

Written Testimony in Support of SB 160

Chairperson Vicki Schmidt and members of the Committee:

My name is Johne Green. Thank you for allowing me to submit written testimony in support of SB 160. My daughter Naomi Green suffered a terrible anoxic brain injury as a complication for jaw surgery. This happened back in June of 2010. Naomi was in hospitals and rehab facilities for nine months before she came back home in February of 2011.

Naomi receives in-home services on the Physical Disability (PD) HCBS Waiver. This allows Naomi to stay at home and not have to be forced into a more expensive institution, like a nursing home. This makes the services more integrated, better for Naomi and better for tax payers, as in-home supports are also less costly on average. Her needs for PD Waiver services will be lifelong. Naomi's supports include feeding and grooming and physical therapies.

Sunflower State Health Plan, Naomi's MCO, tried to implement a gigantic reduction in her service hours. I feared this would had forced Naomi to live in an institution, a nursing home, because these cuts were so great.

When Sunflower first tried to cut Naomi's services, I and my husband, Oliver, dipped into our savings and hired a private attorney to help us advocate on this issue. We are retirees who live on a fixed income. It cost \$1,200, but thanks to the private attorney Sunflower did not go forward with the service cuts to Naomi.

However, this win was temporary. In January of 2015 Sunflower started pushing the cuts again. Naomi had been receiving 126 hours a week of attendant services from Sunflower. Sunflower tried to decrease this to a mere 70 hours a week.

I contacted the internal Ombudsman for KanCare. I want to stress that I have only good things to say about the internal Ombudsman. After all, the Ombudsman

provided me a referral to the Disability Rights Center of Kansas. It is my understanding that under SB 160 the current Ombudsman would and could continue to do what she does for clients. The current Ombudsman was courteous and helpful. However, what I needed was legally-based advocacy to fight the massive cuts to Naomi's service hours. I had received a "notice of action" that the cuts would happen unless an appeal was filed, which is an intensive legal type action. It is my understanding and experience that the internal Ombudsman does not handle these types of extensive appeals to the MCO, Administrative hearing or district court. So, the KanCare Ombudsman referred me to the Disability Rights Center of Kansas, who has attorneys and advocates on staff to help with disability rights legal work. I could not afford to pay another attorney \$1200 or more dollars to get Naomi's hours restored. I was very blessed with this situation. DRC Kansas is not able to take every case because of its limited resources and limited staffing. Thankfully, I was told my case arrived right when another case at DRC had settled, so DRC did take my case. Again, they can't provide this type of intensive legal services to everyone who calls. My timing was lucky. DRC assigned an attorney and advocate to my case, and challenged Sunflower's massive reduction of services for Naomi. A DRC attorney took the case and began drafting an appeal to Sunflower seeking to overturn its decision. DRC did not charge me a penny for the services they provided.

A DRC attorney worked up the appeal and filed it in February. The very next month Sunflower had backed down. Sunflower had decided that Naomi was entitled to these services after all. I honestly do not know what we would have done without DRC Kansas providing us this free intensive legal services and legally-based advocacy. Naomi services were not cut she was not forced into a nursing home.

The KanCare system is extremely confusing to parents and people with disabilities. We are retired and we were able to dip into our savings to hire the private attorney the first time. However, most people with disabilities and their families cannot do this. Also, you should not have to spend thousands of dollars out of your own pocket to get what your daughter is entitled to under the law.

The current KanCare system is hard to navigate. It is not fair to make families do the heavy lifting, like the appeals to hearing officers or district court, on their own. That is not justice. It is downright intimidating to get sent notices of action cutting plans of care without Kansas funding the legal services needed to fight those cuts. This is especially true for recipients of HCBS services. It only makes sense to have an agency outside of state government provide the advocacy and legal services needed to help families and people with disabilities fight these unjust cuts in services.

I see SB 160 as supporting the current Ombudsman and the role she plays. The current Ombudsman can continue to do the things she does to help provide information and referrals. Then this independent Ombudsman program will be there to provide the intensive legal and advocacy services and supports we need to fight these cuts in services and to obtain justice when our rights under Medicaid are violated. Just think. What if I would have called the Disability Rights Center of Kansas a few days later and they accepted a different case? I frankly don't know where our family would be if that had happened. I shudder at the thought. We would be in a very dark place.

I support SB 160 because it will set up a dedicated independent ombudsman program outside of state government in order to help with the legally-based advocacy needs, including but not limited to appeals to the MCOS, hearing officers and district court. It will help KanCare HCBS beneficiaries and it will not harm the current state employee Ombudsman. It will take "all hands on deck" to be able to help families and HCBS beneficiaries navigate the current confusing system and to obtain justice. SB 160 will create some much needed legally-based advocacy "hands" to be able to help us when we desperately need it most.

Thank you again for your favorable consideration of SB 160.

