

To: Senator Vicki Schmidt, Chair
Members of Public Health and Welfare Committee
From: Kathleen Brennon, guardian

Date: February 5, 2018

Re: SB 332

Thank you for the opportunity to share with you my reasons why IDD services should not be a part of KanCare. I am a proud guardian of Lee. Our relationship began when he was four years old and I was his case manager. Lee became very special to me and when he turned 18 I became his guardian and have remained his guardian for the last 14 years. I have also worked in the IDD field for over 25 years.

KanCare has had little impact on Lee's life. He does have to meet with KanCare staff a few times a year, to his displeasure, but all in all there is little change. Let me make it clear there has been no improvement to his services or medical care as was promised with KanCare. I had no communication from the care coordinator until this last year. Thank goodness for Lee's IDD case manager or I would not have known who the care coordinator was. Every year I requested a copy of the Individualized Service Plan (ISP) but I never received a copy. In 2016, I asked the case manager to have the care coordinator send me the ISP. I was sent the signature page and told I needed to sign and return and then the care coordinator would send me the complete ISP; which of course I did not do. The care coordinator finally sent me the ISP. It had mistakes; including the wrong address for Lee. I did not receive a correct ISP until 2017. Four years after KanCare began, Lee finally has a care coordinator that will update and send me the ISP.

So other than having more meetings and people in the mix, Lee and I count as a negative, nothing has changed for Lee and I've had to deal with ill-informed, incompetent care coordinators, a frustration I would preferred not to have had.

Since the implementation of KanCare there has been a significant turnover in case management which concerns me since I rely a great deal on Lee's case manager to develop and monitor Lee's person centered support plan. I know that everyone believes their family member is unique, but in Lee's case it really is true. Identifying Lee's uniqueness and insuring that the services provided accommodates those needs is critical in Lee being happy and successful. Case management is a critical piece to achieving this. Case management also helps me balance my sometimes unrealistic expectations of service providers with realistic compromises.

Case managers who have left the field tell me the burden and utter confusion of navigating KanCare was one of the reasons they left. They also saw how case management was eliminated in other waivers and worried that would happen to IDD case management and felt they needed to find stable employment.

I am a volunteer guardian. I care a great deal for Lee and I am committed to his care, but I have a busy life. I was very comfortable with navigating the system prior to KanCare. I knew who to call and what the expectations were. Now there are more people to deal with, more papers to read, more hoops. I am very familiar with the IDD system and I have problems with navigating it, I can't imagine what it is like for the average person.

It is my opinion that removing IDD HCBS from KanCare would improve the service by eliminating unnecessary bureaucracy, put the focus back on providing person centered services and make it easier for the person, their family members and guardians navigate the system.

Thank you for taking the time to hear my comments.

Sincerely,

A handwritten signature in blue ink that reads "Kathleen Brennon". The signature is written in a cursive, flowing style.

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