

March 21, 2021

Liz Richter
Acting Administrator
Centers for Medicare and Medicaid Services
7500 Security Boulevard,
Baltimore, MD 21244

RE: HCBS and emergency relocation from congregate facilities

Dear Ms. Richter:

We applaud the much-needed \$1.9 billion 'American Rescue Plan' for emergency COVID-19 relief, and the inclusion of Home and Community Based Services (HCBS) as a component of federal response to the pandemic. The multi-faceted ways that people with disabilities (PWDs) benefit from HCBS are central to life, liberty and the pursuit of happiness.

As long as we are still in an emergency, **we urge you and Centers for Medicare and Medicaid Services (CMS) to issue guidance that explicitly enables local agencies the option to use some of this emergency HCBS funding for emergency/temporary relocation of residents from various types of congregate settings into safer housing**, with needed supports. Guidance should also encourage states' long term care emergency response teams to work with local organizations to ensure residents have safer options available to them.

Such guidance can enable cross-disability, locally-driven, coordinated emergency relocation programs, which will enable people of various disabilities to make it through the final months of the pandemic. Such guidance should apply to future disasters as well, when circumstances call for moving people to safety.

As you are well aware, the roughly 1% of our population that is in congregate institutions have accounted for more than 40% of COVID-19 deaths. People living and working in congregate care facilities – which include nursing homes, rehabilitation centers, long-term psychiatric facilities and various group settings for people with intellectual and developmental disabilities – are at far greater risk of infectious outbreaks than people in non-congregate settings. These institutions require residents to live in close quarters, share sleeping, dining and activity spaces, while staff move from person to person in quick succession. Such routines make congregate care less safe, resulting in inordinately high rates of infection amongst both residents and staff.

The shelter-in-place strategy failed people in congregate facilities. Shelter-in-place does not work when the place itself contributes to spread of the disease. We should note that evidence strongly suggests that it is the congregate nature of the facilities, not the health conditions of residents, that accounts for the hugely disparate infection and death rates. Illinois reports that only about 1% of PWDs living independently, by way of the Home Services Program, were infected. Home services participants have similar underlying health profiles as those in institutions.

As far as Covid and congregate care facilities, many of us see a light at the end of the tunnel, but we are still in the tunnel.

Vaccination of residents has helped greatly, but is incomplete. Many facility staff have refused vaccines, and some facilities have failed to make them available. This means residents are still vulnerable to infection in the same enclosed spaces. The congregate conditions that add to infection risk for both residents and staff still exist. We are not yet out of the tunnel.

Despite lack of support from local jurisdictions or the Federal Emergency Management Agency (FEMA), there have been some local groups, centers for independent living (CILs) and others, that have taken the initiative to get people with various types of disabilities out of the settings with the highest danger and into safer settings, such as hotels. Personal attendants (PAs) and other types of support have been provided. Each local group has its own model, but those rescued have survived. There are many other local groups that would undertake emergency relocation if they had resources and help with program design.

Because it was an emergency, these local advocates did what was needed, despite complicated and contradictory bureaucratic obstacles. As long as we are still in an emergency, groups should have the option to use emergency HCBS funds for the wide range of costs required for emergency relocations, including but not limited to: moving/transportation, needs assessment, temporary housing (hotels, et al), personal and health support needs, food and essential items, service coordination, technical assistance in designing and launching a program.

Including this explicitly enabling language in the CMS guidance for this round of HCBS funding will give local groups and states the flexibility and the capacity to address immediate local emergency needs, for that part of our population that has been hardest hit by the pandemic. Enabling more state and local agencies to conduct emergency relocations will also give CMS an experience base on which we can evaluate best practices and suggest models for future disaster relief.

Sincerely,

Abilities In Motion

Access Living

ADAPT Montana

Allies in Advocacy

Anthracite Region Center for Independent Living

APRIL (Association of Programs for Rural Independent Living)

Atlantis Community, Inc.

Blue Ridge Independent Living Center

Brazoria County Center for Independent Living

Bucks County Center for Independent Living

Center for Advocacy for the Rights and Interests of the Elderly (CARIE)

Center for Independent Living of Central PA
Center for Independent Living Opportunities
Champaign County Developmental Disabilities Board
Chicagoland Leadership Council
Community Resources for Independence, Inc.
Connecticut Legal Rights Project
Disabilities Resource Center of Siouxland
Disability Empowerment Center
Disability Rights Maine
Easterseals Joliet Region, Inc
Fort Bend Center for Independent Living
GEORGIA ADAPT
Gulf Coast ADAPT
Houston Center for Independent Living
Illinois Network of Centers for Independent Living
Illinois Single-Payer Coalition
Illinois-Iowa Center for Independent Living
IMPACT CIL
Institutional Rescue & Recovery Coalition
Iowa Statewide Independent Living Council (SILC)
Kansas ADAPT
Lehigh Valley Center for Independent Living, Inc.
Liberty Resources, Inc (CIL - Philly,PA)
Life and Independence for Today
MassADAPT
MindFreedom International
NAMI Northwest Suburban
National Council on Independent Living
North Central PA ADAPT
Northside Action for Justice
Not Dead Yet
PA ADAPT
PA Statewide Independent Living Council (PA SILC)
Pennsylvania Council on Independent Living
Physicians for a National Health Program Illinois
Progress Center for Independent Living
Roads to Freedom Center for Independent Living of North Central PA
SEIU Healthcare PA
Self Advocates in Leadership
Social Service Workers United Chicago
Texas Gray Panthers
The Statewide Independent Living Council of Illinois
Topeka Independent Living Resource Center, Inc.

United Home Care Workers of Pennsylvania
Voices for Independence
World Institute on Disability

cc: Alison Barkoff, Administration for Community Living