Katie Beckett Waiver Program Working Group
Final Report and Recommendations
February 2025

The Chairs would like to dedicate these recommendations to
Chloe Negron and express their deepest sympathies to her family.

Enacting Legislation

In the 2024 legislative session the Connecticut General Assembly enacted Public Act No. 24-130, An Act Concerning Medicaid Coverage of Rapid Whole Genome Sequencing for Critically Ill Infants and Studies Concerning the Elimination or Reduction of the Katie Beckett Waiver Program Waiting List and Medicaid Coverage of Diapers.

Public Act 24-130 established a working group to study and make recommendations concerning the Katie Beckett Waiver Program with the purpose of:

(1) developing a strategy to eliminate the waiting list for services and an alternate strategy to reduce the waiting list, with estimated costs;
(2) developing a model for how DSS could track children and young adults on the waitlist by type of disease or disability and life expectancy;
(3) estimating costs and amount of time needed to implement the tracking model;
(4) recommending statutory definitions for terminal illness, limited life expectancy, and other terms deemed appropriate for the working group's use when setting any priority tier on the waitlist;
(5) determining average life expectancy associated with certain rare diseases and extremely rare diseases;
(6) analyzing other states' models for offering similar services to those offered under the Katie Beckett waiver, determining whether and how they establish priority placements for services, and estimating costs to adopt these models or priority placement processes in Connecticut;
(7) determining the extent to which the waiver program is serving all eligible people in the state and, if needed, developing a public awareness strategy to increase participation to the program's estimated future capacity; and
(8) developing protocols to ensure private health information is protected for waiver participants and people on the waitlist in accordance with state and federal law.

The working group is required to submit its findings and recommendations to the Appropriations and Human Services committees no later than February 15, 2025 and terminates on the date of submission.

Working Group Membership

Under the act, the working group includes the Human Services Committee chairpersons and ranking members, the DSS commissioner and Office of Policy and Management secretary or their designees, and the following members appointed by the Human Services Committee chairpersons:

1. two parents or legal guardians of children on the waitlist with terminal illnesses, one with a child with a rare disease (affecting fewer than 200,000 people in the United States) and one with a child with an extremely rare disease (affecting fewer than 5,000 people in the United States, as recorded by the National Institutes of Health's Genetic and Rare Diseases Information Center);
2. one young adult on the waitlist with a rare disease, terminal illness, or both, or the young adult's parent or legal guardian;
3. one Connecticut Children's Medical Center representative with expertise in pediatric rare genetic diseases or medical treatments for terminal illness;
4. one UConn Health Center Department of Pediatrics representative with expertise in pediatric rare genetic diseases or terminal illness research;
5. one representative from Yale School of Medicine's Department of Pediatrics; and
6. one Connecticut Rare Disease Advisory Council representative.

Appointed Members

- Senator Matt Lesser, Human Services Co-Chair
- Representative Jillian Gilchrest, Human Services Co-Chair
- Molly Cole – Parent of Child with rare disease, daughter was first recipient of KB Waiver in CT
- Beth Fresa – Parent of child with Pontocerebellar hypoplasia
- Christine Weston – Director of Community Options, Department of Social Services
- Nicholas Venditto – OPM designee for DSS
- David Negron – Parent of a child with Tay-Sachs disease
- Jennifer Handt – Parent of child with Duchenne Muscular Dystrophy, currently on waiting list
- Dr. Louisa Kalsner – Pediatric Neurologist and Division Head of Genetics at Connecticut Children's Hospital
- Dr. Emily Germain-Lee – Pediatric Endocrinologist at UConn Health, member of Rare Disease Advisory Council
- Veronica Menses – Yale School of Medicine Department of Prediatrics
- Lesley Bennett – Co-Chair Rare Disease Advisory Council, Parent of child with rare disease

Meetings and Presentations

September 30, 2023
Agenda | Meeting Summary | Recording | DSS Presentation | CRS Research Memo

October 21, 2024
Agenda | Meeting Summary | Recording | DSS Memo

November 12, 2024
Agenda | Meeting Summary | Recording | OLR Report

December 2, 2024
Agenda | Meeting Summary | Recording

December 16, 2024
Agenda | Meeting Summary | Recording

February 11, 2025
Agenda | Meeting Summary | Recording

Formal Recommendations

The Katie Beckett Waiver Working Group was convened to work with the Department of Social Services (DSS) to reduce and/or eliminate the waiting list for the Katie Beckett Waiver. Currently there is approximately a 5-year waitlist for eligible persons.

Information was provided by the Department of Social Services on why they are experiencing long waitlists for the Katie Beckett Waiver, the Congressional Research Services provided analysis of Katie Beckett Waiver Programs in other states that have no or small waiting lists, and the Office of Legislative Research provided information for waiver programs in Minnesota, Wisconsin, and Rhode Island. Robust conversations led to the working group developing the following recommendations.

The working group makes the formal recommendations below:

1. DSS should establish a KB Waiver website portal that will:
    - Allow individuals on the waitlist to check status -- currently individuals are <u>not</u> notified of their standing until a spot opens
    - Allow individuals on the waitlist to update contact information
    - Outline any financial restrictions for families or children
    - Outline services available under the waiver program
    - Provide available resources for families, including disease specialists, advocacy groups, and outside funding for care needs not covered under Medicaid
    - Share the contact information for the Office of Healthcare Advocate who can help with primary payer insurance and coverage information
    - Outline the various waiver program and the eligibility for each

2. DSS should issue an annual letter at end of each fiscal year to individuals/families on the waitlist regarding their status on the waitlist and if they have moved up,

3. DSS should create a Katie Beckett Waiver Program brochure to disseminate to community providers, including but not limited to: pediatricians, children’s hospitals, geneticists, nurses, and social workers.

4. Rare Disease Council and other advocates should disseminate information on KB Waiver Program to the rare disease community and its providers.

5. DSS should establish a maximum age limit for KB Waiver Program eligibility by capping the age at 18 years. For individuals who are 18 years and older, individuals should be transitioned to Social Security and HUSKY rather than remaining on the waitlist.

6. DSS should consider coverage of home modifications as a Waiver benefit.

7. DSS should develop a five-year plan that identifies policies and funds needed to eliminate the waiting list.