Topeka Independent Living Resource Center

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Testimony to:

Senate Committee on Public Health and Welfare
Senator Vicki Schmidt, Assistant Majority Leader &
Committee Chair

"The Need for the State to Fully Comply with KSA 39-7100 Governing the Rights of Medicaid HCBS Consumers to Have an Option to Direct and Control Their Attendant Care Services"

Presented by:

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Advocacy and services provided by and for people with disabilities.

The Topeka Independent Living Resource Center (TILRC) is a civil and human rights organization. Our mission is to advocate for justice, equality and essential services for a fully integrated and accessible society for all people with disabilities. TILRC has been providing cross-age, cross-disability advocacy and services for over 30 years to people with disabilities across the state of Kansas. Our agency has been particularly interested in and committed to assuring that people who require long term care services have access to information, services and supports that offer choices; choices that promote freedom, independent lifestyles and dignity, including the dignity of risk.

We believe that over the years, the State of Kansas has increasingly come to support these interests, as well, as evinced by increasing the number of home and community program options and by increasing the funding for these programs. At the same time, there has been a significant struggle to continue to find the budgetary resources necessary to fund both the facilities and the home and community alternatives to facility-based long term care services. This struggle has been acute for the past twelve to thirteen years and has culminated in the Brownback Administration's proposed radical experiment in very rapidly converting the entire current state Medicaid service system into managed care. TILRC is not opposed to managed care, per se. It is recognized that managed care is a tool for states to control costs and move toward more budget certainty within the Medicaid program. There is, however, great concern around the plans to use this new tool. Simply put, the current plan goes too far, too fast. (Full disclosure: I have just recently been selected to serve on Centene's National Disability Advisory Board.)

No other state has even attempted to convert their entire Medicaid program over to managed care so quickly. No other state has attempted the move into managed care without first engaging in limited impact modeling of the new managed care program. Limited impact means that program size and scope are limited to begin with and growth controlled over a fixed time frame. Size and scope can be controlled by limiting the population(s) to be served and/or limiting where geographically the modeling takes place and/or limiting the numbers to be served. In addition to the need for modeling, consideration needs to also be given to people on the waiting lists and to existing service cuts and caps. Otherwise, an appearance arises of a lack of concern about these problems.

The main, largest HCBS Waivers have just recently been submitted and approved by CMS. This routine Waiver renewal is required every five years by CMS. However, notwithstanding the routine nature of the requirement to re-submit the Waivers, there have been a lot of very significant changes to the Waivers ranging from eliminating paper timesheets and utilizing an electronic verification system to selecting the "Agency with Choice" template for structuring and delivering services. It continues to be a lot of work to convert the old systems and implement the new. It is very frustrating and fiscally illogically for my company to have to spend its own resources to do this. The new Waivers significantly cut the self directed provider reimbursement rate and has not otherwise provided a source of funding to pay these costs. In any case, it would be good to be able to implement and evaluate these current, very significantly different Waivers and related tools before adding the additional burden and risk of moving all of HCBS into managed care with no modeling and no history upon which to rely. Perhaps consideration should be given to starting the managed care experiment on the health care / medical card side.

TILRC is of the opinion that the "Agency with Choice" model selected by the State and the rules developed to implement it do not comply with State Law. Consumers have lost employer status. Consumers have less control over scheduling their workers and managing their services. The electronic verification system that requires "procedure codes" takes away even more flexibility and control and is overly bureaucratic, inflexible, complicated and unnecessarily punitive. These programs should comply with State law and not take away peoples' rights. TILRC is not opposed to "Agency with Choice" or to the use of electronic verification. They just should be implemented in a manner consistent with state law and that respects the rights of people with disabilities.

A critical issue, then, that should be addressed is that the State is out of compliance with its own laws; laws on the books since 1989 governing the rights of disabled Medicaid beneficiaries to control, direct and manage their HCBS attendant care services.

KSA 39-7100 (2)(b)(1-4) says:

> *(2) "Secretary" means either the secretary of social and rehabilitation services or the secretary of aging.*
>
> > *(b) The secretary as part of the home and community based services programs, subject to social security act grant requirements, shall provide that:*
>
> *(1) Priority recipients of attendant care services shall be those individuals in need of in-home care who are at the greatest risk of being placed in an institutional setting;*
>
> *(2) individuals in need of in-home care who are recipients of attendant care services and the parents or guardians of individuals who are at least 16 years of age and who are in need of in-home care shall have the right to choose the option to make decisions about, direct the provisions of and control the attendant care services received by such individuals including, but not limited to, selecting, training, managing, paying and dismissing of an attendant;*
>
> *(3) any proposals to provide attendant care services solicited by the secretary shall be selected based on service priorities developed by the secretary, except that priority shall be given to proposals that will serve those at greatest risk of being placed in an institution as determined by the secretary;*
>
> *(4) providers, where appropriate, shall include individuals in need of in-home care in the planning, startup, delivery and administration of attendant care services and the training of personal care attendants;*

The background to this law, as can be referenced by the legislative research, public testimony and committee discussion, clearly indicates that the general meaning of this language requires the state to develop a program, if possible, so that an HCBS consumer would be able to choose to be her own employer of her own attendants. At the time and up until relatively recently, CMS rules completely prohibited a consumer from being able to employ and pay his own worker. No such barrier currently exists and, in fact there are several, high quality, cost effective options available, including the Community First Choice Option which also nets the state a 6% increase in federal share of payment for this option.

If we the State of Kansas are in a time of Medicaid long term care reform, including much debate around giving the State more control over the Medicaid program, should we not set the right example and follow our own State's laws? Besides being able to bring our State into full compliance with KSA 39-7100, the Community First Choice Option also provides for training of both consumers and workers, improved consumer oversight of the program and many other best-practices in home and community long term care.

A final issue that really needs to be reformed is the "Protected Income Level / Client Obligation" required of PD, FE, TBI and some DD HCBS Waiver consumers. The protected income level is set by the State and is the maximum amount of monthly income that HCBS consumers are allowed to have for all living expenses; currently $728 per month. Consumers whose income, typically Social Security Retirement and/or Social Security Disability Income, exceeds $728 per month are required to pay a co-pay called a "client obligation" to their HCBS provider. This co-pay can be well over a thousand dollars for individuals who qualify financially for HCBS/Medicaid near the maximum allowed (300% of SSI). This is an obviously unfair method for establishing insurance co-payments. Some pay nothing. Some pay a little. Some pay a lot. Additionally, if reform means allowing citizens to keep more of their own money in their pockets, then this philosophy should apply to our senior and disabled citizens' hard earned Social Security Retirement and/or Social Security Disability Income. After all, these benefits only accrue after usually a lifetime of hard work and paying taxes, including payroll deductions.

Thank you very much for allowing time to express my views and for your time and attention. I would be happy to answer questions or to provide such follow-up information as I may have.