

SB 332 TESTIMONIAL

Dear Committee Members,

Thank you for taking time to read my testimony on behalf of our family and others affected by disability. My name is Shari Sauer. I have worked in education for 30 years, currently as an elementary counselor, serving families with children, much like mine when they were little. My husband and I have three wonderful children; Grant, 22; Reed, 21; and Annie, 19. Annie is currently attending her first year at Kansas State University.

Grant and Reed were diagnosed with autism at ages 3 and 2 years old respectively. When they were young, they slept very little, were up shrieking, crying, jumping, running, and were inconsolable. My husband and I took turns sleeping, while we both continued to work and provide for our family. We researched forms of treatment and therapy, and were an integral part of creating an Autism program in the schools in Rice County. We have been exceedingly grateful for the services provided through the public school system. When the boys were 5 and 6 years old, neither were potty trained, and both were nonverbal, with disruptive and inappropriate behaviors intensifying, I was at the point of desperation, and reached out to our local Community Developmental Disability Organization (CDDO) for help. Thank goodness I didn't have to navigate KanCare at that time because it can be quite overwhelming! Within a day, through our local CDDO, our sons received crisis funding, were both put on the Mentally Retarded Developmental Disability (MRDD) Waiver, now referred to as the Intellectual/Developmental Disability (I/DD) Waiver, and began to receive Home and Community Based Services, which included In-Home Support and Respite. These two services largely contributed to our family's ability to remain together and sane. Our marriage is stronger today than ever, by the grace of God and support through Home and Community Based Services.

Within the last three years, we have finally realized that as we are aging, we are not as capable to care for our sons as we once were. Grant is 6 foot, and weighs over 250 pounds. He is extremely strong and nonverbal, so his disruptive behavior is his main form of communication. Reed is 6'4", weighs around 340 pounds, and is extremely strong as well. His language is mostly echolalic (repeating what he's heard), and communicates largely through inappropriate behavior also. Reed has partial complex seizures, in which he goes into an "uncontrolled rage" and hurts himself, belongings, and others. It is vital that both Grant and Reed have well trained, capable staff with them at all times. In September of 2015, Grant and Reed moved into an apartment through STARKEY in Wichita, and receive 24/7 supervision, as they are not able to care for themselves. They need assistance with hygiene, meals, medication, leisure activities, housekeeping, and transportation. They attend a day program called "Gateway", in which they are closely supervised and are able to participate in community outings such as going to the YMCA, fishing at the park, and even delivering "Meals on Wheels." We are extremely grateful for this opportunity for them. Without programs like STARKEY, I honestly don't know how our family would have survived.

While we are grateful for the adult day and residential programs offered through various agencies, much can be done to improve them. I am thankful to have been able to work on a task force, through the state, when KanCare was in its infancy; however, I felt like my voice truly didn't matter. The "State Machine" was simply too vast to even begin to improve services for those with Intellectual/Developmental Disabilities. My desire is to be able to work at a local level (the County Developmental Disability Organization) to improve, particularly, the housing opportunities available for adults in situations like our sons. Fortunately, our family has had a positive experience with KanCare. We have had two amazing Care Coordinators through United, who have worked alongside our family and our Caseworkers, through this journey from child to adult services. My belief is that family counseling, through this transition, would be helpful and appreciated. It seems logical that the local level, with local experts, not insurance, would be most able to provide the framework to assist individuals with I/DD to live life as independently and happily as anyone not affected by disability. My hope is that we, at the local level, can work together -- families and agencies -- to provide the very best for our loved ones.

As I read through SB 332, it seems to be written in a way that would support these goals. I appreciate the steps taken to continually raise the salary for people who work with our loved ones on a daily basis. They deserve to be well compensated. I strongly believe that when we offer better pay, we will get more highly qualified staff, something that is desperately needed, and that I am certain you would want for your own loved ones in this situation as well.

Again, thank you for taking time to read this. Please work to advance this bill, and carve out I/DD long-term supports and services from KanCare, and bring it back to the local level.

Shari and Shannon Sauer
8201 East Harry, #1501
Wichita, KS 67207
316-833-3293 (Shari)
316-833-3297 (Shannon)
Shari: sauers@usd385.org
Shannon: chiroshan78@gmail.com