

Healthcare Extension and Accessibility for Developmentally disabled and Underserved Population Act of 2018

The Healthcare Extension and Accessibility for Developmentally disabled and Underserved Population Act of 2018, or HEADs UP Act, would designate people with Intellectual and Developmental Disabilities (I/DD) as a Medically Underserved Population (MUP) under the Health Services and Resources Administration (HRSA). People with I/DD experience poorer health, shortened life expectancies, and lack access to even the most basic forms of care when compared to the non-disabled population. A designation as a MUP would help to close these gaps and achieve better health outcomes for the entire I/DD population.

The Health Centers Consolidation Act of 1996 first put together the three “special medically underserved populations” – migratory and seasonal agricultural workers, the homeless, and residents of public housing. Populations that do not fall under one of the “special medically underserved population” categories must meet certain criteria to be designated as a MUP *and* live in the same geographic area. These criteria are: ratio of primary care physicians to population; infant mortality rate; percentage of the population with incomes below the poverty level; and percentage of the population which is age 65 and over. Though the I/DD population meets all of these criteria and has been fighting for this designation for over 40 years, they still have not been recognized as a MUP.

1. Despite the large and growing size of the population with I/DD, there are few primary care providers and even fewer specialists who are trained to treat the I/DD population. Research commissioned by the Special Olympics found that in the United States, on average, a person with I/DD would need to contact approximately 50 doctors before finding one with training and experience to treat him or her.
2. Infant mortality rates for the I/DD population also far exceed those of the non-disabled population. A study of 1,305 infants born from 1990 to 2006 with I/DD showed a mortality rate of 74 per 1,000. The infant mortality rate for the non-disabled population is 5.82 per 1,000 births.
3. People with I/DD also live in poverty at grossly higher rates than the non-disabled population. According to U.S. Census data, 28.6% of individuals with severe disabilities live in poverty. According to the same U.S. Census data, the poverty rate for the entire population is 12.7%.
4. Finally, adults with I/DD are experiencing increased longevity despite the fact that adults with I/DD generally die at an earlier age than adults in the general population. 2010 Census data estimates that 850,600 individuals with I/DD aged 60 and older live in the community, and this number is expected to double by 2020. It is imperative that there are enough providers to care for and treat this growing population.

The only criteria for a MUP that the I/DD population does not meet is the requirement that the population live in the same residential area. Requiring the I/DD population to live in the same area in order to receive the MUP designation would require undoing all of the progress that has been made towards their integration into society. This leaves legislation as the only solution to provide better care and improved outcomes to Americans with I/DD by designating them as a “special medically underserved population.”

The MUP designation would open up over 25 government programs within HRSA and other federal agencies for the I/DD population. These programs include:

- Federal funding for health centers and public health infrastructure such as Federally Qualified Health Centers (FQHC),
- Eligibility to apply for federal funding to develop and operate Community Health Centers,
- Access to loan repayment and training programs in HRSA’s Workforce Development and Training Programs including the national Health Service Corps Scholarships,
- Incentives for physicians to treat this population in the form of higher CMS reimbursement rates for physician services delivered in Health Professional Shortage Areas, a designation closely related to MUP,
- Preference given to research at federal agencies, including the NIH, that studies medically underserved population.

There is ample evidence that people with I/DD meet all of the criteria and would benefit greatly from being designated as a MUP. Inclusion in the programs that are tied to MUP status would help to build a workforce to treat this population, including primary care providers and specialists. Providers who go into this field would have access to loan forgiveness, training and research grants, and enhanced levels of reimbursement. The designation would also allow people with I/DD to be seen at clinics they were previously excluded from and would reclassify existing clinics that provide care as Community Health Centers. All of these newly available benefits would create progress towards closing the large gaps in health outcomes experienced by people with I/DD when compared to the non-disabled population.

The I/DD population deserves to live long, healthy lives, just like any other American. Please join in cosponsoring the HEADs UP Act to make this a reality. To sign on, please contact Chrissy Raymond in Congressman Moulton’s office at Christine.Raymond@mail.house.gov or 202-225-8020.