Re: KDADS Proposed Changes

Fr: Kay Soltz, parent, guardian, advocate

Dear Committee Members,

I am the guardian of a 43 year old man who has Fragile X Syndrome which is on the autism spectrum. He lives with me, his widowed mother, but we have been fortunate to receive HCBS funding for day program, respite care, and case management services. I am not exaggerating when I say I could not make it through life without those services.

I am very concerned about KDADS proposed changes that would make life more difficult for my son and me. For starters, KDADS plans a different method of evaluating the need for disability services. Currently I have to keep daily records about him for a year as does the day program before a reassessment is done. Instead of looking at the whole year, the new system plans to use just 3 days. My son can have three good days where he does not throw a massive fit, does not hit himself in the temple hard enough to bruise, does not cause damage to property, and does not wander away. He has many more days in a year that he does these things. What if KDADS determines that because the three days they chose do not show any problems, my son does not need supports or very few supports and funding can be reduced? This will be a problem for any agency serving him. If individuals are evaluated by 3 days out of context of their whole lives, it will reduce funding to agencies and they won't be able to provide adequate care to keep these individuals safe, let alone help them acquire skills to become more independent. I am glad that the implementation date of this method has been delayed from March to July, but I think KDADS needs input from families and agencies to make the new tool they propose to change to more appropriate to I/DD individuals.

I am also concerned about "conflict free case management." My son's case manager has been working with us for 9 years. She is employed by the same agency that runs his day program. If conflict free case management is imposed, we would lose her. We have had many problems in those 9 years, and she has been a terrific support. Bureaucrats should not limit my choice of my son's case manager. Life with I/DD as an adult is difficult for both the person and family. Please don't allow changes that make it harder.

There are other problems with KDADS proposed changes. They are coming too fast on top of each other. Slow down.

Please contact me if you want further information.

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