

October 19, 2021

To The Special Committee on Home and Community Based Serves Intellectual and Developmental Disability Waiver:

My name is Anna Slattery. I am a pediatrician in Lenexa and I am a parent living in Leavenworth, KS. My husband and I have a daughter Erin and a son Micah. Micah is seven years old and has a form of congenital muscular dystrophy called Muscle Eye Brain disease. From before Micah was born, we knew he would have brain differences. Once he was born it became very apparent that he would have significant medical and learning concerns. Because Micah has so many brain abnormalities, he is nonverbal. He is nonmobile and can not sit on his own. He has muscle weakness from the muscular dystrophy but he also has significant difficulties moving his body. He can not hold things or use a pointer finger to push buttons, etc. He also has significant vision problems. He is legally blind, he has cortical visual impairment which means his brain does not correctly interpret what he sees and he has had multiple retina detachments. He has a significant risk of becoming blind. He also has seizures and several other medical problems.

Micah requires full care for everything. He has to be fed pureed foods which we make special for him. We have to hold his cup for him to drink through a straw. Micah is still in diapers and always will be. He can not even help with getting dressed. He is 55 pounds at 7 years old. We have to carry him and lift him in and out of the bathtub. He needs help to turn over in the night. His wheelchair weighs almost 60 pounds and needs lifted in and out of the vehicle each time we go somewhere. He requires medicines four times a day. His sleep is extremely poor due to his brain abnormalities, muscle spasms, and vision disturbance. He is sometimes up for hours in the night.

Life with Micah has its shares of joys with smiles and laughs but we also have hours each day with crying. He has few ways to communicate and sometimes he cries because of pain or frustration or boredom.

Micah has been on the IDD waitlist since the week he turned five years old. We are told the wait could be 8-10 years. In the meantime, my husband had to quit his job to care for Micah. We have no nursing or patient care attendant coverage. We have had to pay \$1200 a month for our medical insurance through my job. We pay an additional \$15000 in out of pocket expenses to meet our out of pocket maximum and to get equipment and services our insurance does not cover. We have to pay out of pocket for diapers. We have no help for home or car renovations to care for Micah. We have a limited number of therapy visits for Micah's physical, occupational, feeding, and speech therapy.

Waiting years means we struggle through difficult financial situations, days without support, and years that we are not able to prepare for the future with Micah. Getting off the waitlist and receiving at least some of these services and coverage would be life changing and would help us to not be stretched so very thin.

Please contact me with questions or to work through the complex planning as you begin to make changes. Families would like to be a part of creating change for ourselves but also families to come after us. I know you want to be a part of that change too.

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