



**CONSORTIUM FOR CITIZENS
WITH DISABILITIES**

January 10, 2020

Representative Mary Gay Scanlon
1535 Longworth House Office Building
Washington, DC 20515

Representative Tom Emmer
315 Cannon House Office Building
Washington, DC 20515

Dear Representative Scanlon and Representative Emmer:

The undersigned members of the Consortium for Citizens with Disabilities (CCD) Long-Term Services and Supports (LTSS) Task Force strongly support the Isaiah Baker and Margie Austin-Harris Act of 2019 (Isaiah and Margie's Act/H.R. 5443). The Consortium for Citizens with Disabilities (CCD) is the largest coalition of national organizations working together to advocate for federal public policy that ensures the self-determination, independence, empowerment, integration and inclusion of children and adults with disabilities in all aspects of society. The Long-Term Services and Supports Task Force focuses on ensuring that people with disabilities and aging adults have access to the LTSS, particularly Home and Community Based Services (HCBS), they need to live, work and participate in their communities.

Isaiah and Margie's Act aims to correct a longstanding policy challenge in the 1915(c) Home and Community-Based Services (HCBS) waiver program. This challenge effectively prevents individuals with disabilities and seniors who go to the hospital from bringing with them the Direct Support Professionals (DSPs) who know them best to provide them with the support they rely on. The legislation brings 1915(c) in line with other HCBS authorities by allowing payment for DSPs to provide personal assistance and other services when the individual they support experiences a short-term stay in an acute care hospital.

Although this may appear to be a small policy change, the legislation will make a big difference in the lives of people with disabilities and seniors who rely on these services. DSPs and the people they support build relationships and familiarity that can play a crucial role in avoiding unnecessary trauma during hospital stays. Hospital stays are often stressful under the best of circumstances, and that stress can be greatly compounded for people with disabilities. People with specific behavioral support needs, communication needs, or other challenges can become overwhelmed, disoriented, and distressed in hospitals. Without a familiar presence to reassure them, they may not be able to understand requests from medical staff. Waiver recipients with mealtime assistance plans or specific methods to transfer or reposition often do not receive care tailored to their needs by hospital staff because the hospital staff may be unfamiliar with those needs or trained on how to meet them. Individuals may be unable to communicate with hospital staff, may suffer restraint, and may even be unable to eat throughout their stay. These kinds of traumatic experiences can cause additional behavioral challenges when an individual returns home, resulting in intensified service needs or even a change in placement. In the worst cases, this can lead to institutionalization.

Allowing 1915(c) HCBS programs to pay for these individuals to bring familiar staff with them will help

avert these unnecessary and tragic outcomes. The presence of these staff will help to ensure smoother, shorter, and more successful hospital stays, and will also improve continuity of care, as the staff that supports an individual in their home will be able to learn directly from hospital staff about necessary ongoing care.

We thank you for your commitment to this important policy fix that will dramatically improve the hospital experience and health outcomes of individuals with disabilities and seniors who rely on Direct Support Professionals.

Sincerely,

Allies for Independence
American Association on Health and Disability
American Association on Intellectual and Developmental Disabilities
American Dance Therapy Association
American Network of Community Options & Resources (ANCOR)
American Therapeutic Recreation Association
The Arc of the United States
Autism Society of America
Autism Speaks
Autistic Self Advocacy Network
Brain Injury Association of America
Center for Public Representation
Communication FIRST
Disability Rights Education and Defense Fund (DREDF)
Easterseals
Epilepsy Foundation
The Jewish Federations of North America
Justice in Aging
Lutheran Services in America – Disability Network
National Association of Councils on Developmental Disabilities
National Association of State Directors of Developmental Disabilities Services
National Association of State Head Injury Administrators
National Council on Independent Living
National Disability Rights Network
National Down Syndrome Congress
National Health Law Program
National Respite Association
Paralyzed Veterans of America
TASH

Cc: Energy & Commerce Committee Chair Frank Pallone
Energy & Commerce Committee Ranking Member Greg Walden