Human Services Committee
JOINT FAVORABLE REPORT

Bill No.:	HB-7103
Title:	AN ACT CONCERNING THE KATIE BECKETT WORKING GROUP RECOMMENDATIONS.
Vote Date:	3/14/2025
Vote Action:	Joint Favorable
PH Date:	3/6/2025
File No.:	467

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SPONSORS OF BILL:

Human Services Committee

CO-SPONSORS OF THE BILL

Rep. Sarah Keitt, 134th Dist.
Sen. Christine Cohen, 12th Dist.
Rep. Jillian Gilchrest, 18th Dist.

REASONS FOR BILL:

The Katie Beckett Waiver Program (KBWP) provides Medicaid coverage to children with significant medical needs and has been a lifeline for many families by allowing them access to complex, multispecialty medical care and supportive services, often not covered by commercial insurance. This waiver allows the severely ill/disabled child to receive care at home, avoiding costly hospitalizations. However, the waitlist limits the program's reach, leaving many families without the assistance they desperately need, and some die before services become available. Currently, Connecticut is the only New England state with a cap on the number of children provided with a Katie Beckett Waiver, leaving 331 individuals on the waitlist. This bill directs DSS to adjust the age range of recipients, to increase the specificity of public information available regarding the waiver, and to develop a 5-year plan to eliminate the waitlist for program services. Expanding access to the waiver or complete removal of the waitlist would provide much needed relief for these children and their families.

RESPONSE FROM ADMINISTRATION/AGENCY:

Connecticut Department of Social Services, Andrea Barton Reeves, Commissioner: supports the goals of this legislation, and actively participated in the Katie Beckett Waiver

Program Working Group, however, DSS expressed concerns about specific provisions of the bill. DSS supports the change in the age range for participants but seeks clarifying "under 18" because upon the 18th birthday, recipients can access HUSKY C, and no longer need the KBWP to qualify for coverage. DSS does not support Section 2 as currently written: several items requested are already available online and more is forthcoming and given the potential costs of developing a portal, DSS does not support adding website content requirements into statute. Section 3 proposes recommendations regarding the creation of a brochure. The Department requests that the mandatory dissemination language be removed and replaced with a more general requirement to plan ways of sharing the information to target families & providers. Section 4 directs development of a 5-year plan to eliminate the waitlist. The Department agrees to work collaboratively to address this goal but do not believe the timeline needs to be set. Based on the current waitlist of 331, DSS estimates the cost to eliminate the waitlist to be approximately $17.1 million in gross costs when fully annualized ($8.6 million state share). The Department is open to working on these recommendations but emphasizes that the central need is funding. The Governor's proposed budget does not include such funding.

NATURE AND SOURCES OF SUPPORT:

Connecticut General Assembly, Senator Christine Cohen (12th District) and Representative Moira Rader (98th District): submitted a joint statement in support of the expansion of the KBWP in honor of their constituent, Chloe Negrón, who passed away earlier this year at the age of 6 while on the KBWP waitlist. Her family had advocated tirelessly for elimination of the waitlist and her father David, volunteered many hours to participate in the KBWP Work Group, even after his daughter's death, to assure other families had access to the resources of the program. A key provision is the creation of a centralized online resource where individuals can determine their eligibility for the waiver program and receive real-time updates on their position on the waitlist. This website will also provide essential information, including family support, guidance on private insurance coverage, options of other state resources, and information on private organizations for home modifications or adaptive equipment. The Senator and Representative applaud the efforts to eliminate the list in 5 years, and request that DSS be required to report key data regarding the KBWP recipients throughout this process, the cost per enrollee, and characteristics of those on the waitlist.

Connecticut Rare Disease Advisory Council (RDAC), Lesley Bennett, Co-Chair: supports this bill. The Katie Beckett Waiver Program (KBWP) is extremely important to the RDAC and Connecticut rare disease community. Families caring for these children are often overwhelmed and overworked trying to care for a child who is physically and medically fragile. The 5-year wait for these services is excessive and many children with rare disease pass before they receive a waiver. Approximately 30% of the children born with a rare disease do not live to see their 5th birthday. Since the KBWP is one of the only Medicaid waivers that families caring for children with devastating rare diseases can apply for, it is essential that the state adopt policies and practices to reduce the waitlist for these services.

Connecticut State Independent Living Council, Molly Cole, Executive Director: supports this bill as the parent of the first child in CT that qualified for the KBWP and a member of the Working Group that drafted the recommendations addressed by this bill. The recommendations were carefully deliberated by a wonderful working group of parents, agency staff and doctors, and was led by Senator Lesser and Representative Gilchrest. It was stated we heard extensively from staff at DSS regarding the current utilization and cost of this program. Our recommendations took into consideration all that we heard, as well as all that we, the parents, know from our own lives. We believe that the best way to serve all the children on the waitlist would be to fully fund or significantly expand the slots for this waiver program. It was stated, "in the forty plus years I have been working in disability advocacy, the issue of expanding the Katie Beckett waiver has repeatedly come up. I have copies of numerous testimonies I have written on this over the years, and frankly it all comes down to the willingness of the state of Connecticut to address the extraordinary needs of these children." The time is now.

Connecticut Children's Medical Center, Center for Care Coordination, Allison Matthews-Wilson, Senior Director: supports the bill and believes it would help streamline the enrollment process and create greater awareness of assistance available through the program by establishing an online portal for applicants and enrollees. Connecticut Children’s often interacts with patients and families utilizing the KBWP that have complex medical needs or significant disabilities that require care at home. We see many more patients/families that are in critical need of help but must wait years before a slot opens, resulting in significant financial hardship and reduced quality of care, making eliminating the waitlist crucial. One recent example is an 8- year-old child with a severe genetic condition, newly discovered heart failure, and multisystem disease. The family will have a roughly 4-year wait to receive a waiver. In the meantime, they are struggling with thousands of dollars of copays for medications, supplements, and care that their child desperately needs.

Individuals that provided testimony in support:

Richard Torres, MD, Medical Director, Urban Health Plan.
Michael Negrón, Grandfather of Chloe Negrón that passed away at age 6 while on waitlist

NATURE AND SOURCES OF OPPOSITION:

None expressed.

Reported by: Rebecca McClanahan **Date: April 2, 2025**