

June 24, 2024

Madame Chair and Members of the Committee:

My name is Kathy Keck. As you have heard in previous testimony, I am a mom of 5 kids. Three have significant developmental and medically complex disabilities.

I appreciate your time and the progress that has been made on some issues.

As a parent of children with complex medical needs, finding the time and energy to testify on systemic issues affecting our family and so many other families like ours has not been easy. Private Citizens, like myself, who come to testify are the only people at the table who are not paid to be present but also have the additional responsibility of ensuring adequate care for our medically complex children to participate. We are also the parties most directly impacted by the topics brought forward but represent the minority of voices being heard. I respectfully ask this committee going forward to designate a public comment time specifically for private citizen and allowing 5-7 minutes for everyone who takes the time to testify to allow for a clearer understanding of the issues directly impacting the most vulnerable.

There has been progress on some issues that I, and others, have brought before you over the last 6 years. The increased rate of Specialized Medical Care is one of the positive changes.

As most of you are aware, our precious daughter Mireya lost her fight in January of 2024.



Increases in the Specialized Medical Care rate allowed our daughter more consistent nursing in the final months of her life. She was able to die with dignity in her home, in my arms. Losing a child is every parent's worst nightmare. The importance of palliative and hospice care at the end of life are critical services to maintain the choice to finish life's race in the manor that ensures dignity and quality of life until the last breath.

In my last testimony before this committee in October of 2023 I provide a timeline and data on home modifications. I have reattached my testimony here: [Bob Bethel Oct 2023 Testimony- KK](#). I will once again emphasize that it should not take close to 2 years to get a home modification approved. My daughter was in hospice care when Sunflower finally approved our full home modification request. The persistent unwillingness and lack of empathy resulted in an appeal that lasted almost 24 months and got hung up on a necessary accommodation (removing walls of an existing closet) that would have allowed enough foot space for Mireya, and all her equipment, in her room connected to an accessible bathroom. ***The cost of time, energy and resources spent on appeals, meetings, phone calls and emails were exceedingly more expensive than the actual work being requested. The current process is so long and arduous that members give up. In our case, we literally fought until our daughter's death was imminent, to get approval- almost two years since beginning. This is shameful.***

The process and accountability for assistive services such as home modifications, specialized medical equipment and vehicle modifications needs revamped. I know and appreciate that KDADS is working on a new policy to help improve this process and I urge this committee to follow through with the implementation and oversight of this process as it crosses both KDADS and KDHE for accountability and follow through with the MCO's to ensure no other individual or family must experience the nightmare we were put through.

Thank you for your time and I will be available for any questions.
Kathy Keck

Attachment 1- Timeline and Topics of Prior Testimony

August 26, 2019

- 1.) Care Crisis to include:
 - a. Insufficient reimbursement rate for Specialized Medical Care
 - b. Training issues
 - c. Lack of Network Adequacy
 - d. Lack of Accountability for MCO's
- 2.) Care Coordination
- 3.) Denials for Service and Appeals

November 18, 2019

- 1.) Increasing Specialized Medical Rate

Feb 28, 2020

- 1.) Increase the reimbursement rate for Specialized Medical Service from \$31.08/hr to \$48/hr
- 2.) Ensure rate increases go toward nurses, training and provide an administrative cap
- 3.) Develop accountability measures for MCO's and providers to increase utilization rates
- 4.) Encourage KDADS to implement recommendations by the TA waiver workgroup

April 22, 2011

- 1.) Increase for Specialized Medical Care
- 2.) Network Adequacy

August 11, 2021

- 1.) Increase the rate for Specialized Medical Care,

- 2.) Expand the SMC increase across all waivers,
- 3.) Accountability to service providers to assure this increase in being passed down to the nurses and;
- 4.) A living wage for Direct Support Professionals.

February 4, 2022

- 1.) Increasing rates for Personal Attendant Services and Specialized Medical Care are steps in the right direction.
- 2.) Benefits are also needed- health insurance the ability to earn leave time, etc. Benefits standard in most industries.
- 3.) Accountability processes need to be put in place to ensure these allocations go to direct workers and nurses, to achieve the desired outcome. Rate increases should not be absorbed into other budgetary baseline items.
- 4.) Accountability measures to ensure MCO's, through providers, deliver services that are medically required and approved are delivered.

September 26, 2022

- 1.) Address the systemic issue and hold providers, MCO's and the State accountable for not providing medically necessary nursing care for children on the TA waiver. This should include caps on allowable administrative costs for providers. If nurses are making an average of \$28/hr and the reimbursement rate is \$47/hr that means 59.6% is being used for administrative cost.
- 2.) Research and determine a way for Specialized Medical Care to be a self-directed service.
- 3.) Fund a state-wide impact campaign to help educate people on the critical roles that nurses provide to children on the TA waiver as well as adults who require personal care assistance.

November 2, 2022

- 1.) Network inadequacy and workforce crisis
The waitlist needs to be eliminated but we cannot ignore the current capacity issues, an inadequate workforce across ALL the waivers. To address this issue the priorities should include 1.) competitive wages by increased Medicaid reimbursement rates, through MCO and provider caps and accountability, directing the funds to the workers providing the care and 2.) competitive worker benefits such as health insurance, sick/vacation days and retirements benefits

April 21, 2023

- 1.) Durable Medical Equipment (DME) and:
- 2.) Home Modifications.

October 11, 2023

- 1.) Home Modifications