LONG TERM CARE SERVICES AND SUPPORTS FOR PERSONS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

MARCH 20, 2013

Newpoint Healthcare Advisors, at the request of InterHab, analyzed the impact of Kansas Medicaid including home and community based services (HCBS) for clients served in the mentally retarded/developmentally disabled (MR/DD) federal waiver via managed care system. For the purpose of this analysis, the discussion will focus on home and community based services for persons with intellectual/developmental disabilities (I/DD). Issues addressed include analysis of published reports and literature currently available regarding:

- Client outcomes as a result of participating in Medicaid managed care;
- Experience in other states with Medicaid managed care focusing on the impact to clients; availability of services; and cost savings; and
- Best-practices on how to implement Medicaid managed care for I/DD clients.

BACKGROUND

Launched in January 2013, *KanCare* (Kansas Medicaid program for 380,000+ consumers) is operated by the Kansas Department of Health and Environment and the Kansas Department for Aging and Disability Services. Kansas contracted with three managed care organizations (MCOs) to coordinate and integrate health care for nearly all Medicaid beneficiaries: Amerigroup of Kansas, Inc. (Amerigroup), Sunflower State Health Plan (Sunflower), and UnitedHealthcare Community Plan of Kansas (United).

Inclusion of services provided through the HCBS waiver for consumers with intellectual or developmental disabilities (I/DD) is delayed until January 2014. Home and Community Based Services provide individualized services and supports to people with intellectual and developmental disabilities who are living with their families, in their own homes or in other community settings, such as small group homes. LTSS for persons with I/DD is based upon habilitation which is the process of supplying supports around the person enabling them to function at their maximum independence in activities of daily living, accomplished via staff support and accommodations to their environment. By contrast, a medical model focuses on rehabilitation which involves treating the individual to bring about an improvement of health or ability to engage in an activity. Long-term services and supports covered through HCBS services help people with disabilities accomplish everyday tasks that many of us take for granted such as bathing, getting dressed, fixing meals and managing a home. Care is typically provided by community service providers (CSP) and managed by a local Community Development Disability Organization (CDDO).

Persons with intellectual and developmental disabilities are included in *KanCare* for their physical and behavioral health needs including the care coordination of these services. The question at hand is whether there is sufficient evidence that there will be a benefit to the clients, the specialized local providers, and the State to including HCBS services for persons with intellectual and developmental disabilities in *KanCare* on January 1, 2014.

Kansas has been a leader in providing home and community based services for persons with intellectual and developmental disabilities. This is demonstrated by the enactment in 1996 of the Developmental Disabilities Reform Act that states:

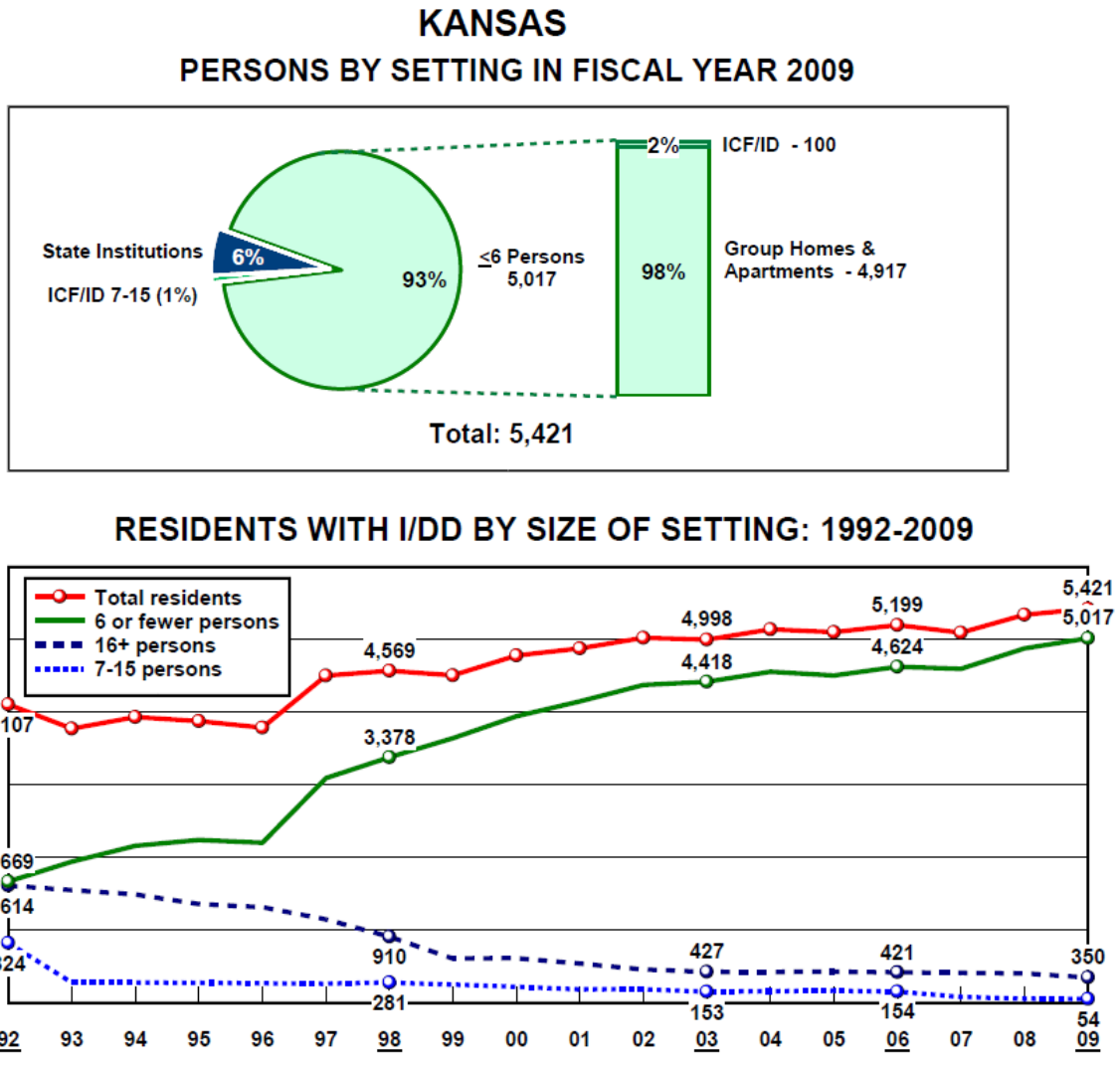
"It is the policy of this state to assist persons who have a developmental disability to have:

(a) Services and supports which allow persons opportunities of choice to increase their independence and productivity and integration and inclusion into the community;

(b) Access to a range of services and supports appropriate to such persons; and

(c) The same dignity and respect as persons who do not have a developmental disability."

The following data demonstrate the effectiveness of the current program at serving clients in their communities and in smaller settings:[1]



[1] http://www.stateofthestates.org/index.php/intellectualdevelopmental-disabilities/state-profiles. Accessed 3/15/2013.

Kansas has also demonstrated significant cost savings through the implementation of the Developmental Disabilities Reform Act. University of Minnesota research has shown an approximately 16 percent decrease in **actual dollars** in Medicaid ICF-MR, HCBS combined per person expenditures between 1993 and 2009.[2] This is due to the decrease in the use of institutions and successfully allowing persons to be integrated into the community.

Managed care experience is limited nationally in providing HCBS services for people with Intellectual and Developmental Disabilities (I/DDs). Managed care research has, until recently, focused on physical and behavioral health outcomes and costs. More recently, as states have begun to implement managed care for dual eligible and I/DD clients, there has been increased interest in determining the effect of various models on outcomes. As stated in the assessment of a proposed Texas pilot to serve people with intellectual and developmental disabilities "people with I/DD generally have long-term support needs that are focused on daily, consistent habilitation… and less apparent opportunities for savings."[3]

RESEARCH FINDINGS

We were unable to identify any research articles that address outcomes for people with intellectual or developmental disabilities enrolled in Medicaid managed care for I/DD services. A 2011 comprehensive assessment of literature on case management outcomes for Medicaid managed care for the disabled by Mathematica Policy Research was not able to report on any research that had examined the impact of care coordination for people with I/DDs.

> "…no studies that examined care coordination for people with developmental/intellectual impairments or sensory impairments met our inclusion criteria."[4]

While outcomes research may be available in the future, it is not currently available to inform the design of managed care for people with intellectual and developmental disabilities.

In their February, 2012 Issue Paper, the Kaiser Commission on Medicaid and the Uninsured reported that managed long-term care programs have promise to be more cost-effective but "experience with and evidence about such programs in Medicaid is still limited."[5] They further report that there is little evidence whether the model saves money or "how it affects outcomes for beneficiaries."[6]

In a July, 2011 Report to the NY Managed Long Term Care Implementation and Waiver Redesign Work Group, James M. Verdier of Mathematica Policy Research observed that the return on investment from Medicaid managed long-term care is "long-term and hard to measure and explain."[7]

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[2] K. Charlie Lakin, Sheryl Larson, Patricia Salmi, and Amanda Webster. *Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2009.* College of Education and Human Development, University of Minnesota. 2010. P. 84, 85.

[3] Health Management Associates. *Final Report*, *Pilot to Serve Persons with Intellectual and Developmental Disabilities.*. October, 2010. P.4

[4] Melanie Au, Samuel Simon, Arnold Chen, Debra Lipson, Gilbert Gimm and Eugene Rich. *Comparative Effectiveness of Care Coordination for Adults with Disabilities.* Mathematica Policy Research. July, 2011.

[5] The Kaiser Commission on Medicaid and the Uninsured. *People with Disabilities and Medicaid Managed Care: Key Issues to Consider*. February, 2012. .p.ii.

[6] Ibid.p.ii.

[7] James M. Verdier. **Managed Long Term Care: Options for New York and Examples from other states.** Mathematica Policy Research, Inc. for the Medicaid Redesign Team. New York, NY., July 8, 2011. P.25.

Laura Summer and Joan Alker of the Health Policy Institute at Georgetown University assessed the implementation of Florida's proposed Long-Term Care managed care program. They reported that current research indicates that managed long-term care (including facility-based care) "reduces the use of institutional services and increases access to home and community-based services" but they reported there was no definitive research showing that these programs save money or how it affects consumers.[8] In their recommendations concerning the Florida implementation, they express concerns about a hasty implementation specifically concerning managed long-term care and the potential risks to a needy and vulnerable population.[9]

There appear to be no current outcome studies measuring the impact (in terms of quality, client outcomes or cost) of providing HCBS services to individuals with intellectual and developmental disabilities through managed care systems.

Since financing has a strong relationship with access to care and the way services are rendered, the lack of outcomes research is concerning as Kansas considers including LTSS services into managed care for people with intellectual/developmental disabilities.

THE STATE OF THE NATION: WHAT IS THE EXPERIENCE NATIONALLY?

States are moving rapidly to implement new financing and service delivery models. The Centers for Medicare and Medicaid Services (CMS) reported that between 2004 and 2012 managed long-term services and supports programs doubled for the Disabled and Elderly populations. The number is projected to reach 26 by 2014.[10]

States are proposing new plans and waivers at a rapid rate. The literature and even state websites may not be up-to-date. Based on the most current information available, approaches to Medicaid long-term managed care across the states is extremely diverse.

- Eight of the sixteen states in the CMS survey reported voluntary enrollment;
- Half of the states do not include children with disabilities in the managed care arrangements;
- Programs have often been phased in gradually, focusing on specific counties to gain support and assess the approach until the systems can be proven to work effectively. This includes Wisconsin, Texas and Massachusetts;
- States that include people with intellectual and developmental disabilities in managed care often focus managed care on physical and behavioral health as a way to improve outcomes and reduce costs and do not include (or include in separate programs) long-term care services; and
- Alternatively, there are states that have separate managed care systems for clients with special needs, including individuals with intellectual and developmental disabilities, recognizing the very different needs of the clients and services provided. This includes Texas, Wisconsin, New Mexico and Arizona, to name a few.

[8] Laura Summer and Joan Alker. *Proposed Medicaid Long-Term Care Changes Raise Host of Questions About Impact*. Health Policy Institute at Georgetown University. Pg 4.
[9] Ibid, pg 1
[10] Paul Saucier, Jessica Kasten, Brian Burwell and Lisa Gold. *The Growth of Managed Long-Term Services and Supports (MLTSS) Programs: a 2012 Update.* Centers for Medicare and Medicaid Services. July, 2012.

COST SAVINGS

The opportunities for cost saving in managed care for clients with disabilities are reported to be generated from:

- Improved coordination of physical and behavioral health (e.g., improving medication adherence, reducing hospitalization); and
- Deinstitutionalization from ICF/MR facilities into community settings.

Although stated slightly differently, these are the goals of the Kansas Developmental Disabilities Reform Act that appear to have been implemented in Kansas. The studies referenced above (Braddock, et al and the University of Minnesota)[11] demonstrate that 98% of individuals with developmental disabilities are living in the community which is consistent with Kansas law and recommended best practice, and at a cost significantly below that which Kansas experienced in 1993.

In 2010, an analysis in Texas to develop a plan to implement a **managed care pilot for Long Term Services and Supports (LTSS) for individuals with I/DDs** was undertaken at the direction of the legislature. The report of the Texas LTSS pilot analysis states that there is some "disagreement among researchers concerning the validity of cost-saving estimates associated with managed long term care" as well as concerns about the ability to project savings across states given the vast differences in programs.[12] In an article by H. Stephen Kaye, et al, it was reported that long-term care spending was lower for states with established non-institutional programs than states with less reliance on non-institutionalization. This is consistent with other research that finds that Medicaid long-term care cost savings have been generated primarily from deinstitutionalization.

The Texas Pilot analysis further found that:

- ***capitated models (for I/DD LTSS services) are not likely to yield net savings to the State to warrant implementing a capitated pilot from a cost perspective.***[13] and
- ***There is not sufficient knowledge about the potential cost savings from including I/DD services in a capitated model.***[14]

The report recommended a **three-year pilot using a non-capitated enhanced care management model** to test strategies such as use of utilization management guidelines and development of more cost-effective forms of residential care while avoiding:

> "a major redesign of the I/DD service system until there is evidence to justify this level of change." [15]

[11] Braddock, et al. http://www.stateofthestates.org/documents/Kansas.pdf and University of Minnesota. *Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2009.*
[12] Health Management Associates. *Final Report*, *Pilot to Serve Persons with Intellectual and Developmental Disabilities.* p. 15.
[13] Ibid. p 2.
[14] Ibid. p. 42.
[15] Ibid, pg 2

The Kansas pilot, discussed in more detail below, is structured quite differently. It is proposed for less than one year (March 1, 2013 through December 31, 2013) to introduce clients to *KanCare*, not to test strategies or implementation plans.

In their February 2012 Issue Paper on "People with Disabilities and Medicaid Managed Care: Key Issues to Consider," the Kaiser Commission on Medicaid and the Uninsured reported research on four states that:

> "*The potential for savings… lies in more appropriate patterns of care over time, especially reduced hospital utilization, that may result from better management of prescription drug use and more advanced clinical management and care coordination for people with disabilities."*

KanCare includes a comprehensive managed care model with clinical management and care coordination for physical and behavioral health for all Medicaid clients including persons with intellectual and developmental disabilities. The outcomes described above in the Kaiser Commission paper of reduced hospitalization resulting from better management of prescription drug use and other clinical care management approaches are built into the *KanCare* program implemented 1/1/2013. The discussion here focuses on **care management and service delivery of the highly specialized long-term care services and supports (described above) for people with intellectual/developmental disabilities. We were unable to find research that identifies cost savings resulting from including LTSS services for (deinstitutionalized) I/DD clients living in the community.**

OPERATIONAL READINESS

A pilot program has been included in the *KanCare* design to "allow providers and beneficiaries to become familiar with the benefits of managed care for their HCBS and will help the MOCs to learn more about the unique needs of this population and program."[16] The state has been quoted as saying that the pilot was not intended as a test but to "help people get used to it."[17] The purpose of pilot studies is typically to test that the proposed new approach works in the defined setting. As described in a CMS Pilot study of changing to e-prescribing standards in long term care settings, CMS implemented a pilot: "To study the effects of (the intervention)… on cost, quality and safety."[18]

Colorado has a regional care coordination program (Accountable Care Collaborative Program) in place and has incrementally included eligibility categories into that program. An evaluation of the program is being done by the independent organization to report on the impact of the ACC regarding the central goals and key components of the program. Colorado is currently soliciting proposals from their Regional Care Collaborative organizations for a three-year pilot to test new methods of delivering and paying for Medicaid beneficiaries' care that aim to coordinate a broad range of health and social services—and shift some financial risk for the costs and quality of care to providers.[19]

[16] waiver approval letter from Marilyn Tavenner, Acting Administrator, Centers for Medicare and Medicaid Services, Department of Health and Human Services, December 27, 2012.
[17] Kansas Health Institute, February 11, 2013, by Mike Shields, KHI News Service, p.3.
[18] http://healthit.ahrq.gov/images/sep17erxwebconference/e_rx_standards_files/textmostly/slide32.html. Accessed 3/15/2013.
[19] Sharon Silow-Carroll, Jennifer N. Edwards, and Diana Rodin. *How Colorado, Minnesota and Vermont are Reforming Care Delivery and Payment to Improve Health and Lower Costs*. The Commonwealth Fund, March, 2013.p.3.

Texas performed a comprehensive assessment of the potential cost-savings and risks of various pilot models. The assessment recommended a three-year pilot prior to implementing managed care for LTSS services for people with intellectual and developmental disabilities in order to allow sufficient time to fully implement the pilot and collect and evaluate data. The report further recommended that there be a formal evaluation of the pilot that analyzed the impact mid-way through the pilot and at the conclusion.[20]

Another important area to consider in operational readiness is assuring that there is effective oversight and performance monitoring that is tailored to LTSS services for people with disabilities. In an AARP Public Policy brief, the authors reported that states with experience in Medicaid managed LTSS (MLTSS) stressed that it was important to "establish clear and measurable system and population specific goals in the early stage of program planning." [21] They further reported that states that are new to MLTSS may find it difficult at first to implement the oversight and norms that are needed and that they may need to consider "readiness-reviews" for MCOs before adding Medicaid managed LTSS.[22]

Success of any change initiative, large or small, is largely dependent upon the following:

- Building stakeholder readiness for the changes before they are implemented in order to build support for what will transpire, including creating a process to engage stakeholders affected by the changes;
- Developing a transparent operational/implementation plan that identifies all major tasks, individual accountabilities and an evaluation process that includes feedback loops and a defined method for using the results to modify operations as necessary;
- Implementing a communication plan that aligns all messaging, reinforces frequently the urgency for why the change is taking place, clarifies the impact on stakeholders and what will occur by when. To support a successful implementation, the communication process needs two-way dialogue so stakeholders can engage in meaningful dialogue about their questions and concerns; and
- Commitment from key executive sponsors and openness to dialogue about how to improve implementation plans and modify the process as a result of new information through evaluation.

When large system change transpires without an ability to adapt as the process ensues, the outcome is often the inability to reach intended goals. **The benefits of driving a change that is not well planned and evaluated, even if it is a potential improvement, rarely outweigh the resulting disruptive consequences.** Further, during the course of change, inevitably there are unintended and costly problems that can threaten the entire initiative if not addressed prior to implementation.

[20] Health Management Associates. *Final Report*, *Pilot to Serve Persons with Intellectual and Developmental Disabilities.* p. 43.
[21] Debra J. Lipson, Jenna Libersky, Rachel Machta (Mathematica Policy Research). Lynda Flowers, Wendy Fox-Grage (AARP Public Policy Institute) Keeping Watch: Building State Capacity to Oversee Medicaid Managed Long-Term Services and Supports. AARP Public Policy Institute. July, 2012. p.36.
[22] Ibid. p.38

It appears that the state engaged in planning and stakeholder input in developing *KanCare*, although advocates do not believe that the concerns they raised were addressed. However, on the issue of including LTSS for clients with intellectual and developmental disabilities, there remain unresolved questions and serious concerns on the part of the stakeholder community that were reported to the Consultants.

- How will clients and local community providers be affected by the change?
- What effects may occur that will be high risk?
- How can stakeholders be engaged in meaningful planning and communication efforts?
- What resources are needed to support planning, communication, evaluation, etc.?
- What does success look like and how will it be measured? How will we know if we are being successful?
- What performance measures are being used to assess the managed care organizations specifically addressing processes or practices associated with successful delivery of person-centered services for people with developmental/intellectual disabilities including structure and quality of life outcomes?[23]
- How have cost savings been calculated? Are these reasonable given that clients are already living in the community and receiving services from local community providers with case management and monitoring occurring from community developmental disability organizations?
- What data do we need to support the operational plans?
- How will data be used in a transparent and meaningful manner to modify program design and implementation on an ongoing basis?

At this point in time, the existence of unresolved operational and outcomes issues suggests the need for additional time and evaluation to assure that the program can be implemented with minimum disruption to clients and local service systems and not have a negative impact on client outcomes. A pilot program that is consistent with approaches used by other states and CMS would test:

- Operational systems;
- Interfaces between local providers and managed care administration;
- Include an outside independent evaluation; and
- Adequate time to synthesize results and make needed changes

This approach may allay the concerns of clients, their families, providers and advocacy groups and result in a more effective system of care.

[23] HSRI Study. *What Really Matters:An Initiative on Excellence in Person-Centered Services, Principles and Practices in Person-Centered Services.* The Council on Quality and Leadership. Towson, MD. 2009. p.3.

RECOMMENDATIONS

1. At a minimum, delay implementation of LTSS for persons with intellectual and developmental disabilities in *KanCare* until a comprehensive pilot is implemented that measures system readiness at all three MCOs and:
    a. Determines realistic potential cost savings including how cost savings will be generated;
    b. Is designed using recognized program evaluation methods by an independent third-party;
    c. Operates for at least a year with an evaluation and corrective action period to follow;
    d. Is transparent to stakeholders;
    e. Identifies all issues that may need to be considered prior to implementation including the care management model, potential for cost savings, use of recognized performance measures, operational interfaces between the MCO and local providers, etc.;
    f. Identifies current resources and strengths, and engages community service providers, families and CDDOs in building successful relationships; and
    g. Includes a process for resolving issues and a reasonable timeframe for implementing program design changes that are critical to successfully caring for persons with intellectual and developmental disabilities.
2. Further evaluate the potential cost savings from including long-term services and supports for individuals with developmental disabilities in *KanCare* in a transparent manner with all information shared with stakeholders to determine whether:
    a. All MCO and state agency administrative costs have been included;
    b. Cost savings have been computed and if they are derived from reductions in service or payment to providers; and
    c. Cost savings reflect the additional staffing needed to meet performance objectives especially in the area of improving supported employment goals.
3. Establish performance objectives and benchmarks that reflect the specific needs of persons with intellectual and developmental disabilities being served in community settings in a collaborative processes with all stakeholders (state agencies, the legislature, local community providers, clients/families and MCOs). Best practices suggest that this process is a component of the planning stage and should be in place prior to implementation.