CONSORTIUM FOR CONSTITUENTS WITH DISABILITIES

Community Living and Medicaid Home and Community-Based Services (HCBS)

Long Term Services and Supports: Many people with disabilities and older adults need for long-term supports and services. When these services are provided in the community, they are called "home and community-based services" (HCBS). HCBS include a broad range of services that include assistance with activities such as bathing, dressing, eating, personal care, support with work, meal preparation, money management, house cleaning, medication management, shopping, and telephone use. Most of these services are covered only by Medicaid.

Medicaid: The federal/state Medicaid program is the major – and often the *only* – source of funding for HCBS. This effective and cost-efficient program makes it possible for people with disabilities to live and work in their own communities, among their neighbors. That is why any proposal to cut or cap the Medicaid program disproportionally hurts people with disabilities.

Waiting Lists: Many states have long waiting lists for participation in Medicaid-funded HCBS. Due to historic underinvestment in HCBS and growing demand as the population ages, there are waiting lists for HCBS in the majority of states. There are currently 700,000 people who are on waiting lists, waiting for the help they need, and even more who are underserved. To meet these growing needs, Medicaid should be strengthened, and other proposals should be developed, to expand access to HCBS.

Workforce Crisis: People with disabilities rely on direct care workers to provide the supports and services that they need to live in their homes and communities. A skilled, properly trained, and well-paid workforce is the lynchpin for success for so many people with disabilities to live the life they choose. For people with disabilities, the workforce includes personal assistance, home care workers, and Direct Support Professionals. Their work varies, but can include providing personal care (help with bathing, dressing, etc.), and support with communication, household tasks, building relationships, and navigating the community. Most of these workers are women and black, indigenous, or other people of color, and barely receive minimum wage. In many places, the rates that states pay for these services does not keep pace with wages in competing occupations. Sometimes, rates have been not been increased for years, not even for a cost-of-living adjustment. Years of inadequate Medicaid rates prevent these workers from receiving compensation commensurate with the value they produce for our nation, leading to high turnover and job vacancies. For people with disabilities, this means that even if they can get off a waitlist and get services covered, they may not be able to find staff to support them.

Removing the institutional bias: Because states can put people who need HCBS on waitlists, it can be much easier for a person with a disability to get services in an institution than it is for them to get HCBS in the community. The federal government and states have led efforts to rebalance our long-term care system to provide supports and services to older adults and people with disabilities in appropriate, permanent, integrated community-based settings instead of costlier congregate institutional settings. One program that has successfully supported the rebalancing efforts of states is the Money Follows the Person (MFP) program. MFP incentivizes investment in HCBS by providing additional federal funding for transitional services for individuals who wish to leave a nursing facility or other institution. However, Rebalancing continues to be a focus of federal and state governments, but additional investments and changes to the Medicaid law to remove existing institutional bias would allow investment in community services to grow.

Strict Financial Eligibility Requirements: Much more needs to be done to address the looming need for an affordable and accessible system of LTSS and this includes addressing Medicaid's strict income and asset limits. People should not have to become impoverished in order to become eligible to receive needed LTSS. Finding ways to address the need for LTSS before people become impoverished can save Medicaid dollars.

Unpaid Family Caregivers: When individuals do not qualify for Medicaid, or are sitting on waiting lists or are otherwise underserved by Medicaid, they must rely on a mix of unpaid family, friends and neighbors, often at both personal and financial sacrifice. We have a fragmented system, with uneven access, and increasing costs.

For more information, please contact the CCD Long Term Services and Supports Task Force Co-Chairs:

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