

October 20, 2021

TO: Chair and Members of the I/DD Waiver Committee

FR: Dr. Bongi Wenyika, PhD

RE: Parent Testimony in Support of Additional Funding to Eliminate IDD Waiver Waiting List

Members of the committee, thank you for the opportunity to provide testimony and your consideration in supporting additional funding to eliminate the IDD Waiver waiting list. Elimination of the IDD waiting list will positively change the lives of many Kansas citizens and their families including my own.

I am the proud mother of a 19 year-old son, Kudzai, who lives with autism spectrum disorder, intellectual disabilities and bipolar disorder. When our family moved to Kansas three years ago, from Oklahoma for my husband's new job in Ottawa, our family's transition was both challenging and traumatic. As some of you might know, transitions of any kind, are a huge challenge for individuals with disabilities because routines and familiar surroundings play a huge role in daily functions that many families take for granted.

For us, transferring our son to the local high school was worrisome because we knew the transition would probably result in Kudzai experiencing some behavioral challenges. Moving into a new home was hard for him and the next worry as parents, was the availability of services and resources in our new home State to support him. 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.

As we predicted, Kudzai 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. That Fall, following a week of numerous aggressive episodes, the high school suspended him for 10 days and then told us they could not meet his needs. We kept Kudzai at home for the remainder of the school year until he transitioned to Lakemary School in Paola, Kansas. Thanks to the army of trained professionals the support Lakemary School has provided while he is at school, Kudzai continues to do well both academically and behaviorally. He knows he is in a supportive environment where he is loved and positive reinforcement has done wonders for him. This year Kudzai was offered a paying shredding job at school. He works 20 hours a week and loves working.

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 2023 when Kudzai turns 21 and graduates from Lakemary School. He is currently on the I/DD waiting list and near the bottom of 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.

Having I/DD services post-graduation would mean that Kudzai can continue to work as well as us as a family looking for opportunities to help him transition to living outside our home with supports. These are our wishes for his future.

Like many families we have dreams and aspirations for him and our future. Ten years ago I graduated with my PhD ready to conquer academia, financially contribute to my family and be an active member in my community. Kudzai's needs and the hands-on support that he requires, it led to me deferring that dream and having to adjust my daily as well as future plans professionally. Without support, the couple of years, even before the pandemic 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 couple of years increased stress as a primary caregiver has led to diagnoses of sleep apnea, insomnia and diabetes in addition to high blood pressure, depression and anxiety. I am also talking to a therapist and paying out-of-pocket because that is an important resource for me.

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 19 year-old think 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 waiting list for services means his future as well as mine and my husband's are in limbo. How old will we or he be when Kudzai 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 observes him acting a certain way in the community, calls the police and if at that moment he has no advocate, 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. Our family needs the I/DD waiting list eliminated, Kudzai's long-term well-being depends on it.

Thank you for your consideration.

Dr. Bongsi Wenyika, PhD

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