

Wisconsin Care Coordination for Children and Youth Mapping Project



Fall 2015 – Spring 2017

Acknowledgements

The Wisconsin Children and Youth with Special Health Care Needs Medical Home Systems Integration Project Team wishes to acknowledge the contribution of the Medical Home Implementation Team partners listed below that were instrumental in the design of the project.

Wisconsin Medical Home Implementation Team Partners

Wisconsin Department of Health Services

- Division of Medicaid Services

 - Birth to 3 Early Intervention Program

- Division of Public Health

 - Family Health Section

 - Children and Youth with Special Health Care Needs Program

 - Maternal Child Health

 - Minority Health Program

- Office of Children's Mental Health

Wisconsin Department of Children and Families

- Bureau of Milwaukee Child Welfare

- Home Visiting Program

Wisconsin Department of Public Instruction, Head Start Program

ABC for Health

American Academy of Pediatrics, Wisconsin Chapter

Children's Hospital of Wisconsin

- Children's Community Health Plan

- Children's Health Alliance of Wisconsin

- Care4Kids (Foster Care Medical Home Program)

- Northeast and Southeast Regional Center for CYSHCN Programs

- Parent to Parent of Wisconsin

- Wisconsin Statewide Medical Home Initiatives Program (WISMHI)

Chippewa County Health Department, Western Regional Center for CYSHCN Program

Great Lakes Intertribal Council

Group Health Cooperative of South Central Wisconsin

Gundersen Lutheran Health System, Wisconsin First Step

Family Voices of Wisconsin

Marathon County Health Department, Northern Regional Center for CYSHCN Program

Marshfield Clinic Health System

Medical College of Wisconsin

Ministry Medical Group

United Healthcare Community Plan

University of Wisconsin Health

University of Wisconsin-Madison Waisman Center University Center for Excellence in Developmental Disabilities (UCEDD)

- Southern Regional Center for CYSHCN Program

- Youth Health Transition Program

- WI Leadership Education in Neurodevelopmental Disabilities (LEND) Training Program

Wisconsin Council on Children and Families

Wisconsin Primary Health Care Association

Table of Contents

Executive Summary	2
Background	3
Project Design.....	4
Methods.....	5
Interview Questions for System and Provider Representatives.....	6
Interview Questions for Family Representatives	7
Interview Demographics.....	8
Findings: Elements of Care Coordination for Children and Youth	9
Elements of Care Coordination	9
Populations Receiving Care Coordination Services	14
Funding for Care Coordination Services	15
Disciplines Providing Care Coordination	16
Communication as a Key Element of Care Coordination	16
Family Engagement in their Own Family Member's Care	18
Families as Advisors on Care Coordination	19
Shared Plans of Care	20
Benefits and Challenges of Care Coordination: System and Provider Perspective*	23
Conclusion and Next Steps.....	24
Appendices	25
Appendix A: Key Informants List.....	25
Appendix B: Reviewed Materials and References List	27
Appendix C: Definitions List.....	28
Appendix D: System and Provider Interview Script.....	30
Appendix E: Family Interview Script and Screening Tool	31
Appendix F: Theory of Change Diagram	33

Executive Summary

The Wisconsin Department of Health Services' Children and Youth with Special Health Care Needs (CYSHCN) Program received notification of funding for a three-year grant project titled the Wisconsin CYSHCN Medical Home Systems Integration Project beginning September 1, 2014. Funded by the federal Maternal and Child Health Bureau of the Health Resources and Services Administration, this project aims to increase the number of CYSHCN served within a medical home by 20% or approximately 17,735 more CYSHCN by September 2017. To achieve the goal of having more children served within a medical home, the project was required to develop a state plan to serve as a road map in its efforts. A team of over 40 professionals and families was established to collaboratively develop, promote, implement, and evaluate a state plan to increase the number of Wisconsin children and youth served within a medical home, particularly those with special health care needs. This team was designated the Wisconsin Medical Home Implementation Team, or MHIT. One activity recommended by MHIT members during the state plan development process was to complete a strength and gap analysis (mapping exercise) of current care coordination activities being implemented in different systems and organizations across the state and to disseminate the results. More specifically, the purpose of the mapping exercise was to answer the following questions:

- What and how is care coordination being implemented for children and youth currently in Wisconsin?
- What gaps exist?
- What assets can we build upon and share?

Interviews were conducted with a diverse group of systems, providers, and family representatives from across the state to answer these questions. A total of 40 interviews were conducted between October 2015 and December 2016.

Here are some key findings.

- Due to resource limitations, care coordination services were routinely offered at a level designed to ensure more families could receive at least some care coordination. Most models are designed to build family skill and confidence in taking on their own child's care coordination over time.
- Having access to information about what services/supports were available and where to receive them shortly after the diagnosis and continuing through the lifespan was a consistent challenge cited by families. More than one parent indicated that dealing with insurance issues is the most challenging aspect of having a child with special health needs.
- No provider or system representatives indicated that they knew of an existing model that would fully cover the cost of pediatric care coordination for all children.
- Electronic health records (EHRs) can facilitate the use of care plans when there are templates within the system, when they can auto populate, and when they can be shared in locations where others can access them. The lack of flexible EHRs creates more work for providers to create, update and share care plans. All families indicated that they had access to written plans or medical summaries in some form, and that they were the ones who facilitated communication between providers about their child's care needs, including providing copies of written care plans.

Background

The Wisconsin Department of Health Services' Children and Youth with Special Health Care Needs (CYSHCN) Program received notification of funding for a three-year grant project titled the Wisconsin CYSHCN Medical Home Systems Integration Project beginning September 1, 2014. Funded by the federal Maternal and Child Health Bureau of the Health Resources and Services Administration, this project aimed to increase the number of CYSHCN served within a medical home by 20% or approximately 17,735 more CYSHCN by September 2017. The most recent National Survey of CYSHCN (2009-2010) estimated approximately 200,000 Wisconsin children have special health care needs, and 44% of them receive care within a medical home. Care within a medical home is typically provided by a primary care clinician and his or her care team, in partnership with parents. Health care outcomes and family satisfaction are consistently higher for children served within medical homes.



To achieve the goal of having more children served within a medical home, the project was required to develop a state plan to serve as a road map in its efforts. A team of over 40 professionals serving CYSHCN and their families was assembled to assist with this effort. The team included family leaders, primary care clinicians, public and private payers, community resource professionals, and state professionals from multiple agencies, including the Department of Health Services, Department of Children and Families, and Department of Public Instruction. This team was designated the Wisconsin Medical Home Implementation Team, or MHIT. The MHIT mission is to collaboratively develop, promote, implement, and evaluate a state plan to increase the number of Wisconsin children and youth served within a medical home, particularly those with special health care needs.

A theory of change diagram (included in Appendix F) illustrates the essential pieces contained within the state plan. The second goal included in the state plan is that best-practice medical home care provision for children (including those with special health care needs) is achieved through continuous quality improvement and care coordination. One activity recommended by MHIT members to achieve that goal was to complete a strength and gap analysis (mapping exercise) of current care coordination activities being implemented in different systems and organizations across the state and to disseminate the results to collaborating partners, including MHIT members, and representatives of different health care systems. More specifically, the purpose of this care-mapping project is to answer the questions listed to the right.

What and how is care coordination being implemented for children and youth currently in Wisconsin?

What gaps exist?

What assets can we build upon and share?

Project Design

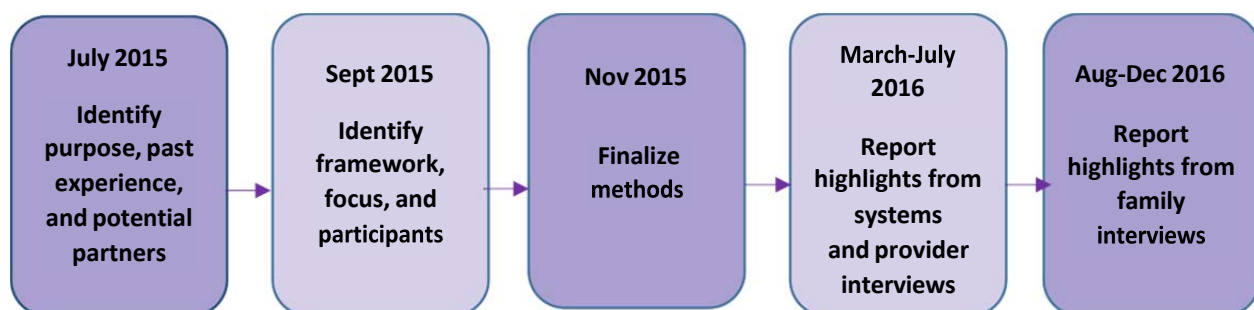
In July 2015, a small group exercise was conducted during a Wisconsin Medical Home Implementation Team (MHIT) meeting to help determine the mapping project purpose, timeline, and scope; member past experience and lessons learned with similar projects; and potential partners of the endeavor.

In September 2015, MHIT members determined that the Agency for Healthcare Research and Quality's (AHRQ) Care Coordination Measures Atlas would serve as a guiding framework for the mapping project. Definitions of care coordination from the AHRQ and the American Academy of Pediatrics were also reviewed. The team decided that the project should focus on identifying contributing activities of care coordination rather than adopting or creating a definition for care coordination, then prioritized the care coordination activities to be included in this project. The team also generated a list of potential system and provider representatives for the interview. It was the intention of the MHIT team to include a diverse group of respondents. See the box on the right for a listing of those invited to participate. In regards to family representatives, the following were considered when offering interview invitations: type of identified concern (physical, developmental, behavioral, or emotional), current age of child, age when concern was identified, main source of health care (primary care, specialty care), area of the state, size of the home community, and caregiver type (birth parent, adopted parent, foster parent, grandparent, etc.). While the design team decided against asking about insurance type or race/ethnicity of the child, this information typically was identified during the interview process.

Participation was requested from the following entities:

- Children's Long Term Support Program
- Centers for Medicare and Medicaid Services (CMS) Innovation Grant
- Early intervention programs
- Family navigators
- Family representatives
- Federally qualified health centers
- Foster care programs
- Home visiting programs
- Wisconsin Medicaid program
- Organizations supporting those with mental health concerns
- Medical durable equipment providers
- School nurses
- Tribal health programs
- Migrant health programs
- A variety of health care systems and specialties

In November 2015, the team agreed with the evaluator recommendation of conducting key informant interviews to gather the necessary information. Interviews would begin with those individuals identified by MHIT members, but would be enhanced with a snowball sample technique (asking the first set of informants for further informant suggestions). Family representatives would be identified through social media and existing relationships with system or provider interview subjects.



Methods

A script for the interview invitation to participate was developed and interview questions were drafted based upon instruments included in the AHRQ Measures Atlas and a brief literature review. The script and questions were reviewed by members of the Medical Home Systems Integration Grant management team. Additionally staff at agencies serving families were asked to review the questions designed for families. To ensure that a diverse group of families were included, a screener survey was developed. The interview invitation scripts and screener questions can be found in Appendices D and E. The actual questions are on pages 8 and 9.

Stakeholders were invited to participate in interviews conducted from March to December 2016. Potential interview subjects were contacted via email up to three times. Those not responding to email requests received a phone call. Interviews were conducted via telephone, and were recorded for transcription purposes. Participants were given the interview questions and information related to the purpose of the interview before the scheduled interview time so that they had time to prepare. The invitation script is included in Appendix D. Interviews were scheduled for 45-60 minutes, depending upon availability of the stakeholder. They were rescheduled up to three times. Interview participants were given an opportunity to review themes taken from the interview in order to verify content and allow them an opportunity to elaborate.

A total of 40 interviews were completed with system, provider, or family representatives. Appendix A provides a listing of those that participated in the interview process. More than 50 system and provider representatives were invited to participate in the project, and 26 completed the interview. More than 60 families expressed interest in project participation from social media-based announcements. These were screened using the criteria and 19 were extended an interview request.

Fifteen family interviews were completed. Page 10 includes more information about the interview respondents.

Materials to be reviewed were also suggested by interview subjects in some cases. A listing of materials reviewed is included in Appendix B.



Interview Questions for System and Provider Representatives

- 1 What does care coordination look like for a “typical” family/youth? If there is no “typical” family/youth, can you describe a minimum and maximum of services? What does care coordination look like for a child with special health care needs? Is transition addressed? Does care coordination apply to mental health, housing, hunger, or transportation? If so, which?
- 2 What population is provided care coordination services through your system/agency?
- 3 How many families, on average, receive care coordination services in a given year?
- 4 How is care coordination funded?
- 5 Who provides care coordination services? How many FTEs exist currently and what disciplines (RN, LCSW, etc.)? How many children or families does each FTE, on average, serve?
- 6 With whom does your agency/system communicate with the most when coordinating services? How does communication happen (telephone, email, form processing, care conferences, etc.)? How are data sharing barriers being addressed (joint releases, etc.)?
- 7 How does your agency/system partner with families to help define their role in their child’s care? How are families invited to share their perspectives on care integration and/or serve in an advisory capacity to your agency/system?
- 8 To what extent does your agency/system utilize shared plans of care for children with special health needs to promote care coordination? Who contributes to a shared plan of care? Who has access to the shared plans of care? What are the major components of the shared plan of care?
- 9 What do you feel are the benefits/outcomes of care coordination? How, if at all, is this being tracked by your agency/system? Can you share a story/example of what is working well? What do you feel are the most significant challenges to care coordination?
- 10 Is there anything else that you would like to share?
- 11 Are there others that you suggest we interview for this project?

Interview Questions for Family Representatives

Is there anyone...

- 1 Helping you to schedule the child's appointments with other doctors or service providers? Tracking and following up on assessments, tests, or labs for the child, even if they were done at a different place?
Assessing the child's emotional or behavioral needs, and making referrals when necessary? Helping to ease transitions for the child such as in/out of the hospital, in/out of rehabilitation, or between providers?
Helping you with accessing or using health insurance to cover the cost of the child's care? Who offers to help find food, housing, or transportation for the child?
- 2 How does the child's doctor include you in the child's care? Do you know which tasks are your responsibility and what will be done by the doctor or other members of the health care practice/care team?
- 3 Does the child have a plan filled out by caregivers and the health care team that is meant to make sure that everyone caring for the child knows about his/her medical condition, the next steps, and long term goals of his/her care?
If yes:
Who decides which goals to include in the plan?
Who can edit or add to the plan?
Who gets a copy of the plan?
Do you have a paper copy or electronic copy of the plan?
How do you use it?
With whom do you share it?
- 4 How do the child's doctors and other service providers use the same plan to talk to each other, if at all?
- 5 How can you share your views on the quality of care provided to the child? Examples could be telling the staff directly, completing surveys, or serving on advisory groups.
- 6 Can you share a story/example of when you felt very included and supported by the child's care team? Or can you share a story/example of when you didn't feel included or supported by the child's care team?
- 7 Is there anything else that you would like to share?

Interview Demographics

12 system interviews



13 provider interviews



15 family Interviews



Systems Represented in Interviews

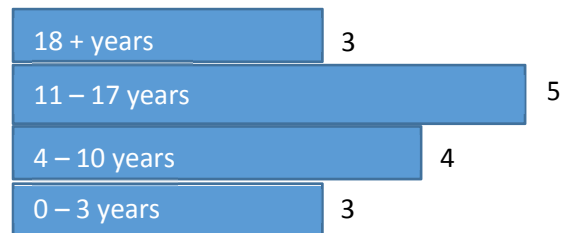
- Children's Long Term Support Program
- CMS Innovation Grant
- Early intervention programs
- Family navigators
- Foster care program
- Health care systems
- Home visiting programs
- Medicaid
- Mental health
- School nurses
- Tribal health

Counties Represented in Family Interviews

2-4 per Division of Public Health geographic region
All urban/rural categories represented

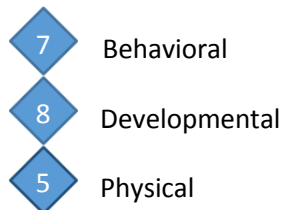


Age of CYSHCN Represented in Family Interviews



Type of Identified Concern or Diagnosis Represented in Family Interviews

(Individuals may have reported more than one category)



Care Source Represented in Family Interviews



5 of CYSHCN represented sought most care from Primary Care



10 of CYSHCN represented sought most care from Specialty Care

Icon source: The Noun Project Creative Commons License (Person by Mark Claus and Physician by Gan Khoo Lay)

Findings: Elements of Care Coordination for Children and Youth

Elements of Care Coordination: System and Provider Perspective

Due to resource limitations, care coordination services were routinely offered at a level designed to ensure more families could receive at least some care coordination. While most of those interviewed described at least two of the six elements listed to the right, only two felt that they were addressing all six elements. Those interviewed most often cited assistance with the top two elements and cited the bottom two elements least often. Caseloads per FTE (full-time equivalent) ranged from less than five families up to 100 families. Care coordinators shared that they flexed the time with families based on who was neediest at the moment. Some families are able to take on more aspects of their child's care than others based on parent availability, confidence, and literacy levels. **Most models are designed to build family skill and confidence in taking on their own child's care coordination over time.**

Elements of Care Coordination: Family Perspective

No one indicated that they have or have been offered comprehensive care coordination (includes all six elements listed to the right), though a small number of families reported assistance in at least one aspect of care coordination. The elements most often provided to families that participated in the interview project were assistance in scheduling appointments and tracking and following up on at least some assessments, tests, or labs. Helping with accessing or using health insurance and offering to help find food, housing, or transportation were the elements reported as being offered to the lowest number of families. The source of the assistance varied by the element. The need for having "a coordinator of the coordinators" to organize their child's care was brought up by more than one family.

Six Elements of Care Coordination:

1. Helping to schedule the child's appointments with other doctors or service providers such as physical therapy, medical specialists or community service providers.
2. Tracking and following up on assessments, tests, or labs for the child, even if they were done at a different place.
3. Assessing the child's emotional or behavioral needs, and making referrals when necessary.
4. Helping to ease transitions for the child such as in/out of the hospital, in/out of rehabilitation, or between providers.
5. Helping to access or use health insurance to cover the cost of the child's care.
6. Helping to find food, housing, or transportation for the child, if needed.

Based upon the Agency for Healthcare Research and Quality (AHRQ) Care Coordination Measures Framework – Coordination activities and Wisconsin Medical Home Implementation Team identified priorities for the project.

Element 1: Help scheduling appointments:

No families indicated that someone coordinated the scheduling of all of their child's appointments. The number of providers being seen per child varied greatly from three in one community to more than 12 spread across two states. Appointments scheduled within one health care system may be scheduled for the family, especially when children need to see some part-time providers on the same day. **More**

frequently, families are given contact information, asked to make their own appointments, and to

follow up if they are unable to get something scheduled. Lists of scheduled meetings are often sent home in medical summaries, which help families to not double-book themselves. **Health care team members do make suggestions when there are special considerations or may make the first connection.** For example, one family shared how the sound of the child's ventilator interfered with a hearing test so the family needed to find a place that was able to block out the noise. The child's speech therapist called on the family's behalf to find an appropriate place. In another instance, a health care team member facilitated an encrypted line in the patient's home so that web-based appointments were a possibility. This was essential for a family unable to transport their child to a medical facility due to his transport needs and fragility.

"I often joke that I am my child's secretary, but in reality, coordinating all of his care is my part-time job. There is something to be done nearly every day of the week. Some days it takes 5-15 minutes, but on other days, it takes 5 hours or more."

~ family representative

Families noted that when appointments can get scheduled may be dictated by what insurance will cover, or where the child is living. One parent described how appointments are handled for her child living in a treatment facility 300 miles away; she schedules all appointments for providers that the child will need to continue to see in their hometown. The treatment facility schedules all appointments for acute illnesses in the community closest to the treatment facility.

Element 2: Help tracking and following up on assessments, tests, or labs:

Families reported a variety of scenarios:

- Nurse at pediatrician's office called with results that were entered into their electronic health record (EHR), but not for any outside labs or tests.
- Families had to track down results that needed to be shared outside health care systems or when they didn't receive results in a timely fashion.
- Health care team tracked them all but didn't usually communicate results to the family.
- Family was trained to draw all the bloodwork and send them to a local lab. When the results were received, the lab would send them on to the health care team.
- Residential treatment facility tracked most labs but some things fell through the cracks.
- Home health care nurse that re-ordered supplies also tracked the labs.

Element 3: Assessing the child's emotional or behavioral needs and making referrals when necessary

Families reported a variety of scenarios:

- Families were told that their child's emotional or behavioral concerns could be addressed once the child is older.
- Families were told that the parents' concerns are normal or typical child behaviors and not something of concern.
- Social and emotional assessment performed by:
 - Primary care provider/pediatrician/family practice
 - Neuropsychologist
 - Cardiologist
 - School psychologist/psychotherapist
 - Birth to 3 Program professional

Element 4: Help to ease transitions

When asked who helps with transitions, families' most common response was "no one." However, several individuals were mentioned as assisting with health care related transitions:

- Discharge nurse at hospital
- Care coordinator at health care systems
- Medical home care team member
- Pulmonologist
- Children's long term support waiver service coordinator

For non-health care related transitions, the following were mentioned:

- School counselor
- Department of Vocational Rehabilitation professional
- County social worker
- Family members and friends
- Professionals from Children and Youth with Special Health Care Needs- serving organizations

"It's hard to ease the stress and keep positive when dealing with insurance, especially as children approach transition age. I can't get my questions answered; I get sent from one office to another and the wait lists are so long for patients using Medical Assistance. Once I find a provider, they may not be a good fit for my child."

~ family representative

Element 5: Help with accessing or using health insurance

More than one parent indicated that dealing with insurance issues is the most challenging aspect of having a child with special health needs. These challenges are exacerbated when youth transition into adulthood, when families move or change jobs, when both private and public insurance coverage are provided, when a specific brand or type of equipment is needed, when the child is not living in the guardian's home, and when insurance companies change what they will cover. Families expressed that insurance company denials were the expectation for them, and that they often serve as the liaison between the provider and the insurer. More than one family indicated that they hired a lawyer to dispute charges for medical care or supports when there was a misstep in paperwork. They shared that there are so many intricate aspects of the system that it's easy to miss something. They can sometimes find assistance in navigating insurance from social workers if they have public insurance coverage, but they are hard to reach and there is a lot of turnover. Physicians will provide samples and write letters of support for families but their time to help with insurance issues is limited. Some families indicated that the billing department within their health care system was very helpful in getting insurance coverage for their child's needs, but acknowledged that it was a slow process even with their assistance. Some families have opted to pay out of pocket for equipment or services that their child needs because it was less stressful than dealing with the insurance companies. Another aspect of insurance that is challenging is that what gets covered by one plan isn't covered by another. They will hear about a medication or service that is covered for one family during a support group, but eventually find out that it's not covered by their insurance. More than one family indicated frustration about having to complete overwhelming paperwork annually to get insurance coverage for a chronic condition.

"This was the first time I had to do a medical review and the packet was an inch thick—every provider, test, order, etc., to determine if he is eligible. We need MA to cover what my own insurance doesn't cover. I sent in the packet months ago and I still haven't heard. Autism is not something you recover from; my child's stuck this way for life. Why does it take this long to figure that out? The future of my child is sitting on someone's desk."

~ family representative

"My child's service coordinator helps me every year with my application. She comes to my house, walks through every section with me, takes it back to her office to type it up and then sends it back to me for my signature. I don't know how I'd do this without her."

~ family representative

Element 6: Help with food, housing, transportation, etc.

Most families indicated that they had a lot of support but that it wasn't usually coming from their child's care team.

Other families, close friends, schools, and religious groups were major sources of support in ensuring that they had food, housing, and reliable and safe transportation for their child.

"I've learned to be persistent. I may have to call 27 people to get the help we need, but I know that one of those 27 people will help."

~ family representative

"It took us 18 months but we were able to get changes at the county level to be able to get my child's needs met. 911 services has placed an addendum on file about children with special needs, which automatically comes up with the child's name and our doctor's care plan. We are also now on a list to be contacted if the heat or power goes out. They are able to either transport us or bring us what we need in an emergency so that my child's machines will keep working."

~ family representative



One family with an older child indicated that a support person comes to the child's home weekly or checks in over the phone to help with getting to the grocery store and appointments. They helped the young adult figure out public transportation and assist with problem solving of everyday situations. Getting transportation to medical appointments, reimbursement for mileage, or equipment for a family vehicle to make transportation possible was working very well for some families but not all families. This is an example of a resource that some families found out about years after their child was diagnosed. There is confusion about what is and is not covered, and families have turned to charities or organizations like Ronald McDonald or the local fire department to get their needs met. One parent described how her struggle to get safe emergency transportation will now benefit other families in her county (see adjacent box).

Every family described having a champion that helped them cope, whether it was a teacher, provider, social worker, parent support group or parent-serving agency.

Findings: Populations Receiving Care Coordination Services

Populations Receiving Care Coordination Services: System and Provider Perspectives

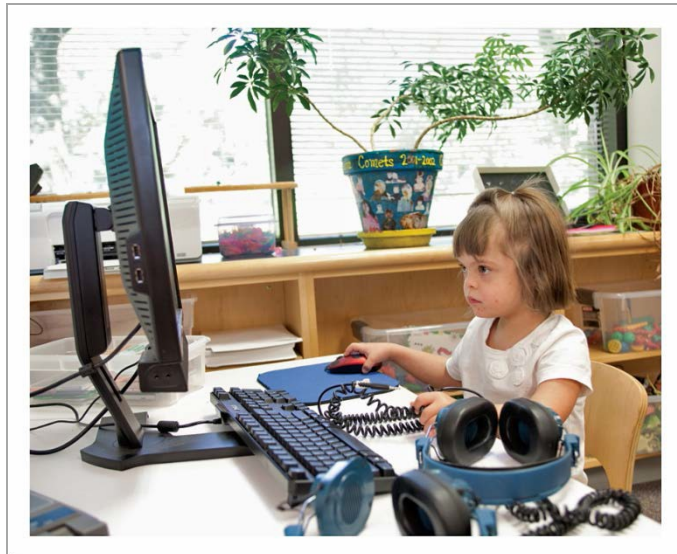
Care coordination is provided along a continuum with some providing almost no services and others providing very comprehensive services. The populations that are most often offered care coordination services are the children whose care is the most complex. Different systems have different definitions but care coordination often requires involvement of primary care along with multiple specialties and a minimum number of inpatient and outpatient stays during a specified period of time. Children with conditions that contribute the most to health care expenses are those that are assisted with care coordination services first.

"We know that care coordination services can be so impactful for children with complex health issues. If it was up to me and resources weren't so limited, we'd offer care coordination to every family that wanted it. It can be a game changer."

~ system representative

Populations Receiving Care Coordination Services: Family Perspective

While most families indicated that they would greatly benefit from care coordination services, some families indicated that they prefer to coordinate their child's care themselves as long as they have someone to call when they get stuck or overwhelmed. These families indicated they had learned a lot throughout their children's journeys and felt others may benefit more from care coordination services, especially those families with newly diagnosed children, lower literacy levels, or those families that need to work full time. Some families suggested that not all providers are aware of care coordination resources as they weren't offered any of these services until they changed locations or providers.



Findings: Funding for Care Coordination Services

Funding for Care Coordination Services: System and Provider Perspective*

No provider or system representatives indicated that they knew of an existing model that would fully cover the cost of pediatric care coordination for all children. Those systems offering the highest levels of care coordination were those with outside short-term funding or whose leadership was committed to the idea of care coordination. Some systems were covering the cost of care coordination staff through general funds with no attempts to recover the costs from insurance or patients themselves. They felt that the paperwork costs were higher than if they would build it into their own budgets, especially when there were frequent changes in policies or ambiguity in how services could be reimbursed. Some expressed concern that pediatric care coordination services were being reduced or eliminated because leadership could not point to short-term health care cost savings with this population.

Providers and systems alike expressed interest in Wisconsin pilots and other national models of cost-effective pediatric care coordination services. This was a key area of interest for future learning.

**No family perspective gathered for this area.*

“There is a lot of exciting work being done now to determine how to pay for care coordination over the long haul. Unfortunately, we just don’t have those answers yet, especially not for the pediatric population.”

~ system representative



Findings: Disciplines Providing Care Coordination

Disciplines Providing Care Coordination: System and Provider Perspective

Teams are often assembled to provide comprehensive care coordination services. The team may include a registered nurse, a family navigator, a social worker, and a physician. Some systems round out this team by including students or community health workers to address more of the nonmedical family needs such as housing, food, and transportation, or financial specialists to provide guidance on billing or insurance.

Disciplines Providing Care Coordination: Family Perspective

Below are the individuals that families named as providing care coordination:

- Care coordination team
- Palliative care team
- Family practice physician and care team
- Coordinated services team or comprehensive community services team

Families indicated that while physicians were typically part of the team, they did not communicate directly with them outside of appointments. Rather, families communicated most with nurses, social workers, or other support positions (such as billing) to get their day-to-day needs met.

Findings: Communication as a Key Element of Care Coordination

Communication as a Key Element of Care Coordination: System and Provider Perspectives

“Determining how I can best support families is my most important role.”

~ provider representative

System and provider representatives indicated that communication with families was the most important step in providing high-quality care coordination services. They utilized all methods for communicating with families depending on family preference.

One challenge mentioned in communicating with other health care providers and community providers was the lack of time or misaligned schedules. Health care providers did not feel that the Health Insurance Portability and Accountability Act (HIPAA) limited them in what they could communicate as consent was a regular part of their intake process. Community providers felt that HIPAA and the Family Educational Rights and Privacy Act (FERPA) were barriers in what they could communicate and the timeliness of that communication. Some expressed excitement about new data systems that were allowing better communication between health care and community providers but acknowledged that it would be awhile before those would be available for most Wisconsin families.

Communication as a Key Element of Care Coordination: Family Perspective

"I feel like the education about services and supports isn't happening. We finally learned about a program a year ago. I didn't find them through Birth to 3, doctors or the school. It was suggested by other families."

~ family representative

Having access to information about what services/supports were available and where to receive them shortly after the diagnosis and continuing through the lifespan was a consistent challenge. They also told stories of needing to be a strong advocate. Families described reading books and doing research on what was recommended for their child's condition in order to determine how or if they could access resources in their community. One family indicated that there is a lot of support in place but because it's from different organizations, it's confusing and time consuming.

Another family shared that having a child with special needs can feel very lonely. They have a community of support within their county, but don't often get to connect with families going through the same thing as the child's condition is rare. They feel the pressure of being the expert on their child's condition. They know anecdotally from other families that something is an issue or potential treatment, but there is no research. The health care team wants to listen, but their options are limited if strong evidence doesn't exist. Sometimes families needed to shine a light on something so that change can be facilitated. They do advocate, but feel it shouldn't be so hard to do what's right for families and children.

Some parents also shared stories of needing more communication from health care teams. One parent described her concern about being asked to participate in a care conference where all of the child's health care providers would be in the same room. She was concerned that it could be too overwhelming to get the full perspective of the child's care, or that she would not be prepared and supported throughout the process. Other families described learning who was most responsive to their needs. In some cases, the primary care provider could assist families more quickly than specialists. In other cases, the reverse was true.



Findings: Family Engagement in their Own Family Member's Care

Family Engagement in their Own Family Member's Care: System and Provider Perspectives

All system and provider representatives agreed that engaging families in their child's care is of utmost importance to ensure that high-quality care is provided. Some systems indicated that professional development opportunities were being offered to help staff learn new strategies in family engagement.

Family Engagement in their Own Family Member's Care: Family Perspective

Nearly every participant indicated they feel included in the medical aspects of their child's care. Many described how they have grown into a more shared role by learning to ask more questions and being more assertive in care decisions.

For example, one family expressed taking her child with special needs to the doctor for things that she would never bring her other child in to the doctor for, but feels like the health care team has always trusted her opinion.

Another family shared how they have been included in every step along the way. If some medications or procedures are recommended, parents are asked their opinions about how to proceed. The health care team has been honest that they don't know all of the answers because the condition is rare and situations are unique.

Most families indicated that their role in the child's care was clear. If they were not clear, they kept asking questions during or after the appointment.

In contrast, one family reported having struggles with one specialty because they were not taking the child's discomfort seriously and were trying to solve the symptom with a medication rather than looking to solve the root problem. Another family shared stories about changes in the level of engagement during transitions between providers. In some situations, she had been shut out of care decisions until she could assert herself as an equal partner.

"Through training with his teachers and other parents, I gained confidence to let providers know his needs. One day, he was at an eye appointment and they were asking him to look at the screen and the card with house, apple, and other images. I had to tell them that he needs time to process and they were using too many words. We refocused his attention, and then he was able to do the test."

~ family representative

"I don't feel that people have meetings without me or my husband. They will Skype him in so that the whole family knows what's going on."

~family representative

Findings: Families as Advisors on Care Coordination

Families as Advisors on Care Coordination: System and Provider Perspectives

“The information collected from families has been useful ... to see a situation from a different perspective.”

~provider representative

Representatives indicated that how, and how often, families are asked to provide feedback was influenced by system policy and protocols. Most indicated that families are given at least one avenue for providing feedback, with patient surveys and feedback boxes in lobbies the most popular options. Advisory groups were valued but representatives admitted that they were not implemented consistently. Some cited system efforts geared towards improving this work over the next one to two years.

Families as Advisors on Care Coordination: Family Perspective

Most participants report being asked regularly and/or feeling comfortable in sharing feedback about their child’s care with providers directly. They shared that they communicate when things could be improved but also make sure they give compliments when they receive exceptional care. Not every provider is open to relying on what one parent referred to as a “layman’s opinion,” but parents feel empowered to change providers as needed.

Families indicated fewer opportunities to provide feedback on behavioral or emotional health care when compared to physical or developmental care. One parent shared that there is such a shortage for pediatric behavioral therapists that they have brief and focused appointments.

About half of the families indicated that they receive surveys from the health care system. The few participants that have served on advisory committees valued that opportunity.

“It’s been such a great experience serving on the Family Advisory Group. I’ve learned about challenges in providing care from another perspective and learned new concepts such as the idea of care coordination. I am more independent and educated now but some things still get lost in translation.”

~family representative



Findings: Shared Plans of Care

Shared Plans of Care: System and Provider Perspectives

Tools and resources available within the health care setting often dictate what care plans look like and how they are shared with other health care providers, community providers, and families. **Electronic health records (EHRs) can facilitate the use of care plans when there are templates within the system, when they can auto-populate, and when they can be shared in locations where others can access them. When EHRs are not this flexible, it creates more work for providers to create, update, and share care plans.**

Systems and providers indicated that they are trying to share their care plans, but they are rarely creating them together across disciplines. Some providers expressed fears that trying to incorporate too many specialties into one plan would make the document too cumbersome and no longer helpful.

A few systems, especially nonmedical partners, shared that while they felt they could contribute to care teams and care plans specifically, they were not always asked to the table. School nurses and home visitors are just two examples. These representatives felt that they could help families in implementing and updating their care plans between medical appointments but the importance of including these families on the team was not communicated from medical partners to families. They felt that this was a missed opportunity to provide more holistic care to families, though they acknowledged that school nurses and family visitors are not available in all areas of the state.

Shared Plans of Care: Family Perspective

Two families described having a comprehensive care plan that included more than one discipline and contained short-term and long-term goals, that they had input into developing. Both of these families had children with very complex physical and developmental needs.

Most families indicated that they had care plans related to one specialty, support, or purpose that may have included short- and long-term goals that may have been developed with their input. For example, one parent described having a crisis behavioral health plan that was updated every six months but that did not contain all the necessary medical information. Another parent described having

A Shared Plan of Care is a living document completed by parents and health care providers that includes information necessary to assure issues affecting a child's health are identified and the information is accessible across systems, and that activities and accountability for addressing those activities are documented. Key components include:

- Medical summary
- Family strengths and preferences
- Negotiated plan of action (including clinical and family goals, actions to address goals, responsible partners, and timelines); ideally both short- and long-term goals are included
- Other necessary attachments (such as emergency plans, chronic condition protocols, and relevant legal documents such as IEPs or 504 plans)

Based on “Achieving a Shared Plan of Care with Children and Youth with Special Health Care Needs” by Jeanne W. McAllister with support from the Lucille Packard Foundation for Children’s Health and Wisconsin’s Medical Home System Integration Project work.

separate asthma and gastrointestinal care plans—both contained family input, but only one contained both short- and long-term goals. A third parent described having more than three separate care plans that addressed different aspects of needed care with varying levels of detail.

Other parents described not having any care plans, but instead receiving copies of discharge or appointment summaries that were not comprehensive and did not contain either short- and long term goals, and that may or may not have been developed with family input. One parent described frustration that her child's care plan was designed to be reactive after something went wrong rather than focusing on how to prevent a problem. **Families with children experiencing behavioral or emotional concerns were the least likely to report having written care plans.**

A few families expressed disinterest in comprehensive care plans. For example, one family indicated that because their child was no longer in school and medically stable that a shared plan of care wasn't necessary. Another parent indicated that because their child was medically unstable, the only care plan that made sense for them was an emergency crisis plan with only immediate action steps needed to keep the child alive. They felt that any other care plans would need to be updated too frequently to be practical. A third family expressed concern that their care plan was not a living document and, therefore, not something that they pulled out and used.

Sharing Care Plans with Health Care Providers

Many families indicated that they were the ones who facilitated communication between providers about their child's care needs, including providing copies of written care plans. Some parents shared that they believe providers are looking at the same records if they work within the same system, but find that they each concentrate on their own expertise. Unless they bring up a plan or concern from another discipline, another specialist won't consider or address it. For example, one parent shared her experience preparing for an upcoming surgery. She felt that various specialty providers only spoke to each other about the child's needs during and after surgery once she asked for it. She knows that the care needs and plans are documented somewhere in her child's EHR but that providers often don't have enough time to read them completely, or don't have access. Having a shared plan of care may have made this experience easier for their family.

"I've been frustrated and overwhelmed when each specialist had their own plans, especially when the majority work at the same clinic. I've taken my child to appointments and had to spend the first 20 minutes explaining her condition and recent appointments to the nurse and then the doctor. I've learned to call in advance of the appointment to let them know that my child was recently seen by another specialty and to ask the doctors to please review that appointment's notes before our appointment. This has worked well for me and I encourage others to try it too."

~ family representative

A second parent described different experiences with provider-to-provider communication depending on where they lived. In the community where the family lived when the child was diagnosed, there appeared to be very little communication between providers. She found herself having to describe her child's health condition every time she met with a new provider even if they worked in the same health care system. In contrast, once the family moved to a new area and transferred their care to a new system, the parent was pleasantly surprised to see that health care providers had studied her child's health records before they walked in the door for their appointment.

A third parent indicated that she regularly shares topic-specific plans with all of her child's other providers, which she has found to be very helpful. She also reviews them to see what appointments need to be scheduled or when she needs to re-order equipment.

In addition, a few families expressed that they wished their children would have had a shared plan of care or had some other mechanism to get all of the providers in the same room to discuss a child's case because it might have resulted in an earlier diagnosis or lessened their child's discomfort. One family indicated that a conversation with multiple disciplines during rounds, where she provided input, was what led to a proper diagnosis for her child after years of testing and consultation.

Sharing Care Plans with Community Providers

Care plans were not consistently shared with community providers. One parent shared an experience where the school nurse, teacher, parents, and the health care provider all collectively developed a medical plan to be used in the school. No student had ever needed a pulse oximeter or oxygen tank in school before. The parent met with school personnel and then communicated their questions and concerns back to the child's pediatrician. The child's pediatrician wrote a medical plan while consulting the parent and the parent brought the medical plan back to the school for implementation. Similar stories were shared by other families.

Sharing updates and care plans occurs in the form of telephone conference calls for one family whose child is living in a treatment facility hours away from their home. The family feels this is an effective strategy when all parties attend the calls.

By contrast, some parents expressed concern about being able to incorporate medical care plans or health care team expertise into the school's individualized education plan (IEP) development. This was especially true for parents of children with behavioral or emotional concerns. While the health care providers communicated willingness to attend or provide input, scheduling of the IEP meeting by the school district often didn't allow for the provider's attendance or input.

While most parents welcomed the opportunity to increase communication between health care and community providers (such as schools and therapists), a few parents expressed concern over not being able to control what information about their child got shared. There was concern that information could be used to negatively impact their child's experience in school or access to community services.

Access to Written Care Plans or Electronic Health Records (EHRs)

All families indicated that they had access to written plans or medical summaries in some form. Most families indicated that they received paper copies of plans either at the end of the visit or received them in the mail.

A few families indicated that they had access to plans or medical summaries through EHRs and that they found this type of access extremely helpful. Another perspective shared by some families was that they had access to EHRs but they were not using them for various reasons. Some chose not to use EHRs because they preferred written documents and phone communications over online communication because they received the information they needed more quickly. One parent indicated that she could only access the EHR if she provided her child's Social Security number to the health system, which she was not willing to do. Another parent indicated that getting access to the EHR was too confusing and time consuming.

Findings: Benefits and Challenges of Care Coordination

Benefits and Challenges of Care Coordination: System and Provider Perspective*

Professionals offering care coordination believe that there are many benefits, but only a few are tracking outcomes in a way that makes the information usable beyond the child's direct care. There are many qualitative stories about the impacts of care coordination but not many quantitative measures. Defining care coordination and finding time-efficient and valid ways to measure it was cited as a key challenge.

"There is no doubt in my mind that care coordination offers the best care to families."

~system provider

As mentioned above, having sustainable funding and support for comprehensive care coordination was a concern. Shifting health care policy made this seem even more uncertain.

**No family perspective gathered for this area.*

Conclusion and Next Steps

Systems, providers, and families spoke of the potential benefits awaiting Wisconsin children and families once care coordination can be offered to all that need and desire it. Some steps that can move us in the right direction are to further document and spread the story of what care coordination is; how care coordination is being provided now; the impact on patient, family, and provider experience; and the cost of care over the long term. We can also continue to educate on shared plans of care as a means of communication for patients and their entire care team and to support quality improvement strategies that advance these tools within systems and communities. It is essential to the successful implementation of care coordination to continue to engage families and amplify their voices so that we can quickly determine how best to support families along their health care journey.

In the meantime, families want:

- More funding to support the work of those helping families such as Birth to 3 programs, comprehensive community supports teams, coordinated service teams, regional centers for Children and Youth with Special Health Care Needs, condition-specific organizations, sibling support organizations, Parent to Parent, and other family led organizations.
- Family navigation and support that is flexible enough to meet their family needs when they need it.
- More training for providers and other supports on disorders and concerns, especially in behavioral health.
- Better tools to diagnose concerns earlier.
- Comprehensive and easily accessible resources that include the most recent evidence-based supports.
- Transition services from pediatric to adult care, as well as in the education system, that begin early and are available to all families.
- Respite support for families so that they can attend to the various care coordination tasks.
- Family leadership training so that families can use their voice to benefit all families.
- Education for professionals across the care system in trauma informed care.
- Health care student education and mentoring programs that give students a chance to hear the perspective of the family and their lived experience, and how that impacts their health and the ability to care for their child.

Appendices

Appendix A: Key Informants List

This table includes a list of key informants who completed an interview during this project.

Key Informants – Systems representatives (12)		
Name	Title	Organization
Linda Benton, MSN, FNP-BC, PHN, RN	Former MCH Home Visiting Nurse Consultant – Bureau of Community Health Promotion	Wisconsin Department of Health Services
Bette Carr, MSN, RN, NCSN	School Nursing and Health Services Consultant	Wisconsin Department of Public Instruction
Ryan Collier, MD, MPH	Assistant Professor, Department of Pediatrics – Hospital Medicine and Research Director of the Pediatric Complex Care Program	American Family Children’s Hospital
Teresa Duchateau, DNP, RN, CPNP	School Health Services Consultant	School Health Associates
Terri Enters, MS IMH-E(I)	Wisconsin Birth to 3 Program Supervisor/Part C Coordinator	Wisconsin Department of Health Services
John B. Gordon, MD	Former Medical Director of Special Needs Program and Professor	Children’s Hospital of Wisconsin Medical College of Wisconsin
Kim Eithun Harshner	Operations Lead	Office of Children’s Mental Health
Rebecca McAtee	Deputy Director - Bureau of Benefits Management in the Division Medicaid Services	Wisconsin Department of Health Services
Deborah Rathermel	Director - Bureau of Children’s Services in the Division of Medicaid Services	Wisconsin Department of Health Services
Robert Rohloff, MD	Pediatrician and Associate Professor of Pediatrics	Children’s Hospital of Wisconsin Medical College of Wisconsin
Michelle Urban, MD	Medical Director	Division of Milwaukee Child Protective Services
Lora Wiggins, MD	Chief Medical Officer - Bureau of Benefits Management in the Division of Medicaid Services	Wisconsin Department of Health Services

Key Informants – Provider representatives (14)		
Name	Title	Organization
Tara Bartelt, MS, PCNS-BC, RN	Ambulatory Manager/APN	Children’s Hospital of Wisconsin
Becky Birchmeier, RN, MS	Nursing Pediatric Clinical Nurse Specialist	Marshfield Clinic
Jenny Bisonette, MSSW	Program Coordinator – Mino Maajisewin Home Visitation Program	Lac Courte Oreilles Tribe
Diane Gerlach, DO	Pediatrician	Aurora Medical Center
Marcee Gohr, BSN, RN, NCSN	Retired School Nurse	Pulaski Middle School
Lynn Havemann, MEd	Family Navigator – Autism and Developmental Disabilities Clinic and Feeding Clinic Coordinator	University of Wisconsin Waisman Center
Michael Hoffman	Director of Early Intervention Services – Washington County	The Threshold Inc.
Marcia Kyes, RN, BSN	Pediatric Care Coordinator	Chippewa Falls Center, Marshfield Clinic
Cecilia Lang, APNP	Clinical Nurse Specialist – Tracheostomy Home Ventilator Program	Children’s Hospital of Wisconsin
Mala Mathur, MD, MPH	Pediatrician	University of Wisconsin Health
Mary Pulchinski, RN, BSN	Public Health Nurse	Adams County Health and Human Services Department
Katie Schlipmann, RN, BSN	Health Project Coordinator of Empowering Families of Milwaukee	City of Milwaukee Health Department
Lori Weaver, MSW	Long Term Care Supervisor	Brown County Human Services
Lisa Zetley, MD	Consulting Medical Director of Care4Kids, Pediatrician and Assistant Professor of Pediatrics in the Downtown Health Center	Children’s Hospital of Wisconsin

Key Informants – Parent/Family representatives (15)
Wisconsin Communities Represented
Belleville
Eau Claire
Fremont
Green Bay
Kaukauna
La Crosse
Madison
Milwaukee
Oak Creek
Plover
Shawano
Wausau
Williams Bay

Appendix B: Reviewed Materials and References List

Name / Author	Web Address
<p>Achieving a Shared Plan of Care with Children and Youth with Special Health Care Needs</p> <p>By Jeanne W. McAllister, BSN, MS, MHA, with support from the Lucille Packard Foundation for Children’s Health</p>	<p>http://www.lpfch.org/publication/achieving-shared-plan-care-children-and-youth-special-health-care-needs</p> <p>Full report, implementation guide, white paper, and slides are available</p>
<p>The Care Coordination Conundrum and Children and Youth with Special Health Care Needs</p> <p>By Sara S. Bachman, PhD; Meg Comeau, MHA; and Katharyn M. Jankovsky, MSW, of the Catalyst Center at the Boston University School of Public Health, with funding from the Lucile Packard Foundation for Children’s Health</p>	<p>http://www.lpfch.org/publication/care-coordination-conundrum</p> <p>Full report, webinar recording and slides are available</p>
<p>Care Coordination Measures Atlas (June 2014 update)</p> <p>By the Agency for Healthcare Research and Quality</p>	<p>https://www.ahrq.gov/professionals/prevention-chronic-care/improve/coordination/atlas2014/index.html</p>
<p>Mapping the State of Cross-Systems Care Coordination for CYSHN in Minnesota: Assessment and Recommendations: March 2015 Report</p> <p>By the Minnesota Department of Health</p>	<p>http://www.health.state.mn.us/divs/cfh/program/cyshn/mapping.cfm</p>
<p>Patient- and Family-Centered Care Coordination: A Framework for Integrating Care for Children and Youth Across Multiple Systems</p> <p>By the Council on Children with Disabilities and Medical Home Implementation Project Advisory Committee of the American Academy of Pediatrics</p>	<p>http://pediatrics.aappublications.org/content/133/5/e1451.full</p> <p>Published in Pediatrics, May 2014, Volume 133/Issue 5</p>
<p>Wisconsin State Plan to Serve More Children and Youth within Medical Homes (including those with special health care needs)</p> <p>By the Wisconsin Title V Children and Youth with Special Health Care Needs Program</p>	<p>https://www.dhs.wisconsin.gov/cyshcn/medical-home.htm</p>

Appendix C: Definitions List

Care Coordination: Care coordination is the process that links children and their families with needed health care and services, along with other supports and services. A child and family's needs, goals, and choices are included in a care plan that is shared with all team members.

Based on Lucile Packard Foundation for Children's Health and the Catalyst Center's paper "[The Care Coordination Conundrum](#)"

CYSHCN (Children and Youth with Special Health Care Needs): The federal Maternal and Child Health Bureau defines CYSHCN as "those who have 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." The CYSHCN Screener® (a parent-based survey tool) was designed to reflect this definition. Children with a positive screen on this instrument are those up to age 18 with prescription medication dependence, above average use of services, and/or functional limitations expected to last or lasting at least one year. The National Survey of Children with Special Health Care Needs (2009-2010) estimated approximately 200,000 Wisconsin children have special health care needs according to these criteria.

Family Engagement and Leadership: Family engagement refers to the support for family members from an organization, agency, or program, as well as community stakeholders, to ensure that families are given the opportunity to participate in multiple ways. Family engagement reflects a belief in the value of family leadership at all levels from an individual, community, and policy. Furthermore, family engagement is the active intention of infusing the family perspective in all areas of systems design, implementation and evaluation. Family leadership is successful when effective partnerships are built upon mutual respect and shared responsibility, expertise, and decision-making.

The following characterizes family leadership at a variety of levels:

- **Family level:** Families are supported in their role as an expert on and advocate for their children. Families participate in the development of goals and service plans, as well as program decisions that affect their child/family (e.g., parents learn how to read infant cues or understand child development and identify areas of needed support).
- **Peer Support level:** Families have opportunities to connect with and support other families in their communities and more broadly (e.g., parent matching, family support groups, planning community activities on behalf of children in addition to their own).
- **Agency decision-making level:** Families as partners with other families, providers, and policy makers in the areas of policy, program development and evaluation, professional education, and the delivery of supports and services to increase the likelihood that systems of support and services are helpful, effective, and responsive to families (e.g., they are involved in program advisory committees or participate on work groups about program changes).
- **Systems change level:** Family perspectives contribute to the quality of systems of supports and services and are essential for effective policies and practices at all levels of care and systems planning, including access, integration, accountability, and equity (e.g., families offer public comments at health and human services board meetings or participate in community coalitions).

Note: This definition was developed collaboratively with the Department of Health Services Title V CYSHCN Program, the Department of Children and Families Home Visiting Program, Family Voices of Wisconsin, and others.

Medical Home: A comprehensive way of providing health care to children and youth, medical homes are most commonly composed of primary care clinicians (such as pediatricians, family physicians, pediatric nurse practitioners, and physician assistants), care team members, and family members. In a medical home, care is coordinated based on family priorities. It is also accessible, continuous, comprehensive, compassionate, and culturally effective. There is growing evidence that care provided within the medical home model supports the Institute for Healthcare Improvement's Triple Aim, including improved patient and family experience, overall improvement in population health, and for certain patient populations, reduced cost of care.

MHIT (Medical Home Implementation Team): A team of over 40 professionals serving CYSHCN and their families established collaboratively to develop, promote, implement, and evaluate a state plan to increase the number of Wisconsin children and youth served within a medical home, particularly those with special health care needs.

Appendix D: System and Provider Interview Script

You have been identified as a *systems/health care* representative that could provide invaluable information about [care coordination services](#) for children within Wisconsin. The Wisconsin Medical Home Implementation Team (MHIT) is conducting phone interviews with individuals like yourself in order to:

- a. Identify what current practice is around care coordination.
- b. Identify opportunities that can be built upon and/or shared with others.
- c. Identify gaps in care coordination in Wisconsin that the MHIT can help to address in the future.

Your involvement is voluntary. Content analysis of the information you share will result in aggregated feedback. Names and affiliations will only be identified with comments after consent has been received. The questions you will be provided are a general frame for our conversation, but do not limit us. I may ask related questions, or questions based on feedback from others. I encourage you to add any information that you feel is relevant as well. Any examples or stories you can provide will be very helpful. You will be given an opportunity to review themes taken from our discussion in order to verify content and allow you an opportunity to elaborate, if you so choose.

Would you be willing to discuss this with me for 45-60 minutes during a phone interview? If so, can you please send me some potential dates/times over the next two weeks? The questions I will be asking around care coordination are listed below so that you can prepare yourself for the discussion, if needed. If some of the questions are not applicable or you do not know the answer, that is fine. If you have any questions or concerns, please let me know at hrabik@wisc.edu or 920-427-5262.

Appendix E: Family Interview Script and Screening Tool

Invitation to parents/families of children with special health needs

You have been identified as a family member or caregiver of a child with special health needs that could provide important information about [care coordination services](#) for children in Wisconsin.

The Wisconsin Medical Home Implementation Team (MHIT) is conducting phone interviews with families in order to:

- a. Find out if care coordination is provided to families and what it looks like.
- b. Find areas where care coordination is working well and help spread that to other areas.
- c. Find areas where care coordination is not working well and help figure out how make it better in the future.

Those who complete a phone interview will be given a \$30 stipend for their time. Involvement in the project is voluntary. Information collected during the interviews will be summarized and participants can review the discussion notes to make sure the information is accurate. Names will only be identified with comments after consent has been received.

Interested? Please complete this brief survey to set up a 45-60-minute interview. If you have any questions or concerns, please let me know at hrabik@wisc.edu or 920-427-5262.

Survey introduction/questions: Thank you for your interest. We want to make sure that we are talking with families that have diverse experiences and backgrounds. Please complete this short survey and I will contact you with next steps. You can contact me, Lynn Hrabik, at any time with questions at 920-427-5262 or hrabik@wisc.edu.

1. Which of the following categories best fits the child's special health need?

Choose all answers that apply.

- ☐ Physical concern
- ☐ Developmental concern
- ☐ Behavioral or emotional concern
- ☐ Other: Please list _____

2. How old is the child now?

- ☐ 0-3 years old
- ☐ 4-10 years old
- ☐ 11-17 years old
- ☐ 18 years or older

3. At what age was the child first identified with a special health need?

- ☐ 0-3 years old
- ☐ 4-10 years old
- ☐ 11-17 years old
- ☐ 18 years or older
- ☐ Not applicable; there is no identified special health need

4. Where does the child receive most of his/her health care?

- ☐ Primary care; for example, pediatrician or general practice
- ☐ Specialty care; for example, cardiologist, pulmonologist or multidisciplinary clinic

5. What city, village, or town does the child live in?

6. Please complete the following so that we can set up an interview.

Your name: _____

Telephone number: _____

Email address: _____

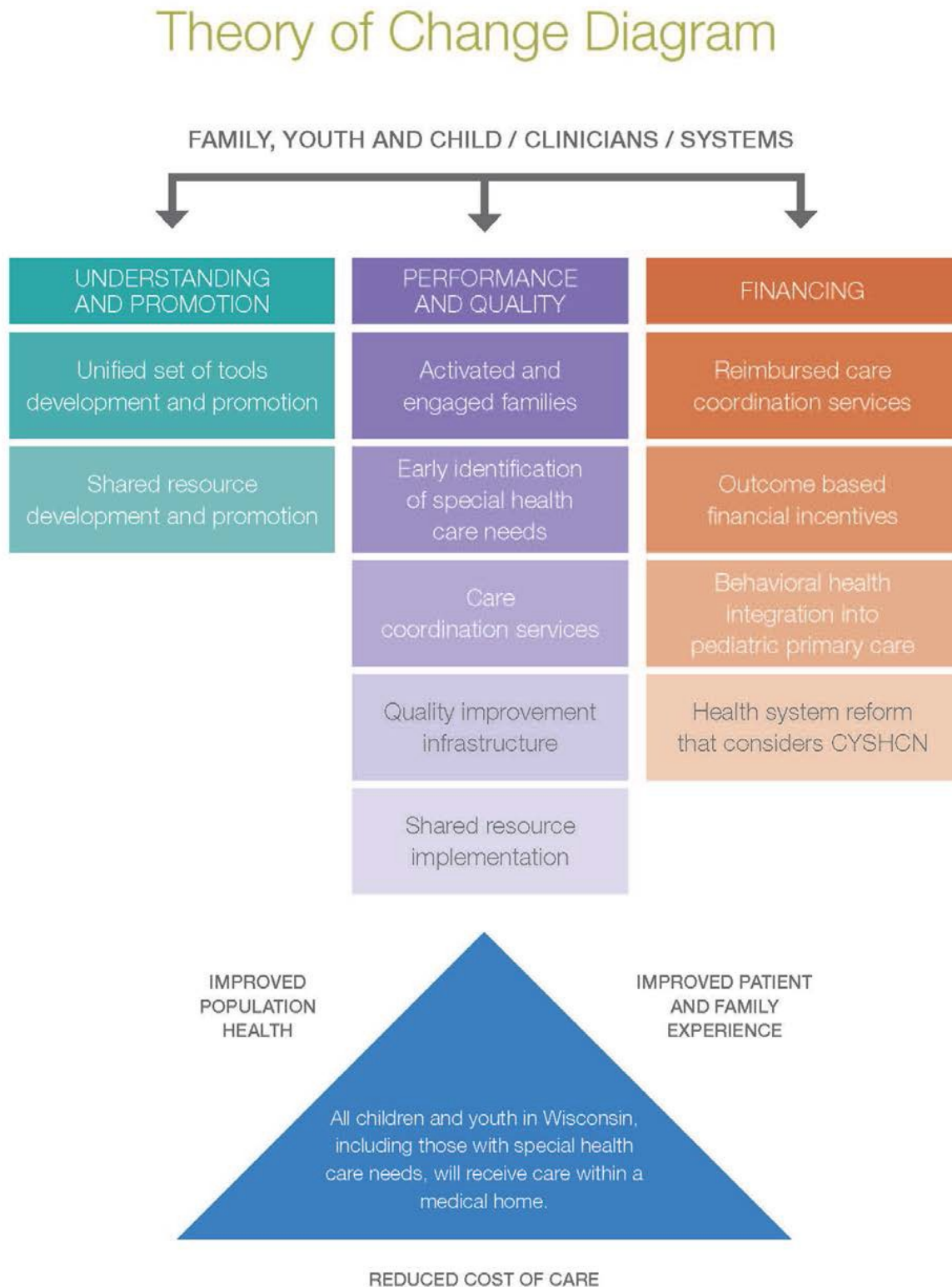
7. How would you like to be contacted to set up an interview? Choose all responses that apply.

- ☐ Telephone call
- ☐ Text
- ☐ Email

8. Are you the child's:

	Yes	No
Primary caregiver?	<input type="radio"/>	<input type="radio"/>
Parent?	<input type="radio"/>	<input type="radio"/>
Grandparent?	<input type="radio"/>	<input type="radio"/>
Foster parent?	<input type="radio"/>	<input type="radio"/>

Appendix F: Theory of Change Diagram





Wisconsin Title V Children
and Youth with Special
Health Care Needs Program



Wisconsin
Department of Health Services

Wisconsin Children and Youth with Special
Health Care Needs Program
1 W. Wilson, P.O. Box 2659
Madison, Wisconsin 53701-2659

This project was completed as part of the
Wisconsin Medical Home Systems
Integration Grant and supported by
funding from the U.S. Health Resources
and Services Administration, Maternal and
Child Health Bureau, through grant
number 70MC27553, Integrated
Community Systems for Children with
Special Health Care Needs.

P-01840 (07/2017)