



General Assembly

**Amendment**

February Session, 2024

LCO No. 5826



Offered by:  
REP. GILCHREST, 18<sup>th</sup> Dist.

To: Subst. House Bill No. 5367

File No. 282

Cal. No. 199

**"AN ACT CONCERNING MEDICAID COVERAGE OF RAPID WHOLE  
GENOME SEQUENCING FOR CRITICALLY ILL INFANTS."**

1 Strike everything after the enacting clause and substitute the  
2 following in lieu thereof:

3 "Section 1. (NEW) (*Effective July 1, 2024*) (a) As used in this section, (1)  
4 "rapid whole genome sequencing" means a test designed to diagnose  
5 genetic disorders in time to inform or change acute medical or surgical  
6 management of a critically ill infant, and (2) "infant" means a child from  
7 birth to age twelve months. The Commissioner of Social Services shall,  
8 within available appropriations, provide medically necessary Medicaid  
9 coverage for rapid whole genome sequencing of a critically ill infant  
10 enrolled in the Medicaid program who is being treated in a neonatal  
11 intensive care or pediatric intensive care unit.

12 (b) The commissioner shall require that any health care provider  
13 receiving reimbursement for such test certify, in writing, that any  
14 genetic data resulting from such test is (1) used only to assist in  
15 diagnosing and treating the infant, (2) protected in accordance with the

16 federal Health Insurance Portability and Accountability Act of 1996, P.L.  
17 104-191, as amended from time to time, and (3) not used in scientific  
18 research unless a parent or legal guardian of the infant expressly  
19 consents to such use.

20 (c) The commissioner shall take actions necessary to implement the  
21 provisions of this section, including, but not limited to, (1) promulgating  
22 regulations in accordance with chapter 54 of the general statutes to  
23 provide payment for such rapid whole genome sequencing, and (2)  
24 submitting to the Centers for Medicare and Medicaid Services any new  
25 waiver application, amendment to an existing waiver or Medicaid state  
26 plan amendment necessary to ensure federal financial participation for  
27 Medicaid coverage of such rapid whole genome sequencing.

28 (d) In developing regulations pursuant to subsection (c) of this  
29 section, the commissioner shall establish evidence-based medical  
30 necessity criteria for such rapid whole genome sequencing coverage that  
31 shall include, but need not be limited to: (1) The infant has symptoms  
32 that suggest a broad differential diagnosis that would require an  
33 evaluation by multiple genetic tests if rapid whole genome sequencing  
34 is not performed, (2) the infant's treating health care provider has  
35 provided a written determination that rapid whole genome sequencing  
36 is necessary to guide clinical decision making, and (3) the infant has  
37 complex or acute illness of unknown etiology, which may include (A)  
38 congenital anomalies involving at least two organ systems or complex  
39 or multiple congenital anomalies in one organ system, (B) specific organ  
40 malformations highly suggestive of a genetic etiology, or (C) abnormal  
41 laboratory tests or abnormal chemistry profiles suggesting the presence  
42 of a genetic disease.

43 Sec. 2. (*Effective July 1, 2024*) (a) As used in this section, (1) "Katie  
44 Beckett Waiver Program" means the waiver program for children and  
45 young adults with disabilities established pursuant to section 17b-283 of  
46 the general statutes, (2) "rare disease" means a disease or condition  
47 affecting fewer than two hundred thousand persons in the United  
48 States, (3) "extremely rare disease" means a disease affecting fewer than

49 five thousand people in the United States, as such diseases are recorded  
50 by the Genetic and Rare Diseases Information Center of the National  
51 Institutes of Health, and (4) "terminal illness" means an illness or  
52 condition that is incurable and can lead to death.

53 (b) The House and Senate chairpersons of the joint standing  
54 committee of the General Assembly having cognizance of matters  
55 relating to human services shall appoint a working group to study and  
56 make recommendations concerning eliminating or reducing the waiting  
57 list for services in the Katie Beckett Waiver Program and establishing  
58 priority placements on such list based on illness and life expectancy.

59 (c) Said chairpersons shall convene the first meeting of the working  
60 group not later than August 1, 2024. The working group shall consist of:

61 (1) The House and Senate chairpersons of the joint standing  
62 committee of the General Assembly having cognizance of matters  
63 relating to human services, or their designees, who shall serve as  
64 chairpersons of the working group;

65 (2) The ranking House and Senate members of the joint standing  
66 committee of the General Assembly having cognizance of matters  
67 relating to human services, or their designees;

68 (3) The following members appointed by the House and Senate  
69 chairpersons of the joint standing committee of the General Assembly  
70 having cognizance of matters relating to human services:

71 (A) One parent or legal guardian of a child on the waiting list with an  
72 extremely rare disease that is a terminal illness;

73 (B) One parent or legal guardian of a child on the waiting list with a  
74 rare disease that is a terminal illness;

75 (C) One young adult on the waiting list with a rare disease, terminal  
76 illness or both, or such young adult's parent or legal guardian;

77 (D) One representative of the Connecticut Children's Medical Center

78 with expertise in pediatric rare genetic diseases or medical treatments  
79 for terminal illness;

80 (E) One representative of The University of Connecticut Health  
81 Center's Department of Pediatrics with expertise in pediatric rare  
82 genetic diseases or terminal illness research;

83 (F) One representative of the Yale School of Medicine's Department  
84 of Pediatrics; and

85 (G) One representative of the Connecticut Rare Disease Advisory  
86 Council;

87 (4) The Commissioner of Social Services, or the commissioner's  
88 designee; and

89 (5) The Secretary of the Office of Policy and Management, or the  
90 secretary's designee.

91 (d) The working group shall:

92 (1) Develop a strategy to eliminate the waiting list for services and an  
93 alternate strategy to reduce the waiting list, with estimated state costs;

94 (2) Develop a model for how the Department of Social Services could  
95 track children and young adults on the waiting list by type of disease or  
96 disability and life expectancy;

97 (3) Estimate costs to implement such tracking model and amount of  
98 time needed to implement such model;

99 (4) Recommend statutory definitions for terminal illness, limited life  
100 expectancy and other terms deemed appropriate for use by the working  
101 group in the establishment of any priority tier on the waiting list for  
102 services in the waiver program;

103 (5) Determine average life expectancy associated with certain rare  
104 diseases and extremely rare diseases;

105 (6) (A) Analyze models in other states for offering similar services to  
106 those offered by the Katie Beckett Waiver Program, (B) determine  
107 whether and how other states establish priority placements for such  
108 services, and (C) estimate costs to adopt any such models or priority  
109 placement programs in this state;

110 (7) Determine to what extent the waiver program is serving all  
111 eligible persons in the state and, if necessary, develop a public  
112 awareness strategy to increase participation to the estimated capacity of  
113 the program in the future; and

114 (8) Develop protocols to ensure the protection of private health  
115 information of participants in the waiver program and those on the  
116 waiting list for such program in accordance with state and federal law.

117 (e) The administrative staff of the joint standing committee of the  
118 General Assembly having cognizance of matters relating to human  
119 services shall provide administrative support to the working group.

120 (f) Not later than February 15, 2025, the working group shall submit  
121 a report, in accordance with the provisions of section 11-4a of the general  
122 statutes, to the joint standing committees of the General Assembly  
123 having cognizance of matters relating to appropriations and human  
124 services on the results of the study and the working group's  
125 recommendations. The working group shall terminate on the date the  
126 report is submitted, or February 15, 2025, whichever is earlier.

127 *Sec. 3. (Effective from passage)* (a) The Commissioner of Social Services  
128 shall study the feasibility of expanding Medicaid coverage for diapers  
129 to children from birth to age three for whom diapers are medically  
130 necessary in accordance with section 17b-259b of the general statutes.

131 (b) Not later than January 1, 2025, the commissioner shall file a report  
132 on the study, in accordance with the provisions of section 11-4a of the  
133 general statutes, with the joint standing committee of the General  
134 Assembly having cognizance of matters relating to human services. The  
135 report shall include, but need not be limited to, analysis of and

136 recommendations concerning: (1) Federal requirements for Medicaid  
137 coverage of diapers for such children, (2) a summary of diaper coverage  
138 under Medicaid programs in other states, (3) clinical best practices, (4)  
139 operational and programmatic considerations, (5) opportunities to  
140 utilize the existing diaper coverage system for certain Medicaid  
141 recipients, (6) coverage options, and (7) fiscal impact to the state."

This act shall take effect as follows and shall amend the following sections:		
Section 1	<i>July 1, 2024</i>	New section
Sec. 2	<i>July 1, 2024</i>	New section
Sec. 3	<i>from passage</i>	New section