Mapping Care Coordination for Children in Minnesota

MINNEAPOLIS - SAINT PAUL METROPOLITAN AREA REGIONAL REPORT



Mapping Care Coordination for Children in Minnesota: Metro Region Report

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Minneapolis – Saint Paul Metropolitan Region Findings

The following section details the findings of the regional care coordination systems mapping activities that occurred in the Twin Cities Metro 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 Twin Cities Metro area of the state are highlighted in Figure 1 below. Two meetings were held in the Eastern and Western regions of the metropolitan area, which are 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 included the following counties: Anoka, Carver, Dakota, Hennepin, Ramsey, Scott, and Washington.

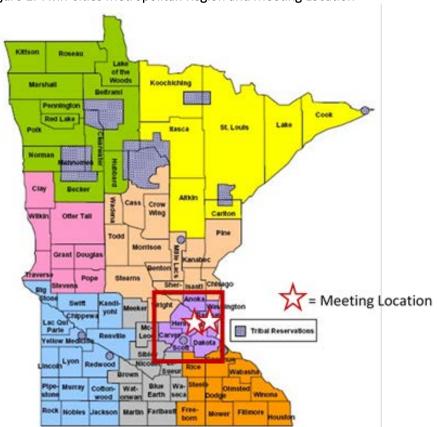


Figure 1: Twin Cities Metropolitan Region and Meeting Location

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 the Twin Cities Metro are listed below.

"Care coordination of CYSHN in the Twin Cities Metro currently works because..."

- Care coordinators are dedicated and passionate about helping families
- Care coordinators are being more creative in finding ways to link families with needed services
- Parents play an active role in doing the care coordination
- Coordinators are collaborating more across agencies/organizations
- Time is allocated to providing care coordination/working with families
- Awareness of care coordination is growing in the community/state and it is getting more investment
- Coordinators are knowledgeable of available resources and connect families with needed ones
- Clinics have a dedicated "point person" as a care coordinator
- Care coordinator is occurring within the health care homes (medical home) model
- Social workers/care coordinators have been providing care coordination for a long time and know the resources
- Local Public Health Nurses are helping link families with resources
- Specialty care clinics are increasingly providing care coordination for families
- School nurses understand family systems, spend quite a bit of time with families, and are able to help them plan how to get through the day/link with services
- Strong relationships have been established between coordinators in various systems serving the child

"Care coordination of CYSHN in the Twin Cities Metro would work better if..."

- Those providing care coordination would look at the needs of the child and family in a broader way
- There were more partnerships/connections between the different types of coordinators/service providers
- A more "strengths-based" approach were utilized with families
- More parent peer support was available
- More dedicated funding was available for care coordination
- More resources were available for families
- Families/coordinators knew more about the resources that are available
- Care plans would be more family-centered
- Care teams would include more partners that are serving the child/family
- Language barriers and miscommunications were reduced
- More communication would occur between different partners
- Electronic health records were more able to communicate with each other (including hospitals)
- Roles of various coordinators were clearer (e.g., county workers)
- There was less paperwork for families to fill out to obtain financial assistance, services, etc.
- There was less burnout and subsequent turnover of care coordinators
- More schools had school nurses on board to work with children/families
- There was a central point person or "coordinator of coordinators"
- Parents were not relied upon as the "bridge" between the different systems/services if parents didn't have to "coordinate the coordinators"
- Parents were included more in decision-making around systems and services

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 Twin Cities Metro.

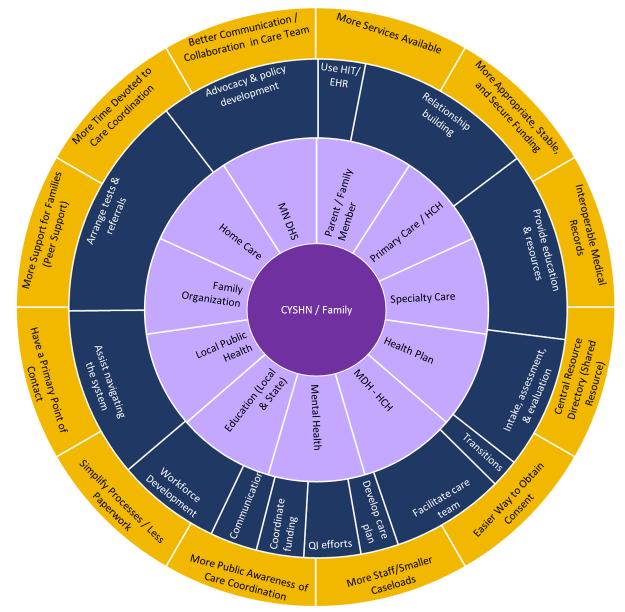


Figure 2: Twin Cities Metro Care Coordination Framework

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 <u>increasingly growing body of literature</u> 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 are many different players involved in providing care coordination, or many different types of coordinators from different service/support systems. There were a total of 43 participants in the two care coordination systems mapping meetings in the Twin Cities Metro area. Participants represented the following areas: parents of CYSHN, primary care, local public health, specialty care, state agency staff, education, MDH-Health Care Homes, mental health, and home care.

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 and third rows include the number who participated in the East and West Metro Meetings. As you can see, there were some stakeholder groups missing from the meetings. These roles/organizations are not included in regional care coordination framework (Figure 2).

Table 1: Care Coordination Systems Mapping Participant Organizations/Roles in Twin Cities Metro

	East	West		
Participant Organizations/Roles	Metro	Metro	TOTAL	Percent
Primary Care	8	6	14	33%
Parents	3	3	6	14%
Local Public Health	1	3	4	9%
Specialty Care	1	3	4	9%
Health Plans	2	3	5	12%
MDH – Health Care Homes	1	1	2	5%
Education (District & State)	1	3	4	9%
Head Start/Early Head Start	0	0	0	-
County Human Services	0	0	0	-
Mental Health	0	1	1	2%
Family Organization	1	0	1	2%
MN DHS	1	0	1	2%
School Nurse	0	0	0	-
Interagency Early Intervention Committee	0	0	0	-
Home Care	1	0	1	2%
TOTAL	20	23	43	

Missing Partners

Table 2 above includes the various roles or organizations of the participants in the Twin Cities Metro meetings. As you can see, there were quite a few different stakeholder groups who were not present, including: head start/ early head state, county human services, school nurses (though a representative from the Department of Education was present to represent school nurses), and interagency early intervention committees.

The participants in the meeting were also asked to list out other partners who were missing in the meeting. Responses included: primary care/specialty care providers (physicians), local school district representatives (including special education), financial workers (including workers for waiver services), community-based organizations, NAMI, legislators/policy-makers, fathers of children with special health

needs, youth with special health needs, child protection workers, child care providers, the Minnesota Disability Law Center, representatives from IT/data departments that work on the electronic medical records, transportation providers, school administrators, clinic administrators, staff from the Department of Human Services who work in the Medical Assistance (Medicaid) program, and more culturally-diverse representation from providers and families.

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 each of the meetings in the Twin Cities metro. The most reported responsibility in the West Metro was arranging for, setting up, coordinating, and tracking tests, referrals, and treatment. This included activities such as helping to coordinate services, assisting with crisis prevention and management, guiding families so they can receive

needed services and supports, and working to remove barriers experienced by families in navigating the system.

The most reported responsibility in the East Metro was relationship building. Specific activities that fell under relationship building included: collaborating with other care coordinators/providers, establishing trusting relationships with families, and helping families to ensure they have a support system in place.

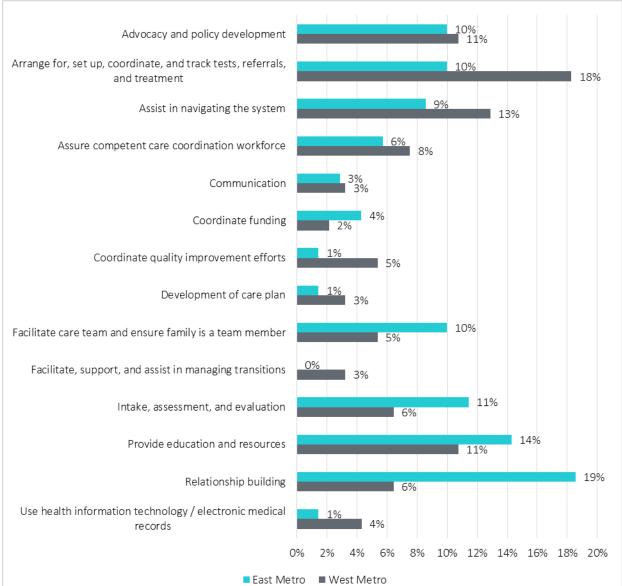


Figure 3: Twin Cities Metro Primary Responsibilities in Providing Care Coordination

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 Twin Cities Metro included:

- More services available for families: Wishes under this category included having more resources
 for respite care and peer-to-peer support. Another wish was for a skeletal dysplasia clinic that
 would occur quarterly.
- Medical records that span multi-systems and are family-friendly: Wishes included having better transmission of information between providers, having centralized access to medical records, and electronic medical records that are more interoperable. They also wished that all families would have access to an electronic table where they can access medical records, contact doctors, etc.
- More appropriate, stable, and secure funding for services and care coordination: Participants wished for a "healthy" reimbursement model for care coordination (especially in health care homes), for time and funding for systems building, and for insurance companies to stop being able to dictate where children can get care, what medications they can take, etc.
- Better communication/collaboration between care team members (including family): Wishes included things such as: more standardized approaches toward assessment so families do not have to repeat themselves many times, more communication across the system,
- More support for families / family-centered care: Participants wishes for stronger patient/families partnerships, for systems that would empower families, for increased bilingual communication options for families, that there would be "no wrong doors" to enter the system, and that families could be connected with peer support right away. They also wished that families would be seen as more than a "number or patient" that they would be seen as equal partners.
- Central resource directory / shared resource: Participants wished for a centralized child-focused linkage line that has 24/7 availability, for a central location where providers and families can get information on services,
- Having a primary point of contact "coordinator for the coordinators": This category included a wish for a primary contact for families to call rather than always being re-routed.
- Simplify processes for obtaining financial assistance / services less paperwork, less duplication:

 Participants wished for a reduction in paperwork and for less red tape when accessing services specifically they wished that families would not need to continually fill out paperwork every year or multiple times a year.
- Easier way to obtain consent / Release of Information: Wishes in this category included having a method of being able to communicate more efficiently with multiple organizations using just one Release of Information.
- More public awareness of care coordination: Participants wished that everyone would recognize care coordination and the roles of coordinators. They wishes that there was the "political will" to make the needs of CYSHN and their families a priority.
- More staff/smaller caseloads: Wishes included having smaller caseloads for care coordinators and for more time to be able to devote to care coordination.

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 Twin Cities Metro 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 2. Responses are not included in any specific rank. Responses were unduplicated and those included more than once are included in bold font in the table.

Table 2: Twin Cities Metro Action Planning Themes and Examples

Action Planning Theme	Can be completed within 1 month, alone	Can be completed within 3-12 months, within organization/team	Can be completed within 6-12 months, with others in region
Taking information	Update my team on the day's	 Share information at care coordination staff meeting on discussion and ideas here today Share the ideas from the meeting Take back the discussion of wishes and determine where can we have an impact 	Share information with
from meeting back	events to share what I learned		other parents in the
to staff	from other participants		dwarfism community

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Action Planning Theme	Can be completed within 1 month, alone	Can be completed within 3-12 months, within organization/team	Can be completed within 6-12 months, with others in region
Education, providing training, and sharing information and resources	 Awareness and sharing information Identify some peer-to-peer care coordination learnings and success stories that can be shared broadly Provide education on care coordination Educate myself on who is doing what in the community Build family stories into Minnesota Department of Education social work training Learn more about care coordination within hospitals Look at Family Voices to learn more about services they have available 	 Organize a workshop/ training Fall 2015 on parent leadership and partnering with providers Education around cultural sensitivity/ competence Focus resources on training opportunities in sharing data across agencies Complete an educational session on healthcare transition planning 	Connect with those interested to share information about Parent-to-Parent, Family-Centered Care, and starting and maintaining family advisory committees

Action Planning Theme	Can be completed within 1 month, alone	Can be completed within 3-12 months, within organization/team	Can be completed within 6-12 months, with others in region
Involving families, learning about their needs, and promoting family-centered care	 Ask families about their support team – What kind of help can they expect and what kind of support do they need? Spend some time researching the needs of my individual patients. – What needs face the Native American community I work in? Select a few attainable goals that will address these needs. Continue to listen and advocate for the needs of the families I work with Learn needs of families across spectrum of CYSHN (including learning more from parent experiences) Help care coordinators learn how to connect parents of children with disabilities with a support group/peer group/mentor Involve families more in goal setting/planning Communicate needs of families with other care coordinators, case managers, schools Stay committed to patient/parent involvement and advocating for non-English-speaking populations Schedule consistent communication with patients/caregivers to check in, even if it seems they are functioning well or don't need anything Continue to communicate and build relationships with families 	 Create and maintain a Parent/Family Advisory Committee Continue to think of more avenues for providing different kinds of information and support to our families and children engaged in the care coordination services. Care coordination system to include family priorities, include communication to school contacts. Reach out to clinic systems to request meetings and share information on Parent Support program Increase patient/family partnerships with Health Care Homes model Connect with parent support groups more regularly and/or be more involved in Minnesota Special Education Advisory Councils Use patient advisory to determine how care planning is more useable for them 	 Share my stories with others Ask families to come and share their experiences/stories at meetings/etc. Provide information to parents on how best to navigate our system. Parent support and self-care resources

Action Planning Theme	Can be completed within 1 month, alone	Can be completed within 3-12 months, within organization/team	Can be completed within 6-12 months, with others in region
Improving internal clinic/agency/organ ization care coordination processes	 Pay more attention to how I approach my caseload during this time in transition Continue to work on standard order sets for common care delivery, reducing administrative burdens. Share order sets with referring doctors and hospitals to add to their EMR. Review consumer survey we conducted and incorporate feedback into planning Meet with care coordinators at clinic to discuss what resources they have available and brainstorm where we need more support Talk with triage nurses about common resources and questions they have, or support they might need Better communication internally in my setting 	 Pull together a group at my clinic who can work on improving care coordination. We can reach out to community resources and try to establish a working relationship and work as a team on "case studies" by sitting down as a group and looking at an individual patient Better care coordination between doctors Start a conversation with Employment and Economic Assistance department about how to better support families receiving MA/TEFRA Work with administration to push hiring a social worker to help support this work at the clinic Meet with providers and families to see where we as an organization could improve Focus on EMR training for care coordination Obtain a better understanding of the issues faced by the different care coordination stakeholders and determine how to how to ultimately tackle those issues Work on standardizing process for transition to adult medicine providers and communicating and sharing resources Continue to refine work flows for standardization of care, including transitioning from pediatrics to family medicine/ internal medicine 	 Collaborate with other Native American Community Clinic RN Push for certain care coordination elements to be included in new EMR content: supports, motivators, perceived barriers, email capabilities, require emergency contact info, inclusion of external care plan content Stress working together as a team as clinic/system is going through a lot of change Reach out to and work with county to be aware of services and getting info to patients streamlined Identify ways to increase more time for care coordination Identify ways to free up more time for care coordination Collaborate with coworker to have more information and resources to support and ways to participate in this effort Expand current children's stakeholder group.

Action Planning Theme	Can be completed within 1 month, alone	Can be completed within 3-12 months, within organization/team	Can be completed within 6-12 months, with others in region
Improving communication and collaboration with others	 Promote Family Voices of MN via social media to get people connected Send out an email reminding staff about services offered by Family Voices of MN Initiate conversation with Public Health Nurses to increase levels of dedication and compassion for families and brainstorm about resources Build topic into fall agenda of Region 7 IEIC Make sure that care coordinators at other types of organizations who wants to be the "coordinators" Find a contact person in each of the six metro counties Communicate better with those outside my organization Work to communicate better primary care clinics re: ongoing needs of children and differing roles of community care coordinators Consult with school nurse more frequently Be more deliberate when connecting with other care coordinators after interactions with patients to ensure fluid communication regarding action items and division of services Review health/family history assessment components Visit home transition planning clinic to gather information on their resources and services Continue to build relationships with resources outside my agency 	 Talk about streamlining medical and educational systems Bring up care coordination with local inter-agency committees Collaborate with Family Voices of MN so they can provide a training to staff on their programs so more families can be connected Network with organizations that most frequently work with our coordinated patients Discuss with Director how to better collaborate with other agencies Find experts to come to team meetings to talk about county services/processes, SMRT, TEFRA, CFSS, etc. waivers More overall consistency in communicating with outside resources; potentially in a written care plan format More "networking" with PCP offices, MDH, MDE, grant writers Involve school nurse in care coordination and annual meetings Continue to collaborate with CYSHN unit @MDH to discuss mutual goals/shared visions around care coordination and medical home implementation Share family stories and mapping with related services specialist 	 Collaborate with Family Voices of MN – connect more families with their programs Partner with Children's Hospitals & Clinics on care planning Collaborate with resources or partners (Behavioral Health) Collaborate with Health Plans – learn more about resources available (care manager role), share gaps and needs of families Collaborate with MDH-HCH staff on role of care coordinators and alignment of trainings Collaborate with payers re: home care process so have efficient, timely access Explore ways to collaborate with other CC's to streamline Collaborate more with school nurses to get a better idea of their role Working to get care coordinators to be a part of the IEP "team" (MDE) Developing relationships with specialty clinic coordinators as well as connection to staff in the school systems Increase communication before transitions from hospital to home
Improving release of information / data sharing processes			Work with coordinators from clinics in my area so information can be shared while respecting data privacy rules

Action Planning Theme	Can be completed within 1 month, alone	Can be completed within 3-12 months, within organization/team	Can be completed within 6-12 months, with others in region
Improving resource directories and databases	 Research local resources for families and share with care coordinators Condense resources list and post on shared drive/folder Keep track of what resources were useful to patients and what didn't work 	 Identify resources within our system and make that information easy for everyone to access Cross training opportunities to share resources Create a list of resources/contacts Compile personal resource/database for resources available to families to know what options are available 	Share resources that may be helpful/ unknown to other participants
Further implementing systems support mapping	Encourage parents to complete a systems support map.	 Use the system support mapping process with our Board Develop electronic version of map to share with other parents Make a more comprehensive care map Invite chair of organization to participate in a future systems mapping event Mapping exercise: this exercise would be valuable for all our care coordinators and supervisors to identify common themes and needs within our organization Suggest mapping activity for Minnesota State Interagency Committee 	Be proactive and share electronic version of map with other parents
Promoting shared care plans	 Review child's shared care plan Share plans of care with supporting agencies and clinics Keep care plans up to date 	 Include specialty clinics, schools, and other service providers in shared care plan Integrate shared care plan in electronic medical record Standardize care plan template and make more useful for families 	

Action Planning Theme	Can be completed within 1 month, alone	Can be completed within 3-12 months, within organization/team	Can be completed within 6-12 months, with others in region		
Promoting care coordination and better defining roles of care coordinators (both at clinic/organization and at a systems level)	 Spread the word regarding the importance of care coordination Identify more patients that may benefit from care coordination 	 Participate more in care coordination efforts and determine ways we can support care coordination Continue work on care coordination model Expand care coordination in specialty healthcare setting Learn more about roles of public health nurses to better utilize their help with families in communities Connections to public health and social services to serve our members 	 Look into Family Home Visiting service coordination to better understand roles of PHNs and Early Intervention/ School/ Birth-to-Three staff Discuss idea of care coordination with more people and different professionals Understand roles of PHN's in community to better utilize them for our complex families 		

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

1	Conduct trainings for care coordinators (e.g., webinars)	Involve familie discussions Be more	s in all Hold HCH accountable for comprehensive care	Creating apps or o means of making E accessible by famil on their mobile ph	MR care	and standards for plans to better it needs of families	Create universal release of information Increase funding for care coordination in	Care plans should be completely electronic & accessible on the internet by any member
	Conduct trainings for families on medical home / care coordination Encourage families	transparent about current legislative items that impact families Convene regular regional	More funding greater suppo LEP families Share successful car coordination stories with broad audience	ort for director provider e Determine & p	for s & families ublish	Standardize the the care coordi		Meet with legislators to help them understand and prioritize the needs of CYSHN and families
	to be proactive in expressing their needs rather than waiting for someone else to ask	meetings of care- coordinators Share more information a state agencies	determine roles	ns mapping s to	19.14 - 7.1 - 4.4 (2.2)	vebsite on rdination	require legislation	Require all pediatric practices to hire a care coordinator
Tool III had	Hold regular meetings between MDH & MDE about population –as oftentimes we are serving the same families	of school	can serve	Review health / far assessments to det what is duplicative can be standardize	ermine & what	HC	crease # of certified H & Behavioral Health mes	

Appendix: Data Tables from Figures/Charts

Primary Responsibilities in Providing Care Coordination (Data from Figure 3)

Responsibility	West Metro	East Metro
Use health information technology / electronic medical	4%	1%
records		
Relationship building	6%	19%
Provide education and resources	11%	14%
Intake, assessment, and evaluation	6%	11%
Facilitate, support, and assist in managing transitions	3%	0%
Facilitate care team and ensure family is a team member	5%	10%
Development of care plan	3%	1%
Coordinate quality improvement efforts	5%	1%
Coordinate funding	2%	4%
Communication	3%	3%
Assure competent care coordination workforce	8%	6%
Assist in navigating the system	13%	9%
Arrange for, set up, coordinate, and track tests, referrals,	18%	10%
and treatment		
Advocacy and policy development	11%	10%

Systems Mapping Action Priority Matrix (Data from Figure 4)

	1	2	3	4	5	6	7
	Easy to Implement						Hard to Implement
5 High Impact	Conduct trainings for care coordinators (e.g., webinars)	Involve families in all discussions	Hold health care homes accountable for comprehensive care	Creating apps or other means of making electronic medical records accessible by families on their mobile phones	Expand standards for care plans to better meet needs of families	Create universal release of information	Care plans should be completely electronic and accessible on the internet by any member of the care team
4	Conduct trainings for families on medical home / care coordination	Be more transparent about current legislative items that impact families	More funding to bring greater support for limited English proficient families	Central resource directory for providers and families	Standardize the role of the care coordinator	Increase funding for care coordination in primary and specialty care	Meet with legislators to help them understand and prioritize the needs of CYSHN and families
3	Encourage families to be proactive in expressing their needs rather than waiting for someone else to ask	Convene regular regional meetings of care coordinators	Share successful care coordination stories with broad audience	Determine and publish measureable outcomes of care coordination for CYSHN		Include home-based services in meaningful use (EMR) – would require legislation	Require all pediatric practices to have a care coordinator
2	Hold regular meetings between MDH & MDE about population – as oftentimes we are serving the same families	Share more information across state agencies	Conduct systems mapping in other settings to determine roles (MnSIC)	Start a website on care coordination in MN		Increase # of certified health care homes and behavioral health homes	
1 Low Impact		Increase knowledge of school nurses & how they can serve CYSHN / families		Review health / family assessments to determine what is duplicative and what can be standardized			

