



## Care Integration for Children with Medical Complexity

**Michael J. Bresnan**  
**Child Neurology Course**  
**Boston Children's Hospital**

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# Disclosure

I have no conflicts to disclose.



## Learning Objectives

Understand how to implement a framework of care integration

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

Gain confidence in advancing implementation of care integration with measurable high value outcomes, especially for vulnerable populations





## 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



# 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 Aaff, MSW, and Madeline Wachman, MSW, MPH*



## Miguel

- 4 year old Hispanic boy; he and mother immigrated from Guatemala
  - Diagnosed-- asthma by PCP at 9 months
  - Referred for “poor attention”
  - ED visit 3 times in prior year for asthma
  - No assessment/ intervention for attention
- All care quality measures were met
  - Referrals made
  - Care Coordination measures require completing a loop



## Innovation Begins by Identifying an Opportunity

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

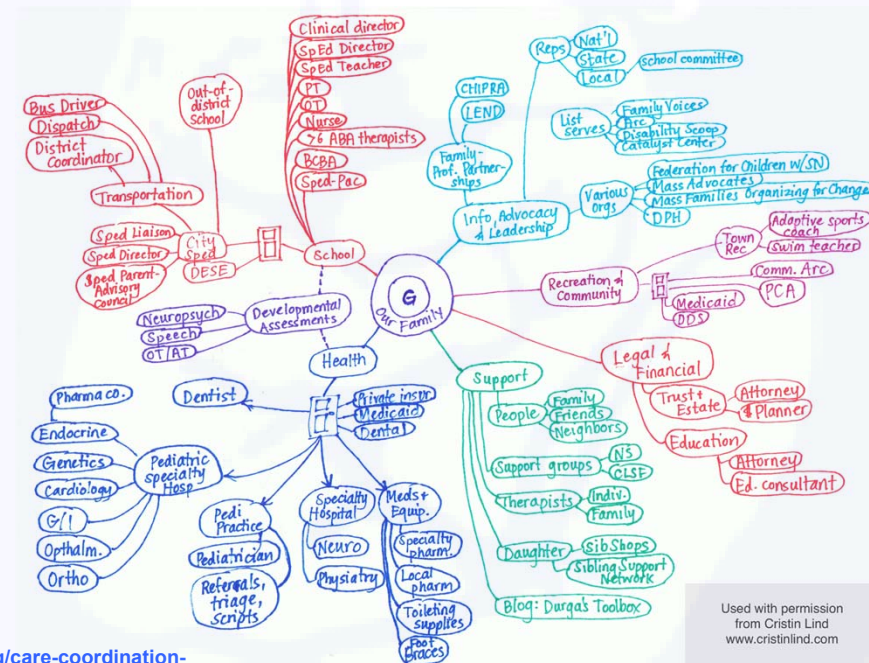
### Playbook

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





# One Family's Care Map



[www.childrenshospital.org/care-coordination-curriculum/care-mapping](http://www.childrenshospital.org/care-coordination-curriculum/care-mapping)

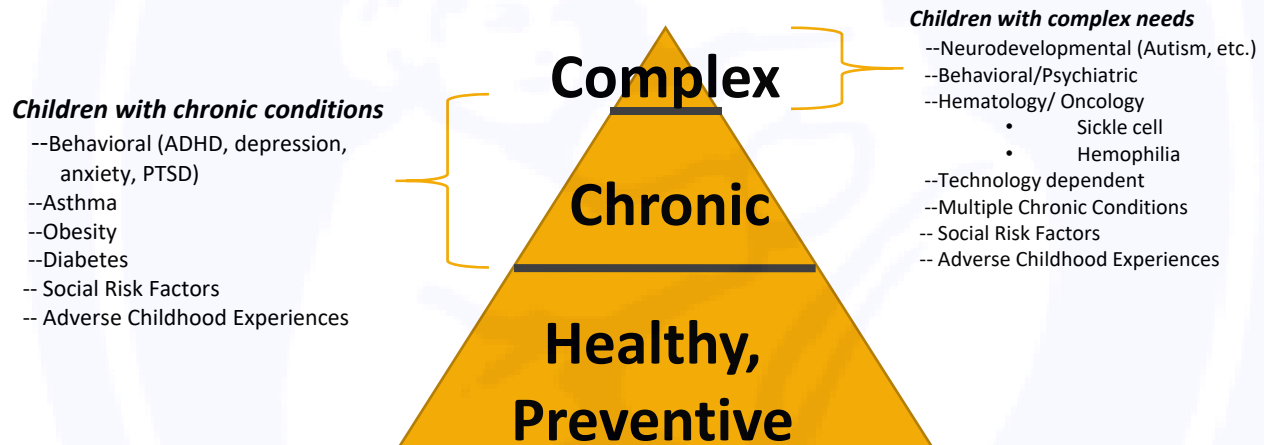


# Mind the gap



# Matching Services to Complexity

## Including Social, Medical, and Behavioral



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



## Current Activities

Care Integration Collaborations	Primary Care Relationships
<ul style="list-style-type: none"> <li>• Neurology/Epilepsy (CP, Ketogenic Diet, Rett)</li> <li>• Urology (Spina Bifida, Bladder Exstrophy)</li> <li>• Medicine - GI/Nutrition (Aerodigestive, IBD, HPN, Enteral Tube, GNP)</li> <li>• Adolescent Medicine – Hybrid Transition Model</li> <li>• NICU GraDS Program</li> <li>• Genetics</li> <li>• Complex Care Service</li> <li>• Community-Based Integrated Model for Weight Management– funded by New Balance Foundation</li> </ul>	<ul style="list-style-type: none"> <li>• Local and Regional Affiliations</li> </ul>
	External Relationships
	<ul style="list-style-type: none"> <li>• National Care Coordination Academy (HRSA funded)</li> <li>• National Center Care Coordination Technical Assistance (HRSA funded)               <ul style="list-style-type: none"> <li>• CHOP, Cincinnati Children's, Nationwide, many others</li> </ul> </li> <li>• Global Partnerships               <ul style="list-style-type: none"> <li>• Australia, Chile, Canada, Germany, France</li> </ul> </li> <li>• Visiting International Fellow in Integrated Care</li> </ul>





## 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

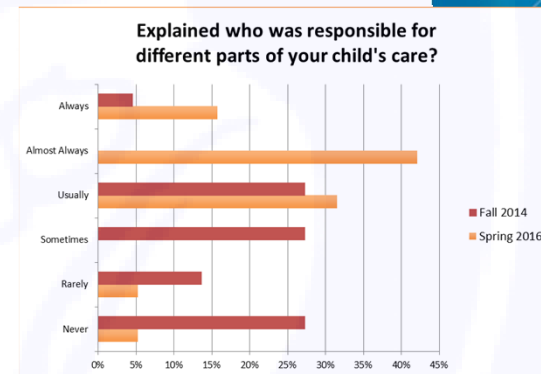
Communication with Care Team

Family Impact

Care Goal Creation/ Planning

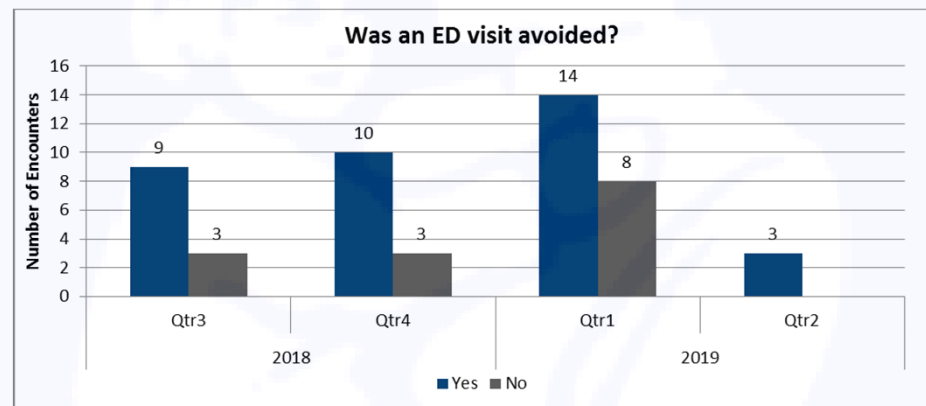
Team Functioning/Quality

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



# Improving Care and Decreasing Cost

## Measuring outcomes of the BCH Urgent Epilepsy Clinic with the CCMT

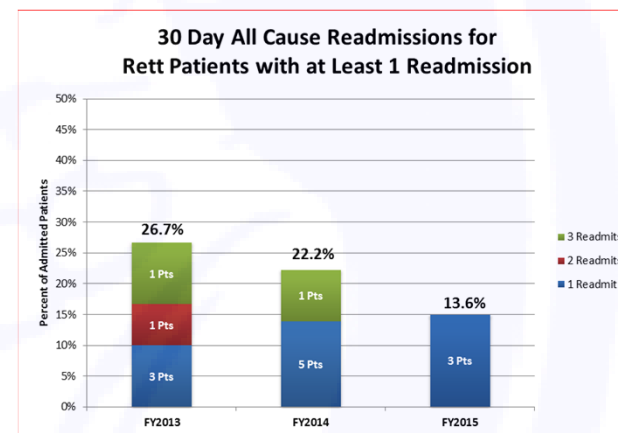
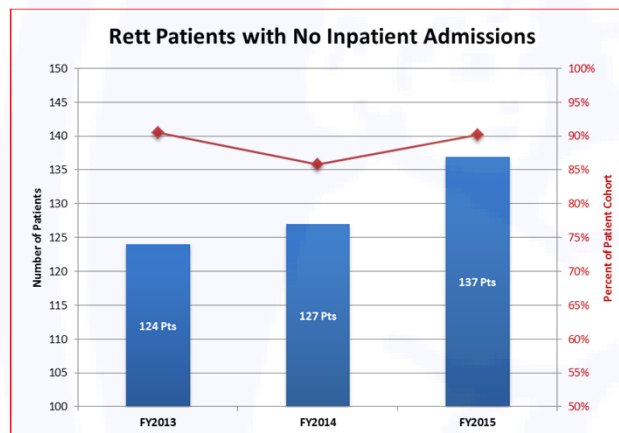


Based on documentation of 50 encounters by Neurology staff conducted from July 2018 through April 2019 as part of the DSRIP project work. ED visit was avoided 72% of the time. Courtesy of Phillip Pearl, MD

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## BCH Rett Syndrome Clinic



Courtesy of David Lieberman, MD, PhD

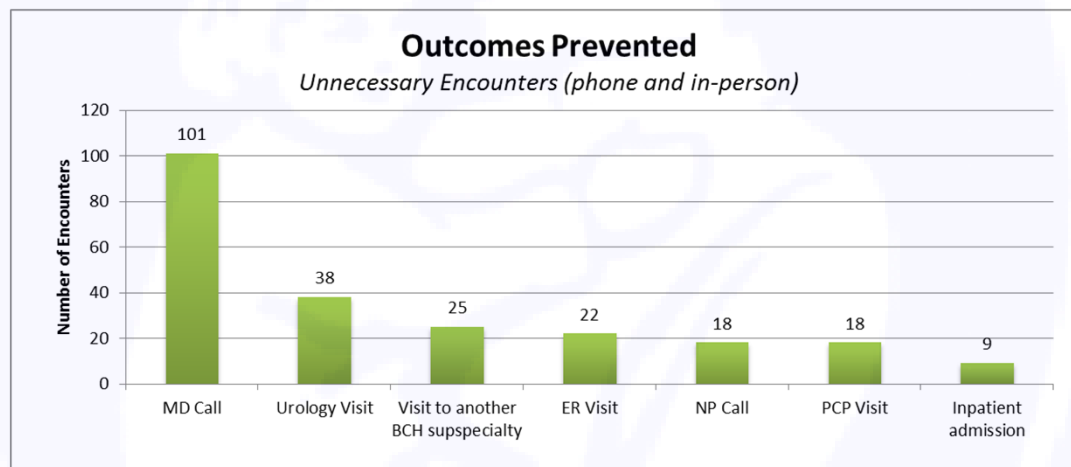
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# Quantifying the Value of Care Coordination

## 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



## Results – Primary Care Perspective

### Atrius Health– Community-based provider organization

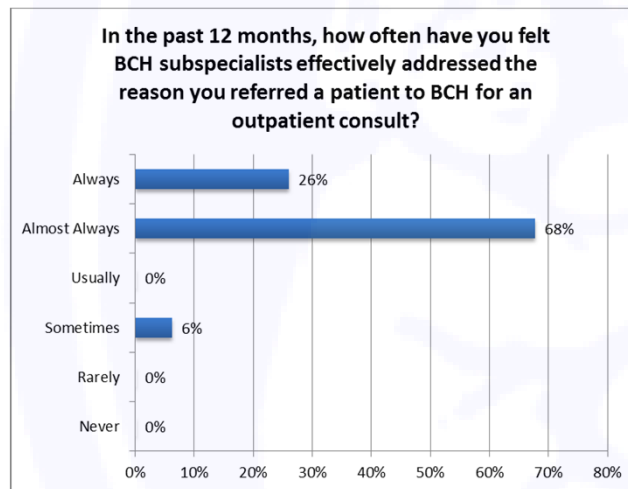
- Reductions in ED utilization, hospital admissions, and overall total medical expense
  - Sustained beyond 3 years
- Aim to keep care in highest value setting
  - Primary Care

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



# 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.

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## 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



## 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



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# Value Capture Measurement Tools

## Goals and Differences

Care  
Coordination  
Measurement Tool  
(CCMT)

- Captures activities during the “space” between encounters to coordinate care
- Implemented across BCH clinics (14 implementations and counting...)
- Quantifies value of care coordination activities (generally non-billable)
- REDCap link to survey in PowerChart
- Highly adaptable to clinic needs

Care  
Management  
Measurement Tool  
(CMMT)

- Captures activities and processes of the clinic encounter
- New survey instrument adapted from the CCMT
- Quantifies value of care management (i.e. telemedicine, phone, etc)
- REDCap link to survey in PowerChart
- Adaptable, with a standard template

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## 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 \_\_\_\_\_



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## CMMT: COVID-19 related questions....

**10. Would this encounter have typically occurred as an in person encounter prior to COVID-19 social distancing restrictions?**

- ☐ Yes
- ☐ No

**15. Compared to an in-person encounter, please rate your opinion on the level of difficulty or ease with which you provided care management services to the patient and/or family?**

- ☐ 1 – Significantly more difficult
- ☐ 2 – More difficult
- ☐ 3 – The same
- ☐ 4 – Easier
- ☐ 5 – Significantly easier

**16. Please describe what made the visit easier or more difficult? (optional)**

[Free Text]



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## Spreading Care Integration: US

### 1) BCH Child Neurology Training Program

Curriculum Development in collaboration with Dr. Bernson-Leung  
Care Integration and Interprofessional Education

### 2) Health Resources and Services Administration (HRSA)/ Maternal and Child Health Bureau funded National Care Coordination Academy

3) HRSA funded Award to develop policy recommendations for use of virtual care to improve outcomes for children, youth, young adults with complex needs, especially NDD/ autism



## Spreading Care Integration: Global

### Calgary: 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 Alberta  
Children's Hospital



## Validation of a Spanish version of a Parent-Reported Experience Measure of Integrated Care

**Collaborators:** Juan Carlos Flores<sup>1</sup>, Sonja Zinief<sup>2</sup>, Richard Antonelli<sup>3</sup>, Maria A. Paul<sup>1</sup>, Marta Smith<sup>4</sup>, Fernando Gonzalez<sup>5</sup>


Division of Pediatrics, Pontificia Universidad Católica de Chile; 2. University of Colorado Denver - Anschutz Medical Campus, United States; 3. Integrated Care, Harvard Medical School, Boston, MA; Faculty of Medicine, Universidad del Desarrollo, Santiago, Chile; 5. Hospital Exequiel Gonzalez Cortes, Santiago, Chile

- General: Validation of a Spanish version of the Parent-Reported Experience Measure of Integrated Care (PICS).
- Specific:
  - Psychometrically validate the Spanish version of the PICS, in a sample of Chilean parents of children and youth with special health care needs (CYSHCN).
  - Describe measures of care integration among 3 different programs taking care of CYSHCN, in different settings of the healthcare system in Chile: public and private.
  - Identify factors associated with care integration among a sample of families of CYSHCN and varying degrees of healthcare utilization.



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The screenshot displays the Boston Children's Hospital website. At the top, the hospital's logo is on the left, and navigation links for "Pay Your Bill", "MyChildren's Patient Portal", "International Visitors", "Ways to Help", "Careers", and "Donate" are on the right. A dark blue navigation bar contains links for "For Patients", "For Health Care Professionals", "Programs & Services", "Conditions & Treatments", "Research", "Innovation", and a search icon. The main content area features a sidebar with a list of topics: "Integrated Care Program", "Care Mapping", "Care Coordination Curriculum", "Care Coordination Measurement", "Patient & Family Experience Outcome", "High Quality Handoffs", "Multidisciplinary Care Planning", and "National Center for Care Coordination Technical Assistance". The main content area is titled "Integrated Care at Boston Children's Hospital" and includes a section titled "Integrated Care is Important to Everyone!". This section contains three perspectives: "Family/ Patient Perspective" (citing a 37% statistic on care team communication), "Referring Provider Perspective" (discussing the benefits of consulting subspecialists), and "Subspecialist Perspective" (emphasizing the importance of knowing the referral reason). Below these perspectives, a paragraph explains the challenges of care coordination and the role of integrated care. The footer of the page features the Boston Children's Hospital logo and the Harvard Medical School Teaching Hospital logo.

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**Integrated Care Program**

Care Mapping

Care Coordination Curriculum

Care Coordination Measurement

Patient & Family Experience Outcome

High Quality Handoffs

Multidisciplinary Care Planning

National Center for Care Coordination Technical Assistance

## 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<sup>1</sup>. 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<sup>2</sup>.

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

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

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  - ☐ Lesson 3: Tools and Processes that Support Care Coordination
  - ☐ Lesson 4: Application of Tools and Processes - Case Example
  - ☐ Attestation

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<p><b>Official Accreditation</b> Courses are approved through Boston Children's Hospital by Joint Accreditation™</p> <p><b>Relevant Content</b> Each course has been reviewed and has up-to-date content in many areas of expertise</p> <p><b>Certificate</b> Upon completion of the course, you will receive a certificate</p> <p><b>Transcripts</b></p>	<p><b>Cost:</b> An accredited certificate for \$25 Non-accredited certificate for \$0</p> <p><b>Audience:</b> Physician, Nurse, Social Worker</p> <p><b>Topic:</b> Care Coordination, Patient/Family Centered Care</p> <p><b>Credits:</b> CME, CEU, MOC, ACE CE</p>
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## So...What can we do right 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







## Select References

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- **Making Care Coordination a Critical Component of the Pediatric Health System: A Multidisciplinary Framework**. Antonelli R, McAllister J, Popp J.. The Commonwealth Fund. May, 2009.
- **MA Child Health Quality Coalition Care Coordination Framework**. *Funded by the Centers for Medicare and Medicaid Services (CMS) through grant funds issued pursuant to CHIPRA section 401(d)*. Contact: [grogers@mhqp.org](mailto:grogers@mhqp.org) [www.masschildhealthquality.org/work/care-coordination/](http://www.masschildhealthquality.org/work/care-coordination/)
- **AAP Policy Statement: Patient- and Family-Centered Care Coordination: A Framework for Integrating Care For Children and Youth Across Multiple Systems**. *Pediatrics*. May 2014.
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- **Care Coordination Curriculum and Care Mapping Tool User Guides**: Antonelli, Browning, Hackett-Hunter, McAllister, Risko; Lind. Boston Children's Hospital; funded thru Family Voices/MCHB HRSA grant. 2012. [www.childrenshospital.org/care-coordination-curriculum](http://www.childrenshospital.org/care-coordination-curriculum)
- **Continuity and Coordination of Care: a practice brief to support implementation of the WHO framework on integrated people-centered health services**. Geneva: World Health Organization, 2018. Licence CC-BY-NC-SA 3.0 IGO.





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