**Minnesota Care Coordination Systems Assessment and Action Planning**

**Location:** Minnesota  
**Date Submitted:** 11/2016  
**Category:** Emerging Practice

**BACKGROUND**

Children and youth with special health needs (CYSHN) and their families often benefit from a wide variety of medical, psychosocial, educational, and support resources. Without effective care coordination, CYSHN often receive fragmented or duplicative services, which can cause unnecessary stress and frustration to parents and family members of the CYSHN. “Care coordination is part of many local, State, and Federal health and social service funding streams, but it is delivered in a silo-based structure. Multiple care coordinators can be assigned to one person based on the specific needs that care coordinator is addressing” (Agency for Healthcare Research and Quality, 2016). Duplication of care coordination services can be a challenge to providers, families, and everyone’s budget.

In Minnesota, there has been much uncertainty on what is occurring across the state regarding care coordination. When we spoke with families and providers, they reported a great deal of confusion on “who” is supposed to be doing “what” when it comes to coordinating care. This confusion, combined with the low percentage of families who reported receiving effective care coordination, was the catalyst behind the care coordination systems assessment efforts undertaken in the state.

The care coordination systems assessment utilized a systems mapping process, which gathered input from stakeholders in regions across the state, was undertaken to assess strengths, challenges, gaps, and redundancies inherent in providing and receiving care coordination amongst CYSHN and their families.

**PROGRAM OBJECTIVES**

The purpose of Minnesota Care Coordination Systems Assessment and Action Planning process is twofold: 1) to assess what is occurring regionally across the state around the provision and receipt of care coordination services, and 2) to bring systems players together as a means of fostering connections and networks. The objectives of the process include:

1. Discuss greatest opportunities and challenges in coordinating care for CYSHN.
2. Gain an understanding of the complexity of care coordination from the family and care coordinator perspectives.
3. Complete individual systems support maps to identify roles, responsibilities, needs, resources, and wishes involved in coordinating care for CYSHN.
4. Share regional experiences and resources in coordinating care to aid in the development of a regional systems framework in provision of care coordination.
5. Brainstorm ideas on ways each participant can improve how they practice care coordination.
6. Discuss and plan for ways that care coordination can be improved.
7. Improve communication among community stakeholders.

**TARGET POPULATION SERVED**

A combined total of 125 stakeholders gathered in six regions across the state to complete the systems mapping. Participants at the meetings represented the following areas: parents/family members, education, social services, children’s mental health, primary care clinics (including health care homes), hospitals, home care, and health plans. The following criteria were used in recruiting participants:

- First-hand experience or knowledge of care coordination/service coordination/case management for CYSHN;
- Interest in improving the state-wide system of care for CYSHN;

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**TITLE V/MCH BLOCK GRANT MEASURES ADDRESSED**

| #11. | Percent of children with and without special health care needs having a medical home |
| #12. | Percent of children with and without special health care needs who received services necessary to make transitions to adult health care |
| #15. | Percent of children 0 through 17 years who are adequately insured |
• Ability to represent more than your individual experience and speak to the broader care coordination needs of families with CYSHN:
• Balanced representation from families and from different programs/services (e.g., local public health, health care, education, social services, mental health, etc.).

PROGRAM ACTIVITIES

The care coordination systems assessment and action planning activities primarily took place via regional meetings held across the state. A mixed methods approach was used to conduct systems mapping around the coordination of care for CYSHN in the state. The approach utilized a number of tools, including Systems Support Mapping and Circle of Care Framework Modeling, to identify the types of care coordinators and their roles in each region, determine the communications/collaborations occurring, and ascertain strengths, challenges, and opportunities in the system of care coordination for CYSHN and their families.

Each stakeholder participating in a systems assessment meeting was walked through the process of creating their own support map. They were asked to: 1) articulate their role and primary responsibilities within the system; 2) delineate what they need to meet these responsibilities; 3) reflect on personal strengths, knowledge, and/or external resources that have and have not supported them in fulfilling their needs; and 4) identify their top three wishes to address unmet needs or help meet their responsibilities.

After each participant created their own map, the information from the maps was aggregated using the Circle of Care Modeling (CCM) approach to create a Regional Care Coordination Framework. The regional frameworks were then combined to form a statewide framework. More information on the regional and statewide frameworks can be found on the MDH CYSHN Care Coordination Mapping website: [http://www.health.state.mn.us/divs/cfh/program/cyshn/mapping.cfm](http://www.health.state.mn.us/divs/cfh/program/cyshn/mapping.cfm). The frameworks not only helped to summarize what was occurring around care coordination, but also highlighted areas that could be targeted to help improve the infrastructure around care coordination across the state.

After the frameworks were developed, the stakeholders participated in an action planning activity. During this action planning, participants were able to actualize their suggestions/recommendations for improvement and were able to put them into actionable steps.

Finally, follow-up was conducted both virtually (via emails to participants) and in-person (via a follow-up meeting that occurred one year after the original assessment meeting). By following up with participants, we were better able as a state to make sure that our findings were indeed accurate and were also able to see what steps had been taken by participants to improve their individual and organizational care coordination practices.

PROGRAM OUTCOMES/EVALUATION DATA

The intended outcomes of the care coordination systems assessment and action planning process include:

1. A better understanding of strengths and challenges in providing care coordination, primary responsibilities of care coordinator stakeholders, and aspects of system that can be strengthened to improve care coordination at regional and state levels
2. Prioritization and action planning to improve care coordination at regional and state levels
3. Changes in the way stakeholders perceive the bigger system – who does what, how the system should function, what is needed to improve care coordination
4. Increased connections and collaboration between care coordinators

Evaluation for the systems assessment and action planning activities occurred primarily via pre and post evaluations at the regional assessment meetings.

As discussed above, one of the intended outcomes of the care coordination systems assessment was increased connections and collaboration between care coordinators. We received many examples of anecdotal evidence that the connections and networks increased via feedback from participants. One example of such feedback is illustrated in the quote below from a care coordinator for a Specialty Care Provider in the state:

“At the meeting, I met a pediatric care coordinator from a primary care clinic. About a week later, one of her colleagues contacted me because we had a shared patient who was on our [specialty care] rehabilitation unit. I was able to connect the colleague with the staff from our unit who were working with the family, and they were able to hold a care conference over the telephone. If it hadn’t been for that connection made at the meeting, I don’t think that the shared planning would have occurred, and the family wouldn’t have had such a smooth transition back home.”

When it comes to the overall evaluations of the systems assessment meetings, participants expressed high satisfaction with the assessment meetings, and agreed that the intended objectives were met. More than 90% of participants agreed or strongly agreed that the meeting 1) helped them to understand the opportunities and challenges...
in coordinating care for CYSHN (100% agreed/strongly agreed), 2) helped them to understand the complexity of care coordination from the family and care coordinator perspectives (99% agreed/strongly agreed), 3) helped them to individual their individual roles, responsibilities, needs, resources, and wishes in coordinating care for CYSHN (97% agreed/strongly agreed), and 4) helped them to understand ways they can improve how they practice care coordination (91% agreed/strongly agreed). In addition, participants reported that the most effective parts of the meeting included care mapping, conversations between the participants (hearing other perspectives), family involvement and stories, and having the ability to network with others in region.

Another intended outcome of the systems assessments was that participants would report changed perceptions of the complexity of the system. To measure this, participants were asked to respond to a set of statements at the beginning of the meeting, and then were asked to rate them again on the post evaluation. Participants used a unique identifier on their evaluations and then we could link them to see if they experienced any changes in their perception of care coordination over the course of the meeting. The statements that showed the greatest amount of change from pre-evaluation to post-evaluation included:

- “Other organizations, agencies, and stakeholders appreciate the challenges I face in supporting care coordination.” This statement had an average increase from pre-evaluation to post-evaluation of 21.3%. This suggests that participants felt they were heard over the meeting and that other better understood the challenges faced.

- “Parents/caregivers need a coordinator to coordinate their care coordinators.” From pre-evaluation to post-evaluation, the average score on this statement increased 23.8%. This suggests that participants developed a better understanding of the amount of work it takes for families to coordinate all the different partners that are working with their child with special health needs.

Specific findings from each of our meetings can be found on the Minnesota Department of Health’s Children and Youth with Special Health Needs website at: http://www.health.state.mn.us/divs/cfh/program/cyshn/mapping.cfm.

**PROGRAM COST**

Below are cost estimates for Minnesota’s care coordination systems assessment and action planning activities. Lunch was also provided to attendees, which was an additional cost.

<table>
<thead>
<tr>
<th>Line Item</th>
<th>Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parent Stipends (Meetings are 4 hours, we allocated around $25/hour for parents who attended the meetings)</td>
<td>$100/mtg/parent</td>
</tr>
<tr>
<td>Meeting Logistics (Facility costs)</td>
<td>$250/room</td>
</tr>
<tr>
<td>Meeting Supplies (Supplies for systems support maps)</td>
<td>$50/meeting</td>
</tr>
</tbody>
</table>

Another cost to take into consideration is that of staff time. The following are estimates of staff time per meeting.

<table>
<thead>
<tr>
<th>Activity</th>
<th># of Hours</th>
</tr>
</thead>
<tbody>
<tr>
<td>Meeting Prep Work (Locating facility, setting agenda, assembling materials, etc.)</td>
<td>5</td>
</tr>
<tr>
<td>Participant Recruitment and Managing Registrations</td>
<td>1</td>
</tr>
<tr>
<td>Holding Meeting</td>
<td>4</td>
</tr>
<tr>
<td>Follow-Up Work (Aggregating Action Plans, Follow-Up Emails)</td>
<td>2</td>
</tr>
<tr>
<td>Analysis and Report Writing</td>
<td>5-10</td>
</tr>
</tbody>
</table>

**ASSETS & CHALLENGES**

**Assets**

This assessment process is worth sharing because it takes a different approach toward conducting a system needs assessment. Typical needs assessments focus on gathering information on strengths, challenges, and opportunities from the community but do not typically include collecting and analyzing that information at the individual, community and systems level. This process is also unique in that it includes follow-up to identify any changes that resulted in system improvement and provides encouragement to empower communities to continue improvement efforts. This process is highly interactive and focuses on building knowledge and connections. By using the systems assessment as a way of bringing stakeholders together and making connections, the assessment process in and of itself becomes a public health intervention and a quality improvement method.

Additionally, the methods incorporated into the systems assessment are rooted in theoretical foundations. The care coordination systems assessment and action planning process directly applies ideas from life course theory, systems theory, and the social ecological model.

**Challenges**

Challenges experienced during the systems assessment and action planning process included:

- Recruiting parent partners
- Having adequate representation from different systems that provide coordination to CYSHN/families
Overcoming Challenges
One challenge we experienced was around the recruitment of parent partners. To overcome this challenge, we worked with a statewide family organization who provided direct outreach to families who lived in the regions where the meetings were held. The family organization also worked directly with the families prior to the meeting to ensure they understood expectations and background information on the meetings.

Related to recruiting partners from diverse systems that serve CYSHN and their families, we also took a direct approach in our outreach efforts. We worked with our parent partners in the regions to inquire which partners they were working with and tried to get those individuals in the room. At times, our recruitment took on a snowball approach – where someone from the Minnesota Department of Health would contact a parent or care coordinator, who then would reach out to their colleagues, and then those colleagues would reach out to even others, and so on. Even with our recruitment efforts, however, we still were missing some key partners at the table and took note of those missing partners at the meetings.

LESSONS LEARNED
Lessons learned while conducting the care coordination systems assessment and action planning process included:

- Importance of reaching out to as many stakeholders as possible from as many systems partners as possible. This way you are able to gather more information to have a better understanding of what is occurring in the system. When you are missing a key partner in providing care coordination, your findings may be skewed.
- Importance of utilizing a quality improvement approach toward the systems assessment meetings. The mapping process itself was loosely implemented as a plan – do – study – act cycle. This helped us to continue to improve the process as we progressed through the assessment process.
- Flexibility in the timing of the agenda of the systems assessment meetings is crucial to ensure that adequate time is given to topics of concern to the different partners. Sometimes the best information was gathered when we held off on moving to the next item on the agenda because we were able to continue productive conversations.

FUTURE STEPS
Future steps related to Minnesota’s care coordination systems mapping and action planning process include:

1. Holding follow-up meetings in each of the regions where the systems assessment occurred.
2. Following up with participants on action plan items that have been completed since the assessment occurred.
3. Educating stakeholders on the systems support mapping process and expanding how it can be utilized in systems assessments related to topics in addition to care coordination.

COLLABORATIONS
Minnesota’s care coordination and systems assessment process was a successful endeavor in part due to our collaborations with the National MCH Workforce Development Center and with Family Voices of Minnesota.

PEER REVIEW & REPLICAION
Practice not peer reviewed or replicated at the time of submission.

RESOURCES PROVIDED
More information on the care coordination mapping process and reports detailing Minnesota’s findings can be found on the Minnesota Department of Health’s Children and Youth with Special Health Needs website at: http://www.health.state.mn.us/divs/cfh/program/cyshn/mapping.cfm. More information on systems assessment tools can be found on the National MCH Workforce Development Center’s website at: http://mchwdc.unc.edu/

REFERENCES:

Key words: Care Coordination, Children and Youth with Special Health Care Needs, Systems Mapping, Systems Assessment, Action Planning

**For more information about this program please contact:
Sarah Cox, Minnesota Department of Health, Children and Youth with Special Health Needs Program, Email: sarah.cox@state.mn.us

Kristen Hassmiller Lich, Systems Integration Core Lead, National Maternal and Child Health Workforce Development Center, Email: klich@unc.edu