Mapping Care Coordination for Children in Minnesota

CENTRAL REGIONAL REPORT
Mapping Care Coordination for Children in Minnesota: Central Report

Minnesota Department of Health
Community and Family Health – Children and Youth with Special Health Needs
PO Box 64882
St. Paul, MN 55164-0882
1–800–728–5420
health.cyshn@state.mn.us
www.health.state.mn.us

Upon request, this material will be made available in an alternative format such as large print, Braille or audio recording. Printed on recycled paper.
## Contents

**Mapping Care Coordination for Children in Minnesota** ................................................................. 0

Central Minnesota Findings .................................................................................................................. 3

Regional Boundaries .............................................................................................................................. 3

Regional Care Coordination Framework ............................................................................................ 5

Child and Family at the Center ........................................................................................................... 6

Roles of Partners ................................................................................................................................. 7

Primary Responsibilities ....................................................................................................................... 8

Infrastructure/Supports Needed to Improve Care Coordination (“Wishes”) ................................. 9

Action Planning .................................................................................................................................... 10

Appendix: Data Tables from Figures/Charts .................................................................................... 15
Central Minnesota Findings

The following section details the findings of the regional care coordination systems mapping activities that occurred in the Central Region of the State. Separate reports for each of the other regions can be found on the “Mapping Care Coordination in Minnesota” webpage on the MDH CYSHN website.

Regional Boundaries

The regional boundaries of the Central area of the state are highlighted in Figure 1 below. The meeting took place in St. Cloud, MN, which is denoted with a star on the map. Participants represented families, agencies, clinics, and organizations located within the counties in the box outlined in red on the map. The region stretched from Mille Lacs, Sherburne, Aitkin, and Wright counties on the east, to Wadena, Todd, and Stearns counties on the west. It stretches from Wadena, Cass, and Crow Wing counties north to Stearns, Meeker, and Wright counties on the south.

Figure 1: Central Region and Meeting Location

Strengths and Challenges in Providing Care Coordination

In conducting systems mapping, it was important to begin by developing an understanding of what works well and what needs improvement in providing care coordination. The main themes from in strengths and challenges experienced around care coordination in Central Minnesota are listed below.
“Care coordination of CYSHN in Central Minnesota currently works because…”

- People know how to access resources outside area
- Parents do everything
- Referral system locally works well
- Lots are working together
- Learning/knowing what questions to ask
- CentraCare does care coordination
- Parents are strongest advocate
- Bigger clinics do good job working with time
- Families offering support to each other
- Parents end up doing most of the work
- Communication with English speaking families
- Lots of people willing to help/coordinate
- Collaboration within certain areas (HMG, Gillette)
- Families do their own thing
- Connection within CentraCare (feedback)
- Agencies really care
- Good relationships within community
- Parents coordinate care, coordinators working with each other, provider champions
- Networking of Parents

“Care coordination of CYSHN in Central Minnesota would be better if…”

- Actually have MN services in cities
- Health systems communicated
- Monthly/Quarterly meetings between care coordinators in region
- Better understanding of care coordinators of needs
- Being able to integrate referrals locally
- Better identification of who the care coordinators are—more integration and “funneling” through a more central care coordination who knows family
- Release of information
- Interoperability and getting together
- All clinic did care coordination (outside CentraCare)
- Communication is lost outside of county/area
- Clinics outside St. Cloud area working with HMG
- Connection/Access to more services is needed
- Communication with non-English speaking families
- Duplication of services/gaps because there are so many helping coordination
- Having the direct contacts/connections at providers
- Need more time to do more in-depth planning (safety, etc.) with families
- Ensuring children have a PCP when leaving hospital
- Too many releases of information for families to sign—not able to talk to each other because of ROI
- Network of resources of care coordinators within the different systems so know who to call etc.
• Communication- development of community/countrywide/ statewide ROI
• Streamlining of paperwork

Regional Care Coordination Framework

All participants completed individual systems support maps (see Statewide Summary for more details), and then all the maps were compiled to create a regional care coordination framework using the Circle of Care Modeling (CCM) approach. CCM was used to identify the different various partners providing care coordination services, their primary responsibilities, and their common wishes on how to improve the system. The CCM approach positioned CYSHN and their families at the center of the system; the roles of care coordinators and their responsibilities were then modeled around the family. By mapping out the various partners providing care coordination and their responsibilities, we were able to expand our understanding of what families are experiencing in care coordination, and were also able to determine areas where the infrastructure needs to be built up to improve care coordination for CYSHN and their families.

The systems mapping approach is described in the next section, and is incorporated into Figure 2. We begin by describing the various partners who provide care coordination, and then move to their primary responsibilities in coordinating care. Finally, we explore wishes or opportunities for improvement at a systems-level; providing recommendations on how to build up the infrastructure to improve the provision of care coordination for CYSHN in Central Minnesota.
Child and Family at the Center

For both the Statewide and Regional Care Coordination Frameworks, the child and family are placed at the center of the system. An increasingly growing body of literature points out that when the patient and/or family experience is placed at the center of care, more favorable outcomes are produced. By placing the child and family at the center of the framework, we are not only ensuring we think of their needs and experiences first, but that we also actively partner with them first when determining what systems-level improvements need to be made.
Roles of Partners

The next level of the Statewide Care Coordination Framework are the various roles of partners involved in care coordination. There were a total of 16 participants in the care coordination systems mapping meeting in Central MN. Participants represented the following areas: parents of CYSHN, primary care, local public health, specialty care, state agency staff, Head Start, and county human services. There are many different players involved in providing care coordination, or many different types of coordinators from different service/support systems. Also of note is that families often reported that they are the main coordinator of their child’s care – or at times can be the “coordinator of all the coordinators.”

A breakdown of the organizations/roles of participants by region is included below in Table 1. The first row of the table includes all the types of different stakeholder groups who participated in any of the five regional meetings. The second row includes the number who participated in the Central Regional Meeting. As you can see, there were some stakeholder groups missing in the region. These roles/organizations are not included in regional care coordination framework (Figure 2).

Table 1: Care Coordination Systems Mapping Participant Organizations/Roles in Central MN

<table>
<thead>
<tr>
<th>Participant Organizations/Roles</th>
<th>Central</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary Care</td>
<td>7</td>
<td>28%</td>
</tr>
<tr>
<td>Parents</td>
<td>3</td>
<td>12%</td>
</tr>
<tr>
<td>Local Public Health</td>
<td>4</td>
<td>16%</td>
</tr>
<tr>
<td>Specialty Care</td>
<td>2</td>
<td>8%</td>
</tr>
<tr>
<td>Health Plans</td>
<td>0</td>
<td>-</td>
</tr>
<tr>
<td>MDH – Health Care Homes</td>
<td>1</td>
<td>4%</td>
</tr>
<tr>
<td>Education (District &amp; State)</td>
<td>4</td>
<td>16%</td>
</tr>
<tr>
<td>Head Start/Early Head Start</td>
<td>0</td>
<td>-</td>
</tr>
<tr>
<td>County Human Services</td>
<td>3</td>
<td>12%</td>
</tr>
<tr>
<td>Mental Health</td>
<td>0</td>
<td>-</td>
</tr>
<tr>
<td>Family Organization</td>
<td>0</td>
<td>-</td>
</tr>
<tr>
<td>MN DHS</td>
<td>0</td>
<td>-</td>
</tr>
<tr>
<td>School Nurse</td>
<td>0</td>
<td>-</td>
</tr>
<tr>
<td>Interagency Early Intervention Committee</td>
<td>0</td>
<td>-</td>
</tr>
<tr>
<td>Home Care</td>
<td>1</td>
<td>4%</td>
</tr>
<tr>
<td>TOTAL</td>
<td>25</td>
<td></td>
</tr>
</tbody>
</table>

Missing Partners

Table 1 above includes the various roles or organizations of the participants in the Central Minnesota Regional Meeting. As you can see, there were quite a few different stakeholder groups who were not present, including: health plans, school nurses, interagency early intervention committees, and family organizations.

The participants in the meeting were also asked to list out other partners who were missing in the meeting. Responses included: law enforcement, representatives from more community-based organizations (e.g., Central Minnesota Mental Health Center), school social workers, special education instructors, county and state human services workers, youth/adolescents, county attorneys, home
health/home nursing agencies, and policy makers (school administrators, political leaders, county commissioners).

Primary Responsibilities

Moving out to the next level of the care coordination framework are the primary responsibilities of the providers of care coordination. Participants were asked to identify their top five responsibilities when it comes to providing care coordination for CYSHN. It is important to understand these responsibilities because they can help point toward the areas that care coordinators spend most of their time and effort. The responsibilities reported by the participants were aggregated utilizing an affinity diagraming process, and then were grouped into 14 different categories, including:

1. Advocacy and policy development
2. Arrange for, set up, coordinate, and track tests, referrals, and treatment
3. Assist in navigating the system
4. Assure competent care coordination workforce
5. Communication
6. Coordinate funding
7. Coordinate quality improvement efforts
8. Development of care plan
9. Facilitate care team and ensure family is a team member
10. Facilitate, support, and assist in managing transitions
11. Intake, assessment, and evaluation
12. Provide education and resources
13. Relationship building
14. Use health information technology/electronic medical record

Figure 3 provides the overall responsibilities reported by care coordinators in the Central Region. The most reported responsibilities of care coordinators in the region were providing education and resources, and arrange for set up, coordinate, track tests, referrals, and treatment. Some of the more specific activities under providing education and resources included: educate family and local care team on specialty care needs, link resources, services and supports with or for family, Facilitate family access to medical, home providers, staff, and resources, and serve as a contact point advocate and information resource.

The second most reported responsibility was relationship building and communication. This included activities such as coordination with community organizations to support good relationships, communication and collaboration with child’s primary care clinic, build relationship among family and team, and communication with other providers.
Infrastructure/Supports Needed to Improve Care Coordination (“Wishes”)

The final level of the Care Coordination Framework includes the systems-level actions that are needed to be able to improve care coordination. The participants were asked to give the top three things that they “wish” for that could help improve care coordination. We focused on calling these “wishes” because we wanted to encourage participants to think “big” when brainstorming things that could improve care coordination. Sometimes when stakeholders are asked to think of things that can improve the system or make it more easily navigable, responses can be stifled because they only will think of the smaller level things rather than the bigger problems or solutions – calling them wishes increased the creativity and honesty of the responses. All the responses statewide were compiled and grouped using an affinity diagramming process – categories were then determined based on the groups. The top “wishes” in the Central Region included:
• **More services available for families**: Related to this category, participants wished for more information about available community resources, more resources for Greater MN (for family, staff), supportive providers, and equitable coordination of care.

• **Medical records that span multi-systems and are family-friendly**: Participants wished for expanded technology (including telehealth and data exchanges).

• **More appropriate, stable, and secure funding for services and care coordination**: Some of the wishes that fit within this category included: funding to support the number of social workers needed to actually case manage families, adequate funding of established programs and funding and simplified access to services and more resources.

• **Better communication/collaboration between care team members (including family)**: Participants wished to be able to more easily communicate with other providers, a virtual care conference for all persons coordinating care for a child including parents, family access to all documents/information in their child’s EMR, sharing medical/patient information easily.

• **More support for families / family-centered care**: Participants wished that families would be the focus rather than the systems or costs. They also wished that they could reach families earlier (referrals) and better communication with non-English speaking patient families.

• **Central resource directory / shared resource**: Participants wished for a central location for resources by region and master list, and medical/patient information was shared easily.

• **Easier way to obtain consent / Release of Information**: Participants wished for a quick and easy way to obtain consent from families so that providers/coordinators can speak with one another using Universal ROI adopted/recognized by health systems

• **More time devoted to care coordination**: participants wished for more staff to allow for more time to fulfill responsibilities

• **More public awareness of care coordination**: Participants wished that there was an online resource guide of care coordinator contacts amongst providers i.e. out of our rural network

**Action Planning**

After developing the Care Coordination Framework, participants were asked to take into consideration the various roles, responsibilities, and wishes discussed and brainstorm some concrete action steps that could be taken to improve care coordination. The action step planning was done at four levels to gather both short and long term steps as well as get at the different stakeholders involved in the steps. These four levels included: The overall action planning responses from the Northeast Region were grouped with those from other regions to create a set of major themes action steps. They were asked to think of four levels of action planning, including:

1. Things they can do right away, on their own, in the next week to month
2. Things they can take back to their organization/team to work on over the next 3 to 12 months
3. Things they can collaborate with someone else in their region over the next 6 to 12 months
4. Things that can be worked on at the broader state level over the next 1 to 2 years

For the first three levels, participants completed a worksheet in which they listed out action steps. Some common themes and examples from these levels are included in Table 3. Responses are not included in any specific rank. Those responses included more than once are bolded.
<table>
<thead>
<tr>
<th>Action Planning Theme</th>
<th>Can be completed within 1 month, alone</th>
<th>Can be completed within 3-12 months, within organization/team</th>
<th>Can be completed within 6-12 months, with others in region</th>
</tr>
</thead>
</table>
| Improving Communication / Collaboration with Others in Region | • Involve the new community health worker with care coordination families  
• Continue networking  
• Reach out to county health workers to meet to discuss what we do  
• Communicate with local partners, co-workers  
• Work on improving communication  
• Keep early intervention team/service coordinators better informed of other agencies and programs by sharing monthly information from THRIVE and IEIC meetings  
• Develop a support group even if it is specific for parents of special needs | • Collaboration- find contact with specialty care providers to work as a team  
• More collaboration with communities  
• Forming a community group with different entities like school, county, mental health etc.  
• Need for better communication within our human services agency and with other agencies in my county and surrounding counties  
• Facilitate for care coordinators to connect with others | • Make contacts, develop relationships for better care and mutual patients  
• Collaborate with CentraCare coordinators to share methods and ideas  
• Collaborate with the local health system to ensure needed equipment |
| Improving Internal Clinic / Agency / Organization Care Coordination Processes | • Bring information from today back to internal care coordination team at Gillette  
• Connect Gillette care coordination team with care management team within CentraCare | • Bring mapping exercise to my supervisor so that it can be done within our agency to improve our care coordination | |
| Improving Release of Information / Data Sharing Processes | • Send universal release of information link to Sue Ewy and Sarah Cox  
• Share information from today with early intervention team | • Streamline paperwork for families  
• Talk to health information management about the release that a family can bring and put all agencies on | • Work with other organizations to advocate on improving laws for sharing health information between providers  
• Getting releases signed by families in order to be able to communicate with other agencies (most difficult with physicians)  
• Collaborate with the local health system to be in the loop and status of each client being mutually served |
<table>
<thead>
<tr>
<th>Action Planning Theme</th>
<th>Can be completed within 1 month, alone</th>
<th>Can be completed within 3-12 months, within organization/team</th>
<th>Can be completed within 6-12 months, with others in region</th>
</tr>
</thead>
</table>
| Improving resource directories and databases | • Compile a list of representatives in Mille Lacs county so know who to contact for referrals | • Ensure documentation of care coordination in electronic medical record  
• Include CYSHN resource in development of Family Home Visiting program  
• Seek resources I feel are missing | • Work with doctors at Gillette to increase willingness to add protocols to other health system care plans for Gillette patients when they present to ER in outstate communities (seizures and how to treat, shunt malfunction)  
• Develop a contact and resource list |
| Increasing Awareness / Providing General Education or Training | • Take what I learned today back to my team  
• Consider doing this same mapping exercise with the team coalitions that Public Health works with  
• Orient/ facilitate orientation of new Public Health Nurses  
• Encourage family access to medical home providers  
• Increase the understanding and use of new behavioral health smart-text in order to ensure no behavioral health patient need is missed  
• Post chart on my wall to use as a guide | • Be more upfront and transparent with new families that they are the best advocates for services and to connect with other parents (while we work to improve care coordination  
• Training and information from Family Voices of MN and Gillette | • Invite Gillette to present to early intervention team on their program/system |
<table>
<thead>
<tr>
<th>Action Planning Theme</th>
<th>Can be completed within 1 month, alone</th>
<th>Can be completed within 3-12 months, within organization/team</th>
<th>Can be completed within 6-12 months, with others in region</th>
</tr>
</thead>
</table>
| **Promote Care Coordination** | • Check on frequency on dedicated care coordination appointments  
• Hire new Public Health Nurse staff to serve Community Alternative Care (CAC) waiver clients  
• Link families to services or resources within our community  
• Learn more about case load of other care coordinators - tools to manage case load  
• Contact political leaders who create red tape to share story of how caregivers not communicating affects care  
• Advocate for more time for care planning and talk about needs  
• Contact political leaders who create red tape to share story of how caregivers not communicating affects care | • Identify primary care coordinators of Gillette patients  
• Developing a plan to implement a care team approach when serving our families  
• Importance of and support for care coordination | • Identify specialty patients shared with CentraCare  
• Email Sandy about PACT for Families and trying to do something similar  
• Increase the number of referrals to Help Me Grow from our NICU as well as improve the tracking system of HMG within CentraCare Health.  
• Share initiatives the CentraCare is working with MDH on a regular basis |
| **Promoting Shared Care Plans** | • Being part of care plan for protocols for outstate patients presenting to local ER’s  
• Work towards a stronger unified care plan that provides contact information at minimum and resources of outside providers/specialists | | |

Finally, participants were asked to identify state-level action steps that could be taken to improve care coordination for families of CYSHN. They then placed these action steps on an action priority matrix based on their perceptions of the potential level of impact and feasibility of the items. A summary matrix of is included in Figure 4.
## Figure 4: Systems Mapping Action Priority Matrix

<table>
<thead>
<tr>
<th>Knowledge of incentives to students in social work/mental health fields to work/live in communities</th>
<th>Contact Legislators to communicate how difficult communication is due to red tape</th>
<th>County/Region family event to connect families for informal support</th>
<th>Mandate case load numbers for waivers in any management at the county level</th>
<th>Increase awareness and then use of legislatively approved release that can cover entire team</th>
<th>Discharging hospitals had a system that triggers automatic referrals to public health &amp; early intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td>Develop a tool for care coordinators to understand the steps needed for mental health services.</td>
<td>Sharing stories about how too much data privacy or not being able to share information can hinder care/outcomes</td>
<td>Have someone be in charge of updating or removing helpful links/resources</td>
<td>Streamline of eligibility for services</td>
<td>Work with legal to try to implement a more streamlined release of information form</td>
<td>Health care systems include community partners in care conferences</td>
</tr>
<tr>
<td>Communicate what MnDH is doing now to improve care coordination</td>
<td>Inform parents/caregivers what a care coordinator is and how to find one</td>
<td>Propose a bill or a workgroup to focus on care coordination for children</td>
<td>Increase the availability of care coordinators who are culturally diverse</td>
<td>Networking opportunities for care coordinators</td>
<td></td>
</tr>
<tr>
<td>Care coordinators work together and not independently</td>
<td>Web resource of area care coordinator</td>
<td>HCH site already lists certified HCHs statewide. Add care coordination contact info for each clinic site</td>
<td>Patient access to all information in their EMR</td>
<td>Interoperable EMR at least statewide</td>
<td>Offer/Coordinate service/resource update regionally</td>
</tr>
<tr>
<td>Education/CEUs on different diagnoses and care paths if any so children are staying on track with medical needs</td>
<td>Assigned workers with county specific activities</td>
<td>More educational opportunities for care coordinators and tying with resources available</td>
<td>Online resource of care coordinators (effective, efficient, communicating)</td>
<td>Develop a community resource and/or contact list for families and staff</td>
<td>On-line list of agency resources that is kept up-to-date</td>
</tr>
</tbody>
</table>
### Primary Responsibilities in Providing Care Coordination (Data from Figure 3)

<table>
<thead>
<tr>
<th>Primary Responsibility Group</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Use health information technology / electronic medical records</td>
<td>4%</td>
</tr>
<tr>
<td>Development of care plan</td>
<td>7%</td>
</tr>
<tr>
<td>Coordinate quality improvement efforts</td>
<td>6%</td>
</tr>
<tr>
<td>Assure competent care coordination workforce</td>
<td>7%</td>
</tr>
<tr>
<td>Relationship building</td>
<td>10%</td>
</tr>
<tr>
<td>Facilitate, support, and assist in managing transitions</td>
<td>1%</td>
</tr>
<tr>
<td>Facilitate care team and ensure family is a team member</td>
<td>3%</td>
</tr>
<tr>
<td>Intake, assessment, and evaluation</td>
<td>7%</td>
</tr>
<tr>
<td>Coordinate funding</td>
<td>0%</td>
</tr>
<tr>
<td>Communication</td>
<td>10%</td>
</tr>
<tr>
<td>Advocacy and policy development</td>
<td>6%</td>
</tr>
<tr>
<td>Assist in navigating the system</td>
<td>4%</td>
</tr>
<tr>
<td>Arrange for, set up, coordinate, and track tests, referrals, and treatment</td>
<td>17%</td>
</tr>
<tr>
<td>Provide education and resources</td>
<td>17%</td>
</tr>
<tr>
<td></td>
<td>Easy to Implement</td>
</tr>
<tr>
<td>---</td>
<td>-----------------------------------------------------------------------------------</td>
</tr>
<tr>
<td><strong>1</strong></td>
<td>Online resource of care coordinators (effective, efficient, communicating)</td>
</tr>
<tr>
<td><strong>2</strong></td>
<td>Education/CEU on different diagnosis and care paths so children are staying on track with medical needs</td>
</tr>
<tr>
<td><strong>3</strong></td>
<td>Care coordinators work together and not independently</td>
</tr>
<tr>
<td></td>
<td>Web resource of area care coordinators</td>
</tr>
<tr>
<td></td>
<td>HCH site already lists certified HCHs statewide – add care coordination contact information for each clinic site</td>
</tr>
<tr>
<td></td>
<td>Patient access to all information in their electronic medical record (EMR)</td>
</tr>
<tr>
<td><strong>4</strong></td>
<td>Communicate what MDH is doing now to improve care coordination</td>
</tr>
<tr>
<td></td>
<td>Inform patients/caregivers what a care coordinator is and how to find one</td>
</tr>
<tr>
<td></td>
<td>Propose a bill or workgroup to focus on care coordination for children</td>
</tr>
<tr>
<td></td>
<td>Increase the availability of care coordinators who are culturally diverse</td>
</tr>
<tr>
<td><strong>5</strong></td>
<td>Develop a tool for care coordinators to understand the steps needed for mental health services</td>
</tr>
<tr>
<td></td>
<td>Sharing stories about how too much data privacy or not being able to share information can hinder care/outcomes</td>
</tr>
<tr>
<td></td>
<td>Have someone be in charge of updating or removing helpful links/resources</td>
</tr>
<tr>
<td><strong>6</strong></td>
<td>Knowledge of incentives to students in social work/mental health fields to work/live in communities</td>
</tr>
</tbody>
</table>