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My name is Brenda Jackson. I formerly worked for the Centers for Medicare and Medicaid services. Now I design health care programs for elders and persons with disabilities for states throughout the country including programs for persons with intellectual and developmental disabilities. My husband – who teaches law at Washburn - and I are small town Kansas kids from Fairview and Fredonia. We have a son on the KanCare I/DD waiver.

Thank you, Senator Schmidt and members of the committee for providing me the opportunity to appear today regarding the KanCare program.

Traditional integrated MCOs are struggling nationwide with care management and service authorization decisions for I/DD populations.

Traditional integrated MCOs who are experienced in the medical model are struggling in their administration of long-term services for individuals with I/DD. MCOs across the nation must be explicitly taught to rethink how care management and service authorization decisions are made for conditions that are not treated or cured medically and when decisions must respect individual choice.

The Medical Model does not serve I/DD populations well.

A medical model does not align well with supporting persons with I/DD because medical models focus on the impairment of the individual and base service approval decisions on medical research of whether a person's physical, mental or sensory function will be corrected. When an individual has a disability that will either not improve or eventually be "cured", medical care and supports are not justified under a medical model.

Traditional insurance plans such as Medicare and Blue Cross have historically utilized medical models of approving services. An MCO applying this model uses national utilization review criteria and does not approve a service unless the impairments or disability could be 'fixed' or changed by medical and other treatments. A medical model also does not traditionally cover services for long-term impairment that does not cause pain or illness. For example, Medicare does not provide home health or nursing facility care for longer than 90 days or to individuals who are not home bound.

A person-centered planning model looks at supporting individuals with disabilities in the community outside of institutions and removing barriers that restrict life choices for disabled people. When barriers are removed, disabled people can live in the community in less expensive more inclusive settings with their families, be independent, and have choice and control over their own lives. Community living can result in better health outcomes and significantly less medical expenses and institutional costs.

To do this, a person-centered planning model looks at personal goals and needs of the individual. For example, a person-centered planning model would look at the richness of individuals' lives which in turn improves health outcomes. For example, person-centered planning fundamentally addresses the 30-35% of IDD individuals who have mental illness through community integration and support of meaningful activities such as work instead of solely through medication and therapy or institutionalizing individuals in facilities or isolating them in their homes

Other States are looking at Alternatives to integrated managed care organizations that leverage traditional provider experience.

Many states such as North Carolina, Arkansas, and New York are instead looking at alternative delivery system models with leadership by traditional providers of LTSS to ensure that care managers and service authorization decision makers in the new delivery system understand the needs and tradition of person-centered planning associated with the I/DD community. These states have found that the traditional medical model managed care plan structure and utilization review did not incentivize supports for individuals with I/DD that improves quality of life, outcomes, and protects health and welfare.

Example of HCBS Model working for a young adult with IDD

For example, a medical model for a young adult with IDD who has high triglycerides because of his impulse control and anti-anxiety medications would authorize and pay for the young man to have medical tests and a visit to the Children's Mercy Preventive Cardiology clinic.

While a medical model would not pay to help the family implement the Cardiologist's recommendations, the person-centered planning model would pay for assistance to the family such as providing 24 hour supervision with an attendant if the Cardiologist found that the young man could not/will not follow if the instructions the doctor gives because of his cognitive ability.

The person-centered planning approach would require the young man's family to provide supports to the best of their ability. The plan would provide additional supports to help the young man follow the instructions and learn to follow the instructions in different settings that met family and personal goals, such as during Sunday School when his family also attends church or attending job skill classes while his parents work.

The person-centered planning model recognizes that a disabled youth wants to work in competitive employment and that the family needs supports and respite breaks to support the individual with IDD outside of an institution.