

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

5 WHEREAS, individuals who are medically fragile and medically complex
6 encounter many barriers in accessing community-based services, including but not
7 limited to waiting lists for services, lack of service providers who are willing and
8 qualified to provide services, and low reimbursement rates;

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

12 WHEREAS, the care available to some individuals younger than 21 who are
13 medically fragile and medically complex and who may require daily skilled nursing
14 intervention such as ventilators, dialysis machines, feeding tubes, or continuous oxygen
15 receive care in pediatric nursing facilities that allows many individuals to thrive prior to
16 age 21; and

17 WHEREAS, because of the lack of community-based services, young people who
18 are medically fragile and medically complex are sometimes placed in traditional nursing
19 facilities designed for end-of-life care;

20 WHEREAS, because of lack of funds at the federal and state levels, the nurse-to-
21 patient ratio drops from about one nurse for every eight patients in a pediatric nursing
22 facility to one nurse for every 24 patients in a traditional nursing facility; and

23 WHEREAS, many medically fragile and medically complex residents are
24 nonverbal, and their needs require anticipation by experienced staff; and

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

1 WHEREAS, young adults have different socialization needs than what is available
2 in adult nursing homes; and

3 WHEREAS, medication timing and frequency changes as these individuals grow
4 older and their care situations change; and

5 WHEREAS, tub bathing for the medically fragile and medically complex often is
6 reduced from once per day in most care settings prior to age 21 to twice per week or
7 fewer in a nursing home; and

8 WHEREAS, access to community age-appropriate activities is greatly reduced for
9 many residents; and

10 WHEREAS, access to educational programs, peer modeling, and socialization is
11 greatly reduced for these citizens after age 21; and

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

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

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

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

22 WHEREAS, properly equipped ambulances for transportation of a patient from a
23 nursing facility to a hospital are often not available; and

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

26 WHEREAS, many of these patients have thrived and survived thanks to medical
27 advances and outstanding care available for medically fragile and medically complex

1 children; and

2 WHEREAS, like other citizens, individuals who are medically fragile and medically
3 complex should have the opportunity to live in the communities of their choice;

4 WHEREAS, the Commonwealth has the opportunity to expand community based
5 services to empower these individuals to continue to thrive;

6 NOW, THEREFORE,

7 ***Be it resolved by the House of Representatives of the General Assembly of the***
8 ***Commonwealth of Kentucky, the Senate concurring therein:***

9 ➔Section 1. The General Assembly recognizes the important work that the
10 Cabinet for Health and Family Services has begun to redesign the way that services and
11 supports are provided to this vulnerable population through its work with the 1915(c)
12 Waiver Redesign Working Group. The General Assembly directs that a presentation and
13 testimony concerning the progress of this working group be given during the August
14 meeting of the Interim Joint Committee on Health and Welfare and the Medicaid
15 Oversight and Advisory Committee.

16 ➔Section 2. The General Assembly further directs that one Representative
17 selected by the Speaker of the House and one Senator selected by the President of the
18 Senate be added to the 1915(c) Waiver Redesign Working Group to provide legislative
19 input and to address the constituent concerns about medically fragile and medically
20 complex populations in the Medicaid system.

21 ➔Section 3. Sections 1 and 2 of this Act to the contrary notwithstanding, the
22 Legislative Research Commission shall have the authority to alternatively assign the
23 issues identified herein to an interim joint committee or subcommittee thereof and to
24 designate a study completion date.