

February 11, 2020

TO: Will Carpenter, Chair and Members of the House Social Services Budget Committee

FR: Dr. Bongi Wenyika, PhD

RE: Parent Testimony in Support of HB 2550

Chairman Carpenter and members of the committee, thank you for the opportunity to provide testimony and your consideration of HB 2550. This bill will change the lives of many Kansas citizens and their families including my own.

I am the proud mother of a 17 year-old son, Kudzai, who was diagnosed with autism spectrum disorder, intellectual disabilities and bipolar disorder. Our family moved to Kansas 19 months ago for a new job for my husband. Transitions of any kind are hard for families, but when you have a child with disabilities, who needs routine, familiar surroundings and change, no matter how small, results in anxiety, moving away from a familiar environment and support system, is a daunting experience.

For us, after figuring out where we were going to live, the next worry as parents, was the availability of services and resources to support Kudzai. As hard as it is for us parents to accept and acknowledge, we know that Kudzai will always need hands-on support for the duration of his life.

When we Kudzai transitioned to our local high school he had immediate serious behavioral challenges that could not be accommodated in the only special education classroom and resulted in him being secluded for two years. It was hard for professionals within the school system to direct us to resources that could help us. The struggle for information and the lack of access for services to support Kudzai was immediate. Last October, following a week of aggressive episodes, the high school suspended him for 10 days and then told us they could not meet his needs. This January, Kudzai transitioned to Lake Mary School in Paola and thanks to trained professionals and support while he is at school, Kudzai is doing well both academically and behaviorally.

As a parent, I wonder, since the high school failed to integrate him with his peers and some school staff said they were afraid of him and did not want to work with him, what does that mean for his integration and acceptance in our community? It is beyond challenging when some school employees openly refuse to work with your child because the only circle of support becomes non-existent.

My worry is what happens in June when Kudzai turns 18. We have just started the application process for services and found out that there are more than 4,000 individuals waiting for support services.

Kudzai has to wait 8 years to access services that we believe would help and support him to live successfully in our community. The current reality of Kudzai waiting eight years keeps me up at night.

Like many families we have dreams and aspirations for our future. I graduated with my PhD ready to conquer academia, financially contribute to my family and be an active member in our community, but because of Kudzai's needs and the hands-on support that he requires, I have had to defer that dream. Without support, the last 19 months have resulted in isolation and limited social interactions outside the home, for Kudzai and us as a family. Our social network is non-existent. Routine outings that many families take for granted, for example, going to church or going to the grocery store are impossible. The lack of support has put our life on hold and this has had negative impact on my life, but most importantly Kudzai's life.

The lack of support has also had negative impacts on my physical and mental health. Although primary care givers are advised to take care of themselves, first so they can do a better job caring for others, without support and resources, this is hard and impossible to do. In the last year the increased stress as a primary caregiver has led to diagnoses of sleep apnea and diabetes in addition to high blood pressure, depression and anxiety.

Like every parent, my hopes for Kudzai is for him to have a level of independence which can only be possible with support outside of what my husband and I can provide. Right now, most parents of a 17 year-old are thinking about college, access to financial aid and the possibilities of a future for their children. As Kudzai's mom, the thought of what the eight year wait for services means for his future is consuming. How old will he be when he finally has access to support?

Due to his history of aggressive episodes and the challenge of the general public understanding the behaviors of individuals on the autism spectrum and mental health, I worry that without support, there is a possibility someone observe him in the community, call the police and without support or someone to advocate for him in that moment, that could start a snowball effect that would be tough to stop, if at all. Kudzai may be not able to wait eight years for support.

Thank you for your consideration.

Dr. Bongsi Wenyika, PhD

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