Holistic Care Coordination
Provider Input Summary

September 2021

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Overview
Holistic care coordination (HCC) models should center services around a child and family, addressing goals as identified in partnership with the family and sharing information among providers and community support partners for the best possible experience. The Kansas Special Health Care Needs (KS-SHCN) model is an effective holistic model that focuses on all aspects of family life, allowing for stronger supports around cross-system navigation to address the primary needs identified by the family, including physical, social, and emotional health services, housing, education, legal, and financial needs.

The goal of the Holistic Care Coordination (HCC) work is to expand the Kansas Special Health Care Needs (KS-SHCN) HCC model across Title V and MCH programs and beyond the formal Title V program delivery, such as provision of technical assistance for primary care and community health providers. To do this, we have been working to develop an implementation toolkit to assist programs, partners, and providers to develop or implement HCC for their clients or patients. Along with development of the toolkit, we identified a need to hear more about care coordination experiences and desires from health care providers. To date, we (1) hosted virtual roundtable sessions; (2) presented at the Turn a Page, Touch a Mind (TAP-TAM) spring meeting series in partnership with the Kansas Chapter of the American Academy of Pediatrics (KAAP); and (3) conducted a survey to identify knowledge, attitudes, and practices around holistic care coordination. This report will outline the qualitative information gathered and feedback received from these activities.

This Fall the project will shift a new phase of work, including launching Project Advisory Teams with providers for an in-depth, hands-on review of the toolkit. Starting in October, we will host a Project ECHO 6-series session for providers which will coincide with selecting practice teams for the Community of Practice projects to pilot the toolkit and establish holistic care coordination programs across the state.

Activities
Survey
We launched a survey to gain information on current knowledge, attitudes, and practices around holistic care coordination on March 22nd and closed the survey on May 31st. Thirty-eight individuals started the survey, but ten individuals were removed because only demographics were completed. Of the 28
responses, two left the survey half-way through (question 20/42), and two more left in the final section of the survey. This leaves a total of 24 completed surveys. The response summary is included at the end of this report as Appendix C.

Roundtable Sessions
The goals of the four (4) roundtable sessions on holistic care coordination were to:

- Discuss the concepts around holistic care coordination.
- Review the National Care Coordination Standards for Children and Youth with Special Health Care Needs and specifically cover the domains laid out for the specific session.
- Hear from the participants on their beliefs, practices, and needs (tools/resources) around holistic care coordination and the standards.

Each session discussed different domains from the National Care Coordination Standards for Children and Youth with Special Health Care Needs as listed below. There were twenty participants among the four sessions. Two individuals participated in two sessions and one individual participated in three sessions making the number of individual participants sixteen. Ten out of the sixteen participants directly provided care coordination services. The participants held various positions including physicians, program managers, directors of organizations, and outreach or engagement coordinators.

- April 7th Screening, Identification, and Assessment
- April 8th Shared Plan of Care / Child and Family Empowerment and Skills Development
- April 14th Team-Based Communication
- April 21st Care Coordination Workforce / Care Transitions

Turn a Page, Touch a Mind Program Meetings
We were invited to discuss holistic care coordination with providers that participate in the Turn a Page, Touch a Mind (TAP-TAM) Program, in partnership with KAAP. This opportunity connected us to 133 providers overall. Provider types ranged from local health departments (n=20), hospital primary care practice/clinic (n=53), community health center/federally qualified health center/safety net clinic (n=21), and other providers (n=39), presumed to primarily be from a private practice. Similar to the goals of the roundtable sessions, we discussed holistic care coordination, reviewed the National Care Coordination Standards at a high level and provided more space for open discussion and participant conversation.

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<th>Date</th>
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<td>April 29th</td>
<td>20</td>
<td>May 14th</td>
<td>13</td>
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During the TAP-TAM sessions, five poll questions were asked. The response summary is included at the end of this report as Appendix A.
Findings

Holistic Care Coordination

The majority of participants actively engaged in the discussion about holistic care coordination seemed to have a good sense of what it means – even before our presentation, which was encouraging. We invited participants to share what they believe the term “holistic” to mean with regard to providing care coordination services. Their descriptions included words such as: “whole person,” “person centered,” “social determinants of health,” “education and empowerment,” and phrases like “meeting the family where they are.”

Differences in Terms

One objective in the development of the toolkit is to identify or clarify the differences between the terms “case management,” “targeted care management,” and “service coordination,” in comparison to what we mean when referring to “holistic care coordination,” or the supports often associated with community health workers. The most common response was “I don’t know, you tell me.” Other responses indicated that perhaps the difference in terminology is only based upon the system in which the service is being offered, or for whom the person providing the service works. Some providers noted concern of duplication of services, and that these individuals work in silos and not collaboratively with primary care providers. Ultimately, it was noted that often the perception is that among these terms, there are far more similarities than differences and they are all integrated in some way and share a common goal – to support the individual patient and/or family in meeting their needs within a specific system or service area.

Tools or Resources for Providing Holistic Care Coordination

When asked what would be most helpful to their goals of providing more holistic services to their patients, clients, or families, the most common responses revolved around staffing and staffing supports, billing and opportunity for adequate reimbursement, information on ways to engage and educate families, trainings for care coordinators, hiring materials, and lists of community programs. Providers shared that a helpful tool would include a way to manage screening forms in electronic health records, or something similar to WebIZ, to easily share these across systems.

Barriers to Providing Holistic Care Coordination

The most commonly noted barriers to providing holistic care coordination included: cost, billing, time, recruiting and maintaining staff, trainings, and differing views from administration.

Billing

The ability to bill for care coordination services was one of the main points of conversation regarding the perceived and real barriers to providing holistic care coordination. For providers, and to support sustainable care coordination programs, adequate reimbursement is crucial to being able to provide stable, quality care coordination.

Reimbursement for care coordination services is currently only available for certain populations, most commonly associated with specific Medicaid managed care or chronic medical needs, or home and community-based services. This type of care coordination is often only covered for certain providers or through the managed care organizations specifically. Coverage is often difficult and/or not adequate for community or primary care providers.
Some providers noted success as part of an Accountable Care Organization (ACO) with value-based payment models. Others have had success sharing a care coordinator with others in the area such as local hospitals and other clinics.

During the discussion, many providers offered recommendations, ideas, or even requests on how we could better support them in this area. Some of these more tangible, action-oriented items include:

- Revise the Kansas Managed Care Organization contracts to allow for stronger partnership and care coordination to occur locally.
- Increase reimbursement for complicated patient management and counseling services.
- Expand who is eligible to provide care coordination services (e.g., community health workers, home visitors, social workers, nurses).
- Address the funding differences between rural health clinics and private practice.

There were also innovative ideas on ways to support families better through care coordination and other insurer-based policies:

- Expand Medicaid for parents to improve their health so more focus could go to the child.
- Change the Medicaid transportation approval process to address more urgent needs.

National Care Coordination Standards – Domain Reflections

Common themes identified as related to the six domains outlined in the National Care Coordination Standards. A detailed summary is included at the end of this report as Appendix B.

- Identify ways to streamline and share screenings and assessments across providers and services to reduce duplication for families.
- Importance of including families to create shared plans of care (SPoC) that include information needed during an emergency or health crisis, as well as community and social needs.
- Knowledge of local resources and strong relationships with these programs to support a “close loop referral system.”
- Inclusion of families as key members of the care team, recognizing barriers and strengths to provide care that best meets the family’s needs and support self-advocacy skills.
- Recognizing the need for trained, qualified staff, while valuing lived experience, with regard to the care coordination workforce.
- Need to provide the appropriate supports for care coordinators (e.g., dedicated staff, adequate payment, flexibility).
- Coordination, communication and collaboration are important for successful transitions.

Action Steps

Differences in Terms / Payment

The following activities were noted as a benefit in the future: (1) research the various terms associated with care coordination (identify similarities and differences); (2) explore opportunities to expand billing and reimbursement; (3) identify best practices; and (4) highlight programs that have shown the value of care coordination to the family, provider, and system – to support sustainability.
Tools or Resources for Providing Holistic Care Coordination

Additional research or activity is needed to find, identify, and create desired tools and resources to include in the toolkit. Some examples include:

- Streamline and share screenings
- Resources/recommendations for SPoC development
- Sample hiring materials
- Materials for including/communicating with families in the care team
- Transition tools or guidelines

Upcoming Projects

Launch of the HCC Project Advisory Team – October 2021

Beginning in October, we plan to work directly with practices who already providing care coordination services to gather insight, feedback, and ideas to finalize the development of our implementation toolkit.

Provider ECHO Series on HCC – October 2021 through March 2022

We are offering a six session provider education series on HCC. Each session will feature a topic guided by the National Care Coordination Standards and provide:

- October 26: Building Relationships with Patients and Communities
- November 16: Empowering and Partnering with Patients and Families
- December 14: Sustaining a Quality Care Coordination Workforce
- January 19: Identifying Patients and Families to Benefit from Care Coordination
- February 16: Creating Family- and Patient-Driven Action Plans
- March 16: Helping Patients and Families with Care Transitions

HCC Community of Practice – January 2022

A limited number of practices will be selected for the first Community of Practice cohort to compliment the launch of HCC Implementation Toolkit. Participants will receive individualized supports and have opportunities for peer to peer sharing.
Appendix A: TAP-TAM Poll Summary

Please select the standard that you feel that most care coordination programs are lacking.

n=102

<table>
<thead>
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<th>Standard</th>
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<tr>
<td>Address social, behavioral, environmental, and health care needs</td>
<td>31</td>
</tr>
<tr>
<td>Be culturally competent, linguistically appropriate, and accessible</td>
<td>18</td>
</tr>
<tr>
<td>Assess performance with outcome measures</td>
<td>17</td>
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<tr>
<td>Consider insurance coverage as key to accessibility</td>
<td>17</td>
</tr>
<tr>
<td>Include families as core partners</td>
<td>11</td>
</tr>
<tr>
<td>Use evidence-based, evidence-informed, and promising practice</td>
<td>6</td>
</tr>
<tr>
<td>Based on health equity</td>
<td>2</td>
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</tbody>
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There are seven foundational standards for holistic care coordination that were used to guide the National Care Coordination Standards for Children and Youth with Special Health Care Needs. We asked participants to select one of these foundational standards that they feel most care coordination programs are lacking. Addressing social, behavioral, environmental, and health care needs was selected the most by TAP/TAM participants.

In our roundtable sessions, “Assess performance with outcome measures” was the most selected (six out of sixteen). Some of the conversation around the reasoning for that selection was that outcome measures are available but not used to make improvements. Time was noted as the main reason these outcome measures are not used. Another discussion point was collecting data, such as the social determinants of health, in one place, such as at the state level.
The most selected option was “No, but I would to have one!” The next highest was “Yes, I have someone in my office that serves in this role, but they do many other things as well.” An important note here was that there were a lot of comments about care coordination falling on the shoulders of doctors or nurses who may not have the time to spend on providing quality holistic care coordination.
This poll question was multiple selection, meaning that participants could select as many services as they wanted. Some additional services that were mentioned as possibly needing coordinated included spiritual and recreational needs. While we were initially shocked that specialty medical care was selected the least amount of times, it was discussed that a lot of specialty medical care is already being coordinated elsewhere. We did have school health nurses participate in our roundtable sessions and complete the survey, with interest in connecting schools to providers. This is interesting as educational needs was the second most selected service that providers during TAP/TAM saw as needing to be coordinated.
We asked TAP/TAM participants to anonymously rate their care coordination services in terms of being holistic.

- **One Star** – Well, I don’t provide any care coordination services.
- **Two Stars** – I provide care coordination but haven’t even thought about any of the holistic concepts we just discussed.
- **Three Stars** – I provide care coordination, but we could be more holistic in what we do.
- **Four Stars** – I try to provide holistic care coordination but am missing some pieces.
- **Five Stars** – I can’t get any more holistic if I tried.

The majority of providers (74/104) selected three or four stars showing that they could be more holistic or that they are missing some pieces.
While most participants did not believe it matters where care coordination takes place, it was important for primary care providers to be kept in the loop. Some providers noted not knowing what care coordination services their patients were receiving.
Appendix B: Domain-Specific Findings

Domain 1 – Screening, Identification, and Assessment
Providers complete varying levels of screening with their patients. One common theme was that families are asked to complete many forms, which can be a barrier. Identifying a way to streamline and share these screenings across providers and services could be beneficial to families and providers in not duplicating screenings or services. Some rural providers noted that screening for social determinants of health can be frustrating if they do not have solutions to offer.

Domain 2 – Shared Plan of Care
Providers using shared plans of care (SPoC) made known the importance of including families through starting the conversation with them, even using the statement “nothing about us, without us.” From a clinical perspective, these plans need to be selective and include crucial information needed during an emergency or health crisis, but it was noted that community and social needs are also important to include in a SPoC. Communication must be strong for a SPoC to be beneficial and they needed to be updated any times changes are made.

Domain 3 – Team-Based Communication
One of the key conversations around communication was community resources. Providers noted the importance of not only knowing local resources but maintaining relationships with these programs. Relationships with these programs were beneficial to follow-up or “close the loop.” Additional conversations included the importance of including families as key members of the care team, by learning barriers and strengths from the families, utilizing visual aids or pre-prepared questions/lists, and including families in the communication.

Domain 4 – Child and Family Empowerment and Skills Development
Providers noted the importance of helping individuals and families learn to advocate for themselves in all sectors of life. Identifying goals and strengths is an important piece of working with families. Some providers spoke about utilizing a strengths-based perspective when working with families to help build their story. One provider spoke about pointing out and emphasizing things as strengths that the family or individual may not have seen as a strength originally.

Domain 5 – Care Coordination Workforce
There are many different titles used for individuals who serve in care coordination positions. Offices that were able to provide care coordination often did so as one of the many other tasks of someone already in the office (e.g., nurse, provider), leading to less time to devote to care coordination services. Providers were interested in what credentials a care coordinator should hold, although not all agreed they must be a licensed/credentialed individual. The value of lived experience and ability to form relationships was also highly regarded in this work. Challenges included filling the role (e.g., payment, recruitment), flexibility of position (e.g., ability to work across silos) and taking language and culture of patient population into account when hiring.

Domain 6 – Care Transitions
Coordination, communication and collaboration were noted as important for successful transitions. In our conversations around care transitions, participants mentioned losing families into the “wild blue yonder.” Items identified as possibly being beneficial to transitions included: following up with the family to ensure they received care that was needed; creating an integrated system that defines the next support; and utilizing warm handoffs.
Appendix C: HCC Knowledge, Attitudes, and Practices Survey Findings

The survey was intended to gain information on current knowledge, attitudes, and practices around holistic care coordination. The survey opened on March 22nd and closed on May 31st. Thirty-eight individuals started the survey, but ten individuals were removed because only demographics were completed. Of the 28 responses, two left the survey half-way through (question 20/42), and two more left in the final section of the survey. This leaves a total of 24 completed surveys.

One question on beliefs around who should be responsible for care coordination showed most people selecting that they believe the patient/family should be offered care coordination services by a member of the office staff.

Which of the following best represents your view?

Answered: 28  Skipped: 0

<table>
<thead>
<tr>
<th>ANSWER CHOICES</th>
<th>RESPONSES</th>
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<tbody>
<tr>
<td>I believe the patient/family should be solely responsible for coordinating the care they need, without support from their primary care officer.</td>
<td>0.00% 0</td>
</tr>
<tr>
<td>I believe the patient/family should be responsible for requesting support from the provider or staff member within the office in order to receive care coordination services.</td>
<td>3.57% 1</td>
</tr>
<tr>
<td>I believe the patient/family should be offered care coordination supports, to address their individual needs at that time, at each appointment, by a provider or staff member within the office.</td>
<td>96.43% 27</td>
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TOTAL 28

Another question asked “In your opinion, what is the number one barrier to providing care coordination services in primary care practices?” The answers to the open ended question most frequently used words around lack of resources or time, as well as payment and cost.

Other questions were more specific to the domains within the national standards. To see the full survey results, please visit: [https://www.kdheks.gov/hcc/download/HCC_SURVEY_ONLINE.pdf](https://www.kdheks.gov/hcc/download/HCC_SURVEY_ONLINE.pdf).