Medical Home Implementation Team
August 21, 2017

Lynn Hrabik, MPH, RDN

Family Voices of Wisconsin

WISCONSIN Medical Home
Children's Health Alliance of Wisconsin

WAISMAN CENTER
UNIVERSITY OF WISCONSIN-MADISON

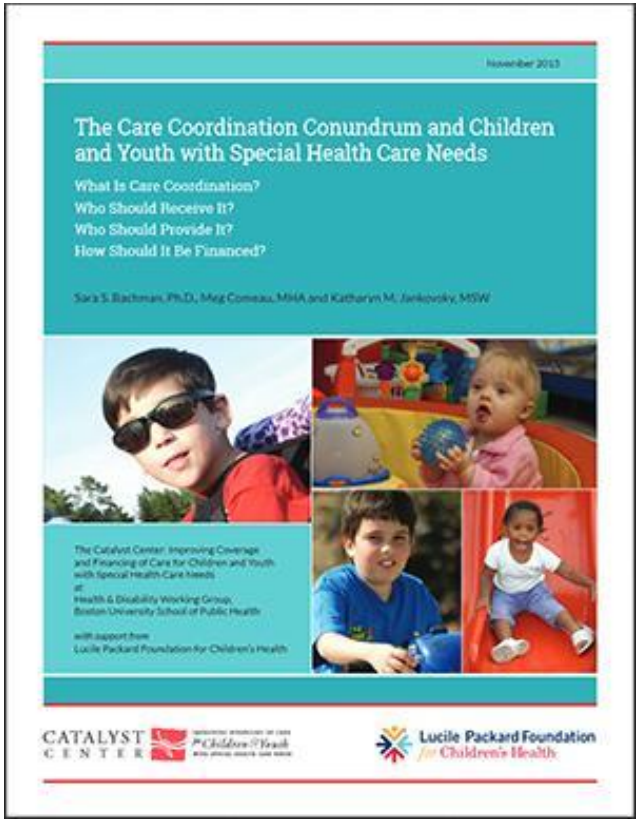
Presentation Objectives

Increase your understanding of the Wisconsin Medical Home Systems Integration Grant's care coordination mapping project:

- Methods to include systems, provider and family voice in project design and evaluation.
- Findings from the project.

Definition of 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."



Take Action on Care Coordination

4/13/16 webinar

Lucile Packard Foundation for Children's Health

CATALYST CENTER — Improving Financing of Care for Children & Youth with Special Health Care Needs

Key findings

- No consensus about what care coordination is, who should provide it, who should receive it, and how to pay for it
- Care coordination return on investment (ROI) has not been determined
- CPT billing codes for care coordination are not catching on
- Current models will not support a high-quality, sustainable care coordination system
- Care coordination falls to the child's family – can be a financial, labor intensive burden

BU

Boston University School of Public Health
Health & Disability Working Group

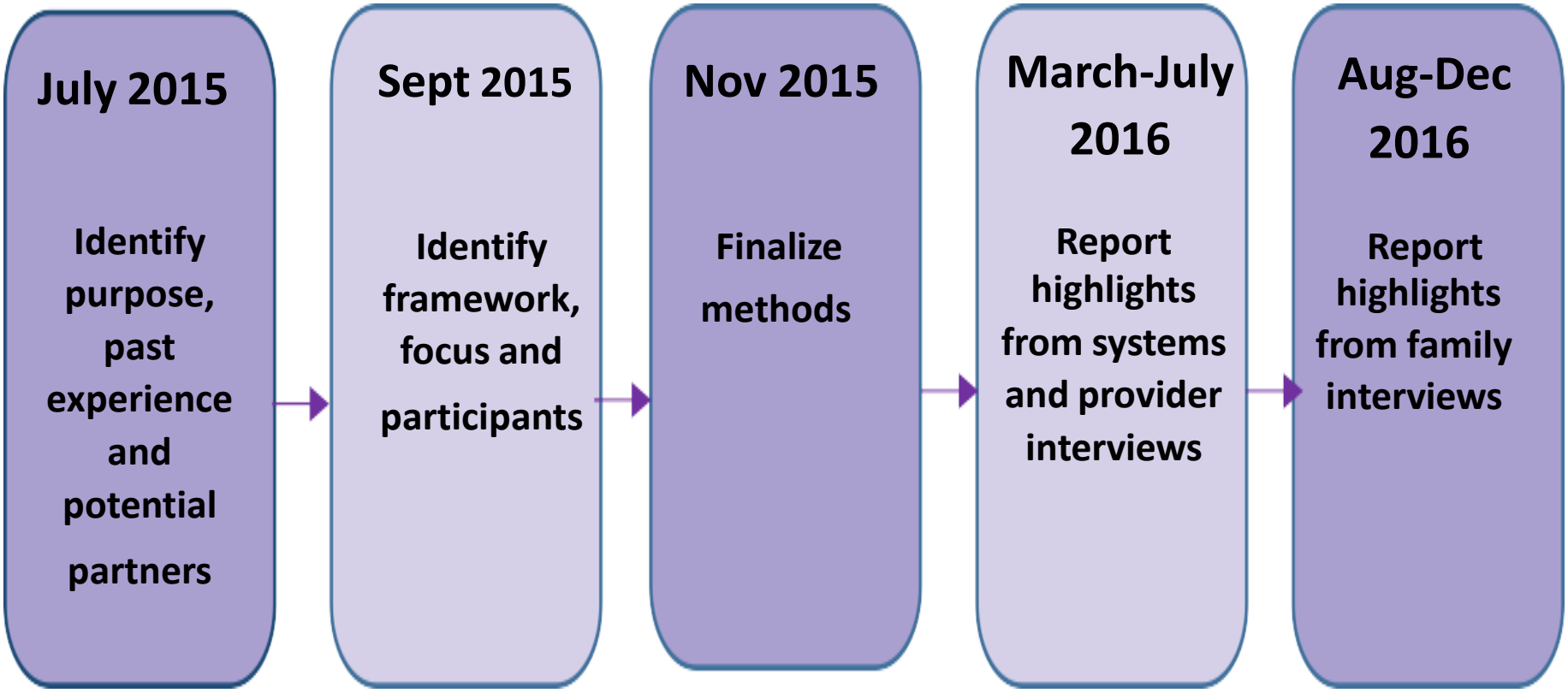
Mapping Purpose

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

2. What gaps exist?

3. What assets can we build upon and share?

Mapping Process



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

County Represented in Family Interviews

2-4 per Division of Public Health geographic region

All urban/rural categories represented

Care Source Represented in Family Interviews

5 of CYSHCN represented sought most care from Primary Care

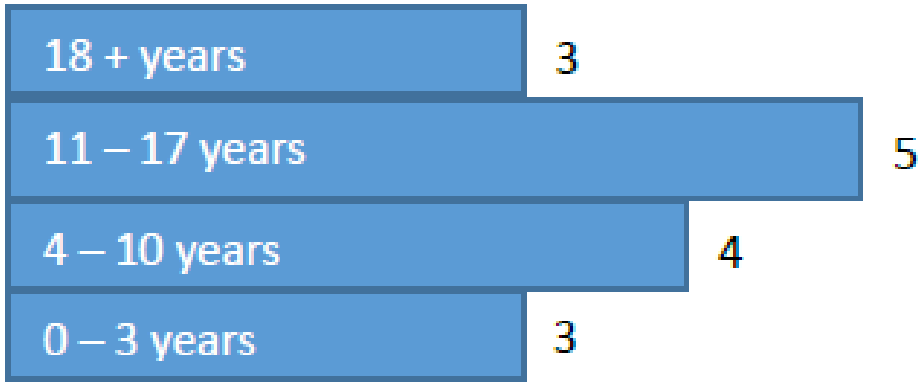
10 of CYSHCN represented sought most care from Specialty Care

Type of Identified Concern or Diagnosis Represented in Family Interviews

(Individuals may have reported more than one category)

- 7 Behavioral
- 8 Developmental
- 5 Physical

Age of CYSHCN Represented in Family Interviews



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.

Elements of Care Coordination

continued

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.

7 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?

8 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?

- 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?
- How do the child's doctors and other service providers use the same plan to talk to each other, if at all?

9 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.

10 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?

11 Is there **anything else** that you would like to share?

Reflecting on your personal or professional experiences, what do you expect to hear about care coordination in Wisconsin?

Findings:

Elements of Care Coordination

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.

“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

Findings:
Populations Receiving Care Coordination

Those with the **highest complexity or the lowest ability** were more likely to be offered more elements of care coordination.

Families found great **variety** in what they were offered depending on where their child received care.

Findings:
Funding for Care Coordination

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.**

Families found insurance to be very challenging.

Findings:
Disciplines Providing Care Coordination

Care coordination is often **provided by teams**.

Nurses, social workers and other support personnel provided the most support outside of appointments.

Findings:
Communication within Care Coordination

Very challenging and yet essential piece of care coordination.

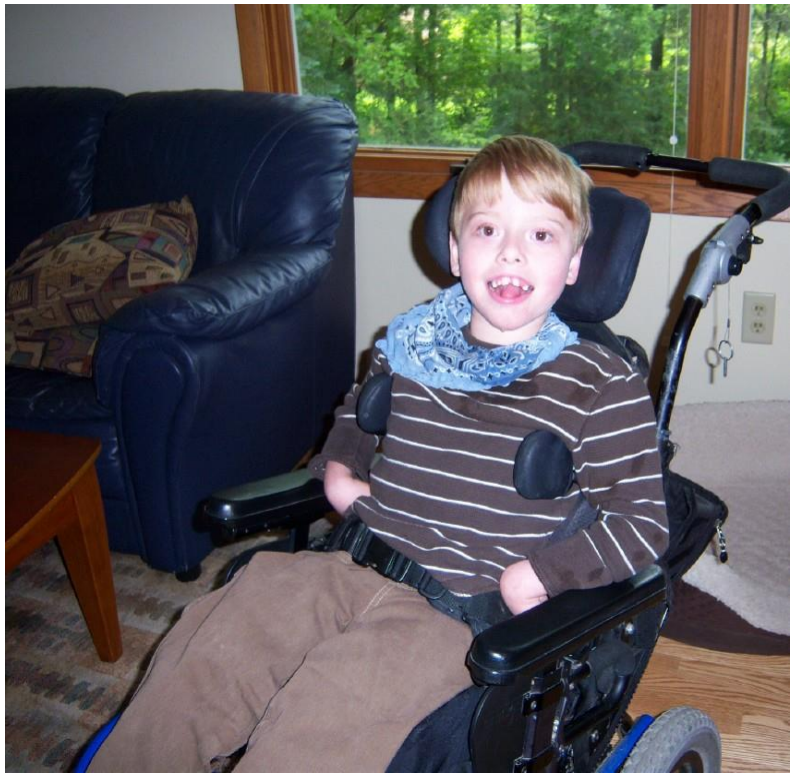
HIPAA/FERPA not cited as challenges when speaking with medical providers, but were limiting community-based providers.

Findings:
Family Engagement within Care

Families felt able to provide feedback in most cases to medical providers.

Those serving in advisory roles found it very rewarding and informative.

Findings:
Shared Plans of Care



Shared plans of care are more feasible when included in the EHR.

Sharing is more common within medical systems. Community-based providers included least often.

Hope…

Every family described having someone that helped them cope.

All systems and health care representatives indicated that care coordination was valuable.

Families, systems and health care representatives shared examples of trying to making system level changes.

“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

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

--provider representative

“…we were able to get changes made at the county level to get my child’s needs met….will benefit all children that live here.”

--family representative