Mapping Care Coordination for Children in Minnesota

STATEWIDE REPORT

MDH Minnesota Department *of* Health

CHILDREN AND YOUTH WITH SPECIAL HEALTH NEEDS

Mapping Care Coordination for Children in Minnesota: Statewide Report

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Introduction

Children and youth with special health needs (CYSHN) and their families often need a wide variety of medical, psychosocial, educational, and support services. Without effective care coordination, CYSHN can receive fragmented or duplicative services – ultimately receiving less than optimal care and causing unnecessary stress and frustration for families. In order to improve care coordination for CYSHN, stakeholders need to have a better understanding of current cross-system care coordination efforts. In Minnesota, a systems mapping process, which gathered input from stakeholders from five regions across the state, was undertaken to assess strengths, challenges, gaps, and redundancies inherent in providing and receiving care coordination amongst CYSHCN and their families.

Background

In 2014, the Minnesota Department of Health's Children and Youth with Special Health Needs (CYSHN) Program was selected to receive a three-year Systems Integration Grant from the Maternal and Child Health Bureau. The primary goal of the grant is to achieve a comprehensive, coordinated and integrated state and community system of services and supports for CYSHN through three objectives:

1. Increasing CYSHN stakeholder engagement and partnerships within statewide initiatives.
2. Increasing cross-systems integration through providing more effective care coordination services for CYSHN.
3. Increasing the knowledge of services and supports available through the development of a "shared resource" for providers and families of CYSHN.

In order to help accomplish the second objective, a needs assessment through five regional systems mapping meetings was conducted in June and July, 2015.

The CYSHN Program partnered with Family Voices of Minnesota to accomplish the care coordination needs assessment. Family Voices is a grassroots family organization that aims to achieve family–centered care for all children, youth, and young adults with special health care needs.

The following report will detail the findings, outcomes, and recommendations from the five regional stakeholder meetings.

Definition and Prevalence of CYSHN

Children and youth with special health needs, also referred to as children with special health care needs, are defined as:

> *those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.*[1]

The 2011-2012 National Survey of Children's Health (NSCH) estimated there are 236,953 children and youth with special health care needs (CYSHCN) birth to age 18 years in Minnesota, which is approximately 18.5% of the state's population under the age of 18 (n = 1,277,521). Minnesota's prevalence of CYSHCN is slightly lower than the national rate, which is 19.8%. In Minnesota, the age group with the most children with special health needs is that between the ages of 12 through 17 years old, with 28.9% of children having a special health care need. This is followed by 15.6% of those ages 6 through 11 years old, and 11.6% of those 0 through 5 years old. Male children have a higher prevalence of special health care needs than female children. In Minnesota, 21.4% of males aged birth to 18 years had special health care needs, compared to 15.6% of females. Figure 8 shows the prevalence of children with special health care needs by race and ethnicity. The highest prevalence is in White, non-Hispanic children, where 19.9% have a special health need. Those who identify as being from multiple races and who are non-Hispanic have the lowest prevalence at 12.1%. It is important to note that the sample sizes used to gather the racial/ethnic data are small, so the indicators for some races should be interpreted with caution (Data Resource Center for Child and Adolescent Health, 2012).

Definition of Care Coordination

For the purposes of this project, the following definition of care coordination was used:

> *Care coordination for children and youth with special health needs (CYSHN) is a family-centered, relationship-based, assessment-driven, team-based, and interdisciplinary activity designed to meet the needs of CYSHN, while enhancing the caregiving capabilities of families. Care coordination takes into consideration a continuum of child/family needs – including: health, medical, education, social, early intervention, nutrition, mental/behavioral/emotional health, community partnerships, and financial – to achieve optimal health and wellness.*

This definition was created based upon consensus following a thorough literature review. In particular, Minnesota's definition is based on the care coordination definitions of Antonelli et al. (2009), Turchi and Mann (2013), and the National Center for Medical Home Implementation.

Why Focus on Care Coordination?

CYSHN and their families often need a wide variety of medical, psychosocial, educational, and support services. Without effective care coordination, CYSHN can often receive fragmented or duplicative services – ultimately receiving less than optimal care. This often causes unnecessary stress and frustration to parents and family members of the CYSHN. On the other hand, when care coordination is provided effectively, parents report that this relieves a great deal of stress in the care of their child. When families reported receiving care coordination, they were also more likely to report receiving family-centered care

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[1] As defined by the US Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau.

which resulted in greater "partnerships with professionals, satisfaction with services, ease of getting referrals, lower out of pocket expenses and family financial burden, fewer hours per week spent coordinating care, less impact on parents employment, and fewer school absences and ED visits" (Rosenburg et al., 2005).

Current Status of Care Coordination in Minnesota

Current data on care coordination for CYSHN is found in the 2011-2012 National Survey of Children's Health (NSCH). According to the 2011-2012 NSCH, around 56.3% of children with special health needs received effective care coordination, which was measured by receiving all the needed components of care coordination.

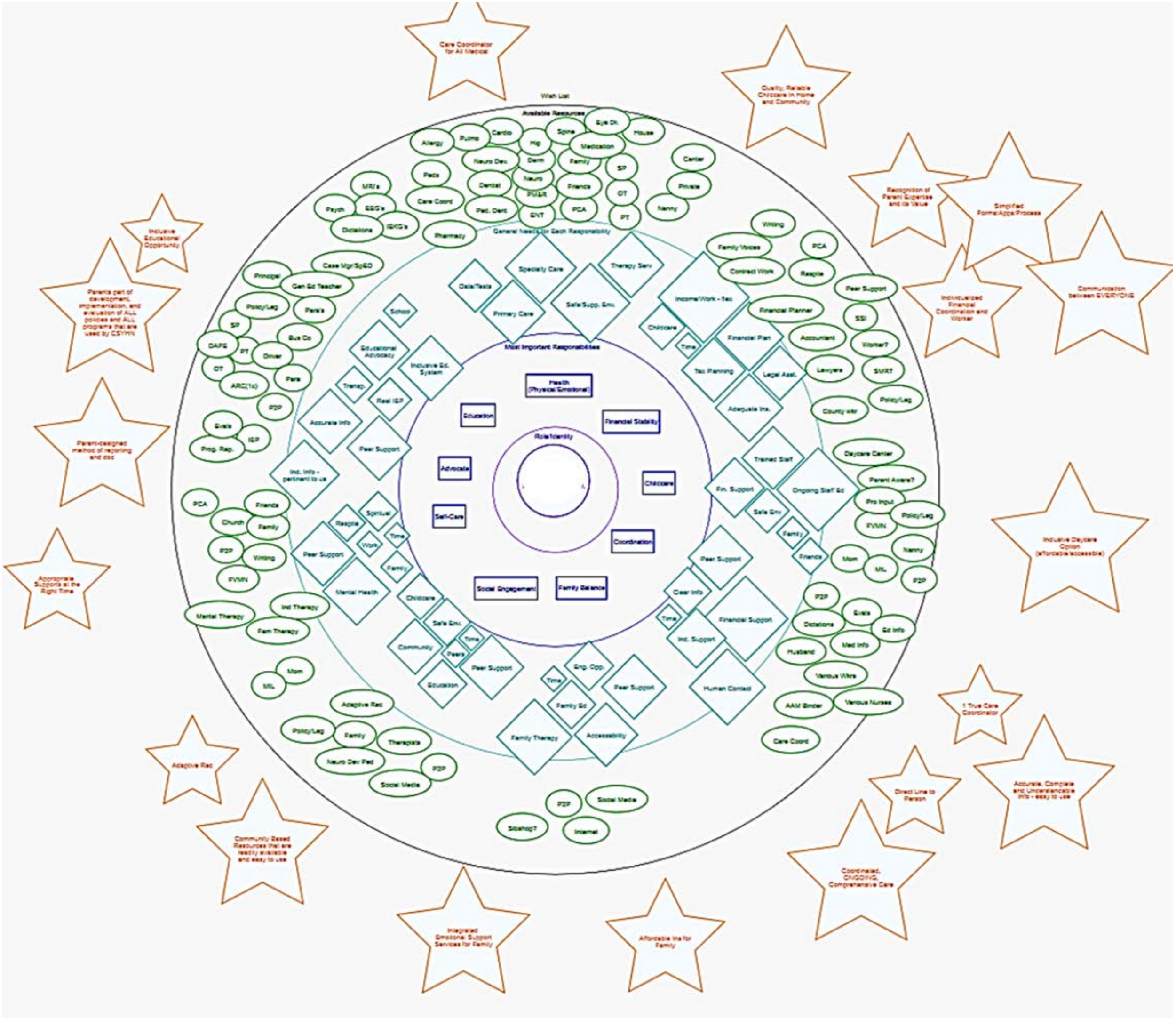
Current Family Experience of Care Coordination

In order to "set the stage" while doing the care coordination systems mapping assessments, family stories were used to frame the conversations and begin to communicate the strengths and challenges of the system of care. During the regional meetings, parents of children and youth with special health needs presented their care maps (also known as "systems support maps"), which provided visual depictions of family experiences in navigating the system of care and receiving help in coordinating services and supports. An example of a systems support map presented at one of the regional meetings is included in Figure 1.

When viewing the map, one can begin to grasp the complexity of both the family's needs and the system of services and supports built around this family. Places of connection and gaps become clearer. By using the care map, the mother was able to provide insight into what is working well for her family and what doesn't work. Many CYSHN have multiple types of care coordinators who are coming from different systems – and the systems support map provided a look into the number of systems interacted with by just one family. According to the mother who created the map:

> *"Ultimately, I am in charge of coordinating EVERYTHING included in this map and I face many challenges in doing so. It all takes so much time…making calls, attending appointments, gathering necessary paperwork...it's a full-time job with no paycheck. It's also time taken away from my other children and my family. Sometimes it's even difficult to know 'who' can help with 'what.' Whenever a service provider or professional truly views me as the expert on my child, we can work together give my son the best opportunities in his life. And that is all any of us really want for our children."*

Figure 1: Example of Family Systems Support Map (Care Map)



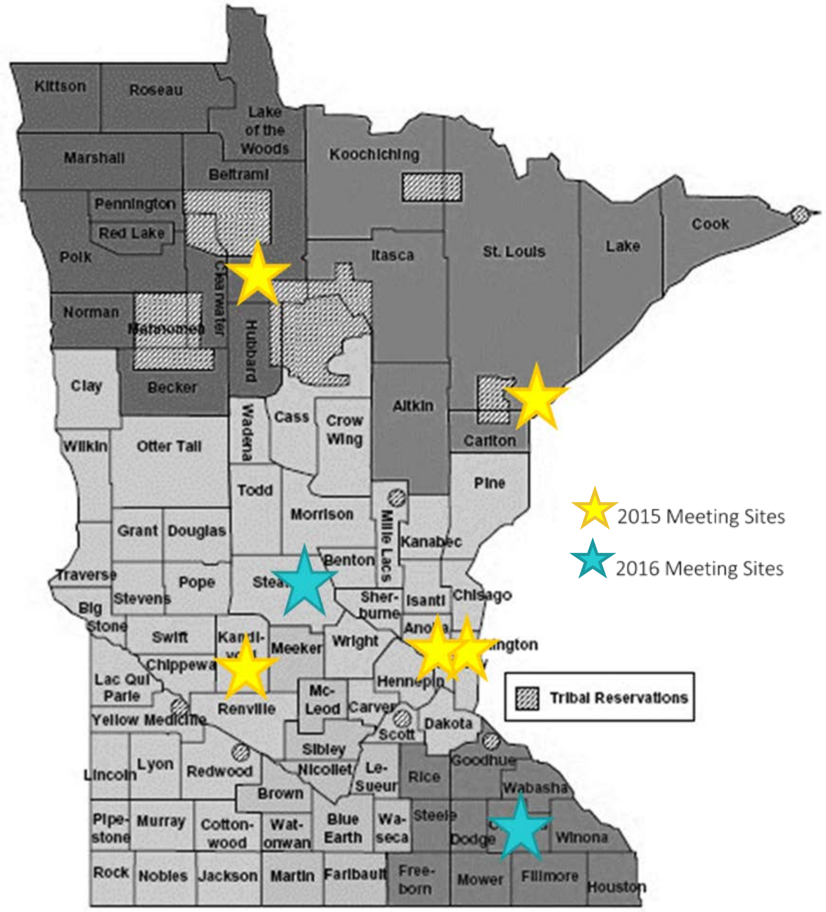
Methods

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.

Regional Meetings

In order to conduct the systems mapping, a series of five regional meetings were held in June – July 2015. Two additional meetings are being conducted in July 2016 to ensure reach to the whole state. In Figure 2, you can see the locations where the systems mapping occurred, which included the Northeast, Northwest, South Central/Southwest, and Twins Cities metropolitan areas of the state. Two mapping sessions were conducted in the Twin Cities, including one in the East Metro and one in the West. Two additional regional meetings occurred during July 2016 in Southeast and Central Minnesota. Findings from these meetings will be added to this report once completed.

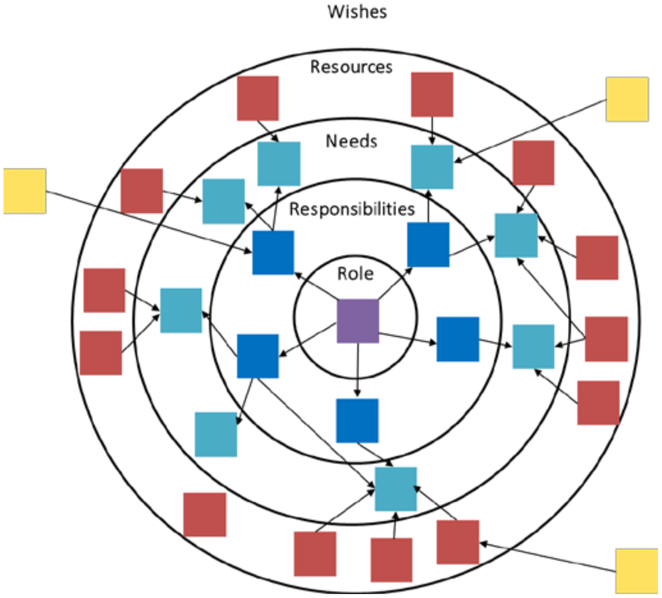
Figure 2: Regional Care Coordination Mapping Locations



Systems Support Mapping

The process was organized around a structured systems-thinking data collection tool, System Support Maps. To introduce the process, a family member from each region prepared and presented on their own individual map. Next, all participants were walked through the process of creating their own individual systems 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. A visual representation of a systems support map is included below in Figure 3.

Figure 3: Systems Support Map Diagram



Each participant created their own map and 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.

Participant Criteria

A combined total of 125 stakeholders gathered in the five regions 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;
- 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.).

Statewide Findings

The following section details the aggregated statewide findings of the regional care coordination systems mapping activities. Separate reports for each of the regions can be found on the "Mapping Care Coordination in Minnesota" webpage on the MDH CYSHN website.

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 in strengths and challenges experienced across the state are listed below.

"Care coordination of CYSHN in Minnesota currently works because…"

- Care coordinators are passionate and dedicated to helping families
- A lot of focus has been placed on early childhood
- There is strong networking and collaboration between care coordinators
- More care coordinators are being employed by primary care and specialty care
- Certified health care homes have care coordinators
- There is a focus on developing relationships and a sense of community
- Care coordinators are knowledgeable of the needs of families
- Care coordinators do a good job linking families with resources
- There are a lot of resources available (*more applicable to Metro*)

"Care coordination of CYSHN in Minnesota would be better if…"

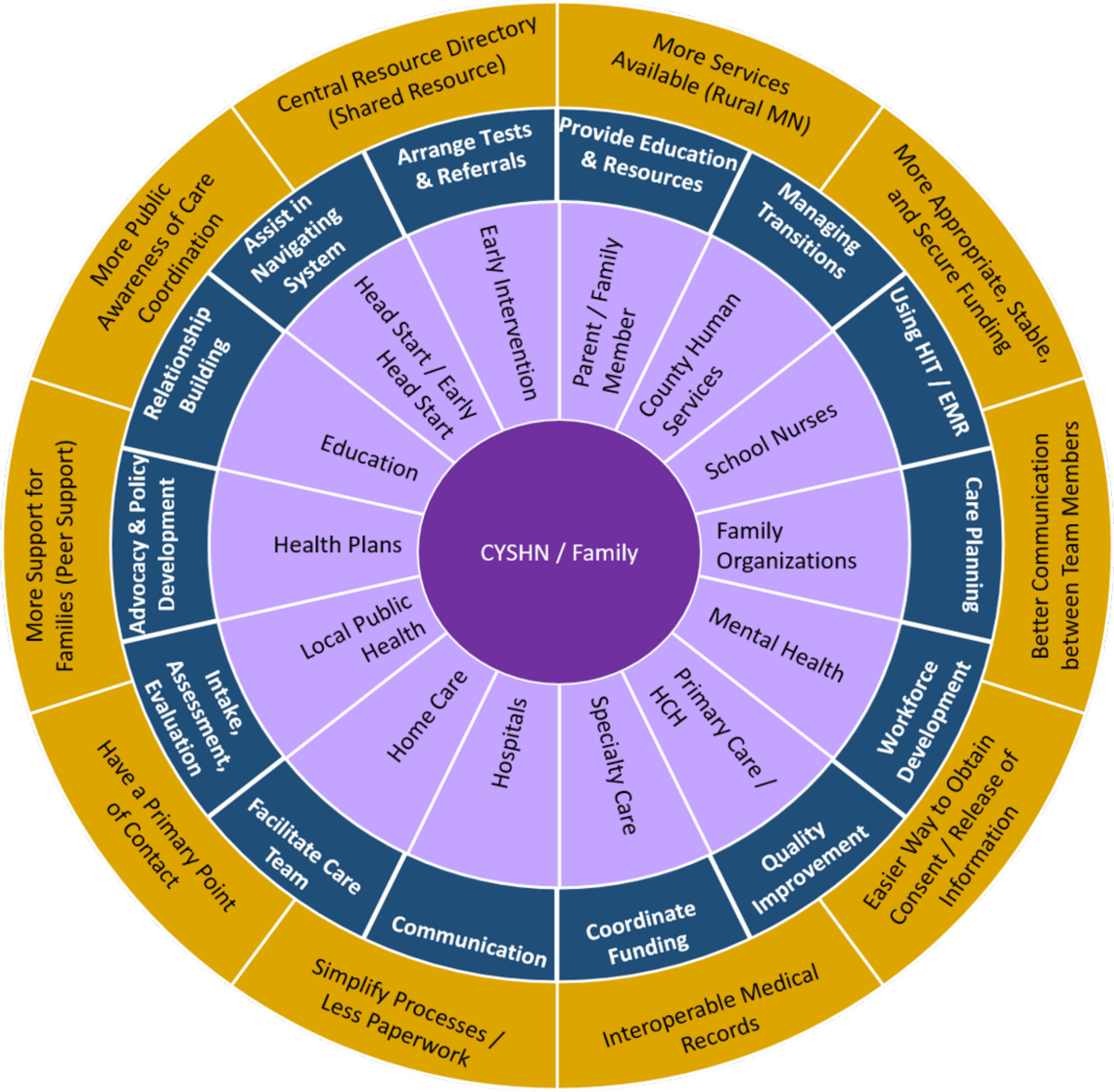
- Parents would not have to coordinate all the care coordinators
- Coordinators would communicate more with each other and not rely on the family to do the back and forth
- There were more sustainable funding for care coordination (and the funding better met the needs of children and families)
- A universal Release of Information was available
- Data sharing laws and practices didn't get in the way
- Electronic health records would communicate between each other
- There was more collaboration between schools and health care
- There were more resources available (more applicable to out-state regions)

Statewide Care Coordination Framework

As discussed above, all participants completed their individual systems support map and then all the maps were compiled to create regional care coordination frameworks 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 4. We begin by describing the various partners who provide care coordination, and then move 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 Minnesota.

Figure 4: Minnesota Statewide 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 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. As stated above, there were a total of 89 participants in the care coordination systems mapping meetings. Participants represented the following areas: parents of CYSHN, education, Head Start/Early Head Start, Interagency Early Intervention Committees, family organizations, health plans, home care, local public health, mental health, primary care, specialty care, school nurses, and state agency staff. A breakdown of the organizations/roles of participants by region is included below in Table 2. Each of the roles/organizations is also included in Figure 2: Minnesota Care Coordination Framework. As you can see, there were only a few roles that were represented within all five regions – parents, primary care, specialty care, local public health, and MDH-Health Care Homes. Primary care had the largest percentage of participants at 28%, this was followed by parents, who were 17% of the participants.

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 oftentimes families reported that they are the main coordinator of their child's care – or at times can be the "coordinator of all the coordinators."

Table 2: Care Coordination Systems Mapping Participant Organizations/Roles, by Region

Participant Organizations/Roles	**Northeast**	**Northwest**	**Southwest/ South Central**	**East Twin Cities Metro**	**West Metro**	**Southeast**	**Central**	**Total**	**Percent**
Primary Care	2	5	5	8	6	2	7	**35**	**281%**
Parents	3	2	5	3	3	2	3	**21**	**17%**
Local Public Health	1	3	2	1	3	2	4	**16**	**13%**
Specialty Care	3	1	1	1	3	3	2	**14**	**11%**
Health Plans	0	0	0	2	3	0	0	**5**	**4%**
MDH – Health Care Homes & Other	1	1	1	1	1	2	1	**8**	**6%**
Education (District & State)	1	1	0	1	3	0	4	**10**	**8%**
Head Start/ Early Head Start	1	1	1	0	0	0	0	**3**	**2%**
County Human Services	1	0	1	0	0	0	3	**5**	**4%**
Mental Health	1	0	0	0	1	0	0	**2**	**2%**
Home Care	0	0	0	1	0	0	1	**2**	**2%**
Family Organization	0	0	0	1	0	0	0	**1**	**1%**
MN DHS	0	0	0	1	0	0	0	**1**	**1%**
School Nurse	0	1	0	0	0	0	0	**1**	**1%**
Interagency Early Intervention Committee	0	1	0	0	0	0	0	**1**	**1%**
TOTAL	**14**	**16**	**16**	**20**	**23**	**11**	**25**	**125**	

Missing Partners

The participants in the meetings were asked to list out other partners who were missing from the discussions. Common responses that arose in more than one of the regional meetings included: fathers of children with special health needs, youth/young adults with special health needs, more culturally-diverse representation from providers and families, physicians, law enforcement representatives, representatives from more community-based organizations, policy makers (including political leaders and legislators), financial workers (including workers for waiver services), administrators from hospitals and clinics, local school district administrators (including special education administrators), personal care assistants, representatives from IT/data departments that work on the electronic medical records, and transportation providers.

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 5 provides the overall responsibilities reported by care coordinators across the state. The most reported responsibility of care coordinators was providing education and resources. The least reported responsibilities was facilitating, supporting, and assisting in managing transitions, which included transitions between health care settings and transition to adulthood.

Figure 6 provides a breakdown of the primary responsibilities reported by all participants, listed by region. The most reported responsibility in the Northwest and West Metro regions is arranging for, setting up, coordinating, and tracking tests, referrals and treatment. The most reported in the Northeast and Southwest regions is providing education and resources. The East Metro had relationship building as their most reported responsibility in providing care coordination.

Figure 5: Primary Responsibilities in Providing Care Coordination, Statewide

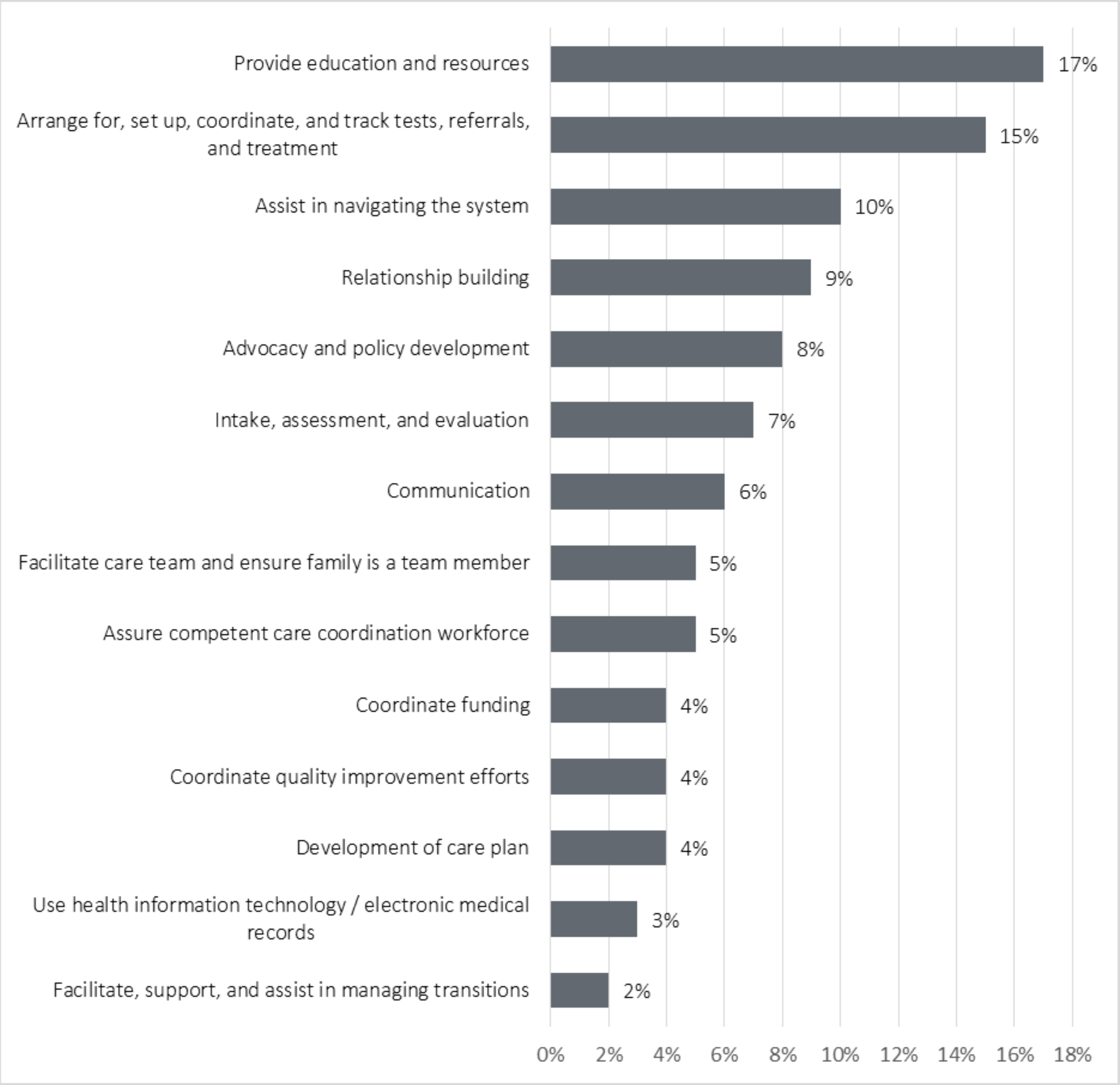
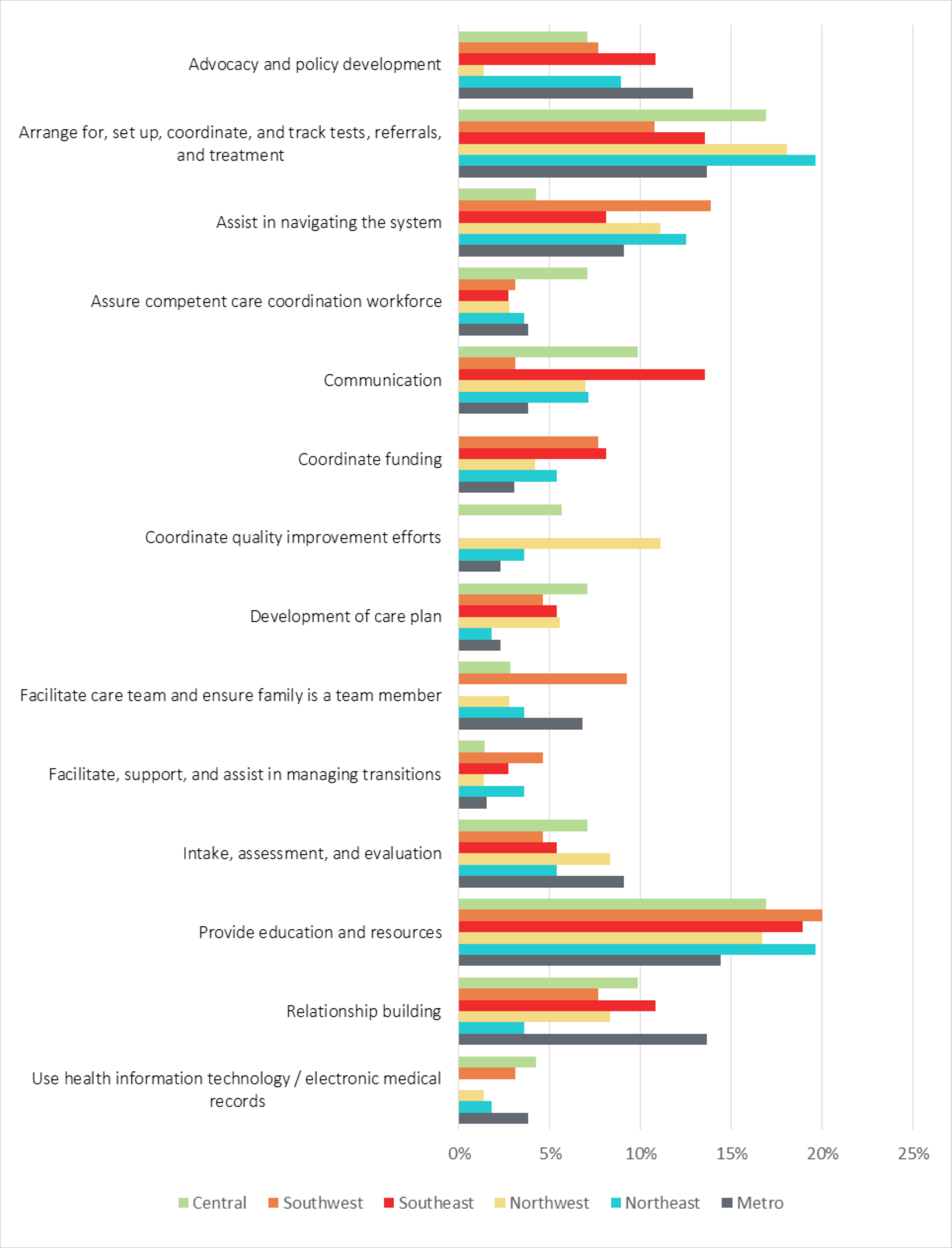


Figure 6: Primary Responsibilities, by Region



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. All the responses were compiled and grouped using an affinity diagramming process – categories were then determined based on the groups. Those categories that had more than three responses each, included:

- **More services available for families (especially in rural MN):** Participants, especially those in rural Minnesota, wished for more services to be available for families for their CYSHN. The services most wished for included: respite care, mental health services, community activities especially for teens with special health needs, nurses in the schools, and culturally-competent services.
- **More appropriate, stable, and secure funding for services and care coordination**: Participants reported they wished funding was based on "need" rather than income level. They also reported the need for a reimbursement structure for care coordination in primary care that better meets the needs of pediatric populations.
- **Better communication/collaboration between care team members (including family):** The need for more open channels of community and collaboration at all levels (clinic, local, and state) was a common wish in this category. This also includes communication that is more family-centered (i.e., bilingual and/or in the method preferred most by the family).
- **Easier way to obtain consent / Release of Information:** Participants wished for a more universal and easier method to often consent, which could include a Universal Release of Information method.
- **Medical records that span multi-systems and are family-friendly:** Participants reported wishing there was a more centralized medical record for families, which could include a cloud-based medical record and shared plan of care.
- **Simplify processes for obtaining financial assistance / services – less paperwork, less duplication:** Under this category, participants wished that processes for getting financial assistance would be easier and less stressful for families. They wished for less ambiguity in the financial assistance process and a more streamlined way to apply for assistance that would not require having to repeatedly complete the same paperwork.
- **Having a primary point of contact – "coordinator for the coordinators":** Families especially reporting that they wished they would have a centralized care coordinator so that they would not have to continue to be the one to ensure all coordinators communicate with each other. They also wanted to be able to choose the system that this coordinator came from (i.e., some families would want the central care coordinator to be within the primary care clinic, some the school, and so on).
- **More support for families / family-centered care:** Many of the family participants wished for more support for their family – including both peer support from other families as well as increased utilization of family-centered care principals by providers. They wished to be considered an equal member of the care team and to be seen more as a patient/family than a number.
- **More public awareness of care coordination – to build the "political will":** Participants wished that there would be more awareness of care coordination is both within the general public

and with decision-makers. They wished more people would advocate for the need for evidence-based care coordination for families.

- **Central resource directory / shared resource:** Many participants wished for a centralized directory that could be used as a statewide resource to increase knowledge of services and supports that are available for families of CYSHN.
- **Lower caseloads / more time for those who are assisting in coordinating care:** Participants also wished for smaller caseloads and for more funding to hire staff who can be dedicated to providing 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. 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.

Table 3: Action Planning Themes and Examples

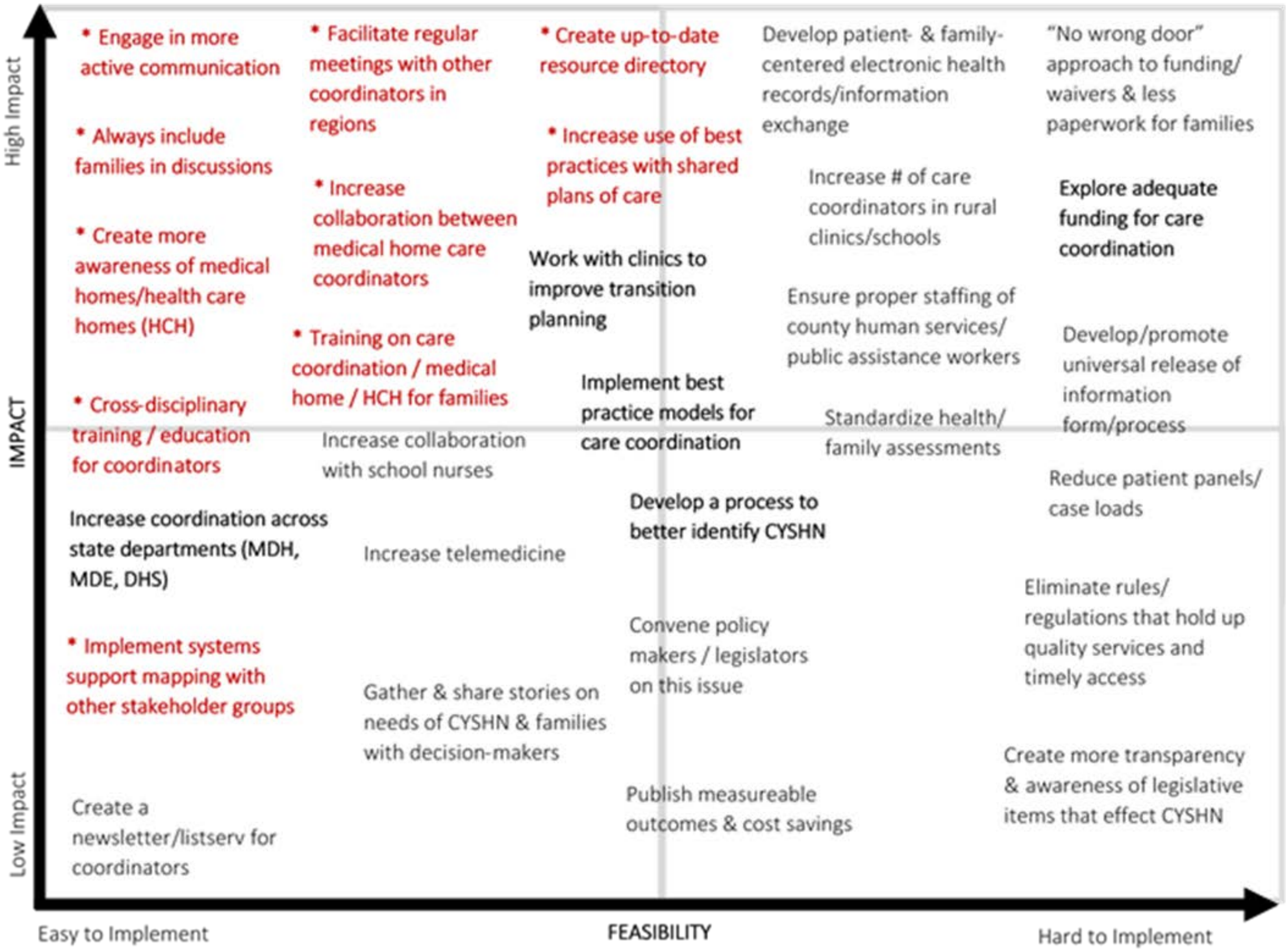
Action Planning Theme	Can be completed within 1 month, alone	Can be completed within 3-12 months, within organization/team	Can be completed within 6-12 months, with others in region
Education, providing training, and sharing information and resources	• Bring back information from today's meeting to care coordination team at organization • Identify care coordination learnings and success stories that can be shared broadly • Provide education on care coordination • Read more about specific health conditions (i.e., Autism Spectrum Disorders, Fetal Alcohol Syndrome Disorders)	• Taking back additional resources that are available learned about at this meeting • Follow-up with management in my own agency on the meeting outcomes • Share what I learned today on family experiences and what they go through	• Integrating trainings for care coordinators from different areas (i.e., schools, primary care)

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	• Set up meetings and/or support groups with parents • Connect with those here interested and share information about Parent-to-Parent Peer Support, Family-Centered Care, and Family Advisory Committees	• Create and maintain a Parent/Family Advisory Committee • Organize a workshop/training this Fall 2015 on parent leadership and partnering with providers	• Work with parent advocates to bring awareness to care coordinators about their organization • Connect with those interested to share information about Parent-to-Parent, Family-Centered Care, and starting and maintaining family advisory committees
Improving internal clinic/agency/organization care coordination processes	• Communicate with peers and administration • Continue to work on standard order sets for common care delivery, reducing administrative burdens. Share order sets with referring doctors and hospitals to add their EMR	• Integration of pediatrics in clinics • Build in time for chart reviews before appointments • Work on standardizing process for transition to adult medicine providers and communicating and sharing resources	• Share ideas within our CHB education/update the other nurses/staff about the information to improve services • Collaborate with health coach to understand how to effectively do my job and learn resources
Improving communication and collaboration with others	• Make visits to collaborating partners and increase awareness, find out what is working • Talk to county social services to attempt to increase involvement • Make follow-up calls/emails to contacts made today in order to support and encourage relationship building • Initiate conversation with Public Health Nurses • Start developing more relationships with family organizations	• Increase communication with schools • Increase communication with community entities • Work with Head Start to build understanding of school system	• Connect with appropriate contacts at schools to increase communication for mutual patients • Brainstorm and planning for early, childhood services coordination and transition mapping • Collaborate with family organizations • Build working relationships with care coordinators in specialty care settings

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	• Determine who community resource contacts are • Find more resources in the community that will be helpful for my patients other than the sources in my agency • Contact the United Way-211 to discuss improvement of resource listing	• Set up resource list for parent-to-parent contact • Give pediatric nurses direct phone numbers of resources • Develop spreadsheet with community resources for parents • Continue conversations about resource development	• Coordinate quarterly resource meeting in Fargo-Moorhead area
Further implementing systems support mapping with families, practices, and organizations	• Share my map with family and friends • Show staff the systems support mapping tool so they can use with families	• Use care mapping to define care coordination model • Use the system support mapping process with our Board	• Share our maps as parents with PACT for Families and how it may be useful as a collaborative
Promoting shared care plans	• Ask for shared care plan	• Continue to work on our Care Plan to standardize the information highlighted today and make more patient/family friendly/useful • Work to have one care plan – especially within a system that shared an electronic health record	• Creation and communication of inclusive care plans that can be easily communicated when needed
Promoting care coordination and better defining roles of care coordinators (both at clinic/organization and at a systems level)	• Creating a clearer message around how we can support families through care coordination • Spread the word regarding the importance of care coordination • Identify more patients that may benefit from care coordination	• Reach out to more community resources to make them aware of care coordination services at organization • Ask public health nurse consultants in other regions if we can explore the role of care coordination and public health nursing	• Work with Family Home Visiting nurses to better understand their roles • Work with Early Intervention / Birth-to-Three workers to better understand their roles • Continue to talk with insurance providers to explore better funding for providing care coordination

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 item. A summary matrix of is included in Figure 7. Items that will be focused on in the CYSHN Systems Integration Project have been bolded and are in red font. Additional items that relate to current work of the MDH CYSHN program, but may not apply to the grant project, have been included in bold black font.

Figure 7: Systems Mapping Action Priority Matrix



Appendix A: References and Resources

Antonelli RC, Browning DM, Hackett-Hunter P, McAllister J, Risko W. *Pediatric Care Coordination Curriculum,* 2014.

Antonelli RC, McAllister JW, Popp J. Making care coordination a critical component of the pediatric health system: A multidisciplinary framework. 2009, *The Commonwealth Fund.* Available at: http://www.commonwealthfund.org/Publications/Fund-Reports/2009/May/Making-Care-Coordination-a-Critical-Component-of-the-Pediatric-Health-System.aspx.

Commission for Case Manager Certification. Definition and Philosophy of Case Management. Available at: http://ccmcertification.org/about-us/about-case-management/definition-and-philosophy-case-management.

Council on Children with Disabilities: American Academy of Pediatrics. Policy statement. Care coordination in the medical home: Integrating health and related systems of care for children with special health care needs. *Pediatrics*. 2005; 116; 1238.

Council on Children with Disabilities and Medical Home Implementation Project Advisory Committee: American Academy of Pediatrics. Patient- and family-centered care coordination: A framework for integrating care for children and youth across multiple systems. *Pediatrics*. 2014; 133; e1451.

Institute of Medicine Committee on Quality of Health Care in America. Crossing the Quality Chasm: A New Health System for the 21st Century. 2001. Washington, DC: National Academy Press.

McAllister JW, Presler E, Cooley WC. Practice-based care coordination: A medical home essential. *Pediatrics*. 2007; 120; e723.

McDonald KM, Schultz E, Albin L, Pineda N, Lonhart J, Sundaram V, Smith-Spangler C, Brustrom J, Malcolm E, Rohn L, Davies S. Care Coordination Measures Atlas Update: Chapter 2. What is Care Coordination? *AHRQ Publication No. 14-0037-EF*; 2014. Rockville, MD: Agency for Healthcare Research and Quality. Available at: http://www.ahrq.gov/professionals/prevention-chronic-care/improve/coordination/atlas2014/chapter2.html.

Minnesota Administrative Rules. Health, Health Care Homes Rule, 4764.0020, Subpar. 3. 2013. Available at: https://www.revisor.leg.state.mn.us/rules/?id=4764.0020.

Minnesota State Statutes. Public Welfare and Related Activities, Chapter 245, Section 245.4871 Subd. 3. 2014. Available at: https://www.revisor.mn.gov/statutes/?id=245.4871.

Minnesota State Statutes. Public Welfare and Related Activities, Chapter 256B, Section 256B.092 Subd. 1a. 2014. Available at: https://www.revisor.mn.gov/statutes/?id=256B.092.

National Center for Medical Home Implementation. Care coordination fact sheet. Available at: https://medicalhomes.aap.org/Documents/CareCoordinationFactsheet.pdf.

Presler B. Care coordination for children with special health care needs. *Orthopedic Nursing*. 1998; Supplement, 45-51.

Rosenberg, D., Onufer, C., Clark, G., Wilkin, T., Rankin, K., & Gupta, K. (2005). The need for care coordination among children with special health care needs in Illinois. *Maternal and Child Health Journal*, *9*, S41-S47.

Standards for Systems of Care for Children and Youth with Special Health Care Needs. 2014. Available at: http://lpfch-cshcn.org/publications/research-reports/developing-structure-and-process-standards-for-systems-of-care-serving-children-and-youth-with-special-health-care-needs/.

Turchi RM, Mann M. Building a medical home for children and youth with special health needs. In: Hollar, D., ed. *Handbook of Children with Special Health Care Needs*. New York, NY: Springer-Verlag; 2012: 399-418.

United States Code of Federal Regulations. Title 34: Education, 303.23: Service Coordination (Case Management. 2006. Available at: http://www.gpo.gov/fdsys/pkg/CFR-2006-title34-vol2/pdf/CFR-2006-title34-vol2-sec303-23.pdf.

Wise PH, Huffman LC, Brat G. A critical analysis of care coordination strategies for children with special health care needs. Technical Review No. 14. (Prepared by the Stanford University – UCSF Evidence-Based Practice Center under Contract No. 290-02-0017). *AHRQ Publication No. 07-0054*; 2007. Rockville, MD: Agency for Healthcare Research and Quality.

Appendix B: Data Tables from Figures/Charts

Primary Responsibilities in Providing Care Coordination (Data from Figure 5)

Primary Responsibility Group	Percent
Facilitate, support, and assist in managing transitions	2%
Use health information technology / electronic medical records	3%
Development of care plan	4%
Coordinate quality improvement efforts	4%
Coordinate funding	4%
Assure competent care coordination workforce	5%
Facilitate care team and ensure family is a team member	5%
Communication	6%
Intake, assessment, and evaluation	7%
Advocacy and policy development	8%
Relationship building	9%
Assist in navigating the system	10%
Arrange for, set up, coordinate, and track tests, referrals, and treatment	15%
Provide education and resources	17%

Primary Responsibilities, by Region (Data from Figure 6)

Primary Responsibility Group	Metro	Northeast	Northwest	Southeast	Southwest	Central
Use health information technology / electronic medical records	4%	2%	1%	0%	3%	4%
Relationship building	14%	4%	8%	11%	8%	10%
Provide education and resources	14%	20%	17%	19%	20%	17%
Intake, assessment, and evaluation	9%	5%	8%	5%	5%	7%
Facilitate, support, and assist in managing transitions	2%	4%	1%	3%	5%	1%
Facilitate care team and ensure family is a team member	7%	4%	3%	0%	9%	3%
Development of care plan	2%	2%	6%	5%	5%	7%
Coordinate quality improvement efforts	2%	4%	11%	0%	0%	6%
Coordinate funding	3%	5%	4%	8%	8%	0%
Communication	4%	7%	7%	14%	3%	10%
Assure competent care coordination workforce	4%	4%	3%	3%	3%	7%
Assist in navigating the system	9%	13%	11%	8%	14%	4%
Arrange for, set up, coordinate, and track tests, referrals, and treatment	14%	20%	18%	14%	11%	17%
Advocacy and policy development	13%	9%	1%	11%	8%	7%

Systems Mapping Action Priority Matrix (Data from Figure 4)

	1 Easy to Implement	2	3	4	5 Hard to Implement
7 High Impact	**Engage in more active communication***	**Facilitate regular meetings with other coordinators in regions***	**Create up-to-date resource directory***	Develop patient- and family-centered electronic health records/information exchange	“No wrong door” approach to funding/waivers, and less paperwork for families
6	**Always include families in discussions***	**Increase collaboration between medical home care coordinators***	**Increase use of best practices with shared plans of care***	Increase # of care coordinators in rural clinics/schools	**Explore adequate funding for care coordination****
5	**Create more awareness of medical home / health care homes (HCH)***	**Training on care coordination / medical home / HCH for families***	**Work with clinics to improve transition planning****	Ensure proper staffing of county human services / public assistance workers	Develop/promote universal release of information form / process
4	**Cross-disciplinary training / education for coordinators***	Increase collaboration with school nurses	**Implement best practice models for care coordination****	Standardize health / family assessments	Reduce patient panels / care loads
3	**Increase coordination across state departments (MDH, MDE, DHS)****	Increase telemedicine	**Develop a process to better identify CYSHN****		Eliminate rules that hold up quality services and timely access
2	**Implement systems support mapping with other stakeholder groups***		Convene policy makers / legislators on this issue		Create more transparency and awareness of legislative items that effect CYSHN
1 Low Impact	Create a newsletter / listserv for coordinators		Public measureable outcomes and cost savings		

* Items being implemented/worked on via CYSHN Systems Integration Grant Project

**Items being implemented/worked on via other MDH CYSHN Program initiatives