Primary/Specialty Coordination in Complex Care

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Pediatric Care Coordination Populations

Children and Youth with Special Health Needs (CYSHN)

- Defined 25 years ago
- Having or at risk for developing a chronic condition
- ~15% of US children

Children with Medical Complexity (CMC)

- Defined 10 years ago
- Multiple chronic conditions, functional limitations, frequent technology dependence, high health care cost and needs
- < 1% of US children
- ~ 40% pediatric health resource utilization

McPherson, M., Arango, P., Fox, H., Lauver, C., McManus, M., Newacheck, P. W., . . . Strickland, B. (1998). A new definition of children with special health care needs. Pediatrics, 102(1 Pt 1), 137-140.

Cohen, E., Kuo, D. Z., Agrawal, R., Berry, J. G., Bhagat, S. K., Simon, T. D., & Srivastava, R. (2011). Children with medical complexity: an emerging population for clinical and research initiatives. Pediatrics, 127(3), 529-538.

Essential Characteristics of Care Coordination

- Family-centered, team-based function with defined tasks and supporting infrastructure
- Health and psychosocial assessment identifies level of care coordination services
- Health and psychosocial assessment and family-defined goals ➔ jointly developed plan of care
- Plan of care goals monitored and modified as needed
- 'Single point of contact' that communicates and coordinates with patients, families, clinicians and services
- 'Between clinic visit' communication conducted by telephone, email or telehealth, to enhance care coordination relationship and partnership
- Patient and family given tools to develop self-management competencies
- Care coordination 'neighborhood' includes all clinicians and services the support patient
- Method of sharing relevant health information, ideally electronic, between patient/family and care coordination neighborhood
- Monitors and facilitates transitions of care (i.e.: hospital discharge, pediatric to adult care)

Schor, E. L. (2018). Ten essential characteristics of care coordination. *JAMA Pediatrics*. doi:10.1001/jamapediatrics.2018.3107

Foundational Standards for Care Coordination

1. Care coordination for CYSHCN is based on the **premise of health equity**, that all children and families should have an equal opportunity to attain their full health potential, and no barriers should exist to prevent children and their families from achieving this potential.
2. Care coordination **addresses the full range of social, behavioral, environmental, and health care needs** of CYSHCN.
3. **Families are co-creators of care coordination processes and are active, core partners** in decision making as members of the care team. CYSHCN, families, and care coordinators work together to build trusting relationships.
4. Care coordination is **evidence based where possible, and evidence informed** and/or based on promising practices where evidence-based approaches do not exist.
5. Care coordination is **implemented and delivered in a culturally competent, linguistically appropriate, and accessible manner** to best serve CYSHCN and their families.
6. **Insurance coverage of care coordination** for CYSHCN allows for it to be accessible, affordable, and comprehensive.
7. Performance of care coordination activities is **assessed with outcome measures** that evaluate areas including:
    a) The **process of care coordination** (e.g., number of families with a shared plan of care)
    b) Family experience with **integration of care** across medical, behavioral, social and other sectors and systems
    c) Quality of life for CYSHCN and families
    d) Reduction in duplicative and/or preventable health care utilization

National Academy for State Health Policy. (2020). National Care Coordination Standards for Children and Youth with Special Health Care Needs. In (pp. 31): National Academy for State Health Policy.

Models of Care Coordination

Episodic

Specific illness or transition period
- Cancer
- Transplant
- New trach/vent

Condition specific guidelines and plan of care

Metrics well-defined

Primary Care

Healthy and single condition CYSHN

Population-based guidelines, plan of care and metrics

Community-based

High risk of fragmented care for CMC

Consultative / Co-Management

CMC

Patient-specific guidelines, plan of care

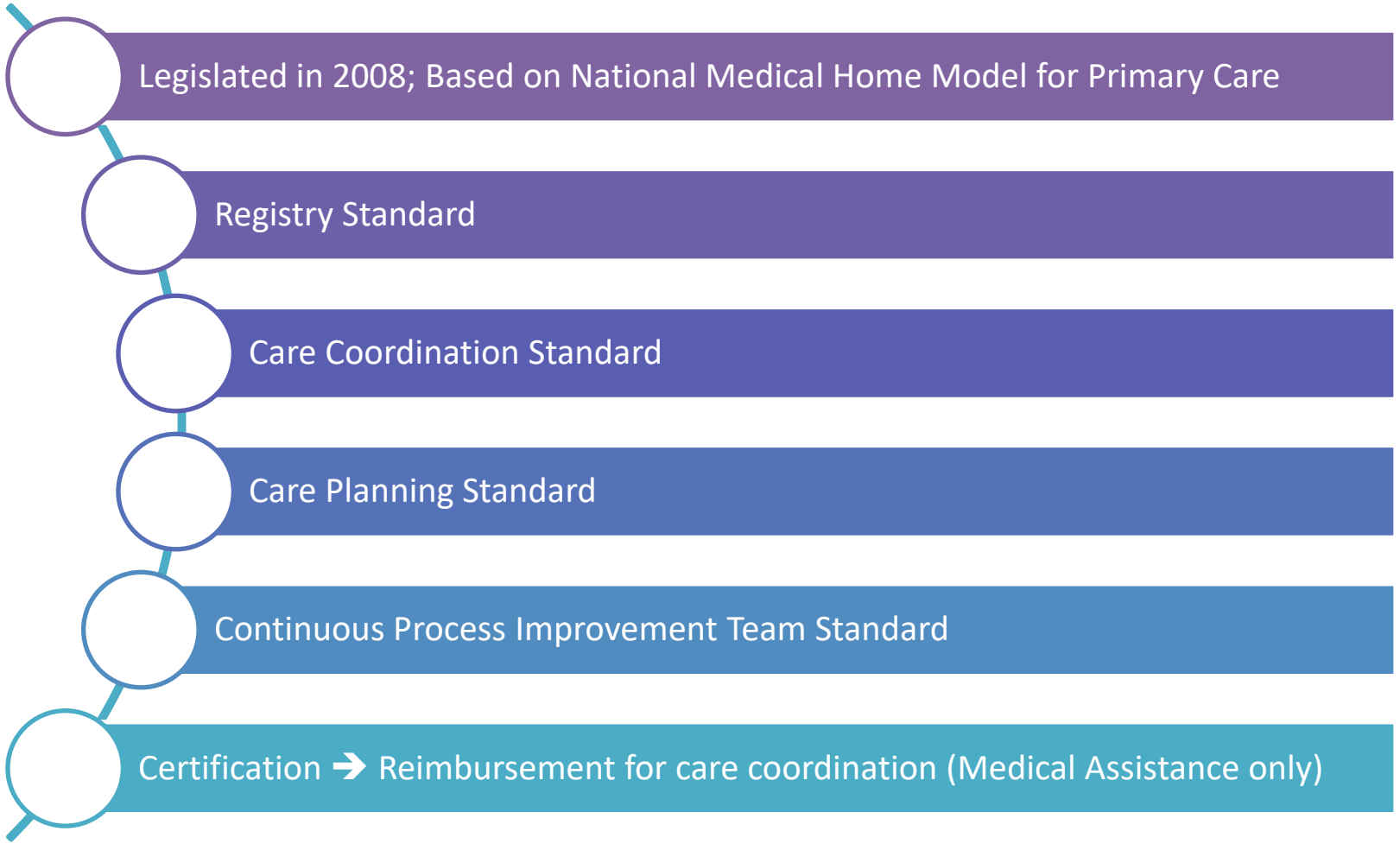
Reduced care fragmentation

Tertiary, specialty-based

Risk of poor communication with PCC and local services

Metrics difficult

Minnesota Health Care Home Model



Collaborative Improvement and Innovation Network (CoIIN) to Advance Care for CMC

The CoIIN for CMC is a **four year, HRSA funded collaborative** that aims to ***improve the quality of life*** for children with medical complexity (CMC), the ***wellbeing of their families***, and the ***cost-effectiveness of their care*** through the development and implementation of innovative care and payment models

Project timeline: *8/1/2017—7/31/2021*

Anticipated Enrollment: *150-300/site ➔ 1500-3000 CMC and their Families*

Who's involved?

Center for Innovation in Social Work and Health at Boston University (CoIIN Management and Supervision)

National Advisory Committee

Family Voices (Family Partnership)

American Academy of Pediatrics (Care Delivery Support, Dissemination)

Boston University Evaluation Team

Health Management Associates (Medicaid)

AMCHP (CoIIN Expertise)

Population Health Improvement Partners (QI Expertise)

10 State Teams: AL, CO, IN, KY, MA, MN, OR, TX, WA, WI

Each State Team includes: Title V, Medicaid, Patient/Caregiver Advisors, CMC Complex Care Clinics (Primary and Specialty Clinic locations)

Evaluation of CoIIN for CMC Aims

Clinic Level:
Parent Survey ➔ 10 evidence-based care coordination constructs
Yearly Parent Focus Groups to measure child and family quality of life

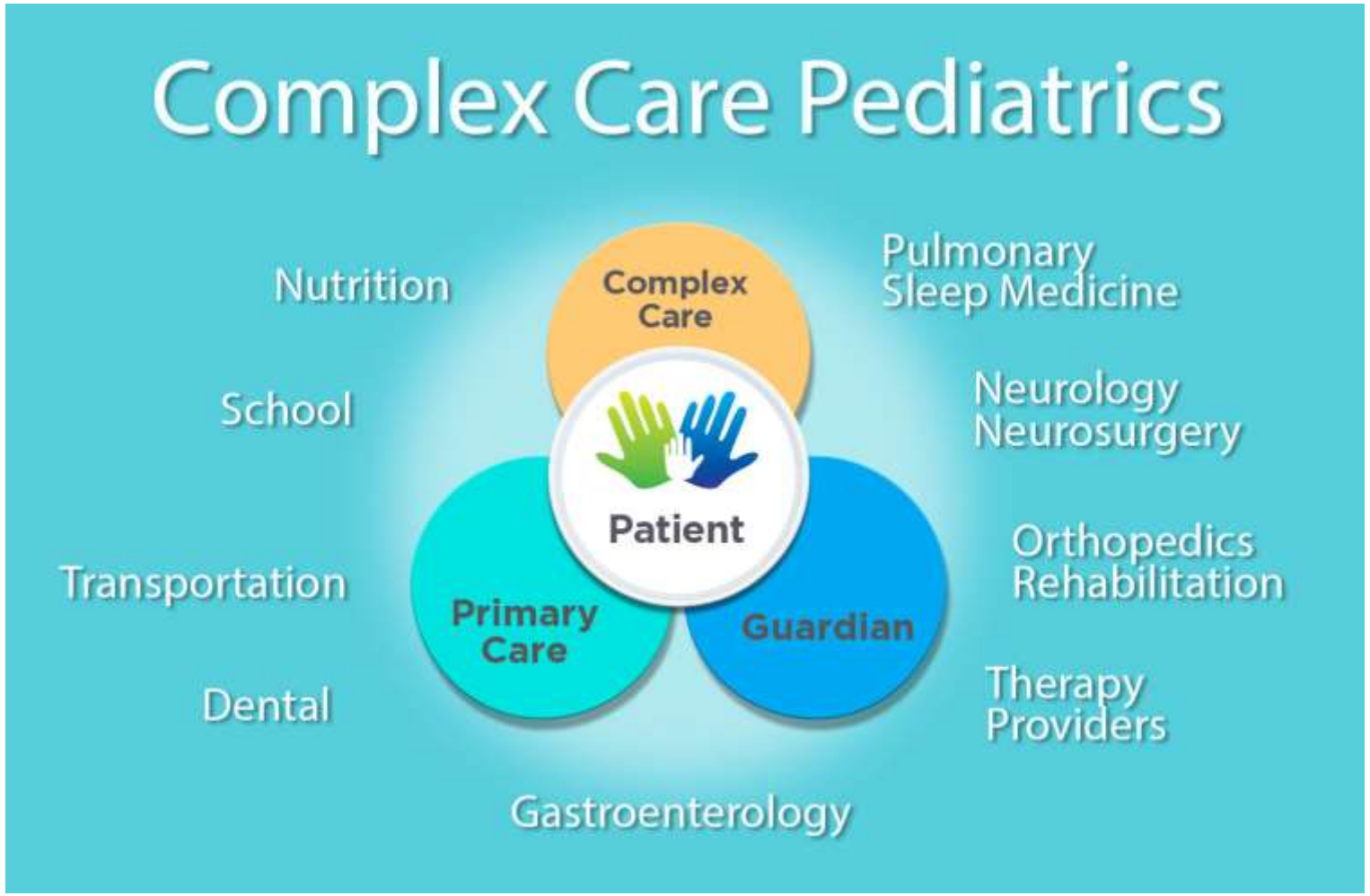
Medical Home
Shared Plan of Care
Family Well-Being
Unmet Needs
Family Engagement

QI Team Level:
Family Engagement in Systems Tool (FESAT)

Payment Models:
State specific *Medicaid evaluation* via Health Management

Collaborative:
Yearly interviews with state team members
Qualitative data collected by state teams

Gillette Complex Care Clinic



- Established 2017
- Consultative / Co-Management Model of Care Coordination
- Certified Health Care Home ➔ 2019
- Tertiary Medical Home for CMC
- MN Clinical Setting for CoIIN for CMC Project
- Dr. Madeleine Gagnon

Remaining Slides are for filler, answering questions, etc.

Team MN Background and Members

Setting

- Gillette's Complex Care Clinic

Team Members

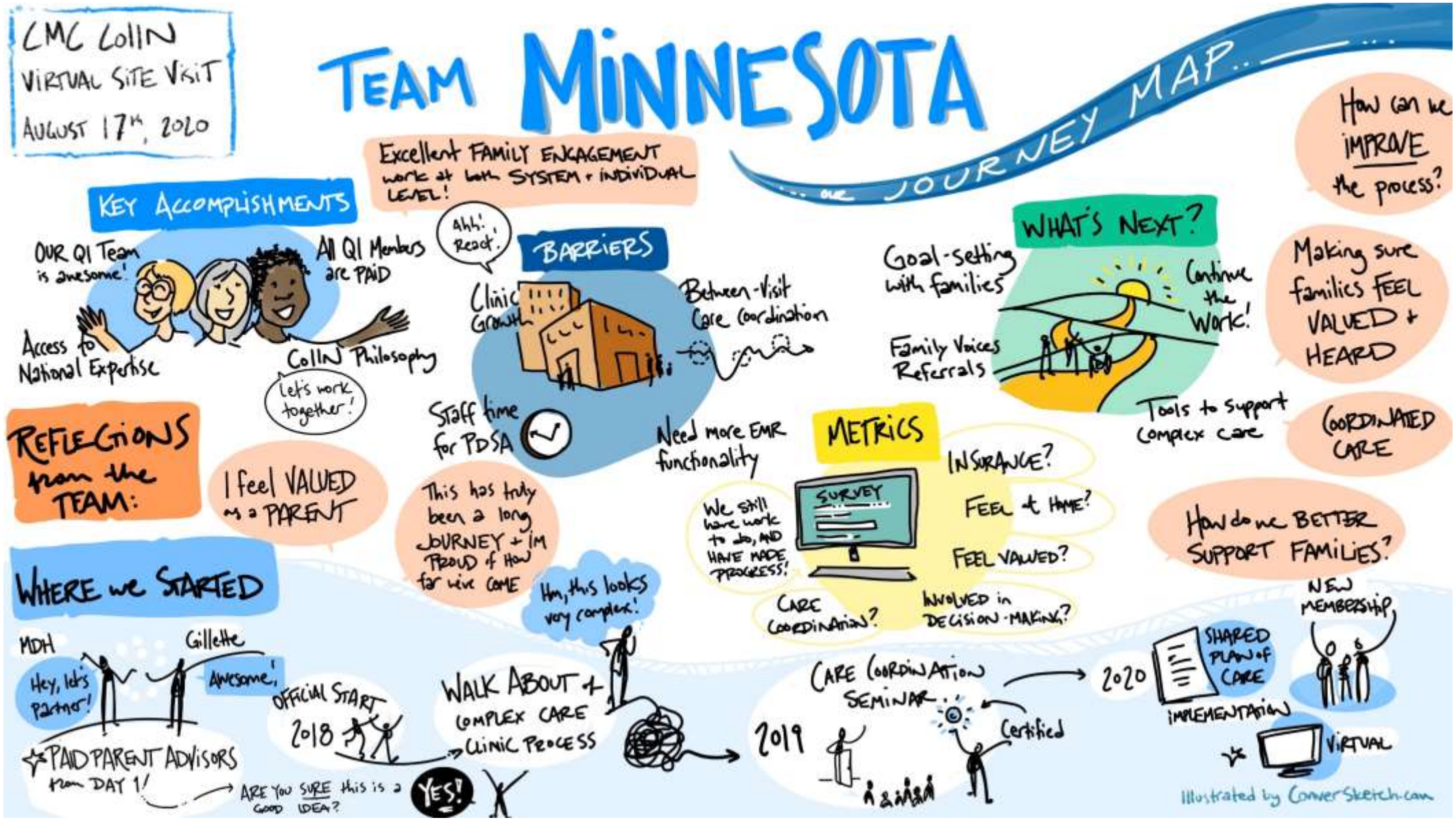
- Clinic Admin
- Clinic Nurse Care Coordinators
- Manager of Care Managers
- Nurse Researcher
- Scheduling
- **Parent Advisors**
- Physicians and Nurse Practitioners
- QI Specialist – MDH
- Social Worker

Background

- CoIIN participation ➔ Spring 2018
- First QI team meeting ➔Sept 2018
- Utilized CARE Award Model of incorporating paid parent advisors as equal members, involved in all aspects of QI initiative planning, design, implementation and evaluation

How Improvement Work Identified

- Walk-about of Complex Care Clinic processes
- Compared our 'current state' to 4C (Cohesive Complex Care Coordination) Package principles
- Identified and prioritized areas for improvement


CMC CoIIN
VIRTUAL SITE VISIT
AUGUST 17TH, 2020
TEAM MINNESOTA
... OUR JOURNEY MAP ...
Excellent FAMILY ENGAGEMENT work at both SYSTEM + INDIVIDUAL LEVEL!
How can we IMPROVE the process?
KEY ACCOMPLISHMENTS
OUR QI Team is awesome!
All QI Members are PAID
Access to National Expertise
CoIIN Philosophy
Let's work together!
Ahh! Reach!
BARRIERS
Clinic Growth
Between-Visit Care Coordination
Staff time for PDSA
Need more EMR functionality
WHAT'S NEXT?
Goal-setting with families
Continue the Work!
Family Voices Referrals
Tools to support complex care
Making sure families FEEL VALUED + HEARD
COORDINATED CARE
REFLECTIONS from the TEAM:
I feel VALUED as a PARENT
This has truly been a long JOURNEY + I'm PROUD of how far we've COME
METRICS
SURVEY
We still have work to do, AND HAVE MADE PROGRESS!
INSURANCE?
FEEL at HOME?
FEEL VALUED?
CARE COORDINATION?
INVOLVED in DECISION-MAKING?
How do we BETTER SUPPORT FAMILIES?
WHERE we STARTED
MDH
Gillette
Hey, let's partner!
Awesome!
PAID PARENT ADVISORS from DAY 1!
OFFICIAL START 2018
ARE YOU SURE this is a GOOD IDEA?
YES!
WALK ABOUT + COMPLEX CARE CLINIC PROCESS
Hm, this looks very complex!
2019
CARE COORDINATION SEMINAR
Certified
2020
SHARED PLAN of CARE IMPLEMENTATION
NEW MEMBERSHIP
VIRTUAL
Illustrated by ConverSketch.com

Measuring Our CoIIN Participation Impact

- 47 Question Parent Survey
- Asked to Complete Post-Complex Care Clinic Visit
- 4 Data Collection Cycles
- 40 surveys each 6 Month Cycle
- Cycle 3 Ends 10/31/20

During the past 12 months .....

	Never	Rarely	Sometimes	Usually	Almost Always	Always
10. How often has a doctor, nurse or other staff person from the Complex Care Clinic talked with you about specific goals for your child/teen's health care?	☐	☐	☐	☐	☐	☐
11. How often has a doctor, nurse or other staff person from the Complex Care Clinic talked with you about specific goals for other things that are important to you about your child/teen? (For example, attending school regularly, having friends, going on vacation, etc.)	☐	☐	☐	☐	☐	☐

During the past 12 months .....

	Yes	No	I Don't Know	Changes Were Not Needed
12. Has a doctor, nurse or other staff person from the Complex Care Clinic documented these goals in the form of a written plan of care?	☐	☐		
13. Did you and/or your family members contribute to the content of this written plan of care?	☐	☐		
14. Was this written plan of care easily accessible to you?	☐	☐		
15. Was this plan of care written in a way that you could easily understand?	☐	☐		
16. Has a doctor, nurse or other staff person from the Complex Care Clinic regularly updated this written plan of care to reflect changes and progress?	☐	☐	☐	☐

The written care plan developed for my child/teen by the Complex Care Clinic staff .....

	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
17. Helps me better understand my role in managing my child/teen's care.	☐	☐	☐	☐	☐
18. Helps make sure more of my child/teen's needs are met	☐	☐	☐	☐	☐
19. Helps the doctors, nurses and other staff who take care of my child communicate better with each other	☐	☐	☐	☐	☐

The Complex Care Clinic has a staff person or 'care manager' who .....

	Yes	No	I Don't Know
20. Helps me with difficult referrals, payment issues, and follow-up activities	☐	☐	☐
21. Helps to find needed services (e.g. transportation, durable equipment or home care)	☐	☐	☐
22. Helps each person involved in my child/teen's care to communicate with each other (with my consent)	☐	☐	☐

What Our Complex Care Clinic Parents Told Us

99% - Adequate Insurance Coverage

63% - Clinic Provides ‘Medical Homeness’

25% - Involved in Goal Setting and Receive a ‘Shared Plan of Care’

80% - Feel Clinic Knows and Values Child, Helps Child Have Meaningful Life

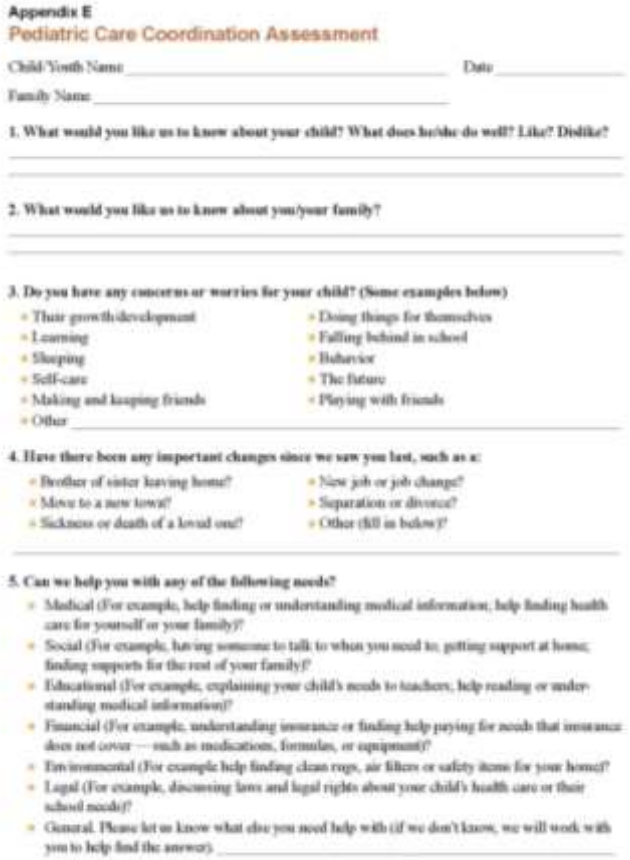
63% - Parent Asked about Their Health or Emotional Stresses/Well-Being

79% - Involved Parent in Shared-Decision Making

68% - Receive Care Coordination

Understanding Care Coordination Need

Shared Plan of Care Assessment Tool



Appendix E

Pediatric Care Coordination Assessment

Child/Youth Name _____ Date _____

Family Name _____

1. What would you like us to know about your child? What does he/she do well? Like? Dislike?

2. What would you like us to know about you/your family?

3. Do you have any concerns or worries for your child? (Some examples below)

- Their growth/development
- Learning
- Sleeping
- Self-care
- Making and keeping friends
- Other
- Doing things for themselves
- Falling behind in school
- Behavior
- The future
- Playing with friends

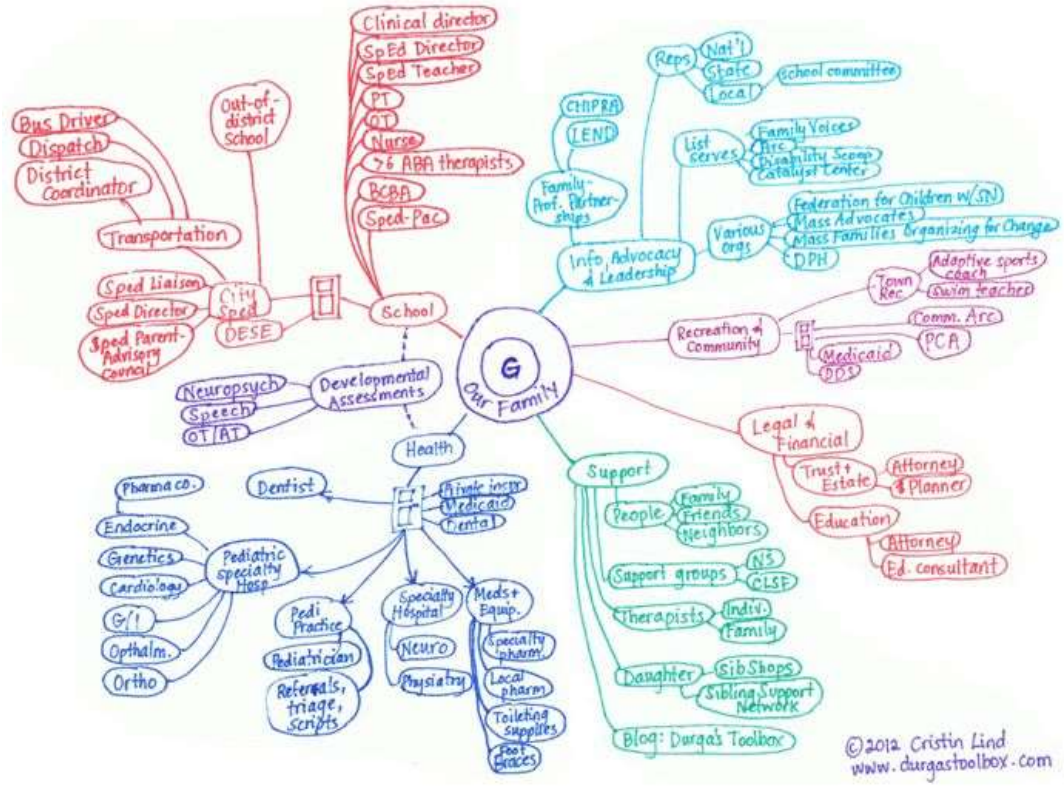
4. Have there been any important changes since we saw you last, such as a:

- Brother or sister leaving home?
- Move to a new town?
- Sickness or death of a loved one?
- New job or job change?
- Separation or divorce?
- Other (fill in below)?

5. Can we help you with any of the following needs?

- Medical (For example, help finding or understanding medical information; help finding health care for yourself or your family)?
- Social (For example, having someone to talk to when you need to; getting support at home; finding supports for the rest of your family)?
- Educational (For example, explaining your child's needs to teachers; help reading or understanding medical information)?
- Financial (For example, understanding insurance or finding help paying for needs that insurance does not cover — such as medications, formulas, or equipment)?
- Environmental (For example help finding clean rugs, air filters or safety items for your home)?
- Legal (For example, discussing laws and legal rights about your child's health care or their school needs)?
- General. Please let us know what else you need help with (if we don't know, we will work with you to help find the answer).

Care Mapping



Notes: McAllister, J. W. (2014). Achieving a shared plan of care with children and youth with special health care needs. Retrieved from http://lpfch-cshcn.org/publications/research-reports/achieving-a-shared-plan-of-care-with-children-and-youth-with-special-health-care-needs/