

Kansas HCBS-IDD Stakeholder Session September 20, 2013

Report for KDADS and HCBS-IDD Participants

Background

In September 2013, the Kansas Department for Aging and Disability Services (KDADS) hosted a Stakeholder Listening Session for HCBS-IDD Participants, Providers, Friends and Family with national advocates for intellectual and/or developmental disabilities. The Home and Community Based Services (HCBS) Division at KDADS hosted national speakers to provide training and information about intellectual and developmental disabilities, managed care, and upcoming transition into KanCare. Ari'e Ne'eman from the Autism Self-Advocacy Network, Barbara Brent from the National Association for State Directors of Developmental Disability Services (NASDDDS), and Nancy Thaler, the Executive Director of NASDDDS, presented three separate half-days sessions for 1) KDADS and KDHE, 2) Managed Care Organizations, and 3) for HCBS-IDD Participants, Friends and Family members.

During the State session, the national speakers shared the national perspective with the KDADS and discussed ways to help the IDD community engage with the managed care organizations to improve our system. In the Managed Care session, Ari'e, Barbara and Nancy presented and discussed the unique options available for MCOs under KanCare and how different the long term supports and services for the I/DD population are to other populations. This training session included a historical look at person-centered planning philosophy, comparison of community living between Kansas and the nation, and creative solutions for building an individualized service plan of care to meet a person's needs.

The Participant and Provider session was designed to be a listening session instead of a presentation and/or education session. The three national speakers served as panelists for roundtable discussions about specific topics related to IDD and KanCare. Nancy Thaler moderated the discussion. The questions and responses found below were

recorded during those sessions. The session included members from the Friends and Family Advisory Council and the I/DD Pilot Workgroup.

The purpose of the Listening Session was designed to create an open forum where individuals could actively engage in the conversation with national experts and share their concerns and recommendations with the State. The goals were to:

- Provide an open forum for candid discussion
- Provide a space for self-advocates to ask questions and share discussions
- Provide an opportunity for the State to hear directly from consumers

The following questions were posed by the panelists of national speakers, and the answers were provided by those in attendance. Although they have been organized under category headings and reordered, the content has not been altered except to correct spelling or major grammatical errors.

1. What Do We Cherish About the Current System of Services and Supports for Kansans with I/DD and their Families?

HCBS-IDD Participant Responses

- Relationships
 - Long-standing relationships between providers/and people and families receiving services and supports
 - Long relationships between the providers/CDDO systems and the state, and these relationships help with problem solving with individual problems/situations
 - Self-advocates have community relationships, resources, and case manager helps with resources such as finding volunteer opportunities
 - Local case management — cherished relationships
 - Understood roles and responsibilities — clarity of roles for everyone
 - Local case manager is in the community, of the community, know their communities, easy access for interaction
 - Good communication within and across the system through:
 - Person/family talk to case manager and it is raised forward (direct communication)
 - "all hands on deck", direct problem solving
- Person-Centered Practice
 - Consumer choice and control

- Shaping services to meet the needs/interests of people being served through the relationships

HCBS-Provider Responses

- Clarity on data and what needs to be reported; therefore, there are accurate data on both quality and fiscal reporting
- Data Tracking
 - Discreetness and specificity of the data being reporting — broken down in ways to easy to track (not "lumped in" and can currently analyze and trend)
 - Transparency of data — valued data are publically available
 - Long-standing relationships create data that are understood, can be trended and can be used to for improvement and innovation
- System Funding
 - Low overhead in the system currently
 - Keeping jobs and, related, if case managers leave, what quality will be lost for people with disabilities/families?
 - Value discretionary funding that solves problems for people who aren't eligible for Medicaid or otherwise don't have access to services
 - Providers that have revenue in excess of expenses and/or local funds available who can use it to solve problems for people
- When there are "oopses" they are usually to the benefit of people receiving services and supports
- Timely payments without complications
 - Minimal disputes
 - Easy authorizations

2. What would make the service system better? What Do We Want to for People to Have a Good Life in their Community?

● HCBS-IDD Participant Responses

- Flexibility that allows people to live in family settings
 - keeps families together
 - family friendly policies
 - Allow family budget authority that enables self-direction.
 - Families need access to easily understood information about the system
- Community Options & Employment

- Person-centered plan being more accessible to individuals who do not read
 - Quality community options for people who with complex needs
 - More people getting employment opportunities — real competitive community-based jobs
 - Post education transition opportunities, i.e. secondary education;
 - Support through the transition from school to adult life to make it playful and smooth. Requires better coordination between school and LTS system.
 - Elimination of sheltered workshop, replacing them with something better.
 - Long-term service system focusing on true community inclusion/engagement
 - More support for self-advocacy; more advocacy training
- Waiting List
 - The people feel confident they will get what they need when they need it and they don't feel like they have to ask for everything now for fear there will be nothing in the future.
 - Eliminate the waiting list — more funding and investing savings from efficiencies and service changes into the waiting list
- **HCBS-IDD Provider Responses**
 - **Quality Improvement**
 - Better oversight over family/relative paid caregivers in self-directed services to improve quality
 - Rates that enable the retention of direct support professionals
 - A provide network that is robust and can meet the needs of everyone, everywhere and there can be oversight.
 - Consistent interpretations of rules across the state — need one interpretation — not multiple
 - **Employment**
 - VR and the long-term services (LTS) system restructured to reimburse based on employment outcomes

3. How can you make sure that the voices of individuals with disabilities and families' voices are heard?

- **HCBS-IDD Participants**

- **Positive Interactions**

- Perceptions of relationships between providers/state feels like families are in the middle — toxic environment. Then it feels like it isn't productive
- Create experiences that are positive
- Messaging that people understand that input is valued and it can shape and change minds

- **State Support**

- The state can support Parent-to-Parent networks, self-advocacy networks and Parents in Policy Making grads to hold forums on the state's behalf (and covered the respite and other support services)
- **SIDE NOTE** Re: Rural families — use social networking and communication technology to reach out to people and connect with and inform them.
- Partners in Policy Making is also good.

- **Engagement in the Community**

- Having family members present — family members with their loved ones with disabilities
- Self-Advocacy — Nothing about us without us — don't make decisions without talking with us — Come to a self-advocacy meeting — There are 18 to 26 self-advocacy groups across the state
- And to maximize the state's available time:
 - QA satisfaction staff used to come out to family homes; now there are monthly contacts with people on the waiver (families and people with I/DD)
 - The state needs to go to the families — go to existing family groups, go to the schools, go to their homes, go to providers
 - Go when there is time when a family is free to talk in a meeting room, i.e. Rainbows — or even appointments if a group setting doesn't work

- **Allow Input and Provide Information**

- Make forums for everybody — what will make people feel welcome
 - Worried about losing existing services
 - Worried about speaking up — and leads to concerns about losing to existing providers
- Get input from people in rural areas of the state

- A variety of voices rather than the "spokespeople" that generally speak up
 - People are involved — need the opportunity
 - Respite and or childcare — what resources might be available?
- **Forums & Education Sessions**
 - More frequency and more areas of Kansas
 - Electronic network and using technology; participating remotely
 - Adequate lead time to make arrangements; people need more time to plan
 - Spell out what are the benefits of coming to participate
 - Consider some communication forums that have families and self-advocates as sole participants
 - "Language Barrier" self-advocates and families are still learning the language
 - They could gather information neutrally around the feedback
 - Use the systems in place to get the information out (teachers, other groups to get information out to the families)
 - Need an independent peer voice (no other agenda)

4. What are your worst fears?

HCBS-IDD Participant response:

- **Relationships**
 - All the support staff will leave because they get paid less or won't get paid at all
 - We will become a number that that doesn't have an individual case manager that knows us
 - My son will never be able to live in the community without me
- **Services**
 - That services will be reduced
 - Older parents taking care of their adult children with I/DD who have their own issues/needs (mom wanted to quit services because of EVV for Personal Attendant Services)* Note: Nancy Thaler explained that EVV (electronic visit verification) is not specific to Managed Care and there are Federal lawsuits/criminal cases related to lack of EVV (or similar situation)
 - Fear of losing consumer choice

- **Managed Care**
 - Services will be reduced
 - Providers will leave because they can't get paid or pay is reduced
 - Balance of power will shift from consumers and families to other organization
 - That people won't understanding that you cannot cure someone or take away someone's disability (they are always going to have it)

HCBS-IDD Provider responses:

- **Provider Role**
 - Providers will close
 - Length of the transition (the length is causing stress on staff → then the people → then to the quality of the services) — The fear is the unknown
 - From a provider who runs a family created organization → how are we going to adapt, what is going to happen, and how do we make the right moves so that everyone we served is protected and receives the services that they need. Will we continue to exist, survive or be dramatically different, how will that manifest?
 - What happens when those of us who have connections/contacts and the MCOs "take over", how will we continue to get things done
- **Managed Care Organizations**
 - Dismantling system → if MCOs pull out what is left
 - MCOs and others don't understand the LTS system needs of the I/DD population (not the typical services including medical related issues)
 - Quality of care going by the wayside to meet financial targets
 - That this is nothing but a political move; literally gambling with people's lives
 - Fear that those that are served will leave services because they don't want to have to deal with bureaucracy
 - Dealing with three different entities for prior authorizations (DCF, KDHE, KDADS, MCO) don't work well together
 - MCOs are more answerable to shareholders than our stakeholders (consumers)

5. Where do you think your leverage points are in changing policy?

- If an idea/innovative proposal, could show that it would save money

- Vehicles to affect policy-making → legislators, but some families and consumers do not feel like they have a vehicle for effecting change
 - Family and Friends Advisory Council
- **Leverage points in the system**
 - Work with MCOs and state on the MCOs' **Network Plans**, i.e. contracted providers)
 - Insist on a robust provider network that is healthy, has sufficient rates to keep good providers in the system (don't lose the new and innovative one)
 - Advocate for those things that you do not have enough of or need based on your community, in home supports, supportive employment, etc. (Include the supports you want)
 - Traditional plans will not include some of the I/DD services, so you can work with the plans and state to tell them what you want to move toward
- **Performance Improvement Projects/Plans by MCO/State**
 - Some are health and clinically related
 - There are opportunities to have one associated with non-clinical PIPS, i.e. supported employment with a baseline and benchmark; supporting families)
 - The improvement plan and data is reportable and user friendly
 - MCOs can have individual ones focused on key issues
- **Clinical Practice Guidelines**
 - Medical guidelines are required
 - But can have them around Person-Centered Support Plan, Supportive Employment, etc.
 - They can be written in plain English so everyone can understand them
- **Member Handbooks/Consumer Rights and Responsibilities**
 - Right to contact to Human Rights Committee
 - Right to date, marry, etc
 - Right to not have to take too many medications
 - Other rights can be included in the Rights and Responsibilities Handbooks for each of the MCOs
- **Consumer Advisory Committees**
 - All (most) should have them and hold them locally and with local liaisons

- Opportunity to have meetings with families, self-advocates, and providers
- **Training**
 - MCO training for people with I/DD
 - Family members and consumers as trainers and being paid
 - Ongoing training and support — more than just the liaison's but all of the MCO staff
 - These are opportunities for individuals and families to engage the system
- **Contract, Manuals, Guidelines, Operational Tools**
 - Focus groups and other ways that state can engage the stakeholders.
 - Ensure that other binding documents have your input and your recommendations
 - If it is delegated, make sure that you are included in the oversight, along with the state agency
- **Establish a constructive relationship with the MCOs now.**
 - Don't wait to be invited
 - Self-Advocacy organizations scheduled face-to-face meetings with every MCO (example, Advocate in Georgia)
 - Ask MCOs to engage families and self-advocates
 - Ask that nothing go out the door until families and consumers had reviewed it
 - Ask about transition from school, provider choice, support coordinators going into homes, etc.