



Testimony in Support of SB 160 –

Independent Ombudsman Bill

Chair Schmidt and Members of the Committee:

My name is Jill Bronaugh. Thank you for the time to let me speak in support of SB 160, which would create an independent Ombudsman program outside of state government, patterned after Wisconsin.

I am the parent of a beautiful son, Nicholas, who is 9 years old. I know you have a busy schedule, but if you would be so kind as to give me a little latitude to tell my story, it will help with your deliberations.

Nicholas has cerebral palsy and numerous significant health complications. He does not talk. He communicates with very limited sign language. He cannot stand without assistance. Nicholas is not able to walk on his own in any functional way. Nicholas has been on the TA Waiver for the past nine years. He needs skilled nursing hours to keep him out of even more expensive institutions. He requires around the clock tube feedings, complicated medication

administration, oxygen on occasion, is incontinent and is a constant aspiration risk. The skilled nursing hours allow me and my husband to work and obtain private insurance, which greatly reduces the costs Medicaid must cover, including his many hospitalizations.

From the beginning, KanCare has been a nightmare for us. It has been one fight after another to keep Nicholas' care consistent and in tact. I have had Sunflower, our KanCare MCO, harass and bully me multiple times. Federal laws have been ignored. Our rights have been violated. I was realistic enough to expect Sunflower to fight me on some services, as I understand every service dollar they deny is more profit for them.

I did not expect, however, for the state employee Ombudsman to be basically playing on the MCO's team. I tried to work with the Ombudsman's office in 2013-2014. Unfortunately, it became obvious that the relationship between the state employee Ombudsman, the MCO and KDADS was extremely incestuous. When I talked to the Ombudsman's office they never offered solutions or even concrete answers as to why something that had been previously covered was not being covered. The Ombudsman was incredibly vague, and I left each conversation with nothing resolved. At no time did I ever feel like the Ombudsman was on Team Nicholas.

The Ombudsman issue is all about trust. I and other loved ones of HCBS Waiver beneficiaries do not trust the structure of the office. I'm a well-educated mom. However, Kansans of all educational levels can see through the fact that having an employee of the state of Kansas try to act like your advocate and against their own employer and its MCO contractors is just that ... an "act." I and many others have given up on calling the current Ombudsman because they won't do the tough case work and appeals work that we desperately need. They never seem to be on our Team.

I was able to get a huge victory at the office of administrative appeals, reversing a 40-percent cut in hours. However, it had nothing to do with the Ombudsman because I had chosen to bypass her for this most recent fight. You see, they won't do the intensive cases like grievances and appeals. If they did, they would have a conflict of interest. I knew that Kansas and Sunflower were in violation of their provider agreements. Perhaps most importantly, I got lucky, because the Disability Rights Center of Kansas was able to squeeze my appeal into their busy docket. DRC Kansas represented me and we won our appeal. Due to limited resources, DRC can only do a few cases, but the need is gigantic. The difference between the Ombudsman office and DRC Kansas was literally like night and day. DRC provided professional, zealous advocacy for my case and knew all the ethical and professional ways to obtain a legal win for Nicholas. There was never a question that DRC was on Team Nicholas.

Let me just give you a taste of some of the challenges I have faced in fighting for Nicholas. As you hear these, imagine how hard it is knowing that the one place you are supposed to be able to turn to, the KanCare Ombudsman's office, is working for the very entity you are fighting.

- Our most recent fight for skilled nursing hours was a constant merry-go-round of phone calls and emails between KDADS, KDHE, and Sunflower. None would take responsibility for what was clearly a violation of the state's own CMS KanCare application.
- I was flat out lied to and told by the MCO that they wanted to "sit down and have a meeting to try to resolve some of our issues." (Yes, I have the voice mails to prove this). Then, when I met with them they instead wanted to conduct a "surprise" new assessment of Nicholas to cut his hours by 40 percent. Then they engaged in a cover up. It was intimidation, pure and simple.
- I was harassed and bullied in my own home by my MCO. It felt like retaliation.
- We've had an unlicensed nurse working in our home and a nurse announce that she was bipolar manic-depressive who told me she feared dropping our son down the stairs. We even had a nurse pass out in the back seat of my car because of overdosing on prescription drugs.

And that's just a taste of the challenges we've faced over the years on Team Nicholas.

Our family consists of myself, my husband, two teenaged children and Nicholas. My husband and I both work full-time to keep our family afloat. I manage Nicholas' many doctors, his

home health nurses, his various therapies and his educational needs. Some would argue that, in and of itself, is more than a full-time job. Throw in last year's appeal on top of everything else, and our stress level was off of the charts. Having a state employee Ombudsman's office with these inherent conflicts of interest makes my and other families' lives go from extremely stressful to almost unbearable.

We are no different than the thousands of other families in Kansas with children who have disabilities. It is not easy, though, and on most days I doubt myself. I feel like I'm not doing as much as I could, or I worry that I might make a wrong decision. I can't begin to describe the emotion and exhaustion that goes into taking care of our family.

Finally, I would like to correct one thing that was printed in the Capital Journal during the 2014 fight for Nicholas' incontinent supplies. The internal Ombudsman did not obtain those supplies. Coverage for the incontinent supplies was only restored after my testimony to the KanCare Oversight Committee and after the media started asking about it. The Capital Journal mistakenly made it sound like the internal Ombudsman office obtained the approval. That was not the case.

Passing SB 160 and creating a truly independent Ombudsman is one of several steps this Committee can and should take to help fix KanCare. Others include bringing back targeted case management (TCM), carving out the Waivers from KanCare entirely and restoring accountability.

I hope you will consider yourselves honorary members of Team Nicholas. I hope you will pass SB 160. I would stand for questions.