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# Topeka Independent Living Resource Center

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## **Bob Bethel Joint Committee on Home and Community Based Services and KanCare Oversight**

Representative Brenda Landwehr, Chair

Testimony by:

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In Kansas nursing facilities . . .

304 of the 621 people who have died from Coronavirus have occurred.

181 of the “cluster” breakouts have happened.

2,579 people have had a COVID-19 diagnosis.

For Kansans with the same “level of care” needs as the people living in nursing facilities and other institutions but who live in the community, only 174 beneficiaries have had a COVID-19 diagnosis.

These numbers make the case our agency has been making for the past 40 years.

Home and Community Based Services are a better way to provide long term services and supports for aging and disabled Kansans. For almost 40 years, representatives from our agency have come before this body and others, and asked for community alternatives to institutional living as a matter of the dignity and equality of the lives of disabled Kansans. In the past six months, it has become increasingly clear that community living as an alternative to institutional living is a matter of life and death.

In the days following the death of Justice Ruth Bader Ginsburg, her role as author of the *Olmstead* decision has been highlighted. The *Olmstead* decision reinforced the anti-discrimination provisions of the Americans with Disabilities Act as the civil rights provisions establish a right for people using long term services and supports to receive those services and supports in community-based settings. In the decision, the Court encouraged states to protect themselves from violating the rights of disabled citizens by having a “comprehensive, effectively working plan” to guide the development of community-based alternatives to institutional long term services.

***Advocacy and services provided by and for people with disabilities.***

According to the guidance provided in the *Olmstead* decision, such a system should ensure the availability of a robust network of community-based services and supports, and where a waiting list for services exists, such as waiting list must move with “reasonable” speed.

Had Kansas had an *Olmstead* Plan, the equity and access issues confronting aging and disabled Kansans at the onset of the shelter-in-place and associated responses would not have been as disruptive for those people. We would not have been scrambling to get the access, devices and services so that health care, public services and other options that were seamlessly adopted by non-Medicaid users of all these same services.

Wednesday, September 23<sup>rd</sup> the Center for Medicare and Medicaid Services announced additional funding for states where the federal Money Follows the Person program has been extended. Kansas’ program ended in 2017, and the state Administrations since that time have not sought or obtained the available permissions to extend our formal program through repeated federal funding extensions for the program. Since the program has ended and extensions have not been obtained, Kansas lacks a specific, well-defined Money Follows the Person program, relying instead on the variety of approaches employed by each of the managed care organizations as they develop their own approach. As this announcement reinforces, not only has Kansas lost the benefit of having a comprehensive, effectively working plan for supporting people to leave dangerous institutions to move to the community, but Kansas has lost access to additional financial resources to support such a system.

To be clear, it has never been our position that the state lacks programs to support community living. We also acknowledge that institutional transitions are occurring under the current system, and at a higher rate than in past years. Our agency IS receiving referrals from managed care organizations to support individuals transitioning out of nursing facilities. We certainly appreciate the sense of urgency being placed on responding to these referrals given the current pandemic. For the 1/3 of people who have asked but remain in institutions, the lack of a comprehensive, effectively working system leaves us without any information about the barriers they are experiencing or ways a successful community transition could be supported.

A comprehensive, effectively working system also would obviate the need for the patchwork associated with the present “referral” system. We would know that every individual leaving the hospital and needing long term services and supports would have the ability to have those services in place to return to home instead of going to a facility. We would know that even people who have lived in facilities of all types for longer periods of time would have a meaningful opportunity to choose to remain in those settings or move out to their own home. There would be one place to call, and that place would move the levers and switches to get the person on the correct track to home.

Our agency is proud to be working with SKIL in Southeast Kansas and Sunflower State Health Plan/Centene to pilot an Emergency Direct Support Worker program to explore the needs and best ways to respond to the needs of people living in the community when unexpected situations occur with their services. This pilot will help us continue to identify ways resources can be made available to people living in the community. We thank Sunflower for their leadership with this initiative.

Kansans with disabilities living in the community have been able to navigate their way through the current disaster in the absence of a comprehensive, effectively working plan on the part of the State. It is our hope that we will be able to work with policymakers to develop a comprehensive, effectively working system intentionally designed to support community living for disabled Kansans, as a matter of dignity, and as a matter of safety.

We thank the Committee for the opportunity to share our experiences and recommendations for improving services, supports and resources for disabled Kansans.