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TO: House Committee on Health and Human Services

FROM: Lori B. Feldkamp, Big Lakes President & CEO

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RE: Complex Needs of Kansans with I/DD & Autism

Big Lakes is a community service provider in Riley, Geary, Pottawatomie and Clay counties. We support over 200 individuals with intellectual/developmental disabilities (I/DD) and have been successful in our efforts for the past 47 years. I want to emphasis that we are successful because 99% of the time. However, there is a very small segment of the I/DD population that we serve that presents significant challenges for us in terms of staff support, resources and expertise. These individuals have significant behavioral issues that require an extraordinary level of care, support and money to keep them and others safe in the community. And, sometimes what they need is more than what we can provide.

Thank you for the opportunity to provide testimony today. For those of you who participated in the informational hearing on this subject a year ago, my testimony will look very familiar. That is because the situation has not really changed regarding supports for individuals with complex needs. However, I have updated the stories below with what is going on in the lives of the people we serve with complex needs. I hope this will give you some perspective on the obstacles we face on a daily basis to serve just two people.

There is currently a significant gap in Kansas for behavioral health support needs of someone with I/DD and what is available in the community. Twenty years ago, these young men would have been living in a state hospital. Today, we struggle each day to ensure these two individuals do not cause significant harm to themselves or others. When significant behavior escalations occur, many times our only option is to call law enforcement to intervene, as crisis services are not available for this population. The gap in services for those with I/DD and complex behavioral health needs in Kansas must be addressed.

Here are their stories:

Jason's Story

"Jason" came to Big Lakes in October 2015, one month after he turned 18. He was placed in a Big Lakes group home with two-to-one staff supervision during waking hours. He came to us with a long history of police reports for violence, aggression, and property damage, including assaults on his family members and exposing himself to a younger female on the school bus. These behaviors continued into his time at Big Lakes. Four years ago, while visiting his family, he sexually assaulted his three year-old niece. A police report was filed, and family relationships have remained strained. Since that time, he has become increasingly sensitive to perceived transgressions of others; for example, yelling "what are you looking at?" to members of the public and challenging them to fight, and attacking a garbage truck driver because Jason

thought he was driving too fast. In January 2019, Jason became angry because he was asked to wear gloves while shoveling snow. He ran to the nearby highway and began throwing large rocks at passing vehicles. The police were called and two staff members followed in a van. A female police officer arrived, and Jason began chasing her with a piece of cast iron in his hand; she tazed him twice to no effect, as he was wearing a heavy coat, and he continued to pursue her. Staff were able to restrain him while the officer put him in handcuffs, and it took several more officers to get him in the police car. We later received a letter of appreciation from the Director of the Riley County Police Department, stating that had it not been for our staff's intervention, the officer would have had no choice but to "use her duty weapon." In other words, staff prevented Jason from being shot. Jason was arrested eleven times between January, 2019 through March, 2020.

On March 10, 2020, Jason was arrested for the final time while in Big Lakes services after a major incident in which Jason threw large rocks through multiple windows in an effort to hit staff, he caused significant damage to a staff vehicle and verbal threatened to kill staff. He ran out to the road and starting throwing anything he could find at passing vehicles. The police arrived and Jason was taken to jail for violating his probation and new assault charges were added to his record. While in jail, Jason has continued to rack up charges as he assaults his jailors on a regular basis. After many court hearings and attempts to have KDADS determine he is a danger to himself and others; KDADS approved Jason's placement at Parsons State Hospital on October 9, 2020. However, Jason remains in jail because there are no beds available at Parsons.

Luke's Story

"Luke" came to Big Lakes in 2004 at the age of 20 with a history of abuse by his family. Luke is a large man with uncommon strength who was hyper-vigilant to his environment and always at least slightly on edge. He seemed to have only one method of expressing his insecurities and other emotions, and that was to act out with extreme aggression. Over the years, he caused thousands of dollars in property damage; once, in a rage, he pulled a toilet out of the floor and threw it in a bathtub. He injured staff, other clients, and even community members, oftentimes to the point that they required medical care. When he became escalated, for the safety of all, work areas were cleared of clients and four or more staff would be taken from their duties to help manage his behavior.

To make a long story very, very short, in the last year Luke had only three behavioral incidents, none even beginning to approach the severity of those in years past, and is working productively on a farm crew. There were many factors contributing to this substantial turnaround in his behavior, but foremost among them is that for the past nine years he has had one near constant, extraordinarily gifted companion. We hired Dan in 2011, an ex-lineman for the K-State football team. Dan and Luke have developed a special relationship based on trust and mutual respect. Those who knew Luke sixteen years ago would have difficulty recognizing him today. He has lost 100 pounds, is able to carry on a conversation, is usually smiling, and can often be heard singing or humming a tune. This is what happens when you have dedicated staff who are willing to face adversity and stay long term. Why has Dan stayed? He would tell you that he wants to be helpful. We believe this to be true, but it is also true that he has been extraordinarily compensated for his time. In the past three years, largely due to staff vacancies, Dan has averaged 85 hours of work per week and has made in excess of \$200,000 with overtime; which, incidentally, is about \$75,000 more than we were reimbursed for Luke's care, with extraordinary funding. How much longer can Dan keep up this work schedule and provide the stability Luke craves? And how much longer can we pay Dan without adequate reimbursement?

A long term solution is needed to effectively support individuals with complex needs and the staff providing those supports. Adequate staffing, training, funding and a crisis response program that can respond at a moment's notice to deescalate situations and provide an alternative to incarceration or hospital placement is necessary.