

Bethel Joint Committee on HCBS and KanCare

April 20, 2022

Testimonial presented by Michelle Quinn

When I was a child, I used to play a game in the swimming pool with my friends and cousins. Maybe you've played this, as well. We would hold our breath, gently sink under the water, find each other, and then pretend to drink tea and try to talk to each other. Then one of us, running out of air, would point up and push off the bottom of the pool, signaling that we would meet "up top". We'd break the surface of the water laughing and would see how well we understood each other while under the water.

I'm here today, because I wanted to share how this scenario reminds me of what's it's like being a parent of a child with special needs. Instead of cool, crystal clear water, I'm in a murky, muddy lake. I'm treading water, reaching out for help, trying to find help for my child and my family; there are several others swimming in this lake with me. When I reach a point of exhaustion, and I simply must stop, I sink below the surface. When I go under, I frantically look around, hoping to find someone else, someone who understands that my family has reached the point of crisis. When I realize that I cannot see anyone else in the water, I scream out a message for help. But when I force myself up for air, I look around and see if anyone has heard me; has anyone understood my cry for help? There are a few there, watching me struggle in the water. They are resting comfortably in a nearby boat. There are life jackets sitting in the boat, unused. These people would throw out the life jackets to me, you see, and they want to; but there are rules to the process of providing this life saving device. They could bring the boat closer, and desire to do so (their hearts are in the right place, you know). But apparently you can't just go directly to those in need. And so, they sit, and they discuss how to help. At this point, I'm feeling hopeless and helpless. I've told them that I need help; I've asked them to throw the life preserver; I've screamed at them to bring the boat closer. Nothing happens. But still, I tread. Because my son is worth fighting for.

My family and I have been in crisis mode for quite a few years; however, it reached its tipping point last summer. My husband and I faced the difficult decision of applying for "crisis support", so that we could send our son to a psychiatric residential treatment facility (PRTF) to get the help he needed. It took lots of "proof", but we qualified. I knew we would. So then came a mountain of paperwork to apply to the facility of our choice. But, unfortunately, then came the denial from said facility, which happens to be the only one in the state that is appropriate for our son: LakeMary in Paola, KS. We applied again, and attempted to visit with someone besides the receptionist, but they did not return our calls, or respond to our e-mails. In the meantime, I was fielding weekly phone calls from the KanCare/Aetna case manager to determine on-going eligibility. This required relaying any adverse behaviors from the week, in detail, including how many minutes each behavioral episode lasted, what behaviors were exhibited, what strategy was attempted, etc. It was emotionally draining having to relive the experiences and continue to explain why our child was a behavioral nightmare requiring support outside of his own home. I was also challenged to try additional therapies, peer groups, resources, etc., that perhaps we hadn't considered. This was presented weekly during these phone calls. I reassured our Aetna case

manager that everything had been attempted, explained how they hadn't worked or weren't appropriate given our situation, and what additional options we had already tried. How we were supposed to participate in additional "activities" for my son was beyond me. Each week, aside from school, he had doctor's appointments, sometimes involving travel to Children's Mercy Hospital in the Kansas City area, and private occupational therapy an hour from our home. There wasn't room to add anything else. But, the case manager "had to" bring these up, as instructed to her by her supervisors. In addition, I was routinely encouraged to consider other PRTFs in the state. I explained why they weren't appropriate for our son, but it was brought up during every phone call, because "they had to". Finally, I succumbed to the pressure and called three additional facilities in Kansas, speaking with the directors of the program of each location. I laid out our son's diagnoses, his behaviors and then his developmental age, which quickly resulted in an explanation of why they would be unable to provide services in their facility given our son's level of need. This was incredibly frustrating to have to endure these "denials" even though I knew they were coming. The common explanation was lack of staff, or lack of available rooms.

After months of waiting, we finally heard about another option called Children's Residential. This was a new concept to us, and another challenge to face as a parent, because how do you choose another home for your child? But, we were desperate; we needed the help. Our family needed help because we were breaking. My husband and I were assured that we would retain parental rights, and could return our son to our home whenever we chose. So, we backed away from the PRTF approval and let it expire. I cannot express the relief of not having to manage those weekly phone calls! But, Children's Residential did not come as easily as we were led to believe. There were no available homes. But, we were encouraged to "think outside the box", and see what other solutions we might come up with.

Several weeks later, I received a call from our Aetna case manager with a promising idea. (Mind you, this was our third case manager in less than a year). She presented the "out of the box" option of combining HCBS with children's residential. So, essentially, our son would remain in our home the majority of the time, with the following change: the original PCS care + 5 respite nights per month under HCBS (with a minimum of 8 hours, maximum of 9 hours) *changed to*: PCS care + 5 respite nights per month under Children's Residential (with 24 hours respite away from home per "night"). So, rather than 40-45 hours respite per month (primarily in our home), we were looking at 120 hours respite per month (in the home of a family trained specifically to provide support to children with special needs). This was a phenomenal idea and our family would be the "guinea pigs" to try this out and see if this could be an option for other families going through similar situations. The 40-45 hour respite option we had been using was really more like 18 hours a month at best, zero hours at the worst. We just couldn't get it arranged with our staff, and most of the time, it was more comfortable for them to provide this overnight respite in our home. So, it wasn't much "respite" for us at all. This combination idea presented to us was perfect. The foster agency we had talked with previously when considering children's residential found a family that would work perfectly for our son; and this option would work well for them, as they were unable to take on a "full-time" children's residential child. The next mountain of paperwork was completed, and we arranged a meeting with this new family. It was truly a great match! Even knowing all of this, my husband and I were emotional to initiate this new normal. Our son was emotional, as well, as any

change in routine is a struggle for him. But we moved forward knowing this was best not only for our son, but for our three other children at home that needed more from their parents.

I spent time on the phone with the foster agency and our Aetna case manager learning how to manage PCS workers and Children's Residential. This was necessary in order to accurately clock in our PCS workers without doubling up on Children's Residential days. As I manage all of our son's workers, this was an easy adjustment. I was required to e-mail the foster agency the dates that my son would be with the foster family, so they would know ahead of time. This went on without a hitch for three weeks, for a total of 4 nights of Children's Residential used.

Then came the message from the foster agency that the arrangement would not work after all, as KDADS determined that there can't be two different billing codes, with one coming from HCBS and one coming from the foster agency. Essentially, my son couldn't continue this arrangement because KDADS decided they couldn't, or wouldn't, figure out a way to bill for these two separate services. Finally, I was on a phone call with three individuals from Aetna apologizing for moving forward without proper authorization from the state.

I would like to present to you that this option is an excellent opportunity for the state of Kansas to step out as a leader in this nation-wide crisis in mental health/behavioral health services. There is an abundance of children without proper services; and there's a family struggling to survive for each of these children. There are too few hospital beds, PRTFs, and special needs foster homes to meet the demand. It's entirely insurmountable. Governor Kelly recently announced the new acute psychiatric hospital in Hays that will be a 14 bed treatment facility. 14 beds! 14 children! That doesn't even begin to touch the problem. But the solution that our family had so briefly? That's a real solution. Think of the number of families this would impact! There are foster families out there that are unable to accept a full-time child; but 5 24-hour days per month may be entirely more feasible! And families in crisis with a child with special needs receiving 120 hours per month of respite? This equals real and true respite, enabling families to keep their child in their home for the majority of the time, without having to move their child into a facility, or find another family for their child to live with on a permanent basis. What steps would need to be taken in order for this to happen? I'm proposing that this committee work through the red tape here to come up with a billing solution to enable this option for families in crisis. For the families on a wait list, this could be the alternative that gives hope. For the state of Kansas, this could be the thing that puts us on the map for having actually provided a real solution addressing the mental health crisis across the country. I urge you to take this into serious consideration!

Thank you for your time and for your willingness to serve on this important committee.