



Alone we are rare. Together we are strong.®

March 6, 2024

The Honorable Matthew Lesser  
Co-Chair, Committee on Human Services  
Legislative Office Building, Rm. 2800  
Hartford, CT 06106

The Honorable Jillian Gilcrest  
Co-Chair, Committee on Human Services  
Legislative Office Building, Rm. 2002  
Hartford, CT 06106

**Re: NORD Supports for Raised S.B No. 206, An Act Concerning the Expansion of the Katie Beckett Wavier Program**

Dear Senator Lesser and Representative Gilcrest,

The National Organization for Rare Disorders® (NORD) writes today in support of [Raised S.B. No. 206 \(S.B. No. 206\)](#), legislation that directs the State's Medicaid Program (HUSKY) to expand the Katie Beckett Wavier program to reduce the waiting list and the time children spend waiting to be able to receive care in the comfort of their own home.

NORD is a federation of non-profits and health organizations dedicated to improving the health and wellbeing of people living with rare diseases. Cumulatively, there are more than 10,000 rare diseases affecting more than 30 million Americans. It is estimated that half of all people living with a rare disease are children and many rare diseases come with or lead to physical disability that require consistent care. For over 40 years, NORD has been at the forefront of advocacy for policies and programs, such as the Katie Beckett Wavier Program and other home-and-community-based services (HCBS) waivers, that improve the health and well-being of people with rare diseases.

Under the Katie Beckett waiver program, medically fragile children who would otherwise require round-the-clock care in an inpatient setting are able to receive the same, high-quality care in the home. To qualify, individuals must be under the age of 21, have a physical disability and would otherwise receive care in an institutional setting.<sup>1</sup> The Katie Beckett waiver is one of the few non-income restricted Medicaid waivers available to Connecticut families, as the waiver exclusively considers the child's income rather than the parent income, meaning all Connecticut families are eligible to apply.

Unfortunately, applications for the program have historically outpaced the limited appropriations the program currently receives. Though the program is authorized to provide care to 300 children in Connecticut, a 2023 survey conducted by KFF found there are an additional 291 individuals on the waiting list. Time on the waitlist has traditionally ranged from 6-7 years.<sup>2</sup>

This legislation could reduce the time spent on the waiting list by directing the HUSKY program to utilize available appropriations to expand the program to reduce the amount of time children spend waiting to receive care in a more familiar and comfortable setting. In addition to providing more timely access to

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<sup>1</sup>MyPlaceCT. (N.D.). *Assistance for individuals 21 and younger who have a physical disability*. Connecticut Department of Social Services. <https://www.myplacect.org/services-and-supports/financial-options/katie-beckett-waiver/>

<sup>2</sup> KFF. (2023). *Medicaid HCBS waiver waiting list enrollment, by target population and whether states screen for eligibility*. [Link](#).

care, expansion of the waiver could ameliorate some of the financial burden on parents of children with special health care needs. A 2019 survey found that 81% of parents of children with special health care needs on Medicaid said that out-of-pocket costs are always reasonable, compared to only 19% of respondents with private insurance. Further, only 3% of respondents with children covered by Medicaid had out-of-pocket medical expenses more than \$1,000, compared to 38% of respondents with private insurance.<sup>3</sup>

NORD is proud to support S.B. No. 206 and the Sponsors' intent to see the number of children on the waiting list for these services reduced. We hope to be considered a resource as the bill moves through the legislative process and stand ready to offer input and guidance on implementation ensuring the expansion is done in an equitable way that will benefit all patients.

Sincerely,



**Carolyn G. Sheridan, MPH**  
State Policy Manager, Eastern Region  
National Organization for Rare Disorders®



**Mason Barrett**  
Policy Analyst  
National Organization for Rare Disorders®

CC:  
Chandra Persaud, Clerk for Joint Committee on Human Services  
Matt Plourd, Legislative Aide for Sen. Matt Lesser

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<sup>3</sup> Williams, Elizabeth and Musumeci, MaryBeth. KFF. (Oct. 4, 2021). *Children with special health care needs: coverage, affordability and HCBS access.* [LINK](#).