

Bob Bethel Committee on HCBS and KanCare Oversight
Testimony by Kathy Keck- Parent advocate and concerned citizen
April 20, 2022

Good morning, Mrs Chairman and Members of the Committee. Thank you for allowing me to come before you today. My name is Kathy Keck. I am a mom of five kids, three with significant developmental and medically complex disabilities.

I feel like a broken record but am dedicated to advocating for change until we resolve the care crisis and capacity crisis. Increasing rates for Personal Attendant Services and Specialized Medical Care are steps in the right direction. Other benefits are also needed- health insurance the ability to earn leave time, etc. Benefits standard in most industries. In addition, 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. Accountability measures to ensure MCO's, through providers, deliver services that are medically required and approved are delivered.

Families, like ours, and others you met at previous committee meeting, continue to be physically and emotionally EXHAUSTED. Parents and families are paying the price for being the safety net in a system that has a capacity crisis. Changes to improve these dilemmas are needed immediately.

Families are often forced to leave employment to cover the gaps in care, removing on parent from being a tax paying citizen. If my daughter has a medical appointment on a day we don't have a nurse it requires two people to take her to an appointment. One drives and the other provides lifesaving care such as suctioning while traveling. This crisis has left me unable to rejoin the workforce and results in my husband taking leave. It is UNACCEPTABLE that this crisis in care is affecting the employment of both parents! And this crisis is not limited to my daughter but also my son who is on the IDD waiver. The IDD waiver provides the lowest reimbursement to personal care attendants making it nearly impossible to cover his needed and approved hours.

My request today:

- Hold a special Bob Bethel Committee listening session to hear solely from parents, families and self-advocates on system concerns and brainstormed solutions. This committee was developed and designed to inform the legislature of the impact of implementation of KANCARE. Based on the typical design of these meetings 90 % of the time allocated is reports from state officials, MCO's and providers with a financial interest in the effectiveness and efficiency of how Kancare is going. Typically 1.5 hours or less of each meeting is allocated for public comment which includes, private citizen, and concerned agencies.
- Attend community meetings, when invited, hosted by your constituents on issues they face daily.
- Commit to watching the Global Online Premiere May 20-26 of a documentary: UNSEEN- How We're Failing Parent Caregivers & Why It Matters. Tax paying families, that each of you represent are affected by this. I guarantee that none of us will escape the effects of a disability at some point in our lives.

Please remember these "issues" are ***our everyday life***. Sleepless nights, missed wages, multiple doctor appointments, sounds of medical equipment 24 hours a day, over-used bodies from lifting and transferring and missed social events. Families are committed to their loved ones, progress has been made through the years on behalf of families and those with complex needs. But we have more work to do to resolve the care

crisis and improve systems so that quality care can be provided and families can get the support they need to allow them to contribute and thrive in their communities.

Thank you for your time and consideration.

My Best,

Kathy Keck

785-633-2836

kappylight@yahoo.com