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HARVARD MEDICAL SCHOOL
TEACHING HOSPITAL

Implementing Effective Care Coordination and Integrated Care Management for Children and Youth with Special Health Care Needs

All In: Creating Synergy in Pediatric Complex Care
Children's Healthcare Canada

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Boston Children's Hospital
Harvard Medical School

25 March, 2021

Disclosures

- Richard Antonelli has no financial relationships to disclose or conflicts of interest to resolve.
- There will be no discussion of unapproved or off-label, experimental or investigational use.

Learning Objectives

Understand how to implement a framework of care integration

- Be able to adapt it for implementation in response to COVID19 pandemic

Develop and sustain leadership skills by advancing implementation of care integration with measurable, equitable high value outcomes, especially for vulnerable and underserved populations

Gain confidence in adapting and utilizing tools, processes, and measures which support care coordination and integration for children with medical complexity and children and youth with special health care needs

Acknowledgements

Department of Accountable Care and Clinical Integration, Clinical Integration Team

- Casey Fee, MS – Program Director
- Michele Sasso, MBA, Director, Clinical Programs and Technology
- Christine Geer, MPH – Project Coordinator
- Alexandra Frey, MPH – Project Manager
- Alanna Raskin, MPH – Project Manager
- Sara Pateras, LICSW – Project Manager

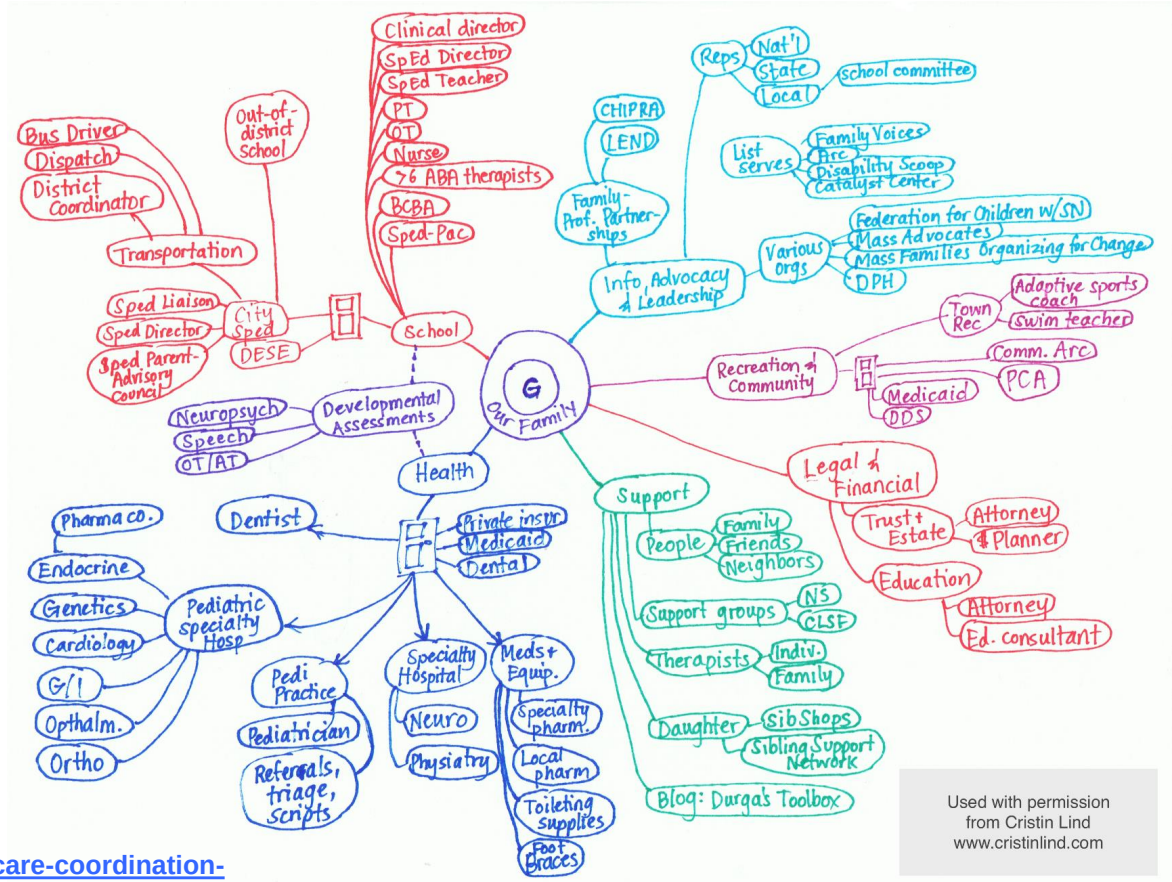
Important relationships with families, nursing, social work community health, health policy, and quality experts– state, national, and global

BD

- 18 year old Latina female, born in US. Mother immigrated from Brazil
  - Diagnosed with Rett syndrome as toddler
  - Followed by pediatric PCP and multiple subspecialists over many years
  - Patient referred to me to assess readiness for “transition” to adult care
  - Mother not sure who is in charge of the many aspects of her daughter’s care
    - Medical
    - Behavioral
    - PT/ OT, S/L
    - Family support

- Begin at the Beginning– identify BD’s and her family’s needs

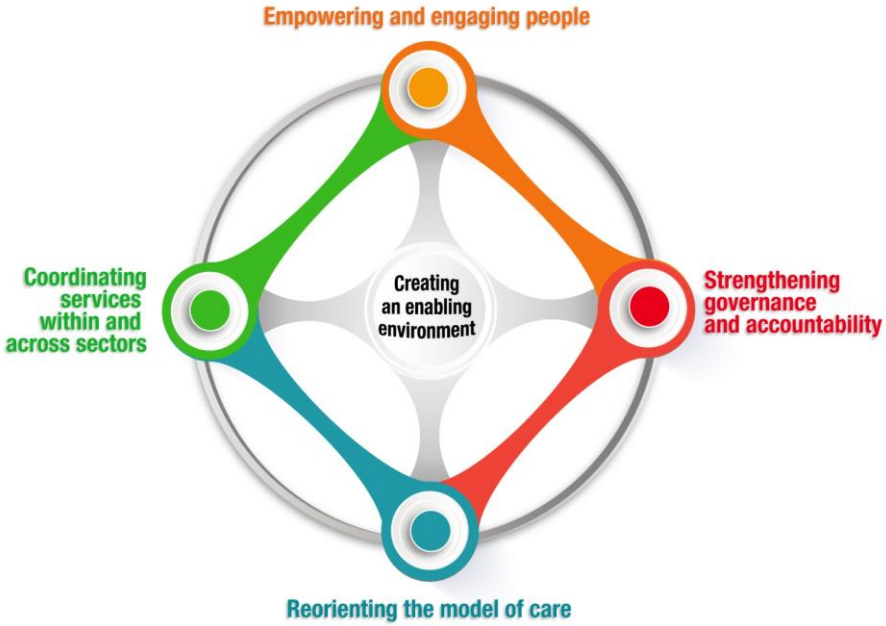
One Family's Care Map



Used with permission from Cristin Lind www.cristinlind.com

www.childrenshospital.org/care-coordination-curriculum/care-mapping

Integrated People-Centered Health Services



All In: Pathway Forward

Strategy 2019-2021

Vision:
Healthy vibrant children and youth.

Mission:
Through purposeful partnerships, we accelerate excellence and innovation in health systems caring for children and youth.

Value Statements:

- **Collaboration:** We work best when we partner with others.
- **Courage:** We demonstrate leadership to make brave decisions.
- **Fresh Thinking:** We seek out novel opportunities to deliver value to members.
- **Inclusiveness:** We embrace the unique and diverse populations our members serve.
- **Focus:** We direct our resources to what matters most to our members.

Strategic Priorities

We will:

Inform the development of innovative and integrated health systems

Share evidence and accelerate implementation of high quality, child, youth and family centred health care wherever it

Unite strategic partners to foster excellence in children's health

a. Develop relationships

Advocate to improve children's health and health systems

a. Broker subject matter expertise to inform

Innovation Requires Leadership

Some of the most fragmented care we have measured occurs for patients with complex needs receiving care in academic medical centers.

Why?

Form follows function

Chart Your Journey

- Articulate Vision
- Leverage Interprofessional Relationships and Existing Resources
- Measurement, Repeat, …..
- Value Optimization

Aligning Mission, Vision, Versatility

Challenges:

Balance competing demands (e.g., do more with fewer resources) and escalation of disruptive innovation– especially in healthcare

“It is not an overstatement to say that versatility is the most important component of leading effectively today”.

The Best Leaders Are Versatile Ones, Robert Kaise, Harvard Business Review, March, 2020

Emphasis for this discussion:

“Leading from the Middle”

Evidence

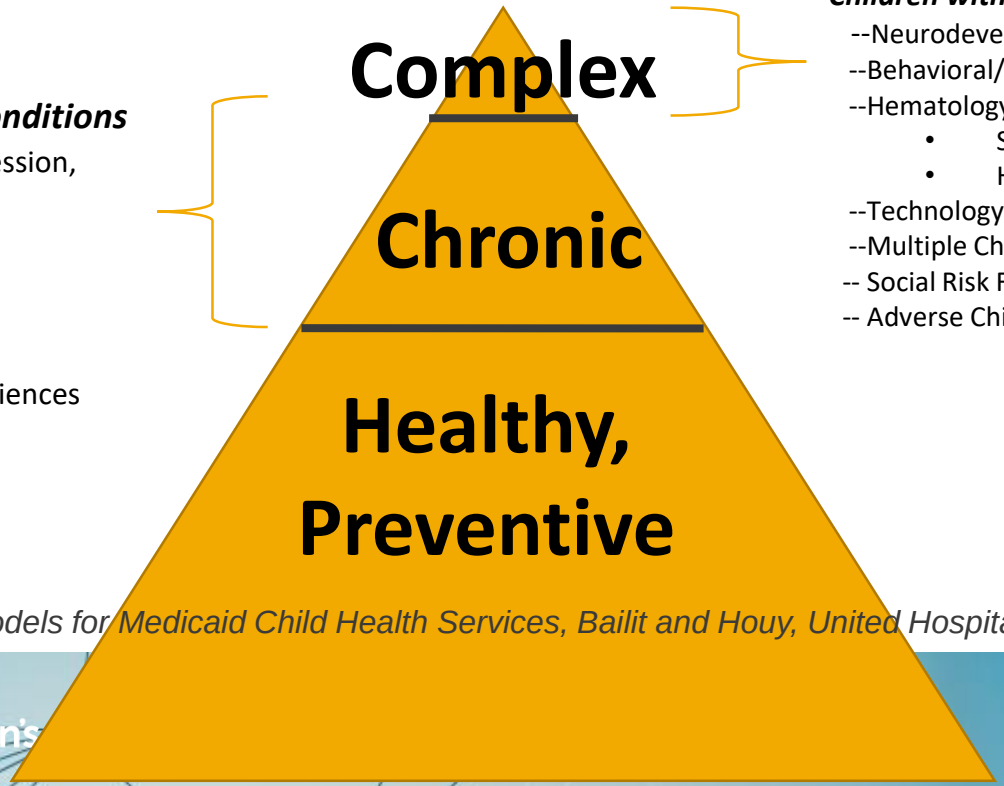
- Integration reduces waste associated with fragmentation in care delivery
- Inter-professional integration essential to reduce disparities due to Health Related Social Needs– housing, food, poverty, violence
- Behavioral Health– **Hint: Commonality between Adult and Child Care!!**
  - Substance Abuse and Dependence
  - Mental Health
  - Developmental Disabilities

Matching Services to Complexity

Including Social, Medical, and Behavioral Needs

Children with chronic conditions

--Behavioral (ADHD, depression, anxiety, PTSD)
--Asthma
--Obesity
--Diabetes
-- Social Risk Factors
-- Adverse Childhood Experiences



Children with complex needs

--Neurodevelopmental (Autism, etc.)
--Behavioral/Psychiatric
--Hematology/ Oncology
- Sickle cell
- Hemophilia

--Technology dependent
--Multiple Chronic Conditions
-- Social Risk Factors
-- Adverse Childhood Experiences

Value–Based Payment Models for Medicaid Child Health Services, Bailit and Houy, United Hospital Fund – July, 2016

Activities in Integrated Care

Care Integration Collaborations

- Neurology/Epilepsy (CP, Ketogenic Diet, Rett)
- Urology (Spina Bifida, Bladder Exstrophy)
- Medicine - GI/Nutrition (Aerodigestive, IBD, HPN, Enteral Tube, GNP)
- Adolescent Medicine – Hybrid Transition Model
- NICU GraDS Program
- Genetics
- Complex Care Service
- Community-Based Integrated Model for Weight Management– funded by New Balance Foundation

Primary Care Relationships

- Local and Regional Affiliations

External Relationships

- National Care Coordination Academy (HRSA funded)
- National Center Care Coordination Technical Assistance (HRSA funded)
    - CHOP, Cincinnati Children's, Nationwide, Orlando, Children's of Orange County, many others
- Global Partnerships
    - Australia, Chile, Canada, Germany, France
- International Rett Syndrome Foundation
- Visiting International Fellow in Integrated Care

Integrated Care Management Model; Boston Children's Hospital

Four interdependent activities to improve care integration

Registry Create registry to support tracking of key care components for a defined complex patient population	***Care Planning*** Improve care planning activities and expectations across the care team; Include PCP (BCH and external) as appropriate
Care Integration Education Provide inter-professional education on care integration and care coordination	***Population Health Management*** Align care management across multi-disciplinary roles (social work, nursing, and admin staff) and measure the value of roles across the GNP team.

Courtesy Casey Fee, SM, Michele Sasso, MBA, Christine Geer, MPH

Naming the Problem

Integrated Care

seamless provision of health care services, from the perspective of the patient and family, across entire care continuum. It results from coordinating the efforts of all providers, irrespective of institutional, departmental, or community-based organizational boundaries.

Care Coordination

activities in “the space between”- Visits, Providers, Hospital Stays that co-create (with patient and family) and implement a plan of care

2014 AAP Policy Statement: Patient-and Family-Centered Care Coordination: A Framework for Integrating Care for Children and Youth Across Multiple Systems

Boston Children's Hospital

Measure What Matters

Domains of Integrated Care

Care Coordination

- Care Coordination Measurement Tool (CCMT)
- High Quality Handoffs: Clinician Reason for BCH Visit and Action Grid
- Inter-professional Education: Care Coordination Curriculum and Integrated Care Bootcamp

Person, Patient, Family, Caregiver Experience

- Pediatric Integrated Care Survey (PICS)

Provider Experience

- PCP Experience of Care Integration Survey

Utilization and Financial Outcomes

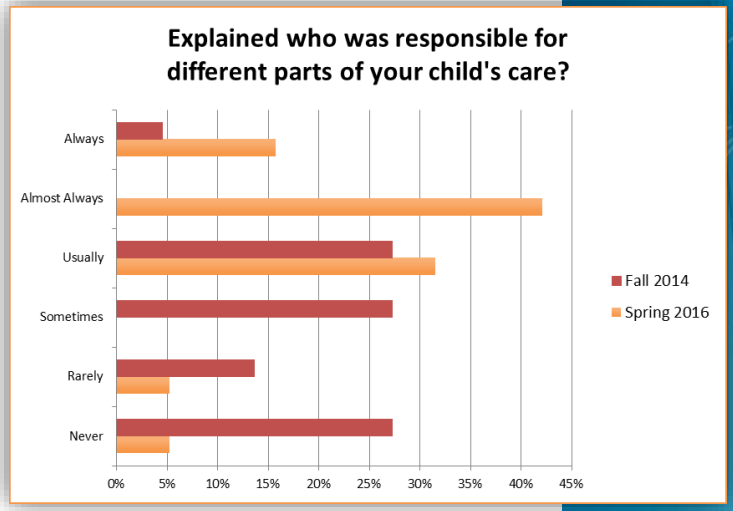
- Total Medical Expense (as relevant and available)
- Admissions, Readmissions, Emergency Department Utilization

Pediatric Integrated Care Survey

PICS

Five Core Domains

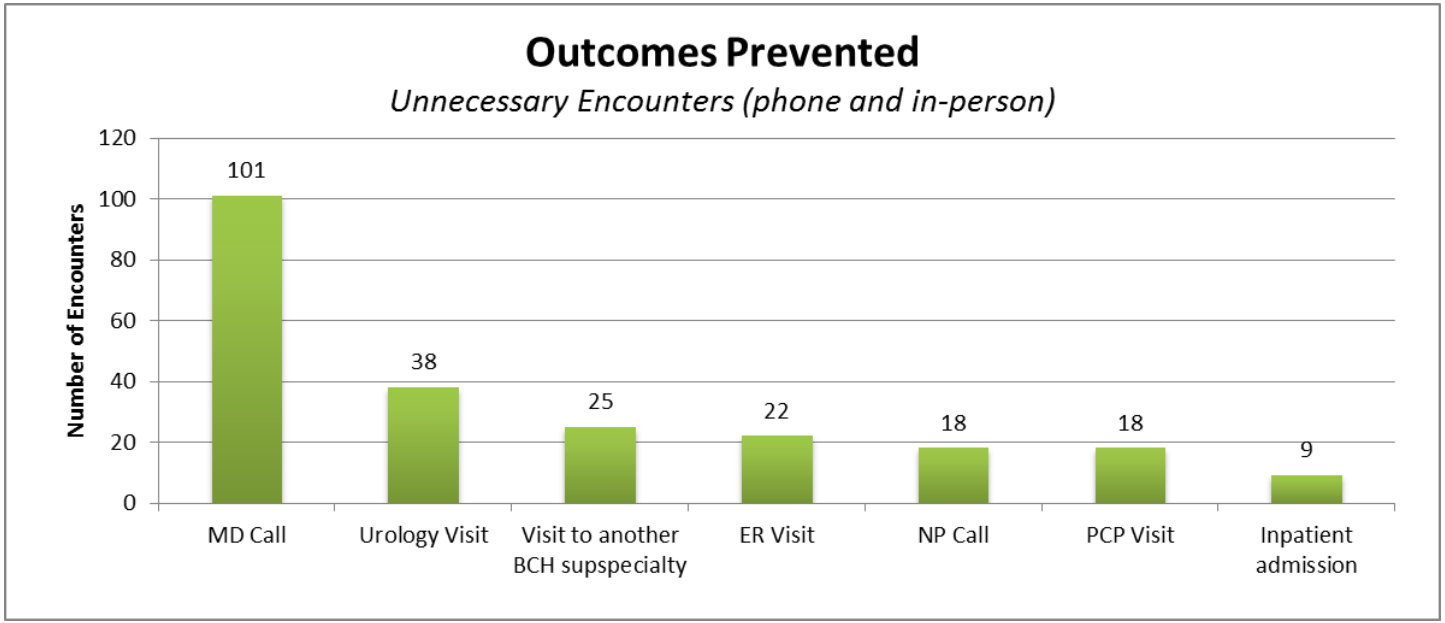
- Access to Care
- Communication with Care Team
- Family Impact
- Care Goal Creation/ Planning
- Team Functioning/Quality



Validated assessment of the family's experience of integration across the care team: medical, behavioral, social, educational, and family support

Quantifying the Value of Care Coordination

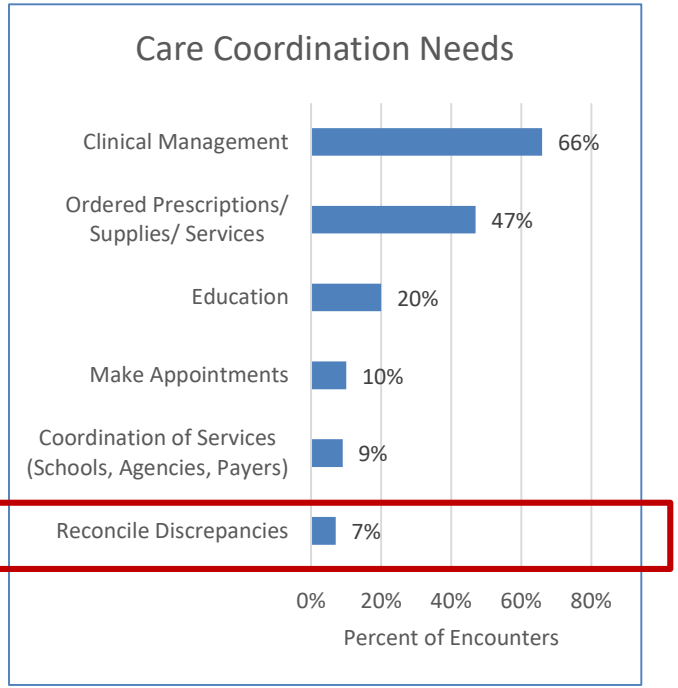
Use of the CCMT Instrument BCH Dept. of Urology

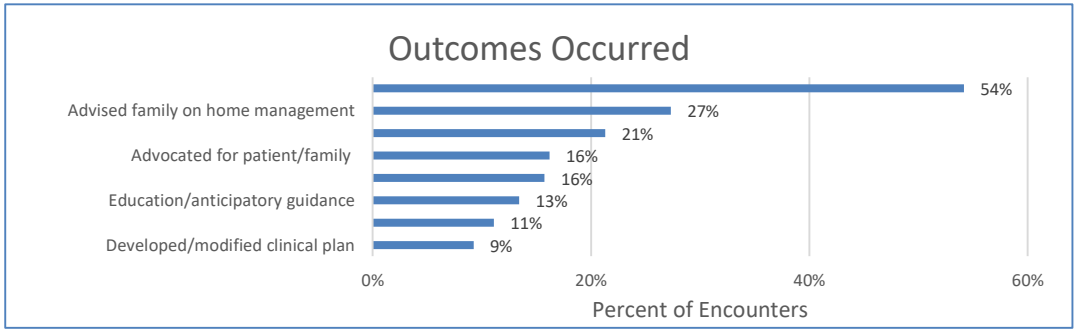


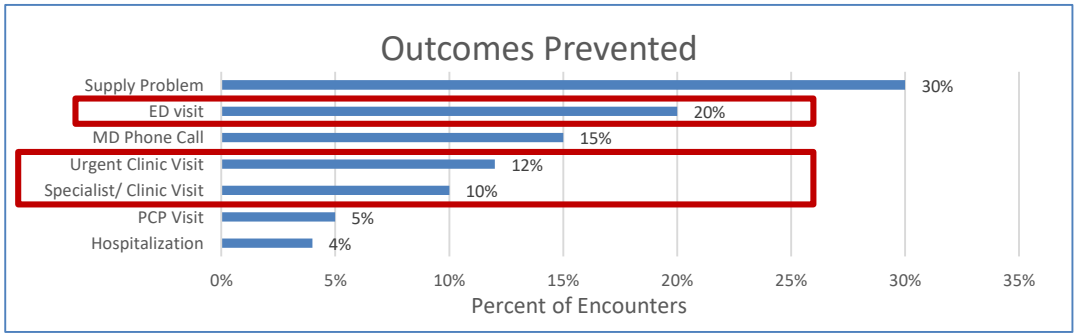
Based on documentation of 577 encounters by Urology staff across the Spina Bifida, Stone, and Bladder Exstrophy Clinics conducted from August 2018 through April 2019 as part of the DSRIP project work. Courtesy Rebecca Sherlock, NP, Rosemary Grant, RN

Value Capture – Specialty Setting

Division of BCH Gastroenterology CCMT



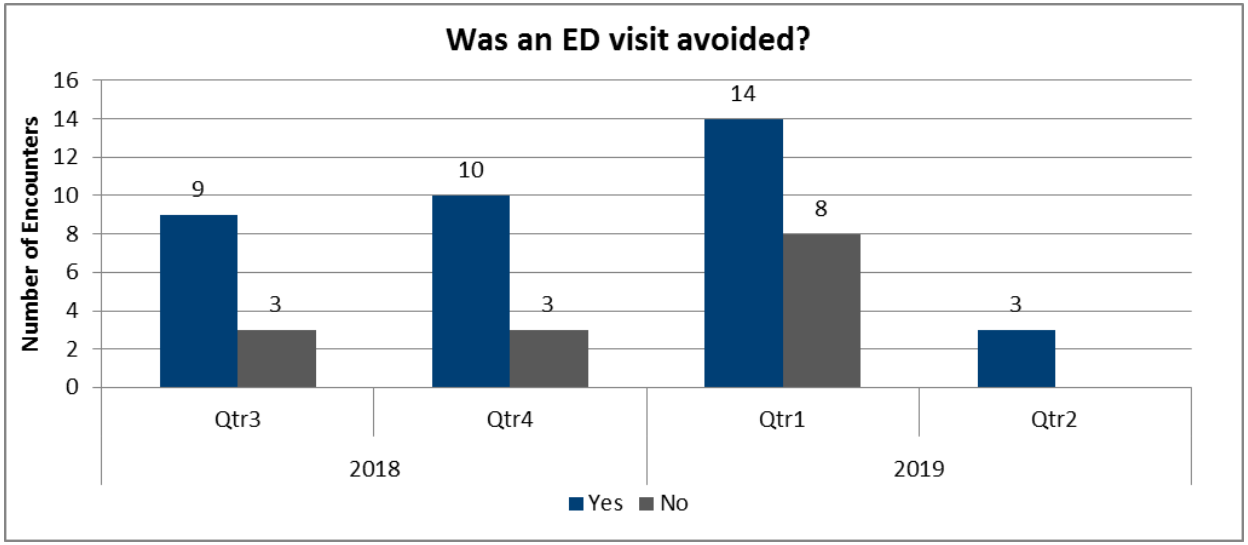




Represents 216 CC encounters for patients with enteral tubes recorded by RNs over four separate weeks occurring between Oct 2015 & Jan 2016. Courtesy Lori Hartigan, RN, NP

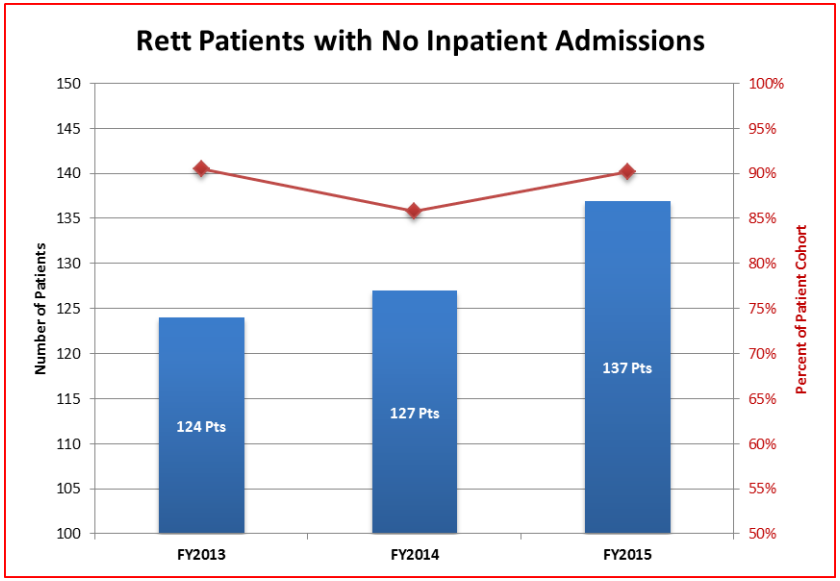
Improving Care and Decreasing Cost

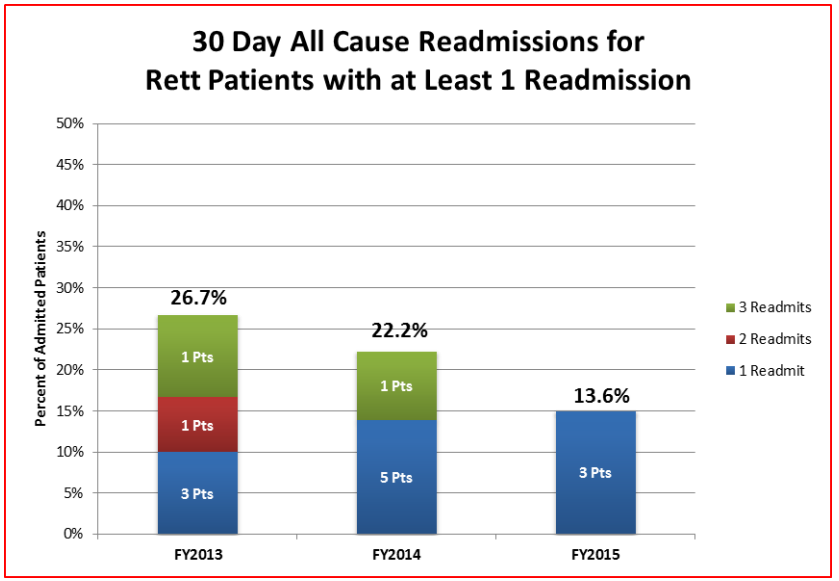
Measuring outcomes of the BCH Urgent Epilepsy Clinic with the CCMT



Based on documentation of 50 encounters by Neurology staff conducted from July 2018 through April 2019 as part of the DSRIP project work. ED visit was avoided 72% of the time. Courtesy of Phillip Pearl, MD

BCH Rett Syndrome Clinic

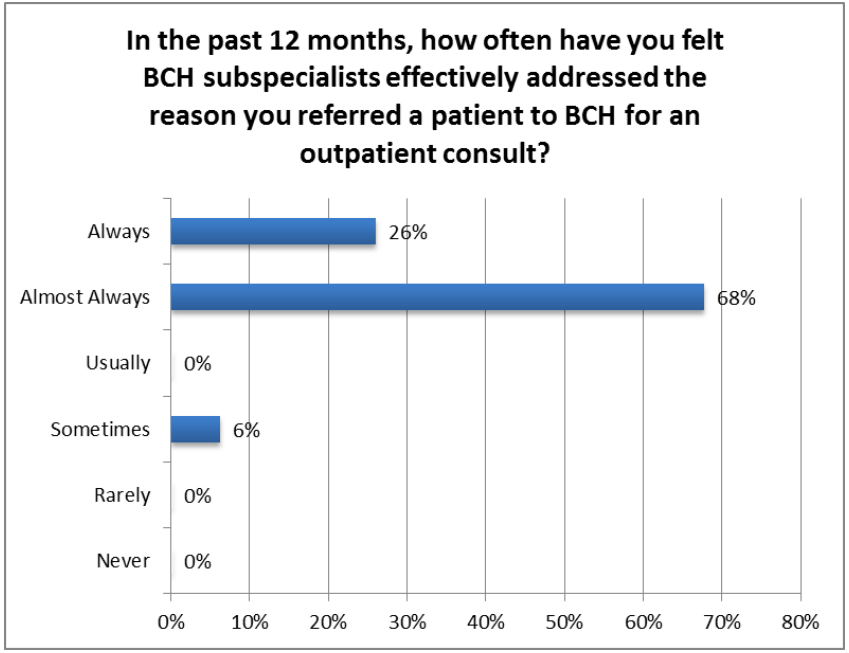


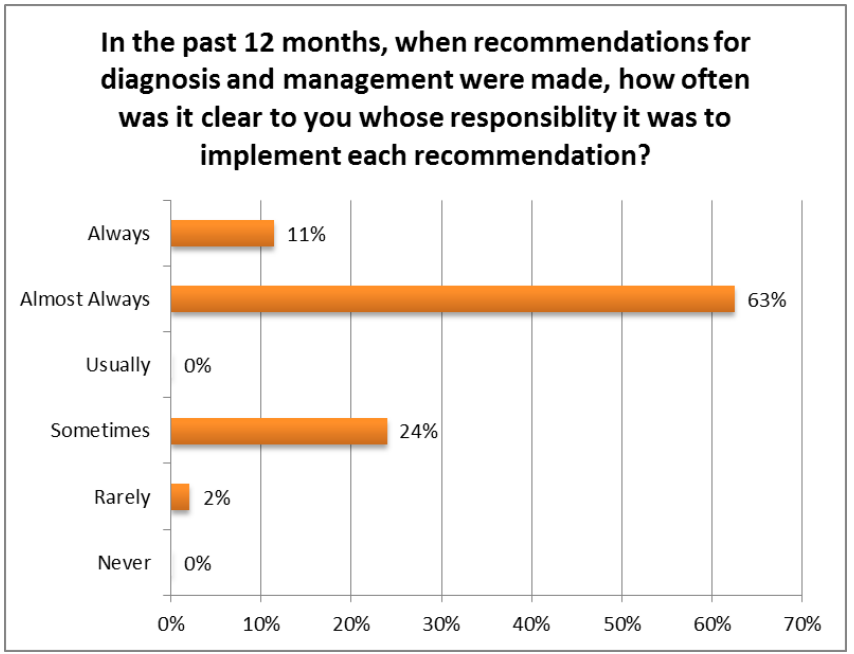


Courtesy of David Lieberman, MD, PhD

PCP Experience of Care Integration

Connection with BCH Subspecialist





Data represents 96 responses collected between 12/5/2017 and 2/22/2018 from referring providers associated with BCH's key integration partners.

Results – Primary Care Perspective

Atrius Health– Community-based provider organization

- Reductions in ED utilization, hospital admissions, and overall total medical expense
  - Sustained beyond 3 years

- Aim to keep care in highest value setting
  - Primary Care

Achieving High Value Outcomes: Care Integration at Atrius Health Pediatrics, Slater, D, Dvorkis, Y, Antonelli, R, Pediatric Academic Societies meeting, 2019.

High Quality Handoffs to Subspecialty Care

I am referring Patient Baby Girl to Gastroenterology at BOSTON CHILDREN'S HOSPITAL for further evaluation.

Reason for referral: Failure to thrive.

Relevant clinical and/or psychosocial information: This is a 4 month old female who has fallen from 20%ile to below 2nd%ile on her weight curve. Length and HC are maintained. She has had intermittent diarrhea without blood or mucus. No fevers. Chemistry and metabolic panels are normal. She was born at 40 weeks gestation, uncomplicated pregnancy and delivery. She is breastfed. Family is appropriately concerned. I have attached the growth curve, and labs, and the relevant notes from my office.

Expectations for ongoing care: Consult and Co-Manage

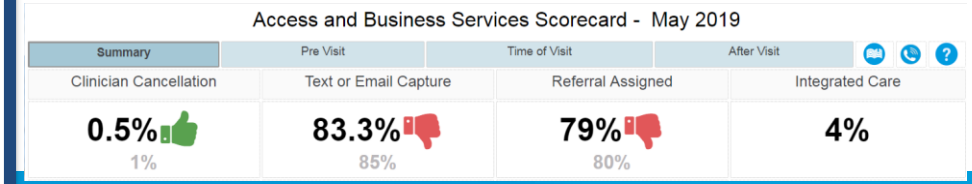
I appreciate your assistance in her care and look forward to your findings and recommendations.

Sincerely,

Best Primary Care Pediatrics

Making Handoffs Standard Work

- Embedded the BCH tool with local referring providers (including tool integration into EHRs where available)
  - PPOC, Atrius Health, LCPN (BILPN), MACIPA, SSMC
- Created the "Clinician Reason for BCH Visit" note type
- Launched handoff measure



Tool to Integrate Care: Action Grid

Goal What is action contributing to?	Action What needs to be completed?	Who Who is responsible for completing action?	When What is the timeline that the action needs to be completed?	Contingency If there is an issue or barrier, what are next steps?
Complete necessary genetic testing	Lab orders will be placed for ### Test	Genetics - Dr. Bodamer	One month	Parents should contact Dr. Bodamer's office (123-456-7890) if unable to complete testing within one-month's time
Maintain stable blood sugar	Test blood sugar 3 times per day and control with small, frequent meals	Parents, with guidance from Endocrinology and Nutritionist	Daily, beginning immediately and to continue until reassessed at next Endocrinology appointment	Blood sugars between XXX and XXX should be reported to Dr. Example's office (123-456-7890). If a sugar is over XXX, parents will bring patient to the nearest Emergency Department
Take medication for epilepsy as prescribed	Order for medication will be sent to Longwood Galleria	Neurology, with follow up phone call by Nurse Jane Doe	RX to be started no later than 3/7/2020 and should continue until next appointment unless otherwise noted	Please call Nurse Jane Doe if any problems arise with the prescription at 123-456-7890
IEP documentation request will be updated with school system	Required school documentation and phone call to Teacher Smith	Neuropsychology and Teacher	Two weeks from most recent visit: XX/XX/XXXX	Teacher Smith should contact patient's parents with any noticeable adverse changes in behavior or understanding

Courtesy of Olaf Bodamer, MD, PhD

Spreading Care Integration Improvements

Alberta Children's Hospital: Children with Autism

- Families reported improved communication across care team, including school
- Decreased ED and in-patient care
- Fewer behavioral issues for children
- Improved child function at home and school

Courtesy V. Nadine Gall, MSc., Manager, NeuroDevelopmental Disorders Integrated Brain Health Initiative, Child Development Services

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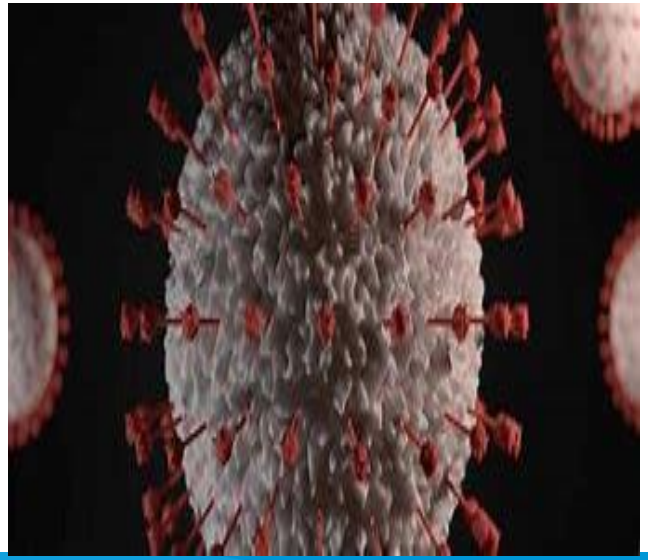
Don’t Let a Crisis Go to Waste



Our goal - Prove that virtual care is ***added value*** for:

- Patients/ families
- Clinicians
- Payers/ Policy makers
- Advocates

Characteristics of patients who benefit the most from virtual care

- Access issues (e.g., transportation)
- Behavioral health needs
- Care management for patients with complex needs whose services are coordinated within a Care Plan/ Action Grid

CMMT: key outcomes of virtual care

14. As a result of this encounter, the following *occurred* (choose ALL that apply)

- ❑ Affirmed existing plan of care (no changes made)
- ❑ Progressed to the next step in the existing plan of care (i.e. due to a change in clinical status or lab results, etc.)
- ❑ Developed a new plan of care
- ❑ Conducted health literacy education
- ❑ Provided guidance or family support for behavioral or psychosocial needs
- ❑ Reconciled medication discrepancies
- ❑ Reconciled or addressed other discrepancies (e.g. miscommunications, adherence to plan of care, missing data)
- ❑ Referred back to PCP for ongoing management of care
- ❑ Assessed for adequacy of supplies
- ❑ Ordered medical supplies
- ❑ Provided/refilled prescriptions
- ❑ Assessed the home environment
- ❑ Assessed for the appropriate use of durable medical equipment
- ❑ Counseled on COVID-19 risk reduction strategies or advice given the patient's presenting condition
- ❑ Managed care due to a disruption in receiving care services due to the COVID-19 pandemic
- ❑ Managed care for a patient with suspected or confirmed COVID-19 infection
- ❑ Some needs could not be addressed
- ❑ Other_____

Current Efforts

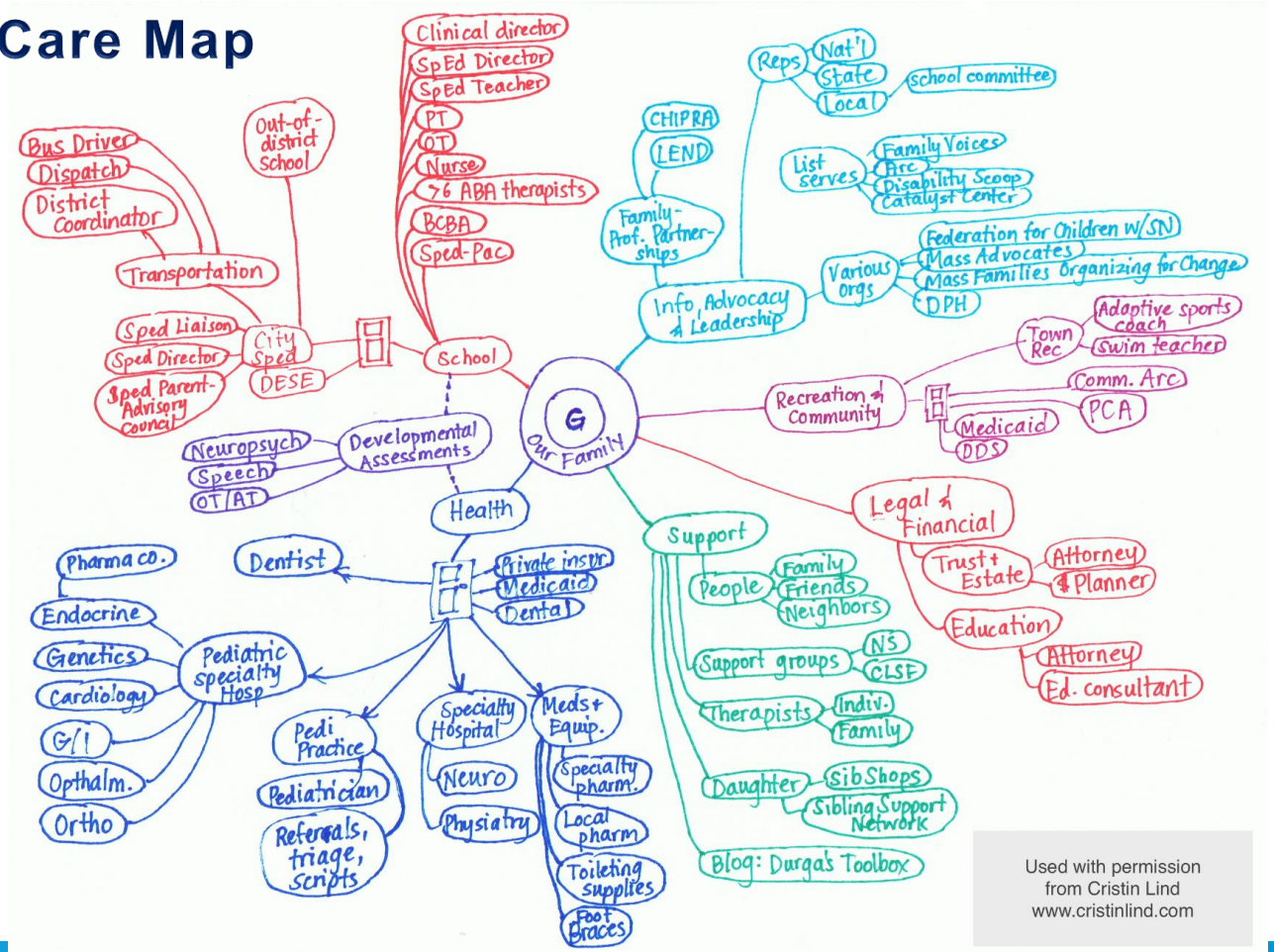
Leveraging Electronic Health Record (EHR) Sourced Measures to Improve Care Communication and Coordination

American Academy of Pediatrics

Supporting Providers and Families to Access Telehealth and Distant Care Services for Pediatric Care

- focus on children with complex needs, including NDD, IDD, social risk factors

Care Map



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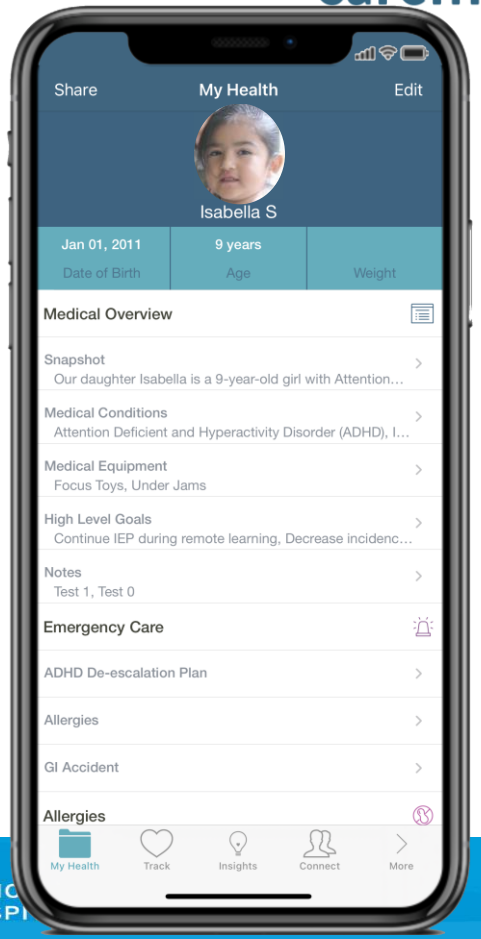
caremap



IT Solution that Puts Families at Center of Care Team– Enhancing Integration and Coordination

US Maternal and Child Health Bureau Grand Challenge for CYSHCN

Care Coordination for CSHCN

Caremap is a tool to coordinate care

A personal health record – by families, for families

Organized longitudinal care plan accessible to patients/families anywhere, anytime
- Medical overview
- Care goals
- Emergency care
- Allergies
- Conditions
- Medications
- Recent admissions and procedures

Patient/family-level personalization
- Flag items to review with the care team
- Record additional details (new OTC medication)
  - Record notes for self or for care team

Leverage technology
- Connect to EHR using open standards (FHIR)

Boston Children's Hospital | FAMILY VOICES | DukeHealth

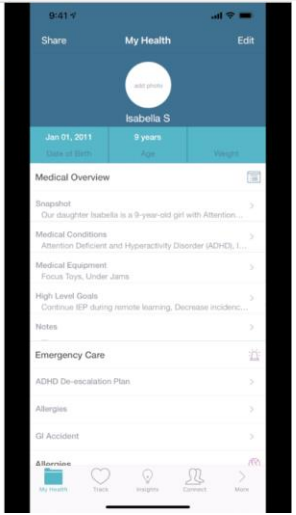
Caremap connects the care team

Active communication across the ecosystem of care

Care insights shared with providers
- Real-time access facilitates timely communication with care team
- Facilitates clinical decision-making

Control rests at user level
- Insights shared with multiple providers facilitates cross-sector care integration

Boston Children's Hospital | FAMILY VOICES | DukeHealth



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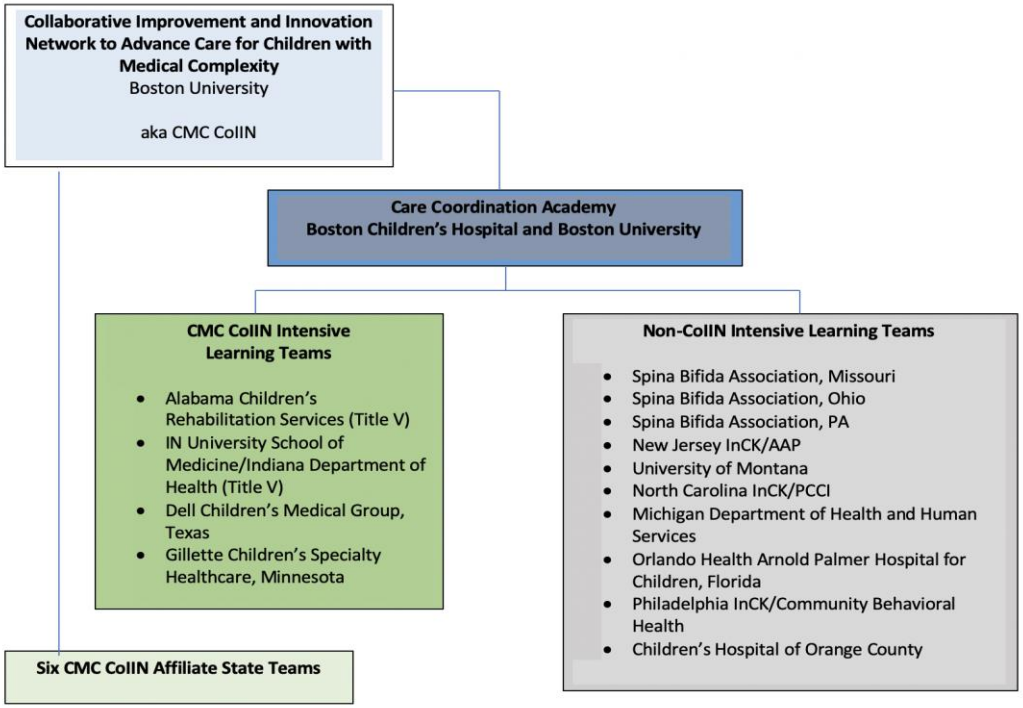
US National Care Coordination
Academy, funded by US Health Resources and Services Administration



THE GREAT DIVIDE

Educational inequality likely to widen this fall as white students return to school and students of color learn from home

The Boston Globe

September 20, 2020

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Strategies to Achieve Health Equity

AJPH PERSPECTIVES

No Equity, No Triple Aim: Strategic Proposals to Advance Health Equity in a Volatile Policy Environment

Health professionals, including social workers, community health workers, public health workers, and licensed

Geoffrey W. Wilkinson, MSW, Alan Sager, PhD, Sara Selig, MD, MPH, Richard Antonelli, MD, Samantha Morton, JD, Gail Hirsch, MEd, Celeste Reid Lee, MEd, Abigail Ortiz, MSW, MPH, Durrell Fox, CHW, Monica Valdes Lupi, JD, MPH, Cecilia Acuff, MSW, and Madeline Wachman, MSW, MPH

Children With Special Needs: Social Determinants of Health and Care Coordination

Clinical Pediatrics
1–8

DOI: 10.1177/0009922820941206
journals.sagepub.com/home/cpj
SAGE

Aaron Pankewicz, DO, MPH[1], Renee K. Davis, MD, MPH[2], John Kim, MPH, CPH[2], Richard Antonelli, MD, MS[3,4], Hannah Rosenberg, MSc[3,4], Zekarias Berhane, PhD[2], and Renee M. Turchi, MD, MPH, FAAP[2,5]

Abstract

Care coordination (CC) facilitates access to resources/services for children/youth with special health care needs (CYSHCN). We conducted a cross-sectional analysis of the 2009-2010 National Survey of CSHCN to examine socioeconomic factors related to report of receiving adequate CC services for CYSHCN. Descriptive statistics were used to describe sociodemographic characteristics of respondents and examine socioeconomic factors. Receiving adequate CC varied by socioeconomic variables including income (100% to 199% federal poverty line [FPL]; aOR [adjusted odds ratio] = 0.848; 95% CI [confidence interval] = 0.722-0.997; $P < .05$), insurance (uninsured; aOR = 0.446; 95% CI = 0.326-0.609; $P < .0001$), and marital status (never married; aOR = 0.79; 95% CI = 0.64-0.97; $P < .05$). More families reporting adequate CC had private insurance, non-Hispanic white ethnicity, income >400% federal poverty level, and 2-parent households. Findings suggest unmet needs in terms of adequate access or knowledge leading to insufficient provision of CC for families with the greatest needs. Further analysis identifying specific deficits and implementing strategies to address these disparities is warranted.

Viewpoint | COVID-19: Beyond Tomorrow

ONLINE FIRST FREE

May 4, 2020

Choices for the "New Normal"

Donald M. Berwick, MD, MPP[1]

» Author Affiliations | Article Information

JAMA. Published online May 4, 2020. doi:10.1001/jama.2020.6949

Editorial Comment | Interviews | Multimedia

The severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) has only 15 genes, compared with 30 000 in the human genome. But it is a stern teacher, indeed. Answers to the questions it has raised may reshape both health care and society as a whole.

No one can say with certainty what the consequences of this pandemic will be in 6 months, let alone 6 years or 60. Some "new normal" may emerge, in which novel systems and assumptions will replace many others long taken for granted. But at this early stage, it is more honest to frame the new, post–COVID-19 normal not as predictions, but as a series of choices. Specifically, the pandemic nominates at least 6 properties of care for durable change: tempo, standards, working conditions, proximity, preparedness, and equity.

Integrated Care at Boston Children's Hospital

Integrated Care is Important to Everyone!

Family/ Patient Perspective
A national sample of parents whose children have special health care needs reported that 37% of the time, their child's care team members rarely or never explained who was responsible for different elements of their child's care[1]. Families expect this to be 100%.

Referring Provider Perspective
More effective care could be offered in the primary care setting if consulting subspecialists would give clear and actionable information that addressed their concerns.

Subspecialist Perspective
Knowing why the primary care provider refers the patient to the subspecialty setting would allow them to know what has been done to date, and what is expected from them.

Today's care teams are challenged to coordinate activities and recommendations across settings. Often , families must take the lead on these responsibilities. Along with adding substantial strain to families, these challenges often result in uncoordinated and inefficient care. Integrated care is the seamless provision of health services, from the perspective of the patient and family, across the entire care continuum and is essential to achieving the best health outcomes for every patient. Care coordination is the set of activities and functions that is necessary to create and implement a multidisciplinary plan of care in partnership with the patient and family[2].

The Integrated Care Program at Boston Children's Hospital creates and validates processes, tools, and measures

https://www.openpediatrics.org/course/pediatric-care-coordination-curriculum

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CE

Accreditation | Course Information | Learning Objectives | Contributors | Disclosures

What do you receive with an accredited certificate?

Official Accreditation
Courses are approved through Boston Children's Hospital by Joint Accreditation™

Relevant Content
Each course has been reviewed and has up-to-date content in many areas of expertise

Certificate
Upon completion of the course, you will receive a certificate

Transcripts

Cost:	An accredited certificate for $25 Non-accredited certificate for $0
Audience:	Physician, Nurse, Social Worker
Topic:	Care Coordination, Patient/Family Centered Care
Credits:	CME, CEU, MOC, ACE CE

CURRICULUM OUTLINE

- **Module 1-Core Curriculum**
  - Lesson 1: Core Curriculum Introduction
  - Lesson 2: Key Components of Care Coordination
  - Lesson 3: Tools and Processes that Support Care Coordination
  - Lesson 4: Application of Tools and Processes - Case Example
  - Attestation

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So…What can we do now?

- Persist with Compelling, Civil, Global Advocacy
  - Bring Data!
- Build Capacity of Families and Work Force
  - Inter-professional education
- Implement Measures of Integration, CC, and Value
  - Assess equity by stratification while specific measures being developed
- Form alliances across disciplines, sectors
- Leverage Adult Priorities for Maternal and Child Health
  - Integrated Behavioral Health
  - SDoH
  - Social Justice
  - Equity

Children and Families FIRST!!!

Select References

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