

To: Bob Bethell Joint Committee on Home and Community Based Services and KanCare Oversight

From: Mark Dugan

Date: April 16, 2018

Subject: Traumatic Brain Injury Waiver

As some of you may know on April 28 last year, my daughter Joyce suffered a traumatic brain injury falling out of a PowerWheels car in our driveway.

Joyce is doing well today. We feel lucky and blessed. She's going to have a good life with lots of blessings and joy. She will never be just like she was before the accident but we are optimistic, with God's grace, that she can live a full and meaningful life.

My testimony today is not about Joyce but rather about some of the kids and families that we've met along our journey and how a few tweaks in the Traumatic Brain Injury Waiver could make a big difference to kids and families for generations.

For a bit of background, after Joyce's fall, she was rushed into emergency surgery to relieve pressure from her brain. Joyce then spent 20 days in the ICU at Wesley Hospital in Wichita and then transferred to Madonna Rehabilitation Hospital in Lincoln, Nebraska. Joyce was an inpatient at Madonna for close to three months. Following her inpatient treatment at Madonna, Joyce spent 5 months in an outpatient day program at Ability KC, located in Kansas City, MO. She continues with outpatient therapy in Wichita today.

During these times, we met lots of families that shared our experiences. One young man I want to tell you about is a 12-year-old boy named Mason.

One day, an otherwise healthy Mason began having seizures. After lots of attempts to treat his condition with medicine, the doctors decided they needed to operate on a part of his brain that was not growing. During surgery, Mason had a major stroke. Thankfully the doctors were able to save Mason but he had a significant brain injury due to the blood loss during the stroke.

Mason was an inpatient at Madonna when we arrived. He is the 3rd of five kids from a small town in Nebraska. His family farmed for a living. We grew very close with his family, especially his mom Lindy.

One of my favorite moments from Madonna was when I was pitching wiffle balls to Mason (like Joyce he only has full use of one arm) in the indoor gym. Mason and I got in trouble from the head nurse because other patients in the hospital were a little annoyed with our loud trash talking throughout the game. Mason was so proud every time he cranked a ball past the swingset and wasn't afraid to let me know it.

Mason's insurance covered the entirety of his inpatient stay at Madonna. But when he was discharged is when the challenges began. **Mason's insurance had a cap on outpatient therapy visits for the year. Something like 45 outpatient visits per year.**

Back to Joyce's experience for a moment so you understand why Mason's predicament is such a problem.

After her brain injury, it was as if we watched Joyce have a 3 year development process in 6 months' time. She had to learn to eat, to talk, to walk. During her outpatient program in KC, she had at least three separate therapies a day for 4-5 days per week (15 billable sessions per week). If Joyce's insurance was similar to Mason's she would have expired her insurance benefits 3 weeks after leaving Madonna in July.

Here's some context for how expensive these services would be to pay out of pocket. Therapists bill between \$100-\$150/hour for their services. Insurance companies negotiate a discount, but therapists typically don't honor it for individuals. **If you assume a rate of \$120/hour of intensive outpatient therapy for six months, this would cost an individual \$46,800.**

Mason's family was not able to afford such onerous out of pocket expenses, just like about every other Kansas family.

Why is this so devastating? Why is it so important to have intensive outpatient care after a brain injury? Most research indicates that the first 18 months, particularly for young people, is when the brain does the most healing and rewiring to gain functionality.

Fortunately for Joyce - Kansas BCBS does not have a similar cap in physical and occupational therapies, though they do have a speech cap and cognitive exclusion. And we are beyond grateful for the folks at Blue Cross.

But what if Mason lived in Kansas? And we have come to know several kids in Mason's situation right here in our state. **He would qualify for the Traumatic Brain Injury waiver, right? Unfortunately not. For two reasons.**

First, for reasons no one can seem to explain, eligibility for the TBI waiver does not begin until the age of 16. After talking to agency personnel, the best guess is that it was part of an initial compromise to pass the TBI legislation. There appears to be no medical or other public policy reasons to restrict eligibility to the ages of 16-65.

Second, the TBI waiver is reserved to injuries acquired from external physical force. This would exclude Mason because his brain was injured through a stroke, not an external physical force.

When Karissa and I visited with our ER doctor who had ordered an MRI, in one of the more difficult conversations we had, she solemnly shared with us that Joyce's long-term injury would be "stroke-like." As we've come to know kids like Mason and others with acquired brain injuries, their recovery needs and protocols are close to identical to Joyce's TBI protocol.

So, what can you do?

Place a proviso in the 2018 omnibus bill that corrects the current policies limiting eligibility for the TBI waiver. I have included draft language below.

For background, the TBI Waiver is one of the best dollar for dollar programs in the state. The TBI waiver is a time limited, “rehabilitative waiver.” These folks with disabilities from their brain injuries, if not rehabilitated early, will undoubtedly qualify for Medicaid later in life – and likely for their whole life.

The good news from a budget perspective is the TBI waiver in Kansas is underutilized. While the agency would have the best numbers, there are several hundred slots that are funded and not being utilized. This proviso would not alter the currently funded number of slots for the agency, it would only expand the number of folks eligible to fill the currently available slots.

In closing, thank you for the difficult work you do. You struggle to balance the needs of many worthy causes.

As I started my testimony, this is not about my daughter Joyce, as she would not apply for these services. I do hope her story, and the story of our friend Mason, helps you to understand the gaps in the system and how some smart investments today can save the state major dollars down the road.

Brain Injury Waiver Proviso

To be attached to the KDADS line item funding Home and Community Based Services (HCBS) Waivers. Both KDADS and KDHE are listed because KDHE is the agency recognized by HHS and CMS as the single Medicaid agency, and KDHE has KDADS handle HCBS Waivers.

During fiscal year 2018, fiscal year 2019 and fiscal year 2020, notwithstanding any other provision of law, the Kansas Department of Aging and Disability Services and Kansas Department of Health and Environment shall expend moneys appropriated from the above line item to make modifications to the current Traumatic Brain Injury Home and Community Based Services Medicaid Waiver program which will result in lowering this Waiver’s entry age to birth and will add acquired brain injuries to this HCBS Waiver program.