



The Home and Community-Based Services Access Act (HAA), a new piece of legislation in development aims to “establish a baseline criteria for the delivery of HCBS across the country and to make those foundational services an entitlement under Medicaid. Creating a minimum set of services, that states can enhance, and requiring HCBS as part of Medicaid for those who are eligible, will help states create a network of providers and workers to deliver critical services and support. It will also eliminate the long waiting lists for services experienced by many eligible people in an estimated 41 states across the country.”

Leaders of the Disability Community have been gathering each and every day since the beginning of the pandemic to address disability-related rising issues, good and promising practices, and information and resource sharing related to the COVID-19 pandemic.

On March 5, 2021 we released our [\*National Call To Action: A Year Later\*](#) where we call out the inequitable results of the response to the COVID-19 pandemic, where now [Despite making up less than 1% of the nation's population, people living in nursing homes and other long-term-care facilities account for at least 35% of the nation's COVID-19 deaths.](#) In other words, at least 175,000+ of all COVID-19 deaths were people with disabilities in nursing homes and [most were Black, Brown, Indigenous and other multiply marginalized people.](#)

Thus, the HAA **Guiding Principles** need to **Center on Equity and Disability Justice!**

- HCBS First: CHANGE THE ENTITLEMENT
  - Any changes to entitlement must be to the advantage of having the right to receive HCBS first
- Ensure rights of Consumers including, but not limited to, the Consumer's right to select supervise, directly train, schedule and change personal assistance
- Consumers who use personal assistance need to be the majority of “committees,” “councils,” “advisories,” etcetera
- The right to choice and decision making in health care and HCBS service providers



- Presumptive and expedited eligibility based on functional needs
- Eliminate waiting lists and silos
- HCBS must be portable across all geographies
- Emergency planning, response, and recovery must be integrated in every aspect of HCBS with a twin track focus on both, specific emergency management issues and baking emergency management throughout
- Incorporate public health safety measures
- Optimum opportunities for employment without penalty
- No negative consequences for people who purchase their own personal assistance services
- Protect consumers privacy - Eliminate Electronic Visit Verification
- HCBS must be available to people across their lifespan
  - To enable children with disabilities and their families to navigate daily life in the community
  - Recognizing older adults receiving HCBS are people with disabilities, and as such, are entitled to both the civil rights protections and a justice-based system
- Affordable accessible integrated safe housing
- Accessible transportation can be routinely used by all persons receiving and/or eligible for HCBS without barriers
- Health care providers need to contract with disability-led organizations, like Centers for Independent Living to divert people from going into institutions and assisting people transition back to the community.



- Tools, services, technologies that support independence won't be bound by limited list-making
- If FMAP used or tapered - there needs to be strong maintenance of effort provision
  - Maintenance of effort must protect and preserve level of care/services
- Achieve and maintain fair living wages, healthcare, PTO, hazard pay and other benefits for personal assistants
- Opportunities for family and spouses to be eligible to be employed to provide personal assistance
- Opportunities for undocumented workers
- Terms get defined and are transparent
- Every action made prioritizes most disproportionately impacted folks
- No negative consequences/penalties for people with significant needs
  - Prioritize people with most needs -
  - "Prioritize the risk and protective factors associated with the substance misuse problems that have been identified" and "Prioritize the risk and protective factors associated with independence and community living."
- Desegregate data by disability, gender, age, race/ethnicity, and income

You can find the draft HAA bill [here](#).

Send your comments by Monday, April 26 to [HCBSComments@aging.senate.gov](mailto:HCBSComments@aging.senate.gov).

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