

Phaedra A. Moll

Good morning members of the Bob Bethell Joint Committee on Home and Community Based Services and KanCare Oversight,

Thank you for the opportunity to share my story with you today. I hope to reveal to you that because of KanCare's investment in me, I am a healthier person than I was when I first enrolled in the program in 2013. As a direct result in my plan of care these past four years, I am now able to work part-time as a Peer Support Specialist at Johnson County Mental Health in Shawnee, KS.

Four years ago I was hit by another driver when his vehicle T-boned my driver's door. It was a very unfortunate accident that rendered me unable to work for 3 years, and I am now only able to work part-time. I had extreme sensory issues as even a small amount of light or sound would cause my already severe migraines to become unbearable.

I was diagnosed with a Traumatic Brain Injury, impacting cognitive functioning and rendering me with severe chronic pain. Over the next few months and multiple visits to the neurologist, I found myself out of work and home-bound. Three years later I was finally able to return to work, working only about 8 hours a week. Even then, I called in sick often due to the massive migraines I continued to rival.

This has gradually improved over the past year, allowing me to now work closer to 20 hours a week.

I have learned and experienced how brain injuries upset the chemistry of the brain, creating challenges to overall mental wellness. So during the past four years, I have fought both physical and mental obstacles.

KanCare-UHC provided me with many resources, especially since I qualified for the TBI Waiver. I feel I was more fortunate than most because of this waiver, allowing me to receive care I wouldn't have otherwise been able to access. Because my cognitive functioning was compromised, my basic needs to survive, financially and physically were threatened. It took weeks, not days, to put my thoughts together. I had no support network to guide me through the process of accessing services and help.

Several times it took me months to comprehend what someone had said to me. While I sat in silence;

in the dark, aching, I kept trying to figure out how to get better. This was not the life I wanted to live. This was not the legacy I wanted to leave. I was not going to go down without a fight. There was no one available, in or out of the government, to guide me. Days turned into weeks, weeks into months, and after about 8 months I was approved for KanCare. Then it was nearly another year and two appeals before I was approved for the TBI waiver. I moved slowly, which is partly why services were slow to becoming available to me.

Key areas of KanCare-UHC I feel impacted my life, both positively and negatively are as follows:

Transportation – a super helpful tool! My only frustration was, and is, the 3-day notice required to schedule a ride was/is not always an option when there is an emergent situation. This includes visits to the ED, Critical Care, and pain management clinics.

Socialization – It would have been nice to have someone walk beside me at the various stages in this manner, whether it would have been sitting quietly, graduating to having conversations, moving on to stepping out for a walk, and eventually going out for a quick bite to eat. The lack of social interaction challenged me emotionally to a length words fail to describe. I wonder if without that interaction and distraction, the physical pain was sometimes pronounced, causing hospital stays and trips to the ED.

Recreation – As my health improved, I needed to experience social and recreational events, to laugh. The “world’s best medicine”. Again, having someone assist with making connections and getting out to discover new limitations, and help me stretch myself, was – and is – a necessary part of the overall recovery and wellness scaffolding.

Peer Support – This person was a help to me. I believe having someone who had walked this road before me was a critical element in my recovery. Although, I did not see her nearly often enough and I did a very poor job of expressing my interest in seeing her more. I figured there were others who were worse off than me, so I didn’t want to be a burden. I needed human contact, and would have liked this person to be a regular part of each week, rather than just occasional. In my opinion: *Living life*

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through friends and socialization is the bedrock for finding purpose to fight toward health and wellness.

Doctor & Treatment Options – On the most part I have been very pleased with the doctors and treatments I have had access to over the past 4 years. The two areas of frustration have been finding a dentist, getting my dental care needs met; and finding a psychiatrist who accepts KanCare-UHC and also has openings. Both of these areas have the potential of making, or breaking, a person's health – both physically and emotionally. We do not have a powerful enough platform for proper dental care, which can impact other organs of the body and our self-esteem. The right medications and a doctor who specializes in medication management is a key to all of us who suffer from chronic pain and/or mental health.

As I stated, I am now a Peer Support Specialist. Figuring out my new role in life has been a journey.

Funding for that journey has been critical. Without investing in my life, and those like mine, the path toward health and wellness seems impossible. Yes, I am advocating funding for positions like the one I hold at this time. Peer Support can provide the roles of almost all areas of weakness I feel are in the current system of care. Kansas is a state that once led the nation in ground-breaking mental health initiatives but is now lagging behind most. Those of us who suffer with any type of mental challenge, including chronic pain, stress and anxiety, may give up when we hit that proverbial wall and end up on the receiving end of social services. We need each other to help discover something that will motivate us toward a better life. For me, that pilgrimage started with my treatment team and the book, *Pathways to Hope*, prepared by the University of Kansas. A tool no longer available due to funding cuts.

As time goes on, my benefits are changing in a way that concerns me. If the only attention a person gets is at the doctor's office, because that is all the state pays for, then he or she will go there more often. This will drive up medical costs. I had issues with not being institutionalized because when I

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was inpatient I had “friends”, activities and people taking care of me. It was judgement free. I felt safer from myself and my fears. It was like a family, really. The vested interest by the insurance companies and my care providers has driven down the cost of my health care as time has gone on, allowing me to become an asset in the socio-economic fabric of our state. I am grateful I was granted access to KanCare-UHC and the TBI Waiver, because without it I wouldn't be working and weaning off assistance, but would still be fully dependent upon the social services of Kansas and federal governments.

Bottom line, I ask you to re-examine the cost-benefit analysis of investing in people and support options during difficult medical and mental health times of need. Thank you for the opportunity to share my thoughts with you today.