

# Human Services Committee JOINT FAVORABLE REPORT

**Bill No.:** SB-206

AN ACT CONCERNING THE EXPANSION OF THE KATIE BECKETT WAIVER

**Title:** PROGRAM.

**Vote Date:** 3/19/2024

**Vote Action:** Joint Favorable Substitute Change of Reference to Appropriations

**PH Date:** 3/7/2024

**File No.:**

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## **SPONSORS OF BILL:**

Human Services Committee

## **CO-SPONSORS OF BILL:**

Sen. Saud Anwar, 3rd Dist.

Sen. Christine Cohen, 12th Dist.

Rep. Moira Rader, 98th Dist.

Sen. Martha Marx, 20th Dist.

Sen. Matthew L. Lesser, 9th Dist.

Rep. Geraldo C. Reyes, 75th Dist.

## **REASONS FOR BILL:**

The Katie Beckett Waiver Program 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 terminally ill child to remain at home, avoiding costly hospitalizations. However, the current waitlist limits the program's reach, leaving many families without the assistance they desperately need. Currently, Connecticut is the only New England state with a cap on the number of physically/medically disabled children provided with a Katie Beckett Waiver, leaving 307 individuals on the waitlist. This bill directs DSS to expand the waiver program to reduce the waiting list for program services. Expanding access to the waiver or complete removal of the waitlist would provide relief for these children and their families.

## **SUBSTITUTE LANGUAGE:**

The substitute language expands the Katie Beckett Waiver by an additional 50 slots, with two such slots reserved for children with juvenile Tay-Sachs disease, or, if there are not two such children, children with another rare, life-threatening disease.

## **RESPONSE FROM ADMINISTRATION/AGENCY:**

**Department of Social Services (DSS), Commissioner Andrea Barton Reeves;** opposes the elimination of the waiver stating the proposed costs are not accounted for in the Governor's recommended budget. It is stated there are 326 active individuals on the Katie Beckett Waiver and 307 individuals are on the waitlist, with an average wait time of approximately 5 years. It is stated the average annual cost for an individual is approximately \$53,500 per person and an applicant must meet both the medical and Medicaid financial eligibility requirements. It is stated that adding 50 people to the waiver would cost approximately \$2.6 million per year, with a state share of roughly \$1.3 million per year. It is also stated that eliminating the waitlist would cost approximately \$16 million, with a state share of roughly \$8 million, without factoring in the additional administrative and infrastructure funding needed.

## **NATURE AND SOURCES OF SUPPORT:**

**Connecticut General Assembly, State Senator, Saud Anwar;** supports this bill stating the expansion of the Katie Beckett Waiver Program will increase access to care and more families will be able to access critical medical services, therapies, and equipment. It is stated this is crucial in improving the health outcomes of children with complex medical conditions. It is also stated that this will alleviate the financial burden for families allowing them to focus on their child's well-being

**Connecticut General Assembly, State Senator, Christine Cohen;** supports this bill sharing that her attention was drawn to this issue upon working with the Negrón family in her district whose 5-year-old daughter, Chloe, was diagnosed 1 year ago with juvenile Tay-Sachs disease, a rare, terminal, neurodegenerative disease. It is stated that while on the waitlist, these families are sometimes forced to forgo certain treatment options or sacrifice their savings, including their retirement, take time off from work, or leave their jobs to care for their children. It stated that reserving slots for these children who need at-home services, special therapies, and expensive equipment is not always covered by private insurance.

**Connecticut General Assembly, State Representative, Moira Rader;** supports giving priority access to the Katie Beckett Waiver for those on the waitlist with terminal illnesses. It is stated that her constituents, David and Rennie Negrón, drew attention to the challenges faced in caring for their daughter, Chloe while supporting their family and waiting for coverage that may not come before the end of her life. It is stated that the waiver, just out of the family's reach, would provide desperately needed coverage of uncovered medical expenses, therapies, equipment, nursing care, and end-of-life care.

**CT State Independent Living Council, Executive Director, Molly Cole;** supports the expansion of the waiver. It is stated that in 1981, their daughter, Mariyama, was the first child in CT to receive the waiver. It is shared that her daughter had very complex medical needs, a

life expectancy of 6 months, and many significant disabilities. It is stated these conditions required skilled nursing care, and they had reached the limit on their insurance (at the time). It is stated they had no way to give her the care she needed and when the Katie Beckett waiver program became available, it allowed them to stabilize her health and keep her at home and in her community. It is stated that Marie lived 18 years, passing away in 1995 and the waiver gave their entire family a gift.

**National Tay-Sachs & Allied Diseases Assoc. (NTSAD), Kathleen M. Flynn, CEO, and Diana Jussila, Dir. of Family Serv.;** supports access to the Katie Beckett waiver for children diagnosed with rare and life-limiting diseases. It is stated that providing home care for children living with a life-limiting illness has a significant impact on their quality of life, not only from a social-emotional perspective but also from maintaining health and preventing exposure to germs. It is stated that families must make difficult decisions on how they can manage that care while providing for the whole family financially and emotionally, especially if there are other children. It is stated, like other states, that they urge the state of Connecticut to restructure the process for the Katie Beckett Waiver program for families like the Negrons, whose children may not live long enough to receive the benefits of this program.

**Rare Disease Advisory Council, Member, Lesley Bennet;** supports this bill stating that the waitlist is as long as 5-7 years, which is often longer than the life expectancy of a child in desperate need of the covered services. It is stated that rare diseases are often degenerative, life-limiting conditions that cause severe neurologic impairments (including seizures), and a child diagnosed shortly after birth may only have a life expectancy of 2-4 years. It is also stated that other New England states such as MA, RI, ME, NH, NY, and VT do not have waiting lists for their Katie Beckett programs, and these states "fast-track" medically fragile children born with rare disorders or terminal illnesses. Additionally, it is stated that 37 other states prioritize services for these children in need of in-home nursing services, physical therapy support, respite services, and medical equipment or supplies that are often not covered by private insurance.

**Parent of a medically fragile child, Amy Bergerson;** supports the elimination of the waitlist for the Katie Beckett Waiver and gave [testimony](#) regarding her son and what they have gone through to get medical coverage through their employer-based insurance. It is stated that it is hard enough to have a sick child but having to prove over and over that he needs care should not be necessary. It is stated that Connecticut is currently failing the middle class that does not qualify for traditional Medicaid and yet is funding the program for our state.

**The parent of a child with Autism, Victoria Pommer;** supports the expansion of the waiver. It is stated that her own family found themselves being let down by the narrow scope of the waiver program when their then 3-year-old autistic son aged out of birth to three and the vital ABA therapy he was receiving was suddenly discontinued. It is stated that this therapy was not covered by their private health insurance, and they did not qualify for Medicaid. It is stated that they then learned about the Katie Beckett Waiver and thought their problems were solved until they were told he would be on a waitlist for 5-6 years, which was too much time for a young child with autism to go without therapy.

**Parents of a Child with a rare genetic disorder, William Vincent & Erin Wegner-Vincent;** support the expansion of the waiver to include their 5-year-old son, Turner, diagnosed with 16p12.2, CMT (Charcot Marie Tooth), who was added 2 weeks ago to the waitlist for Katie

Beckett Waiver. It is stated that their family discussed the lengths they will go to ensure their son gets what he needs while ensuring his sisters feel loved supported and valued. It is stated that Wegner-Vincent gave up job opportunities and advancing their career to ensure that they have the flexibility to take their son to his many appointments by picking up per diem shifts. It is stated that expanding this waiver is a recognition and acknowledgment of their son's disease and the impact that it has on him and his family.

**The following organizations and advocates have submitted written testimony in support of the bill.** It is stated support for the expansion of the waiver would improve care and outcomes for children with severe, terminal illnesses.

National Organization for Rare Disorders (NORD), State Policy Manager, Carolyn G. Sheridan

National Organization for Rare Disorders (NORD), Policy Analyst, Mason Barrett, Mount Sinai Department of Genetics and Genomic Sciences, Assistant Professor of Clinical Genetics, Dr. Cassie S. Mintz

Mount Sinai Department of Genetics and Genomic Sciences, Associate Professor, Dr. Jaya Ganesh

Mount Sinai Department of Genetics and Genomic Sciences, Assistant Professor, Randi Zinberg

Urban Health Plan, Dr. Richard Torres, MD, MPH, FACP, FACGS, Medical Director Grandmother and caregiver for grandson, Jack, Jane Walker

Parents of Elizabeth, a child with Sanfilippo Syndrome, Josephine Shamaly & Kerry Shamaly

**The following professional clinicians and providers have submitted written testimony in support of this bill.** It is stated expanding the waiver to include children with neurodegenerative, terminal illness, will be beneficial for children and their families. It is stated that these children require the care of multiple medical and therapy specialists, have frequent healthcare & ED visits, and are at high risk for prolonged and costly hospitalizations often not covered by private insurance creating financial strain and medical debt. It is stated that receiving care at home is particularly critical for the child, lessening the burden on the family, and allowing the child to have the highest quality of life possible. It is stated the sort of safety net contemplated by this legislation is precisely what is needed in such circumstances.

Yale School of Medicine, Assoc. Prof. of Pediatrics & Emerg.Med, Dr. Paul Aronson, MD

Yale New Haven Health System, Pediatric Neurologist, Dr. Kathleen Cardinale, MD,

Yale University, Professor of Medicine and Hospice Physician, Dr. Nicholas Christakis, MD

Yale New Haven, LCSW, Kelli Garrington

Yale Health Pediatrics, Pediatric Nurse Practitioner, Susan Marchitto

Yale Health, Manager of Claims & Referrals, Lindsay Rodriguez

Assistant Professor & Internal Medicine/Nephrology, Dr. Dinushika Mohottige, MD

Dr. of Chiropractic, Dr. Paul Heeren, D.C

PCP & Researcher, Professor & Dean, Carol Horowitz

Speech & Language Pathologist, Keri Climie

Pediatric Nurse, Patrick Madley, MSN, RN

Coastal KIDS Physical Therapy, CEO, Dr. Kali Penders, D.Pt.

Rehabilitation Associates of CT, Pediatric Physical Therapist, Patricia Plunkett

Speech Language Pathologist, Paulina Serafin

Nurse for 35 years, Kristin Smith

Guilford Public Schools, Occupational Therapist, Stephanie Albino  
Guilford Public Schools, School Nurse, Eileen Borowiec  
Guilford Board of Education, Dr. Cheryl Briganti  
Guilford Public Schools, Speech Language Pathologist, Clare Gravina  
Guilford Public Schools, Pre-K Special Education Teacher, Lori Luyckx  
Guilford Lakes School, Special Education Teacher, Christine Paolini

**The following individuals have submitted written testimony in support of this bill.**

Testimony has been submitted by family members and friends of Chloe Negrón requesting expansion of the waitlist or establishing priorities for those with terminal illness. It is stated that Chloe was diagnosed with juvenile Tay Sachs disease, a neurodegenerative terminal illness, approximately 1 year ago after an 18-month diagnosis process. Family members gave testimony of the tragic implications of being on the waitlist and unable to access additional services, although the family has already spent thousands of dollars on her care. It is stated that family members believe they will be unable to financially sustain her upcoming medical needs. It is also stated that providers have suggested they move to another state without a waitlist to receive care. Lastly, it is stated that Medicaid supplemental insurance is critical for families dealing with a medically fragile child that would be made possible by the expansion of the waiver and reduction of the waitlist or providing slots for those children with a rare neurodegenerative, terminal disease.

[Father of Chloe, David Negrón](#)

[Mother of Chloe, Rennie Negrón](#)

[Grandmother of Chloe, Norma Negrón](#)

[Grandfather of Chloe, Michael Negrón](#)

[Great-grandmother of Chloe, Gerda Negrón,](#)

[Great grandfather \(age 92\) of Chloe, Jose Negrón](#)

[Family member, Justin Negrón](#)

[Family member, Kevin Negrón](#)

[Family member, Kimberly Negrón](#)

[Uncle of Chloe Steven Negrón](#)

[Family friend, Lillian Cruz](#)

[Family friends, Linda Danz & Paul Fairall](#)

[Family friend, Maria Denizard](#)

[Co-Chair, Guilford Special Ed PTO, Kristy Faulkner](#)

[Family friends, Julie Fitzpatrick-Palumbo & Peter Palumbo](#)

[Family friend, Kristin Foster](#)

[Assistant Professor of Neuroscience & Uncle of Chloe, Dr. Eduardo Gallo](#)

[Family friend, Emily Gallo](#)

[Family member, Carly Giannone](#)

[Family member, Jonathan Giannone](#)

[Professor of Music \(retired\), Guilford, Kathryn Taylor Haggans](#)

[Member, Christ Episcopal Church, Guilford, Jennifer Huebner](#)

[Family friend, Donna LaFata](#)

[Family friend, Patricia Lawn](#)

[Medical student & family friend, Sang Won Lee](#)

[Co-founder, Cure & Action for Tay-Sachs \(CATS\) Foundation and family friend, Daniel Lewi](#)

[Former Owner & CEO, of The Bilco Company & family friend, Robert Lyons, Jr.](#)

[Work colleague & family friend, Devin Madden](#)

Family friend, Brian McGlone  
Family friend, Susan McGlone  
Family friend, Reshma Mehta  
Family friend, Karen Mills  
Data scientist, Yale University & family friend, Elizabeth Nicoll  
Uncle of Chloe, Daniel Pimentel  
Friend & parent of a child with autism, Victoria Pommer  
Priest, Christ Episcopal Church, Guilford, The Rev. Mary Anne Osborn  
Member, Christ Episcopal Church, Guilford, David Oshana  
Family friend, Jerry Pastre  
Uncle of Chloe, Daniel Pimentel  
Aunt of Chloe, Debra Pimentel  
Episcopal Church in CT, Rev. Felix Rivera  
Family friend, Dr. Jen Rockfeld  
Family friend, Joe Salem  
Family friend, Maria Secki  
An extended family member of Chloe and California Grandfather of Avery, a child with a severely disabling, terminal illness, Jesse Slome  
Family friend and parent of a child with autism, Margaret Teape

**The following individuals submitted written testimony in support of this bill.** It is stated that this bill will assist Connecticut residents on the waitlist.

David Addams	Jessica Matthias
Maureen Afeltra	Priscilla McCue
Helen Bartek	Shannon Panda
Regis Body	Jaclyn Paulsen
Donna Carlucci	James Pommer
Marion Carlucci	Lana Rowan
Jerry Collazo	Jake Rinaldi
Monica Cretella	Laura Rinaldi
Anthony Dellicurti	Ray Rinaldi
Barbara Dellicurti	Anthony Schreck
Patricia Frattaroli	Sallie Schwartz
Paul Gebauer	Winnie Seibert
Claudia Grazioso	Robert Thorsen
Nicole Grotheer	Michael Yuhas
Caroline Herrick	Nancy Yuhas
Vinit Jagdish	

**Three people have submitted written testimony anonymously in support of this bill.**

#### **NATURE AND SOURCES OF OPPOSITION:**

None expressed.

**Reported by: Rebecca McClanahan**

**Date: March 27, 2024**