

FROM: MICHAEL S. JONES
PARENT/GUARDIAN OF TREVOR JONES

TO: KANSAS LEGISLATURE JOINT COMMITTEE ON HOME AND
COMMUNITY BASED SERVICES AND KANCARE OVERSIGHT

DATE: November 9, 2016

RE: WRITTEN TESTIMONY FOR HEARING ON NOVEMBER 17, 2016

Our son, Trevor Jones, is a 22 year old developmentally disabled individual. He has Prader-Willi Syndrome. PWS is a complex genetic disorder affecting appetite, growth, metabolism, cognitive function and behavior. PWS is characterized by behavioral problems linked to chronic feelings of insatiable hunger and a slowed metabolism that can lead to excessive eating and life-threatening obesity. Imagine an individual with extreme OCD and ODD behaviors that is as hungry and you will ever be, 24/7, 365. Individuals with PWS require intervention and strict external controls including padlocking access to food to maintain normal weight and to help save their lives.

The core concept of PWS management is that food is like oxygen. It must be available and predictable. No hope of extra food means no disappointment means no behaviors. His target diet is 800 to 1,000 calories per day to maintain a healthy weight.

Trevor was not diagnosed with PWS until age 4. As he got older, his behaviors became more extreme and often violent. He qualified for emergency crisis HCBS funding at age 9. Mostly through trial-and-error, we learned to find and train "Helpers" to work with Trevor and help manage food and behaviors. He progressed through the Blue Valley School District with some success. Through our efforts as parents and with the help and dedication of other key individuals and educators, he was generally happy, successful, and healthy. His adult weight was about 185 pounds.

In 2014, DD services were rolled into KanCare. At age 19, Trevor received funding for residential and day services. Our goal for Trevor was to provide a home for him to live in with other individuals receiving residential services in a safe, happy, family-like setting. For the first couple of months, things were great. He was proud of his new home and was thriving as a happy, independent young adult. The situation quickly deteriorated and became and became an abject failure.

The "shift based" residential staffing model allowed Trevor to manipulate staff to exploit inconsistencies. Staff members were not all adequately predisposed, trained, supervised or otherwise properly equipped to work with Trevor. His behaviors escalated rapidly, including daily tantrums, hitting staff members, police involvement and other extreme behaviors. The residential providers were not trained in managing PWS and could not provide the right

environment for Trevor. His roommates all moved out. Two residential providers threw up their hands and quit. Trevor's weight continued to climb.

We turned to Community Living Opportunities in March, 2016. Our belief was that a shared living Extended Family Teaching residential model would be best for Trevor. He would live with one well-trained family or individual who could understand and manage his unique and complex health and behavioral needs. This all sounded great in theory, but we could not identify an appropriate EFT provider right away.

Despite everyone's great efforts, Trevor continued to fail in a shift-based staffing model. We were able to work with CLO to provide initial training and obtain some level of staff consistency. But by now, his weight was at 235 pounds and continuing to climb. The situation was becoming critical. Initial applications for extraordinary funding for dedicated staff were denied by the MCO, Sunflower. He exhausted his targeted case management hours before summer. It was truly a crisis situation. The status quo was not situationally or financially sustainable for anyone.

Trevor needed a reset. With CLO's cooperation and assistance, we submitted an application for him to obtain treatment and counseling at The Center for Prader-Willi Syndrome at The Children's Institute of Pittsburgh. It is the world's only comprehensive hospital-based inpatient program for medical, behavioral and rehabilitation management of children and adults with PWS. The program uses an interdisciplinary team of physicians, psychologists, nurses, dietitians, OT and PT therapists and others. That team teaches behavioral control in the living environment, nutrition awareness, physical exercise and motor control, as well as social skills and self-motivation. Patients learn behavioral self-control while families and caregivers receive extensive training to help maintain the structure and support of the program following discharge.

We submitted an application to the MCO to approve Trevor to attend the Center. CLO submitted another application for extraordinary funding. On August 16, Trevor's application was denied by KanCare/Sunflower due to lack of "medical necessity." CLO's request for additional funding to serve Trevor was similarly denied. We began preparing for the long appeal process and legal action if necessary.

In the meantime, Jamie Price, Senior VP at CLO, pressed forward and requested Sunflower for a peer review of Trevor's claim determination. Dr. Sima Suler, Director of the PWS Center, made a compelling case for Trevor to attend the Center. As a result, we received news on September 2 that Trevor's request to attend the PWS Center for out-of-state services would be approved and he would receive additional funding to make an EFT residential plan possible. We were on a plane to Pittsburgh the following Tuesday.

Trevor was in Pittsburgh for 5 weeks. He was on a 600 calorie per day diet. He received medical attention. He was taught the importance of a proper diet to be healthy with appropriate food

expectations and security measures in place. Our family, CLO and Sunflower staff participated in video conference training sessions conducted by the PWS Center team. During that time, an individual was identified with the qualifications and experience to become an EFT for Trevor who also participated in the training sessions.

By the time Trevor returned, the entire team had been assembled coordinating the efforts of our family, CLO and Sunflower. Trevor is currently living in an EFT setting in Lawrence and doing very well. His behaviors have been managed much more effectively. Food access is secure and a healthy diet of 800 calories per day is in place. His weight is down to about 200 lbs. Trevor is happier and healthier than he has been in a long time. The strain on our family has been significantly reduced.

The KanCare system is not perfect. It has undoubtedly been a long and difficult journey, most of all for Trevor. As with many things, it comes down to the people within the system to make it work. We particularly thank Mike Strouse and Jamie Price at CLO and Melissa Cannon Smith at Sunflower for their advocacy on behalf of Trevor. In our case, our love, diligence and persistence combined with the commitment and support of CLO plus the willingness of the MCO to listen, learn and make the right decisions have resulted in a better long-term, sustainable, living situation for our son where he can be safe, healthy and happy.

Through Trevor's story, we hope that our State leaders and KanCare providers can learn what a positive experience looks like for those families most in need of support and learn how to replicate that approach to better serve the State's most vulnerable population.

Thank you for your time, courtesy and consideration.

Michael S. Jones
14004 Hayes
Overland Park, Kansas 66221
913-220-5544
mike@jones-mccoy.com