

March 28, 2025

The Honorable Robert F. Kennedy, Jr. Secretary U.S. Department of Health and Human Services 200 Independence Ave. SW Washington, D.C. 20201

RE: <u>Urgent Request for Reconsideration of Reorganization of Administration for</u> <u>Community Living</u>

Dear Secretary Kennedy:

We write to urge you in the strongest possible terms to pause your plans to dismantle the Administration for Community Living (ACL), including the National Institute for Disability, Independent Living, and Rehabilitation Research (NIDILRR), meet with national disability, rehabilitation, and other stakeholder organizations to discuss the future of ACL, and seriously reconsider the reorganization of this important government agency for older Americans and individuals with disabilities. As such, *we formally request a meeting with you at your earliest possible opportunity* to discuss this critical issue in depth. We also encourage you to meet with other leaders relevant to ACL in the aging and disability communities.

We make this request on behalf of the Disability & Rehabilitation Research Coalition (DRRC), a list of members of which are attached to this letter. DRRC is a coalition of 28 national research, clinical, and consumer non-profit organizations committed to improving the science of disability, independent living, medical rehabilitation, and chronic illness. The current integrated goals of the service and research programs under ACL could not be more aligned with your initiative to Make America Healthy Again. Maximizing the health and functional status of older Americans and people with disabilities reduces unnecessary and more costly long-term healthcare costs compounded by chronic illness.

ACL is the embodiment of fifty years of our nation's recognition of people with disabilities, as well as the growing positive correlation between disability and aging. The passage of the Rehabilitation Act of 1973, coupled with health care and rehabilitation services available through Medicare and Medicaid, empowered the independent living movement. The landmark Americans with Disabilities Act of 1990 followed, as did the U.S. Supreme Court's decision in the *Olmstead* case, establishing the requirement to provide services to individuals with disabilities in the least restrictive environment and to, whenever possible, provide community-based services rather than institutionalized care.

NIDILRR became the foundational federal agency for cutting edge disability and rehabilitation research, identifying best practices, collecting and analyzing data, and improving the evidence base for supports and services to maximize the return on investment in the disability population. For example, NIDILRR-funded research has led to accessible voting machines, the technology that supports tactile maps for those who are blind, and accessible lavatories on airplanes. NIDILRR's fine work continues unabated today. The efforts to support aging, disability, rehabilitation and independent living are interrelated and complementary of each other, helping to inform the research agenda driven by NIDILRR.

In 2012, the Administration for Community Living was established, recognizing the commonalities between aging and disability services and programs, and designed to maximize efficiencies in federal programs. By all accounts, ACL has been one of the most successful federal agency efforts over the past 13 years. From a disability and rehabilitation research perspective, NIDILRR serves as the head of the Interagency Committee on Disability Research (ICDR) which coordinates disability and rehabilitation science across the federal government to maximize efficiencies and government resources.

The work of the ACL is indispensable in ensuring that individuals with disabilities have the opportunity to live independently, thrive, and fully participate in their communities. The concept of ACL as an agency was to leverage the common interests of programs, supports, and research applicable to both older Americans and individuals with disabilities. Aging with a disability, and the unique issues this creates, is a prime example of the common threads that bind these two communities. The ACL concept has been fully realized and is operational today. Since its inception, ACL has proven the value of this organizing principle through the success and effectiveness of its programs.

Through programs like the Independent Living Services, the National Family Caregiver Support Program, the Senior Medicare Patrol, the Limb Loss Information Center, the Paralysis Resource Center, and the Traumatic Brain Injury (TBI) state grant program, the Centers for Independent Living (CILs), the State Assistive Technology Act Programs, programs serving persons with intellectual and developmental disabilities (IDD), and the TBI, Spinal Cord Injury (SCI), and Burn Model Systems, ACL has transformed the lives of countless individuals by supporting their ability to adapt to disability and aging, and meaningfully exercise their right to remain active, engaged, and live as independently as possible in their communities.

DRRC organizations have seen firsthand how ACL's and NIDILRR's work has positively impacted individuals and communities across the country for decades. The threat of compromising the current structure and underfunding the programs within ACL jeopardizes this progress and risks reversing years of hard-earned gains by the disability community. What is most alarming is the lack of upside potential to the plan to dissolve ACL and scatter its programs across other subagencies within the Department of Health and Human Services. Candidly, we fear this plan will result in these vital programs losing their focus and withering on the vine with the passage of time. Short of achieving some modest savings by consolidating certain back-office functions, we fail to recognize any compelling reason to pursue this approach. We implore you to reconsider this restructuring of programs under the jurisdiction of ACL and meet with us to discuss further how we can elevate ACL and NIDILRR to help facilitate the goals of reducing chronic illness and addressing disability in America.

From the infancy of medical rehabilitation in the 1960s through the present day, disability, rehabilitation and independent living programs have matured and taken root at ACL. Please do not take steps to turn the clock back on decades of progress. It is essential that ACL's programs remain intact and fully funded so that all individuals, regardless of their disability or age, can have the opportunity to live with dignity and participate fully in society.

To arrange a meeting, please contact Peter Thomas and Natalie Keller by email at <u>Peter.Thomas@powerslaw.com</u> or <u>Natalie.Keller@powerslaw.com</u> or call at 202-607-5780.

Sincerely,

to W. homes

Peter W. Thomas, J.D. DRRC Co-Coordinator

Watahe Keller

Natalie Keller DRRC Co-Coordinator

Cc: Mary Lazare ACL Principal Deputy Administrator

Members of the Disability and Rehabilitation Research Coalition

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 Informatics Association American Medical Rehabilitation Providers Association American Music Therapy Association American Occupational Therapy Association* American Physical Therapy Association* American Spinal Injury Association American Therapeutic Recreation Association Amputee Coalition Association of Academic Physiatrists* Association of Rehabilitation Nurses Association of University Centers on Disabilities **Brain Injury Association of America*** Christopher & Dana Reeve Foundation Clinician Task Force National Association for the Advancement of Orthotics & Prosthetics National Association of State Head Injury Administrators NARRTC* National Neurotrauma Society Paralyzed Veterans of America Rehabilitation Engineering and Assistive Technology Society of North American (RESNA) Spina Bifida Association United Spinal Association VisionServe Alliance

*DRRC Steering Committee Members