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CONTACT

NEWS FROM COTTONWOOD

DATE: January 23, 2012

TO: Senator Vicki Schmidt, Chair

Members, Senate Public Health and Welfare Committee

FROM: Sharon S. Spratt, CEO – Cottonwood, Incorporated

RE: KanKare - Proposed Managed Care and the Kansas I/DD Long-Term Care System

Thank you for allowing me the opportunity to speak with you today. My name is Sharon Spratt and I am the CEO for Cottonwood, Incorporated. I have worked in the Developmental Disability field for nearly 40 years and been witness to the many positive changes that now allow for individuals with Intellectual/Developmental Disabilities (I/DD) to live full and rewarding lives in their own communities. Where futures were once bleak, they are now bright with opportunity. We have made great gains. I am here today to voice my hopes that those gains are not undone by carelessly leaping ahead without due consideration.

Knowing that Medicaid Reform was high on the radar nationally, and in an effort to be proactive, our state association InterHab, at its fall 2010 Strategic Planning Retreat, formed a Medicaid Reform/Managed Care Task Force. I, along with Ron Pasmore of KETCH in Wichita, serve as Co-Chairs for the Task Force. The Task Force's early predictions were confirmed with the announcement that the new Administration would propose a fully encompassing Managed Care plan for Medicaid reform.

Our Task Force went quickly to work – researching what was happening in other states, developing our White Paper (see attached), and contacting professionals on a national level to learn more. A few of us met with Lt. Gov. Colyer in February and have continued since then to meet with members of the Administration to share our concerns about being included, or carved into, KanCare. We learned that many states were implementing some sort of Managed Care model, but only on the medical and mental health programs. We also learned that long term supports and services for persons with I/DD were being excluded. The administration indicated that they were hearing the opposite, i.e. that more and more states were including I/DD in Managed Care proposals.

So in October 2011, eight members of our state association, InterHab, attended a Managed Care Summit in Washington, DC. The Summit was sponsored by ANCOR, The American Network of Community Options and Resources, a national group which advocates for organizations serving persons

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with developmental disabilities. The summit was neither 'pro- managed care' nor 'anti-managed care', but was merely a forum where the experiences of the States were being reported. It was at that summit we learned that only four states have included long term services for persons with I/DD in their Managed Care plans and they all vary in different ways as you have heard in recent testimonies. While medical needs of persons with I/DD were covered by medical managed care models, their day, residential and case management services generally were not. That is an important point.

When we looked at what's really happening in these and other states, we found again as we had previously, that states are excluding long term supports and services for persons with I/DD from their Managed Care system. See Kaiser Commission chart of various states (attached). Please note, the report in its entirety can be found online at http://www.kff.org/medicaid/upload/8243.pdf.

We believe that Medicaid Waiver Services for persons with I/DD are not a good fit for Managed Care. Our system initiated Medicaid Reform over 15 years ago with the implementation of the Developmental Disability Reform Act (DDRA) which includes a capitated Tiered System of services. The costs of our system are predictable and there are strong systems in place to manage the I/DD system effectively efficiently and without undue conflict of interest, using a peer-based quality oversight system.

Our system has always strongly advocated for obtaining funding to provide quality community-based services. The Medicaid Waiver has been an effective funding stream for that purpose; however, perhaps it is unfortunate there wasn't a single dedicated funding source just for the persons we serve. Then, perhaps we wouldn't be grouped together with the medical Medicaid Managed Care piece. We, in the DD field, have worked tirelessly over the past 40+ years to correct the misimpression that the people we support are 'sick'. They are not 'sick'. These individuals have life-long, 24/7 disabilities and we provide daily supports and services to help them live a safe and productive life.

Recently, the administration acknowledged that Kansas, in its drive for Managed Care, proposes things that no other state is doing – i.e. full implementation of long-term waiver services for persons with I/DD into a managed care model – without studying it and without conducting pilot sites to see how it works.

Two weeks ago Secretary Sullivan and some of his staff met with several InterHab members to clarify concerns voiced by consumers and their families that with Managed Care, they would lose their case manager. The Secretary assured us in that meeting, as well in meetings later on that week, that no changes would be made to the I/DD system. Consumers could keep their case managers, CDDOs would continue to operate in the current manner. Our system, since it is run so well, would operate as a parallel system within the KanCare model. Then last Thursday at a CDDO/Stakeholders meeting, we were told that under KanCare, our system would continue to operate as usual for the short term...? Our fears and concerns were once again heightened.

It's too much change, too fast, by an administration that does not fully understand our system. MCOs readily admit they have not served our population in other states where they operate Managed Care, however they are compelled to submit their bids for the I/DD system because the administration insists on keeping the proposal generally as is.

We would urge you to slow this proposal down and allow the medical and mental health managed care model to be implemented, before considering moving long-term I/DD services into the same model. We have all worked too long and hard to let the gains of the last 40 years fall away in the rush to implement a plan which has not been thoroughly vetted. Once again, thank you for the opportunity to voice my concerns.

Sincerely,

Sharon S. Spratt

CEO

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INTERHAB

August 17, 2011

Medicaid Reform Recommendations: *Improving Services for Kansans with Developmental Disabilities*

I. Introduction:

a. The membership of InterHab is determined to be constructively engaged with the Administration in working to maintain a broad community network of quality services and supports for persons with developmental disabilities (DD). We share the Administration's goal to strive to make Medicaid funded services the highest in quality and most efficient in cost as possible. InterHab convened a workgroup of its members in late 2010 to engage our membership and affiliated service providers in the development of suggestions which can contribute to the Administration's evaluation of Medicaid cost concerns.

b. The Kansas community-based system of supports for persons with developmental disabilities is a remarkable example of locally-designed and controlled privatized managed care. The Kansas DD system exhibits many classic managed care features including annual assessments to ensure continued eligibility, an individualized needs assessment process used to determine the services that are necessary are being provided, a system to address persons with extraordinary needs, strict definitions for persons requesting services who are in crisis, referral of persons to other less costly service options, a capitated payment structure for services rendered; management of the system through a network of locally-designated gatekeeping entities called Community Developmental Disability Organizations (CDDOs); a quality assurance and data system managed by the CDDO's, a State-operated licensing system for many providers of service, local stakeholder councils (made up by a majority of people with disabilities and family members) who collaborate with CDDOs on program delivery and design, and utilization management reviews conducted through CDDO's.

c. As with long-term care for older Kansans, long-term services and supports needed by Kansans with developmental disabilities (DD) are not typically medical and cannot be weighed on the same scale as the care provided by physicians, hospitals, pharmacies, etc. While medical services are episodic in nature with the intended result of resolving the medical problem or illness, supports for persons with developmental disabilities are needed on a life-long basis with the desired

outcome of improving or maintaining optimal functioning in daily activities of life. Community services for persons with DD strive to reduce costs through helping individuals achieve increased levels of independence, and assist in the development of natural supports where feasible. A developmental disability affects the entire family, often requiring family members to make life-long sacrifices to provide care to an adult child. This creates an economic burden to the family that negatively affects their ability to be self-supporting, putting pressure on other State-funded human service systems.

d. Growth in the cost of the HCBS-DD program cannot be credited to a growth in the cost of service delivery so much as growth in the number of persons being served in the program. The number of persons and families served with HCBS since January 2000 has increased by 2,781 or 53%. Growth in the rates paid to providers increased at about one half the rate of inflation since 1993.Each time Kansas has closed a state institution or private ICF/MR, residents have entered community services funded by the HCBS-DD waiver. Their medical costs also shifted from the institution's medical care providers to the community paid for by Medicaid. Children with developmental disabilities at risk of going into the foster care system, served by the foster care system or exiting the foster care system are automatically added to the HCBS-DD waiver. Individuals who are MR/DD eligible and on time-limited waivers (Technology Assisted, Autism and Traumatic Brain Injury waivers) many times are automatically added to the HCBS-DD Waiver. To date there are over 7,016 adults and 1,044 families with children receiving services through the HCBS-DD waiver. Despite this, over 4,500 families and adults remain in need of services and are on the State's waiting list.

e. Community services funded through the HCBS-DD waiver have been recognized within Kansas and nationally as the lower cost alternative to institutional and nursing home care. Kansas was one of the most progressive states in the early 1990's when we started to aggressively utilize the HCBS-DD waiver program by re-financing pure state general fund dollars into the Medicaid program in order to incorporate the federal match. Many states have only recently begun a similar strategy and are much more heavily invested in costly institutional services still today.

f. Special Education students currently wait for four to five years on the State's waiting lists to obtain community services. While waiting, they lose the skills learned during their school years – leading to regression and more costly re-training once they are finally able to enter adult services. Some of the students waiting for HCBS services could perhaps be directed to apply to Vocational Rehabilitation Services that could lead to competitive employment.

g. It is critical that the community service provider system continue to maintain an acceptable level of quality in the provision of services to persons with developmental disabilities. As the State moves forward with plans to manage the costs of community services, monitoring the quality of those services becomes even more critical to assure that system performance quality and outcomes are not sacrificed. Some States have successfully utilized nationally-recognized

standards as an independent benchmark to enhance their in-house quality assurance systems. It is recommended that Kansas consider enhancing its own quality management system through encouraging its providers to seek adherence to nationally-recognized standards. It is further recommended that the State consider incentives such as start-up costs to assist providers in this regard.

II. Principle Statements and Recommendations:

a. InterHab's members formulated principles by which recommended Medicaid reform initiatives could be gauged. It was our goal to approach Medicaid reform from the standpoint of how the current community service system could be improved, while still meeting the Governor's stated objective of improving services and lowering costs. Identified principles include:

Principles:

i. "Do no harm" to persons served or families.

ii. "Local management" - as contained within the KS Developmental Disabilities Reform Act, local communities best know how to meet the needs of the persons they support.

iii. Public/private partnerships that promote increased independence should be fostered and incentivized.

Recommendation 1: The opportunity for cost savings of the HCBS-DD services through managed care is limited at best, while the potential for decrease in the quality of services received is high. As envisioned in the Developmental Disability Act of 1995, long term care supports for persons with developmental disabilities are most effectively managed when done so as close to the person receiving services as possible. Most states that have introduced managed care over their Medicaid programs have chosen to carve-out most HCBS services. We strongly recommend that the State of Kansas also carve out these services.

Principle:

iv. Any proposal would need to fully address the problem of direct-care staff turnover - the key to quality and cost containment outcomes.

Recommendation 2: We hope the administration will evaluate the HCBS-DD program to assure that adequate and necessary resources are currently provided in the reimbursement model. The State's own rate studies have presented clear evidence that our community service reimbursement rates are insufficient. High direct care staff turnover leads to inefficiencies in the service system in addition to degraded quality of services.

Principle:

v. *Any proposal must maximize "family friendliness" - accessibility to the service system by families needing services must be maintained and enhanced.*

Recommendation 3: One initiative that has been in development for the past few years, a "Family Support Waiver", is right in line with efforts to maximize the effectiveness of available funding. The Family Support Waiver concept would offer families of school-aged children the opportunity to select a service plan that is more flexible than current support offerings to better meet specific needs of the individual. Young people who are living in the family home typically can only access hourly support staff when services are made available. The new waiver concept would allow families to utilize available funding to select from services, therapies and/or items that would best meet the needs of a child with disabilities. Efficiencies will occur related both to the effectiveness of using services that are targeted to specific needs of the individual, by capping the maximum cost of the average service plan at an amount that is less than the current average plan cost, and preventing possible entry into foster care. By reducing the average expense for service plans on the Family Support Waiver, the intent is to create "savings" that would allow services to be offered to those who are currently waiting.

Principle:

vi. *Better emphasis on early intervention and seamless transition from special education is needed.*

Recommendation 4: Early intervention services are extremely cost-effective investments for Kansas taxpayers, as a significant number of children who receive these services early in life will not need more expensive supports throughout their lifetime. Infant and toddler providers have ascertained that as many as three out of five children receiving "tiny-k" early intervention services will not need special education services by the time they enter school. As a proven preventative method, we recommend that Kansas place emphasis on providing enhanced funding to bolster early intervention services for infants and toddlers with developmental disabilities.

Principle:

vii. *Lack of access to medical care, such as dental care, in the community is a major barrier to cost containment, because unmet basic needs become expensive emergencies.*

Recommendation 5: Explore integrated care model concepts, which are specialized around the medical needs of persons with developmental disabilities. The community service system currently utilizes medically trained professionals who manage medical services provided to persons receiving services, including preventative health care, medication management, and integration of health care

recommendations into our service plans. Building on the expertise that currently exists with our providers using the integrated care models would serve to assure service needs of this complex population are integrated with their other needs, and over the longer term reduce costs.

Principles:

viii. *Any proposal must promote the program goals contained in the DD Reform Act of greater independence, integration, inclusion, and productivity.*

ix. *Any proposal should promote expected outcomes that enable persons with developmental disabilities to live lives similar to others in the community. Employment and self-determination should be emphasized in order to reduce reliance on supports to the greatest extent possible.*

Recommendation 6: Continue to support the cost effective programs provided under the HCBS-DD waiver. Pursue movement of persons from more expensive nursing home care, utilizing the Money Follows the Person federal program. Eliminate the use of state-operated institutions in favor of waiver funded community services. Re-direct the resources currently being spent on institutions to fund the waiting list and to reduce community services reliance on institutionalization.

Recommendation 7: The DD Reform Act includes a goal that community services increase the productivity of the persons being served. The recently passed Employment First legislation seeks to improve competitive employment outcomes for persons with disabilities. It is recommended that Kansas pursue maximizing opportunities for persons with developmental disabilities to increase their productivity through services that result in employment in the community. Over time, the more economically independent a person with a disability becomes, the less costly their long term service needs will be. Systems change should: expand job development and vocational supports by creating incentives to operate such programs, and address long-term services necessary to sustain employment. Such priority does not lessen the value of center-based programs people with the most severe disabilities who may need to develop their skills for private sector employment.

Principle:

x. *The State should engage in vigorous pursuit of eliminating barriers in the community to a fully inclusive life for persons with developmental disabilities, such as transportation, attitudinal barriers, housing, employment, etc.*

Recommendation 8: Explore the use of technology to increase efficiencies, promote staff retention, better meet individuals" needs, and meet overall goals of fostering the health, well-being and independence of Kansans with developmental disabilities. Technology may include simple adaptations in the workplace that allow a person to become employed, or adaptations in the home

that allow a person be more independent. Some states reimburse for services such as tele-monitoring in the home environment which can promote more individual independence. Transportation is generally regarded as a primary barrier for access to employment and amenities in most communities.

Principle:

xi. Persons eligible for services should receive them in a timely manner.

Recommendation 9: Eliminate the waiting list and develop methods to provide services seamlessly as individuals graduate from special education. The current system of waiting for services is very inefficient. Skills learned during school years are lost while young adults wait for services. Currently, services are usually accessed only after an individual, or their family, are in crisis, usually requiring more expensive forms of services. Keeping individuals on the track toward maximizing their capabilities requires less costly services. Some states have pursued federal programs which provide incentives to states to address their waiting lists in exchange for an enhanced match rate. We recommend that these opportunities be fully explored and used.

Recommendation 10: It is recommended that the State take full advantage of federal incentives within Medicaid to better serve Kansans with developmental disabilities. For example, this year all SGF funding has been eliminated that was providing supports for persons with developmental disabilities who do not qualify for the HCBS Waiver. CMS has recently authorized a 1915 (i) waiver which allows states to develop services for persons with disabilities who do not qualify for services under the current HCBS waiver. The State could develop a waiver 1915 (i) that seeks to increase competitive employment outcomes for persons who no longer qualify for state only funding. Maximization of the use of federal dollars would save the state money in the long term because by not serving this population, other service systems will be dealing with persons who cannot access appropriate supports from the developmental disability service system. The State could write such a waiver to very narrowly serve a group who cannot access the current waiver in employment related services only.

III. Conclusion:

The State of Kansas, through decades of highly successful public/private partnership, has built a quality community-based service system for persons with developmental disabilities. The system is considered to be one of the State's most successful privatization effort to date. What is needed at this juncture is an understanding of the value of such a mature and developed network of supports, and an effort to assist community providers in continuing to improve the system.

The membership of InterHab strongly values the outcomes embodied in the KS Developmental Disabilities Reform Act, which include Independence, Inclusion, Integration and Productivity. Our membership places a high value on supports that will assist Kansans with developmental disabilities in attaining those

outcomes. Improvements can be made that ultimately strengthen the outcomes envisioned in the Developmental Disabilities Reform Act that include:

- Carve out HCBS services for persons with developmental disabilities within any plan to implement managed care
- Support a reimbursement model that improves the availability and stability of our direct care workforce.
- Development of a Family Support Service waiver
- Continue and expand support for infant and toddler services
- Build upon the current expertise within the developmental disability provider community to coordinate preventative medical care
- Continue to pursue movement of persons with developmental disabilities from institutional based services to community based services
- Pursue policies that will reduce the barriers to and increase incentives for competitive employment
- Fully exploit opportunities available to eliminate the current waiting list and to fund services for persons who recently lost state only funding

Our membership looks forward to collaborating with the Brownback Administration in exploring opportunities to improve the Kansas developmental disability service system.

Table 1: Design Features for 11 Capitated Medicaid MLTSS Programs

State	Program	Target Population	Mandatory or Voluntary Enrollment	Scope of Services in Addition to Community-Based LTSS	Integrated with Medicare
Arizona	ALTCS	Frail elderly; people of all ages with disabilities, except developmental disabilities	M	Institutional LTSS; medical	N
Florida	Nursing Home Diversion	Frail elderly	V	Institutional LTSS; medical	Y
Hawaii	QExA	Frail elderly; people of all ages with disabilities, except developmental disabilities	M	Institutional LTSS; medical	N
Massachusetts	Senior Care Options	Frail elderly	V	Institutional LTSS; medical	Y
Minnesota	Senior Health Options	Frail elderly	V	Limited institutional LTSS*; medical	Y
New Mexico	CoLTS	Frail elderly; people with disabilities, expect developmental disabilities	M	Institutional LTSS; medical	N
New York	Managed Long-Term Care	Primarily frail elderly; some younger adults with physical disabilities**	V	Institutional LTSS; limited medical**	Y
Tennessee	CHOICES	Frail elderly; younger adults with physical disabilities	M	Institutional LTSS; medical	N
Texas	STAR+PLUS	Frail elderly; younger adults with physical and mental disabilities	M	Limited institutional LTSS; limited medical***	N
Washington	Medicaid Integration Partnership	Frail elderly; younger adults with disabilities****	V	Institutional LTSS; medical	N
Wisconsin	Family Care	Frail elderly; younger adults with physical or developmental disabilities	V	Institutional LTSS*****	Y

* Medicaid pays for institutional LTSS beyond 180 days on a fee-for-service basis.
** Age of eligibility and scope of medical services may differ by plan. Medical services that are not covered by the plan are covered on a fee-for-service basis by Medicaid or, for dually eligible beneficiaries, by Medicare MA plans.
*** Medicaid pays for institutional LTSS beyond 120 days and for in-patient hospital services on a fee-for-service basis.
**** The program operates in only one county in Washington.
***** Medical services are covered on a fee-for-service basis by Medicaid or, for dually eligible beneficiaries, by Medicare.