



KANSAS SYSTEM OF CARE

2017

Listening Tour Full Report

Between May 1 and June 21, 2017, representatives of the Kansas System of Care (SOC) from the Kansas Department for Aging and Disabilities Services (KDADS) and Wichita State University's Center for Behavioral Health Initiatives (CBHI) conducted a statewide listening tour in order to gauge the strengths, challenges, and needs of youth and families as they engage behavioral health services.

The tour included the catchment areas of the four community mental health centers contracted under the current federal SOC Cooperative Agreement: Compass Behavioral Health (southwest Kansas), South Central Mental Health (Butler County), Sumner Mental Health (Sumner County), and PACES/Wyandot Center (Wyandotte County). The listening session at Compass Behavioral Health's Garden City location included a video-conferencing component, allowing participation of those for whom transportation might otherwise have been a barrier.

A listening session was also conducted at the 2017 Kansas Recovery Conference, with participants from many areas throughout the state. Additionally, an online survey was conducted using prompts similar to those created for the listening session but modified for the online environment. Ninety-six people including youth, families, educators, behavioral health center staff, and other interested individuals participated in the listening tour sessions, with approximately another twenty participants at the Recovery Conference, and twenty-nine engaging online.

Focus Questions and Listening Tour Topics

Listening tour sessions were focused around the following questions or discussion areas:

1. What resources do you notice youth and families in your community using for mental health help? (This could be anything. It could be places where they go for support: mental health center, library, church youth group, etc. It could be things that they use to feel better: a band, addictive substances, video games, etc.)
2. What helps? What hurts? (Some of these resources could be helpful or have helpful parts about them. Some of it could be hurtful. Explain what you have noticed.)

Follow-up questions were planned as the following, or addressing the following topics
How are families supported in the community?

- What does the community need more of to help youth with mental health needs?

The online survey used the following questions:

- What is your role here today?
- Do you see yourself becoming actively involved in the Kansas System of Care within your community? If so, how?
- What areas would you like to know more about?
- How do you currently get help with your mental health needs in your community?
- In what ways do you see people in your community getting mental health help?
- What changes could be made to help make getting mental health care easier?
- What works? What doesn't?

- What problems or barriers do you see in getting youth and families to connect with local mental health services?
- What do you like about your current mental health services? What don't you like? Please offer any suggestions for improvements.
- What works well with the current mental health system? What doesn't work? Please offer any suggestions for improvement.

Online participants were also queried about which county they lived in in order to match respondents with the above community mental health center (CMHC) catchment areas, and they were given an opportunity to input contact information for follow-up.

During listening sessions, questions were modified to meet the language appropriate to participants' age range and roles, but all began by asking how and where participants accessed help for behavioral health challenges. The words "mental health" were used for listening sessions since that language is still more common than "behavioral health," though more inclusive language is used throughout this report. Discussion was often wide-ranging, and facilitators attempted to use the varying nature of responses to solicit a deeper understanding of the pertinent issues and keep things focused on topics germane to the System of Care. The sessions were relatively informal in order to increase the comfort level of participants and allow for more candid responses.

Responses were recorded on flip-charts by facilitators who later transcribed them onto Word documents. These documents were then shared with other facilitators present so that accuracy and completeness could be maintained. Those responses, plus responses pulled from the online survey software, were consulted for this report.

Listening sessions lasted approximately two hours, and \$15 gift cards were offered to youth and families as incentives for participation. Light snacks were served.

Because of the nature of the listening tour events and open-ended online comments, it is difficult to come up with quantitative measures of some responses. For example, complex responses such as "What needs improvement is more resources to offer the services that are needed by a workforce that is compensated for the hard work that they do" encompasses several ideas that facilitators encountered over the course of the tour: access and availability of services, consistency and compensation of staff, and structural issues that undergird the system as a whole. Therefore, this report takes a qualitative approach, providing quantitative data only when it is both clear and helpful (such as total number of participants). "Raw" responses can be made available upon request.

Major Themes

The following sections group responses by major themes observed throughout the listening tour and important points or subthemes within them. A few outliers (not frequently noted but potentially important) are included as well.

Access to care and availability of services:

Participants frequently mentioned that cost of care and availability of insurance coverage were barriers to receiving services. One noted that “There needs to be a way to cover the whole family,” and another “Kids are able to have services paid for, but parents who may need them don’t qualify.” When services that are not available at the community mental health center can be found via private practice, higher costs may incur, and eligibility may again be an issue. Coverage and participating providers may vary by managed care organization, and needed services may not qualify under Medicaid, creating either out-of-pocket costs for families or uncompensated/unbillable costs for mental health centers. Participants recognized that some youth were “too well” to qualify for services but still needed help. This was seen as particularly a problem for transitional-age youth, who might be facing the challenges and opportunities of continuing their education, starting a career, and possibly requiring adult-services. At this point, they are often caught between a conflicting set of desires and needs, and it may be difficult to determine their eligibility for assistance.

CMHC (though not state) policies often make it hard for youth and families to access services across the lines of CMHC catchment areas, a problem compounded by families whose work situations and home-lives cross those boundaries every day (common in Sumner and Butler counties). Consistency of care also becomes an issue when a preferred provider is no longer available when a family moves.

Travel costs, especially in rural areas, were mentioned at almost every listening session, and opinions varied on the ability to use Medicaid dollars to pay for it. One notable issue is when the transportation for an eligible child is covered but not for the parent, making it impossible for a parent to bring a child to a service. Availability of transportation was also noted. Even in urban areas, such as Wyandotte County, transportation that is reliable, cost-effective, and safe for children and families who may have low incomes can be difficult to come by. For southwest Kansas, public transportation is rare, often takes a long time for pickup and delivery, and must be planned for long in advance. Access to medication providers and psychiatric services was also noted as a barrier, with some participants opting to drive hundreds of miles to an urban center in order to receive psychiatric services.

Overall costs to the system were also frequently mentioned as both a practical barrier and as a source of organizational stress, with many participants noting that the system was “underfunded.” This problem is compounded by lack of human and monetary resources in other aspects of the child-serving system such as foster care, schools, and juvenile justice.

Systemic financial struggles also impact accessibility by creating high staff turnover as good people leave for better paying jobs. This makes consistent services and positive relationship-building between providers, families, and youth more difficult to achieve. Lack of financial resources also leads to higher caseloads, making individualized care more difficult and increasing staff burnout.

Cultural barriers, stigma, and the possibility of discrimination were mentioned on several occasions as barriers to service. One participant, who works in the public schools, noted that kids

were being singled out: when the therapist from the local mental health center was available at the school, those with appointments were pulled from class. The same participant noted that the “special groups” available to students facing behavioral health challenges were both places of safety and sources of shame.

Similarly, parents are often afraid to access behavioral health services out of fear that the Department for Children and Families (DCF) would place their kids in foster care. Parents also found it difficult to schedule appointments that accommodated their work schedules, with few options for after-hours or at-the-workplace meetings with providers.

As noted below, partnerships between CMHCs and schools were also seen as important ways to access services, and teachers and school counselors are often the first people to notice a child’s behavioral challenge. One participant even noted that it was a teacher who both identified his behavioral health needs and also helped guide him toward a better life.

Appropriateness of how youth and families access services was also noted, with some youth only gaining behavioral health care through involvement with the juvenile justice, residential crisis, or foster care systems. Participants agreed that this was often traumatizing in and of itself, even if it led eventually to good care, and that the best route to the best outcome would be to access care prior to justice system involvement or out-of-home placement.

In-home care was mentioned many times as important and preferred. Participants also responded with a variety of places that people were accessing care: as well as the aforementioned schools and mental health centers, people were getting help from clergy, family, primary care providers, peers, public libraries, gaming clubs, and Boys and Girls Clubs. As one youth participant said, “You’re going to find help wherever you can,” and not necessarily always healthy help, implying that youth will sometimes drift towards alcohol, drugs, and unhealthy relationships as coping mechanisms when formal supports and resources aren’t there.

When people were able to access mental health centers, satisfaction was generally high. South-Central Mental Health was praised for “get[ing] right out there” for initial evaluation and placement, and one participant emphasized that “We need more Compass!”

Partnership:

The listening tour painted a large and dynamic picture of the existing system of care. Broadly speaking, the system already includes the schools and libraries, foster homes and neighborhoods where youth and their families find help.

But coordination between these organizations and elements remains a challenge. At one listening session, both a youth who had used one and a school counselor in her district complained that a regional psychiatric residential treatment facility (PRTF) just “dumped” kids back into schools and home life with little follow up or support. Residential facility staff have also changed medication regimens without notifying others providing care, making it difficult to determine if continued behavioral challenges are due to presenting conditions or rapid changes in medication. Participants also noted a lack of coordination with foster care contractors and a lack of education for foster parents on youth who have behavioral health challenges and/or a history of trauma. The state’s contracted Medicaid managed care organizations were called out as sometimes

creating barriers to partnership through coverage restrictions. It was hard for certain services that coordinated with other organizations to be paid for if they occurred outside of the framework of current billing codes.

A striking example of lack of coordination and partnership came from the online survey:

I have observed many situations where barriers (time, funds, informal support etc.) impact the parent(s)' ability to engage with mental health services which has declined the functioning of the family to the point of DCF/state intervention in the court system. When the parent has successfully had their mental health needs met, they are able to provide a safe and stable home for their child. Unfortunately, the additional supports and services provided by court involvement end when the case is dismissed and some of the barriers return which then leads to continued involvement with child welfare services, continued instability/abuse/neglect for the children, and often times mental health needs for the children themselves.

Schools and CMHCs have also found it challenging to share information, with differing regulations governing what private information can be shared and with whom and when.

It was even called out that there is sometimes a lack of coordination between frontline staff, other members of a care team, and other employees at the same CMHC. Ongoing collaborations were frequently cited as bright spots as well, often via longstanding relationships between CMCHs and regional school districts, colocation of CMHC staff in the schools themselves, and even informal understandings with local public libraries as a safe “3rd place” for meetings between providers and service recipients.

Summer programs for youth facing behavioral health challenges were mentioned by name, as well as efforts to strengthen the network of “natural supports” for families and youth. One CMHC invited the local school superintendent to be on its governing board, creating integration at a high level in order to better enable coordination throughout each organization’s structure.

Respondents wanted to see more collaboration and coordination outside the existing partnerships or expected places, however, including with churches, parks and recreation departments, the state Department of Education, community groups, and primary care doctors. One person summed it up this way: “Effective ‘Systems of Care’ begins with effective cross-system collaboration. There must be authentic collaboration around/mutual ownership of processes and resources across ALL systems that children and families encounter.”

Training, support, and resources:

Conversations about coordination and access needs led to many participants pointing out the importance of training, support, and resources for those providing services, for those receiving them, and for community partners.

Both educators and youth cited the need for better training for teachers and school staff on behavioral health issues and trauma. One participant said “Teachers don’t have the skillset to

deal with these issues; they are not trained in trauma and are afraid of kids with mental health issues.” A Recovery Conference respondent pointed out that poorly trained teachers over-rely on seclusion and restraint, which can compound trauma for children as teachers try to maintain control of the classroom.

Foster parents present were frustrated that there was very little training for them, making it difficult to properly care for the children entrusted to them. An understanding of behavioral problems as trauma responses was rare and led to greater instability for kids who act out as they are shuffled from placement to placement.

Training for law enforcement in crisis intervention techniques was mentioned in several different locations and contexts. One youth noted that police involvement “just made it worse,” and that it is important to provide training for law enforcement on de-escalation techniques for youth. The same youth said that police need better options to help kids “get out of bad situations,” centering the reality of trauma in kids’ lives and the complexity of their situations.

In this and other crisis contexts, both Mental Health First Aid and Emotional CPR were called out by name; however, as the next section shows, this also pointed toward philosophical differences between respondents.

Training for parents was mentioned by parents, services providers, and youth. Across the state, two curricula, Love and Logic and The Incredible Years, were noted as being particularly helpful ways to help parents manage when kids are facing behavioral health challenges. No matter the intervention, participants agreed that in-home training, coaching, and role modeling from parent support workers was vital for making these parenting concepts “real.”

Participants also said that parents are often caught in destructive intergenerational cycles that training in different parenting styles may be able to break. One parent even found herself training others in her neighborhood in Love and Logic as those parents saw how well it worked. This implies that training efforts should support both formal and informal (culture and context-driven) ways of disseminating knowledge. Parent support workers mentioned that training should involve self-advocacy so that parents can help solve longstanding familial problems in proactive ways.

Training for PRTF staff in what it’s like to be a kid was an important part of one listening session and bears noting for its cogency and power. The youth involved in this case saw a difference between the strengths-based approach of the mental health center and the residential facility’s way of using “more commands than care.” She went on to say that “They don’t treat us like we’re sick; they treat us like we’re bad.” Training based on the Strengths Model, that’s trauma-informed and responsive to youth culture, could help address this problem.

Cultural and philosophical differences:

The difference in approaches between PRTFs and CMHCs is one of several philosophical and cultural gaps the listening tour revealed.

Differences in administrative needs and service delivery also came to the fore, with a focus on

“red tape,” billing restrictions, and staffing needs forcing people to tell their stories over and over, re-traumatizing people and delaying therapeutic progress.

School cultures that treat behavior problems punitively and trauma-informed approaches as “coddling” struggling kids clash with more supportive ways of approaching behavioral challenges. Similar differences in philosophy were noted between PRTFs and other intensive interventions and CMHCs. The former two were viewed as working toward merely stopping “bad” behaviors; whereas the latter was viewed as actively working toward solutions.

Likewise, DCF was often seen as essentially punitive and the CMHCs and (sometimes) private therapists as essentially supportive. Fear of DCF involvement made parents reluctant to seek behavioral health services for them.

Participants saw a need for gay-straight alliances in schools, for bilingual staff, and for services in “3rd places,” places such as libraries and coffee shops where diverse sets of people from the community feel comfortable being.

Another cultural difference is between a more broadly-based idea of what causes behavioral health problems and a more limited and clinical one. Said one youth, being a “kid with an SED” diagnosis is a lot about “being in the wrong place at the wrong time.” Both youth and parents called out personal and intergenerational trauma as important aspects of presenting problems, and some felt judged and not listened to by providers.

One respondent went so far as to emphasize the need to “DE MEDICALIZE help seeking” to overcome these philosophical and cultural barriers. The differences between the more clinical Mental Health First Aid and Emotional CPR, which is based on interpersonal connection, is an example specifically noted of how this might impact training and delivery of support.

Some younger youth, in asking for donut walls and mental health centers made of peanut butter and jelly sandwiches, were actually underscoring larger themes: youth want to be active and to have incentives. They want behavioral health support to be kid-friendly and not boringly clinical (fidget spinners, field trips, cooking classes, and iPad apps were also mentioned).

Where do we go from here?

The 2017 Kansas System of Care Listening Tour suggested the following needs:

- **Break down barriers to care.** This may be practical, as in providing flexible funding to meet transportation needs. This may be a matter of policy such as working across catchment area lines and opening up service definitions and billing codes to meet needs. This may be structural by increasing system and organizational resources and capacities or alleviating the perceived threat to children’s custody for parents who seek their own behavioral health services.
- **Foster partnership between local, regional, and statewide agencies and organizations.** Participants called out for seamless services that “speak with one voice,” coordinate care, and focus on strengths. The strengthening of care coordination will

require renewed commitment to cross-agency partnerships that reflect the full spectrum of services and supports that are vital to a child's success in school, at home and throughout life. Such a comprehensive approach may require a braided/blended funding approach. This would enable, for example, a high-fidelity Wraparound model and make it easier for entire families to access the services they need.

- **Increase training and education across child-serving systems.** This would make the coordination and common purpose noted above easier to achieve, and it would help struggling teachers, law enforcement officers, foster parents, and the like feel more knowledgeable and empowered to help suffering kids.
- **Open dialog and inclusivity.** Parents/caregivers and youth should be involved in all levels of planning, policy-making and service delivery. Creating safe and supportive spaces for communities and stakeholders, especially youth and family members, to openly discuss their perceptions of behavioral health, their health beliefs, and their approaches to what helps can lead to a broader understanding of desired outcomes and what is achievable. One participant brought forward the rallying cry of the disability rights movement: "Nothing about us without us." Philosophical and cultural differences will likely remain barriers unless all voices can be heard and respected. This listening tour also suggests the need for future tours, focus groups, and participatory research models in order to clearly map the way forward as the needs of youth and their families adapt and change.