

Testimony

Tuesday, November 18th, 2014

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Hello,

My name is Marilyn Kubler. I have testified a couple of times previously to this committee on behalf of individuals I support on the Intellectual Developmental Disability (IDD) Home and Community Based (HCBS) waiver. Many families across the state have sent letters and personally pleaded with Kansas Department of Aging and Disability Services (KDADS), Kansas Department of Health and Environment (KDHE) and this administration to consider how disruptive KanCare has been in the lives of the people with disabilities. I am a parent of an adult woman with disabilities who is on the IDD waiver and I have a case management agency.

Individuals on the waiver, their families and providers feel they have not been listened to and instead are told to comply with new rules and additional bureaucracy or they will lose services or their case manager. Many individuals have received notice that they will be moved into Health Homes (HH). We have been told that individuals have the opportunity to "opt out" of HH's but we are finding the Managed Care Organizations (MCO's) are keeping these individuals on their rolls even when families have called in to ask them to be removed. Letters were sent to individuals who cannot read or write or use the telephone and were told, in the letter to let the state know if they didn't want to be included. Some individuals did not even get a letter and yet were "opted in". We have raised the question why these letters were not sent to the guardians as well as the individuals. It seems not only unethical but illegal to put someone in a program they don't understand without consultation with their guardian. Under the federal rules the state had the option to have individuals "opt in" or "opt out" - seems like the fairest way to do this for the individual would be to have them "opt in" after they had the chance to discuss this with their guardian or provider.

As a provider I applied and received notification from both Sunflower and United Health Care that our agency could be a Health Home Partner (HHP). However when I was told the software to implement this new business venture would cost our agency \$68,000 I knew this was not financially feasible for us. I attempted to collaborate with Johnson County who has a contract with Johnson County Mental Health and was told that would not be possible. I am an affiliate with the Johnson County Community Developmental Disabilities Organization (CDDO) and believed, since Johnson County Developmental Supports could contract with Mental Health then I should be able to do so as well. This is an example of pushing the smaller agencies out and only letting the large agencies provide services as an HHP. As a case manager for twenty years I am perfectly capable of providing the core services needed for an HHP. I understand my case managers could subcontract with the HHP's but where does that leave the agency? At a minimum of \$137 for a monthly encounter the agency has no wiggle room. And many of our encounters are more costly than \$137 per month. Some HHP's are subcontracting at \$170 per

month, per encounter but that still leaves the agency in the hole. As an agency, I have many business expenses that need to be taken into account and still pay my case managers a fair wage. We get frequent requests from families asking for case management services and I would love to grow my business but under this climate I am afraid to add more employees. Residential and day service providers are close to capacity and wary of opening up new homes for fear of not getting paid.

This administration promised families they could keep their IDD case managers. In October a bulletin announcement from KDADs said that case management was encouraged but not required by the HHP. Many families felt betrayed and lied to after they had been told they could keep their case managers.

At a recent family meeting in Overland Park that attracted over 250 people, families described many problematic issues. Family members stood up and spoke about their problems with the MCO's and the inability to either get equipment or medications that they had in the past. This meeting was highlighted in the Kansas City Star on November 8th on the editorial page. Angela DeRocha, a spokeswoman for KDADs, is quoted as saying since the implementation of Health Homes; emergency visits by developmentally disabled Kansans with waivers for services have dropped by 27 percent. The IDD HH's were not even implemented until this month so it's hard to understand where those statistics came from.

We are unable to get a clear answer from KDADs on where anyone is on the waiting list. Families are asking me when their son or daughter's name will come up. Many of these people have been on the list for 6-7 years. They have graduated high school and are sitting at home languishing in front of the TV and losing important skills they learned in school.

The fear families have of losing their case manager and needed services is very real and very frightening. We do not believe that our families should be burdened with bureaucratic entanglements. It takes months to fix what never was a problem before. Our lives are complicated and difficult as it is, and even small changes in routine or case management can create setbacks for people with intellectual or developmental disabilities.

I'm sure you all remember the plea from the mother who asked that this administration carve out IDD from Kancare and to please don't fix something that is not broken. But now you have broken a good program and it's time you fixed it!

We are asking for compassion from this administration and return the coordination of non-medical services for disabled Kansans to the community-based groups that understand these individuals, their families and their special needs.

*Marilyn Kubler*