

SB 332 TESTIMONIAL

Thank you to the members of this committee for your willingness to listen to those most affected by KanCare.

My name is Aldona Carney and my husband Pat, and I have been blessed with five children. Our youngest child Neil is a 23-year-old young man with severe autism. I have the same goals for all my children. I want them all to be happy, healthy, and live as independently as possible.

I would like to ask a favor of this committee. Please, bear with me as I ask you to walk in my shoes for a moment. How would you feel if a doctor told you that your child has a life-long disability that has no cure? Whether you like it or not that one moment will drastically change your life forever. Imagine if you will, that your child is non-verbal and requires 24/7 round the clock care for their health and safety. Try to envision your adult child needing all levels of very intimate care such as: dressing, bathing, shaving and cleaning them up after going to the bathroom. There is no cure and they will not grow out of the disability. Your child will need the same level of supports and services their entire life. Please continue to walk in my shoes just a little longer as you try repeatedly to express your concerns with the program that oversees helping your child make it through each day. You are constantly frustrated because no one appears to be listening or validating your concerns.

Ask any parent of a child with special needs what is one of their biggest fears & they will tell you about their concerns for their child when they are gone. Who will advocate for them? I often tell people that I pray to live one day longer than my son with autism, so I can be here to advocate for his needs. I want my son in a living situation that is stable and will protect his rights if my husband and I are not here to speak up for him. I'm not confident KanCare, and the private insurance companies it employs, will ever do that. Long-term supports for people with disabilities do not fit in a medical model of insurance approvals, denials and

appeals. Our state did it right for more than 25 years and created a stable system that families like mine could count on. The framework for that system still exists! Please listen to those of us who love and work with people who are intellectually and developmentally disabled on a daily basis and carve out the long-term supports and services from KanCare.

I made a promise to God and my son long ago that I would fight for him, protect him, be his voice, and always love him. I have no doubt that all of you would make those same promises. This committee has a wonderful opportunity to help me give Neil a voice. Please be a voice for all the voiceless!

Thank you so much for listening!

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