

## **Disability Rights Center of Kansas**

214 SW 6<sup>th</sup> Avenue, Suite 100 ♦ Topeka, KS 66603 Phone: 785.273.9661 ♦ Toll Free: 1.877.776.1541 Toll Free TDD: 1.877.335.3725 ♦ Fax: 785-273-9414 www.drckansas.org info@drckansas.org

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Robert G. (Bob) Bethell Joint Committee on Home and Community Based Services and KanCare Oversight

## Chair Landwehr and members of the committee:

My name is Mike Burgess. I am the Director of Policy & Outreach at the Disability Rights Center of Kansas (DRC). DRC is a public interest legal advocacy organization that is part of a national network of federally mandated organizations empowered to advocate for Kansans with disabilities. DRC is officially designated by the State of Kansas as Kansas' protection and advocacy system. DRC is a private, 501(c)(3) nonprofit corporation, organizationally independent of state government and whose focus is the protection and enhancement of the rights of Kansans with disabilities.

I would like to address the following two topics in my testimony today:

- 1) Encourage KDHE to partner with stakeholders to do significant outreach around the positive changes to EPSDT in Kansas; and
- 2) Hundreds of Kansas foster care youth with disabilities are currently stuck on the IDD waiting list and the challenges that accompany that situation.

First, please encourage KDHE to work with stakeholders on the implementation of the EPSDT funding the legislature appropriated for kids under 21 who are enrolled in Medicaid. It is important to do an effective campaign so parents, providers, and the community know about this important effort.

A brief and extremely simplified recap on this is that over the last year CMS provided additional guidance on how Kansas should be implementing the Early and Periodic Screening, Diagnostic and Treatment (EPSDT) program to comply with the federal law. In Kansas, the EPSDT program is called Kan-Be-Healthy.

Due to the need to comply with federal law, additional funding was needed (and funded by you all) to better implement this important program. Essentially the Medicaid program requires every state to provide what is medically necessary for children on Medicaid. Our specific interest in this is that the Kan-Be-Healthy program is an important tool to help address the needs of Kansas children with disabilites who are enrolled in Medicaid. This can include what are known as state plan services (including a couple of "waiver-like" services) that should be available today for children on a waiting list for HCBS waiver services. While not a replacement for a waiver slot, these services can definitely help meet the needs of children who qualify.

Helping Kansas better meet these needs (and comply with federal law) is a very positive step as we all work to continually improve the Kansas Medicaid program and ensure it operates effectively and efficiently to achieve the best outcomes for this investment.

But this improvement will only be realized if parents, providers, and the community are aware of this program and how it should be used to provide medically necessary services to youth who qualify. And while many of these stakeholders may be aware of the program, outreach is needed to help them to know how to truly access it.

The second topic is to make you aware of work that is being done to help address some significant challenges that exist with children with disabilities in the foster care system. As has been discussed here (and in several other committees), children in the foster care system are considered a priority population for IDD waiver services. KDADS maintains a reserve capacity to help facilitate children in the foster care system to begin IDD waiver services without having to deal with the waiting list. This seemed like a process that should be somewhat automatic, and that when a child with disabilities enters the foster care system they seamlessly move onto the IDD waiver.

I was shocked to learn during a recent meeting, that the process of quite the opposite of automatic and in fact there are more than 200 children in state custody who currently are on the IDD waiting list.

This complicated process involves multiple state agencies and multiple service systems. Some of the parties involved include DCF staff, KDADS staff, CDDO staff, MCO staff, foster care provider staff, and the foster parents who all have different processes to begin to identify what the needs are for the child and how to navigate the various bureaucracies to access the services the child needs (which may include both behavioral health and IDD waiver services along with any additional medical needs.

I do want to share my appreciation for the KDADS and DCF staff who have started collaborating with several stakeholders to help us (and each other) to better understand what the actual processes looks like on the ground along with what the policies are across both programs. Both agencies are mapping out processes in the community to better address this situation and hopefully prevent this from happening again.

Again, there are many challenges (and players) involved with quickly identifying and assisting youth who come into state custody to get them into a safe placement and to identify what their needs are. It appears that there are several tools, including an enhanced rate for the foster family to help offset some of the additional costs a child with a disability will have, but those families are then forced to decide between this enhanced rate or having their foster child receive waiver services (despite many of the additional costs continuing even with waiver services). This can put the needs of the foster family in contrast to the needs of the foster youth, which is not fair to either of them.

I know these last few paragraphs only scratch the surface on this complicated issue, but I wanted to be sure to bring this situation along with the discussions that are currently happening to your attention.

Thank you for the opportunity to share our testimony today. Please feel free to contact me with any questions.