, Priya. “State Reporting of Cases and Deaths Due to COVID-19 in Long-Term Care Facilities,” *Kaiser Family Foundation*, 23 April 2020. <https://www.kff.org/medicaid/issue-brief/state-reporting-of-cases-and-deaths-due-to-covid-19-in-long-term-care-facilities/>

⁵ Servick, Kelly. “For Survivors of Severe COVID-19, Beating the Virus Is Just the Beginning,” *Science*, 8 April 2020. <https://www.sciencemag.org/news/2020/04/survivors-severe-covid-19-beating-virus-just-beginning>

⁶ Cancino, Alejandra. “Aides Caring for Vulnerable Seniors Amid Coronavirus Still on the Job Despite Lack of Masks, Protective Gear and Social Distancing,” *Better Government Association*, 8 April 2020. <https://www.bettergov.org/news/aides-caring-for-vulnerable-seniors-amid-coronavirus-still-on-the-job-despite-lack-of-masks/>

4. For people with intellectual/developmental disabilities (I/DD), COVID-19 appears to have a particularly outsized impact.⁷ We need systematic collection of data to understand why, including the barriers to testing, risk, and adherence to infection control measures for these populations. We know, for example, that people with I/DD may have difficulty understanding the directions for tests, treatment, and other services, and they may need the support of a familiar person, take extra time, or require other accommodations. It may be difficult to quarantine a person who is COVID-positive in a group home, yet many alternative facilities being constructed for the care of COVID-19 patients who do not require hospitalization have not taken into consideration the needs of people with disabilities, leading to many being refused admission. If hospitalized, people with I/DD may need a support person to be allowed to shelter in place with them to avoid preventable problems due to poor communication, inaccurate information, or behavioral difficulties that can flare up in unfamiliar and frightening circumstances.
5. We know that people with disabilities are 30% more likely to be obese, are over 2.5 times more likely to develop diabetes, and are approximately 3 times more likely to develop cardiovascular disease. These chronic illnesses also impact COVID-19 morbidity and mortality. Better data will allow researchers to examine whether people with disabilities who have these chronic illnesses are at the same or higher risk as people without disabilities.

These examples represent only a small sampling of the burdens that people with disabilities face during the pandemic, and data collection and reporting will be the first step towards designing a comprehensive response to protect this population.

⁷ Stevens, Dalton and Scott Landes. "Potential Impacts of COVID-19 on Individuals with Intellectual and Developmental Disability: A Call for Accurate Cause of Death Reporting," *Lerner Center for Public Health Promotion, Syracuse University*, 14 April 2020. <https://lernercenter.syr.edu/2020/04/14/potential-impacts-of-covid-19-on-individuals-with-intellectual-and-developmental-disability-a-call-for-accurate-cause-of-death-reporting/>

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

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, 21st 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.

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, Bobby.Silverstein@powerslaw.com, and 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
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
*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

June 11, 2020

The Honorable Rosa DeLauro
U.S. House of Representatives
2413 Rayburn House Office Building
Washington, D.C. 20515

The Honorable Tom Cole
U.S. House of Representatives
2207 Rayburn House Office Building
Washington, D.C. 20515

Re: COVID-19 Related Research: Increase Funding for National Institute on Disability, Independent Living, and Rehabilitation Research; Report Language Request on Research Priorities for Federal Research Agencies

Dear Chairwoman DeLauro and Ranking Member Cole:

On behalf of the Disability and Rehabilitation Research Coalition (DRRC), we write to support a recent request by NARRTC to increase COVID-19-related funding in Fiscal Year (FY) 2021 for the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR). In addition, we are requesting As federal research agencies are only beginning to grapple with the impact of the COVID-19 pandemic, the DRRC has urged the federal government to prioritize research and data collection on COVID-19 relating to people with disabilities, who are at extremely high risk for COVID infection, serious complications, and death. Increasing NIDILRR funding specifically to fund COVID-19 disability research will be crucial to developing and strengthening the federal pandemic response for people with disabilities.

COVID-19 and Disability-Related Research Funding at the National Institute on Disability, Independent Living, and Rehabilitation Research

NIDILRR's mission is to generate and promote new knowledge that improves the abilities of people with disabilities to perform activities of their choice in the community. Not only are people with disabilities an at-risk minority group facing significant health disparities even before the pandemic, case reports are indicating that the long-term clinical complications of this virus are leading previously nondisabled individuals to develop potentially lifelong disabilities as a result of their infection.

Prior to the COVID-19 outbreak, the House Bipartisan Disabilities Caucus requested a \$3 million increase for NIDILRR in FY 2021 to carry out its mission. Now, NARRTC, the professional association of NIDILRR grantees, has circulated a call to action requesting an additional \$5-10 million funding increase for NIDILRR in FY 2021 to address the urgent research and policy questions around the impact of COVID-19 on the disability population, for a total NIDILRR budget of \$120-\$125 million. On behalf the members of the DRRC, we urge you to support this funding increase in the next appropriations cycle to ensure that NIDILRR can appropriately address the dire research needs stemming from this pandemic.

Report Language on Disability Research Priorities at the National Institutes of Health, Centers for Disease Control and Prevention, and Other Federal Research Agencies

While additional NIDILRR funding is crucial to developing applied research for long-term outcomes in the disability population, NIDILRR is not the only federal agency conducting critical disability research. Therefore, we are also requesting report language to be added to the FY 2021 Labor, Health and Human Services, Education, and Related Agencies appropriations bill emphasizing the importance of disability research across all federal agencies conducting COVID-19 research, expected to be a major priority for federal funding over the coming (and future) fiscal year. We respectfully propose the following language:

“The Committee urges the National Institutes of Health, the Centers for Disease Control and Prevention, and other federal agencies conducting research on COVID-19 to ensure that their research plans address and prioritize disability, independent living, and rehabilitation research, especially regarding COVID-19 testing and diagnoses; treatment, including admissions and denials to hospitals and intensive care units, denials of needed accommodations, virus interactions with chronic disease and disability, and recovery patterns; and outcomes, including morbidities, mortalities, rehabilitation, and recovery for individuals with 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 listed below.

Sincerely,

Bobby Silverstein, DRRC Coordinator

Bobby.Silverstein@PowersLaw.com

Peter Thomas, DRRC Coordinator

Peter.Thomas@PowersLaw.com

Joe Nahra, DRRC Coordinator

Joseph.Nahra@PowersLaw.com

The COVID-19 Pandemic and Americans with Disabilities: A Call to Action for the National Institute on Disability, Independent Living and Rehabilitation Research

People with disabilities are at much higher risk of COVID-19 exposure, infection, hospitalization, and death than those without disabilities. This situation is most evident in the shockingly high rates of COVID-19 mortality among residents of nursing homes and other residential facilities, nearly all of whom are disabled. Most adults with disabilities live in the community, but they share many of the same risk factors as those who live in institutions (e.g. multiple comorbid health conditions, older age, frequent interactions with medical professionals and service providers). It is therefore likely that the recent surge in excess COVID-19 mortality¹ is also concentrated among people with disabilities.²

People with disabilities are an at-risk minority group that already faces significant inequities in income, education, employment, housing, transportation, and community participation. Disability also intersects with other sources of disadvantage and discrimination – with higher rates among racial, ethnic, gender and sexual minorities. By definition, people with disabilities also have chronic health conditions or injuries, and therefore require much higher levels of healthcare and support services than those without disabilities. This combination of limited resources and high needs creates a relatively thin “margin of health” and a much greater vulnerability to communicable disease.

A growing body of case reports also indicate that an unknown but potentially large number of survivors are experiencing long-term clinical complications of COVID-19, including impaired function of the lungs, heart, brain, kidneys and circulatory system. People with pre-existing chronic health conditions and disabilities will be at higher risk for these complications, but a portion of previously nondisabled individuals will also develop disabilities as a result of COVID-19, increasing demand for disability benefits and support services.

The pandemic and associated economic and political disruptions raise urgent research and policy questions that will require a coordinated and sustained federal response, including:

- How to protect people with disabilities from COVID-19 infection, hospitalization and death.
- How to minimize the adverse health effects of pandemic policies, including quarantine, social distancing and restricted access to medical, rehabilitative and social services.
- How to strengthen social support networks, including relationships with family, friends and peers with disabilities, and maintain critical disability services such as paratransit, rehabilitation counseling, personal assistance, and independent living services.
- How to cope with significant economic disruptions, including unemployment, wage loss, loss of health insurance, food insecurity, eviction, and catastrophic healthcare costs.
- How to synthesize new and emerging information about COVID-19 and disability, including vetting, curating, organizing and updating population-specific resources.

¹ The World Health Organization defines excess mortality as a surge in population death rates above pre-crisis levels. In this case, excess mortality can be attributed to people who died at home with COVID-19 but weren't diagnosed, and people who didn't obtain critical medical care because of hospital crowding and/or restricted access to clinics and healthcare providers.

² Although current public health data is limited, it seems likely that people with disabilities will also be at greater risk of “deaths of despair” from drug or alcohol abuse and suicide, due to increased unemployment, social isolation, depression and anxiety.

The National Institute on Disability, Independent Living and Rehabilitation Research (NIDILRR) is the federal agency best positioned to lead this national effort. NIDILRR is the research arm of the Administration for Community Living (ACL) at the US Department of Health and Human Services. The NIDILRR director holds a government-wide leadership role in this area, as the position is traditionally designated by the Secretary of HHS to lead the Interagency Committee on Disability Research (ICDR). ICDR promotes “coordination and cooperation among federal departments and agencies conducting disability, independent living, and rehabilitation research.” To fully assume this expanded federal role, NIDILRR will need dedicated Congressional support. Unfortunately, NIDILRR’s adjusted annual budget peaked in 2001, and did not return to the pre-sequestration funding level of \$112 million until Fiscal Year (FY) 2020.

The Bipartisan Disabilities Caucus in the US House of Representatives has called for a \$3m increase in NIDILRR funding for FY2021, but this allocation was recommended before COVID-19 began to sweep through the disability community like a wildfire. **NARRTC, the professional association of NIDILRR grantees, now calls for an additional \$5-10 million funding increase in FY2021 for COVID-19 related research and program administration, for a total NIDILRR budget of \$120-\$125 million.**

To build the case for how this funding could be used in the disability research community, NARRTC president Jae Kennedy and executive committee member Kathleen Murphy issued a call to members, asking for examples of realizable, ready-to-implement project supplements and ideas for new research projects. In less than two weeks, we received dozens of responses, which we organize by research domain in Appendix 1. In summary:

- Many NIDILRR grantees have already modified their work to encompass COVID-19 research questions, but these efforts could be sustained and focused, without interrupting pre-pandemic programs, by providing relatively modest supplemental funding.
- More urgent research on the public health and economic consequences of the pandemic should be funded under new grant NIDILRR competitions, with expedited review and award procedures.
- The time to study the impact of COVID-19 among people with disabilities is now.

Though no researcher would have chosen to be in these circumstances, we are in the midst of an enormous natural experiment, where environmental changes have confounded the effect of many current experimental and quasi-experimental research interventions. With supplemental funding and appropriate design changes, some of these projects could pivot to timely and relevant studies of pandemic outcomes.

For example, a group activities intervention to reduce social isolation among *young adults with autism spectrum disorder* would be disrupted by stay-at-home orders, but a pre-post comparison could now be used to assess the impact of suddenly restricted peer networks on cognitive and emotional function. Likewise, special populations of adults with disabilities whose conditions are not studied by other federal research institutes (e.g. *people with spinal cord injury, traumatic brain injury, or serious burns*) are experiencing dramatic disruptions in their medical, rehabilitative and social supports, and NIDILRR researchers can help document the impact of these disruptions and then develop and test interventions to help minimize them.

Supplemental research funding for current NIDILRR projects, like the already established research supplements to existing National Institutes of Health (NIH), National Science Foundation (NSF), or Agency for Healthcare Research and Quality (AHRQ) grants, could provide invaluable insights on how to support *people with serious mental or physical health problems* during a public health crisis, informing not only the COVID-19 pandemic but future national emergencies.

New funding will also be required to evaluate the impact of the pandemic on people of all ages with disabilities, including *children with individualized education plans (IEPs)* whose schools are now closed, *parents* providing in-home special education, *high school graduates* with disabilities considering current college or work options, *college students* with disabilities wondering if they can and should continue their undergraduate or graduate studies, *working-age adults* with disabilities deciding whether to seek employment or enroll in federal disability programs, and *retirees* with disabilities evaluating housing options that protect their economic and physical well-being. The size and attributes of *the population of newly disabled by COVID-19* must also be determined, particularly if we hope to fully realize the gains of early medical, rehabilitative and social interventions.

In the context of trillions of dollars in new federal spending, investing several million in new COVID-19 related disability research is a smart investment that will impact a wide swath of constituents. We urge the House and Senate to support this research component of the federal budget.

Sincerely,

Jae Kennedy, NARRTC President, Washington State University, WA

NARRTC Executive Committee Members:

- Dana Barton, Rocky Mountain ADA Center, CO
- Jessica Chaiken, HeiTech Services Inc., MD
- Marsha Ellison, University of Massachusetts, MA
- Marianne Farkas, Boston University, MA
- Robert Gould, University of Illinois Chicago, IL
- Mark Harniss, University of Washington, WA
- Rose Mason, Purdue University, IN
- Kathleen Murphy, American Institutes for Research (AIR), TX
- Mark Odum, HeiTech Services Inc., MD
- Sarah Parker-Harris, University of Illinois Chicago, IL
- E. Sally Rogers, Boston University, MA
- Joann Starks, American Institutes for Research (AIR), TX
- Wendy Strobel Gower, Institute on Employment and Disability, Cornell University, NY

Appendix 1: COVID-19 Research Project Ideas from NARRTC Members

I. Examples of current and proposed COVID-19 research under NIDILRR grants

A. Current (unfunded) research initiated by current NIDILRR grantees

- National needs assessment on how COVID-19 has impacted services in Centers of Independent Living (CILs) (Lex Frieden, *Collaborative on Health Reform and Independent Living*, TX)
- Survey with CIL consumers in 4 states, asking how COVID-19 has affected their access to employment, education, health care, food, personal assistance services (PAS), food, and ability to live independently (*Research and Training Center on Promoting Interventions for Community Living*, Jean Hall, KS)
- Interviews with employees with disabilities about their changing workplace accommodation needs during the pandemic (Rob Gould, *Great Lakes ADA Center*, IL)
- Rapid COVID-related survey of workers with disabilities using Mturk (Amazon's crowdsourcing platform), including questions about trust in information sources, current health status, presence of high-risk conditions that the Centers for Disease Control (CDC) has identified for COVID-19 complications, safety practices, change in access to medical and community resources, social activity and feelings of isolation (Catherine Ipsen, *Research and Training Center on Disability in Rural Communities*, MT)
- COVID-19 items and research questions added to a randomized trial on the efficacy of a telehealth pain self-management intervention, a national survey on employer, client, job, and environment-related barriers and facilitators for promoting job retention for people with physical disabilities, and a study on intervening early to support employment for people with Parkinson's disease (Allen Heinemann, *RRTC on Employment and Disability*, IL).

B. Supplemental projects that could be conducted by current grantees

- Project to develop and implement interventions to help people who are blind or visually impaired to access to the physical distancing signage that is increasingly common in buildings and public spaces (Mike May, *Access Explorer*, KY)
- Survey of youth and young adults with disabilities with serious mental health conditions on the impact of the pandemic on school, work and career development and related intervention development; and (Maryann Davis, *Learning and Working During the Transition to Adulthood Rehabilitation Research and Training Center* MA)
- COVID-19 seed grants and mentorships for faculty and postdocs at minority-serving institutions to conduct disparities research (Corey Moore, *Langston University Rehabilitation Research and Training Center*, OK)
- Virtual workshops and webcasts on inclusive remote learning and work, to proactively invent strategies that ensure full engagement and performance during and after the pandemic (Valerie Fletcher, *New England ADA Center*, MA)

- Survey of campus and vocational rehabilitation agency staff to assess support services for college students with psychiatric disabilities following campus closures and conversion to online classes (Michelle Mullen-Gonzalez, *Helping Youth on the Path to Employment*, MA)
- Evaluation of mobile health (mHealth) interventions to support the health, function, and independent living of people with disabilities and their families (Bambang Parmanto, *Rehabilitation Engineering Research Center: from Cloud to Smartphone*, PA)
- International virtual summit on emerging initiatives and innovations in increasing employment outcomes for people with disabilities in the COVID-19 crisis and its aftermath (Marianne Farkas, *Center for Psychiatric Rehabilitation*, MA)

II. New project ideas (by NIDILRR research domain)

A. Community living and participation

- Multi-measure study of social, economic and emotional well-being of families that have members with disabilities during and after the pandemic (Chung-Yi Chiu, IL; Malachy Bishop, WI)
- Mixed method study of PAS recipients, evaluating the impact of the pandemic on recruitment, retention, payment, and health practices of attendants and consumers (Jae Kennedy, WA)
- Food insecurity project for people with disabilities during and after the pandemic assessing their nutrition, body mass index (BMI), overall health, and participation in federal, state and local nutrition assistance programs (Debra Brucker, NH)
- Study of work/life balance among people with disabilities who use PAS – remote working and parenting challenges in a public health emergency (LaWanda Cook, NY)

B. Health and function

- Creation of a database of people who either: 1) acquire disabilities because of the sequelae of COVID-19, or 2) already have a disability but become infected with COVID-19; tracking clinical and psychosocial impacts of infection and treatment (Jeffrey Schneider, MA)
- Study of mental and economic stability of adults with serious mental illness as public transportation, supported employment, and disability support services are disrupted by the pandemic (Nev Jones, FL)
- Evaluate the accessibility, use and financing of telehealth and online disability support services for adults with disabilities during and after the COVID-19 pandemic (Gilbert Gimm, VA)
- Project on COVID-19 related disruptions to access to primary care, specialty care, durable medical equipment, and rehabilitative and habilitative services and associated outcomes (e.g. self-assessed health, out-of-pocket healthcare expenditures, and health related quality of life) among adults with disabilities (Noelle Kurth, KS)

C. Employment

- Research on the COVID recession and employment opportunities for workers and job-seekers with disabilities; comparing work and disability program participation rates in the current crisis and the Great Recession of 2008 (Andrew Houtenville, NH)
- Study of how the pandemic has complicated school to work transitions for youth with disabilities, with particular focus on special education, participation in unemployment and Supplemental Security Income (SSI) programs, full and part-time work (Maryann Davis, MA)
- Research on return-to-work decisions with limited job opportunities and heightened health risks (LaWanda Cook, NY)

D. Cross-cutting research activities

- Project on the comparatively low access rural residents with disabilities have to online communities, education, and employment, and how this limited internet access, speed, and penetration accentuate COVID-19 disparities (Catherine Ipsen, MT).
- Research on utilization of telehealth and mHealth services for consumers, families and providers during a pandemic (Brad Dicianno, PA).

E. Activities to promote quality and use of disability research

- Knowledge translation activities to support NIDILRR in its efforts to promote use and adoption of the new knowledge and products to respond to the impact of COVID-19 (i.e. synthesizing existing products that address similar topics, identifying and compiling an inventory of accessible products that meet the needs of specific disability communities, providing a public clearinghouse and hosting dialogues to allow for continued discussion and research in the aftermath of the virus) (Kathleen Murphy, TX).
- Classification and tracking of COVID-19 related technical assistance requests at the 10 regional Americans with Disabilities Act (ADA) centers throughout the US, and development of appropriate and consistent resources for employers and workers with disabilities (Mark Harniss, WA).

DISABILITY AND REHABILITATION RESEARCH COALITION

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

July 25, 2019

The Honorable Alex M. Azar, II
Secretary
U.S. Department of Health and Human Services
Hubert H. Humphrey Building
200 Independence Avenue, SW
Washington, DC 20201

Re: Implementation of the Government-Wide Strategic Plan on Disability, Independent Living, and Rehabilitation Research

Dear Secretary Azar:

People experiencing significant disabilities, resulting from illness, trauma, developmental disability, war-related injury, or the effects of chronic illness, depend on state-of-the-art, cross-cutting research and knowledge translation to lead proud, productive lives in the American mainstream. To maximize our Nation's return on investment, Congress in 2014 mandated the design and implementation of a Government-Wide Strategic Plan for Disability, Independent Living, and Rehabilitation Research (the Plan).¹ Congress directed the Secretary of Health and Human Services, in his or her capacity as chair of the Interagency Committee on Disability Research (ICDR), to fulfill this mandate.² The Plan was released by ICDR in March of this year.³

On behalf of the 24 member organizations of the Disability and Rehabilitation Research Coalition (DRRC), we express our gratitude for releasing the Plan. At the same time, we are deeply concerned that the objectives and outcomes set out in the Plan may not be realized without your personal leadership. The purpose of this letter is to request a meeting with you to discuss the government-wide efforts to implement the Plan and how the DRRC can help you and your team to translate the promises of the Plan into realities for the approximately 54 million Americans living with disabilities today.

DRRC recently met with Jim Whitehead, the former director of the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR), and Mary Lazare, the Principal Deputy Administrator of the Administration for Community Living. We were encouraged by their commitment, experience, and vision for the future of disability, independent living, and rehabilitation research. As you know, Jim had also been designated to serve as the

¹ Section 434(5) of the Workforce Innovation and Opportunity Act (WIOA), which added Section 203(c) to the Rehabilitation Act of 1973, as amended [29 U.S.C. 763(c)].

² Section 434(1)(A)(ii) of WIOA, which amended Section 203(a)(1) of the Rehabilitation Act of 1973, as amended [29 U.S.C. 763(a)(1)]

³ [The Government-Wide Strategic Plan on Disability, Independent Living, and Rehabilitation Research.](#)

DISABILITY AND REHABILITATION RESEARCH COALITION

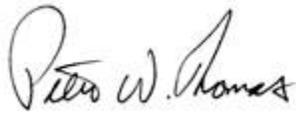
1501 M STREET, N.W. SUITE 700 WASHINGTON, D.C. 20005

chair of the ICDR in your stead. We believe that the next NIDILRR director, if selected as your

designee to chair the ICDR, will be able to successfully administer the Plan *if, and only if*, other program operating components within HHS (such as NIH, CDC, AHRQ, and ASPE) and other departments of the federal government (such as the VA) understand that he or she is unequivocally acting on your behalf as ICDR Chair, not in their capacity as director of NIDILRR. It is certainly understandable that the director of NIH, for example, is more likely to make critically necessary commitments of resources and high-level staff to the implementation of the Plan if it is clear that he is accountable to the Secretary for making and carrying out specified responsibilities under the Plan, rather than being accountable to the Director of an agency that has a budget 1/390 its size.

Thank you for considering our request to meet in person to discuss the implementation of the Government-Wide Strategic Plan on Disability, Independent Living, and Rehabilitation Research and how the federal government can maximize its return on investment in this crucial area of research. If the DRRC can be of any assistance, please do not hesitate to contact the DRRC coordinators, Peter Thomas and Bobby Silverstein, at 202-466-6550 or by email at Peter.Thomas@PowersLaw.com and Bobby.Silverstein@PowersLaw.com.

Sincerely,



Peter Thomas



Robert Silverstein

cc: Mary Lazare
Principal Deputy Administrator
Administration for Community Living
U.S. Department of Health and Human Services
Mary E. Switzer Building
330 C Street SW
Washington, DC 20201

Kristi Hill
Acting Director
National Institute on Disability, Independent Living, and Rehabilitation Research
U.S. Department of Health and Human Services
Mary E. Switzer Building
330 C Street SW
Washington, DC 20201