The undersigned members of the Consortium for Constituents with Disabilities (CCD) Long Term Services and Supports (LTSS) Task Force write in support of the Recognizing the Role of Direct Support Professionals Act, a bill that would help to create a standard occupational classification (SOC) for direct support professionals (DSPs). Earlier this year, the Senate passed its version of the legislation, S. 1332, which ensures that when the Office of Management and Budget revises the standard occupational classification system, it considers the importance of a code for DSPs. We now ask that you support passage of S. 1332 in the U.S. House of Representatives.

The creation of a distinct occupational classification for DSPs is a necessary first step in addressing a decades-long workforce crisis that threatens individuals with disabilities’ access to critical supports and services through the Medicaid Home and Community Based Services (HCBS) program. The HCBS program supports individuals with disabilities to live full and independent lives in their homes and community. The foundation of these services are the DSPs who not only provide essential caregiving services, but also promote independence and community inclusion through services that range from employment coaching and career development to assistance with relationship building and decision-making. The supports DSPs provide help individuals with disabilities avoid unnecessary institutionalization and hospitalization.

The critical supports provided by DSPs are threatened by a longstanding workforce crisis that has been exacerbated by the COVID-19 pandemic. According to the most recent Staff Stability Survey conducted by National Core Indicators® Intellectual and Developmental Disabilities (NCI), the national turnover rate among DSPs is approximately 41% and ranges as high as 59%
in some states.\footnote{National Core Indicators Intellectual and Developmental Disabilities 2022 State of the Workforce Survey Report, available at https://idd.nationalcoreindicators.org/wp-content/uploads/2024/02/ACCESSIBLE_2022NCI-IDDStateoftheWorkforceReport.pdf.} The loss of DSPs across the field has left many individuals without stable access to home and community-based supports. In fact, a 2023 survey of community providers across the country indicated that the devastating impact of the COVID-19 pandemic and continued exodus of DSPs from the field has forced providers to stop accepting new referrals, delay the implementation of new programs and, in too many instances, shutter existing services altogether.\footnote{American Network of Community Options & Resources, The State of America’s Direct Support Workforce Crisis 2023, available at https://www.ancor.org/resources/the-state-of-americas-direct-support-workforce-crisis-2023/} As a result, individuals with disabilities are left without consistent access to critical support and at a higher risk for hospitalization and institutionalization.\footnote{Dan Goldberg, POLITICO, ‘People Will Die Waiting’: America’s System for the Disabled is Nearing Collapse (Aug. 10, 2022) https://www.politico.com/news/2022/08/10/americas-system-for-the-disabled-is-nearing-collapse-00050713.}

There is currently no mechanism to comprehensively collect employment and wage data specifically for DSPs. Without comprehensive data, the totality of the workforce crisis cannot be properly assessed. A unique DSP occupational code will ensure the U.S. Bureau of Labor Statistics can accurately capture employment and wage data specific to the profession, which will in turn assist federal and state policymakers to inform and impact future policy. Accurate and comprehensive data on DSPs is crucial for understanding the workforce crisis and developing effective solutions. Designating DSPs as a distinct occupation will provide the necessary granularity to capture their unique contributions, challenges, and workforce trends.

Without an occupational code, DSPs are often inaccurately and inconsistently incorporated into a variety of SOCs that do not capture their full spectrum of work activities in a variety of home and community settings. DSPs provide supports that are primarily funded by Medicaid and cover a wide range of services. A DSP’s work is interdisciplinary and distinct—DSPs perform tasks geared toward supporting self-direction and independence, such as developing and implementing effective strategies to teach people new skills, helping to communicate with and use assistive technology devices, supporting individuals to find and retain jobs and work toward their personal career goals, and helping people connect socially and participate in recreation activities, education, cultural events, spiritual activities, and civic functions. Accordingly, DSPs receive comprehensive training centered around supporting independence, teaching decision-making skills, and fostering community living and social participation. As noted in a 2017 report from the President’s Committee for People with Intellectual Disabilities, a DSP’s “role is much more focused on being community navigators” and accordingly, the training for DSPs centers on a social model rather than a medical model.\footnote{President’s Committee for People with Intellectual Disabilities, Report to the President 2017: America’s Direct Support Workforce Crisis, available at https://acl.gov/sites/default/files/programs/2018-02/2017%20PCPID%20Full%20Report_0.PDF.}

Such differentiations, not only in job responsibilities but also in training, point to the distinction between DSPs and other occupations currently represented in the federal occupational...
classification system. To ensure the greatest level of accuracy in federal data collection, DSPs must have their own distinct occupational code.

The Medicaid HCBS program has grown exponentially since its inception 40 years ago and plays a critical role in ensuring people can be supported in their homes and communities. However, absent the necessary policy changes to sustain the DSP workforce, Medicaid HCBS programs will continue to fail to reach everyone in need. S. 1332 will help ensure federal recognition of the critical role DSPs play in providing supports for people with disabilities and will help in addressing the ongoing DSP workforce crisis by ensuring there is adequate data collection to inform future policymaking. We urge your support for S. 1332.

Sincerely,

Access Ready Inc.
American Association of People with Disabilities
American Association on Health and Disability
American Network of Community Options and Resources (ANCOR)
Amputee Coalition
The Arc of the United States
Autistic Self Advocacy Network
Autism Society of America
Autism Speaks
Christopher & Dana Reeve Foundation
Council of State Administrators of Vocational Rehabilitation (CSAVR)
Cure SMA
Family Voices
Lakeshore Foundation
National Alliance of Direct Support Professionals
National Association of Councils on Developmental Disabilities
National Association of State Directors of Developmental Disabilities Services
National Disability Rights Network (NDRN)
National Down Syndrome Society
National Health Law Program
National Respite Coalition
National Women's Law Center
RespectAbility
SAGE
TASH