

Wednesday, March 14, 2012

TO: House Health and Human Services Committee

FROM: Gayle V. Richardson

RE: Family Concerns about KanCare for People with Developmental Disabilities (DD)

Representative Landwehr and members of the Committee, thank you for the opportunity to speak with you today. I represent Kansas families who would be impacted by the KanCare proposal. The Administration's plan has many flaws, but in the short time I have to speak, I would like to highlight four main points that we families find untrue and injurious to the long-term care of our children with developmental disabilities.

1. This proposal as it relates to our kids' care will NOT save the State of Kansas any money.
2. The rationale for this radical change is filled with inaccuracies.
3. The proposal would remove local control and responsibility for the care of our kids.
4. The proposed system will be harmful to our children with developmental disabilities.

This Administration has proposed a huge change in the system of care for people with developmental disabilities. In fact, they have, without legislative consultation or adequate notice to families, moved to transfer care decisions for our kids away from local control to out-of-state for-profit insurance companies that have no experience with our care needs.

This change would be disruptive to our families. It would degrade the system of care, and it would not save money for the State of Kansas. It would transfer \$2.9 billion annually from the State of Kansas to for-profit out-of-state insurance companies that have no experience with our care needs. It would add a burdensome layer of bureaucracy between the parents and the decision makers. It would reduce the funds available for direct care by diverting them to profits for the insurance companies.

The Administration states that this change will provide better outcomes, make our kids healthier and save money by wringing out waste in the system. They say this without having done their homework. Here are a few of their assumptions that are totally incorrect:

- Our kids are not receiving good medical care.
- Other states have successfully transitioned to a better system than Kansas has by out-sourcing the care of people with developmental disabilities to insurance companies.
- There is waste and inefficiency in the current system.
- Medical and long-term care costs for our cohort have been increasing.

- (This one makes us laugh.) 20% of people with DD in Kansas have a substance abuse problem.

- The insurance companies will provide more community jobs for our kids. (This is one of the goals built into the proposal.) How is an insurance company located in another state going to do that?

They either do not know our people's needs or they are confusing us with some other group.

They have distorted a couple of academic studies to make their case. Meanwhile, parents and care staff, who are the real experts in managing the care of our folk, have not been consulted. If we had been included in the planning and our concerns taken into account, these meetings would not have been necessary. Instead, our thousands of letters to the Governor and Lieutenant Governor have gone unread. What kind of government refuses to listen to its citizens?

The assumption driving the Administration's proposal is that the current system is wasteful. We parents have worked with people in the community and state government over many years to develop comprehensive care for people with DD. It is a very lean and efficient system, and due to inadequate funding, we have a waiting list of over 5,000 young people who are not receiving services.

The current system is local and works well at extremely low cost. Parents meet several times a year with their providers and case managers to coordinate all services – day programs, residential care, transportation and medical care. In between, we often contact our child's case managers to discuss issues that pop up and make required adjustments in their program of care. How is that going to work when insurance company staff will be making these decisions?

In fact, reputable insurance companies such as Blue Cross Blue Shield have refused to bid on this proposal, citing a lack of expertise in the long-term care needs of people with DD. If I were an insurance executive and had done my due diligence, I would realize there is no way to make money for my shareholders in this arena short of restricting needed services.

Medical care for our folk is a small part of the funds used to care for them. They are not primarily sick, and their health care costs are often no greater than the general population. This is a misconception that is prevalent in the community. My son, for example, takes medications and sees a doctor once in a while, but he has no costly medical needs. What he does need is a continuum of care for his day program, transportation and residential needs. This is not the sort of care that an insurance company is equipped to administer.

We are in favor of one piece of this proposal, the inclusion of our population in the medical care portion, which is the area of health insurance companies' expertise.

It seems then, that no one is convinced there are savings to be made by turning over the present system of care to a for-profit entity. Reimbursement from Medicaid is already tight and has led to the closing of several providers over the past few years. Most organizations that provide care can survive only through generous donations from the public or additional funds provided by the county.

We parents are rightfully proud and grateful for the care our children receive from the State of Kansas. And we prefer to keep the funds and responsibility for care of our kids in Kansas.

The refusal of this Administration, particularly Lt. Gov. Colyer, to discuss this plan with the people it affects, together with his statement that there is no reason to alter it, is an insult to the families it affects.

We urgently ask you to carve out the DD population from the KanCare system. At the very least, please vote to delay implementation of this plan. It will not save money and it will not enhance our kid's care.

If it ain't broke, don't break it.