

# Kansas Mental Health Coalition

*Speaking with one voice to meet critical needs of people with mental illness.*

## Minutes

**June 26, 2019 Monthly Meeting**

**Valeo Behavioral Health Center, basement conference room, 330 SW Oakley, Topeka, KS**

**Introductions and sign-in sheet** Eric Harkness, President

Steve Solomon, Merging Trends

Dana Schoffelman, Florence Crittenton

Monica Kurz, Headquarters Inc

Mallory Lutz, BHAK

Sherrie Watkins, JCMHC

Sue Lewis, MHAH

Mike Burgess, DRC

Rocky Nichols, DRC

Bill Persinger, Valeo

Shereen Ellis, Aetna

Kyle Kessler, ACMHCK

Louis Brown

Matt Spezia

Corinna West, P3

Amy Campbell

On the phone:

Michelle Ponce, ACMHCK

Stacey Manbeck,

Jessie Kaye, Prairie View

Mary Jones, MHASCK

Marcia Epstein

Susan Montague, St. Francis

Heather Elliot, ACMHCK

Cindy Luxem, KHCA

**Minutes of the previous meeting approved.** Solomon motion, Schoffelman second.

### 9:15 a.m. Reports

**Board of Directors** – Meet today after the Coalition.

**Financial Report** – Bank balances \$222.96. Please pay dues to support KMHC. The dues for the community mental health centers are paid in July by the Association of Community Mental Health Centers.

**Advocacy Committee –Grassroots Advocacy Network** - Amy Campbell – Heather is on the phone – 2020 Advocacy Day will be February 19. We will be sharing that day with the Kansas Association of Social Workers. We are still collecting some sponsorships and exhibitor fees from the 2019 event. Next committee meeting is August 28, following the Coalition. All KMHC members are welcome to join the committee.

**Governor’s Behavioral Health Services Planning Council** – reports by members – Shereen Ellis reports that the veteran’s subcommittee is working on a short video for suicide prevention for veterans “Live Connected”. It is a product of the Governor’s Challenge for Veteran’s Suicide Prevention. Eric mentioned that NAMI has a council on veteran’s and families that could be instrumental.

Charlie reported that Wes may be released from his obligations at OSH before too long. The next Council meeting is July 17. Planning a retreat for the Council members and committee chairs to do some strategic planning. Have met with Secretary Howard, who is very familiar with the Council from her work at SAMHSA, and is supportive. Reforming the Aging Subcommittee that had ended a few years ago.

**Big Tent Coalition** - Jane Rhys and Mike Burgess – Secretary Howard will be joining us at our next meeting. Also looking forward to having the Secretary of KDHE and the Secretary of Commerce. BTC is planning another annual fall retreat for collaboration between the four largest coalitions in the state working on disability issues, including the KMHC. Has been late November in the past.

**KanCare Advocates Network** – The Government Accountability Office is to integration between Medicare dual-eligible special needs plans (D-SNP) and state Medicaid programs. See more on GAO and our study at the end of this email. Disability Rights Center has been asked to pass on contacts with stakeholders who are knowledgeable on this issue.

KAN meets weekly and the KDHE Medicaid Director comes regularly to exchange information.

Alliance for a Healthy Kansas recently sent information clarifying the support for Medicaid Expansion by disability advocates and organizations. In-home direct care workers often do not have insurance coverage and could benefit. Could attract more direct care

workers if coverage was available. Discussed the inaccurate use of disability waiver waiting lists as a reason for not expanding Medicaid.

**Consumer Programs** - Corinna West – Matt Spezia reported P3 has been extremely active. Recently had a technical seminar about social media marketing. Coordinating a number of arts advocacy workshops. Excited to be moving forward.

Poetry for Personal Power is one of two statewide consumer networks. Just completed Peer Recovery Network training. KDADS released its peer certification and the first person was certified Level 1 for P3. Next conference September 7-9. Trying to bridge advocacy networks – looking for corporate sponsors for conference. Will be Kauffman Center. Representing the next generation of peer recovery – don't wait in one place for people to come to us. Talked about the measures used by our program.

Our program consumer grant application was killed by KDADS – grant program doesn't award consumer organizations that are not the traditional CROs. Tired of being better than other programs but not having access to the public funds. It is good to protect consumer organizations from competition, until the system excludes important consumer work.

Peer support is at its essence information and relationships. There are many tools to deliver information and to develop relationships. Brick and mortar has its pros and cons, but should be one strategy among many. Peer support in mental health centers have pros and cons, but should be one strategy among many. We look forward to a day when we have equal access to public funds. We need to have equal access to federal grant opportunities, but that requires KDADS as the lead agency. Let's update the RFPs and the scoring processes in order to strengthen all of the consumer programs and peer services. Could be a part of the solution to the NFMH issue. Could create a pot of money with equal access to funds to work to solve the problem. Kansas Appleseed did that three years ago for the youth correctional system – creating a pot of money. We are tired of the way things are working.

Sue – you are not alone. We continue to see RFPs from the state that are targeted to specific entities and do not give opportunity to groups like my own.

SAMHSA put out a grant for youth to provide input to mental health and Colorado put out an RFP to give opportunities for multiple entities to vie for the grant in the name of their state. We need to open those opportunities.

**Parity Committee** - Mike Burgess – Committee met on Monday. This committee is convening to attempt to coordinate input and communicate with the state insurance department regarding where private insurance may be violating the parity act. The recent United Behavioral Health decision reveals industry practices that are not based on health care standards, but are used to reduce cost rather than improve quality of care. Working on a plan and gathering information.

Amy shared several examples of the issues that are emerging. She also read from a letter that could be used as a strong example of how to document the problem – the letter from Valley Hope characterizes the problems they are seeing with private insurance refusing to authorize the length of stay and treatment that the provider deems most appropriate for their needs and failing to provide a medically supported reason for the denial/failure to authorize. Behavioral health conditions are often targeted for denial of service, payment clawbacks after audit, and arbitrary limitations.

**10:00 a.m. Guest Topic: Overview of the Disability Rights Center Investigative Report - Stuck in Institutions: the Crisis of Mental Health Services and Supports in Kansas (NFMH issues)** Rocky Nichols, Executive Director

Rocky began with the examples of institutionalization that created the protection and advocacy system – exposing the need for protection for the civil rights of people with disabilities, occurring after the passage of the Disability Rights Act. DRC does not provide traditional rehab or care services. They have attorneys and advocates on staff to take calls for people with disabilities and represent their rights. We have received calls from people who were living in nursing facilities for mental health.

As a state legislator from 1992 to 2003, represented a district with one NFMH in the district and one on the edge. I received calls at that time from family members of people who were living in these facilities. I spoke to those folks in the 90's and learned about some of the barriers to moving from the nursing facility to the community.

LC v. Olmstead was a case on behalf of an individual in Georgia and decided this month 20 years ago today. When we talk about least restrictive environment and the right to be in the most integrated, community setting. These issues of discrimination are founded in this decision.

If an institution is not the most inclusive setting, is not the least restrictive environment for an individual's care, it is the State's obligation to work to provide that. This report indicates that this is not happening in the nursing facilities for mental health nearly often enough.

Primary findings:

- State has not kept up its obligation to help individuals in NFMH facilities realize their Olmstead rights
- State is not doing enough to prevent people from ending up in NFMH facilities – these barriers occur at the front door, where we are not providing enough community supports for people to avoid admission
- Reductions in community mental health funding have been so significant, that it is has had a negative effect on this situation – creates a status quo situation that harms people with mental illness.

This is an issue that has been around for years – this is not about our hard working state employees, who are doing the best they can with limited state resources. Everyone has seen the news reports that the state government has been hollowed out and there are not enough people in many agencies to do the work. We also recognize that the current administration was just elected and did not create this problem. But it is what it is.

We use the term “de facto” institutionalization. We don’t believe anyone has intended to warehouse people in these facilities. We do not think there is a nefarious plan to keep people here without the ability to leave the facility and reintegrate to the community. In many ways, it is a lack of focus, a lack of imagination. The federal description is “board and care homes” but in essence, it is more a situation of boarding due to the lack of investment in active treatment.

Chart shows that through 2017 the mental health community system had been reduced nearly 50%. Today, still a 16% reduction after some restoration. At the same time, the MHC system is serving 30,000 more Kansans. We all know it costs more now to provide health care since 2007, but we have not kept up with the cost of inflation, with the rising number of people needing services, and failed to grow the community system.

Mental health can’t continue to have a back seat when it comes to the future of our state. We can’t just continue to fight for scraps. We continue to see education pitted against mental health and other disability issues.

The funding for nursing facilities for mental health have increased nearly 50%. It is a stark contrast. They are also operating fewer beds. Do not believe that is sustainable.

On average, an NFMH is paid \$50,000 per person per year – does not include payments from the individuals from their SSI income. Could be millions there.

Even if you have to spend some portion of this to provide supported housing and other supports for someone to live in the community, it would be well worthwhile. NFMHs may not be paid by Medicaid dollars due to the IMD exclusion, but the individuals could be eligible for Medicaid match for the services to the individual in the community.

This is not just a couple of people in facilities who want to get out but can’t. Even if it was, they do have that right. Surprisingly, our survey off nearly one half of the residents of NFMH facilities responded that they do want to move back to the community. The residents are not hearing encouragement to move out, they say they are being discouraged from leaving. It is an ecosystem to keep them where they are at and to maintain the status quo.

NFMH facilities are operated by for-profit companies. They may or may not be making money. (Several are in receivership.)

Residents claim that staff sometimes works to convince their guardians that the facility is the best place for them. They feel that community is not being presented to them as an option. Only 9% said that they had a discharge plan.

Recommendations: (3 categories – 8 recommendations)

- Discharge planning and community integration – support the rights to move to community
- Making Kansas a leader in bridging the gap to community integration – rethinking the way we do this planning. Recommend independent advocates to provide informed choice and help them to be discharged with community supports.
- Rebalancing funding of the mental health system to funding comprehensive community mental health services and away from NFMH beds. (Direct funds to needed regional beds that provide active treatment and robust discharge process.)

We have had advocates help to move people out of NFMHs and it is a lot of work. It should be easier.

Discussed the recommendations in detail.

Don’t really want to see the state apply for the IMD waiver if it will be used to funnel federal dollars into the IMDs and provide rehab services there, that would perhaps improve the facilities but not actively moving people toward integrated community-based settings.

This report also highlights recommendations that have come from the Mental Health Task Force, the Adult Continuum of Care Committee and others.

Bill – The report seems right on – how much of the report focuses on housing alternatives in the community?

Rocky – Mike and my role was to translate the information from our attorneys to person language rather than legaleze. We have a laundry list and supported housing is on that, but that isn't our area of expertise. Our area is the field of the law and civil rights. We are sounding the alarm bells.

Bill – it is a well written report but it is one of scores that I have seen since the early days. It gets at one of the key problems. Our state has horrible housing policies and the lack of housing available to adults with disabilities has really been a problem since 1975. The cuts and frozen CMHC grants have helped to create mini-institutions. Some way to provide services within the NFMHs would be a start. I have to look across the street at Brighton West and grieve at what we can't do there. These folks can't be touched by providers. Ultimately, the real problem has been a lack of housing that wasn't really allowed to be discussed until Secretary Keck. Developing good housing policy can be done, but the current state budget is going to have difficulty funding it. Medicaid rates are far below cost and need to be re-looked at as well. Private insurance treatment is also subsidized by public funds because the rates are so far below cost. If we make investments in only one area, it can't solve the problem.

Rocky – those points are well taken. Another issue is the concern that people who go to these facilities become more disabled over time. The fact that there aren't places to discharge people to is not acceptable.

Sherrie Watkins - It seems like if you want to get anything done in Kansas for marginalized populations, you have to take legal action. See schools for fair funding. If you are tired for being in the back of the bus, you have to take action and be aggressive. I served on an NFMH work group. I helped write the manual for how to move someone out of the NFMHs, 60 pages. Worked to help get a number of people out of NFMHs – one sad case failed to discharge due to her inability to self-administer her insulin and I couldn't get Medicaid to pay for the simple twist injection insulin.

Steve - Are you contemplating a lawsuit? Can't comment on that.

Sue – Housing is the perhaps the biggest problem. One increasing concern I have is that we have people with serious mental illness who are now living long enough to need nursing home care as they age and now have physical disabilities that require care. The typical nursing home isn't really equipped to care for someone who has had a lifetime of mental illness and this seems to me to be the true role of NFMHs, but they still need to be able to offer active treatment.

Louis – shared information of his experience in an institution and how he was able to move out and become an independent member of society. Talked about the number of people who are still stuck in those places without the opportunity or support to learn how to live on their own or to fight for them to be discharge. They live there day in and day out and don't know that there are people who are fighting for their right to live elsewhere, to live better. I could be locked up right now if I hadn't had that opportunity.

Kyle – a few thoughts, support the report and the study. I read it thoroughly and it retained my attention for a long time. This isn't a run of the mill report nor a repetition. The interviews and the statistics are fascinating. It is an additional and powerful tool to aid in our public discussion. The State Constitution does address the state's obligation to provide services to people with disabilities. I did not view this report as overly critical. Nursing facilities for mental health have been a big part of the State's effort to free up state hospital beds. There wasn't enough conversation about the transition of state hospital beds to short term treatment and stabilization beds rather than longer intensive treatment. That also goes to the changes that were made regarding PRTF beds and the care provided to youth.

We are in talks now about Medicaid housing codes and that is an important part of the solution.

Alternative placements from state hospitals were jails and emergency rooms under the state hospital moratorium. We are ten years behind. For me to go to national meetings and to hear about housing codes and reform occurring in Missouri and Oklahoma is unacceptable.

Even recently saw a communication about financing an alternative for these kinds of placements.

Corinna – pointed to the P2 sponsored advocates program as a possible source for the extraction specialists recommended in the report.

Sue – Olmstead advocates would be funded by the State?

Rocky – looked at several states, Wisconsin provides rights advocates funded through Medicaid. California does it as a state funded service. Hawaii, New York and other do it. Some call them rights advocates and other call them ombudsmen. There are all kinds of ways to do it. Doesn't have to be state funded.

Bill – on a collective level, regarding people who want to move out, what would indicate success? (Concerned that the current system couldn't support even a dozen discharges right now.)

Rocky – we aren't the right agency to do that, clients define their own success and justice. A university might be able to do that study. Most people want to move back to the community where they were before life changed. They want what all of us want. Other states have created something akin to adult mental health HCBS waiver services. If you right-size, there are opportunities. Can't wait to help get people out. Agree these things are difficult.

Amy is concerned about the use of the fear of the IMD waiver possibly adding money to keep people in NFMHs. CMS was pretty clear that they won't fund long term residential care and they will require community investments. Hate to see the state hold back on its application for the IMD waiver request for psychiatric care.

#### **10:40 a.m. Lobbyist Report - Amy Campbell**

**June 13 2019 KDADS Post Legislative Stakeholder Meeting** Read handout at

<https://kansasmentalhealthcoalition.wildapricot.org/resources/Documents/6%2013%2019%20KDADS%20Post%20Legislative%20Stakeholder%20Meeting.pdf>

**Family First Prevention Grants** Request for Proposal (RFP). Sealed bids will be accepted no later than 2 p.m. July 15, 2019. A complete copy of the RFP with details of important dates and timelines may be found at <http://www.dcf.ks.gov/Agency/Operations/Pages/OGC/Grant-RFP.aspx>

**Kansas Awarded Pediatric Mental Health Grant** Distributed KDHE press release.

**Legislative Coordinating Council** meets July 1. Will set interim schedule.

**11:00 a.m. KDADS Update** – Charlie – KDADS is in process responding on CMS feedback on the SUD IMD waiver.

KDADS formed new hospital commission, a separate division on the agency flow chart– Kim Lynch, Commissioner; Georgianna Correll, and Mike Dietz are part of the leadership team.

Doug Bowman is the

Interviewing for opiate grant coordinator.

Children's Team position interviews soon

Online training is up now for certified peer specialist

Mental Health Task Force will meet in July to get progress update and have interaction with the new Secretary.

Secretary hosted two stakeholder meetings – remember when these used to be open and annual. Glad to see Laura Howard bring those back.

Yesterday, CMHC contracts went out for signature. Don't remember the last time those went out before the fiscal year. This administration is letting more decisions come through the program and be implemented.

You can reach out to me at [Charles.bartlett@ks.gov](mailto:Charles.bartlett@ks.gov)

#### **11:25 a.m. Announcements**

State Senator Jan Meyers was a leader in the effort to create mental health reform and grants. She passed away this week and will be missed.

#### **11:30 a.m. Adjourned**

#### **Schedule:**

**Mental Health Advocacy Day:** February 19, 2020

**2019 KMHC Meetings:** 9 a.m.–11:30 a.m. Jan 23, Feb. 27, Mar. 27, April 24, May 22, June 26, July 24, Aug 28, Sept. 25, Oct. 23, Nov 27, Dec. 18

**Board Meetings:** 12 noon quarterly the 4<sup>th</sup> Wednesdays (March 27, June 26, Sept. 25, Dec. 18)

**Advocacy Committee Meetings:** January - March: Friday teleconferences, Meet after Coalition meetings: January 23, February 27, April 24, May 22, August 28, October 23

For more information, contact: Kansas Mental Health Coalition

c/o Amy A. Campbell, Lobbyist, P.O. Box 4103, Topeka, KS 66604  
785-969-1617 [campbell525@sbcglobal.net](mailto:campbell525@sbcglobal.net)