A CONCURRENT RESOLUTION decrying the lack of services for medically fragile young adults with intellectual and developmental disabilities and directing the establishment of the Task Force on Subacute Care for Medically Fragile Adults.

WHEREAS, the life expectancy of a medically fragile young adult after the age of 21 is two to three years because of the substandard care available to this population in our Commonwealth; and

WHEREAS, the care available to individuals younger than 21 who are medically fragile and who may require daily skilled nursing intervention such as ventilators, dialysis machines, feeding tubes, or continuous oxygen is adequate and allows many individuals to thrive prior to reaching 21; and

WHEREAS, when individuals age out of these services at the age of 21, the availability of adequate care disappears; and

WHEREAS, because of lack of funds on the federal and state level, the nurse to patient level drops from about one nurse for every eight patients to one nurse for every 24 patients; and

WHEREAS, most medically fragile residents are nonverbal, and their needs have to be anticipated by experienced staff; and

WHEREAS, staff in adult nursing homes are not familiar with the needs of medically fragile young adults, including deep suctioning, feeding tubes, and providing medications through a feeding tube; and

WHEREAS, medication timing and frequency changes when individuals age out of care; and

WHEREAS, tub bathing for the medically fragile is reduced from once per day in most care prior to age 21 to twice per week or less in a nursing home; and

WHEREAS, access to community activities is greatly reduced for many residents; and

WHEREAS, access to educational programs, peer modeling, and socialization is

greatly reduced for these citizens after age 21; and

WHEREAS, access to critical assistive technology such as standers, gait trainers and other necessary equipment is compromised; and

WHEREAS, private rooms are not available for this population, and they may share rooms with individuals prone to behavior issues, which is particularly concerning for this nonverbal population; and

WHEREAS, family members cannot spend the night to visit their family member at many adult nursing facilities; and

WHEREAS, there is little availability of bus transportation or other public transportation to many nursing facilities, which further impacts the ability of families to visit residents; and

WHEREAS, targeted therapies for this population are extremely limited because many nursing facilities are focused toward the aged; and

WHEREAS, subacute care is very limited in the Commonwealth, with one of the most effective treatment facilities having an eight-year or greater waiting list; and

WHEREAS, subacute care could be a health care growth area in the Commonwealth as additional therapies are covered and developed; and

WHEREAS, many of these patients have defeated the odds thanks to medical advances and outstanding care available in facilities that serve medically fragile children; and

WHEREAS, the Commonwealth has the opportunity to expand subacute care and empower these individuals to continue to thrive; and

WHEREAS, once again, the lack of adequate placement options for medically fragile individuals means that they have a life expectancy of 18 months to three years after the therapies available to them at age 20 are discontinued at age 21;

NOW, THEREFORE,

Be it resolved by the House of Representatives of the General Assembly of the

Commonwealth of Kentucky, the Senate concurring therein:

➔Section 1. The Legislative Research Commission is directed to establish the Task Force on Subacute Care for Medically Fragile Adults to develop a strategy and funding mechanism to provide medically fragile adults with intellectual and developmental disabilities with care that is equivalent and synergistic to the care received by children with Intellectual and Developmental Disabilities with Medical Complexity. The task force shall invite representatives of agencies, hospitals, providers, businesses, civic organizations, and others who may provide information and resources in developing and implementing a strategy, legislation, research, and funding mechanism for better serving the underserved medically fragile adults with intellectual and developmental disabilities population.

➔Section 2. (1) The task force of the Legislative Research Commission shall be composed of the following members with final membership of the task force being subject to the consideration and approval of the Legislative Research Commission:

(a) The chair of the Senate Health and Welfare Committee;

(b) The chair of the House Health and Welfare Committee;

(c) The chair of the Senate Licensing, Occupations and Administrative Regulations Committee;

(d) The chair of the House Licensing and Occupations Committee;

(e) Three members of the Senate, two to be appointed by the President of the Senate, and one to be appointed by the Minority Floor Leader of the Senate; and

(f) Three members of the House of Representatives, two to be appointed by the Speaker of the House, and one to be appointed by the Minority Floor Leader of the House.

(2) The President of the Senate and the Speaker of the House shall each appoint one co-chair of the task force from among the members of the task force.

➔Section 3. The task force shall report its findings to the Legislative Research

Commission for referral to the appropriate committee or committees no later than December 1, 2016.

➔Section 4. Provisions of Sections 1 to 3 of this Concurrent Resolution to the contrary notwithstanding, the Legislative Research Commission shall have the authority to alternatively assign the issues identified in this Concurrent Resolution to an interim joint committee or subcommittee thereof, and to designate a study completion date.