Getting Started

Pediatric Care Coordination Curriculum

An Interprofessional Resource to Effectively Engage Patients and Families in Achieving Optimal Child Health Outcomes

2ND EDITION

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What Is Pediatric Care Coordination and Why Does It Matter?

Pediatric care coordination is a patient- and family-centered, assessment-driven, team-based activity designed to meet the needs of children and youth while enhancing the caregiving capabilities of families and caregivers. Care coordination reaches across medical and nonmedical domains to address interrelated medical, social, developmental, behavioral, educational, and financial needs to achieve optimal health and wellness outcomes.1,2 Care coordination is an essential component of the services provided by members of the patient- and family-centered medical home (PFCMH) team. For children and youth with special health care needs, including those with significant social determinant of health risk factors, the PFCMH is a critical element of an integrated care model, offering care coordination in collaboration with the members of the diverse care team, across settings. This diverse care team includes patients, families, caregivers, nurses, physicians, social workers, community health workers, care managers, care navigators, case managers, early intervention providers, education professionals, and staff from Title V programs.

Health care is often provided in "silos," where patient care is fragmented due to lack of accountability, communication, and effective coordination. Successful care coordination with structure and measurement processes that support accountability and communication, enabling interprofessional integration to achieve shared goals, is of highest value to families and patients, especially children, youth, and young adults who are medically, socially, and behaviorally complex. Furthermore, since health outcomes are substantially impacted by contributions of providers of essential health-related resources, such as social services, education, family support, housing, transportation, literacy, and social justice, truly effective care coordination must play a key role in aligning and integrating efforts across both medical and nonmedical domains.

In the 8 years since the first edition of the Pediatric Care Coordination Curriculum was published, care coordination has been demonstrated as an essential cross-cutting intervention capable of filling in the gaps of the fragmented U.S. health care system. As new tools and measurements have been developed, this second edition offers valuable updates from the field.

This curriculum was designed to cultivate new learning about the elements of care coordination, emphasizing the central role of families, caregivers, children, youth, and young adults in collaboration with a multidisciplinary group of care team members. It identifies a framework for integrating efforts across time, settings, and disciplines. The curriculum aims to build the capacity of the multidisciplinary care team and families through effective implementation of key components of care coordination, constructive and collaborative communication within interprofessional care teams and families, and investment in technology solutions. It will also provide tools to measure challenges and successes in coordination of care to engage in continuous quality improvement. These competencies will support provisions of high-value patient- and family-centered care.

What Is New in the Second Edition?

Based on user feedback, the modules were adapted for this edition to emphasize development of measurable capabilities and outcomes through shared, interprofessional learning activities. Prior to implementing the curriculum, the facilitator should review all modules to become familiar with materials and decide which modules will best fit the desired learning goals and outcomes relevant to the group's needs for improving care coordination and care integration. Experience with the first edition established that it is not necessary to adapt and implement all the modules concurrently. Many successful implementers planned modules based on local and regional priorities. In other words, it is acceptable to start small!

Considering the audience's purpose for engaging in this learning experience is key. Are participants interested because they share a broad goal (eg, improving outcomes directed by policy, quality, or contractual mandates)? Are they attending because there is a shared passion for providing better care? Is there a marketing driver to be the highest performing delivery system in a region as assessed by outcomes important to family of children and youth with special health care needs?

The facilitator will want to be practical in planning and mindful of tactical and logistical constraints, such as the number of learners, availability of space and time, and preexisting experience and relevant background of the learners. Facilitators should also consider their own experiences and training in relation to the material.

The following is an overview of the content and learning objectives embedded in each module of the second edition of the Pediatric Care Coordination Curriculum. This is intended to guide the leadership group organizing the effort on the adaptation and implementation of the curriculum. Adaptation enables the organizing group to decide how much of the content to deliver based on its priorities. Also essential for the group in the adaptation process is to include information pertinent to local, regional, and state-specific resources. The sections for which adapted resources are especially important are denoted by a blue dot **L**

Curriculum at a Glance

Most stakeholders beginning to implement and measure care coordination will likely find that Module 1 is foundational to the content in the other modules.

Module 1
High-Value Integrated Care Outcomes Depend on Care Coordination

By the end of this module, learners should be able to:
- Discuss key components of care coordination within an integrated model of care delivery.
- Assess current practices that support care coordination and integrated care delivery in a variety of settings, including state, regional, delivery system, community agency, or clinical.
- Prioritize areas of improvement in care integration and care coordination in their current practice.
- Identify established tools and processes that can be used to implement key components of care coordination.
- Develop an action plan outlining specific goals to facilitate care coordination in their practice.

Module 2
Developing and Sustaining Strong Family/ Professional Partnerships

By the end of this module, learners should be able to:
- Explain the value and importance of family/professional partnerships.
- Explain the family role in health care improvement.
- Describe ways to engage families and members of the care team to improve integration.
- Demonstrate knowledge of tools, resources, and strategies to improve family/professional partnerships.
- Demonstrate the ability to operationalize family/professional partnerships through planning an initiative and/or event.

Module 3
Social Determinants of Health

By the end of this module, learners should be able to:
- Understand what social determinants of health and health disparities are.
- Understand how social conditions influence health.
- Recognize 5 core health-related social needs for screening and referral with implications for care coordination.
- Understand the importance of bias and health equity.
- Recognize some innovations aimed at addressing social determinants of health..

Module 4
Measurement Matters: Creating an Effective and Sustainable Integrated Care Model

By the end of this module, learners should be able to:
- Outline key elements of a care coordination measurement framework.
- Use tools and measures to effectively assess elements of care coordination.

Module 5
Using Technology to Improve Care Planning and Coordination

By the end of this module, learners should be able to:
- Assess current practice of care coordination with and without technology.
- Describe ways to use technology to connect key players in care coordination.
- Provide an overview of system requirements.
- Create an action plan for integration of technology platforms.

Those already on this journey may find the Assets and Needs Assessment listed below helpful in guiding where to begin in the curriculum. Facilitators are encouraged to use this tool to assess their current status in performing care coordination and to identify strategic goals and priorities. Although the Assets and Needs Assessment is contained in this module, it is useful for starting with any of the modules.

Assets and Needs Assessment

Please answer the following questions to help us better tailor future learning opportunities.

Demographics

1. Organization type
   - ☐ Clinical practice
   - ☐ Family advocacy organization
   - ☐ Health care delivery system
   - ☐ Community organization (eg, early intervention, school, child care)
   - ☐ Title V, other state agencies
   - ☐ Other (specify): _____

2. Organization size: _____

3. Team membership (disciplines): _____

4. Medical Home Certification (NCQA or JAHCO):   ☐ Yes   ☐ No

5. Practice setting: ☐ Rural   ☐ Urban

Getting Started: Essential Questions

1. Why are you engaging in the process to implement, measure, and improve care coordination?

2. What are your goals?
   - ☐ Quantitative
   - ☐ Qualitative
   - ☐ Other (specify): _____

3. Do you have any incentives or disincentives influencing your commitment to this effort?

4. Given that the effective care of children, youth, and young adults with special health care needs must be coordinated across settings and disciplines, what role do you foresee in integrating into this broader community of care?

   · Are any stakeholders in this broader community of care joining you in this process?

Assets and Needs Assessment

continued

	Does your team:	Yes	No
NEEDS ASSESSMENT AND GOAL-SETTING	Collect feedback on patient experience using a standardized tool?		
	Engage patients/families in quality improvement activities?		
	Conduct behavioral health screenings (depression, anxiety, substance use, ADHD) using a standardized tool?		
	Measure and report on clinical quality measures (ie, immunizations, preventive care, behavioral health)?		
	Identify patients that might benefit from care management (ie, high health care utilization, complex conditions, behavioral issues, social issues)?		
CARE PLANNING AND COMMU-NICATION	Have regular care team meetings, pre-visit huddles, or another structured process for staff to communicate about upcoming appointments, patient needs, and workflow?		
	Offer communication in ways other than an in-person visit (ie, phone, email, Skype, or telehealth) if no physical examination is necessary?		
	Use a patient portal or other means for two-way electronic communication with families (ie, for sharing care plans)?		
	Have care plans for patients in need of care management that are developed collaboratively with patients/families, shared across care team members/settings, and updated routinely?		
FACILITATING CARE TRANSITIONS	Have a staff person or care coordinator who helps families coordinate care?		
	Have a process for following up with patients who have had a hospital admission or emergency department visit?		
	Have a systematic process for referral management (ie, providing pertinent clinical information and timing, tracking referrals, and closing the loop on referrals)?		
CONNECTING WITH COMMUNITY RESOURCES AND SCHOOLS	Work with families to identify needed community-based services (ie, programs or support groups)?		
	Use routinely collected information on social determinants of health (ie, food insecurity or housing instability) to address identified gaps?		
	Engage in supportive partnerships with schools and community agencies?		
	Actively assist in linking families to other families who share similar life situations and challenges?		
	Assess family experience using a standardized tool (ie, the Pediatric Integrated Care Survey)?		
TRANSITION-ING TO ADULT CARE	Collaborate with families to develop a written plan for patients with complex needs who are transitioning to adult care?		
	Consider health literacy and communication preferences in development of patient materials?		

Note to Facilitators

The target audience of this curriculum is intentionally broad because care coordination is a team-based competency. This curriculum is designed to inspire learning in patients, families, caregivers, nurses, physicians, social workers, community health workers, care managers, care navigators, case managers, early intervention providers, education professionals, and staff from Title V programs, Medicaid agencies, and commercial and managed care entities. The learning will proceed more organically if there is a diversity of faculty and learners. While it is important that everyone's perspectives are heard and respected, it is essential that input from patients and families be actively solicited and shared.

Tips for Facilitators: Ways to Keep the Workshop on Track
Sometimes during a workshop or group activity, things can get a bit off track. For example, some participants may feel strongly about adding topics to the training, causing conflict between participants, or efforts for an organized workshop flow may become stymied. Following are ideas that may help with keeping a workshop on course or getting it back n track in a gentle and reassuring manner.

How to handle challenging group dynamics and keep a workshop flowing
· Make everyone feel comfortable, welcome, and valued.
  ~ Welcome people in the roles that brought them to the workshop but also as people with personal experiences
  ~ Consider dedicating time or a method for sharing stories (set aside time in the agenda, collect stories or ideas on sticky notes to discuss later, or form small work groups)
  ~ Allow time for cultural connections

· Present and explain the agenda and expectations frequently—repetition improves connections and keeps everyone on track.
  ~ Encourage participation from all of the learners
  ~ Listen and observe and ensure that others show respect and listen as well
  ~ This ensures that all who participate feel heard

· Clarify group discussions.
· Recognize and appreciate the contributions of all participants.
· Be aware of different learning and processing styles.

How to manage conflict and resolution
Honest disagreement is often a good sign of progress. —Mahatma Gandhi

Dealing with conflict:
· Keep an open mind
· Use "I" statements
· Do not take things personally
· Ask questions
· Stay focused on the topic
· Concentrate on solutions
· Take a break
· Remember the purpose of the workshop and redirect people back to it.

Resolving conflict:
· Pay attention to interests
· Listen first and talk second
· Make good relationships the priority
· Keep people and problems separate
· Present the facts
· Explore options together

Works Cited

1. Antonelli R, McAllister J, Popp J. Making care coordination a critical component of the pediatric health system: a multidisciplinary framework. The Commonwealth Fund. May 2009.

2. American Academy of Pediatrics Council on Children with Disabilities and Medical Home Implementation Project Advisory Committee. Patient- and family-centered care coordination: a framework for integrating care for children and youth across multiple systems. *Pediatrics.* 2014;133(5):e1451-1460

MODULE 1

Pediatric Care Coordination Curriculum

High-Value Integrated Care Outcomes Depend on Care Coordination

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High-Value Integrated Care Outcomes Depend on Care Coordination

Module 1—Objectives

At the end of this session, participants should be able to:

- Discuss key components of care coordination within an integrated model of care delivery.
- Assess current practices that support care coordination and integrated care delivery in a variety of settings including state, regional, delivery system, community agencies, or clinics.
- Prioritize areas of improvement in care integration and care coordination in their current practice.
- Identify established tools and processes that can be used to implement key components of care coordination.
- Develop an action plan outlining specific goals to facilitate care coordination in their practice.

Note to the facilitator:

Please be aware that when implementing this module, it is crucial to include local-, state-, and region-specific content.

A **L** found in the module indicates the need for local content to be added, but facilitators should feel free to include local content wherever they see fit. Local content includes, but is not limited to, the following:

- Cultural aspects of the community (including assets, vulnerabilities, and language)
- Sociodemographic factors
- Geography
- Local, state, and/or regional resources

There are 2 tables included below. The first is a high-level agenda of the module. The second is the facilitator guide that includes a breakdown of slide content and talking points. The facilitator should use the guide as a resource to tailor the training.

The curriculum is intended to be tailored to fit the training needs, and the content can be modified for different audiences. Therefore, content from this module can be selected and incorporated into the tailored training. However, a suggested agenda for implementing this module as a stand-alone is included.

Module Overview

Table 1

Agenda Item	Time	Materials Required	Instruction/Notes
Pre-session reading	N/A	Ten Essential Characteristics of Care Coordination	Can be found at: *https://jamanetwork.com/journals/ jamapediatrics/article-abstract/2716802*
Introduction	5 min	N/A	
Didactic: care coordination from theory to practice	15 min	Slides	Create the slide deck using content from the didactic portion. Make sure there is opportunity for participants to speak. (L) Add local content to the slides as needed.
Team activity: asset and needs assessment	20 min	Handouts, as needed *(The assets and needs assessment can be found in the facilitator guide Getting Started: Identifying and Prioritizing Opportunities for Implementing High-Performing Care Coordination)*	Distribute the handout to teams or individual participants as appropriate. Give participants 5 minutes to do the assets and needs assessment as a team (if applicable). Ask the learners to reflect on their current activities, then ask for some "headlines" to be shared in the larger group.
Case study: Keystone Pediatrics	35 min	Copies of case study, as needed	Give participants an opportunity to practice the concepts and tools they have learned during the training. Case studies can be tailored so that they are relevant to the audience/population.
Shared plan of care	25 min	Slides	Create the slide deck using content from the didactic portion. Make sure there is opportunity for participants to speak. (L) Add local content to the slides as needed. Refer participants to Appendix B of this module for more in-depth information on developing the shared plan of care.
Action-oriented exercise: SMART goals	15 min	Copies of handout, as needed	Participants should complete the worksheet, detailing next steps to take after the session, based on work they have done in the session.
Closing/ summary	5 min	N/A	

Introduction

Note from the authors

The content included in this module provides a framework for facilitators to explore how care coordination activities serve the delivery of integrated health care for patients most vulnerable to care fragmentation. The goal is to provide practical guidance for learners to be able to identify opportunities for implementing care coordination activities in their own practices. Learners may be physicians or nonphysician clinicians of all disciplines, school or community partners, payers, agencies, or patients and families—ensure that all appropriate team members are included in this training opportunity.

General principles and recommendations for care coordination grounded in the literature are shared in this module, while enabling discussion of context-specific challenges and areas for improvement. It is important to embed local information, including resources or contacts, into the content of this module—this will make the learning experience more valuable and relevant. For example, facilitators may consider reaching out to community early intervention programs, school districts, behavioral health clinicians, Title V organizations, American Academy of Pediatrics chapters, and family advocacy groups, among others. There is a wide breadth of services used by families and children with special health care needs, some of which are listed in Appendix A of this module.

An important aspect of this module for understanding the relevant experiences of participating teams is the assets and needs assessment. What do care teams do to facilitate care transitions in their practices? How do they connect patients and families to community resources? These questions will help guide facilitators in determining the key focus points and resources to share throughout the session.

Following are some questions to debrief the learners about the pre-session reading:

- What essential characteristic of care coordination resonated most with your experience?

- Were any of these assumptions a surprise or something you did not realize was an aspect of care coordination?

- Think of your own team. Which of these do you do particularly well, and which have opportunity for improvement?

These questions will be delved into further throughout this module.

Facilitator Guide–Slide Deck

SLIDE 1 » Title Slide

Module 1: High-Value Integrated Care Outcomes Depend on Care Coordination

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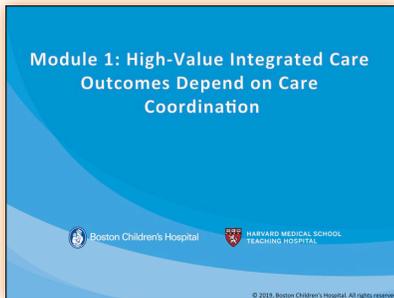
Be mindful that this activity will have optimal impact if it is presented as an interprofessional learning event, with patients and families as co-faculty and co-learners. This multi-stakeholder learning event is intended to set the foundation for a jointly created, shared vision for empowering patients and families to impact the quality of the care processes that impact their outcomes. Tactically, a common language of expectations, terms, and performance measures will be highlighted, ultimately resulting in care team members understanding their respective roles and responsibilities.
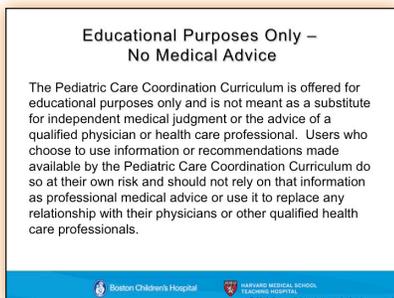
SLIDE 2 » Educational Purpose Only–No Medical Advice

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SLIDE 3 » Objectives

Objectives

- Discuss key components of care coordination within an integrated model of care delivery.
- Assess current practices that support care coordination and integrated care delivery in a variety of settings, including state, regional, delivery system, community agency, or clinics.
- Prioritize areas of improvement in care integration and care coordination in the current practice.
- Identify established tools and processes that can be used to implement key components of care coordination.
- Develop an action plan outlining specific goals to facilitate care coordination in the practice .

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After participating in this module, learners will be able to achieve the objectives included on this slide.

Facilitator Guide–Slide Deck

continued

SLIDE 4 » Overview

Overview

- Care coordination from theory to practice
- Asset and needs assessment
- Case study: introduction to tools
- Shared plan of care
- Action-oriented exercise

This slide is an overview of the activities that support the learning objectives.

SLIDE 5 » Objective

Objective

Participants will be able to…

Discuss key components of care coordination within an integrated model of care delivery.

Inform the learners that the session will start with a discussion about the key components of care coordination within an integrated model of care delivery. The discussion will distinguish between care coordination and care integration and explore how they are related.

SLIDE 6 » Care Coordination

Care Coordination

Explain to the learners that today's portion of the training session will teach them how to take care coordination from an "in-the-clouds" concept to on-the-ground action in their practices and communities.

SLIDE 7 » What is Care Coordination

What is Care Coordination?

2014 AAP Policy Statement

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

Defined care coordination as

A patient- and family-centered, assessment-driven, team-based activity designed to meet the needs of children and youth while enhancing the caregiving capabilities of families. Care coordination addresses interrelated medical, social, developmental, behavioral, educational, and financial needs to achieve optimal health and wellness outcomes.

(American Academy of Pediatrics Council on Children with Disabilities and Medical Home Implementation Project Advisory Committee. Patient and family centered care coordination: a framework for integrating care for children and youth across multiple systems. *Pediatrics.* 2014;133(5): e1451-e1460.)

Care coordination is the set of activities in the space between visits, care team members, and hospital stays. Examples may include booking appointments, following up on test results, and liaising with community services.

Metrics of care coordination include assessments of care transitions (eg, information handoffs) and care plan implementation.

Facilitator Guide—Slide Deck

continued

SLIDE 8 » Care Coordination Enables Integrated Care

Care Coordination Enables Integrated Care

Care Fragmentation → Care Integration

Care coordination

- Lack of communication between care providers
- Gaps in services
- Duplication of services

- Team-based care
- Connections to community
- Collaborative care planning
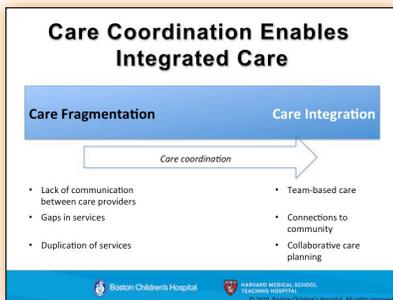
Words matter! It is essential to acknowledge that there may be some variation in terminology, but the facilitator must get the group to come to consensus on how to define, operationalize, and measure performance of care coordination, care integration, case management, etc.

Care planning is an activity of **care coordination,** and care coordination leads to **care integration.** Care coordination is a domain of the broader framework of care integration and is necessary—but insufficient—to achieve integration. When care is integrated, families perceive collaboration between care team members. See Appendix B of this module on how to build a shared plan of care.

Case management is commonly confused with care coordination and care integration. Case management is a process that addresses the health needs of patients. It tends to be focused on a limited set of predetermined diseases or conditions and guided by potential health care cost savings. Traditionally, case management services are provided in a benefits package, often supported by a health plan or managed care organization.

SLIDE 9 » Integrated Care Framework

Integrated Care Framework

Integrated Care "Holistic Care"

- Team-Based Care
  - Team Configuration
  - Communication
  - Knowledge Sharing
- Connection to Community
  - Information
  - Family Impact
- Collaborative Care Planning
  - Long-Term Plan/Roadmap
  - Goals
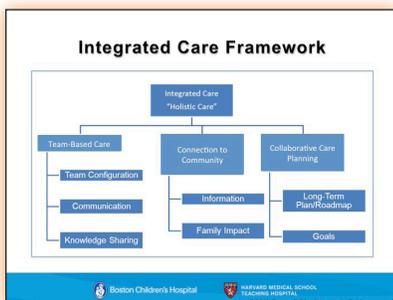
This is the framework for care integration, which is the right side of the care fragmentation ➡ care integration diagram in the previous slide. This framework is foundational to understanding how various activities of care coordination (eg, referral to community resources or planning for the future) support the outcomes of care integration.

Further, it should be emphasized that this broadly inclusive framework is designed to include key priorities (health, medical, nursing, social, behavioral, and educational aspects of health) for care coordination implementation by addressing what is important to families, physicians, nonphysician clinicians, and community leaders.

SLIDE 10 » Who Is Involved in Care Coordination?

Who Is Involved in Care Coordination?

- Patients and families
- Pediatricians and other physicians
- Pediatric medical subspecialists and pediatric surgical specialists
- Case management
- Public and commercial payers
- Community health workers
- Schools
- State agencies
- Title V

Care coordination is a multidisciplinary team sport, and patients and families are essential team members.

Ask the learners whether they have the right people in the room when discussing care coordination and to consider all of the different types of care team members and settings. Agencies might include the Department of Mental Health, the Department of Developmental Services, and the Department of Children and Families.

Facilitator Guide–Slide Deck

continued

SLIDE 11 » One Family's Care Map
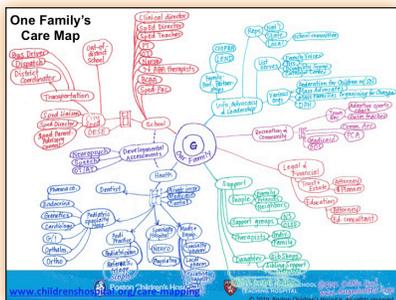
This image of one family's care map depicts all the different "loci" of care. Care mapping is an important activity for framing care coordination. It is a process that guides and supports the ability of families and care team professionals to work together to prioritize needs and achieve the best possible health outcomes.

Source: http://bostonchildrenshospital.org/integrated-care-program/care-mapping

The care mapping process is discussed in more detail in Module 2 as an effective and valuable tool for family-led discussions of care coordination needs and goals.

The care map shown here was developed by Cristin Lind, who invented the care map.

SLIDE 12 » Impact of Care Fragmentation

Consider the impact of fragmented care. Some examples are included on this slide.

Presenteeism is when employees are physically present at work but not fully functioning (eg, due to distractions or concerns for their own health).

Caregivers of children and youth with special health care needs (CYSHCN), particularly caregivers of children with complex medical and behavioral health needs, are more likely to reduce their time or responsibilities at work or to quit, which contributes to their stress. To improve employee job attendance and productivity, suggest that the learners interface with employers in their region to determine how care coordination for CYSHCN impacts work.

Prompt the learners to consider the impact of care fragmentation on patients with behavioral health needs: 86% of families are singularly responsible for coordinating care for mental and behavioral health services (Pond et al., 2012).

Family experience with coordinating care for their children and youth with behavioral health needs demonstrates that this population 4is especially vulnerable to care that is fragmented, leading to significant stressors upon families.

Facilitator Guide–Slide Deck

continued

SLIDE 13 » Measure What Matters

Care coordination is a domain of the broader framework of care integration. Metrics of care coordination include assessments of care transitions (eg, information handoffs) and care plan implementation.

The other domains of care integration are critically important in defining a comprehensive set of performance metrics that are geared toward achieving the Quadruple Aim.

SLIDE 14 » Achieving the Quadruple Aim

Care integration is correlated with Quadruple Aim outcomes.

· **Improved quality indicators:** Care and services are integrated so that decisions are made collectively and ownership of tasks and responsibilities is determined together. This closes gaps in otherwise potentially fragmented systems.

· **Improved family experience:** Families feel more cohesive with their children's care teams.

· **Improved provider experience:** A provider's ability to provide comprehensive care improves.

· **Reduction of unnecessary costs:** The intention is to shift care from high-cost utilization services to lower cost ambulatory, or home- or community-based services.

These are the goals and purposes that care coordination activities can serve.

Share the following evidence for care coordination with the learners using the framework shown on the slide:

· According to an American Academy of Pediatrics (AAP) policy statement, the provision of care coordination was positively associated with patient- and family-reported "receipt of family-centered care," resulting in "partnerships with professionals, satisfaction with services, ease of getting referrals, lower out of pocket expenses and family financial burden, fewer hours per week spent coordinating care, less impact on parental employment, and fewer school absences and ED visits."

· An Illinois study showed that children, youth, and their families had a higher need for care coordination when communication between health care team members was inadequate.

· Care coordination within primary care pediatric practices is associated with decreased unnecessary office and emergency department (ED) visits, enhanced family satisfaction, and reduced unplanned hospitalizations and ED visits.

· Care coordination conducted as a standard of pediatric practice resulted in increased family satisfaction with the quality of care and also decreased barriers to care.

(Reference: AAP CC Policy Statement, 2014)

Facilitator Guide—Slide Deck
continued

SLIDE 15 » Matching Services to Complexity
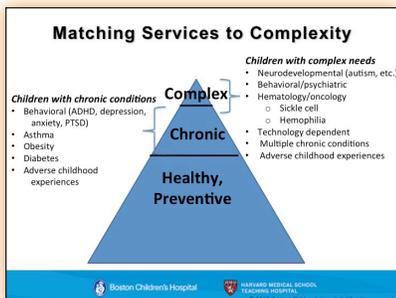
Contributors to complexity include psychosocial, socioeconomic, demographic, medical, behavioral, and environmental factors. Community leaders, advocates, and delivery system leaders must consider the broad needs and assets of the community when defining care coordination competencies and outcomes. Understanding this multifactorial model of health outcomes is essential in designing interprofessional care teams, with the patient and family at the center.

SLIDE 16 » Prevalence of Pediatric Complexity
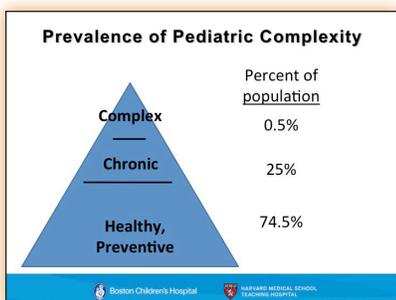
The prevalence of complexity, chronic conditions, and "typically" functioning children and youth suggests the need to define the characteristics of each segment of the pediatric population when one is developing care coordination and care management competencies.

SLIDE 17 » Evolving the Care Model to Achieve High Value
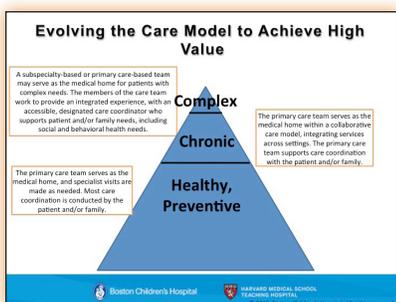
Effective care coordination, especially for children and youth with special health care needs, requires an interprofessional team. The complexity of the given child's or youth's needs often determines the locus of care coordination and integration, along with how multiple stakeholders collaborate to achieve optimal outcomes.

SLIDE 18 » Impact of Care Fragmentation

Family experience with coordinating care for their children and youth with behavioral health needs demonstrates that this population is especially vulnerable to care that is fragmented, leading to significant stressors upon families.

Facilitator Guide–Slide Deck

continued

SLIDE 19 » AAP Policy Statement

Care coordination can seem like a great concept but hard to figure out how to operationalize and systematize.

Based on evidence, the AAP policy statement on care coordination includes recommendations for pursuing care coordination.

This slide includes examples of actionable items that can help achieve some of these recommendations.
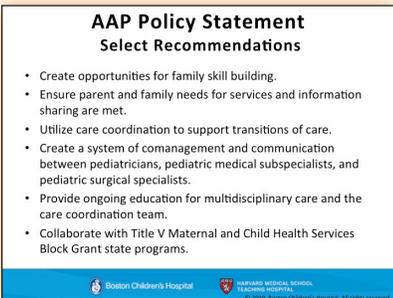
SLIDE 20 » AAP Policy Statement, Select Recommendations

The AAP policy statement facilitates a structured approach to defining activities of care coordination and to aligning key stakeholders in implementation and performance measurements.
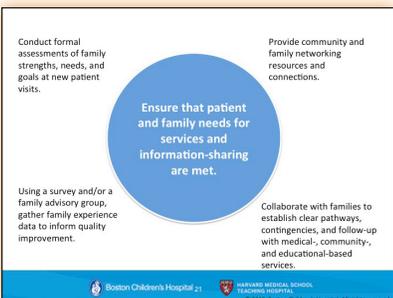
SLIDE 21

Facilitators may wish to highlight a particular AAP recommendation that is pertinent to the learners or team. Using the provided model, suggest actionable items for any recommendations chosen for discussion.

For each recommendation that is discussed, ask learners to share any actions they believe support that recommendation in their current practice. Facilitators can then show some suggested actions like the examples provided in this slide.
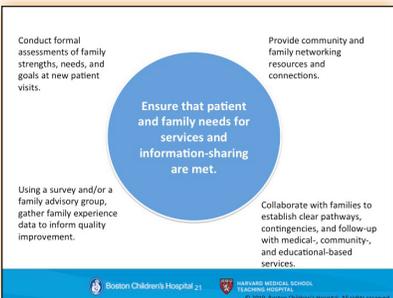
SLIDE 22

Delineation of roles and responsibilities includes the patient and family as well as all members of the care team. This process presages the functionality of the care planning tool known as the action grid, beginning with slide 44 in this module.

Facilitator Guide–Slide Deck

continued

SLIDE 23

Identify members of a child's care team.

The entire team is usually not located in the same physical space and is often *geographically dispersed.*
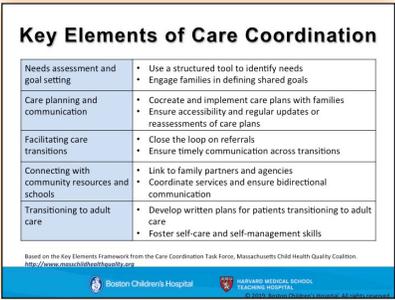
SLIDE 24 » Key Elements of Care Coordination

What are things that the learners do every day that might align with these recommendations? Practically, what do they mean?

This slide includes a framework of what care coordination activities might look like.

Ask the learners to do a practice assets and needs assessment to see what their team is doing to support care coordination in each of the domains included in the framework and which domains may have opportunities for improvement.
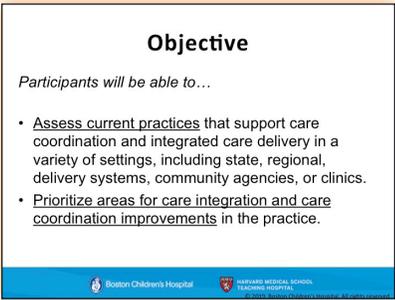
SLIDE 25 » Objective

Facilitators should summarize the objectives here.

Facilitator Guide—Slide Deck

continued

SLIDE 26 » Asset and Needs Assessment

Asset and Needs Assessment

Distribute the handout to teams or individual participants as appropriate. Give participants 5 minutes to complete the asset and needs assessment as a team (if applicable).

Ask learners to reflect on their current activities.

- What are they already doing to provide care coordination for patients?
- What gaps did they identify?
- What area would they like to prioritize as an opportunity for improvement?
    - ~ Encourage them to consider institutional priorities, stakeholder interests, and local resources.

Ask for some "headlines" to be shared in the larger group.

SLIDE 27 » Care Coordination Framework

Care Coordination Framework: Linking to Measures

Gaining consensus on the framework, with its organized approach to defining elements, activities, and roles, will lead to a robust approach to measurement.

SLIDE 28 » Objective

Objective

Participants will be able to…

Identify established tools and processes that can be used to implement key components of care coordination.

Facilitators should summarize the objective here.

Facilitator Guide–Slide Deck

continued

SLIDES 29 & 30 » Case Study: Keystone Pediatrics

Keystone Pediatrics

Case Study: Keystone Pediatrics

- Keystone Primary Care is a community-based primary care office that serves approximately 7,000 pediatric patients, 35% of whom are insured by Medicaid.
- The office leadership receives the Quality Report Card and notes that the metric for adolescent well visits is 30%.
- This presents an opportunity for improvement. As the practice implements a quality improvement initiative to increase adolescent well visit rates, it anticipates that behavioral screening rates will increase.
- Currently, 25% of the screens are returning positive. Providers have started sending referrals to social work. It is unclear how many adolescents are actually connecting with someone from social work, and the clinic team realizes it doesn't have a process for closing the loop on these referrals.

Ask learners:

- Does this case study resonate?
- Is it realistic?
- What are the gaps??

Inform the learners that today's discussion will address common issues associated with adolescent visits.

SLIDE 31 » Identifying Areas for Improvement

Identifying Areas for Improvement

- A gap in the structured process for completing well visits
- A gap in the system of referrals and handoffs between team members

- Keystone Primary Care is a community-based primary care office that serves approximately 7,000 pediatric patients, 35% of whom are insured by Medicaid.
- The office leadership receives the Quality Report Card and notes that the metric for adolescent well visits is 30%.
- This presents an opportunity for improvement. As the practice implements a quality improvement initiative to increase adolescent well visit rates, it anticipates that behavioral screening rates will increase.
- Currently, 25% of the screens are returning positive. Providers have started sending referrals to social work. It is unclear how many adolescents are actually connecting with someone from social work, and the clinic team realizes it doesn't have a process for closing the loop on these referrals.

Ask participants to identify potential areas for improvement. Here are 2 opportunities that can be explored further:

- The gap in the structured process for completing well visits.
- The gap in the system of referrals and handoffs between team members.

SLIDE 32 » Areas of Improvement

Areas of Improvement

- **Identifying how to improve family well-visit attendance**
  - Is there something(s) that is preventing the family from scheduling or attending well-child visits?
  - Are there things that the team could do to make it easier for families?
- **Creating a system for closing the loop on referrals**

- Getting feedback from patients and families
- Communicating more clearly
- Creating a system for handoffs between care team members (including family!)

This slide includes common issues associated with family well-visit attendance.

The AAP policy statement offers several examples of how to improve these issues.

Facilitator Guide–Slide Deck

continued

The Focus With Today's Case

- Ensuring that patient and family needs for services and information sharing are met
- Ensuring clear communication and delineation of responsibility across transitions in care
- Coordinating transitions of care across teams and settings over time

Patient- and Family-Centered Care Coordination: A Framework for Integrating Care for Children and Youth Across Multiple Systems. AAP policy statement, 2014

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SLIDE 33 » The Focus with Today's Case

This module focuses on 2 of the AAP recommendations for care coordination. We will talk through operationalizing these recommendations and implementing tools and measures to support them.

For example, how can meeting the needs of patients and families be ensured? The first step is to understand patient and family experiences with health care.

Measuring Patient and Family Experience

- Family Experiences with Coordination of Care (FECC) Survey
- Pediatric Integrated Care Survey (PICS)

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SLIDE 34 » Measuring Patient and Family Experience

This slide includes 2 tools that can be used to measure patient and family experience. Both tools include questions that are framed as "in the past 12 months." Versions of the tools are available for transitions and handoffs, and both are available in English and Spanish.

- The Family Experiences with Coordination of Care (FECC) survey focuses on **structure** and **process** measures, including tools and resources that are available to support care coordination.

- The Pediatric Integrated Care Survey (PICS) focuses on **outcome** measures, including family expectations of care integration.

Family Experiences with Coordination of Care (FECC)

- Assessment of 20 caregiver-reported care coordination quality measures for children with medical complexity
  - Care coordination services
  - Messaging
  - Protocols/plans

- 12-month time frame

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SLIDE 35 » Family Experience with Coordination of Care

The FECC survey facilitates assessment of 20 caregiver-reported quality measures for children with medical complexity.

Facilitator Guide–Slide Deck

continued

SLIDE 36 » Family Experiences with Coordination of Care

This slide includes 1 sample question from each of the 3 domains covered in the FECC survey.

Different questions can be selected from the survey and shared with the learners, depending on their interests and priorities.

The full tool is available at: https://www.seattlechildrens.org/research/centers-programs/child-health-behavior-and-development/labs/mangione-smith-lab/measurement-tools/

SLIDE 37 » PICS

PICS is a validated outcome measure of patient and family experience with care integration. The survey is already being implemented in multiple settings across the U.S. and is being considered for use by some state Medicaid programs.

SLIDE 38 » PICS

PICS assesses parent and caregiver experience with integration across the entire care team or a specific entity (eg, a particular subspecialty clinic). It assesses parent/family/caregiver experience with medical service delivery, behavioral health, education, and linkage to community organizations.

PICS contains 19 experience-related questions in 5 domains: access, communication, family impact, care goal creation, and team functioning.

SLIDE 39 » PICS

This slide contains some examples from PICS.

Different questions can be selected from the survey and shared with learners, depending on their interests and priorities.

The full tool is available at: http://www.childrenshospital.org/integrated-care-program/patient-and-family-experience-outcome

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Facilitator Guide–Slide Deck

continued

SLIDE 40 » Tools to Support High-Quality Handoffs

Tools to Support High-Quality Handoffs

Collaborative Consults

Sender → Receiver

Closing the Loop: Action Grid

In addition to the tools for measuring patient and family experience that have been shared during the session, patient experience tools are also available from Press Ganey and NRC Health.

However, this next portion of the module will look at tools that can be used to support high-quality handoffs before and after a clinical encounter.
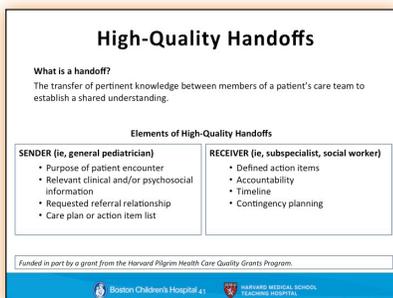
SLIDE 41 » High-Quality Handoffs

High-Quality Handoffs

What is a handoff?
The transfer of pertinent knowledge between members of a patient's care team to establish a shared understanding.

Elements of High-Quality Handoffs

SENDER (ie, general pediatrician)	RECEIVER (ie, subspecialist, social worker)
• Purpose of patient encounter	• Defined action items
• Relevant clinical and/or psychosocial information	• Accountability
• Requested referral relationship	• Timeline
• Care plan or action item list	• Contingency planning

Funded in part by a grant from the Harvard Pilgrim Health Care Quality Grants Program.

What is a handoff?
It is the transfer of pertinent knowledge between members of a patient's care team, enabling a care team member to safely assume responsibility for some aspect of care.

Handoffs occur in numerous contexts:

· To and from pediatricians and other physicians to pediatric subspecialists, pediatric surgical specialists, or nonphysician clinicians

· To and from communities and hospitals

· To and from an on-call physicians and nonphysician clinicians

· To and from pediatric medical subspecialists or pediatric surgical specialists on other services

The goal of a handoff is to enable the care team to maximize the utility of every patient interaction by ensuring knowledge learned by one part of a patient's care team is communicated to other members at the right time and place.

Structured handoff communication using a standardized template in concert with team training has been associated with reduced medical errors (Starmer et al. 2014).

Facilitator Guide—Slide Deck

continued

SLIDE 42 » Collaborative Consults

Collaborative Consults

- Why is the patient being referred (reason for referral)?
- What clinical/psychosocial information is pertinent to the referral?
- What is the requested referral relationship?
- What are the questions to be answered?

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Ask learners what some of the key pieces of information are necessary to optimizing clinical encounters with patients and families.

Inform them that audits across the United States demonstrate that only 5% to 20% of referrals to pediatric medical subspecialists and pediatric surgical specialists(?) include pediatricians' or other physicians' reasons for requesting consultations, and information about evaluations conducted to date, and expectations of consultations.

It may be helpful to clarify here the distinction between a referral request to a payer to obtain approval and a physician-informed or nonphysician **clinician-informed reason for subspecialty consultation.** This curriculum focuses on the latter.

SLIDE 43 » High-Quality Handoffs: Collaborative Consults

High-Quality Handoffs: Collaborative Consults

Reason for Visit

Requested Referral Relationship

Clinical/Psychosocial Information

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This slide features a model template that can be used to ensure that the elements included in the template are available prior to every encounter.

This template is available to learners at: http://www.childrenshospital.org/integrated-care-program/high-quality-handoffs.

The High-Quality Handoffs tool can be used to structure essential information for each member of the care team. This would include care transitions from primary care to subspecialist, subspecialist to other subspecialist, or primary care to other members of the care team, such as nursing, social work, and community-based providers.

SLIDE 44 » High-Quality Handoffs: Closing the Loop

High-Quality Handoffs: Closing the Loop

Families should know the answers to the following questions:

- WHAT will be done before our next appointment? WHAT can I expect?
- WHO will do this? WHO will follow up?
- WHEN should I expect results? WHEN will I receive an update? WHEN should I follow up?
- WHY is this important to my child's health?
- HOW will my primary care provider be informed about this?
- HOW will this affect other parts of my child's care?

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Ask the learners what some of the key pieces of information are that need to be discussed with the patient and family and/or other members of the care team following a clinical encounter. Also, what needs to be done to ensure clear communication of patient and family goals and the plan of care with a timeline and responsibility for important tasks? What practices support reliable information sharing among members of the health care team so that nothing falls through the cracks?

These are common challenges, particularly across transitions in care and when team members are dispersed across multiple sites.

Inform the learners that the next part of the session will describe a tool that supports a shared mental model and closed-loop communication across the care team.

Facilitator Guide—Slide Deck

continued

SLIDE 45 » Closed-Loop Communications: Action Grid
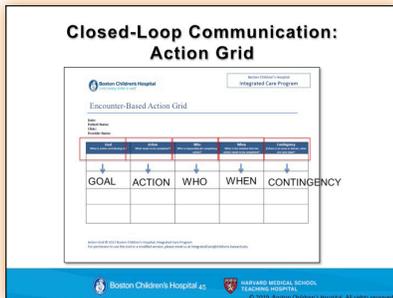
An action item grid is developed with the patient and family. It outlines an overall care goal, task to be completed, who is responsible, timeline for completion, and a contingency plan. The high-quality handoff is a critical first step to inform the patient encounter, and the action grid helps ensure closed-loop communication back to the referring care team.

This template is available to learners at: http://www.childrenshospital.org/integrated-care-program/multidisciplinary-care-planning

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SLIDE 46 » Principles of the Action Grid
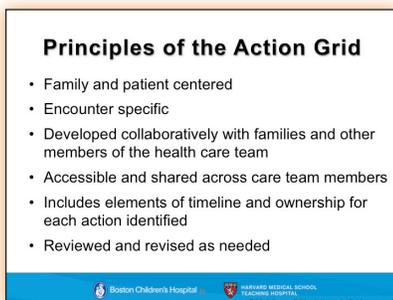
Share the key principles of the action grid from this slide with the learners.

Of note, finalizing the action grid may take more time than what is available during a single appointment. The action grid should be accessible and shared across the whole care team, as defined by family preferences.

If it supports the learners' goals and time permits, use the activity from case study #1 to guide learners through a clinical scenario using the action grid.

SLIDE 47 » Pause for Reflection
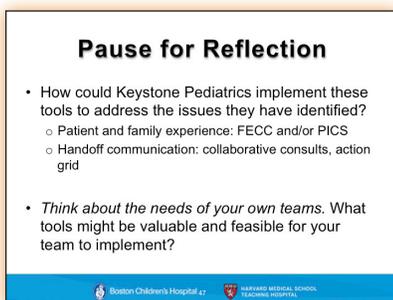
Allow learners to discuss in small groups prior to sharing a few examples with the larger group.

SLIDE 48 » Intervention

Intervention

Keystone Pediatrics re-engineers part of the administrative role of Anne, who is currently an administrative assistant.

- Anne has background knowledge about the health care system and the needs of the patients and families from working in her role. She also has a general understanding of community and state resources from working in the clinic. She will transition her role to spend 10 hours a week focusing on care coordination.
- Anne will manage a registry of adolescent patients to ensure that well visits are scheduled and completed.
- She will help to organize and distribute action grids for families after in-person visits.

Returning to the case study example, ask the learners to think about how these tools can be used to measure and address the gaps in care that were identified.

SLIDE 49 » Collaborative Consults

Collaborative Consults

Requested Subspecialty	Requested Referral Relationship
• School psychologist	• One-time consultation • Comanagement or shared care • Subspecialty-based management • To be determined
Clinician Reason for Visit • First-time evaluation for potential counseling in school setting	**Relevant Clinical/Psychosocial Information** • Patient screened positive for behavioral health concerns at last well visit • Parent shared that patient has not previously received behavioral health support but would be open to it

A structured approach to defining roles and responsibilities is essential, whether it is for patients with chronic and complex needs or those with straightforward and noncomplex needs. The tool featured on this slide can be adapted for nonmedical interactions as well (eg, behavioral health or social service).

SLIDE 50 » Action Grid

Action Grid
Date: 4/27/18
Patient Name: Jane Smith
Clinic: Keystone Primary Care
Provider Name: Dr. Gonzalez

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 HPV immunizations.	Immunization 1,2,3	Jane Smith will review school schedule and call to make appointment for 2nd dose.	Before August 31, 2018	RN will call family August 1 as reminder. If family has questions, call 123-456-7891.
Assess potential need for in-school counseling.	Evaluation with school psychologist	Social worker	Social work will send referral to school psychologist, copy family on note.	If family does not get contacted by school psychologist by June 1, 2018, family will call back social worker at 123-456-7878.

The action grid is cocreated with the patient and the family or caregiver. It assures clarity and transparency across all members of the care team. It also specifies a desired goal, necessary activities, a timeline, and the accountable entity. The action grid template was created as a result of family reports about how to reduce fragmentation of care as part of the project that created the PICS instrument. Experience has since revealed that health care team members also find this tool useful for essentially the same reasons as families.

Facilitator Guide–Slide Deck
continued

SLIDES 51 & 52 » Implementing a Shared Plan of Care

Implementing a Shared Plan of Care

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Implementing a Shared Plan of Care: Case Study

A 3-year-old boy with developmental delay and his family (Burmese refugees) were referred to your clinic by pediatric neurology for care coordination.

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Ask learners to reflect on their experiences as a care team member and/or family member.

These questions are from the Pediatric Integrated Care Survey (PICS). Feel free to use other measures from the PICS if they are more relevant to a case study that has been adapted.

SLIDE 53

Workflow: Five Phases Using a SPoC as an Approach to Family-Centered Care Coordination

Family Outreach & Engagement ➤ | Partnership & Pre-Visit Preparation ➤ | Teamwork & Population on Care ➤ | "Planned Care Visit" & SPoC Coproduction ➤ | Ongoing CC & Community Transfer ➤ ➤

Build Rapport | Assess | Team Prepares | Listen/hear Coproduce | Use, learn & improve

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Ask the learners to consider how they would operationalize the following phases for this particular case:

- **Phase 1: Family outreach/engagement**
  The family was invited and provided with a thorough description of what a care coordination intervention could do to help them, and they agreed to participate.

- **Phase 2: Family and team pre-visit work**
  An assigned care coordinator reached out and learned that the family had no means of transportation, the father had no work leave time, and their English was very limited. They would require the following supports to ensure a successful period of care coordination: a Medicaid cab, a car seat, a specific dialect translator, and a visit timed to the father's schedule because he does the communication for the family.

- **Phase 3: Population-based teamwork**
  The team members shared insights into Burmese culture and addressed the interventions needed to help the family attend a planned care visit (transportation, interpretation, safety, etc.). The team members reviewed the medical record and other documents and began to populate the medical summary.

Facilitator Guide–Slide Deck

continued

Ten Steps to Achieving a Shared Plan of Care

1	Identify who will benefit from having a shared plan of care.
2	Discuss with families and colleagues the value of developing and using a comprehensive and integrated plan of care.
3	Select, use, and review multifaceted assessments with the child, youth, and family.
4	Set shared personal (child and family) and clinical goals.
5	Identify other crucial partners, such as subspecialists or community resource providers, and include them in the process for the plan of care.
6	Develop the medical summary for the plan of care and merge it with negotiated actions.
7	Establish the negotiated actions for the plan of care and merge them with the medical summary.
8	Ensure that the plan of care is accessible, retrievable, and available.
9	Provide tracking, monitoring, and oversight for the plan of care.
10	Systematically use the process for the plan of care as a model for a life course and a population health approach.

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SLIDE 54 » Ten Steps to Achieving a Shared Plan of Care

The 10 steps found on this slide are foundational for ensuring a broad, strategic approach to implementing a shared plan of care.

Objective

Participants will be able to…

<u>Develop an action plan</u> outlining specific goals to facilitate care coordination in the practice.

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SLIDE 55 » Objective

This training session has addressed ideal elements of care coordination in high-functioning clinical teams, potential gaps in clinical practices, and practical strategies and tools for achieving AAP recommendations for care coordination.

The content covered thus far was intended to equip the learners with concrete ideas for implementing needed care coordination activities… *tomorrow!*

Now, it is time work on developing an action plan.
[hand out action plan worksheet]

SMART Goals

Specific

Measurable

Achievable

Relevant

Time-bound

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SLIDE 56 » SMART Goals

Ask the learners to reflect as a team (or individually) on their needs assessment from the beginning of the training and some of the strategies and tools that have been discussed.

Ask learners to identify 1 short-term goal (within 7 days) and 1 long-term goal (within 90 days) they have to improve care coordination in their practices.

Share the following mnemonic for SMART goal setting: goals should be **S**pecific, **M**easurable, **A**chievable, **R**elevant, and **T**ime-bound.

Facilitator Guide—Slide Deck

continued

SLIDE 57 » Your Action Plan

Your Action Plan

Now, ask learners to consider the following questions for each goal:

- What barriers do you anticipate?
- What is your specific plan to achieve this goal?

Considering these types of questions have been shown to improve transfer of training to the work setting and to increase likelihood of follow-through on goals.

Invite 3 to 4 participants to share their goals and action plans with the large group and to obtain feedback.

Then, discuss follow-up.

Consider:

- Having teams mail a letter within a defined timeframe to themselves with a copy of this worksheet.
- Having teams email a supervisor, director, or other identified leader to ensure accountability and to arrange a check-in.
- Arranging a follow-up phone call with the module facilitator.

SLIDE 58 » Take-Home Points

Take-Home Points

- Care coordination is the set of activities that occurs in the space between
  - Visits, providers, hospital stays, agency contacts.
- Care coordination is necessary but insufficient for achieving integration.
  - Integration is essential for achieving optimal value.
- The only way to succeed is to engage all stakeholders—including patients and families—as participants and partners.

The facilitator should get a sense of how the diverse group of learners has reacted to the dynamic of the session, as well as whether the participants have been able to integrate the content into their cognitive framing.

SLIDE 59 » Take-Home Points

Take-Home Points

- Build capacity: families and workforce.
  - Develop competencies to support integration.
  - Improve interprofessional education.
- Implement measures of care integration.
- Track outcomes, including value.
  - Quality and safety
  - Cost
  - Experience

Encourage the group to reflect on the following:

- How can you begin to implement care coordination in your work in the next few days?
- What are some drivers that will encourage broad adoption?
- How can outcome measurement be implemented to assure sustainability?

SLIDE 60 & 61 » Resources

Resources

Citations
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- Zanello E, Calugi S, Sanders LM, et al. Care coordination for children with special health care needs: a cohort study. *Ital J Pediatr.* 2017;43(1):18

Resources (continued)

Links
- **Massachusetts 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 www.masschildhealthquality.org/work/care-coordination/
- **National Resource Center for Patient/Family-Centered Medical Home.** American Academy of Pediatrics. https://medicalhomeinfo.aap.org/about/Pages/National%20Resource%20Center%20Overview.aspx
- **Boston Children's Hospital Integrated Care Program.** http://www.childrenshospital.org/integrated-care-program
- **National Center for Care Coordination Technical Assistance.** Boston Children's Hospital. http://www.childrenshospital.org/integrated-care-program/national-center-for-care-coordination-technical-assistance
- **Lucile Packard Foundation for Children's Health.** https://www.lpfch.org/
- **National Standards for Systems of Care for Children and Youth with Special Health Care Needs.** Association of Maternal and Child Health Programs. http://cyshcnstandards.amchp.org/app-national-standards/#/
- **National Standards for CYSHCN Measures Compendium.** National Academy for State Health Policy. https://nashp.org/national-standards-compendium/

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Case-Based Learning

CASE STUDY #1

Sharing Information and Coordinating Care Across Transitions

AAP policy statement recommendation #3:
Continually involve and engage the patient/family (eg, families as partners/advisors), build on the strengths of the patient/family, clearly delineate responsibilities of team members, and create careful handoffs when transitioning across settings (eg, between inpatient and outpatient settings and between pediatric and adult care providers, systems and/or settings).

AAP policy statement Recommendation #5:
Use care coordination across transitions between entities of the health care system (eg, between and among patient care teams, across settings, between caregivers, and between health care organizations) and with transitions over time (eg, across the life span, between episodes of care, and across trajectory of illnesses).

AAP policy statement recommendation #6:
Ensure that co-management and communication occur among specialists and primary care providers. This care model requires reciprocal and bidirectional communication (eg, secure e-mails, phone calls, notes, and faxes), which can be augmented, but not replaced, with health information technology.

What can be done to ensure clear communication of the patient's and family's needs and planned care with a clear timeline and responsibility for important tasks?

What practices support reliable and bidirectional information sharing among members of the health care team so that nothing falls through the cracks across transitions in care?

Note to the facilitator: This module includes a clinical scenario that can be used to illustrate practical ways to operationalize the above recommendations. This scenario can be adapted or a new scenario can be developed that resonates with the participants. For example, instead of having participants place themselves in the shoes of a pediatrician or other physician, they could discuss the case of a subspecialist or allied health provider who is seeking to develop recommendations and communicate them to primary care, community agencies, or school. Ensure the case has the following elements:

- Patient characteristics (What types of patients do the participants see? Is there a particular disease process or functional challenge commonly faced among the participants?)
- Clinical setting (In what setting are patients typically seen? Is it an interprofessional clinic, private practice, specialty consultant service, or community agency?)
- Need(s) to be addressed outside of the clinical setting (This may include a subspecialty referral that is being placed for a clinical question, a follow-up required with a pediatrician or other physician, or a concern raised in a school or community setting or by a behavioral health clinician.)

Independently read and reflect on the following case then discuss it in your small group. After 5 minutes, we will debrief as a larger group.

Eric

Eric is a 12-year-old boy with sickle cell disease who had a recent ischemic stroke, which has led to the development of a seizure disorder. You coordinate Eric's care in the primary care clinic and are reviewing his case between visits. He is already followed in the general neurology and sickle cell hematology clinics. At his last neurology appointment, transferring recommendation was made to transfer Eric's care to a pediatric stroke team at the local tertiary care center. You also see that Eric's mother called the clinic last week, expressing concern that Eric's learning difficulties have worsened at school, and you recognize that his individualized education plan from school needs to be updated.

- Who are the team members that need to come together to best coordinate Eric's care?

- What transition is occurring?

- What needs and care goals can you identify?

- What **actions** will you take to coordinate Eric's care to ensure a smooth transition for Eric and his family across multiple settings?

- What **challenges** might you face in this process?

    Probe: Who are the new members on Eric's team?
    How will you communicate these roles to the family?

Note to the facilitator: As small groups discuss their responses, consider offering the following probing questions to stimulate discussion:

- How will you communicate with Eric's family regarding the new membership and roles in his health care team?

- How will you share information between members of the health care team?

- What tools or resources might you need to best assist Eric and his family?

After 5-10 minutes, debrief in a larger group. Write 2 headings on the board: "Challenges" and "Actions." Ask each small group to share their "headlines"— 1 or 2 key points that they discussed or key questions that they had.

Case-Based Learning

continued

Actions may include:

- Notify Eric's family of the recommendation to refer him to a stroke clinic.

- Send the referral to the stroke clinic administration with a recommended time frame.

- Contact the family to ensure the school is aware of Eric's medical condition and risks, and communicate with the clinic nurse to ensure that any medications needed at school have an updated medication order.

- Reconvene a meeting with Eric's school team and advocate for a reevaluation to be completed or financially supported through the school. Consider exploring whether having the assessment covered by medical insurance is a feasible and/or faster option.

- Explain to Eric's family exactly who their new health care team is (pediatrician, neuropsychologist, administrative assistant, nurse, etc.) and who to contact for potential issues (i.e., Who will manage fevers or urgent care needs? Who will prescribe and monitor each medication? Identify the need for a fever action plan in the care plan, outlining steps to initiate, who to call, and when to take Eric to the emergency department for a fever or pain crisis.)

- Develop and update a care plan for Eric. Include the names, roles, and contact information for each care team member. (Decide who is responsible for updating and managing the care plan among the multiple partners involved in Eric's care.)

- Ensure the care plan is accessible to all members of the health care team (i.e., in the electronic health record and patient or family portal and give a hard copy to the family).

- Advise the family that if they have not heard from the stroke program administration in 2 weeks, for example, they should contact the clinic directly.

  - ~ Tell the family that this type of action is an example of contingency planning—outlining steps to be taken if expected results do not occur and preparing for alternative outcomes to ensure immediate and appropriate follow up of potential issues.

  - ~ Also, highlight the importance of closing the loop on this referral—make a plan to reconnect with the family or clinic to ensure the appointment was made and attended.

Case-Based Learning

continued

Challenges may include:

- Ensuring Eric is seen by the stroke team in a timely fashion and establishing a mechanism to follow up on this
- Maintaining communication with Eric and his family so they are aware of the transition to the stroke clinic, understand the roles of the new care team members, and understand who is responsible for managing each potential health issue
- Developing a comprehensive care plan and comanaging with care team members in different health care settings
- Identifying a point person to coordinate care team member roles and follow up on action items
- Ensuring accessibility of the care plan—forms of communication that are reliable and secure
- Communicating with Eric's school and arranging for a neuropsychologist evaluation to inform a new individualized education plan
- Ensuring the care plan is updated consistently and accurately, reflecting all of the care by Eric's care team

Didactic

Slide: Coordinating Care Across Transitions

Transitions in care are frequent! Each transition should be accompanied by a thoughtful handoff to ensure important information isn't lost or forgotten.

- Handoff: The transfer of pertinent information between members of a patient's care team, enabling the person to safely assume responsibility for some aspect of care.
- Handoffs occur in multiple contexts:
    - ~ To and from the community and hospital
    - ~ To and from an on-call physician or nonphysician clinician
    - ~ To and from a consultant
    - ~ To and from a medical subspecialist or surgical specialist on another service
    - ~ To and from home care services
    - ~ From pediatric to adult care team members or settings

Facilitator notes: This training session has addressed suggested actions that the learners can take to their practice to facilitate smooth transitions in care for patients like Eric. Here are some tools that can help the learners implement these actions...tomorrow!

Case–Based Learning

continued

Slide: Tools for Ensuring Smooth Transitions in Care

- **Collaborative consults: outlining the purpose of a visit, relevant clinical information, requested referral relationship, and timeline**

- Care mapping: creating a visual representation of a patient's care team members in collaboration with the family, discussing roles and who-to lines of communication

- **Action grid: development of an action item grid with the family outlining the overall care goal, task to be completed and person responsible for completing the task, timeline for completion, and contingency plan**

- Care plan: a comprehensive, integrated, shared, and dynamic document that incorporates a summary of medical issues, care team membership, prioritized goals of care, and necessary actions to achieve the goals

Facilitator notes: Demonstrate how 2 of these tools could be used in Eric's case.

Slide: Collaborative Consults

Pediatric Stroke Program Referral

Reason for Visit	**Relevant Clinical/Psychosocial Information**
First-time evaluation for multidisciplinary care following ischemic stroke in a child with sickle cell disease.	12-year-old boy with history of sickle cell disease. Developed a seizure disorder following ischemic stroke, has been followed in general neurology program up to this point. Learning difficulties noted at school.
Requested Referral Relationship ☐ One-time consultation ☐ Comanagement/shared care ☐ Subspecialty-based management ✖ To be determined	**Question to Be Answered** What surveillance is required given Eric's history of ischemic stroke?

Case-Based Learning

continued

Slide: Action Grid

Goal	Action	Who is responsible	Timeline	Contingency
Ensure appointment management and preventative care for stroke and its sequelae	Transfer of care to the pediatric stroke program	PCP	Referral sent on Jan 2nd requesting an appointment within 4 weeks.	If family has not received a call from the stroke clinic in 2 weeks, they should call the clinic directly at (111) 111-1111. Clinic administrative assistant will contact family in 2 weeks to follow up on referral.
Support Eric's learning at school	Neuropsychological evaluation to inform a new IEP	Social worker	Will establish school contact Jan 9th and convene school team meeting to plan reevaluation.	Social worker will contact family the week of Jan 16th to coordinate meeting and share care plan with school.
	Ensure school has updated medical information	Clinic nurse	Will call school the week of Jan 9th.	Nurse will call family to confirm when contact has been made.
Update/maintain care plan for Eric with input from all team members and family	Incorporate plans/recommendations from all specialists and PCPs, IEP components, specialists into care plan	Clinic nurse/PCP	Will collect this input prior to appointment below.	
	Engage patient and family to obtain input and identify needs and their goals	Clinic nurse/PCP	Appointment arranged for week of Jan 16th to discuss care plan.	
	Distribute care plan to members of the health care team.	Clinic nurse/PCP	Nurse and PCP will send care plan to the patient portal and email/mail a copy to parents, school, specialists for review and to community recreation center after above appointment.	

What practices will YOUR TEAM use to share information and coordinate patient care across transitions?

We have discussed 2 tools that you can use *starting tomorrow:*
- The collaborative consult
- The action item grid

Case-Based Learning
continued

Care Planning and Coordinating Care Across Transitions

AAP policy statement recommendation #1:
Use and create mechanisms for patients/families to learn the skills they may need to be partners in their own care and in decision-making for optimal care coordination.

AAP policy statement Recommendation #2:
Ensure that the patient's and family's needs for services and information sharing (eg, care planning) across people, systems, and functions are met via (a) formal assessments, (b) infrastructure (eg, teams), and (c) tracking (eg, registries); this is crucial in operationalizing care coordination.

AAP policy statement recommendation #4:
Use and develop efficient and accredited health information systems and information technology advances to foster successful transfer of information; to support collaborative communications between patients, families, and the care team; and to facilitate shared decision-making (eg, developing and using care plans).

AAP policy statement recommendation #5:
Use care coordination across transitions between entities of the health care system (eg, between and among patient care teams, across settings, between caregivers, and between health care organizations) and with transitions over time (eg, across the life span, between episodes of care, across trajectory of illnesses).

AAP policy statement recommendation #6:
Ensure that comanagement and communication occur among specialists and primary care providers. This care model requires reciprocal and bidirectional communication (eg, secure e-mail, phone call, note, fax), which can be augmented, but not replaced, with health information technology.

AAP policy statement recommendation #7:
Ensure ongoing education of elements of care coordination and the medical home for practicing physicians, nurse practitioners, physician assistants, nurses, medical students, resident trainees (across disciplines), mental/behavioral health care practitioners, social workers, and other health care professionals via specific training/curricula, continuing medical education programs, and publications.

AAP policy statement recommendation #10:
Understand and use new care coordination codes (99487–99489; 99495-99496) and advocate for payment of these care coordination services by payers.

- What can be done to facilitate shared decision-making for families and foster care integration?
- How should care team members engage patients and families in care planning and shared decision-making?
- What strategies and tools (eg, health information technology) can care team members use in comanagement and to ensure an effective transition of care?
- What billing codes can be used to help support the time spent in coordinating care in practice?

Independently read and reflect on the following case then discuss the case in your small group. After 5 minutes, we will debrief as a larger group.

Case-Based Learning

continued

Lucia

Lucia is a 14-year-old female with spina bifida, who you have cared for since birth. You and your team are the primary care clinicians and work closely with her specialty team, including orthopedics, urology, neurology, and physical medicine and rehabilitation. Her mother, a single caregiver, has been forced to move several times due to housing instability and financial challenges. You have started to address Lucia's adolescence, including learning self-care, in recent visits to allow her independence at school and in the community. Yesterday, her mother left a message for you indicating concern about a recent hospitalization and new urology team. She stated Lucia was recently admitted and there were "changes being made." Uncertain of the new plan and new medications, she also stated they had not received the new catheters from the medical equipment company that were ordered at the last urology visit.

· Discuss the team members who are needed to best coordinate care for Lucia.

· Identify some of the psychosocial issues that need to be addressed with Lucia's mother as one of the care team members.

> Probe: Think about family-centered care and building trust.

· What aspects of care transition need to be addressed for Lucia?
    ~ Transition to adult-oriented systems (self-care)
    ~ Transition of care across settings, from hospital to home

· What is the biggest challenge in coordinating her care?

Facilitator notes: As small groups discuss their responses, consider offering the following probing questions to stimulate discussion:

· Social determinants of health have a profound impact on health outcomes. Some social determinants of health include poverty, literacy, food and housing security, environmental risks, health insurance status, immigration status, interpersonal and neighborhood safety, energy security, and transportation needs.

· What role are the social determinants of health playing in caring for Lucia and her family?

· How can you ensure medical needs, community partners, and identified resources are part of the care team and care planning? Think about the roles of the hospitalist team, discharge planning team, and medical equipment providers.

· What tools can foster comanagement and ensure communication across settings? Think about care planning, patient portals, shared decision-making, and transition of care planning.

After 5-10 minutes, debrief in a larger group. Write 2 headings on the board: "Challenges" and "Actions." Ask each small group to share their "headlines"—1 to 2 key points they discussed or key questions they had.

Case-Based Learning

continued

Actions may include:

- Meet with Lucia's mother to better understand her housing and financial challenges and identify resources that may help her.

    ~ Connect her to community partner(s) and resources that can assist her or a social worker who can discuss potential options with her. Be sure to follow up to confirm that this connection occurred to close the loop.

    ~ Consider employing a screening tool for social determinants of health to facilitate a proactive approach with patients and families. Recognize that families may be more likely to disclose financial struggles and challenges related to social determinants of health on paper versus face-to-face screening.

- Contact the urology group to better understand any changes made and plans for follow-up, necessary equipment, and medication changes. Be sure to check that Lucia's mother is aware of these plans and demonstrates an understanding of the recommendations.

- Work with Lucia's mother to set goals for Lucia's care and ensure her understanding of Lucia's medications, care, and equipment and encourage her understanding of shared decision-making, both in your office and with other care team members.

- Develop and maintain a care plan for Lucia that includes all of her specialist information, medical equipment providers, therapists, IEP information, community nursing services, medications, community providers, school/educational information, names, phone numbers, home nursing information, insurance, and supplies (eg, size, amount, and type of formula).

    ~ Be sure that Lucia and her mother review and inform the content of the care plan prior to finalizing the content.

    ~ Ensure that the role of each care team member is outlined in the care plan so Lucia and her mother know who to contact for issues as they arise.

    ~ Work on reconciling the home nursing orders for Lucia with your care plan, ensuring accuracy, parent goals being met, and smooth communication about Lucia's needs.

    ~ Track your time coordinating care, and bill care coordination codes (99487–99489) as outlined in the contracts with Lucia's insurance carrier.

- Provide Lucia and her mother with several hard copies of Lucia's care plan. Fax or email Lucia's care plan to the specialists involved in her care, the appropriate contacts at her school, her therapists, and her medical equipment providers.

- Add Lucia's care plan to her patient portal to make it easily accessible for her mother.

    ~ Ensure that Lucia's mother understands how to log in to the patient portal and access it via her smart phone, and when Lucia is hospitalized, how to access the patient portal in community settings and communicate the care plan across settings.

- Work with Lucia and her mother on transition care planning for adult-oriented care. Consider using a self-management tool to begin to teach Lucia about self-care and spina bifida and to assess her readiness to take a more active part in her health care.

- Contact the hospitalist team managing Lucia during a hospital admission, and have your care coordinator connect with the discharge planning team to better understand the events that occurred during her admission, recommendations, and her discharge plan.

Case–Based Learning

- Talk with the hospital team to determine the optimal process for achieving bidirectional communication (including phone calls and sharing of information) when your patients are admitted to the hospital.

    ~ Discuss roles, team members, and information sharing, including care plans and reasons for admissions).

    ~ Consider implementing post-discharge follow-up calls for all of your patients following hospitalizations to assess families' understanding of discharge instructions, necessary medications, prior authorizations, and need for follow-up visits.

    ~ Establish a standard of care for scheduling patients for post-hospitalizations within 7 to 14 days.

    ~ Familiarize yourself with the required communication, documentation, timing of post-discharge visits, and billing codes for post-hospital discharge visits (99495 and 99496).

- Explain to Lucia and her mother who the members of Lucia's health care team are (physicians, nonphysician clinicians, mental health practitioners, community partners) and who to contact for potential issues (ie, Who will manage fevers or urgent care needs? Who will prescribe and monitor each medication? Who will order and manage equipment?). Be sure this is clear on Lucia's care plan.

- Set up a meeting with the top 3 insurance carriers to discuss payment for codes associated with care coordination and hospital follow-up. If these codes are not included in your current contract, explain the amount of communication that is required by you and your team for care coordination and hospital follow-up. Discuss possible benefits for patients, your practice, and the payer, and payment structures.

    ~ Transition of care codes (99495 and 99496)
    ~ Care coordination codes (99487–99489)

- Work on regular education sessions and, possibly, a staff retreat on patient- and family-centered care, team building, huddles, transition of care planning and care to adult-oriented systems, and the role of care coordination. Be sure to include physicians, nurse practitioners, physician assistants, nurses, medical students, resident trainees (across disciplines), mental/behavioral health care practitioners, social workers, community health workers, parent partners, and community partners.

- Engage parent partners in your practice to give feedback and participate in care coordination education for your staff supporting the critical role of family-centered care.

- Advise Lucia's mother that if she has not received her new catheters within 24 hours or has any questions about medication administration, she should contact the clinic directly.

    ~ Highlight this type of action as an example of contingency planning— outlining steps to be taken if expected results do not occur and preparing for alternative outcomes to ensure immediate and appropriate follow-up of potential issues.

    ~ Instruct Lucia's mother to make a follow up appointment with the urology office and to contact your office with any issues. Ensure someone from your office is following up with her.

Case–Based Learning

Challenges may include:

· The social determinants of health challenges facing Lucia's mother, including housing and financial instability with the lack of handicapped accessible housing, and lack of resources, time, and social workers in practice.

· Understanding and launching the transition to adult-oriented systems with Lucia and her mother, and addressing self-care.

· Getting team buy-in across the practice for care coordination training and understanding roles and definitions.

· Working with insurance companies on coding and payment for care coordination and transition of care.

· Ensuring adequate communication with the hospitalist team and the specialists caring for Lucia.

· Ensuring that Lucia's mother understands shared decision-making and can advocate for herself.

· Developing a comprehensive care plan and comanaging with care team members in different health care settings.

· Reminding Lucia's mom about the availability of the care plan in the electronic patient portal.

Case-Based Learning

continued

Didactic

Slide: Social Determinants of Health

- Conditions in the places where people live, learn, work, and play that can inform their health risks and outcomes
- The role of patient- and family-centered care and trust
- Examples:
    - ~ Housing
    - ~ Access to food
    - ~ Transportation
    - ~ Exposure to crime, violence, domestic violence, interpersonal violence
    - ~ Social support
    - ~ Access to educational, economic, and job opportunities
- Identify and work with community partners.
    - ~ WIC, housing resources, HUD
- Use tools designed for social determinants of health
    - ~ Food insecurity
    - ~ Adverse childhood events (urban)

Slide: Care Coordination Tools

- Care planning list of components for a care plan
- Instructions for patient access to the patient portal
- Patient huddles
- Shared decision-making for families

Slide: Transition to Adult-Oriented Systems Tools

- Six core elements of transition
    - ~ Transition policy **(Facilitator note:** *Have teams work through what their ideal transition policy might include)*
    - ~ Transition index for practices
- Self-management tools/transition readiness assessment tools
    - ~ On Traq
    - ~ Assess caregivers and youth when appropriate
    - ~ Address guardianship and power of attorney when indicated
- Gottransition.org

Case-Based Learning
continued

Slide: Billing for Care Coordination Services and Transition of Care

CARE COORDINATION 99487–99490
Chronic care management services, at least 20 minutes of clinical staff time directed by a physician or other qualified health care professional, per calendar month, with the following required elements:

- Multiple (2 or more) chronic conditions expected to last at least 12 months, or until the death of the patient
- Chronic conditions place the patient at significant risk of death, acute exacerbation/decompensation, or functional decline
- Comprehensive care plan established, implemented, revised, or monitored

  - 99487: Used if a nonphysician staff member spends more than 1 hour over a 30-day period on care coordination
  - 99488: Includes 1 hour of care coordination with a nonphysician and a face-to-face visit
  - 99489: Used for 30-minute increments over the initial hour of care coordination.

TRANSITION BETWEEN CLINICAL SETTINGS 99495
Transitional care management services with the following required elements:

- Communication (direct telephone contact, telephone, electronic) with the patient and/or caregiver within 2 business days of discharge
- Medical decision-making of at least moderate complexity during the service period
- Face-to-face visit within 14 calendar days of discharge

99496
Transitional care management services with the following required elements:

- Communication (direct contact, telephone, electronic) with the patient and/or caregiver within 2 business days of discharge
- Medical decision making of high complexity during the service period
- Face-to-face within 7 calendar days of discharge

Slide: Tools for Ensuring Smooth Transitions in Care

- **Pre-encounter handoff: outlining the purpose of a visit, relevant clinical information, and requested referral relationship and timeline**
- Care mapping: creating a visual representation of the patient's care team members in collaboration with the family and discussing their roles and who-to lines of communication
- **Post-encounter handoff: development of an action item grid with the family outlining the overall care goal, task to be completed, who is responsible, timeline for completion, and contingency plan**
- Care plan: a comprehensive, integrated, shared, and dynamic document that incorporates a summary of medical issues, care team membership, and prioritized goals of care and actions to achieve them

Facilitator note: Demonstrate the use of 2 of these tools in Lucia's case.

Case-Based Learning
continued

Slide: Action Grid—Develop Care Plan Components for Lucia

Facilitator note: Have participants list core elements of the care plan.

Some ideas are listed below: LUCIA CARE PLAN

Essential Fields/Components
· Name
· Date of birth
· Insurance (primary and secondary)
· Phone number and emergency contact information
· Parent or caregivers' names
· Diagnoses
· Medications
· Allergies with doses
· Specialists' names and phone numbers
· Hospitalizations and surgeries
· Child or youth strengths
· Family goals for their child

Support Services
· Equipment (if applicable, catheters, tracheostomies, gastrostomy tubes, wheelchair, orthotics, etc.)
· Therapies (speech, PT, OT)
· School/child care/IEP
· Home care and/or nursing services
· Pharmacy
· Mental health agencies and providers
· Dental care
· Community agencies
· Transition care plan elements, if applicable

Secondary Elements
· Past medical history and review of systems
· Communication devices
· Home modifications
· Activities of daily living (challenges, toileting, hygiene)
· Respite
· SSI
· School information (grade, teacher, IEP, IFSP)
· Feeding, diet, nutrition
· Housing and transportation needs
· Hearing and vision services

Alternative Medicine, Palliative Care

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Module 1: High-Value Integrated Care Outcomes Depend on Care Coordination

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1

Educational Purposes Only – No Medical Advice

The Pediatric Care Coordination Curriculum is offered for educational purposes only and is not meant as a substitute for independent medical judgment or the advice of a qualified physician or health care professional. Users who choose to use information or recommendations made available by the Pediatric Care Coordination Curriculum do so at their own risk and should not rely on that information as professional medical advice or use it to replace any relationship with their physicians or other qualified health care professionals.

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2

Objectives

- Discuss key components of care coordination within an integrated model of care delivery.
- Assess current practices that support care coordination and integrated care delivery in a variety of settings, including state, regional, delivery system, community agency, or clinics.
- Prioritize areas of improvement in care integration and care coordination in the current practice.
- Identify established tools and processes that can be used to implement key components of care coordination.
- Develop an action plan outlining specific goals to facilitate care coordination in the practice .

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3

Overview

- Care coordination from theory to practice
- Asset and needs assessment
- Case study: introduction to tools
- Shared plan of care
- Action-oriented exercise

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4

Objective

Participants will be able to…

<u>Discuss key components</u> of care coordination within an integrated model of care delivery.

5

6

What is Care Coordination?

<u>2014 AAP Policy Statement</u>

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

<u>Defined care coordination as</u>

A patient- and family-centered, assessment-driven, team-based activity designed to meet the needs of children and youth while enhancing the caregiving capabilities of families. Care coordination addresses interrelated medical, social, developmental, behavioral, educational, and financial needs to achieve optimal health and wellness outcomes.

(American Academy of Pediatrics Council on Children with Disabilities and Medical Home Implementation Project Advisory Committee. Patient- and family-centered care coordination: a framework for integrating care for children and youth across multiple systems. *Pediatrics*. 2014;133(5): e1451–e1460)

7

Care Coordination Enables Integrated Care

Care Fragmentation	Care Integration

Care coordination

- Lack of communication between care providers
- Gaps in services
- Duplication of services

- Team-based care
- Connections to community
- Collaborative care planning

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Integrated Care Framework

Integrated Care "Holistic Care"

- Team-Based Care
  - Team Configuration
  - Communication
  - Knowledge Sharing
- Connection to Community
  - Information
  - Family Impact
- Collaborative Care Planning
  - Long-Term Plan/Roadmap
  - Goals

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Who Is Involved in Care Coordination?

- Patients and families
- Pediatricians and other physicians
- Pediatric medical subspecialists and pediatric surgical specialists
- Case management
- Public and commercial payers
- Community health workers
- Schools
- State agencies
- Title V

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One Family's Care Map

www.childrenshospital.org/care-mapping

©2012 Cristin Lind
www.durgastoolbox.com
Blog: Durga's Toolbox

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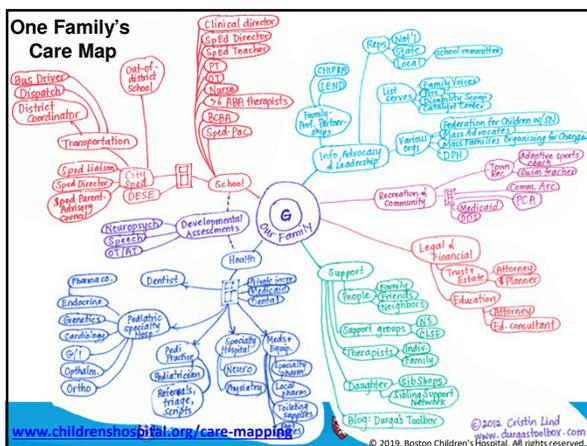
11

Why Is Care Coordination Important? Impact of Care Fragmentation

- Fragmentation leads to inefficient, less safe care
- Impact on families
  - Leaving employment
  - Divorce
- Impact on employers
  - Higher costs
  - Presenteeism and absenteeism

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Slide 13

Measure What Matters
Domains of Integrated Care

Align with the Quadruple Aim for better health, better care, and less cost per capita.

- Person, patient, family, and caregiver experience
- Care coordination
  - Closing the loop
  - High-quality handoffs
  - Care tracking
  - Care planning
- Utilization and financial outcomes
  - Admissions, readmissions, and emergency department utilization
- Provider experience

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Slide 14

Achieving the Quadruple Aim

Improved family experience

Improved provider experience

Care integration

Improved quality

Reduction of cost

[1]Institute for Healthcare Improvement. [http://www.ihi.org]. 2014
[2]American Academy of Pediatrics Council on Children with Disabilities and Medical Home Implementation Project Advisory Committee. Patient- and family-centered care coordination: a framework for integrating care for children and youth across multiple systems. *Pediatrics.* 2014;133(5): e1451–e1460
[3]Berwick DM, Nolan TW, Whittington J. The Triple Aim: care, health, and cost. *Health Aff* (Millwood). 2008;27(3):759–769

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Slide 15

Matching Services to Complexity

Children with chronic conditions
- Behavioral (ADHD, depression, anxiety, PTSD)
- Asthma
- Obesity
- Diabetes
- Adverse childhood experiences

Children with complex needs
- Neurodevelopmental (autism, etc.)
- Behavioral/psychiatric
- Hematology/oncology
  - Sickle cell
  - Hemophilia
- Technology dependent
- Multiple chronic conditions
- Adverse childhood experiences

Complex

Chronic

Healthy, Preventive

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Slide 16

Prevalence of Pediatric Complexity

Complex

Chronic

Healthy, Preventive

Percent of population

0.5%

25%

74.5%

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Slide 17

Evolving the Care Model to Achieve High Value

A subspecialty-based or primary care-based team may serve as the medical home for patients with complex needs. The members of the care team work to provide an integrated experience, with an accessible, designated care coordinator who supports patient and/or family needs, including social and behavioral health needs.

Complex

The primary care team serves as the medical home within a collaborative care model, integrating services across settings. The primary care team supports care coordination with the patient and/or family.

Chronic

The primary care team serves as the medical home, and specialist visits are made as needed. Most care coordination is conducted by the patient and/or family.

Healthy, Preventive

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Slide 18

Impact of Care Fragmentation Patients with Behavioral Health Needs

86% of families are solely responsible for coordinating their children's mental/behavioral health care.

Lambert, Pond, Hickey, Antonelli
Parent/Professional Advocacy League and Boston Children's Hospital
2012

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Slide 19

AAP Policy Statement

POLICY STATEMENT

Patient- and Family-Centered Care Coordination: A Framework for Integrating Care for Children and Youth

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Slide 20

AAP Policy Statement
Select Recommendations

- Create opportunities for family skill building.
- Ensure parent and family needs for services and information sharing are met.
- Utilize care coordination to support transitions of care.
- Create a system of comanagement and communication between pediatricians, pediatric medical subspecialists, and pediatric surgical specialists.
- Provide ongoing education for multidisciplinary care and the care coordination team.
- Collaborate with Title V Maternal and Child Health Services Block Grant state programs.

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Slide 21

Conduct formal assessments of family strengths, needs, and goals at new patient visits.

Provide community and family networking resources and connections.

Ensure that patient and family needs for services and information-sharing are met.

Using a survey and/or a family advisory group, gather family experience data to inform quality improvement.

Collaborate with families to establish clear pathways, contingencies, and follow-up with medical-, community-, and educational-based services.

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Slide 22

Define and record action items resulting from each in-person visit.

Assign accountability and a timeline to every action items.

Ensure clear communication and delineation of responsibility across transitions in care.

Involve patients and families as partners in handoffs, articulating family goals and developing action steps to achieve them.

Establish contingency plans with patients and families, such as saying, "If you don't receive a call in 2 weeks, call us back at xxx-xxx-xxxx."

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Slide 23

Facilitate transitions between entities with warm handoffs, including a standard process for follow-up of action items.

Collaborate on the development of interagency agreements about how patient information will be shared.

Coordinate care across all members of the care team, across multiple settings, and over time.

Define the nature of the relationship between teams and settings (ie, consultations or shared care).

Support information transfer during transitions by using electronic pathways (ie, patient portals).

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Key Elements of Care Coordination

Needs assessment and goal setting	• Use a structured tool to identify needs • Engage families in defining shared goals
Care planning and communication	• Cocreate and implement care plans with families • Ensure accessibility and regular updates or reassessments of care plans
Facilitating care transitions	• Close the loop on referrals • Ensure timely communication across transitions
Connecting with community resources and schools	• Link to family partners and agencies • Coordinate services and ensure bidirectional communication
Transitioning to adult care	• Develop written plans for patients transitioning to adult care • Foster self-care and self-management skills

Based on the Key Elements Framework from the Care Coordination Task Force, Massachusetts Child Health Quality Coalition.
http://www.masschildhealthquality.org

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Objective

Participants will be able to…

- <u>Assess current practices</u> that support care coordination and integrated care delivery in a variety of settings, including state, regional, delivery systems, community agencies, or clinics.
- <u>Prioritize areas for care integration and care coordination improvements</u> in the practice.

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Asset and Needs Assessment

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Care Coordination Framework: Linking to Measures

Key Elements

Needs assessment for care coordination and continuing engagement
- A family-driven, youth-guided needs assessment for goal setting
- Use a standard process to assess care coordination needs (differs from clinical needs)
- Engage team and assign clear roles and responsibilities
- Develop authentic family/care team partnerships; requires family and youth capacity building and professional skill building

Care planning and communication
- Family and care team codevelop care plans
- Ensure communication among all members of the care team
- Monitor, follow-up, respond to changes, and track progress toward goals
- Workforce training occurs, promoting effective care plan implementation

Facilitating care transitions (inpatient and ambulatory)
- Engage family to align transition plan with family goals and needs
- Implement components of successful transitions (8 elements of a family-driven and youth-guided care transition, including physician acknowledgement of responsibility)
- Ensure information needed at transition points is available

Connecting with community resources and schools
- Facilitate connection to family-to-family support organizations, including chapters of Family Voices and federally-funded Family-to-Family Health Information Centers
- Coordinate services with schools, agencies, and payers
- Identify opportunities to reduce duplication of efforts in building knowledge of available community services

Transitioning to adult care
- Implement Center for Health Care Transition Improvement's Six Core Elements
- Teach or model self-care skills, communication skills, and self-advocacy

Source: Adapted from
***Massachusetts Child Health
Quality Coalition Care
Coordination Task Force***

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Objective

Participants will be able to…

<u>Identify established tools and processes</u> that can be used to implement key components of care coordination.

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Keystone Pediatrics

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Case Study: Keystone Pediatrics

- Keystone Primary Care is a community-based primary care office that serves approximately 7,000 pediatric patients, 35% of whom are insured by Medicaid.

- The office leadership receives the Quality Report Card and notes that the metric for adolescent well visits is 30%.

- This presents an opportunity for improvement. As the practice implements a quality improvement initiative to increase adolescent well visit rates, it anticipates that behavioral screening rates will increase.

- Currently, 25% of the screens are returning positive. Providers have started sending referrals to social work. It is unclear how many adolescents are actually connecting with someone from social work, and the clinic team realizes it doesn't have a process for closing the loop on these referrals.

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Identifying Areas for Improvement

- A gap in the structured process for completing well visits
- A gap in the system of referrals and handoffs between team members

- Keystone Primary Care is a community-based primary care office that serves approximately 7,000 pediatric patients, 35% of whom are insured by Medicaid.

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- This presents an opportunity for improvement. As the practice implements a quality improvement initiative to increase adolescent well visit rates, it anticipates that behavioral screening rates will increase.

- Currently, 25% of the screens are returning positive. Providers have started sending referrals to social work. It is unclear how many adolescents are actually connecting with someone from social work, and the clinic team realizes it doesn't have a process for closing the loop on these referrals.

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Areas of Improvement

- **Identifying how to improve family well-visit attendance**
  - o Is there something(s) that is preventing the family from scheduling or attending well-child visits?
  - o Are there things that the team could do to make it easier for families?
- **Creating a system for closing the loop on referrals**

- Getting feedback from patients and families

- Communicating more clearly

- Creating a system for handoffs between care team members (including family!)

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The Focus With Today's Case

- Ensuring that patient and family needs for services and information sharing are met

- Ensuring clear communication and delineation of responsibility across transitions in care

- Coordinating transitions of care across teams and settings over time

Patient- and Family-Centered Care Coordination: A Framework for Integrating Care for Children and Youth Across Multiple Systems. AAP policy statement, 2014

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Measuring Patient and Family Experience

- Family Experiences with Coordination of Care (FECC) Survey

- Pediatric Integrated Care Survey (PICS)

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Family Experiences with Coordination of Care (FECC)

- Assessment of 20 caregiver-reported care coordination quality measures for children with medical complexity
 - Care coordination services
  - Messaging
  - Protocols/plans

- 12-month time frame

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Family Experiences with Coordination of Care (FECC)

3a. Did anyone in the main provider's office help you to manage your child's care or treatment from different doctors or care providers?
    Yes
    No

26. In the last 12 months, did the main provider's office have a web site or app you could use between visits to look up information about your child's visits and health care?
    Yes
    No
    I don't know if my child's main provider's office has a web site or app

29. A shared care plan is a written document that contains information about your child's active health problems, medicines he or she is taking, special considerations that all people caring for your child should know, goals for your child's health, growth and development, and steps to take to reach those goals.
Has the main provider created a **shared care plan** for your child?
    Yes
    No

Gidengil C, Parast L, Burkhart Q, et al. Development and implementation of the Family Experiences with Coordination of Care survey quality measures. Acad Pediatr. 2017;17(8):863-870.

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High-Quality Handoffs

What is a handoff?

The transfer of pertinent knowledge between members of a patient's care team to establish a shared understanding.

Elements of High-Quality Handoffs

SENDER (ie, general pediatrician)	RECEIVER (ie, subspecialist, social worker)
• Purpose of patient encounter • Relevant clinical and/or psychosocial information • Requested referral relationship • Care plan or action item list	• Defined action items • Accountability • Timeline • Contingency planning

Funded in part by a grant from the Harvard Pilgrim Health Care Quality Grants Program.

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Collaborative Consults

- Why is the patient being referred (reason for referral)?
- What clinical/psychosocial information is pertinent to the referral?
- What is the requested referral relationship?
- What are the questions to be answered?

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High-Quality Handoffs: Collaborative Consults

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High-Quality Handoffs: Closing the Loop

Families should know the answers to the following questions:

- WHAT will be done before our next appointment? WHAT can I expect?
- WHO will do this? WHO will follow up?
- WHEN should I expect results? WHEN will I receive an update? WHEN should I follow up?
- WHY is this important to my child's health?
- HOW will my primary care provider be informed about this?
- HOW will this affect other parts of my child's care?

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Closed-Loop Communication: Action Grid

Principles of the Action Grid

- Family and patient centered
- Encounter specific
- Developed collaboratively with families and other members of the health care team
- Accessible and shared across care team members
- Includes elements of timeline and ownership for each action identified
- Reviewed and revised as needed

Pause for Reflection

- How could Keystone Pediatrics implement these tools to address the issues they have identified?
  - Patient and family experience: FECC and/or PICS
  - Handoff communication: collaborative consults, action grid

- *Think about the needs of your own teams.* What tools might be valuable and feasible for your team to implement?

Intervention

Keystone Pediatrics re-engineers part of the administrative role of Anne, who is currently an administrative assistant.

- Anne has background knowledge about the health care system and the needs of the patients and families from working in her role. She also has a general understanding of community and state resources from working in the clinic. She will transition her role to spend 10 hours a week focusing on care coordination.
- Anne will manage a registry of adolescent patients to ensure that well visits are scheduled and completed.
- She will help to organize and distribute action grids for families after in-person visits.

Collaborative Consults

Requested Subspecialty	Requested Referral Relationship
• School psychologist	• One-time consultation • Comanagement or shared care • Subspecialty-based management • To be determined
Clinician Reason for Visit	**Relevant Clinical/Psychosocial Information**
• First-time evaluation for potential counseling in school setting	• Patient screened positive for behavioral health concerns at last well visit • Parent shared that patient has not previously received behavioral health support but would be open to it

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Action Grid

Date: 4/27/18
Patient Name: Jane Smith
Clinic: Keystone Primary Care
Provider Name: Dr. Gonzalez

| 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 HPV immunizations.	Immunization 1,2,3	Jane Smith will review school schedule and call to make appointment for 2nd dose.	Before August 31, 2018	RN will call family August 1 as reminder. If family has questions, call 123-456-7891.
Assess potential need for in-school counseling.	Evaluation with school psychologist	Social worker	Social work will send referral to school psychologist, copy family on note.	If family does not get contacted by school psychologist by June 1, 2018, family will call back social worker at 123-456-7878.

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Implementing a Shared Plan of Care

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Implementing a Shared Plan of Care: Case Study

A 3-year-old boy with developmental delay and his family (Burmese refugees) were referred to your clinic by pediatric neurology for care coordination.

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Workflow: Five Phases Using a SPoC as an Approach to Family-Centered Care Coordination

Family Outreach & Engagement ➤	Partnership & Pre-Visit Preparation ➤	Teamwork & Population Care ➤	"Planned Care Visit" & SPoC Coproduction ➤	Ongoing CC & Community Transfer ➤➤➤
Build Rapport	Assess	Team Prepares	Listen/hear Coproduce	Use, learn & improve

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Ten Steps to Achieving a Shared Plan of Care

1	Identify who will benefit from having a shared plan of care.
2	Discuss with families and colleagues the value of developing and using a comprehensive and integrated plan of care.
3	Select, use, and review multifaceted assessments with the child, youth, and family.
4	Set shared personal (child and family) and clinical goals.
5	Identify other crucial partners, such as subspecialists or community resource providers, and include them in the process for the plan of care.
6	Develop the medical summary for the plan of care and merge it with negotiated actions.
7	Establish the negotiated actions for the plan of care and merge them with the medical summary.
8	Ensure that the plan of care is accessible, retrievable, and available.
9	Provide tracking, monitoring, and oversight for the plan of care.
10	Systematically use the process for the plan of care as a model for a life course and a population health approach.

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Objective

Participants will be able to…

<u>Develop an action plan</u> outlining specific goals to facilitate care coordination in the practice.

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SMART Goals

Specific

Measurable

Achievable

Relevant

Time-bound

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Your Action Plan

Action Planning

1. Identify one short-term and one long-term goal you have to improve care coordination in your clinical practice.

- Specific
- Measurable
- Achievable
- Relevant
- Time-bound

2. Once you have decided on your goals, consider the following:

➤ What barriers do you anticipate in achieving this goal?
➤ What is your plan to achieve this goal? (How? When? Where?)

Goal	Potential Barriers	Specific Action Plan
Within 7 days we will...		
Within 90 days we will...		

DRAFT

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Take-Home Points

- Care coordination is the set of activities that occurs in the space between
  o Visits, providers, hospital stays, agency contacts.
- Care coordination is necessary but insufficient for achieving integration.
  o Integration is essential for achieving optimal value.
- The only way to succeed is to engage all stakeholders– including patients and families–as participants and partners.

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Take-Home Points

- Build capacity: families and workforce.
  o Develop competencies to support integration.
  o Improve interprofessional education.
- Implement measures of care integration.
- Track outcomes, including value.
  o Quality and safety
  o Cost
  o Experience

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Resources

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Resources (continued)

Links

- **Massachusetts 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 www.masschildhealthquality.org/work/care-coordination/
- **National Resource Center for Patient/Family-Centered Medical Home.** American Academy of Pediatrics. https://medicalhomeinfo.aap.org/about/Pages/National%20Resource%20Center%20Overview.aspx
- **Boston Children's Hospital Integrated Care Program.** http://www.childrenshospital.org/integrated-care-program
- **National Center for Care Coordination Technical Assistance.** Boston Children's Hospital. http://www.childrenshospital.org/integrated-care-program/national-center-for-care-coordination-technical-assistance
- **Lucile Packard Foundation for Children's Health.** https://www.lpfch.org/
- **National Standards for Systems of Care for Children and Youth with Special Health Care Needs.** Association of Maternal and Child Health Programs. http://cyshcnstandards.amchp.org/app-national-standards/#/
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Presentations

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Boston Children's Hospital

HARVARD MEDICAL SCHOOL
TEACHING HOSPITAL

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Appendix A

Lucile Packard Foundation *for* **Children's Health**

Fact Sheet

An Almost Complete List of Services Used by Families and Children with Special Health Care Needs

by Edward L. Schor, MD

Children with chronic and complex health conditions and their families require access to a wide array of health care and other services to function optimally. These needs can be identified by patients and families in the creation of shared care plans, or consequent to screenings and assessments. Various referral policies and practices have been developed to facilitate access to these services. The following lists are intended to provide a classified enumeration of services that may be used and of value to children with special health care needs and their families. It can be used for care mapping, care planning, resource database creation and referral system development.

Family Services

Formal Family Support & Advocacy
- Advocacy services
- Care navigation
- Child care
- Family resource center services
- Homemaker services
- Organizing health records
- Parent-to-parent support
- Respite care
- Spiritual support and faith communities
- Categorical/Disease-specific organizations
- Voluntary organizations
- Blogs
- List serv
- Social media

Informal Family Supports
- Blogs
- Extended family
- Friends of child
- Friends of parents
- Neighbors
- Support groups for child, siblings and parents
- Clubs
- Cultural organizations/groups

Social Services
- Human Services Agency (Medicaid, IHSS)
- Child Protective Services (CPS)
- Child welfare agency and foster care
- Court Appointed Special Advocates (CASA)
- Financial assistance (SSI/SSDI)
- Home visiting
- Independent living
- Housing assistance
- Transportation assistance (payers, dispatchers, bus drivers)
- Voluntary organizations (Easter Seals, etc.)
- Food subsidies (Women, Infants and Children Food and Nutrition Service (WIC), food stamps)

Advocacy
- Advisory committees and councils
- Public testimony
- Non-profit voluntary organizations

Employer/Work
- Employer
- Worksite accommodations
- Disability benefits/Ticket to work
- Vocational rehabilitation
- Job placement

Health Services

Physical Health
- Primary pediatric care
- Primary adult care
- Pediatric subspecialty care
- Adult subspecialty care
- Surgical care
- Hospitals
- Emergency departments
- Urgent care
- Dialysis
- Chemotherapy
- Home health care
- Palliative care
- Hospice
- Dental care
- Nutrition education/consultation
- Vision care
- Complementary and alternative medical care (chiropractic, acupuncture, homeopathy, naturopathy)
- Traditional healers

Mental Health
- Behavioral therapy
- Family therapy
- Parent/child dyadic therapy
- Marital counseling
- Mental health care: child
- Mental health care: adult

Ancillary Services
- Interpretation/translation
- Service animals
- Laboratory
- Radiology/imaging
- Participation in research projects
- Genetic counseling
- Pharmacy and medication reconciliation

Developmental Disabilities & Rehabilitation
- Applied Behavioral Analysis (ABA) therapy
- Developmental screening
- Durable Medical Equipment (DME)
- Equipment repair
- Individual Education Planning (IEP)
- Individual Family Service Planning (IFSP/IPP)
- Modification of vehicles
- Needs assessment
- Paratransit and other accommodated transportation (handicapped parking)
- Physical accommodations in home
- Physical therapy
- Music therapy
- Equine therapy
- Feeding therapy
- Occupational therapy
- Speech/language therapy
- Psychological testing/treatment
- Protective supervision

Care/Service Coordination
- Assessment
- Care planning
- Case management
- Coordination among medical providers
- Coordination between medical providers and other community services
- Emergency care planning
- Patient advocacy
- Self-management education and supports
- Transition planning
- Visiting nurses

Long Term Care
- In-home health services (IHSS, private duty nursing)
- Medical supplies
- Residential care

An Almost Complete List of Services Used by Families and Children with Special Health Care Needs

Appendix A
continued

Community Services

Education
- Schools
- Accommodations, modifications, and other services (504 plan)
- Americans with Disabilities Act (ADA) accommodations
- Child care/Head Start/Preschool/Pre-K
- Home schooling
- Individual Education Plan (IEP)
- Public libraries
- School administrators
- School aide
- School nurse
- School teachers
- Special education teacher
- School-based therapists
- Vocational services
- Sign language
- Physical therapy
- Occupational therapy
- Speech therapy
- After-school care

Recreation & Community Resources
- Individual lessons
- Individual recreation
- Teams and group activities and clubs
- Accommodations to access public spaces
- Camps
- Special programs (Special Olympics, community events)

Public Safety
- 5-day supply of medication
- Earthquake preparedness/Earthquake kit
- Evacuation chairs
- First Responders (EMT, police)
- Emergency backup for power outages

Legalistic Services

Legal
- Private and legal aid attorneys
- Conservatorship
- Financial planning, wills, and trusts
- Guardianship
- Durable power of attorney
- Advance healthcare directive
- Public benefits eligibility (health care, SSI, disability care)
- Public benefits denial, reduction, or delay (insurance, treatment)
- Special education services
- Accommodations
- Supported decision-making

Juvenile Justice
- Expungement of records
- Mental/behavioral health services
- Substance abuse/addiction services
- Access to health care
- Medication management
- Special education
- Trauma informed care

Insurance and Financing
- Private health insurance company
- Health plan
- Insurance advocacy
- Public health plan (Medi-Cal/Medicaid, TRICARE)
- Special grants

ABOUT THE FOUNDATION: The Lucile Packard Foundation for Children's Health is a public charity, founded in 1997. Its mission is to elevate the priority of children's health, and to increase the quality and accessibility of children's health care through leadership and direct investment. Through its Program for Children with Special Health Care Needs, the Foundation supports development of a high-quality health care system that results in better health outcomes for children and enhanced quality of life for families.

The Foundation encourages dissemination of its publications. A complete list of publications is available at
http://www.lpfch.org/publications

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An Almost Complete List of Services Used by Families and Children with Special Health Care Needs

Appendix B

by Jeanne W. McAllister, BSN, MS, MHA

Families have long been asking for parent/professional partnerships with easy access to a team of professionals where their children obtain care. They also want and need a plan of care that summarizes coalesced information about their child and family, including medical history, recommendations, preferences, and actionable next steps. An implementation guide[1] from the Lucile Packard Foundation for Children's Health includes operating principles and suggests the use of a 10-step process for professionals to coproduce a plan of care with children and families (Table 1). The product resulting from these outlined steps is a shared plan of care (SPoC). The SPoC is a representation of the dynamic efforts of a trusting family and professional team partnership. A shared plan of care includes critical summative medical information as well as short- and long-term goals resulting from negotiated shared decisions.

Currently, a shared plan of care is being tested through implementation in varying contexts across the country. One study of its implementation[2] summarizes the effects of such an endeavor. Many of the recommendations and ideas outlined below stem from lessons resulting from this study. These ideas hold relevance for a variety of children and families and the health care and community environments that support them.

Table 1
Ten Steps to Achieving a Shared Plan of Care[1]

Step 1	Identify who will benefit from having a shared plan of care (SPoC).
Step 2	Discuss with families and colleagues the value of developing and using a comprehensive and integrated plan of care.
Step 3	Select, use, and review multifaceted assessments with the child, youth, and family.
Step 4	Set shared personal (child and family) and clinical goals.
Step 5	Identify other key partners (subspecialists, community resource providers, and others) and link them into the plan of care process. .
Step 6	Develop the medical summary for the plan of care and merge it with the negotiated actions in step 7.
Step 7	Establish the negotiated actions for the plan of care and merge them with the "medical summary" in step 6.
Step 8	Ensure that the plan of care is accessible, retrievable, and available.
Step 9	Provide tracking, monitoring, and oversight for the plan of care.
Step 10	Systematically use the plan of care model process as a life course and a population health approach.

Appendix B

continued

While the 10-Steps to Creating a Shared Plan of Care serves to walk one through the necessary people, process, and tools for this approach, it is important to start with a prepared, proactive team that possesses the intention to provide evidence-based care coordination. This warrants preparation via a few other essential considerations: identify core team members with clearly articulated roles, who will support one another in care coordination efforts; identify as a team an explicitly named, shared, and generally endorsed care coordination definition and framework; have the team help develop or customize a workflow spelling out phases and responsibilities; and have the team follow the workflow as a directional tool, which also represents quality improvement opportunities. This means the pathway to using a SPoC in partnership with family requires testing and informed improvements as a result of these quality improvement tests of change. In other words, families benefit from care coordination achieved in partnership with a committed core team, one that is willing to test new ideas, discuss results, learn together with families, and redesign accordingly.

Figure 1 illustrates 1 workflow example that could be adapted to local context. Notice within its 5 phases how there is a "run-up" to the actual joint creation, or coproduction, of the SPoC. These run-up or preparatory phases are designed to: 1) gain family agreement to take such an approach together; 2) reach out to families for pre-visit information to begin population of a plan of care; 3) prepare for visits using family input, teammate suggestions, and medical and other sources of data; 4) dedicate time during a care visit to hear what matters most to the family and reflect back what is being heard about its unmet needs, concerns, and priorities and begin to generate a draft plan; and 5) complete the SPoC with family affirmation of its content and use it as a "script" for subsequent care coordination functions and activities. Phase 5 is a specified period of continuous care coordination which includes reevaluation and follow-up. This workflow example was designed for use with a children's specialty hospital initiative; note that communication and collaboration with primary care is an articulated priority.

Figure 1 An approach that uses team preparation and agreement paves the way for the care planning process and tools to generate better outcomes. Table 2 details considerations and/ or recommendations for implementing care coordination using the 10 steps toward achieving a shared plan of care.

Workflow: Five Phases Using a SPoC as an Approach to Family-Centered Care Coordination

Appendix B

continued

Shared Plan of Care: Ten Steps Toward Implementation

Steps	People and Processes with Special Considerations	Tools *(*Samples Available)*
Step 1 Identify who will benefit from having a shared plan of care (SPoC).	Identify a target population/subpopulation that would benefit from having an accessible, comprehensive, integrated, and shared plan of care. Consider the following: · Is there a current organizational population of focus or priority? · May a parent partner or family advisor participate in population selection? · What population is of concern to you/the team right now? · Will the decision about who requires a shared plan of care create lessons that are relevant for children with special health care needs and/or all children? · Has a family or group of families been asking for extra help with navigation? Are there common traits among them? · Have any families been teaching the practice or clinical team lessons resulting from their own extensive efforts? · Will you use levels of complexity in this work; if so how will that process guide you? · What about considerations of broader social determinants of health?	Population or subpopulation criteria (predetermined and articulated by the team)* Complexity levels tool*
Step 2 Discuss with families and colleagues the value of developing and using a comprehensive and integrated plan of care.	Describe the rationale behind using a SPoC approach with families; explain how it is designed to reflect "what matters" to them and how these priorities are integrated with clinical concerns to guide continuous care coordination. · Explain how a well-developed SPoC coalesces information and guides prioritized next-step actions. · Discuss how a SPoC is coproduced, meaning the team and family create it together; it is not done to a family but with them going forward. · Share how other families have found a SPoC useful as an approach to care coordination and provide examples of other family goals (eg, areas with which they have asked for help). · Link the plan of care to better health care, population health, potential costs per capita, and professional joy (The Triple and Quadruple Aims).	Lucile Packard SPoC Guide Family goal examples*

Appendix B

continued

Shared Plan of Care: Ten Steps Toward Implementation *continued*

Steps	People and Processes with Special Considerations	Tools *(*Samples Available)*
Step 3 Select, use, and review multifaceted assessments with the child, youth, and family.	Take every opportunity to help families reflect on their priorities, unmet needs, and concerns they want to address. · Use a simple assessment tool to help families realize the scope of content areas that can be addressed (eg, medical, dental, school, social determinants); this can be done using a pre-visit contact or before a visit. · Take advantage of every interaction with the family to ask, listen, hear, and reflect back child and family needs, strengths, and challenges; discover what their child enjoys or receives well. · During a visit, (or ideally during a specified planned care visit) take time to engage in a goal-directed, open-ended interview to allow families the opportunity to describe their typical day with their child and to reveal their challenges, inherent strengths, and frustrations. · If time does not allow for this, assign a team member (eg, a coordinator) to have this conversation prior to the clinical encounter; explain to the family how information will be captured and shared across the team.	Pediatric care coordination assessment (or pre-visit assessment* [eg, What I Need])*
Step 4 Set shared personal (child and family) and clinical goals.	Build upon the steps above, reflect back to the family the priorities heard; gain the family's affirmation or any deletions and additions. Add essential clinical concerns and/or priorities and gain the families agreement to include these items by using the following approaches: · Suggest that starting with 3 to 4 goals is good. · Encourage families that you believe the team can help them address their needs and goals.	SCRIPT: 3 open-ended, goal-directed interview questions related to activities of daily living, self-management, care partnership support, or system navigation (eg, Can you describe a typical day and the most challenging areas for your child [or you]?)

Shared Plan of Care: Ten Steps Toward Implementation *continued*

Steps	People and Processes with Special Considerations	Tools *(*Samples Available)*
Step 5 Identify other key partners (subspecialists, community resource providers, and others) and link them into the plan of care process.	The child and family probably have a "care neighborhood" of key multidisciplinary professionals (specialists, primary care, educational, therapists, etc.) essential to helping them (and you) achieve their goals. · Ask who these critical members are and whether the SPoC can be shared with them (gain releases). · Determine if there is a designated locus of clinical coordination; if not, determine with each family if this should be you/your team/practice or not? If not, with whom and where can this occur? · Communicate with care neighborhood partners about the SPoC and care coordination process; ask for their input, participation, and help with addressing goals.	Care mapping (highlight key critical partners) Communication agreements[4]*
Step 6 Develop the medical summary for the plan of care and merge it with the negotiated actions in step 7.	Steps 6 and 7 reflect the engagement and trust-building work achieved in prior steps. A SPoC template (identified before beginning) includes both the medical summary and negotiated action sections. Once developed, these can be merged. · The SPoC template should include core elements, while being flexible to the local context; periodically, a team should revise and improve the template using family and team experiences as input. · The medical summary is populated in real time during interactions with the family. Send a blank template to families to acquaint them with the tool; this also allows them to gather and share content (and offer feedback). ~ Be clear that they are not expected to complete the entire document on their own. · Capture family cultural beliefs and preferences; ask how they like to receive information and/or communications (written, oral, online/video).	Sample care plan (on the Lucile Packard Foundation for Children's Health [LPFCH] website[5])*

Shared Plan of Care: Ten Steps Toward Implementation *continued*

Steps	People and Processes with Special Considerations	Tools *(*Samples Available)*
Step 7 Establish the negotiated actions for the plan of care and merge them with the medical summary in step 6.	Once family priorities are established and essential clinical goals are integrated, following are steps to take and data to include to complete the negotiated actions section: · List goals, note aligned strategies next to the goals, and allocate responsibilities (who, by when). · Include relevant resource people, contact information, and links to help with the goals—this helps all partners to learn (draw from care mapping). · Practice "anticipatory guidance" to help families understand what to expect that may lead to important goals. For example, consider pending transitions (between school levels and from hospital to home and pediatric to adult-focused health care) or preemptive nutrition and activity guidance to help with endurance and stamina. · Plan ahead with families for necessary revisions, updates, continuances, or reframing. These activities comprise ongoing care plan development and implementation. · Create and/or use an indicator of progress against set goals (eg, goal is completed, in progress, on hold, or dropped).	Sample care plan (the Lucille Packard Foundation for Children's Health sample care plan is on the LPFCH website)* (and/or replace with your action grid or add as another example)
Step 8 Ensure that the plan of care is accessible, retrievable, and available.	Electronic medical records (EMRs), while helpful, are insufficient for properly sharing a SPoC; think of multiple ways to make the plan available (eg, as the idea goes, communicate 7 times in 7 ways). · Use the SPoC (in whatever form is allowable, such as an editable word document, a scanned version, or an attachment to a secure email) to help make plans sharable and accessible for families and their care partners. · Attach emergency plans, condition-specific guidance, and legal documents to the SPoC. · Use the EMR, family, and team members to notify others of the existence of each SPoC; refer to the plan at every health care encounter or interaction. · Remind families to use their SPoC; emphasize all of the ways it can help them to communicate, advocate, or complete eligibility applications.	(EMR, paper, email, scan—7 times in 7 ways) Provide guidance to the family regarding the benefits of using the completed shared plan of care.

Appendix B

continued

Shared Plan of Care: Ten Steps Toward Implementation *continued*

Steps	People and Processes with Special Considerations	Tools *(*Samples Available)*
Step 9 Provide tracking, monitoring, and oversight for the plan of care.	Continued, feasible use of the SPoC requires ongoing progress tracking (see above), care coordination monitoring of performed functions, and documentation of overall effort. · Track population goals to understand needs and to demonstrate how care coordination helps to better meet set family goals. · Evaluate care coordination implementation and determine its value through efforts with families, teams, and leadership, based on its effectiveness, impact, and fidelity to national standards.	The Pediatric Care Integrated Care Survey Coding (for care conferencing and care plan oversight) Family surveys* (Plan of care/utility, empowerment, unmet needs, worry, coding of goals and progress)
Step 10 Systematically use the plan of care model process as a life course and a population health approach.	After following steps 1 to 9 and subsequently demonstrating value with families and improved joy of clinical staff, persistent system support for a SPoC approach to care coordination with pediatric populations should follow.	Family surveys* Adaptive reserve* Other staff joy measures (available at the Institute of Healthcare Improvement website [ihi.org])

Appendix B

continued

Table 3 describes the use of a SPoC approach to care coordination and particular workflow phases to guide a team in its efforts.

VB, a 3-year-old boy with developmental delay, and his family (Burmese refugees) were referred by pediatric neurology for care coordination

Table 3
The vignette describes a child-, family- and team-based care coordination effort addressing all 5 workflow phases. The vignette is contributed by Holly Paauwe, team care coordinator; Rebecca McNally Keehn, PhD, team clinician; and Jeanne W. McAllister, BSN, MS, MHA, program director.

Phase 1: Family outreach/engagement

The parents were invited and provided with a thorough description of what a care coordination intervention could do to help them and their son, and they agreed to participate.

Phase 2: Family and team pre-visit work

An assigned care coordinator reached out and learned that VB's family had no means of transportation, the father had no work leave time, and their English was very limited. They would require the following supports to ensure a successful period of care coordination: a Medicaid cab, a car seat, a specific dialect translator, and a visit timed to the schedule of VB's father, as he does the communication for the family.

Phase 3: Population-based teamwork

The team members shared insights into Burmese culture and addressed the interventions needed to help the family attend a planned care visit (transportation, interpretation, safety, etc.). They reviewed the medical record and other documents and began to populate the medical summary.

Phase 4: Planned-care visit/SPoC "coproduction"

Using an open-ended, goal-directed interview, the clinician and care coordinator met with VB, his father, mother, their infant, and the Chin interpreter available through the health system. The team observed that VB is a bright, active boy and enjoys loving, engaged parents who work hard to navigate the American experience, while parenting VB and his infant sister. They are working to tackle VB's medical and developmental needs in spite of significant barriers.

The following goals emerged and were captured in an initial shared plan of care (including a medical summary and negotiated next steps): obtain outpatient habilitation therapy within the limits of the family's schedule and transportation access; get support to successfully navigate recommended evaluations and treatments while better understanding VB's needs; and establish adequate health care financing.

Phase 5: Ongoing care coordination and community transfer

A more complete SPoC was translated into Chin for the family's use and shared with partners across the family's care neighborhood (care map). The care coordination team worked with the family to address its goals and integrate care across VB's general pediatrician at a community health center, as well as with multiple specialists within the children's specialty hospital system (eg, physicians, technicians, schedulers, language services). The care team also coordinated with the state's Children's Special Health Care Services and the Bureau of Developmental Disability Services. As a result of continuous, ongoing care coordination, VB and his family accessed options for therapeutic interventions that meet the family's location, transportation, and schedule needs; achieved a neurology consult and 2 genetic assessments; successfully and independently initiated contact with the hospital's language line to maintain communication with the care team; and obtained diapers through Medicaid, which significantly helps the family's budget. The "locus" of care coordination was transitioned back to the general pediatrician and nurse manager, with translation support at the federally qualified community health center, which serves as the family's "medical home."

A Few Other Implementation Lessons Learned

The results of implementation, including family goals, progress against those goals, and building of skills and confidence, are described in the above referenced paper.2 Families and team members agreed that coproducing a shared plan of care was a win-win for all. Coordinating from family goals means everyone is working in agreement. The expression "it's more fun" was frequently used to describe caring in this way. Care neighborhood partners stated they had better, more useful information, which taught them how to help families meet their needs.

Care coordination also served to integrate and inform primary care and various subspecialists, fostering communication with one another. Intention of purpose was a requirement, as was goal prioritization and persistence to achieve them. Families began to learn to use and refer to their SPoCs when speaking with primary and specialty care (and others) team members. Achieving a shared plan of care with children and families meant families, coordinators, and clinicians all learned from and taught one another. Learning is an essential element of a care coordinator's role, and time must be dedicated to learning about families, specialists, systems, services, resources, changes, and communities. A part of team time can be devoted to learning and sharing; this builds infrastructure and spreads capacity.

Care coordination, when coproduced among families and health professionals as a team-based approach, drives better family-centered care, teamwork, care integration, and population health. Care coordination using this approach requires a learning organization environment using quality improvement strategies and studied implementation.

Works Cited

1. McAllister JW. Achieving a Shared Plan of Care for Children and Youth with Special Health Care Needs: An Implementation Guide. Palo Alto, CA: Lucille Packard Foundation for Children's Health; 2014

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3. McAllister JW, McNally Keehn R, Rodgers R, Lock TM. Care coordination using a shared plan of care approach: from model to practice. *J Pediatr Nurs.* 2018;43:88-96

4. Stille CJ, Antonelli RC. Coordination of care for children with special health care needs. *Curr Opin Pediatr.* 2004;16(6):700-705

5. Shared Care Plan. Lucile Packard Foundation for Children's Health. https://www.lpfch.org/publication/achieving-shared-plan-care-children-and-youth-special-health-care-needs

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Pediatric Care Coordination Curriculum

MODULE 2

Developing and Sustaining Strong Family/Professional Partnerships

Cara Coleman, JD, MPH
Brigit Frank, MA
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Developing and Sustaining Strong Family/ Professional Partnerships

> **Module 2—Objectives**
>
> At the end of this session, participants should be able to:
>
> · Explain the value and importance of family/professional partnerships
> · Explain the family role in health care improvement
> · Describe ways to engage families, physicians, and nonphysician clinicians to improve integration
> · Demonstrate knowledge of tools, resources, and strategies to improve family/professional partnerships
> · Demonstrate the ability to operationalize family/professional partnerships through planning an initiative and/or event

Note to the facilitator:

This module includes a didactic portion, a set of tools and resources, case studies, worksheets, and suggested literature.

Please be aware that it is crucial to add local-, state-, and/or regional-specific content to this module.

A **L** found in the module indicates the need for local content to be added, but facilitators should feel free to do so as they see fit. Local content includes, but is not limited to, the following:

· Cultural aspects of the community (including assets, vulnerabilities, and language)
· Sociodemographic factors
· Geography
· Local, state, and/or regional resources

Optimal Facilitation Guidance

To achieve the most efficient and effective outcomes from the learning sessions, it will be essential to assure vital and equitable input from all stakeholders, especially patients and families. Please see the section Tips for the Facilitator: Ways to Keep the Workshop on Track on page 8 of Getting Started: Identifying and Prioritizing Opportunities for Implementing High-Performing Care Coordination.

There are two tables included below. The first is a high-level agenda of the module. The second is the facilitator guide that includes a breakdown of slide content and talking points. The facilitator should use the guide as a resource to tailor training.

The curriculum is intended to be tailored to fit the training needs, and the content can be modified for different audiences. Therefore, facilitators may decide to pick and/or choose content from this module and incorporate it into their training. However, a suggested agenda for implementing this as a stand-alone module is included.

Module Overview

Table 1

Agenda Item	Time	Materials Required	Instruction/Notes
Pre-session readings	N/A	· Welcome to Holland · I Am "That" Parent · From Strangers in a Foreign Land to Active, Engaged Citizens · Patient- and Family-Centered Care and the Pediatrician's Role	Distribute readings prior to the day of the session.
Introduction	20 min	N/A	Introduction activity (paper and pencils may be required, depending on the activity)
Didactic	40 min	· Slides · Handouts, as needed	Create a slide deck using content from the didactic portion. Make sure there are opportunities for participants to speak. Add local content to the slides wherever **L** is indicated. Suggested handouts/worksheets and resources are included in the module.
Case studies	1 hour	· Copies of case studies and discussion questions · Whiteboard or flip chart for report back	Give participants an opportunity to practice the concepts and tools they learned. Case studies can be tailored to fit the relevant audience/population. The case studies are intended for any population, but included below are a few notes about which case study might be most useful, based on the pain points of the group. Case study #1 is best for care teams focused on collaborative decision-making and communication. Case study #2 is best for care teams focused on providing families with tools and resources to guide decisions and care, and for families who want additional resources and/or tactics to guide decision-making and care planning.

Module Overview

Agenda Item	Time	Materials Required	Instruction/Notes
Action-oriented next-step activity	15 min	Worksheet	Participants complete a worksheet detailing the next steps to take after the session, based on work that was completed during the session.

Facilitator Guide–Pre-Session Readings

PRE-SESSION READINGS

From Strangers in a Foreign Land to Active, Engaged Citizens
Scharpen AL and Stille CJ. *Pediatrics.* 2018;141(2):e20171845.
Available at: http://pediatrics.aappublications.org/content/early/2018/01/18/peds.2017-1845

This article uses examples from 3 different stages of parent involvement, as well as parent and care team member responses to each, to depict what families may experience as they evolve into team members in their children's care.

I Am That Parent
Rule ARL. JAMA. 2018;319(5):445.
Available at: https://jamanetwork.com/journals/jama/fullarticle/2671471

An opinion piece uniquely written by a pediatrician and new mother to a child with special health care needs who now finds herself as "that parent" —difficult, determined, and empowered. In the article, Dr. Rule writes, "I wish I could apologize to those families now. Not only did I not 'get it,' I developed a sense of frustration with and a condescending attitude toward many families over the years."

Patient- and Family-Centered Care and the Pediatrician's Role
American Academy of Pediatrics Committee on Hospital Care and Institute for Patient- and Family-Centered Care. *Pediatrics.* 2012; 129(2):394-404.
Available at: https://pediatrics.aappublications.org/content/129/2/394.full

This AAP policy statement outlines the core principles of patient- and family-centered care; lists various expected benefits of engaging in patient- and family-centered pediatric practice; and concludes with specific recommendations for pediatricians to integrate patient- and family-centered care into hospitals, clinics, and community settings, as well as broader systems of care.

Welcome to Holland
Kingsley EP. 1987.
Available at: http://www.our-kids.org/Archives/Holland.html

This essay written by author, social activist, and mother of a child with a disability poignantly describes what it feels like to have a child with special health care needs, resulting in meeting and adapting to unexpected challenges and joys.

Family/Professional Partnerships
Family Voices, Inc. January 2019.

This handout is included in the In-Session Content section of the module but would be valuable for participants to receive ahead of the session because it describes the benefits of family and professional partnerships, as well as other types of partnerships.

Not Just Along For The Ride: Families Are The Engine That Drives Pediatric Home Health Care
Coleman C. April 2019.
Available at: https://www.healthaffairs.org/do/10.1377/hblog20190415.172668/full/

The mother of a child with multiple complex needs writes that families must be supported, valued, and respected as equal partners in care because the pediatric home health care system cannot exist without them. Families, she writes, are not passive observers in the system; they are specialists in medical care, advocacy, and public health, uniquely qualified through their lived experience of providing care across multiple systems.

Facilitator Guide–Slide Deck

SLIDE 1 » Title Slide

Developing and Sustaining Strong Family/Professional Partnerships
Module 2 of
Pediatric Care Coordination Curriculum 2nd Edition

Prior to, or at the beginning of the workshop, distribute the handouts to the learners. Feel free to adjust the handouts as needed in order to best accomplish the goals of the learning session.

SLIDE 2 » Educational Purpose Only–No Medical Advice
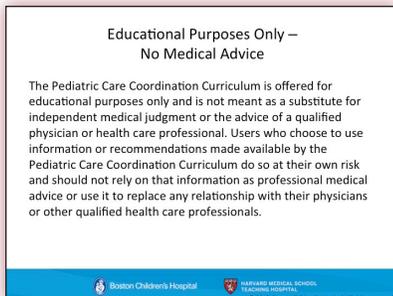
Educational Purposes Only –
No Medical Advice

The Pediatric Care Coordination Curriculum is offered for educational purposes only and is not meant as a substitute for independent medical judgment or the advice of a qualified physician or health care professional. Users who choose to use information or recommendations made available by the Pediatric Care Coordination Curriculum do so at their own risk and should not rely on that information as professional medical advice or use it to replace any relationship with their physicians or other qualified health care professionals.

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Facilitator Guide–Slide Deck

continued

SLIDE 3 » Objectives

Objectives

By the end of this session, the audience will be able to

- Explain the value and importance of family/professional partnerships
- Explain the family role in health care improvement
- Describe ways to engage families, physicians, and nonphysician clinicians to improve integration
- Demonstrate knowledge of tools, resources, and strategies to improve family/professional partnerships
- Demonstrate the ability to operationalize family/professional partnerships through planning an initiative and/or event

This time should be used to introduce the following session objective and clarify the expectation:

- What the session is: collaborative learning geared toward adopting strategies for optimizing family engagement
- What the session is not: a presentation on what families want from their child's care team

Think through the following:

- Why are we here today? To describe ways to engage families and care team members to actively work together on team building, and to learn how families and care team members can collaborate to redesign how care is delivered. Of note, "family" refers to individuals who love and care for the child and may or may not be biologically related.
- What are we going to do today? Discuss tools, resources, and strategies for engaging families and care team members to collaborate then apply these tools, resources, and strategies to case studies. Finally, an action plan will be developed to apply what was learned today to real-life settings.

Remember, objectives, expectations, and the why and what can be tailored to meet the training needs of the audience.

Before jumping in, consider starting with an icebreaker activity, such as telephone or the empathy game. Both of these activities highlight the importance of teamwork. Telephone demonstrates the challenge of communicating clearly when messages are being passed through a chain of individuals, similar to the difficulties families experience in both receiving and sharing messages across multiple team members.

The empathy game encourages participants to think beyond chronic illness care coordination and partnerships to try to feel and simulate some of the varied and complex experiences of living with chronic illness.

General instructions for these icebreakers can be found in the In-Session Content section of the module.

SLIDE 4 » What is Patient- and Family-Centered Care?

What is Patient- and Family- Centered Care?

Definition from the Institute for Patient- and Family-Centered Care

Patient- and family-centered care is an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families.

In patient- and family-centered care, patients and families define their "family" and determine how they will participate in care and decision-making.

Patient- and family-centered care leads to better health outcomes, improved patient and family experience of care, better clinician and staff satisfaction, and wiser allocation of resources.

Important:
Patient and family knowledge, values, beliefs, and cultural backgrounds are incorporated into the planning and delivery of care.

Source: http://www.ipfcc.org/about/pfcc.html

Ask learners to share examples of instances in which they experienced patient- and family-centered care and when they did not (families and care team members both can share their examples). What specifically about the experience made it feel either positive or negative?

Ask learners to think about elements that constitute a good partnership in any setting (talk in small groups or brainstorm as a larger group, and record ideas on a flip chart).

Facilitator Guide—Slide Deck
continued

SLIDE 5 » Core Concepts

Core Concepts of
Patient- and Family-Centered Care

Participation | Information Sharing

Dignity and Respect | Collaboration

=

Authentic Partnerships!

Source: http://www.ipfcc.org/about/pfcc.html

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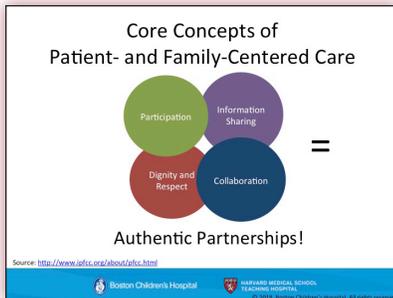
Ask the audience to share what each of these core concepts mean in terms of care: dignity and respect, information sharing, participation, and collaboration. What are some specific examples that demonstrate these concepts? What roles do culture and language play in the delivery of these concepts of care? What roles do culture and language play in the receipt of these concepts of care? Try to convert these concepts from high-level ideas to everyday actions.

Emphasize that care teams can and should be inclusive of and informed by families and also include schools, insurance providers, faith-based organizations, community groups, therapists, and other support groups and people, as appropriate.

Emphasize that all of these components of family-centered care contribute to authentic partnerships.

SLIDE 6 » Principles of Family/Professional Partnerships

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Principles of
Family/Professional Partnerships

- Families and professionals work together in the best interest of the child and the family. As the child is able, she or he assumes a partnership role.
- Everyone respects the skills and expertise brought to the relationship.
- Trust is acknowledged as fundamental.
- Communication and information sharing are open, objective, and in a linguistically and culturally appropriate manner.
- Participants make decisions together, which is known as shared decision-making.
- There is a willingness to negotiate.

Source: http://familyvoices.org

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Putting these pieces together. So if the goal is to create authentic and effective family/professional partnerships, what does that mean?

A set of criteria for effective partnerships, developed by the National Center for Family/Professional Partnerships, is listed in this slide.

Suggested questions and discussion:

- Ask the learners, "Is there anything else that you would add to this list?"
- Additionally, ask the learners, "These concepts sound great in theory, but how can they be helpful and relevant to us?"
- Regarding cultural competence, ask, "When the pieces of the family/professional partnership puzzle are put together, how is diversity of culture, language, ethnicity, race, and thought, among others, included? Are additional pieces needed, or are different strategies used for forming diverse partnerships?
- Present examples that are locally relevant.
- Discuss what is meant by communication. How might this concept differ for each professional and family? Should best communication methods be established at the start of family/professional relationships?

Facilitator Guide–Slide Deck

continued

SLIDE 7 » In Practice

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In Practice

- How can these principles be operationalized?
- What might this look like in real life?

Principles	What ACTIONS can you take to put these principles into practice?
Best interest of the child and the family	
Child grows into a partnership role	
Covet skills and expertise of all	
Trust	
Communication that is open, objective, and culturally and linguistically competent	
Decisions made together	
Willingness to negotiate	

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Principles provide a good framework, but how are they applied to the framework of everyday life? It can seem overwhelming when principles are not adapted to a day-to-day level.

Ask learners, "What does this look like in practice? Do you have examples of how you have seen others do this or how you have done it yourself?"

Encourage the learners to use the provided worksheet to create as many actionable steps as possible. For example:

- Make decisions together. When a change in a patient's life requires a change in care, ask the family how it envisions the change being implemented. Ask the family to share its thoughts, preferences, concerns, etc., rather than making decisions for it.
- Honor skills and expertise of all. Instead of asking families only about deficits (What can we do for you? What do you need help with?), ask families to talk about their strengths (What do you think you are really good at?).
- The facilitator is encouraged to give examples as well, ideally looping in local examples.

> Encourage each group to share with the audience. Generation of new ideas is an added value of an in-person session!

See the In-Session Content section for Family/Professional Partnerships, a resource developed by the National Center for Family/Professional Partnerships. It can be handed out before or during the session and is a good resource to reference during this part of the discussion.

SLIDE 8 » Tools

Tools to Support Family/Professional Partnerships

Tools that will be addressed today
- Pediatric Integrated Care Survey (PICS)
- Action Grid
- Care Map

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Next, ask the learners, "How can tools be an asset to operationalizing these concepts?"

Discussion:

This module focuses on 3 tools. However, there are many other tools that also contribute to family/professional partnership building. Concepts similar to those learned today can be applied to operationalize the other tools (ie, How can tools support effective family/professional partnerships?).

The 3 tools featured in this module address:

- Gathering and utilizing family experiences
- Shared-care planning
- Family-driven discussions

Examples of ways tools can support operationalization of family/professional partnerships
- Gathers experiences and input from the family in a systematic way
- Develops a structured process for family-driven discussion around goal setting

Facilitator Guide—Slide Deck

continued

SLIDE 9 » Family Experience

Family Experience

- Family experience is crucial to engaging families to drive improvement work.
- Ask families to be part of the care transformation team -- they know best!
- What is working, and what is not?
- Qualitative and quantitative experiences can be gathered.

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The first tool that will be discussed focuses on gathering family experiences to drive improvement work.

Why is this important? Instead of making improvements then asking families if their experience improved, reverse the model and begin by asking families to weigh in on what improvements need to occur.

L Ask the learners to consider local cultural norms, language barriers, etc.

Ask the learners to think about ways that family experience can be gathered. The facilitator can initiate a brainstorming session that focuses on the following aspects:

- Qualitative methods, such as focus groups and family advisory council meetings.
- Quantitative methods, such as surveying families.
- How can challenges associated with language barriers, location, access to transportation, socioeconomic status, etc., be addressed to ensure experiences are gathered across all families?

Ask the audience members if they have ever initiated or participated in any of these methods of collecting family experience.

The facilitator might want to introduce personal experiences, such as providing child care at family advisory meetings, allowing virtual (in place of in-person) participation, giving families stipends to participate in work, and providing interpreter services for families who do not speak English as their first language.

> Discuss how gathering family input for quality improvement is part of family/professional partnerships.

Facilitator Guide—Slide Deck
continued

SLIDE 10 » Pediatric Integrated Care Survey

Pediatric Integrated Care Survey

The Pediatric Integrated Care Survey (PICS) asks families to respond about experiences across the care team.

The domains of the instrument are
- Access to care
- Communication
- Family impact
- Care goal creation and planning

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Tool #1: Pediatric Integrated Care Survey (PICS)

The PICS is outlined in Module 1 of the Pediatric Care Coordination Curriculum. However, this module shares how the PICS can be used by families in addition to being used as a physician- and nonphysician clinician-driven tool.

The PICS is a validated instrument that gathers family experiences with care integration. The intention of the tool is to be able to make actionable changes based on feedback and input from families.

Sharing the PICS core tool with the learners is a good way to spark discussion around how to present care integration as a priority and gather information from families, the first steps in partnership building.

Gathering family experiences is a foundational step in building family/professional partnerships. It acknowledges the vital role families play in determining improvements that need to be made in health care delivery. It also gives families a channel for communicating thoughts, beliefs, successes, and frustrations, and it honors family/professional partnerships.

The PICS is available at: http://bostonchildrenshospital.org/integrated-care-program/patient-and-family-experience-outcome

Another example of a family experience measure is the Family-Centered Care Assessment for Families from Family Voices.
The assessment is available at: https://medicalhomes.aap.org/Documents/FCCAquestionnaire.pdf

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SLIDE 11 » PICS

PICS

Data are used to
- Inform priorities for intervention
- Track progress over time from the perspective of families
- Set recommendations for what families should be expecting

How could you use the tool?

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Data collected by the PICS are used to demonstrate where there are gaps in care and the health care delivery system from family perspectives, and as interventions are established, to track progress over time.

Additionally, sharing the PICS with families sets standards for what they should expect. Ask the learners to provide examples of this. For example, "In the past 12 months, how often did your child's care team members explain things in a way that you could understand?"

Parents/guardians could say, for example,

"I never thought to ask or to expect that someone should ensure that information is presented and that I understand it."

Facilitator Guide–Slide Deck
continued

SLIDE 12 » PICS

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> ### PICS
> - Look through the tool yourself or with someone on your child's care team. Pick out specific items that you believe would improve your child's care and your experience.
> - Share the tool with your child's care team members!
> - How might you use it or encourage families to use it?
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Encourage the learners to think about how they could use this family experience tool (or others) in their own settings to collect information. Remind them:

- It is important to start small!
- It is important to consider culture and language when deciding how to use the tool.

  –Is it possible to translate the tool or have interpreters translate questions?

  –Can support be available to help families read the survey in case they have questions? (The facilitator can reference the resource Engaging Broad Audiences in this Module 2 facilitator guide for additional context related to reading levels.)

Remember, the tool can be downloaded and printed from http://bostonchildrenshospital.org/ integrated-care-program/patient-and-family-experience-outcome

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SLIDE 13 » Action Grid

> ### Action Grid
> - The action grid is a care planning tool intended to document action items resulting from an in-person visit or encounter.
> - Even if a clinical care team is not using the grid, families can modify the grid to be applicable to them and bring it to each appointment/visit.
> - Elements on the grid can be used to add to mental checklists, regardless of your role on the care team.
> - What might you expect to find over time as this is consistently implemented?
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Tool #2: Action Grid

The handout Action Grid Guide for Family Leaders included in the In-Session Content section should be passed out for this section.

In addition, the module includes the resource Post-Encounter Action Grid. It is recommended that the facilitator include this as a handout and/or pull information from it for the slide deck and group discussion.

Similar to what was done during the discussion about the PICS tool, the learners can be asked to give specific examples about how the tool or the elements of the tool might be used in their own settings.

Note for the facilitator :
How can the action grid be utilized? For example, the action grid can be completed at the end of an in-person visit then sent to the family via the patient portal after the visit so that the family has an electronic copy of the grid.

An example of a completed action grid:

Facilitator Guide–Slide Deck

continued

SLIDE 14 » Action Grid
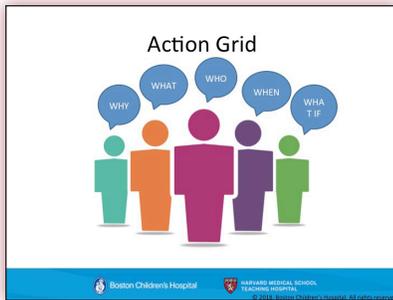
Action Grid

The core elements of the action grid answer the following questions:

- Why is a task/action recommended?
- What is the task?
- Who is responsible for completing the task?
- When does it need to be completed?
- What if things do not go according to plan? What is the contingency plan?

Ask the learners to think about how they could potentially use these core elements in their next patient or care team encounter.

How could having answers to these questions lead to a more productive, healthy partnership?

> Discuss how determining roles and responsibilities together is part of family/professional partnerships.

Facilitator Guide–Slide Deck
continued

SLIDE 15 » Care Map

Tool #3: Care Map

The care map is a family-driven tool designed to allow families to visually map their support networks.

According to the Boston Children's Hospital website:
(http://bostonchildrenshospital.org/integrated-care-program/care-mapping),

"Care mapping is a process which guides and supports the ability of families and care professionals to work together to achieve the best possible health outcomes."

In its most developed form, care mapping is a family-driven, person-centered process which highlights a family's strengths and communicates both the big picture and the small details of all of the resources needed to support a child and their family.

It provides a comprehensive snapshot of a family's needs, and enables the care team to appreciate how each of these aspects relates to each other."

The care map is a tool that enables families and care team members to not only appreciate care but to spot gaps and/or redundancies in care and make changes, enhancements, or improvements. The 2018 article "Care Coordination: Whose Care Is It Anyway" includes examples of how the tool is used to improve not only relationships but care for the child, too.

Note for facilitator: Suggest this article as recommended reading after the session.

The care map shown here was developed by Cristin Lind, who invented the care map concept.

Facilitator Guide–Slide Deck
continued

SLIDE 16 » Author Care Map
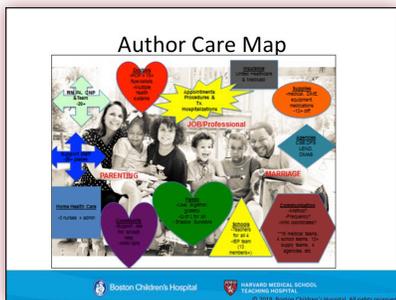
Author Care Map

This care map was developed by module author Cara Coleman.

Following is a note from the author:

This version of a care map was derived from concepts that teach how to prepare for and advocate in an Individualized Education Plan (IEP) meeting in the school system, where many members of the team focus on services, supports, and diagnoses, often forgetting the child at the center of it all. Recognizing that similar instances occur in health care system interactions, the author designed her care map around a family photo, allowing for the complexity of the care to be highlighted, while preventing it from overshadowing the meaning of it all—child/family and family/professional partnerships.

SLIDE 17 » Let's Practice

Let's Practice!

Practice using some of the concepts and tools with case studies.

During the next part of the session, case studies should be presented then discussed in smaller groups or with the entire learner group.

The 2 cases presented in this module provide opportunities for the learners to identify several gaps in integration and family/professional partnerships and to brainstorm methods for closing the gaps. Encourage the learners to think through what they have discussed as part of the session.

Additionally, encourage them to make connections between what they are discussing in the cases and what they can take back to their own institutions.

SLIDE 18 » Next Steps

Next Steps

Think through how you can take content presented in this workshop back to your own setting.
• What do you want to focus on?
• Who do you need to involve?
• How will you begin?
• How will you measure it?
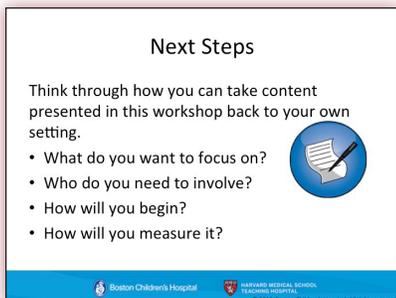
There should be time for the learners to reflect on what was discussed during the session and to consider how to bring it back to their settings.

Encourage the learners to think through the what, who, and how for launching this work.

This could be developed into an action-oriented worksheet.

Worksheets and Handouts

Handout	Notes
Definitions	This handout includes definitions related to family/professional partnerships. Facilitators are encouraged to add their own definitions and/or create specific local examples. Distribute this handout beforehand and have copies available for the learners to review at the in-person setting.
Family Voices: Family/Professional Partnerships	This handout provides an overview of the key definitions and components of family/professional partnerships, including examples of where, how, and with whom families and professionals can partner in the lives of children and youth with special health care needs. As an additional resource, the Family Voices Family-Centered Care Assessment Tool can be found at *http://familyvoices.org/wp-content/uploads/2014/06/FCC-self-assessment-Users-Guide.pdf*
Pediatric Integrated Care Survey Guide for Family Leaders	This guide explains how to utilize the Pediatric Integrated Care Survey (PICS) from the family leader perspective (how to support families in driving use of the PICS). Suggested use would be to pass these handouts out and incorporate elements into the slide deck presentation.
Action Grid Guide for Family Leaders	This guide walks through how to utilize the action grid from the family leader perspective (how to support families in driving use of the grid). Suggested use would be to pass these handouts out and incorporate elements into the slide deck presentation.
Perspectives; Action Grid	This resource was developed to encourage families and care teams to think through how to best use these tools. It should be thought of as a supplement to the Action Grid Guide.
Case studies	Two case studies are included in this module. Facilitators can use the provided case studies or tailor the cases based on the learning objectives. Case studies should be discussed in small groups if the larger group does not lend itself to learner participation.

External Resources

Handout	Notes
Care mapping guide and examples	The intended use of the Care Mapping Guide is to support families in developing and using their own care maps. *Available at: http://bostonchildrenshospital.org/integrated-care-program/care-mapping*
Care coordination strengths and needs assessments	The Massachusetts Child Health Quality Coalition published recommendations for a care coordination strengths and needs assessment tool and a set of example tools. An example of a modified tool is included in this module. Encourage the learners to look through the tool examples and think about what elements might be relevant for an assessment tool in their institution. *Available at: http://www.masschildhealthquality.org/work/care-coordination/*
Care Notebook— Wisconsin	This care notebook was created to support families as they partner with care team members on their child's care coordination. Families can use this notebook to organize their child's medical information and use the resources to guide them when they need answers. It includes resources, forms, and fact sheets, which can be used together or individually to meet the needs of families. *Available at: https://www.familyvoiceswi.org/wp-content/uploads/2019/05/Care-Notebook_Updated-10.13.18.docx*
Strengthening Families— Center for the Study of Social Policy	Center for the Study of Social Policy (CSSP) is a national, nonprofit policy organization that connects community action, public system reform, and policy change to create a fair and just society in which all children and families thrive. *Available at: https://cssp.org/about-us/about-cssp/mission-vision/* Strengthening families is a research-informed approach within CSSP to increase family strengths, enhance child development, and reduce the likelihood of child abuse and neglect. It is based on engaging families, programs, and communities in building 5 key protective factors. *Available at: https://cssp.org/our-work/project/strengthening-families/*

In-Session Content

Telephone and the Empathy Game

Name	Goal	Instructions	Discussion
Telephone	Personify and recognize how easily lines can get crossed in life and in health care	1) Pick a sentence to pass through the telephone. To simulate how information is relayed, heard, and repeated on a health care team, the sentence should be a diagnosis, directions for treatment, and/or a physician's order. 2) Have the group members sit or stand in a circle or lines so that they cannot overhear others. 3) The leader should whisper the message into the first person's ear (or into a disposable cup made into a telephone). 4) The message is passed person to person only once and cannot be repeated. 5) The last person shares the message out loud.	· Has anyone experienced something like the game of telephone play out on a health care team? · What was the impact of miscommunication? · How did lines get crossed? Where did the crossing occur? Was anyone able to discern who misunderstood, misheard, or misspoke? Did it matter who did it? · How was miscommunication handled? · How can simple miscommunication create barriers that prevent patients, families, physicians, nurses, etc., from speaking the same language? What role, if any, does a person's background, culture, beliefs, etc., play in mishearing or miscommunicating the message? How could or would this affect family/professional partnerships? Care coordination?

In-Session Content

Name	Goal	Instructions	Discussion
Empathy Game	Encourage participants to not just *think* about illness, family/professional partnerships, teams, and care coordination but to actually *feel* the depths and ways in which chronic illness can feel and impact a patient, family, and care team.	1) Distribute 4 different colors of sticky notes to each participant. 2) Ask each participant to write examples of the following on the corresponding colored sticky note: · Blue: a favorite activity · Red: a favorite person · Yellow: a favorite thing or object · Green: a favorite family activity 3) For the first round, the facilitator takes 1 blue and 2 yellow sticky notes from each participant. 4) During the second round, ask each participant to hand over 1 red sticky note and 1 green sticky note. 5) During the third round, the facilitator (and a helper if it is a large group) moves throughout the participants, taking some or all of the sticky notes at random. (This last round does not require certain colors or a specific amount to be chosen; the facilitator is modeling the way in which illness and disease may affect a person's life). Be prepared for the room to grow quieter with each round of this activity as it begins to more deeply and harshly imitate the ways illness can affect us; for some it may take everything.	· How did this activity make everyone feel? · Has anyone ever started the patient report or care before asking for the patient's name? Before asking how a patient is feeling? Before asking how a patient's chronic illness is impacting his or her life, relationships, or family function? Before asking about cultural or other beliefs or about roles that may affect a person's ability to accept chronic illness, discuss it with others, or just cope with day-to-day life, etc.? · How can this activity make someone a better patient? Family member? Care team member? How can this activity enable more effective partnerships with patients, families, or professionals?

In-Session Content

continued

Name	Goal	Instructions	Discussion
Additionally, sharing videos as part of the introduction might get people to start thinking. We have suggested some in this column.		**"Language Barrier,"** **an episode of "Getting On"** https://www.youtube.com/watch?v=R2NcwrPZBLM This video can be shared as an introduction or icebreaker or in conjunction with the telephone game. **"What's Her Name,"** **an episode of "Patch Adams"** https://www.youtube.com/watch?v=itixiJmsLsM This video can be shared as an introduction or icebreaker or in conjunction with the empathy game. **"You Treat a Person,"** **an episode of "Patch Adams"** https://www.youtube.com/watch?v=Pr9ruvxA3K4 This video can be shared as an introduction or icebreaker or in conjunction with the empathy game. **"Effective Collaboration,"** **an episode of "The Big Bang Theory"** https://www.youtube.com/watch?v=8Amu3UBj-qw This video can be shared as an introduction or icebreaker to get people to start thinking about the challenges of collaboration. **"Funny Twins – Teamwork"** https://www.youtube.com/watch?v=-SS0HHbFOrM This YouTube video personifies frustration and perseverance that families and care team members may experience with health care.	

Definitions

Term	Definition	Examples
Care team	A group of individuals who work together to achieve a common goal.	Child/youth, family, general pediatrician, social worker, cardiologist, case manager, neurologist, neurology registered nurse, dietician, school nurse, and community supports, including cultural and religious groups, all working together to provide care for a patient.
Care coordination	The co-creation and implementation of a care plan between families and care team members. *Source: American Academy of Pediatrics Council on Children With Disabilities and Medical Home Project Advisory Committee. Patient- and family-centered care coordination: a framework for integrating care for children and youth across multiple care systems.* Pediatrics. *2014;133(5):e1451-e1460*	Coordinating appointments, following up on test results, or liaising with community services
Warm handoff	The transfer of pertinent information between members of a patient's care team (including family) to enable another member to assume responsibility for some aspect of care.	When making a referral to a pediatric medical subspecialist or pediatric surgical specialist, the general pediatrician sends information about the patient before the patient's visit.
Integrated care	The seamless provision of health care services, from the perspective of the patient and family, across the entire care continuum.	The family reports that all members of the child's multidisciplinary team work together to provide the best possible overall care for the child.

Definitions

continued

Term	Definition	Examples
Patient- and family-centered care	Patient- and family-centered care is an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among care team members, patients, and families. Specific elements of family-centered care: · Participation: Patients and families are encouraged and supported in participating in care and decision-making at the level they choose. · Collaboration: Patients, families, health care practitioners, and health care leaders collaborate in policy and program development, implementation, and evaluation and research, facility design, professional education, and delivery of care. · Dignity and respect: Care team members listen to and honor patient and family perspectives and choices. Patient and family knowledge, values, beliefs, and cultural backgrounds are incorporated into the planning and delivery of care. · Information sharing: Care team members communicate and share complete and unbiased information with patients and families in ways that are affirming and useful. Patients and families receive timely, complete, and accurate information in order to effectively participate in care and decision-making. *Available at: http://www.ipfcc.org/about/pfcc.html*	Creating a plan of care that is guided by the patient's and family's hopes, dreams, wishes, priorities, and goals for care
Family/ professional partnerships	A partnership is a relationship between individuals or groups that is characterized by mutual cooperation and responsibility for the achievement of a specified goal. In health care, evidence has shown that strong doctor-patient relationships improve patient and family health outcomes. *Source: American Academy of Pediatrics Committee on Hospital Care. Family-centered care and the pediatrician's role. Pediatrics. 2003; 112(3):691-696 https://pediatrics.aappublications. org/content/112/3/691*	Ensuring that there is shared understanding, accountability, and decision-making across members of the care team
Family	Families define themselves. Families are big, small, extended, nuclear, multi-generational, with one parent, two parents, and grandparents. We live under one roof or many. A family can be as temporary as a few weeks, as permanent as forever. We become part of a family by birth, adoption, marriage, or from a desire for mutual support. As family members, we nurture, protect, and influence each other. Families are dynamic and are cultures unto themselves, with different values and unique ways of realizing dreams. Together, our families become the source of our rich cultural heritage and spiritual diversity. Each family has strengths and qualities that flow from individual members and from the family as a unit. Our families create neighborhoods, communities, states, and nations. *Developed and adopted by the New Mexico Legislative Young Children's Continuum and New Mexico Coalition for Children, June 1990.*	

Definitions
continued

Term	Definition	Examples
Care team member	In the context of this module, care team member refers to any person that provides services within the care setting.	Physician, nurse, nurse practitioner, social worker, care coordinator, family liaison
Shared decision-making	A process in which patients, family, and care team members engage in making a health care decision together. Shared decision-making is a process that involves care team members communicating information about treatment options, and patients and family communicating their priorities, wishes and guiding principles to reach an agreement on the best strategy for the patient. *Source: https://www.cincinnatichildrens.org/service/j/anderson-center/evidence-based-care/shared*	Discussing all options when a child is newly diagnosed with health issues that involve 2 or more medical options for care, empowering the family to negotiate with care team members about the best care for the child.
Patient and family engagement	The patient and family engagement framework is built on the fundamental principle that a patient- and family-centered health care system cannot be improved unless patients are more than passive recipients of directives from the medical care system. Patients, families, and care team members partner to improve health and redesign the parts of the system that are not working. *Source: http://www.aircpce.org/pfe-framework*	A family works with care team members via a patient and family advisory council or other means to address a safety issue, such as a medication error, family training on broviac or g-tube care, or gaps in discharge planning.
Transition	Transition consists of joint planning with youth and parents or caregivers to foster development of self-care skills and to cultivate active participation in decision-making. It also helps with identifying adult physicians and ensuring a smooth transfer to adult-centered care with current medical information. There are 6 core elements of health care transition: policy, tracking and monitoring, readiness, planning, transfer of care, and transfer completion. Examples of transition include having conversations with patients and families as early as 12 to 14 years of age about their needs and goals for self-care; holding team conversations about the transition from pediatric care to an adult physician; and discussing the changes that may occur moving from school to work life. *Source: White PH, Cooley WC, Transitions Clinical Report Authoring Group, American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians. Supporting the health care transitions from adolescence to adulthood in the medical home. Pediatrics. 2018;142(5):e20182587 http://pediatrics.aappublications.org/content/142/5/e20182587*	

Principles of Family/Professional Partnerships– Turning Concept into Action

Priniciples	What ACTIONS can you take to put these principles into practice?
Best interest of the child and the family	
Child grows into a partnership role	
Covet skills and expertise of all	
Trust	
Communication that is open, objective, and culturally and/or linguistically competent	
Decisions made together	
Willingness to negotiate	

Engaging Broad Audiences

It is universally accepted that children deserve the best health care possible. Issues arise, however, when care team members are not *speaking the same language* as families. For care team members, establishing a medical home and providing coordinated care are the best ways to connect and partner with families, but families may not see the benefits. This is when care team members need to become outreach specialists, which means being aware of any differences.

- **Pay attention to reading levels.** The average American reads at the seventh- or eighth-grade level. This means that some technical or medical terms may need to be explained and that written materials should include short sentences and simple vocabulary.

- **Reach out to families before appointments** to determine if a translator will be needed because translators may be difficult to locate at the last minute.

- **Consider distance learning opportunities** for families, such as brief educational pieces that families can watch online and ask their care team members about at a later time.

- **Do not use jargon.** It is shorthand for care team members, but it is indecipherable to families.

- **People learn differently.** If someone does not understand an in-person explanation, try calling that person or writing an email that, if possible, includes a link for further education.

- **Residents in rural areas may not have access to technology,** such as a 4G network, to communicate electronically and view online charts. It might work best to ensure that these families are given hard copies of forms at each office visit.

- **Recognize that parents who have children with complex care needs are tired and stressed.** They may not hear the first or second explanation, and it might be necessary to follow up with a call or email offering to go over the details again. These families are also busy trying to navigate normal daily activities, so communication may need to happen outside of normal business hours.

- **Families living in poverty most likely will not have access to technology in their homes.** They may have a smart phone, but it is important to them to limit use. Try to communicate as much as possible in the fewest messages.

- **Try establishing groups of families to brainstorm** about care coordination problems and solutions. These groups can meet in-person or virtually, depending on the needs.

- **Actions speak louder than words!** The chasm between care team members and families may be enormous, but families will know instantly if care team members care, which may be the most important communication they receive.

Family Voices Family/Professional Partnerships Handout

FAMILY VOICES®
...keeping families at the center of children's health care

FAMILY/PROFESSIONAL PARTNERSHIPS

WHAT ARE PARTNERSHIPS?

A partnership is a relationship between individuals or groups that is characterized by mutual cooperation and responsibility for the achievement of a specified goal. Partnerships have been used as successful models in many disciplines. In health care, evidence has shown that strong doctor-patient relationships improve patient and family health outcomes[1]. Key to such partnerships are the following principles[2]:

- Families and professionals work together in the best interest of the child and the family. As the child grows, s/he assumes a partnership role.
- Everyone respects the skills and expertise brought to the relationship.
- Trust is acknowledged as fundamental.
- Communication and information sharing are open and objective.
- Participants make decisions together.
- There is a willingness to negotiate.

WHY ARE FAMILY/PROFESSIONAL PARTNERSHIPS IMPORTANT IN HEALTH CARE?

Families lived experience makes them uniquely qualified to partner not only on the individual level with the care of their own child, but to also partner at the systems level shaping polices that improve health and outcomes for all CYSHCN. As primary caregivers, families are deeply affected by issues such as care fragmentation that results from lack of communication on the individual level, and ineffective and outdated health care policies and practices on the systems level. Evidence indicates that family/professional partnership at the individual level improves care coordination and health outcomes. Furthermore, meaningful family at the systems and other levels can be a powerful catalyst for reducing system fragmentation, removing barriers to health care and improving the quality of health care.

Effective partnership is the foundation of family-centered care, as families and providers work together in the best interest of the child and the family. Just as meaningful family/professional partnership at the individual level involves a shared, family-centered approach to providing care, meaningful partnership at the systems level integrates the importance and value of basing policies, programs, and services on the lived experiences of families who navigate fragmentation and these barriers daily for their CYSHCN.

HOW DO FAMILIES PARTNER WITH PROFESSIONALS TO IMPROVE CARE FOR CYSCHN?

Partnering with a child's provider: As their child's most consistent caregiver, families know their child with SHCN in ways that no one else can, and have the most vested interest in ensuring that their child's health care needs are met. Family input when something is wrong or how a treatment or medication is working is essential to the providers who treat CYSHCN. Communication is critical to developing a partnership with a child's provider.

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Family Voices Family/Professional Partnerships Handout

continued

Partnering with health plans: The financing of health care for many children with special health care needs is provided by managed care plans, which by definition, control access to services and programs. Many children with special healthcare needs are served by both private health insurance and public programs such as Medicaid. Just as you do with your child's provider, you can help health insurance plans to understand what works well and what doesn't with their programs and policies. Many health insurance providers work with family advisors to learn more about the populations they serve.

Partnering with Title V: There is a federally-funded Title V Program in each state that provides services to enhance the health of women and children, including children/youth with special healthcare needs. State Title V programs are required to partner with families to ensure that family perspectives and lived experience/expertise help to guide these programs. Families in these partnership roles are critical to helping our government understand family needs in caring for our children with special health care needs.

Partnering with Programs and Agencies: Many stakeholder groups contribute to the setting of policies that affect children/youth with special health care needs. Families often become involved with a broad spectrum of programs and agencies, filling roles from volunteer, to staff, to appointed advisory board members.

Partnering with other family leaders: In advocating for their child, many parents have learned the importance and value of speaking out for larger systems change. Advocacy groups, whether disability-specific or broader (such as Family Voices), arose because a few individuals wanted a better life for their child and believed they could make a difference. By joining your voice with others, your message and potential impact is stronger.

SOURCES

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January 2019

Pediatric Integrated Survey Guide for Family Leaders

Pediatric Integrated Care Survey (PICS)

A measure of care integration that captures experiences of families working with their child's care team to plan, manage, and track their child's care.

How it can be used:

The PICS is intended to be used to gather family experience(s) of care integration in order to make improvements in individual settings or system wide. The ultimate goal of the PICS is to improve the experiences and outcomes for children and youth with special health care needs and their families.

How can you, as a family leader and advocate for your child, use a tool like the PICS?

---

1 » Look through the tool yourself or with someone on your child's care team. Pick out specific items that you believe would improve your child's care and your experience.

Then, talk to your child's care team members, using some of the following examples:

PICS: In the past 12 months, how often has someone on your child's care team explained to you who was responsible for different parts of your child's care?

During your next appointment, this might help you to think about whether or not the care team members explained who was going to take accountability for the tasks that were discussed.

PICS: In the past 12 months, how often have your child's care team members offered you opportunities to connect with other families who they thought might be of help to you?

If no one ever has talked to you about this, then maybe this is not something you ever expected or even thought about! Think through who you might approach to talk about this possibility.

---

2 » Share the tool with your child's care team members!

If a family experience tool is not being used by your child's care team, consider bringing it to their attention.

Action Grid Guide for Family Leaders

Boston Children's Hospital
Until every child is well®

Boston Children's Hospital
Integrated Care Program

Post-Encounter Action Grid

Date:
Patient Name:
Clinic:
Provider Name:

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?

Action Grid © 2017 Boston Children's Hospital, Integrated Care Program
For permission to use this tool or a modified version, please email us at IntegratedCare@childrens.harvard.edu

Action Grid

The post-encounter action grid is intended to define a set of action items with accountability, a timeline, and contingency plans that result from in-person visits. It is meant to be part of shared-care planning.

How can this grid be used:

---

1 » Bring a grid (you can modify it to make sense to you) to each appointment/visit.

Ask the care team member you are meeting with to walk through the grid with you, ensuring that all of their recommendations for next steps, including the timeline and who is responsible for each step, are captured and clear to both of you.

---

2 » Review elements on the grid to add to your mental checklist.

Even if you are not prepared with the grid, you can use the elements in the grid to add to a mental checklist. When you are leaving an appointment or visit, you can think through the following:

· Do I know what all of the next steps are? Can I repeat them back to my child's care team members to ensure we are on the same page?
· Do I know who is responsible for carrying out each task?
· Do I know what the timeline is to complete each task?
· Do I know who to call if I run into a problem?

Perspectives on the Action Grid

How Families Can Use the Action Grid to Engage as Care Team Members
Brigit Frank

Families can encourage care teams to use the action grid for the following reasons:

- It helps the family understand why a care team member is recommending an appointment, treatment, or other action. (goals)

- It is a way to track next steps to be completed by the care team for the child's care. (actions)

- It increases family understanding of each care team member's purpose. (who)

- It prioritizes and organizes appointments to fit with the family's daily schedule. (when)

- It increases family confidence to know there is a backup plan if the care team runs into a problem. (contingency)

- It reduces the chances of duplicate tests and appointments.

- It enables a family to monitor progress on the child's long-term goals from the care team's perspective.

- It can be kept in a file as a tool to help track a child's progress toward long-term goals.

- It can serve as a visual aid to show status to other care team members (eg, school nurses).

- It keeps care team members informed, including those in different hospital systems.

How Care Team Members Can Use the Action Grid to Engage in Family/Professional Partnerships
Cara Coleman

In addition to using the post-encounter action grid as a method of delineating, the following are some different ways to think about the grid or use it to further engagement of all members of the team and to foster family/professional partnerships:

Communication

- TALKING TOOL:
  The grid can be used as a neutral way to broach a sensitive topic, bring clarity, or make tasks related to care manageable.

- GETTING ON THE SAME PAGE:
  The grid can be used to foster open and honest dialogue so that each member of the team fully understands and is on the same page.

Perspectives on the Action Grid
continued

Education

- CLINICAL ACCESSIBILITY:
  If a patient or family is struggling to understand an issue and/or build a skill for care, use the action grid to provide education about a specific aspect of care.

- INTRODUCE AND INFORM:
  Use parts of the action grid, or the grid in its entirety, to inform patients and families or to introduce them to new members of the team or new aspects of care.

- TRIGGER TO LEARN:
  Using the grid as a way to make health care knowledge and practice accessible triggers patient ability to learn (what is in front of them and so much more), thus fostering engagement in their own care, empowerment to communicate and participate, and ultimately, the ability to feel comfort and strength in the partnership and shared decision-making.

Organization

- OF CARE:
  Use the grid during each visit with each patient so that there is continuity of care with each family, as well as in the clinic overall.

- OF COMMUNICATION:
  Use the grid to ensure that a visit flows in a smooth and methodical way so that all issues are addressed.

- OF PATIENTS AND FAMILIES:
  In addition to filling out the grid at each visit, blank copies of the grid can be given to patients' families to help organize their thoughts, questions, needs, desires, priorities, wishes, and goals. In turn, when patients and/or families are more organized in these thoughts, they are more likely to communicate them with their care team and engage in all aspects of care.

- OF OTHER CARE TEAM MEMBERS:
  The grid can be used within the practice, but it is especially helpful to share it with care team members outside of the clinic so that they are also informed, engaged, reinforcing, contributing, fostering, and partnering.

Expectations

- Each visit is made tangible.
- Each issue is addressed.
- Who, when, where, what, how, and why are all accounted for on one page.

Accountability

- Are there any sub-bullet points that can be added here?

Perspectives on the Action Grid

continued

Following are other examples of tangible ways to use the grid to foster communication, build trust, and engage partnerships:

· Use the information recorded in each action grid cumulatively over a specific time span to help identify gaps, needs, strengths, and progress to inform updating or creation of a care plan.

· Use the action grid with new parents receiving a new diagnosis(es) who may feel overwhelmed. The grid can break down various aspects of care to make them more digestible. It may inform them at the level they are ready to receive and, eventually, at the level at which they are ready to engage. Furthermore, for new parents who are unwilling or not yet able to accept and engage, the action grid requires them to engage as a member of the team. The grid can also begin to teach the language of the new world they have entered, while also equipping them with the necessary skills to communicate clinical and other relevant information, provide care, become organized, be flexible, and move forward, among others.

· Use the action grid when there is a break down in care with communication, goals, or shared decision-making. The grid neutralizes some of the raw emotions, shines a light on the gaps in care, and provides a platform to co-develop the goals, action, and accountability so that care can be shared and progress.

Case-Based Learning

CASE STUDY #1

Alexis and David's 8-year old daughter, Trinity, has been in the hospital for more than a week. Trinity is a medically complex child with Down syndrome and a heart condition, so Alexis and David have been talking with many different specialists and therapists. They have not been able to talk to each other much, so they have not compared notes on the different care team members they have met. The couple is also worried about all the time David has been missing from work, and the thought of more medical bills is concerning for them both. This morning at the hospital, Alexis meets a different doctor who recommends that Trinity have a surgery to place a g-tube port, which, the doctor explains, will help her maintain her weight. Alexis is tired and confused. Her daughter is in the hospital for a completely different reason. She is not sure if she should give consent for the surgery, and she is wondering if her daughter's other care team members would agree with the surgery.

When Alexis sees her daughter's nurse, she tells him that she is feeling overwhelmed. The nurse asks the social worker to join them to discuss options for Trinity. They recommend a care coordination meeting for everyone on the team. They explain that this will allow Alexis and David, as team members, to ask questions and enable the care team members to compare care plans, responsibilities, and timelines.

At the care coordination meeting, the social worker has everyone in the conference room, and those joining by phone introduce themselves and explain their roles on the team. But, before they can begin, Trinity's neurologist stands, states his name and title, and says that he is too busy to participate. He tells the group that they can read his notes and contact him with any questions. The social worker calmly listens to the neurologist and asks him for a few more minutes of his time. She then tells the group the purpose of the meeting is to build a care team around Trinity and her family to ensure better outcomes for everyone on the team. She tells the neurologist that he can give his information first and hopes that he will stay to learn how the treatment plans from other members and information from the family, including financial concerns, may affect his plans for Trinity.

With clear direction and goals from the social worker, the rest of the meeting goes smoothly. Alexis and David get answers to their questions and are relieved to see a team working together to support Trinity and their family. They also understand how the g-tube surgery will benefit Trinity's health and will help the team meet its goals for her, and they give consent for the surgery.

Case-Based Learning
continued

Discussion Questions

- **Is there something that could have been done before Trinity's care coordination meeting to make sure that the care team members knew the goals for the meeting?**

- **Do you think that the neurologist thought of David, Alexis, and Trinity as members of the care team? Do you think the social worker's explanation of the meeting's purpose helped him understand the team concept?**

- **Alexis and David felt overwhelmed by the number of specialists and therapists who were caring for their daughter. Can you think of a way to show families in a similar situation that these specialists and therapists are working together and communicating as a team?**

- **In this case, the nurse and social worker stepped into the role of integrator. What could David and Alexis have said or done if the nurse and social worker had not played that role?**

CASE STUDY #2

Nine-year-old Javier has cystic fibrosis and Crohn's disease. Three months ago, after losing a great deal of weight, he received a gastrostomy feeding tube. Javier lives with his mother and father, Maria and Jose, and he is 1 of 4 boys, ranging in age from 10 to 14. The Hernandez household is busy: all the boys play sports, Jose works full time and often travels for work, and Maria works part time. All 3 boys are U.S. citizens, but Maria and Jose are not; they never discuss their immigration status but always refer to it as in process. While Maria and Jose speak English, they both left formal education in sixth grade. Both grandmothers live with the family, and they both have been experiencing health issues. Therefore, Maria has become the primary caregiver, handling all of their appointments, treatments, and supplies. Javier does not have nursing care at home, but both grandmothers have an aide who comes for a few hours when Maria is at work. Despite his medical issues, Javier is a happy and well-adjusted kid. His recent weight loss has been hard for him to handle, but he is determined to be normal by continuing to play sports and go to school.

The feeding tube has helped Javier gain back a bit of weight but not as easily as the physicians had anticipated. At the last 3 biweekly feeding tube appointments at the clinic, the care team has handed Maria a new g-tube feeding regimen without discussing its timing and schedule with the family. Also at the appointment, Maria shares observations she records in a feeding journal, answers any questions the care team may have, and works diligently to learn how to care for the skin around the g-tube site and how to best use the feeding equipment. Maria sometimes feels timid in sharing all of her concerns at clinic visits because she worries she is either giving too much or the wrong information (she does not want to mix up Javier's medical information with that of his grandmothers and wants to give the right information to the right physicians). She is also sometimes fearful that she does not understand everything being said in English, but she has never been offered an interpreter, a review of

Case-Based Learning

continued

information in her native language, nor verification that she understands. She has also been too afraid and embarrassed to share her worry about not understanding the language well enough.

At the current feeding clinic visit, Maria shares her primary concern at the beginning of the appointment: Javier has not been sleeping well because the current feeding regimen involves overnight feedings, and he has required more breathing treatments around the clock. While the feeding regimen has been designed so that Javier does not have to use the g-tube at school in order to eat normally with other kids at lunch, she is concerned that the feedings are too heavy on his stomach at night and that she keeps waking him up to turn feedings off and on. Maria also shared that Javier is too tired, does not want to go to school (saying, "What's the point? I am not normal, so why go to school?"), and looks like he is losing weight. The nutritionist, nurse, and physician listen to Maria and suggest she talk with the pulmonologist about the breathing treatment schedule at night.

At the end of the clinic visit, Maria is handed a feeding schedule. When she asks if they can talk about it, the team says this feeding schedule is best for Javier and that she will have to save her concerns for the next visit in 2 weeks.

Discussion Questions

- How can this team work together better to develop a feeding schedule that works for Javier?

- Are there are any strategies Maria can use to feel more confident in her ability to share her concerns as a parent and caregiver? Are there any strategies the health care team can use to make the plan of care and decision-making genuinely shared?

- What are some of the ways that Maria's embarrassment over her fear that she may not be understanding English be handled in a way that offers her dignity and respect?

- Why did the nutritionist, nurse, and physician respond the way they did when Maria asked about the feeding schedule? How could they create a structure and process so they are able to incorporate family input and feedback into care instructions and process family concerns?

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**Developing and Sustaining Strong
Family/Professional Partnerships**
Module 2 of
Pediatric Care Coordination Curriculum 2nd Edition

1

Educational Purposes Only – No Medical Advice

The Pediatric Care Coordination Curriculum is offered for educational purposes only and is not meant as a substitute for independent medical judgment or the advice of a qualified physician or health care professional. Users who choose to use information or recommendations made available by the Pediatric Care Coordination Curriculum do so at their own risk and should not rely on that information as professional medical advice or use it to replace any relationship with their physicians or other qualified health care professionals.

2

Objectives

By the end of this session, the audience will be able to

- Explain the value and importance of family/professional partnerships
- Explain the family role in health care improvement
- Describe ways to engage families, physicians, and nonphysician clinicians to improve integration
- Demonstrate knowledge of tools, resources, and strategies to improve family/professional partnerships
- Demonstrate the ability to operationalize family/ professional partnerships through planning an initiative and/or event

3

What is Patient- and Family- Centered Care?

Definition from the Institute for Patient- and Family-Centered Care

Patient- and family-centered care is an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families.

In patient- and family-centered care, patients and families define their "family" and determine how they will participate in care and decision-making.

Patient- and family-centered care leads to better health outcomes, improved patient and family experience of care, better clinician and staff satisfaction, and wiser allocation of resources.

Important:
Patient and family knowledge, values, beliefs, and cultural backgrounds are incorporated into the planning and delivery of care.

Source: http://www.ipfcc.org/about/pfcc.html

4

Core Concepts of Patient- and Family-Centered Care

Participation

Information Sharing

Dignity and Respect

Collaboration

=

Authentic Partnerships!

Source: http://www.ipfcc.org/about/pfcc.html

Boston Children's Hospital

HARVARD MEDICAL SCHOOL
TEACHING HOSPITAL

5

Principles of *Family/Professional Partnerships*

- Families and professionals work together in the best interest of the child and the family. As the child is able, she or he assumes a partnership role.

- Everyone respects the skills and expertise brought to the relationship.

- Trust is acknowledged as fundamental.

- Communication and information sharing are open, objective, and in a linguistically and culturally appropriate manner.

- Participants make decisions together, which is known as shared decision-making.

- There is a willingness to negotiate.

Source: http://familyvoices.org

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6

In Practice

- How can these principles be operationalized?
- What might this look like in real life?

Principles	What ACTIONS can you take to put these principles into practice?
Best interest of the child and the family	
Child grows into a partnership role	
Covet skills and expertise of all	
Trust	
Communication that is open, objective, and culturally and linguistically competent	
Decisions made together	
Willingness to negotiate	

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7

Tools to Support Family/Professional Partnerships

Tools that will be addressed today

- Pediatric Integrated Care Survey (PICS)
- Action Grid
- Care Map

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8

Family Experience

- Family experience is crucial to engaging families to drive improvement work.
- Ask families to be part of the care transformation team -- they know best!
- What is working, and what is not?
- Qualitative and quantitative experiences can be gathered.

9

Pediatric Integrated Care Survey

The Pediatric Integrated Care Survey (PICS) asks families to respond about experiences across the care team.

The domains of the instrument are
- Access to care
- Communication
- Family impact
- Care goal creation and planning

10

PICS

Data are used to
- Inform priorities for intervention
- Track progress over time from the perspective of families
- Set recommendations for what families should be expecting

How could you use the tool?

11

PICS

- Look through the tool yourself or with someone on your child's care team. Pick out specific items that you believe would improve your child's care and your experience.

- Share the tool with your child's care team members!

- How might you use it or encourage families to use it?

12

Action Grid

- The action grid is a care planning tool intended to document action items resulting from an in-person visit or encounter.

- Even if a clinical care team is not using the grid, families can modify the grid to be applicable to them and bring it to each appointment/visit.

- Elements on the grid can be used to add to mental checklists, regardless of your role on the care team.

- What might you expect to find over time as this is consistently implemented?

13

Action Grid

14

Care Map

15

Author Care Map

16

Let's Practice!

Practice using some of the concepts and tools with case studies.

17

Next Steps

Think through how you can take content presented in this workshop back to your own setting.

- What do you want to focus on?
- Who do you need to involve?
- How will you begin?
- How will you measure it?

18

Pediatric Care Coordination Curriculum

MODULE 3

Social Determinants of Health

Clement Bottino, MD, MPH
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Richard Antonelli, MD, MS, FAAP

**Dr. Fleegler is a consultant to Veta Health.
Otherwise, the authors have no conflicts
of interest to disclose.*

Module 3—Objectives and Learning Goals

By the end of this session, participants should be able to:

- Understand what social determinants of health and health disparities are.
- Understand how social conditions influence health.
- Recognize 5 core health-related social needs for screening and referral with implications for care coordination.
- Understand the importance of bias and health equity.
- Recognize some innovations aimed at addressing social determinants of health.

Note to the facilitator:

This module includes a didactic portion, a set of tools and resources, case studies, worksheets, and suggested literature.

Please be aware that it is crucial to include local-, state-, and region-specific content if this module is being implemented.

An **L** found in the module indicates places where the authors specifically call out the need for local content, but facilitators should feel free to include local content wherever they see fit. Local content includes, but is not limited to, the following:

- Cultural aspects of community (including assets, vulnerabilities, and language)
- Sociodemographic factors
- Geography
- Local, state, and regional resources

This module aims to assist learners in operationalizing the concepts related to social determinants of health, providing effective training to staff to deliver trauma-informed care and using language that does not alienate.

Two tables are included below. The first is a high-level agenda of the module. The second is the Facilitator Guide that includes a breakdown of slide content and talking points. The facilitator should use the guide as a resource to tailor the training.

The curriculum is intended to be customized to fit the training needs of different audiences. Therefore, content from this module can be selected and incorporated into the training. However, a suggested agenda for implementing this module as a stand-alone is included.

Module Overview

Agenda Item	Time	Materials Required	Instruction/Notes
Presentation	45-60 min	· PowerPoint slide deck · Computer · Projector	Learners may follow along using the PDF of the slide deck, which can be viewed on a laptop, tablet, or smartphone.
Case vignettes and group discussion	45-60 min	Case studies	The case studies can be found at the end of this Facilitator Guide. They can be printed or viewed on a laptop, tablet, or smartphone.

Orientation to the Module

Social determinants of health (SDoH) are the conditions in which people are born and live, learn, work, play, and age.[1] SDoH are mostly responsible for *health disparities*—the higher burden of illness, injury, disability, or mortality experienced by one population group relative to another. *Health equity* is the opportunity for people to attain their full health potential without disadvantage because of social position or circumstance. SDoH, health disparities, and health equity are central themes of Module 3.

Learners may come to Module 3 with varying levels of understanding, comfort, and enthusiasm regarding the material. The authors have found that taking an inclusive approach that welcomes all viewpoints facilitates open discussion and perspective sharing. Including pieces of local information, resources, and contacts may help to complement the core material provided here.

Works Cited

1. Promoting lifelong health for families and communities. In: Hagan JF, Shaw JS, Duncan PM, eds. *Bright Futures: Guidelines for Health Supervision of Infants, Children, and Adolescents.* 4th ed. Elk Grove Village, IL: American Academy of Pediatrics; 2017:15-40 https://brightfutures.aap.org/Bright%20Futures%20Documents/BF4_LifelongHealth.pdf
   Accessed June 3, 2019

2. Social Determinants of Health. https://www.who.int/social_determinants/sdh_definition/en/
   Accessed June 3, 2019

Abbreviations

ACEs – adverse childhood experiences
ADHD – attention deficit hyperactivity disorder
AAP – American Academy of Pediatrics
CDC – Centers for Disease Control and Prevention
CHW – community health worker
CMS – Centers for Medicare & Medicaid Services
HRSNs – health-related social needs
MIECHV – Maternal, Infant, and Early Childhood Home Visiting Program
PN – patient navigator
SDoH – social determinants of health
WHO – World Health Organization

Facilitator Guide–Slide Deck
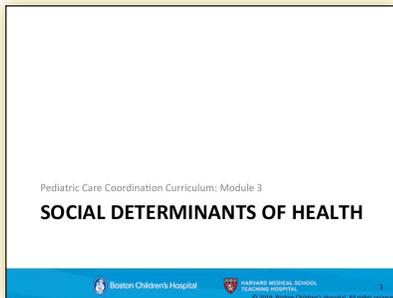
SLIDE 1 » Title Slide

Pediatric Care Coordination Curriculum: Module 3

SOCIAL DETERMINANTS OF HEALTH

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SLIDE 2 » Educational Purpose Only–No Medical Advice

The Pediatric Care Coordination Curriculum is offered for educational purposes only and is not meant as a substitute for independent medical judgment or the advice of a qualified physician or health care professional. Users who choose to use information or recommendations made available by the Pediatric Care Coordination Curriculum do so at their own risk and should not rely on that information as professional medical advice or use it to replace any relationship with their physicians or other qualified health care professionals.

SLIDE 3 » Authors

Authors

- Clement Bottino, MD, MPH
- Linda Sprague Martinez, PhD
- Geoff Wilkinson, MSW
- Eric Fleegler, MD, MPH*
- Hannah Rosenberg, MSc
- Richard Antonelli, MD, MS, FAAP

Dr. Fleegler is a consultant to Veta Health. Otherwise, the authors have no conflicts of interest to disclose.

Facilitator Guide–Slide Deck
continued

SLIDE 4 » Learning Goals

Learning Goals

1. Understand *what* social determinants of health and health disparities are.
2. Understand *how* social conditions influence health.
3. Recognize *5 core health-related social needs* for screening and referral.
4. Understand the importance of *bias* and *health equity*.
5. Recognize some *innovations* aimed at addressing social determinants of health.

The goal of Module 3 is to provide an overview of SDoH and explain how they impact the implementation of care coordination activities. Addressing SDoH has the potential to improve health outcomes and enhance family engagement and experience of care. Clinicians should practice trauma-informed care, address unconscious biases, and strive for health equity. Application of these techniques also has the potential to support care team member wellness.

Facilitation Technique

Learners may feel reluctant to engage with the concepts presented in Module 3. They may have concerns about how and why health care should take on social issues. Individual political stances or personal identifications may also affect the dynamics of the learning environment. The authors have found that SDoH-learning audiences are often divided into groups of thirds: one-third may already feel on board (ie, engaged, enthusiastic, or perhaps concerned with social justice); one-third may feel resigned (ie, disengaged or perhaps feeling that SDoH are "not my problem" or "that's just the way things are"); and one-third may feel resistant (ie, antagonistic toward the material or perhaps feeling that it represents a liberal agenda). These divisions may correlate with learners' cultural backgrounds and/or political beliefs. Strive to promote a calm and respectful learning environment where all viewpoints are welcome. During group discussion, encourage learners to share their experiences as a way to encourage perspective sharing.

SLIDE 5 » Micro-Chapters

Contents:
5 Micro-Chapters

1. *What* Are Social Determinants of Health and Health Disparities?
2. Let's Talk About *Bias* and *Health Equity*
3. *How* Do Social Conditions Influence Health?
4. *Health-Related Social Needs*: Screening and Referral
5. *Innovations* for Social Determinants of Health

The slide deck is organized into 5 micro-chapters consisting of 10 to 15 slides each. Depending on time availability, short breaks may be taken after each micro-chapter.

Facilitator Guide–Slide Deck

continued

SLIDE 6 » Micro-Chapter 1: What Are Social Determinants of Health and Health Disparities?
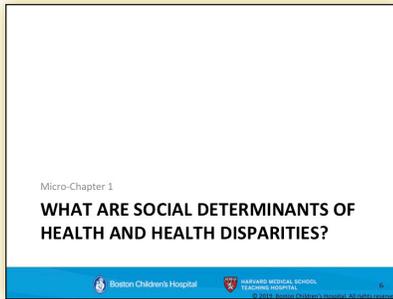
This chapter introduces SDoH and health disparities and provides a high-altitude view of how they can be understood using a socio-ecological framework.

SLIDE 7

There is no single definition of SDoH, but there is broad consensus that social factors impact health. In general, SDoH are the economic and social conditions that influence individual and group differences in health status.

Facilitation Technique

Depending on time, ask learners to share what the definition of SDoH means to them. In addition, asking them to share personal stories or anecdotes about how social conditions have affected their health or well-being (negative or positive) would also be interesting for discussion.

Useful Resources

Social Determinants of Health. https://en.wikipedia.org/wiki/Social_ determinants_of_health Updated April 3, 2019. *Accessed June 3, 2019*

Braveman P, Gottlieb L. The social determinants of health: it's time to consider the causes of the causes. *Public Health Rep.* 2014;129(Suppl2):19-31. doi: 10.1177/00333549141291S206

American Academy of Pediatrics Council on Community Pediatrics. Poverty and child health in the United States. *Pediatrics.* 2016;137(4):e20160339

Promoting lifelong health for families and communities. In: Hagan JF, Shaw JS, Duncan PM, eds. *Bright Futures: Guidelines for Health Supervision of Infants, Children, and Adolescents.* 4th ed. Elk Grove Village, IL: American Academy of Pediatrics; 2017:15-40 https://brightfutures.aap.org/Bright%20Futures%20 Documents/BF4_LifelongHealth.pdf *Accessed June 3, 2019*

Beck AF, Tschudy MM, Coker TR, et al. Determinants of health and pediatric primary care practices. *Pediatrics.* 2016;137(3):e20153673

Let's Learn Public Health. Social determinants of health – an introduction [video]. 2017. https://www.youtube.com/watch?v=8PH4JYfF4Ns *Accessed June 3, 2019*

Newnham N, Heywood J. *What Counts.* Boston, MA: Health Leads; https://healthleadsusa.org/what-counts/ *Accessed June 4, 2019*

Facilitator Guide–Slide Deck

continued

SLIDE 8

- Think of these *conditions* as being layered like an onion.
- This framework is called the *social-ecological model*.
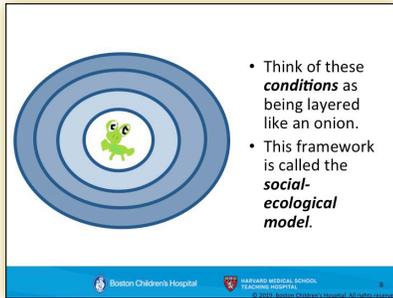
The social-ecological model considers the complex interplay between individual, relationship, community, and societal factors. The overlapping rings in the model illustrate how factors at one level can influence factors at another level.

Useful Resource

The Social-Ecological Model: A Framework for Violence Prevention. https://www.cdc.gov/violenceprevention/publichealthissue/social-ecologicalmodel.html?CDC_AA_refVal=https%3A%2F%2Fwww.cdc.gov%2Fviolencepreventio n%2Foverview%2Fsocial-ecologicalmodel.html Updated January 16, 2019. *Accessed June 3, 2019*

SLIDE 9

Individual conditions include:
- Income
- Education
- Employment
- Housing
- Food
- Transportation
- Health care
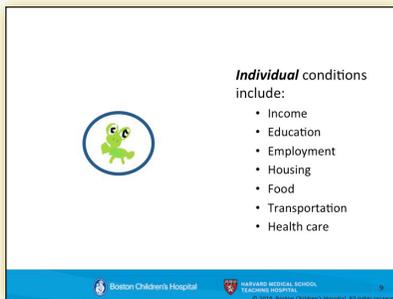
These are personal or individual-level conditions (eg, the particular type and quality of employment or housing that a person experiences).

- *Please note* that this is not an exhaustive list.

- The list here focuses on *social* conditions (as opposed to biological or environmental conditions).
  - ~ For example, a person's employment may be socially influenced (eg, whether women are allowed to join the military), biologically influenced (eg, most professional basketball players are very tall), or environmentally influenced (eg, most fishing jobs are in coastal areas).

- Social, biological, and environmental conditions are mostly inseparable.
  - ~ For example, a person's access to food is socially influenced (eg, whether neighbors are willing to share), biologically influenced (eg, preferentially giving food to daughters or sons), and environmentally influenced (eg, whether there is enough rainfall to grow crops).

Facilitation Technique

It can be helpful here to focus on the big picture:
What are the social conditions in a person's immediate vicinity?

It is okay if learners suggest that a particular factor (eg, health care) is more community-level than individual-level.

Facilitators can encourage participants to keep an open mind and to consider subtle or even counterintuitive ideas and relationships. For example, employment can be an individual-level condition (eg, the specific job that a person has) but also a societal-level condition (eg, the availability of jobs during an economic recession).

Facilitator Guide–Slide Deck
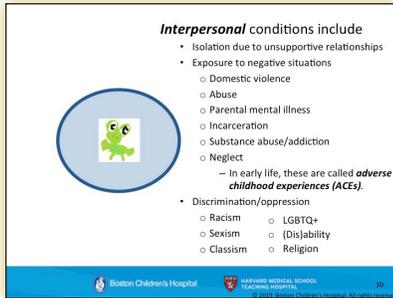
continued

SLIDE 10

Interpersonal conditions include
- Isolation due to unsupportive relationships
- Exposure to negative situations
  - Domestic violence
  - Abuse
  - Parental mental illness
  - Incarceration
  - Substance abuse/addiction
  - Neglect
    - In early life, these are called *adverse childhood experiences (ACEs)*.
- Discrimination/oppression
  - Racism
  - Sexism
  - Classism
  - LGBTQ+
  - (Dis)ability
  - Religion

The same as the key message for Slide 9. ACEs and discrimination/oppression will be presented in greater detail later in the module.

SLIDE 11
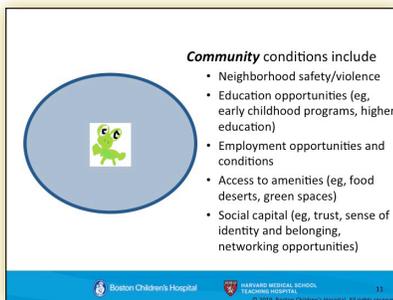
Community conditions include
- Neighborhood safety/violence
- Education opportunities (eg, early childhood programs, higher education)
- Employment opportunities and conditions
- Access to amenities (eg, food deserts, green spaces)
- Social capital (eg, trust, sense of identity and belonging, networking opportunities)

The same as the key message for Slide 9.

Useful Resources

NPR Video. No easy access: food deserts in D.C. [video]. 2018. https://www.youtube.com/watch?v=kQeorPkPLmU *Accessed June 3, 2019*

Urban Green Spaces. World Health Organization website. https://www.who.int/sustainable-development/cities/health-risks/urban-green-space/en/ *Accessed June 3, 2019*

~ "Recent estimates show that physical inactivity, linked to poor walkability and lack of access to recreational areas, accounts for 3.3% of global deaths," according to the website.

Health and Academics. Centers for Disease Control and Prevention website. https://www.cdc.gov/healthyyouth/health_and_academics/index.htm Updated August 17, 2018. *Accessed June 3, 2019*

~ According to the website, "Schools play a critical role in promoting the health and safety of young people and helping them establish lifelong healthy behaviors. Research shows that school health programs reduce the prevalence of health risk behaviors among young people and have a positive effect on academic performance."

Office of Disease Prevention and Health Promotion. Social Cohesion. https://www.healthypeople.gov/2020/topics-objectives/topic/social-determinants-health/interventions-resources/social-cohesion Updated May 31, 2019. *Accessed June 3, 2019*

Facilitator Guide–Slide Deck

continued

SLIDE 12
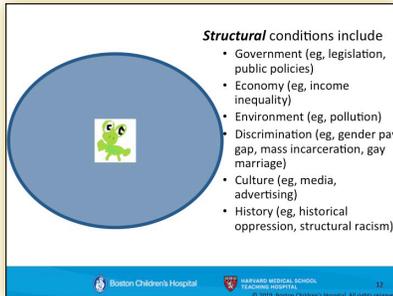
The same as the key message for Slide 9.

Useful Resources

Chokshi DA. Income, poverty, and health inequality. JAMA. 2018;319(13):1312–1313. doi:10.1001/jama.2018.2521

> ~ According to the article, "[there is a] gap in life expectancy of about 15 years for men and 10 years for women when comparing the most affluent 1% of individuals with the poorest 1%. To put this into perspective, the 10-year life expectancy difference for women is equal to the decrement in longevity from a lifetime of smoking."

Pollution: The lead-crime hypothesis posits that the sharp decline in crime in the United States during the 1990s was in large part due to the removal of lead from gasoline during the 1970s (when young adults in the 1990s were infants and toddlers). Further details are available at: Lead-Crime Hypothesis. https://en.wikipedia.org/wiki/Lead%E2%80%93crime_hypothesis Updated May 27, 2019. *Accessed June 3, 2019*

Gender pay gap: Platt J, Prins S, Bates L, Keyes K. Unequal depression for equal work? How the wage gap explains gendered disparities in mood disorders. Soc Sci Med. 2016;149:1-8. https://doi.org/10.1016/j.socscimed.2015.11.056

> ~ "Highlights: Individual-level indicators of productivity do not fully explain the gender wage gap. The gender wage gap is evidence of structural workplace discrimination. Odds of mood disorders increased among women paid less than equally qualified men. Structural discrimination partially explains gender disparities in mood disorders," reports the article.

Mass incarceration: Wildeman C, Wang EA. Mass incarceration, public health, and widening inequality in the USA. Lancet. 2017;389(10077):1464-1474. https://doi.org/10.1016/S0140-6736(17)30259-3

> ~ According to the article, "Nearly one in three black men will ever be imprisoned, and nearly half of black women currently have a family member or extended family member who is in prison…The emerging literature on the family and community effects of mass incarceration points to negative health impacts on the female partners and children of incarcerated men, and raises concerns that excessive incarceration could harm entire communities and thus might partly underlie health disparities both in the USA and between the USA and other developed countries."

Media exposure: Media Influences on Health. RAND Corporation website. https://www.rand.org/topics/media-influences-on-health.html *Accessed June 3, 2019*

> ~ 'The media—everything from television, radio, and film to games, advertising, and social media outlets like Facebook and Twitter—can have significant impacts on individual and population health. Exposure to media, especially among youth, may affect health behaviors such as substance use, sexual activity, and eating habits," according to the website.

Structural racism: Bailey ZD, Krieger N, Agénor M, Graves J, Linos N, Bassett MT. Structural racism and health inequities in the USA: evidence and interventions. Lancet. 2017;389(10077):1453-1463. https://doi.org/10.1016/S0140-6736(17)30569-X

> ~ "Structural racism refers to the totality of ways in which societies foster racial discrimination through mutually reinforcing systems of housing, education, employment, earnings, benefits, credit, media, health care, and criminal justice. These patterns and practices in turn reinforce discriminatory beliefs, values, and distribution of resources," according to the article.

Facilitator Guide–Slide Deck

continued

SLIDE 13
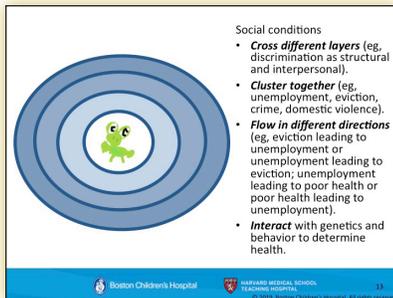
This slide highlights how the various layers of the social-ecological model overlap and flow in different directions.

Facilitation Technique

Depending on time, encourage learners to brainstorm other examples that demonstrate how various SDoH cross, cluster, flow, and interact. For example, a lack of good-quality grocery stores in a community (eg, food deserts) will negatively influence an individual's food and eating behaviors, which will also be influenced by governmental policies about what foods are covered by supplemental nutrition programs (eg, soda). These factors may contribute to obesity, which may lead to interpersonal weight-based discrimination.

Useful Resource

For discussing the role of the Supplemental Nutrition Assistance Program (SNAP): What Can SNAP Buy? U.S. Department of Agriculture, Food and Nutrition Service website. https://www.fns.usda.gov/snap/eligible-food-items Updated September 4, 2013. *Accessed June 3, 2019*

SLIDE 14
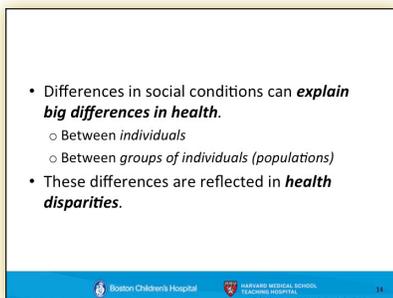
SDoH can explain much of the *variability* in health and well-being between people as well as groups of people. By *"can explain,"* the idea is that social conditions have an impact, but as discussed above, they are not the full story—biology, environment, and behavior also explain variability in health, but again, these factors are intertwined with social conditions. This variability is reflected in *health disparities*, a concept covered in more detail in the next slide.

Facilitation Technique

Encourage learners to consider how SDoH affect *individual patients and populations of patients* (eg, patients with asthma). Also, consider asking learners to share personal experiences with witnessing how social conditions have shaped the health of close individuals (ie, family and friends) and groups (ie, their neighborhood or workplace).

Facilitator Guide–Slide Deck

continued

SLIDE 15

What Are *Health Disparities*?

Health disparities refer to **differences in health between population groups**.
- Disparities occur across many dimensions
  - Race/ethnicity
  - Socioeconomic status
  - Location
  - Gender expression
  - Disability status
  - Sexual orientation
- *Health care disparities* refer to differences in *health care* between different groups.

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Health disparities are about group *differences*. Because these differences are due to social factors (eg, what race or gender a person is or where they live), they are considered to be largely *preventable* (not inevitable). These ideas are explored further in later slides. The article by Ordera and Artiga (see Useful Resource, below) is excellent and highly recommended for reading.

Useful Resources
Orgera K, Artiga S. Disparities in health and health care: five key questions and answers. https://www.kff.org/disparities-policy/issue-brief/disparities-in-health-and-health-care-five-key-questions-and-answers/ Published August 8, 2018. *Accessed June 3, 2018*

SLIDE 16

Why Do Health Disparities *Matter*?

- Disparities create **unfair advantages and disadvantages**
  - By systematically structuring opportunity and assigning value on the social interpretation of how one looks (eg, race or gender).
- Disparities **sap the strength of the whole society through the waste of human resources**.
- Disparities result in **unnecessary costs**.
  - *Addressing health disparities is increasingly important as the population becomes more diverse.*

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This slide highlights how health disparities are both a cause and a consequence of unfairness at the population level. As stated above, the article by Ordera and Artiga (see Useful Resource below) is excellent and highly recommended.

Facilitation Technique
Depending on time, ask learners to discuss if (and, if so, how) disparities affect the health and well-being of their patients, their communities, or themselves.

Useful Resource
Orgera K, Artiga S. Disparities in health and health care: five key questions and answers. Henry J. Kaiser Family Foundation website. https://www.kff.org/disparities-policy/issue-brief/disparities-in-health-and-health-care-five-key-questions-and-answers/ Published August 8, 2018. *Accessed June 3, 2018*

Facilitator Guide–Slide Deck

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SLIDE 17
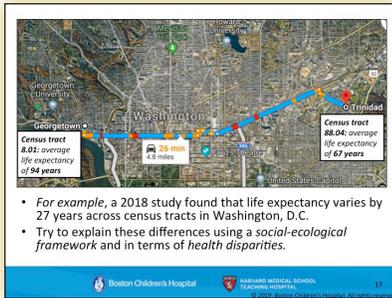
This slide shows a screenshot from Google Maps of Washington, D.C. A 2018 study conducted by the Virginia Commonwealth University Center on Society and Health found that average life expectancy in Washington varies as much as 27 years across census tracts. The highest average life expectancy was in census tract *8.01*, the Foxhall area of Georgetown. The lowest was *88.04*, a neighborhood in Trinidad near Gallaudet University. As shown in the Google Maps screenshot, the driving distance separating these 2 census tracts is 4.8 miles, or 26 minutes by car.

Summary quotes from the study are as follows:

· "The study examined mortality rates across the region's 1,223 census tracts and found that life expectancy at birth—how long a newborn baby can expect to live—varied by 27 years. The census tracts with the lowest and highest life expectancies were both in the District, ranging from 67 years in a neighborhood of Trinidad near Gallaudet University (tract 88.04) to 94 years in the Foxhall area of Georgetown (tract 8.01). Other reports have shown striking geographic differences in other health measures such as infant mortality, obesity, heart disease and diabetes."

· "Findings show that health in metropolitan Washington is shaped less by health care than by factors like income, education, housing, transportation, and the environment. In addition, people of color and immigrants were more likely to live in neighborhoods with fewer resources ("islands of disadvantage"), which lack the conditions for good health."

· What are census tracts? "Census tracts are small, relatively permanent statistical subdivisions of a county (or independent city in states like Virginia) created by the U.S. Census Bureau and updated every 10 years. Designed to provide stable estimates of population data, and typically smaller than ZIP codes, census tracts contain a population between 1,200 and 8,000 people, with an optimum size of 4,000 people."

Facilitation Technique

Encourage learners to explain the large differences in life expectancy using the social-ecological framework detailed above. Learners may be ask about the apparently very high life expectancy in Georgetown. Per the study, the average life expectancy of all of Georgetown is 86 years, whereas the life expectancy in the Foxhall area of Georgetown is 94 years. Because census tracts are small (smaller than ZIP codes), this area may have a particularly high concentration of healthy older individuals (similar to what are called Blue Zones—regions of the world where life expectancy is much higher than average). For details, see the Blue Zone page on the Wikipedia website (https://en.wikipedia.org/wiki/Blue_Zone).

Useful Resource

Woolf SH, Chapman DA, Hill L, et al. Uneven opportunities: how conditions for wellness vary across the metropolitan Washington region. Richmond, VA: Virginia Commonwealth University Center for Society and Health; 2018. https://www.mwcog.org/healthindicatorsreport/

Facilitator Guide–Slide Deck
continued

SLIDE 18

What Is *Health Equity*?
Health equity is
• The **opportunity** for every person to attain their **full health potential without disadvantage** because of social position or circumstance.
• A **framework** for addressing **health disparities**.

Health equity is about fair opportunities to achieve health and well-being. This means more than *equality*, which implies having the same opportunities (and which is insufficient in light of health disparities). The graphic in the slide shows creatures of different sizes being supported by platforms of different sizes to reach the fruit on the tree branch. The platforms symbolize opportunity, and their different sizes reflect equity. If the platforms were all *equal* (ie, the same) size, the smaller creatures would not be able to reach the fruit. This distinction between *equity* as *fairness* and *equality* as *sameness* is key to understanding. Title V programs can play a key role in assessing and improving health equity. An example is the Health Equity Zones Initiative in Rhode Island, which utilizes community health workers to screen for SDoH and facilitate a smooth referral process to appropriate services.

Facilitation Technique
Depending on time, ask learners to use the teach-back method to explain what health equity means to them or what their clinic (or community or society) would look like if health equity was a reality. The concept of health equity will be discussed again in Micro-Chapter 2.

Useful Resource
Achieving Health Equity. Robert Wood Johnson Foundation website. https://www.rwjf.org/en/library/features/achieving-health-equity.html
Accessed June 3, 2019

Health Equity Zones Initiative. State of Rhode Island Department of Health website. http://www.health.ri.gov/programs/detail.php?pgm_id=1108
Accessed June 3, 2019

SLIDE 19

In Summary
What Are Social Determinants of Health and Health Disparities?
• **Social determinants of health** are the **conditions** in which people are born, live, learn, work, play, and age.
○ Can be understood using a **social-ecological framework**
○ Can **explain big differences in health** between individuals and between population groups
• **Health disparities** refer to **differences** in health between population groups.
○ Occur across **many dimensions** (eg, race, gender, income)
○ **Health equity** means **fair opportunities to be healthier** and is a **framework for addressing health disparities**.

Use the summary slide for Micro-Chapter 1.

Facilitation Technique
Depending on the availability of time, ask learners to do a teach back, summarizing the points in their own words.

Facilitator Guide–Slide Deck

continued

SLIDE 20 » Micro-Chapter 2: Let's Talk About Bias and Health Equity

Facilitation Technique

Discussing bias may be challenging or uncomfortable for some. Practice situational awareness of the learners' group dynamic. In the event that any learners report feeling challenged or uncomfortable, try engaging the group to consider multiple perspectives rather than stopping the conversation. A helpful mnemonic (detailed below) is C.A.R.E.—Conscious empathy, Active listening, Responsible reaction, and Environmental awareness.

SLIDE 21

Why talk about *bias*? To answer this question, let's reconsider the *brain*…
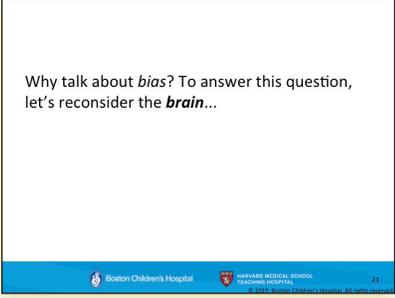
A central idea in this section is that the human brain is predisposed toward bias. This is not to say that bias is destiny. Rather, bias is similar to stress: It has roots in the brain, and with proper awareness and training, it can be managed and mitigated.

Useful Resources

Kristof N. Our biased brains. The New York Times. May 7, 2015. https://www.nytimes.com/2015/05/07/opinion/nicholas-kristof-our-biased-brains.html
Accessed June 3, 2019

Project Implicit. Implicit Association Test. https://implicit.harvard.edu/implicit/takeatest.html

SLIDE 22

Recall that the *brain* is constantly making *predictions*.

For example, when the brain predicts that the body needs energy, it is called *stress*.
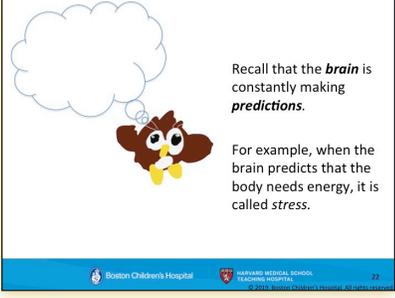
Like stress, bias has its neurological roots in the predictive nature of the brain. See Slide 38 for a detailed explanation of the predictive brain.

Facilitator Guide—Slide Deck
continued
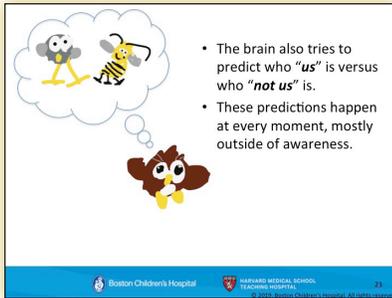
SLIDE 23

The same as Slides 21 and 22.

Useful Resource

Henderson L. Why our brains see the world as "us" versus "them." The Conversation. June 21, 2018. https://theconversation.com/why-our-brains-see-the-world-as-us-versus-them-98661 *Accessed June 3, 2019*
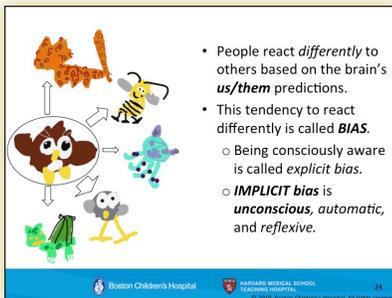
SLIDE 24

Most people think of bias as explicit bias—intentional acts of discrimination, such as hate crimes, racist comments, or sexist jokes. The focus here is on implicit bias, which operates outside of conscious awareness. Implicit bias manifests as patterns and habits of thought that influence gut reactions and decision-making processes. These, in turn, can influence care provision and, on a macro-level, health care disparities.

Useful Resource

Gupta A, Institute for Healthcare Improvement. What is bias, and what can medical professionals do to address it? [video]. http://www.ihi.org/education/IHIOpenSchool/resources/Pages/AudioandVideo/Anurag-Gupta-What-Is-Bias,-and-What-Can-Medical-Professionals-Do-to-Address-It.aspx *Accessed June 3, 2019*

Facilitator Guide–Slide Deck
continued

SLIDE 25
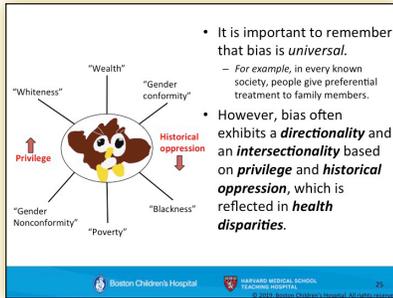
The graphic in this slide shows what are called "axes of privilege/oppression." The idea is that biases often follow a gradient, from high to low, with greater privilege at the higher end and greater historical oppression at the lower end. This graphic shows only a few of the many axes of oppression/privilege that have been described. An important point here is that people on the more privileged end of the axis (whiteness, for example) may have limited awareness of it because the experiences of oppression and discrimination (which bring the axis into awareness) may not be internalized as lived experience. This slide presents a conceptual bridge between implicit bias (present in individual brains) and, on a population-level, axes of privilege and health disparities. Healthy People 2020 defines a health disparity as:

> "…a particular type of health difference that is closely linked with social, economic, and/or environmental disadvantage. Health disparities adversely affect groups of people who have systematically experienced greater obstacles to health based on their racial or ethnic group; religion; socioeconomic status; gender; age; mental health; cognitive, sensory, or physical disability; sexual orientation or gender identity; geographic location; or other characteristics historically linked to discrimination or exclusion."

Facilitation Technique

As mentioned above, learners may engage with the material, disengage (ie, "not my problem"), or feel antagonistic toward it. Practicing open-mindedness, intellectual humility, and empathetic curiosity toward the perspectives and experiences of others can help build personal awareness and group cohesion.

Useful Resources

Gupta A; Institute for Healthcare Improvement. How does implicit bias affect health care? [video]. http://www.ihi.org/education/IHIOpenSchool/resources/Pages/AudioandVideo/Anurag-Gupta-How-Does-Implicit-Bias-Affect-Health-Care.aspx *Accessed June 3, 2019*

Disparities. https://www.healthypeople.gov/2020/about/foundation-health-measures/Disparities Updated May 31, 2019. *Accessed June 3, 2019*

Crenshaw K. Why intersectionality can't wait. *The Washington Post*. September 24, 2015. https://www.washingtonpost.com/news/in-theory/wp/2015/09/24/why-intersectionality-cant-wait/ *Accessed June 3, 2019*

Carbado DW, Crenshaw KW, Mays VM, Tomlinson B. Intersectionality: mapping the movements of a theory. *Du Bois Rev*. 2013;10(2):303-12. doi: 10.1017/S1742058X13000349

SLIDE 26

- *For example*, research indicates that *white patients* receive more and better pain treatment than *black patients*.
- Is there racial bias in pain perception?
  - In one 2016 study, 40% of first-year medical students endorsed the false belief that *black skin is thicker than white skin.*
  - Students who held false beliefs often rated pain as being lower in black patients than white patients and made less appropriate recommendations about how they should be treated.

This study presents some startling findings. Probe learners' reactions to the findings and encourage learners to describe their interpretations through the lens of implicit bias.

Details About the Study (from the abstract)

"Black Americans are systematically undertreated for pain relative to white Americans. We examine whether this racial bias is related to false beliefs about biological differences between blacks and whites (e.g., "black people's skin is thicker than white people's skin"). Study 1 documented these beliefs among white laypersons and revealed that participants who more strongly endorsed false beliefs about biological differences reported lower pain ratings for a black (vs. white) target. Study 2 extended these findings to the medical context and found that half of a sample of white medical students and residents endorsed these beliefs. Moreover, participants who endorsed these beliefs rated the black (vs. white) patient's pain as lower and made less accurate treatment recommendations. Participants who did not endorse these beliefs rated the black (vs. white) patient's pain as higher, but showed no bias in treatment recommendations. These findings suggest that individuals with at least some medical training hold and may use false beliefs about biological differences between blacks and whites to inform medical judgments, which may contribute to racial disparities in pain assessment and treatment."

Useful Resources

Hoffman KM, Trawalter S, Axt JR, Oliver MN. Racial bias in pain assessment and treatment recommendations, and false beliefs about biological differences between blacks and whites. *Proc Natl Acad Sci USA*. 2016;113(16):4296-4301. doi: 10.1073/pnas.1516047113

Somashekhar S. The disturbing reason some African Americans may be undertreated for pain. *The Washington Post*. April 4, 2016. https://www.washingtonpost.com/news/to-your-health/wp/2016/04/04/do-blacks-feel-less-pain-than-whites-their-doctors-may-think-so/?utm_term=.2cbc894e459a
Accessed June 3, 2019

SLIDE 27

If *everyone* has **bias** that is *automatic* and *reflexive*, what should be done?

This slide sets up the upcoming slides focusing on strategies and solutions.

Facilitator Guide–Slide Deck
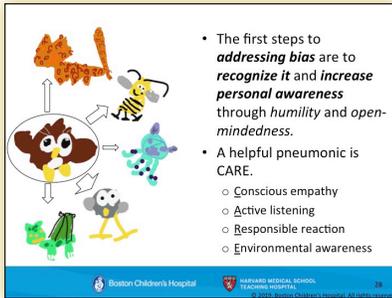
continued

SLIDE 28

- The first steps to **addressing bias** are to **recognize it** and **increase personal awareness** through *humility* and *open-mindedness.*
- A helpful pneumonic is CARE.
  ○ <u>C</u>onscious empathy
  ○ <u>A</u>ctive listening
  ○ <u>R</u>esponsible reaction
  ○ <u>E</u>nvironmental awareness

Humility and open-mindedness are considered intellectual virtues because they promote critical thinking and the pursuit of truth. CARE is a helpful technique for building awareness and mitigating the effects of implicit bias. Karith Foster created and teaches the CARE model in her workshops and presentations.

Ask learners if they use any mental tools or approaches for reducing implicit bias.

Useful Resource
Intellectual virtue. https://en.wikipedia.org/wiki/Intellectual_virtue Updated September 20, 2018. *Accessed June 3, 2019*

Foster K. The art of defying stereotypes. TEDx Lincoln Square. March 2017. YouTube. https://www.youtube.com/watch?v=TVGCTS8iiDU Published May 4, 2017. *Accessed June 3, 2019*

SLIDE 29
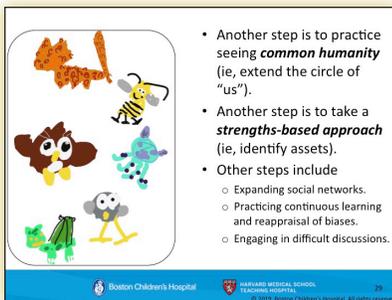
- Another step is to practice seeing **common humanity** (ie, extend the circle of "us").
- Another step is to take a **strengths-based approach** (ie, identify assets).
- Other steps include
  ○ Expanding social networks.
  ○ Practicing continuous learning and reappraisal of biases.
  ○ Engaging in difficult discussions.

This slide aims to provide real-world, practical solutions for addressing implicit bias. Ask learners if they have used these or other approaches to address bias, and if so, what was the result?

Useful Resource
The above-mentioned resources from the Institute of Healthcare Improvement on bias are excellent and highly recommended.

Boynton-Jarrett R, Flacks J. *A Strengths-Based Approach to Screening Families for Health-Related Social Needs.* Washington, DC: Center for the Study of Social Policy; MLBP; 2018. https://cssp.org/wp-content/uploads/2018/08/Strengths-Based-Approaches-Screening-Families-FINAL.pdf *Accessed June 3, 2019*

SLIDE 30

Our common and ultimate goal is to promote *HEALTH EQUITY.*

Health equity is the opportunity for every person to attain their full health potential without disadvantage because of social position or circumstance.

This slide aims to re-center the focus on the shared mission in health care, which is health equity. As detailed in Slide 18, health equity is about fair opportunities to achieve health and well-being. The graphic shown here is the same as that in Slide 17—creatures of different sizes being supported by platforms of different sizes to reach the fruit on the branch above. The platforms symbolize opportunity, and their different sizes reflect equity. If the platforms were all *equal* (eg, the same) size, the smaller creatures would not be able to reach the fruit. This distinction between *equity* as *fairness* and *equality* as *sameness* is key to understanding this. As before, ask learners to teach back what health equity means to them.

Useful Resource
Achieving Health Equity. Robert Wood Johnson Foundation website. https://www.rwjf.org/en/library/features/achieving-health-equity.html *Accessed June 3, 2019*

Facilitator Guide–Slide Deck

continued

SLIDE 31
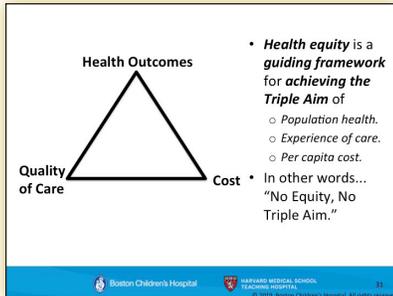
This slide shows the *Triple Aim* developed by the Institute for Healthcare Improvement to optimize health system performance. The Triple Aim is about simultaneously improving patient experience of care (including quality and satisfaction), enhancing population health, and reducing the per capita cost of health care. The key message of this slide is that health equity should serve as the guiding framework for achieving the Triple Aim. This is summarized by the statement "No Equity, No Triple Aim" and detailed in the article by Geoffrey Wilkinson.

Facilitation Technique

Ask learners to explain how health equity relates to the Triple Aim. Encourage learners to use the ideas presented in this module (eg, SDoH, HRSNs, health disparities, and bias) to frame the discussion.

Useful Resources

Wilkinson GW, Sager A, Selig S, et al. No equity, no Triple Aim: strategic proposals to advance health equity in a volatile policy environment. *Am J Pub Health.* 2017;107(S3):S223-S228. doi: 10.2105/AJPH.2017.304000

IHI Triple Aim Initiative. http://www.ihi.org/Engage/Initiatives/TripleAim/Pages/default.aspx *Accessed June 3, 2019*

SLIDE 32

Summary Slide. Encourage learners to teach back the information in their own words.

SLIDE 33 » Micro-Chapter 3: How Do Social Conditions Influence Health?

In this section, the brain takes center stage at the interface between social conditions, particularly adverse childhood experiences, and chronic activation of the stress response.

SLIDE 34

> To understand how social conditions influence health, start by considering the **brain**...
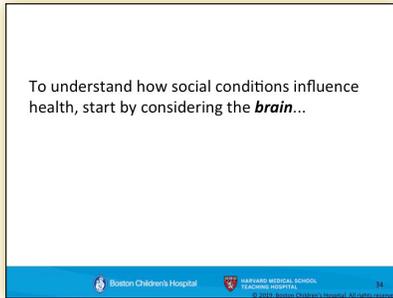
Presentation of the following 6 slides can be relatively brief and rapid. The bulk of time and discussion can be given to Slide 41 (the ACE pyramid) as detailed below.

SLIDE 35

> The **brain** constantly *predicts* the body's *energy needs* from one moment to the next.
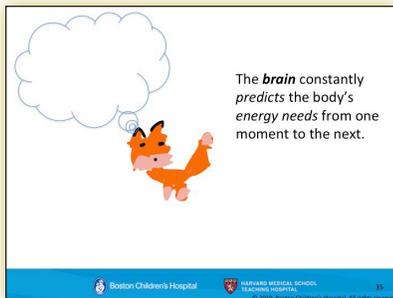
This straightforward statement sets the stage for the upcoming slides. Presentation can be brief (a few seconds) with quick transition to the next slide. Feel free to read the background information or skip it and move on.

Background Information
There is emerging consensus in neuroscience that a primary and fundamental function of the brain is to predict, similar to the idea that the primary function of the heart is to pump (blood). The brain receives information via the 5 senses (eg, sight, sound, smell, taste, and touch) from inside the body (this is called interoception, a rumbling tummy, for example) and from throughout the brain itself (this is called intrinsic brain activity, a daydream, for example). Moment to moment, the brain processes this incoming information and predicts its own activity in the very next moment. These predictions play out in the flow of electrical impulses, neurotransmitters, and hormones, which in turn, influence the state of the body and brain. The brain receives this new information, makes more predictions, and the cycle continues. Most of the time, this cycle occurs outside of awareness, but occasionally, people are aware of predictions, such as while watching a scary movie or swerving a car on a patch of ice.

Useful Resources
Feldman Barrett L. The predictive brain. https://www.edge.org/response-detail/26707 *Accessed June 3, 2019*

Bubic A, von Cramon DY, Schubotz RI. Prediction, cognition and the brain. *Front Hum Neurosci*. 2010;4:25. doi:10.3389/fnhum.2010.00025

Facilitator Guide–Slide Deck
continued
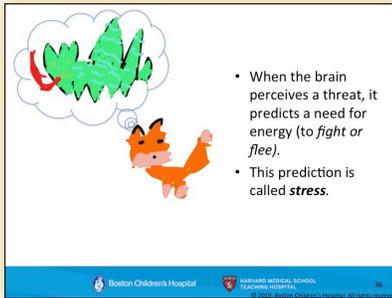
SLIDE 36

As stated above, presentation can be brief. One interesting side note is that it makes no difference to the brain whether the perceived threat is actual (ie, physical danger) or imagined (ie, a scary thought, as shown in this slide).
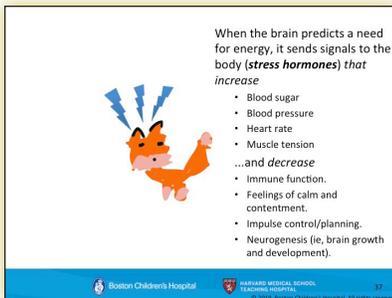
On slide:
- When the brain perceives a threat, it predicts a need for energy (to *fight or flee*).
- This prediction is called *stress*.

SLIDE 37

As stated above, presentation can be brief. The main idea is that when a stress response is activated, the body mobilizes systems that will improve chances for survival (by fighting harder or running away faster) at the expense of longer-term processes like fighting disease, feeling calm, controlling impulses, and growing the brain. This has important consequences for health and brain development, as will be discussed in upcoming slides.

Also, the term neurogenesis means the growth of new brain cells.

On slide:
When the brain predicts a need for energy, it sends signals to the body (*stress hormones*) *that increase*
- Blood sugar
- Blood pressure
- Heart rate
- Muscle tension
...and *decrease*
- Immune function.
- Feelings of calm and contentment.
- Impulse control/planning.
- Neurogenesis (ie, brain growth and development).

Useful Resource
Patton RS; Khan Academy. Responding to stress [video]. https://www.khanacademy.org/test-prep/mcat/processing-the-environment/stress/v/responding-to-stress *Accessed June 3, 2019*

~ This video details the physiology of the fight or flight response.

SLIDE 38
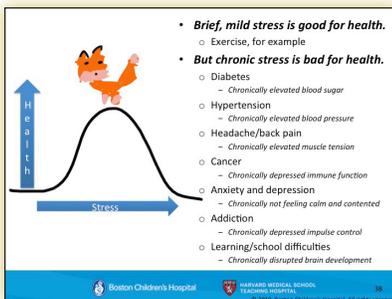
As stated above, presentation can be brief. The main point is that chronic stress is bad for physical and mental health and brain development.

On slide:
- *Brief, mild stress is good for health.*
  - Exercise, for example
- *But chronic stress is bad for health.*
  - Diabetes
    - *Chronically elevated blood sugar*
  - Hypertension
    - *Chronically elevated blood pressure*
  - Headache/back pain
    - *Chronically elevated muscle tension*
  - Cancer
    - *Chronically depressed immune function*
  - Anxiety and depression
    - *Chronically not feeling calm and contented*
  - Addiction
    - *Chronically depressed impulse control*
  - Learning/school difficulties
    - *Chronically disrupted brain development*

Useful Resources
Chronic stress as bad for physical health: Patton RS; Khan Academy. Physical effects of stress [video]. https://www.khanacademy.org/test-prep/mcat/processing-the-environment/stress/v/physical-effects-of-stress *Accessed June 3, 2019*

Chronic stress and anxiety, depression, and addiction: Patton RS; Khan Academy. Behavioral effects of stress [video]. https://www.khanacademy.org/test-prep/mcat/processing-the-environment/stress/v/behavioral-effects-of-stress *Accessed June 3, 2019*

Disrupted brain development: Centers for Disease Control and Prevention. Preventing adverse childhood experiences (ACEs) online training module 1 lesson 1 [video]. https://www.youtube.com/watch?v=d-SSwYTe8TY *Accessed June 3, 2019*

Facilitator Guide–Slide Deck

continued

SLIDE 39
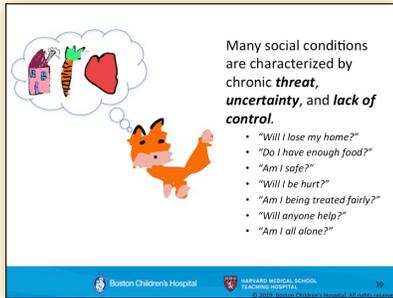
As previously indicated, presentation can be brief. The main idea here, looping back to the predictive brain concept, is that the combination of uncertainty (ie, unpredictability), threat (ie, being on guard), and feeling out of control (ie, feeling powerless or helpless) acts as a toxic cocktail, sending the stress response into overdrive. Children and youth with special health care needs (CYSHCN) are more likely to be exposed to adverse childhood experiences. The 2016 National Survey of Children's Health data show that 37% of CYSHCN had 2 or more ACEs compared to 18% of children without special health care needs. In addition, children with intellectual and developmental disabilities are at higher risk for abuse and neglect.

Facilitation Technique

The core health-related social needs detailed in the next section are each characterized by uncertainty (eg, food *insecurity* and housing *instability*). In addition, consider how ACEs are characterized by both uncertainty and powerlessness. For example, if a parent has been drinking alcohol, will she or he explode with an act of physical violence? And, if so, can anything be done to stop it?

Useful Resources

On the effects of chronic toxic stress: Tough P. The poverty clinic: Can a stressful childhood make you a sick adult? *The New Yorker.* March 14, 2011. https://www.newyorker.com/magazine/2011/03/21/the-poverty-clinic *Accessed June 3, 2019*

Nadine Burke Harris: How does trauma affect a child's DNA? Ted Radio Hour. National Public Radio. August 25, 2017. https://www.npr.org/templates/transcript/transcript.php?storyId=545092982 *Accessed June 3, 2019*

> *Notable quote by Dr. Burke Harris during the interview: "Well, imagine you're walking in the forest, and you see a bear. Immediately, your hypothalamus sends a signal to your pituitary, which sends a signal to your adrenal gland that says, release stress hormones adrenaline, cortisol. And so your heart starts to pound. Your pupils dilate. Your airways open up. And you are ready to either fight that bear or run from the bear. And that is wonderful if you're in a forest, and there's a bear. But the problem is what happens when the bear comes home every night. And this system is activated over and over and over again."*

Mattson G, Kuo DZ; American Academy of Pediatrics Committee on Psychosocial Aspects of Child and Family Health and Council on Children with Disabilities. Psychosocial factors in children and youth with special health care needs and their families. *Pediatrics.* 2019;143(1):e20183171. doi: 10.1542/peds.2018-3171

Facilitator Guide–Slide Deck
continued
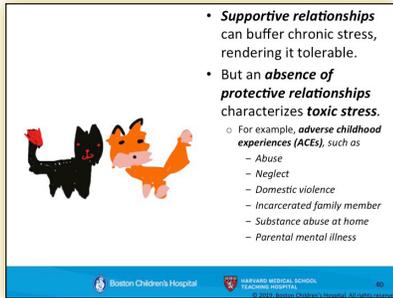
- *Supportive relationships* can buffer chronic stress, rendering it tolerable.
- But an *absence of protective relationships* characterizes *toxic stress*.
  - For example, *adverse childhood experiences (ACEs),* such as
    - Abuse
    - Neglect
    - Domestic violence
    - Incarcerated family member
    - Substance abuse at home
    - Parental mental illness

Same as above (Slide 39). An absence of protective, supportive relationships magnifies the sense of unpredictability and helplessness, turning chronic (but potentially manageable) stress into toxic (unmanageable) stress.

Facilitation Technique
Facilitators or learners may have personal experiences with toxic stress. If time permits and there is a sense of positive receptivity and engagement with this topic among group members, offer an opportunity for sharing experiences. Given that these are potentially sensitive and deeply personal topics, practice moment-to-moment situational awareness and empathetic sensitivity toward all individuals who are present.

Useful Resources
See Useful Resources above (slide 39).

Toxic Stress. Center on the Developing Child at Harvard University website. https://developingchild.harvard.edu/science/key-concepts/toxic-stress/ *Accessed June 3, 2019*

Shonkoff JP, Garner AS; American Academy of Pediatrics Committee on Psychosocial Aspects of Child and Family Health, Committee on Early Childhood, Adoption, and Dependent Care, and Section on Developmental and Behavioral Pediatrics. The lifelong effects of early childhood adversity and toxic stress. *Pediatrics.* 2012;129(1):e232-e246. doi: 10.1542/peds.2011-2663

Garner AS, Shonkoff JP; American Academy of Pediatrics Committee on Psychosocial Aspects of Child and Family Health, Committee on Early Childhood, Adoption, and Dependent Care, and Section on Developmental and Behavioral Pediatrics. Early childhood adversity, toxic stress, and the role of the pediatrician: translating developmental science into lifelong health. *Pediatrics.* 2012;129(1) e224-e231. doi: 10.1542/peds.2011-2662

American Academy of Pediatrics. Toxic Stress on Children: Evidence of Consequences. https://www.aappublications.org/toxic-stress *Accessed June 3, 2019*

Early Brain and Child Development Initiative. https://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/EBCD/Pages/default.aspx *Accessed June 3, 2019*

The Resilience Project Initiative. https://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/resilience/Pages/Resilience-Project.aspx *Accessed June 3, 2019*

SLIDE 41
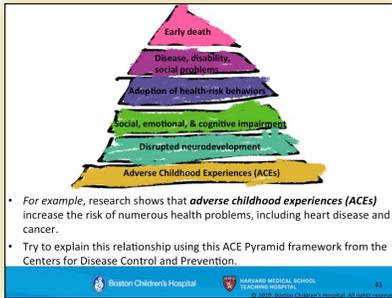
The ACE Pyramid provides a helpful framework for understanding and explaining how ACEs (and adverse social conditions, in general) negatively impact development, behavior, health, and ultimately, mortality.

Facilitation Technique
Encourage learners to explain the ACE Pyramid in their own words.

Useful Resources
About the CDC-Kaiser ACE Study. https://www.cdc.gov/violenceprevention/childabuseandneglect/acestudy/about.html *Accessed June 3, 2019*

Burke N. How childhood trauma affects health across a lifetime [video]. TED Talks. 2015. https://www.youtube.com/watch?v=95ovIJ3dsNk *Accessed June 3, 2019*

SLIDE 42

Summary slide. Encourage learners to explain the information in their own words.

SLIDE 43 » Micro-Chapter 4: Health-Related Social Needs: Screening and Referral

This section focuses on practical approaches for addressing SDoH and the implications for implementing care coordination activities.

Facilitator Guide–Slide Deck
continued

SLIDE 44
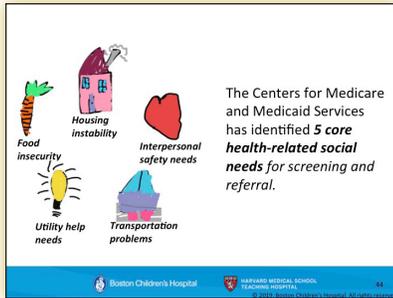
Although SDoH encompasses a broad range of factors, CMS has identified 5 core health-related social needs (HRSNs) for screening and referral by health care teams. These core HRSNs are described in detail in the following slides and, additionally, in the CMS Accountable Health Communities screening tool (see Source/Useful Resource below). The Accountable Health Communities initiative will be discussed in more detail in Micro-Chapter 5.

Facilitation Technique
Emphasize to learners that these core HRSNs are not an exhaustive list of social needs. Rather, these are needs that CMS has identified for targeted *screening and referral;* reasons for selecting these 5 needs are detailed in the next slide.

Useful Resource
Centers for Medicare and Medicaid Services. The Accountable Health Communities Health-Related Social Needs Screening Tool. 2018. https://innovation.cms.gov/files/worksheets/ahcm-screeningtool.pdf
Accessed June 3, 2019

SLIDE 45
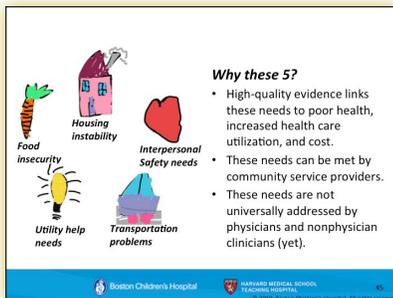
This slide provides the rationale for why these 5 core HRSNs were selected for systematic screening and referral.

Facilitation Technique
Depending on time availability, ask learners to share their thoughts on *why* HRSNs are not universally addressed by health care teams. The upcoming slides go into detail on each of the 5 core HRSNs.

Useful Resource
Billioux A, Verlander K, Anthony S, Alley D. Standardized screening for health-related social needs in clinical settings: the accountable health communities screening tool. National Academy of Medicine. 2017. https://nam.edu/wp-content/uploads/2017/05/Standardized-Screening-for-Health-Related-Social-Needs-in-Clinical-Settings.pdf *Accessed June 4, 2019*

Facilitator Guide–Slide Deck
continued

SLIDE 46

Core Health-Related Social Need:
Housing Instability

Examples
- Homelessness
- Inability to pay mortgage/rent
- Frequent unintended moves
- Eviction

Sample screening question
What is your living situation today?
☐ I have a steady place to live.
☑ I have a place to live today, but I am worried about losing it in the future.
☑ I do not have a steady place to live. (I am temporarily staying with others, in a hotel, in a shelter, living outside on the street, on a beach, in a car, abandoned building, bus or train station, or in a park.)

There is no standard definition of housing instability. However, the common theme in each of the examples presented here (homelessness, frequent unintended moves, and eviction) is a lack of *stability* and the *threat* of losing one's home. Recall from the previous section that *unpredictability* and *threat* are primary contributors to chronic over-activation of the stress response. The sample screening question shown in this slide is sourced from the Accountable Health Communities Health-Related Social Needs Screening Tool (see Useful Resources below). The checked boxes may indicate unmet HRSNs and can prompt further conversation and referral.

Facilitation Technique

Encourage learners to read the sample screening question aloud and discuss their thoughts about how housing instability has impacted their patients or, if they feel comfortable, themselves or people in their lives.

It is important to note that asking these types of questions can be very challenging for physicians and nonphysician clinicians as well as families. There are often cultural barriers, and these questions can be misinterpreted, especially by families who use English as their second language. When screening for SDoH, consider cultural aspects of the populations for whom care is provided. How will the questions be interpreted by diverse communities?

If available, share local or practice-level data on housing. **L**

Finally, it should be emphasized that these screening questions are meant to start a conversation. For example, a person living in sheltered housing (ie, a homeless shelter) is experiencing housing instability. However, if the person is on a waiting list for more stable housing and endorses no current unmet needs related to housing, then a referral may not be necessary.

Learners may have questions about what can be done to improve someone's situation. For example, if a person is living in sheltered housing or having difficulty paying rent or utility bills, learners may respond by saying, "What can be done? We can't be expected to provide money for rent, utility bills, groceries, or gas." Encourage learners to keep an open mind because these are *social* problems (ie, *social determinants* of health), and solutions may be more challenging than standard medical problems (ie, prescribing penicillin for strep throat).

The key point is that *screening starts the conversation*. With time, persistence, diligent efforts, and better resources (across the entire health care and social service systems), the needle will begin to move on these issues.

Also to note is that the sample screening question presented here is neither the only nor the best question for assessing housing instability. There are many other questionnaires and screening tools that can be used.

Useful Resources

Centers for Medicare and Medicaid Services. The Accountable Health Communities Health-Related Social Needs Screening Tool. 2018. https://innovation.cms.gov/files/worksheets/ahcm-screeningtool.pdf *Accessed June 4, 2019*

Housing Instability. https://www.healthypeople.gov/2020/topics-objectives/topic/social-determinants-health/interventions-resources/housing-instability Updated May 31, 2019. *Accessed June 3, 2019*

Braveman P, Dekker M, Egerter S, Sadegh-Nobari T, Pollack C. How does housing affect health? Robert Wood Johnson Foundation website. May 1, 2011. https://www.rwjf.org/en/library/research/2011/05/housing-and-health.html

Facilitator Guide–Slide Deck
continued

SLIDE 47

Core Health-Related Social Need:
Food Insecurity

Example
Limited or uncertain access
to adequate food

Sample screening question
Within the past 12 months, you worried that your food would run out before you got money to buy more.
☑ Often true
☑ Sometimes true
☐ Never true

Food insecurity is generally defined as limited or uncertain access to adequate food. Another definition of food insecurity is the disruption of food intake or eating patterns because of lack of money and other resources. The sample screening question shown here is sourced from the Accountable Health Communities Health-Related Social Needs Screening Tool. The checked boxes may indicate an unmet HRSN and can prompt further conversation and referral.

Background Information
The U.S. Department of Agriculture codified food insecurity as part of ongoing efforts to measure the nutritional status of the American population. An estimated 1 in 6 U.S. children live in food-insecure households.

Facilitation Technique
See Facilitation Technique for housing instability (Slide 46) above.

Useful Resources
Centers for Medicare and Medicaid Services. The Accountable Health Communities Health-Related Social Needs Screening Tool. 2018. https://innovation.cms.gov/files/worksheets/ahcm-screeningtool.pdf *Accessed June 4, 2019*

American Academy of Pediatrics and the Food Research and Action Center. *Assessing Food Insecurity: A Toolkit for Pediatricians.* 2017. http://frac.org/aaptoolkit *Accessed June 4, 2019*

> *An excellent toolkit with summary statistics, screening tips, and informational resources*

Food Insecurity. https://www.healthypeople.gov/2020/topics-objectives/topic/social-determinants-health/interventions-resources/food-insecurity Updated June 4, 2019. *Accessed June 4, 2019*

SLIDE 48

Core Health-Related Social Need:
Utility Help Needs

Examples
• Difficulty paying utility bills
• Shut-off notices
• Disconnected phone

Sample screening question
In the past 12 months, has the electric, gas, oil, or water company threatened to shut off services in your home?
☑ Yes
☐ No
☑ Already shut off

Like housing instability, there is no standard definition of utility help needs (also called energy insecurity). Also, like housing instability, utility help needs encompass challenges related to the ideas of threat and unpredictability, as illustrated in the sample screening question shown here. This question is sourced from the Accountable Health Communities Health-Related Social Needs Screening Tool (See Slide 46, Useful Resources). Here, the checked boxes may indicate an unmet HRSN and can prompt further conversation and referral.

Facilitation Technique
See Facilitation Technique for housing instability (Slide 46) above.

Useful Resources
Centers for Medicare and Medicaid Services. The Accountable Health Communities Health-Related Social Needs Screening Tool. 2018. https://innovation.cms.gov/files/worksheets/ahcm-screeningtool.pdf *Accessed June 4, 2019*

Energy Insecurity. Children's Health Watch website. http://childrenshealthwatch.org/3169-2/ *Accessed June 4, 2019*

Hernández D. Understanding "energy insecurity"' and why it matters to health. *Soc Sci Med.* 2016;167:1-10. https://doi.org/10.1016/j.socscimed.2016.08.029

Facilitator Guide–Slide Deck

continued

SLIDE 49

Core Health-Related Social Need:
Transportation Problems

Example
Difficulty accessing or affording medical or public transportation

Sample screening question
In the past 12 months, has lack of reliable transportation kept you from medical appointments, meetings, work or from getting things needed for daily living?
☑ Yes
☐ No

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There is not a standard definition for transportation problems. However, transportation problems can be viewed as a barrier to accessing care (ie, inability to travel to medical appointments due to transportation-related issues), but—just as with housing instability, food insecurity, and utility help needs—*uncertainty* plays a key role. This is illustrated in the sample screening question shown in this slide: "...has *lack of reliable* transportation kept you from medical appointments..." The sample screening question is sourced from the Accountable Health Communities Health-Related Social Needs Screening Tool (See Slide 45, Useful Resources). The checked boxes may indicate an unmet HRSN and can prompt further conversation and referral.

Facilitation Technique
See Facilitation Technique for housing instability (Slide 46) above.

Useful Resource
Centers for Medicare and Medicaid Services. The Accountable Health Communities Health-Related Social Needs Screening Tool. 2018. https://innovation.cms.gov/files/worksheets/ahcm-screeningtool.pdf
Accessed June 4, 2019

SLIDE 50

Core Health-Related Social Need:
Interpersonal Safety Needs

Examples
• Intimate partner violence
• Abuse
• Adverse childhood experiences

Sample screening question
Because violence and abuse happens to a lot of people and affects their health we are asking the following question. How often does anyone, including family and friends, threaten you with harm?
☐ Never
☐ Rarely
☑ Sometimes
☑ Fairly often
☑ Frequently

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Interpersonal safety needs are the most challenging of the core HRSNs because addressing these needs often requires team members with specialized training and skills (eg, mental health, social work, or child protection). As above, the key point is that *screening gets the conversation started*. The checked boxes may indicate an unmet HRSN and can prompt further conversation and referral.

Facilitation Technique
See Facilitation Technique for housing instability (Slide 46) above.

Useful Resource
Centers for Medicare and Medicaid Services. The Accountable Health Communities Health-Related Social Needs Screening Tool. 2018. https://innovation.cms.gov/files/worksheets/ahcm-screeningtool.pdf
Accessed June 4, 2019

Facilitator Guide–Slide Deck
continued

SLIDE 51

To facilitate *SCREENING* for health-related social needs, the *American Academy of Pediatrics* created the **STAR Center** (*Screening, Technical Assistance, and Resource Center*), which contains an array of online resources:

As part of its Screening in Practice initiative (described in detail in Micro-Chapter 5: Innovations), the American Academy of Pediatrics (AAP) has launched the Screening, Technical Assistance, and Resource (STAR) Center. STAR Center contains a plethora of screening recommendations, screening tools, related AAP initiatives, technical assistance, FAQs, and resources for clinical practices. STAR Center provides technical assistance and resources for screening not only for SDoH but also for child development and maternal depression, which are the 3 target areas of the AAP Screening in Practice initiative, described later in Innovations). This slide shows a screenshot from the STAR Center webpage (see Source/Useful Resource below). Note that the terms SDoH and HRSNs are used interchangeably on the STAR Center webpage.

Facilitation Technique
Read the text at the top of the slide and point out that the STAR Center also provides assistance with and resources for child development and maternal depression screening.

Useful Resource
The Screening Technical Assistance & Resource (STAR) Center. https://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/Screening/ *Accessed June 4, 2019*

SLIDE 52

Community Resource Referral Platforms: A Guide for Health Care Organizations

- There is also a growing number of *online REFERRAL tools* for health-related social needs (see resource guide).
- *211* provides free help finding social service resources in all 50 states.

Before the learning session, search the internet for online referral tools for community services in the area. **L**

Alternatively, depending on time availability, encourage learners to search for these tools during the session. There will also be opportunities to do this during the group discussion portion of the module

Useful Resources
Cartier Y, Fichtenberg C, Gottlieb L. Community Resource Referral Platforms: A Guide for Health Care Organizations. San Francisco, CA: SIREN; 2019. https://sirenetwork.ucsf.edu/sites/sirenetwork.ucsf.edu/files/wysiwyg/Community-Resource-Referral-Platforms-Guide.pdf *Accessed June 4, 2019*

   This SIREN community resource guide was developed with 8 different companies providing community resource services.

211. http://www.211.org/ *Accessed June 4, 2019*

Facilitator Guide–Slide Deck

continued

In Summary **Health-Related Social Needs** • There are *5 core health-related social needs* that Medicare and Medicaid have identified as targets for screening and referral by physicians and nonphysician clinicians. ○ *Housing instability* ○ *Food insecurity* ○ *Utility help needs* ○ *Transportation problems* ○ *Interpersonal safety needs* • To facilitate *screening and referral*, there is a growing number of *online resources* available.	**SLIDE 53** Summary slide. Encourage learners to explain the information in their own words.
Micro-Chapter 5 **INNOVATIONS FOR SOCIAL DETERMINANTS OF HEALTH**	**SLIDE 54 »** Micro-Chapter 5: Innovations for Social Determinants of Health The final chapter of Module 3 provides a high-altitude "forest view" and explores some recent innovations aimed at moving the needle on SDoH.
Let's finally *zoom out* and consider some big-picture initiatives and strategies.	**SLIDE 55** Presentation of the slides in this micro-chapter can be brief. Focus on the big picture, providing learners with a broad overview of each innovation. Learners can feel free to explore each innovation via the applicable websites included in the Case Studies section at the end of the Facilitator Guide.

SLIDE 56

Innovation #1: The Affordable Care Act (ACA) - 2010

- Expanded health insurance coverage to 20 million additional people.
- Helped narrow longstanding *health care disparities* in insurance coverage.
- Included provisions focused on addressing disparities.
  - For example, the Department of Health and Human Services (HHS) Disparities Action Plan
  - Goal: "A nation free of disparities in health and health care."

ACA coverage expansions led to large gains in health insurance for low-income individuals and people of color, helping to narrow longstanding disparities in coverage.

Background Information

HealthCare.gov states that the ACA has 3 primary goals:

- Make affordable health insurance available to more people. The law provides consumers with subsidies (premium tax credits) that lower costs for households with incomes between 100% and 400% of the federal poverty level.
- Expand the Medicaid program to cover all adults with income below 138% of the federal poverty level. (Not all states have expanded their Medicaid programs.)
- Support innovative medical care delivery methods designed to generally lower the costs of health care.

Facilitation Technique

Depending on political stance, learners may have differing opinions about the ACA and the government's overall role in health care. Attempt to keep discussion focused on the ACA as an initiative aimed at reducing disparities and addressing SDoH.

Facilitation Technique

Depending on time, ask learners to discuss if (and, if so, how) disparities affect the health and well-being of their patients, their communities, or themselves.

Useful Resources

Affordable Care Act (ACA). https://www.healthcare.gov/glossary/affordable-care-act/ *Accessed June 4, 2019*

Hayes SL, Riley P, Radley DC, McCarthy D. Reducing racial and ethnic disparities in access to care: Has the Affordable Care Act made a difference? https://www.commonwealthfund.org/publications/issue-briefs/2017/aug/reducing-racial-and-ethnic-disparities-access-care-has Published August 24, 2017. *Accessed June 4, 2019*

Facilitator Guide–Slide Deck

continued

SLIDE 57

Innovation #2: The Screening in Practices Initiative
(*American Academy of Pediatrics*)

STAR CENTER — Screening Technical Assistance & Resource Center

★ CHILD DEVELOPMENT ★ MATERNAL DEPRESSION ★ SOCIAL DETERMINANTS OF HEALTH ★

- *Goal: "Improve the health, wellness, and development of children through practice and system-based interventions to increase rates of early childhood screening, referral, and follow-up for developmental milestones, maternal depression, and social determinants of health."*
- Innovative features
  - **STAR Center** – screening, technical assistance, and resources
  - **Screening Time** – scenario-based online training modules for care teams
  - **The Screen Scene** – a podcast with tips for implementing screening

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According to the AAP website, "The Screening in Practices Initiative offers information and resources, including screening recommendations, practice tools, and individualized assistance, to help pediatric health care providers implement effective screening, referral, and follow-up for developmental milestones, maternal depression, and social determinants of health."

Background Information

As stated on the AAP website, "Funded by a 3-year grant from The JPB Foundation, the overall goal of the Screening in Practices Initiative is to improve the health, wellness, and development of children through practice and system-based interventions to increase rates of early childhood screening, referral, and follow-up for developmental milestones, maternal depression, and social determinants of health."

"The initiative includes 3 major components:

1. The National Technical Assistance Resource Center on Screening (NTARCS) provides evidence-informed technical assistance and resources to assist practices in implementing effective screening, referral, and follow-up for developmental milestones, maternal depression, and social determinants of health.

2. The Screening in Practices Learning Collaborative works with a diverse group of pediatric primary care practices to measure, evaluate, and improve upon screening, referral, and follow-up using quality improvement methodology.

3. The multi-disciplinary National Advisory Board (NAB) on Screening provides high-level strategic oversight for the initiative and works to advance a national agenda on screening."

Useful Resource

About the Initiative. American Academy of Pediatrics website. https://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/Screening/Pages/About-the-Initiative.aspx *Accessed June 4, 2019*

Facilitator Guide–Slide Deck
continued

SLIDE 58

A Screenshot of Screening Time

Background Information

"The American Academy of Pediatrics created this site—which includes video-based training modules, conversation simulations, a screening tool selector, and a resource center—to help you learn more about the screening process for maternal depression, developmental concerns, and social determinants of health. Useful for doctors, nurses, front office staff, care coordinators, and others involved in the process, this resource will help you gain a better understanding of the importance of family-centered screening and how you can work together to implement a comprehensive, effective process," according to the AAP website.

Facilitation Technique

The Screening Time website is excellent and has a range of high-quality resources, including simulation. Depending on time availability, explore this website with learners.

Useful Resource

Where to Start. https://screeningtime.org *Accessed June 4, 2019*

SLIDE 59

Innovation #3: SIREN – Social Interventions Research & Evaluation Network (*University of California, San Francisco*)

Contains an extensive evidence library, screening tools, implementation resources, and archived webinars.
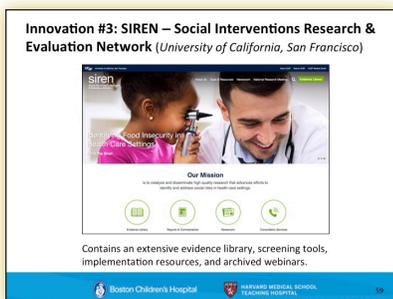
The mission of SIREN "...is to catalyze and disseminate high quality research that advances efforts to identify and address social risks in health care settings."

Background Information

According to the SIREN website, "SIREN projects are focused on:

· Catalyzing high quality research to fill evidence gaps through an innovation grants program and support for researchers in this field;

· Collecting, summarizing, and disseminating research resources and findings to researchers and other industry stakeholders via an interactive website and evidence library, reports, and meetings and presentations;

· Increasing capacity to evaluate SDoH interventions by providing evaluation, research, and analytics consultation services to safety-net and mission-aligned health systems."

· SIREN is supported by Kaiser Permanente and the Robert Wood Johnson Foundation and housed at the Center for Health and Community at the University of California, San Francisco."

Facilitation Technique

Depending on time, explore this website with learners.

Useful Resource

University of California, San Francisco. Social Intervention Research and Evaluation Network (SIREN) website. https://sirenetwork.ucsf.edu *Accessed June 4, 2019*

Innovation #4: The Accountable Health Communities Model (*Centers for Medicare & Medicaid Services*)

SLIDE 60

As stated on the CMS website and circled in red on the slide, "The Accountable Health Communities Model addresses a critical gap between clinical care and community services in the current health care delivery system by testing whether systematically identifying and addressing the health-related social needs of Medicare and Medicaid beneficiaries' through screening, referral, and community navigation services will impact health care costs and reduce health care utilization. There are currently 31 organizations participating in the Accountable Health Communities Model"

Background Information

According to the CMS website, "This model will promote clinical-community collaboration through:

· Screening of community-dwelling beneficiaries to identify certain unmet health-related social needs

· Referral of community-dwelling beneficiaries to increase awareness of community services

· Provision of navigation services to assist high-risk community-dwelling beneficiaries with accessing community services

· Encouragement of alignment between clinical and community services to ensure that community services are available and responsive to the needs of community-dwelling beneficiaries"

"Over a five year period, the model will provide support to community bridge organizations to test promising service delivery approaches aimed at linking beneficiaries with community services that may address their health-related social needs."

Useful Resource

Accountable Health Communities Model. Centers for Medicare and Medicaid Services website. https://innovation.cms.gov/initiatives/ahcm/ Updated April 30, 2019. *Accessed June 4, 2019*

Facilitator Guide–Slide Deck
continued

SLIDE 61
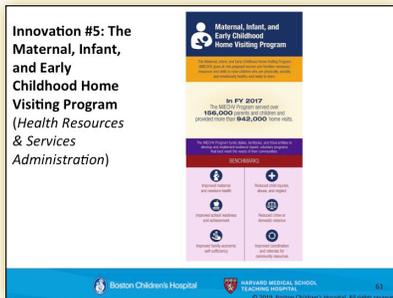
Details on the graphic shown on the slide are as follows:

- "The Maternal, Infant, and Early Childhood Home Visiting Program (MIECHV) gives pregnant women and families, particularly those considered at-risk, necessary resources and skills to raise children who are physically, socially, and emotionally healthy and ready to learn."
- "In FY (fiscal year) 2017 the MIECHV Program served over 156,000 parents and children and provided more than 942,000 home visits."
- "The MIECHV Program funds states, territories, and tribal entities to develop and implement evidence-based, voluntary programs that best meet the needs of their communities."
- "Benchmarks
    - ~ Improved maternal and newborn health
    - ~ Improved school readiness and achievement
    - ~ Improved family economic self-sufficiency
    - ~ Reduced child injuries, abuse, and neglect
    - ~ Reduced crime or domestic violence
    - ~ Improved coordination and referrals for community services"

Facilitator Technique
Ask learners about their experiences with home visiting services for newborns and how they contribute to addressing SDoH.

Useful Resource
Home Visiting. Maternal and Child Health Bureau, Health Resources and Services Administration website. https://mchb.hrsa.gov/maternal-child-health-initiatives/home-visiting-overview *Accessed June 4, 2019*

SLIDE 62

CHWs and PNs underscore the importance of human connection (ie, relationships) in addressing SDoH.

Background Information

The American Public Health Association defines CHWs as

- "...a trusted member of and/or has an unusually close understanding of the community served. This trusting relationship enables the worker to serve as a liaison/link/intermediary between health/social services and the community to facilitate access to services and improve the quality and cultural competence of service delivery."

- "...(a CHW) builds individual and community capacity by increasing health knowledge and self-sufficiency through a range of activities such as outreach, community education, informal counseling, social support and advocacy."

Patient navigators facilitate patient movement through the health care system by removing barriers, such as unmet health-related social needs, and providing support through one-on-one relationships. An increasing number of studies demonstrate the benefit of patient navigation at reducing barriers to care. The first patient navigation program was launched in 1990 and was led by Dr. Harold P. Freeman, a surgical oncologist working at Harlem Hospital in New York. Since then, the concept of patient navigation has grown and spread throughout health care.

A note on terminology—CHW vs. PN: CHW is an umbrella term that encompasses numerous job descriptions and is often understood to include PNs, along with community health representatives who serve tribal nations, *promotores de salud* who serve Latino communities, and many others. There is a combination of nuanced, historical, and legitimate distinctions that can be discussed about the general roles and skills of CHWs compared to PNs, primarily related to the fact that PNs typically work in health care practice settings, whereas CHWs work in health settings and, importantly, also in home and community-based settings.

Facilitator Technique

Ask learners about their experiences with CHWs and/or PNs and how they contribute to addressing SDoH.

Useful Resource

- The Community Health Worker Core Consensus (C3) Project: 2016 Recommendations on CHW Roles, Skills, and Qualities. https://sph.uth.edu/dotAsset/55d79410-46d3-4988-a0c2-94876da1e08d.pdf *Accessed June 4, 2019*

- Freeman HP, Rodriguez RL. History and principles of patient navigation. Cancer. 2011;117(15 Suppl):3539-3542. doi: 10.1002/cncr.26262 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4557777/

- Healthy Homes II Asthma Project. King County, WA. https://www.kingcounty.gov/depts/health/chronic-diseases/asthma/health-care-providers/past-programs/healthy-homes-2.aspx

SLIDE 63

Innovation #7: Medical-Legal Partnerships

National Center for Medical 🔵 Legal Partnership

We're helping to build an integrated health care system that better addresses health-harming social needs by leveraging legal services and expertise to advance individual and population health.

"Medical-legal partnerships integrate the unique expertise of lawyers into health care settings to help clinicians, case managers, and social workers address structural problems at the root of so many health inequities."

"Attorneys in general—and poverty lawyers in particular—have an in-depth understanding of relevant policies, laws, and systems, and seek out solutions at the individual and policy levels to a range of health-related social and legal needs. When embedded as specialists in a health care setting, lawyers can directly resolve specific problems for individual patients, while also helping clinical and non-clinical staff navigate system and policy barriers and transform institutional practices. Using legal expertise and services, the health care system can disrupt the cycle of returning people to the unhealthy conditions that would otherwise bring them right back to the clinic or hospital."
(Source: medical-legalpartnership.org)

Facilitation Technique
Ask learners about their experiences with medical-legal partnerships.

Useful Resource
National Center for Medical-Legal Partnership website.
https://medical-legalpartnership.org/ *Accessed June 4, 2019*

SLIDE 64

In Summary

Innovations for Social Determinants of Health
- **The Affordable Care Act (ACA)**
  - Expanded coverage helped narrow longstanding health care *disparities.*
- **Screening In Practices Initiative**
  - **STAR Center** – screening, technical assistance, and resources
  - **Screening Time** – video-based training modules
- **SIREN – Social Interventions & Research Evaluation Network**
  - Evidence library and informational resources.
- **Accountable Health Communities Model**
  - Systematic screening and referral for health-related social needs.
- **Maternal, Infant, and Early Childhood Home Visiting Program**
  - Aimed at reducing adverse childhood experiences.
- **Community health workers and patient navigators**
  - *Frontline public health and health care workers* who support care coordination, facilitate communication, help address health-related social needs, enhance social support, and advocate for patients and families.
- **Medical-legal partnerships**
  - Integrate the unique expertise of lawyers into health care settings to help address structural problems at the root of health inequities.

Summary slide. Encourage learners to explain the information in their own words.

SLIDE 65

THE END
Thanks for attending.

Questions or feedback: clement.bottino@childrens.harvard.edu
Illustration acknowledgment: Antonia Bottino

THE END
Thanks for attending.

Questions or feedback: clement.bottino@childrens.harvard.edu
Illustration acknowledgment: Antonia Bottino

Facilitator Guide–Slide Deck
continued

Slides
Module 4 of Pediatric Care Coordination Curriculum
Measurement Matters: Creating an Effective and
Sustainable Integrated Care Model

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SLIDE 66
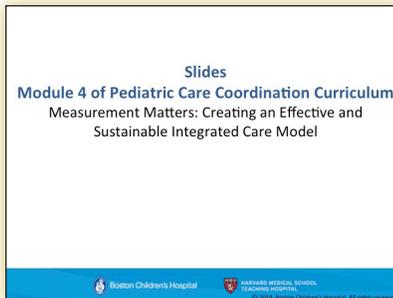
These are the primary sources for the slide deck, also listed above.

Slide 17: Woolf SH, Chapman DA, Hill L, et al. Uneven Opportunities: How conditions for wellness vary across the metropolitan Washington region. Richmond, VA: Virginia Commonwealth University Center for Society and Health; 2018. https://www.mwcog.org/documents/2018/10/26/uneven-opportunities-how-conditions-for-wellness-vary-across-the-metropolitan-washington-region-health-health-data/

Slide 25: Gupta A; Institute for Healthcare Improvement. How does implicit bias affect health care? [video]. http://www.ihi.org/education/IHIOpenSchool/resources/Pages/AudioandVideo/Anurag-Gupta-How-Does-Implicit-Bias-Affect-Health-Care.aspx *Accessed June 3, 2019*

Slide 25: Disparities. https://www.healthypeople.gov/2020/about/foundation-health-measures/Disparities Updated May 31, 2019. *Accessed June 3, 2019*

Slide 26: Hoffman KM, Trawalter S, Axt JR, Oliver MN. Racial bias in pain assessment and treatment recommendations, and false beliefs about biological differences between blacks and whites. *Proc Natl Acad Sci USA*. 2016;113(16):4296-4301. doi: 10.1073/pnas.1516047113

Slide 31: Wilkinson GW, Sager A, Selig S, et al. No equity, no Triple Aim: strategic proposals to advance health equity in a volatile policy environment. *Am J Pub Health*. 2017;107(S3):S223-S228. doi: 10.2105/AJPH.2017.304000

Slide 40: Toxic Stress. Center on the Developing Child at Harvard University website. https://developingchild.harvard.edu/science/key-concepts/toxic-stress/ *Accessed June 3, 2019*

Slide 41: About the CDC-Kaiser ACE Study. https://www.cdc.gov/violenceprevention/childabuseandneglect/acestudy/about.html *Accessed June 4, 2019*

Slides 44, 46-50: Centers for Medicare and Medicaid Services. The Accountable Health Communities Health-Related Social Needs Screening Tool. 2018. https://innovation.cms.gov/files/worksheets/ahcm-screeningtool.pdf *Accessed June 4, 2019*

Slide 45: Billioux A, Verlander K, Anthony S, Alley D. Standardized screening for health-related social needs in clinical settings: the accountable health communities screening tool. National Academy of Medicine. 2017. https://nam.edu/wp-content/uploads/2017/05/Standardized-Screening-for-Health-Related-Social-Needs-in-Clinical-Settings.pdf *Accessed June 4, 2019*

Slide 51: The Screening Technical Assistance & Resource (STAR) Center. https://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/Screening/ *Accessed June 4, 2019*

Slide 52: 211. http://www.211.org/ *Accessed June 4, 2019*

Slide 56: Affordable Care Act (ACA). https://www.healthcare.gov/glossary/affordable-care-act/ *Accessed June 4, 2019*

Slide 57: About the Initiative. https://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/Screening/Pages/About-the-Initiative.aspx *Accessed June 4, 2019*

Slide 58: Where to Start. https://screeningtime.org *Accessed June 4, 2019*

Slide 59: University of California, San Francisco. Social Intervention Research and Evaluation Network (SIREN) website. https://sirenetwork.ucsf.edu *Accessed June 4, 2019*

Slide 60: Accountable Health Communities Model. Centers for Medicare and Medicaid Services website. https://innovation.cms.gov/initiatives/ahcm/ Updated April 30, 2019. *Accessed June 4, 2019*

Slide 61: Home Visiting. Maternal and Child Health Bureau, Health Resources and Services Administration website. https://mchb.hrsa.gov/maternal-child-health-initiatives/home-visiting-overview *Accessed June 4, 2019*

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Case-Based Learning

Social determinants of health are the conditions in which people are born, live, learn, play, work, and age. These conditions can explain big differences in health between individuals as well as groups of individuals (populations).

Below are 3 case vignettes that highlight how social conditions can influence health, health care, and care coordination. The goals of these cases are to stimulate discussion and further inquiry. There are no single solutions or best answers, so think creatively and collaboratively.

At the end of this sheet are some useful resources. For a complete list of sources and resources used in Module 3, please see the Facilitator Guide.

CASE STUDY #1

A 5-week-old infant girl was a no-show at her 2-week and 4-week appointments. The assessment and plan in the newborn visit note reads, "Healthy infant. Mother asking about return to work; provided reassurance." The social history reads, "Lives with mother, 2-year-old brother, and maternal grandmother. Mother works as a barista at a local coffee chain. Father involved; not currently employed." There is also a note from an emergency department visit that reads, "Chief complaint: fussiness; arrived by ambulance." According to an assessment and plan note from that visit, "Fussiness is likely due to gas. Sibling also here for mild upper respiratory infection. Discharge with supportive care." A communications note in her chart reads, "Nursing called and spoke with mother who reported no concerns about the baby. Baby is feeding well, breast and bottle. Mother had questions about transitioning to full formula because she needs to return to work. Reported missing her 4-week appointment because her ride fell through. Plans to reschedule."

Question 1. Do you have any concerns related to care coordination? If so, what are they and why?

Question 2. What social stressors might this family be experiencing? Try to explain them using a *socio-ecological* framework and in terms of *health disparities.*

Question 3. How might these stressors be affecting this family's health? Try to explain these effects in terms of *chronic* or *toxic stress*.

Question 4. What additional pieces of information would be helpful to have and why? How could the care team gather this information in a way that emphasizes family *strengths* and *assets*?

Question 5. What *biases*, conscious or unconscious, might be present? How might they be addressed?

Question 6. What are some *innovative strategies* and *initiatives* that might help this family achieve health equity? Try to identify some specific referral options.

Case-Based Learning

CASE STUDY #2

You receive a faxed discharge summary from a local hospital. A 7-year-old boy, who is a patient in your practice, was admitted overnight for acute asthma exacerbation after presenting to the emergency department (ED). His last routine visit was for well-child care (WCC) 10 months ago, although he has had 3 urgent care visits and an ED visit in the last 6 months. The social history in the WCC note reads, "Mother is home with kids; father works as a truck driver and is often away. Father smokes but only outside." There is also a communication note that the mother called the office requesting a doctor's letter to help prevent the electricity from being shut off. There is a social work note from 2 years ago that reads, "Referred for history of domestic violence. No current safety concerns; mother reports this issue is resolved. Only reported stress is making ends meet. Provided contact information and $20 in grocery cards; further follow-up as needed."

Question 1. Do you have any concerns related to care coordination? If so, what are they and why?

Question 2. What social stressors might this family be experiencing? Try to explain them using a *socio-ecological* framework and in terms of *health disparities.*

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Question 5. What *biases*, conscious or unconscious, might be present? How might they be addressed?

Question 6. What are some *innovative strategies* and *initiatives* that might help this family achieve health equity? Try to identify some specific referral options.

Case-Based Learning

CASE STUDY #3

A 10-year-old girl has been referred to a clinical nutritionist for concerns about elevated body mass index. The notes from her recent health supervision visit show a positive screen for inattentive symptoms although she does not have a diagnosis of ADHD. The nutrition portion of the notes reads, "Working on healthy eating. Sometimes does takeout because mother works nights." The sleep portion reads, "Stays up late watching YouTube videos and playing Fortnite (an online video game)." The assessment and plan reads, "Will refer to clinical nutrition. Had previously been referred to weight management group visit program, but family was unable to attend." There is an emergency department note from 6 months ago that reads, "Chief complaint: homelessness. Family is being evicted from their apartment. Social work consulted; plan is to apply for temporary shelter placement." There is no mention of housing status or concerns at the recent health supervision visit. A review of past appointments shows a 45% no-show rate. On closer review, most of these missed appointments were for non-health supervision follow-up visits labeled "growth follow-up" or "nutrition follow-up."

Question 1. Do you have any concerns related to care coordination? If so, what are they and why?

Question 2. What social stressors might this family be experiencing? Try to explain them using a *socio-ecological* framework and in terms of *health disparities.*

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Question 5. What *biases*, conscious or unconscious, might be present? How might they be addressed?

Question 6. What are some *innovative strategies* and *initiatives* that might help this family achieve health equity? Try to identify some specific referral options.

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Pediatric Care Coordination Curriculum: Module 3

SOCIAL DETERMINANTS OF HEALTH

1

Educational Purposes Only –
No Medical Advice

The Pediatric Care Coordination Curriculum is offered for educational purposes only and is not meant as a substitute for independent medical judgment or the advice of a qualified physician or health care professional. Users who choose to use information or recommendations made available by the Pediatric Care Coordination Curriculum do so at their own risk and should not rely on that information as professional medical advice or use it to replace any relationship with their physicians or other qualified health care professionals.

2

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3

Learning Goals

1. Understand **what** social determinants of health and health disparities are.
2. Understand **how** social conditions influence health.
3. Recognize **5 core health-related social needs** for screening and referral.
4. Understand the importance of **bias** and **health equity**.
5. Recognize some **innovations** aimed at addressing social determinants of health.

4

Contents:
5 Micro-Chapters

1. ***What*** Are Social Determinants of Health and Health Disparities?
2. Let's Talk About ***Bias*** and ***Health Equity***
3. ***How*** Do Social Conditions Influence Health?
4. ***Health-Related Social Needs***: Screening and Referral
5. ***Innovations*** for Social Determinants of Health

5

Micro-Chapter 1

WHAT ARE SOCIAL DETERMINANTS OF HEALTH AND HEALTH DISPARITIES?

6

What Are *Social Determinants of Health*?

Social determinants of health are the ***conditions*** in which people are *born, live, learn, work, play, and age.*

7

- Think of these ***conditions*** as being layered like an onion.
- This framework is called the ***social-ecological model***.

8

Individual conditions include:

- Income
- Education
- Employment
- Housing
- Food
- Transportation
- Health care

9

Interpersonal conditions include

- Isolation due to unsupportive relationships
- Exposure to negative situations
  - Domestic violence
  - Abuse
  - Parental mental illness
  - Incarceration
  - Substance abuse/addiction
  - Neglect
    - In early life, these are called **adverse childhood experiences (ACEs)**.
- Discrimination/oppression
  - Racism
  - Sexism
  - Classism
  - LGBTQ+
  - (Dis)ability
  - Religion

10

Community conditions include

- Neighborhood safety/violence
- Education opportunities (eg, early childhood programs, higher education)
- Employment opportunities and conditions
- Access to amenities (eg, food deserts, green spaces)
- Social capital (eg, trust, sense of identity and belonging, networking opportunities)

11

Structural conditions include

- Government (eg, legislation, public policies)
- Economy (eg, income inequality)
- Environment (eg, pollution)
- Discrimination (eg, gender pay gap, mass incarceration, gay marriage)
- Culture (eg, media, advertising)
- History (eg, historical oppression, structural racism)

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Slide 13

Social conditions

- **Cross different layers** (eg, discrimination as structural and interpersonal).
- **Cluster together** (eg, unemployment, eviction, crime, domestic violence).
- **Flow in different directions** (eg, eviction leading to unemployment or unemployment leading to eviction; unemployment leading to poor health or poor health leading to unemployment).
- **Interact** with genetics and behavior to determine health.

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Slide 14

- Differences in social conditions can **explain big differences in health**.
  - o Between *individuals*
  - o Between *groups of individuals (populations)*
- These differences are reflected in **health disparities**.

14

What Are *Health Disparities*?

Health disparities refer to **differences in health between population groups**.

- Disparities occur across many dimensions
  - o Race/ethnicity
  - o Socioeconomic status
  - o Location
  - o Gender expression
  - o Disability status
  - o Sexual orientation
- *Health care disparities* refer to differences in *health care* between different groups.

15

Why Do Health Disparities *Matter*?

- Disparities create **unfair advantages and disadvantages**
  - o By systematically structuring opportunity and assigning value on the social interpretation of how one looks (eg, race or gender).
- Disparities **sap the strength of the whole society through the waste of human resources**.
- Disparities result in **unnecessary costs**.
  - o *Addressing health disparities is increasingly important as the population becomes more diverse.*

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Slide 17

- *For example*, a 2018 study found that life expectancy varies by 27 years across census tracts in Washington, D.C.
- Try to explain these differences using a *social-ecological framework* and in terms of *health disparities.*

17

What Is *Health Equity*?

Health equity is

- The *opportunity* for every person to attain their *full health potential without disadvantage* because of social position or circumstance.
- A *framework* for addressing *health disparities*.

18

In Summary

What Are Social Determinants of Health and Health Disparities?

- *Social determinants of health* are the *conditions* in which people are born, live, learn, work, play, and age.
  - Can be understood using a *social-ecological framework*
  - Can *explain big differences in health* between individuals and between population groups
- *Health disparities* refer to *differences* in health between population groups.
  - Occur across *many dimensions* (eg, race, gender, income)
  - *Health equity* means *fair opportunities to be healthier* and is a *framework for addressing health disparities.*

19

Micro-Chapter 2

LET'S TALK ABOUT BIAS AND HEALTH EQUITY

20

Why talk about *bias*? To answer this question, let's reconsider the **brain**...

21

Recall that the **brain** is constantly making **predictions**.

For example, when the brain predicts that the body needs energy, it is called *stress.*

22

- The brain also tries to predict who "**us**" is versus who "**not us**" is.
- These predictions happen at every moment, mostly outside of awareness.

23

- People react *differently* to others based on the brain's *us/them* predictions.
- This tendency to react differently is called **BIAS**.
  - Being consciously aware is called *explicit bias.*
  - **IMPLICIT bias** is **unconscious**, *automatic,* and *reflexive.*

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Slide 25

"Wealth"

"Whiteness"

"Gender conformity"

Privilege

Historical oppression

"Gender Nonconformity"

"Poverty"

"Blackness"

- It is important to remember that bias is *universal.*
  - *For example,* in every known society, people give preferential treatment to family members.
- However, bias often exhibits a ***directionality*** and an ***intersectionality*** based on ***privilege*** and ***historical oppression***, which is reflected in ***health disparities***.

25

Slide 26

- *For example*, research indicates that *white patients* receive more and better pain treatment than *black patients.*
- Is there racial bias in pain perception?
  - In one 2016 study, 40% of first-year medical students endorsed the false belief that *black skin is thicker than white skin.*
  - Students who held false beliefs often rated pain as being lower in black patients than white patients and made less appropriate recommendations about how they should be treated.

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Slide 27

If *everyone* has ***bias*** that is *automatic* and *reflexive*, what should be done?

27

Slide 28

- The first steps to ***addressing bias*** are to ***recognize it*** and ***increase personal awareness*** through *humility* and *open-mindedness.*
- A helpful pneumonic is CARE.
  - Conscious empathy
  - Active listening
  - Responsible reaction
  - Environmental awareness

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- Another step is to practice seeing *common humanity* (ie, extend the circle of "us").
- Another step is to take a *strengths-based approach* (ie, identify assets).
- Other steps include
  - Expanding social networks.
  - Practicing continuous learning and reappraisal of biases.
  - Engaging in difficult discussions.

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Our common and ultimate goal is to promote *HEALTH EQUITY*.

Health equity *is the opportunity for every person to attain their full health potential without disadvantage because of social position or circumstance.*

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Health Outcomes

Quality of Care   **Cost**

- *Health equity* is a *guiding framework* for *achieving the Triple Aim* of
  - *Population health.*
  - *Experience of care.*
  - *Per capita cost.*
- In other words... "No Equity, No Triple Aim."

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In Summary

Let's Talk About Bias and Health Equity

- The brain is constantly making predictions about who "*us*" is versus "*not us*."
- Like breathing, this *implicit bias* is automatic, reflexive, universal, and largely outside of awareness.
- Bias often exhibits *directionality* and *intersectionality* of privilege, which is reflected in *health disparities*.
- The first step to addressing *bias* is to *increase personal awareness* though *humility, respect,* and *open-mindedness.*
- The common goal is *health equity*, which is the attainment of every person's full health potential, regardless of social position or circumstance.
  - *"No Equity, No Triple Aim"*

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Micro-Chapter 3

HOW DO SOCIAL CONDITIONS INFLUENCE HEALTH?

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To understand how social conditions influence health, start by considering the ***brain***...

34

The ***brain*** constantly *predicts* the body's *energy needs* from one moment to the next.

35

- When the brain perceives a threat, it predicts a need for energy (to *fight or flee).*
- This prediction is called ***stress****.*

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Slide 37

When the brain predicts a need for energy, it sends signals to the body (**stress hormones**) *that increase*

- Blood sugar
- Blood pressure
- Heart rate
- Muscle tension

...and *decrease*

- Immune function.
- Feelings of calm and contentment.
- Impulse control/planning.
- Neurogenesis (ie, brain growth and development).

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Slide 38

- **Brief, mild stress is good for health.**
  - Exercise, for example
- **But chronic stress is bad for health.**
  - Diabetes
    - Chronically elevated blood sugar
  - Hypertension
    - Chronically elevated blood pressure
  - Headache/back pain
    - Chronically elevated muscle tension
  - Cancer
    - Chronically depressed immune function
  - Anxiety and depression
    - Chronically not feeling calm and contented
  - Addiction
    - Chronically depressed impulse control
  - Learning/school difficulties
    - Chronically disrupted brain development

Health — Stress

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Slide 39

Many social conditions are characterized by chronic **threat**, **uncertainty**, and **lack of control.**

- *"Will I lose my home?"*
- *"Do I have enough food?"*
- *"Am I safe?"*
- *"Will I be hurt?"*
- *"Am I being treated fairly?"*
- *"Will anyone help?"*
- *"Am I all alone?"*

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Slide 40

- **Supportive relationships** can buffer chronic stress, rendering it tolerable.
- But an **absence of protective relationships** characterizes **toxic stress**.
  - For example, **adverse childhood experiences (ACEs)**, such as
    - Abuse
    - Neglect
    - Domestic violence
    - Incarcerated family member
    - Substance abuse at home
    - Parental mental illness

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- *For example*, research shows that ***adverse childhood experiences (ACEs)*** increase the risk of numerous health problems, including heart disease and cancer.
- Try to explain this relationship using this ACE Pyramid framework from the Centers for Disease Control and Prevention.

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In Summary

How Do Social Conditions Influence Health?

- ***Stress*** can be understood as the brain's predictions about the body's energy needs.
- Although some stress is good, ***chronic activation of the stress response*** is bad for health.
  - o For children, in particular, stress ***disrupts brain development***.
- Supportive relationships can buffer chronic stress, but a***dverse childhood experiences***, such as abuse and neglect, characterize ***toxic stress*** that increases the risk of numerous health problems.

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Micro-Chapter 4

HEALTH-RELATED SOCIAL NEEDS: SCREENING AND REFERRAL

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Housing instability

Food insecurity

Interpersonal safety needs

Utility help needs

Transportation problems

The Centers for Medicare and Medicaid Services has identified ***5 core health-related social needs*** *for screening and referral.*

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Why these 5?
- High-quality evidence links these needs to poor health, increased health care utilization, and cost.
- These needs can be met by community service providers.
- These needs are not universally addressed by physicians and nonphysician clinicians (yet).

Food insecurity
Housing instability
Interpersonal Safety needs
Utility help needs
Transportation problems

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Core Health-Related Social Need:
Housing Instability

Examples
- Homelessness
- Inability to pay mortgage/rent
- Frequent unintended moves
- Eviction

Sample screening question
What is your living situation today?
- ☐ I have a steady place to live.
- ☑ I have a place to live today, but I am worried about losing it in the future.
- ☑ I do not have a steady place to live. (I am temporarily staying with others, in a hotel, in a shelter, living outside on the street, on a beach, in a car, abandoned building, bus or train station, or in a park.)

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Core Health-Related Social Need:
Food Insecurity

Example
Limited or uncertain access to adequate food

Sample screening question
Within the past 12 months, you worried that your food would run out before you got money to buy more.
- ☑ Often true
- ☑ Sometimes true
- ☐ Never true

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Core Health-Related Social Need:
Utility Help Needs

Examples
- Difficulty paying utility bills
- Shut-off notices
- Disconnected phone

Sample screening question
In the past 12 months, has the electric, gas, oil, or water company threatened to shut off services in your home?
- ☑ Yes
- ☐ No
- ☑ Already shut off

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Core Health-Related Social Need:
Transportation Problems

Example
Difficulty accessing or affording medical or public transportation

Sample screening question
In the past 12 months, has lack of reliable transportation kept you from medical appointments, meetings, work or from getting things needed for daily living?
☑ Yes
☐ No

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Slide 50

Core Health-Related Social Need:
Interpersonal Safety Needs

Examples
- Intimate partner violence
- Abuse
- Adverse childhood experiences

Sample screening question
Because violence and abuse happens to a lot of people and affects their health we are asking the following question. How often does anyone, including family and friends, threaten you with harm?
☐ Never
☐ Rarely
☑ Sometimes
☑ Fairly often
☑ Frequently

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Slide 51

To facilitate *SCREENING* for health-related social needs, the *American Academy of Pediatrics* created the **STAR Center** (*Screening, Technical Assistance, and Resource Center*), which contains an array of online resources.

American Academy of Pediatrics
STAR CENTER — Screening Technical Assistance & Resource Center

★ CHILD DEVELOPMENT   ★ MATERNAL DEPRESSION   ★ SOCIAL DETERMINANTS OF HEALTH ★
Screening Recomendations   Screening Tools   Related AAP Initiatives

Questions? We Can Help.   FAQs   For Practices

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Slide 52

2-1-1
HOW WE HELP   ABOUT

HELP STARTS HERE
2-1-1 is a nation-wide service connecting over 14 million people to services every year. To get help, you can search for local resources through your local 2-1-1 provider, or simply call 2-1-1
FIND YOUR LOCAL 2-1-1   ZIP CODE   ELK GROVE VILLAGE   SEARCH

Not sure where to turn? We are here for you.

Community Resource Referral Platforms: A Guide for Health Care Organizations
Yuri Cartier, MPH
Caroline Fichtenberg, PhD
Laura Gottlieb, MD, MPH
April 16, 2019
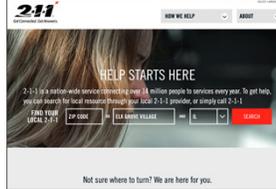
- There is also a growing number of **online REFERRAL tools** for health-related social needs (see resource guide).
- **211** provides free help finding social service resources in all 50 states.

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In Summary

Health-Related Social Needs

- There are *5 core health-related social needs* that Medicare and Medicaid have identified as targets for screening and referral by physicians and nonphysician clinicians.
    - o *Housing instability*
    - o *Food insecurity*
    - o *Utility help needs*
    - o *Transportation problems*
    - o *Interpersonal safety needs*
- To facilitate *screening and referral*, there is a growing number of *online resources* available.

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Micro-Chapter 5

INNOVATIONS FOR SOCIAL DETERMINANTS OF HEALTH

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Let's finally *zoom out* and consider some big-picture initiatives and strategies.

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Innovation #1: The Affordable Care Act (ACA) - 2010

- Expanded health insurance coverage to 20 million additional people.
- Helped narrow longstanding *health care disparities* in insurance coverage.
- Included provisions focused on addressing disparities.
    - o For example, the Department of Health and Human Services (HHS) Disparities Action Plan
    - o Goal: "A nation free of disparities in health and health care."

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Innovation #2: The Screening in Practices Initiative (*American Academy of Pediatrics*)

STAR CENTER | Screening Technical Assistance & Resource Center

★ CHILD DEVELOPMENT ★ MATERNAL DEPRESSION ★ SOCIAL DETERMINANTS OF HEALTH ★

- **Goal**: "*Improve the health, wellness, and development of children through practice and system-based interventions to increase rates of early childhood screening, referral, and follow-up for developmental milestones, maternal depression, and social determinants of health.*"
- Innovative features
  - o **STAR Center** – screening, technical assistance, and resources
  - o **Screening Time** – scenario-based online training modules for care teams
  - o **The Screen Scene** – a podcast with tips for implementing screening

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A Screenshot of Screening Time

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Innovation #3: SIREN – Social Interventions Research & Evaluation Network (*University of California, San Francisco*)

Contains an extensive evidence library, screening tools, implementation resources, and archived webinars.

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Innovation #4: The Accountable Health Communities Model (*Centers for Medicare & Medicaid Services*)

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Innovation #5: The Maternal, Infant, and Early Childhood Home Visiting Program (*Health Resources & Services Administration*)

Maternal, Infant, and Early Childhood Home Visiting Program

The Maternal, Infant, and Early Childhood Home Visiting Program (MIECHV) gives at-risk pregnant women and families necessary resources and skills to raise children who are physically, socially, and emotionally healthy and ready to learn.

In FY 2017
The MIECHV Program served over **156,000** parents and children and provided more than **942,000** home visits.

The MIECHV Program funds states, territories, and tribal entities to develop and implement evidence-based, voluntary programs that best meet the needs of their communities.

BENCHMARKS

Improved maternal and newborn health
Reduced child injuries, abuse, and neglect
Improved school readiness and achievement
Reduced crime or domestic violence
Improved family economic self-sufficiency
Improved coordination and referrals for community resources

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Innovation #6: Community Health Workers (CHWs) and Patient Navigators (PNs)

CHWs and PNs are frontline public health and health care workers who
- *Support care coordination.*
- *Facilitate communication* between patients and care team members.
- Help patients *address health-related social needs*.
- Enhance *social support*.
- *Advocate* for patient and family needs.

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Innovation #7: Medical-Legal Partnerships

National Center for Medical Legal Partnership

We're helping to build an integrated health care system that better addresses health-harming social needs by leveraging legal services and expertise to advance individual and population health.

"Medical-legal partnerships integrate the unique expertise of lawyers into health care settings to help clinicians, case managers, and social workers address structural problems at the root of so many health inequities."

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In Summary

Innovations for Social Determinants of Health
- **The Affordable Care Act (ACA)**
  - Expanded coverage helped narrow longstanding health care *disparities*.
- **Screening In Practices Initiative**
  - **STAR Center** – screening, technical assistance, and resources
  - **Screening Time** – video-based training modules
- **SIREN** – **Social Interventions & Research Evaluation Network**
  - Evidence library and informational resources.
- **Accountable Health Communities Model**
  - Systematic screening and referral for health-related social needs.
- **Maternal, Infant, and Early Childhood Home Visiting Program**
  - Aimed at reducing adverse childhood experiences.
- **Community health workers and patient navigators**
  - *Frontline public health and health care workers* who support care coordination, facilitate communication, help address health-related social needs, enhance social support, and advocate for patients and families.
- **Medical-legal partnerships**
  - Integrate the unique expertise of lawyers into health care settings to help address structural problems at the root of health inequities.

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Slide 65

THE END
Thanks for attending.

Questions or feedback: clement.bottino@childrens.harvard.edu
Illustration acknowledgment: Antonia Bottino

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Pediatric Care Coordination Curriculum

MODULE 4

Measurement Matters: Creating an Effective and Sustainable Integrated Care Model

Richard Antonelli, MD, MS, FAAP
Sonja Ziniel, PhD
Hannah Rosenberg, MSc

Measurement Matters: Creating an Effective and Sustainable Integrated Care Model

> **Module 4—Objectives**
>
> At the end of this session, participants should be able to:
>
> - Outline key elements of a care coordination measurement framework
> - Use tools and measures to effectively assess elements of care coordination
>
> **Module 4—Elements**
> - Overview
> - Facilitator Guide Slide Deck
> - Case-Based Learning

Note to the facilitator:

This module includes a didactic portion, a set of tools and resources, case studies, worksheets, and suggested readings.

The curriculum is intended to be tailored to fit training needs. Therefore, any or all of the content from this module can be incorporated into the training. However, a suggested agenda for implementing this as a stand-alone module is included. Please be aware that it is crucial to input local-, state-, and region-specific content, as applicable, even if the entire module is implemented in its form.

A **(L)** found in the module indicates the need for local content to be added, but facilitators should feel free to do so as they see fit.

Optimal Facilitation Guidance

To achieve the most efficient and effective outcomes from the learning sessions, it will be essential to assure vital and equitable input from all stakeholders, especially patients and families. Please see the section in the introduction (page 4) entitled Tips for the Facilitator: Ways to Keep the Workshop on Track.

There are two tables included below. The first is a high-level agenda of the module. The second is the facilitator guide that includes a breakdown of slide content and talking points. The facilitator should use the guide as a resource to tailor the training.

Module Overview

Table 1

Agenda Item	Time	Materials Required	Instruction/Notes
Pre-session reading	N/A	Vaz LE, Farnstrom CL, Felder KK, Guzman-Cottrill J, Rosenberg H, Antonelli RC. Utilizing a modified care coordination measurement tool to capture value for a pediatric outpatient parenteral and prolonged oral antibiotic therapy program. *J Pediatric Infect Dis Soc. 2018;7(2):136-142.* *Available at:* https://doi.org/10.1093/jpids/pix023	Prior to the day of the training session, the reading can be sent to the participants. The estimated amount of time to complete the reading (ie, it will take approximately 30 minutes to complete) and an explanation about the value of completing the readings beforehand (ie, the session will be drawing from the reading) should be communicated to the participants.
Introduction	10 min	**L** Slide deck/handout	Sample slides and handouts are included with the module, but the facilitator is encouraged to embed local content.
Didactic	30 min	**L** Slides Tools presented in the slide deck can be used as handouts	Content should be pulled from and formatted to be similar to the sample slide deck, and local content should be infused throughout. Review tactical steps toward implementation of measurement, including processes, measures, and tools. Make sure to discuss and/or workshop how the tools, measures, and processes can be incorporated into the learners' environment.
Case studies	30 min	Case studies Questions	Ideally, case studies will be read and discussed in small groups, with one leader per group who can guide the group by jump starting the conversation or redirecting the group back onto the topic, if necessary. Case studies should be read and discussed in small groups, using recommended questions as a guide. Major points to think through include the following: · In each of these case studies, how does the organization or team achieve the Triple Aim of outcomes with the support of measurement, or how is continuous measurement a crucial element in the process? · How can measurement be broken down so it does not seem overwhelming and unattainable?

Module Overview

Agenda Item	Time	Materials Required	Instruction/Notes
Action-oriented next-step activity	10 min	Worksheet	Ask participants to consider up to 5 things they have learned, and based on that, action steps they can take back to their work and teams over the next 1, 3, and 6 months. Perhaps ask them to consider goals they believe are valuable and achievable. This part of the workshop is intended to give participants the opportunity to think through how to apply their learning to their day-to-day work. Encourage them to think small: Are there elements of the overall measurement framework that would be particularly valuable to their work and relatively easy to adopt?
Report and closing	10 min	Whiteboard or flip chart	To close out the module, ask participants to report back to the larger group after small group discussions. A facilitator or volunteer participant can record key points shared by the small groups on a whiteboard or flip chart. This time is intended to summarize and close the loop on the learning. It should be facilitated by a facilitator but driven by participants. The facilitator can either invite anyone from the large group to jump in with thoughts on what was learned during the session or go table to table and ask people to share. Sometimes having the opportunity to speak ideas aloud helps people to formulate next steps. One option is to write down action steps and include them in a summary email sent to participants after the session.
Evaluation	N/A	Evaluation questions	After the workshop, evaluation questions should be emailed to the participants. Feedback from evaluations can be helpful to improving the workshop over time.

Facilitator Guide–Slide Deck

SLIDE 1 » Title Slide

Slides
Module 4 of Pediatric Care Coordination Curriculum
Measurement Matters: Creating an Effective and
Sustainable Integrated Care Model

SLIDE 2 » Educational Purpose Only–No Medical Advice

The Pediatric Care Coordination Curriculum is offered for educational purposes only and is not meant as a substitute for independent medical judgment or the advice of a qualified physician or health care professional. Users who choose to use information or recommendations made available by the Pediatric Care Coordination Curriculum do so at their own risk and should not rely on that information as professional medical advice or use it to replace any relationship with their physicians or other qualified health care professionals.

Slide text:

Educational Purposes Only –
No Medical Advice

The Pediatric Care Coordination Curriculum is offered for educational purposes only and is not meant as a substitute for independent medical judgment or the advice of a qualified physician or health care professional. Users who choose to use information or recommendations made available by the Pediatric Care Coordination Curriculum do so at their own risk and should not rely on that information as professional medical advice or use it to replace any relationship with their physicians or other qualified healthcare professionals.

SLIDE 3 » Why Measure

This time should be used to introduce the session objectives and frame the session. Think through the following:

Why are we here today? To discuss measurement and its importance in the changing health care delivery environment with its critical emphasis on high-value outcomes and accountability. Care coordination and care integration are essential to ensuring our ability to provide high-value care, which will likely be vital in advocating for necessary resources in supporting care coordination.

What are we going to do today? Engage in case-based learning around tools, processes, and measures to support measurement. Conduct thought exercises on how to apply these learnings and resources to our individual settings.

Slide text:

Why measure?

- To assess current gaps
- To prioritize improvement opportunities
- To measure success over time

Add local content

Facilitator Guide–Slide Deck
continued

SLIDE 4 » Key Definitions

Key Definitions

- Accountable Care Organizations (ACOs)
- Value-based care
- Fee-for-service
- Global budgeting

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Accountable Care Organizations (ACOs) are groups of physicians, hospitals, and nonphysician clinicians who come together voluntarily to give coordinated high-quality care to their Medicare patients. The goal of coordinated care is to ensure that patients, especially the chronically ill, get the right care at the right time, while avoiding unnecessary duplication of services and preventing medical errors. When an ACO succeeds both in delivering high-quality care and spending health care dollars more wisely, it will share in the savings it achieves for the Medicare program.
Source: https://www.cms.gov/Medicare/Medicare-Fee-for-Service-Payment/ACO/index.html

Value-based programs reward physicians with incentive payments for the quality of care they provide to patients.
Source: https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/Value-Based-Programs/Value-Based-Programs.html

Fee-for-service is a system of health care payment in which a physician or nonphysician clinician is paid separately for each particular service rendered.
Source: https://www.medicareresources.org/glossary

In **global budgeting,** a government agency determines the total amount of money that it has available to reimburse all hospitals, physicians, nonphysician clinicians, and clinics in the nation. The global budget can be further subdivided in order for a government agency to establish a maximum amount of spending for treating a specific disease or a maximum budget for each hospital in a state.
Source: https://bizfluent.com

SLIDE 5 » Rapid Cycle QI

Rapid Cycle QI

- Rapid cycle is a type of quality improvement that assesses areas of improvement and implements and tests changes over time

- Measurement is extremely important to the success of quality improvement

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Quality improvement (QI) has proven to be a useful strategy for making changes to the health care system to improve performance. In this module, rapid cycle methodology examples will be used in the case studies. The measurement tools and processes that are discussed demonstrate an approach to evaluating rapid cycle quality improvement outcomes.

- The Institute for Healthcare Improvement's Open School has numerous educational modules that anyone can use on quality improvement methodology and practical application. More information and links to the modules are available at: *http://www.ihi.org/education/ihiopenschool/Pages/default.aspx.*

- Oftentimes, measurement and clinical improvement activities can qualify for Maintenance of Certification (MOC) for physician continuing education credit. More about MOC with the American Board of Pediatrics is available at: *https://www.abp.org/content/maintenance-certification-moc.*

- Ask learners to share if they have been involved in rapid cycle QI work in their current or previous roles.

Facilitator Guide–Slide Deck

continued

SLIDE 6 » Quality Measures That Can Drive Implementation of Care Coordination

The Medicaid Child Core Set of quality measures provides an example of the types of outcomes that state Medicaid programs will be tracking going forward. Often, if stakeholders have a goal, such as a quality measure, that they will be expected to perform against, it may catalyze development of a shared vision and commitment to implementing care coordination activities.

The Medicaid Child Core Set is available at: https://www.medicaid.gov/medicaid/quality-of-care/downloads/performance-measurement/2018-child-core-set.pdf

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SLIDE 7 » Types of Measurement
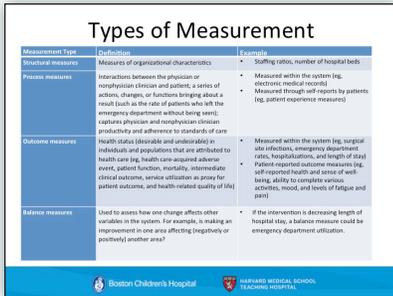
Use this time to describe different types of measures then encourage participants to brainstorm examples of measures, either in small groups or with the entire audience.

This slide can be broken up into different slides for easier readability. Additionally, using this slide as a handout is often helpful.

Source: http://www.ihi.org/resources/Pages/HowtoImprove/ScienceofImprovementEstablishingMeasures.aspx

---

SLIDE 8 » Tools for Measurements

Some measures and measurement tools that will be very helpful are listed on the slide.

L Embed local content here. For example, are there tools that your institution or group use for which you can provide some training?

Facilitator Guide–Slide Deck

continued

SLIDE 9 » Family Experience Measurement

Family Experience Measurement

Family experience (outlined in detail in module 2 of this curriculum) of care integration is a true patient- and family-reported outcome measure. Other measures of care coordination are related to structure or process. None of these measures are mutually exclusive. However, for the sake of parsimonious implementation, prioritizing outcome measurement is recommended.

Introduce different family experience measures

- Pediatric Integrated Care Survey
  Available at: http://www.childrenshospital.org/integrated-care-program/patient-and-family-experience-outcome

- Family Experiences with Care Coordination
  Available at: https://www.ahrq.gov/sites/default/files/wysiwyg/policymakers/chipra/factsheets/chipra_15-p002-ef.pdf

- Family-Centered Care Assessment for Families
  Available at: http://familyvoices.org/wp-content/uploads/2018/06/FCCA-fact-sheet-11-17.pdf

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SLIDE 10 » How to Measure Care Coordination

How to measure care coordination?

- Track activities and associated outcomes
- Suggested tool: Care Coordination Measurement Tool
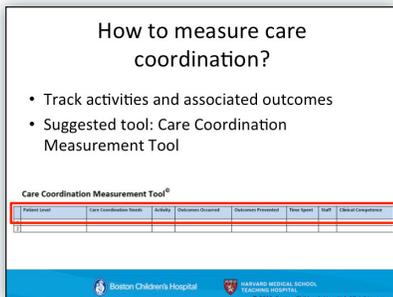
It is important to measure and quantify care coordination and integration. A valuable tool to achieving this is the Care Coordination Measurement Tool, which focuses on process rather than family experience.

This slide shows the domains of the Care Coordination Measurement Tool. Even if the tool will not be used by learners, these domains can be helpful to thinking through what components of care coordination are important to track.

The Care Coordination Measurement Tool template and the accompanying Adaptation and Implementation Guide can be downloaded at the following site: *http://www.childrenshospital.org/integrated-care-program/care-coordination-measurement.*

Facilitator Guide–Slide Deck

continued
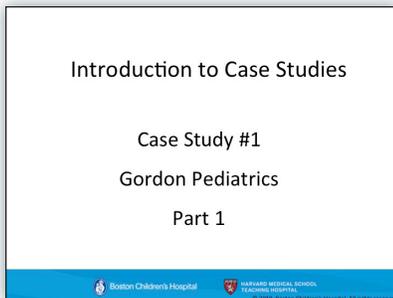
SLIDE 11 » Intro to Case Studies

Introduction to Case Studies

Case Study #1

Gordon Pediatrics

Part 1

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After introducing the framework and definitions, move to case-based learning.

The following case studies introduce 2 distinct groups that are focused on providing integrated care for children and youth:

- **Case Study #1** is an in-depth look at quality improvement.
- **Case Study #2** offers an example of how measurement concepts, tools, and processes can be used in different settings.

L Facilitators are encouraged to amend these cases to best reflect their organization or institution and the patients and families that the module audience serves.

Suggested format for case study learning and discussion

- Read and discuss the case study in small groups.
- Reconvene the larger group, asking 1 representative from each group to share what his or her small group discussed.
- Have one facilitator (or a learner) take notes on a flip chart or board

Start case study #1, which revolves around Gordon Pediatrics, a small community-based pediatric practice

- Depending on the size of the group, either separate people into groups of 3 to 6 people or have one larger group discussion.
- Before reading the case, remind the audience that the goal is to take what has been learned during the session and apply it in a practical application setting.
- Ask groups to read part 1 of case study #1 then pause for reflection.
- Encourage the learners to think through how they might also apply learnings to their own practice.
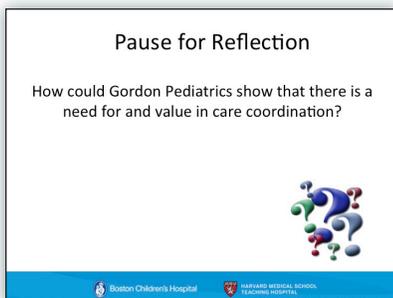
SLIDE 12 » Pause for Reflection

Pause for Reflection

How could Gordon Pediatrics show that there is a need for and value in care coordination?

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The pauses throughout the case study indicate an opportunity to brainstorm and discuss as a group before proceeding.

The facilitator can ask each group to pause at these points in the case and either reflect as a small group or have a larger group discussion.

These pauses are good opportunities for the learners to practice thinking about how to use measurement.

Facilitator Guide–Slide Deck

continued

SLIDE 13 » Gordon Pediatrics

Gordon Pediatrics: Activities and Outcomes

Activities	Outcomes Occurred	Outcomes Prevented	Clinical Competence
40% of the time: reconciled medication discrepancies	30% of the time: connected families to community agencies	20% of the time: prevented gaps in medication	30% of the time: recorded tasks did not require clinical competence (neither social worker nor nurse)
35% of the time: advised families on the information needed for a school individualized education plan and processed additional school forms	45% of the time: advised patients on home management	45% of the time: prevented unnecessary office visits	
30% of the time: discussed insurance options with families	30% of the time: helped patients obtain additional services in school	20% of the time: prevented additional missed school days	
20% of the time: secured prior authorizations			

Nurse and social worker care coordination activities and outcomes

Encourage the learners to discuss the information obtained from the data.

Display this slide during the upcoming pause for reflection so that learners can review it during their discussion time.

SLIDE 14 » Pause for Reflection

Pause for Reflection

- What are conclusions that Gordon Pediatrics can draw based on the data collected with the Care Coordination Measurement Tool?
- What are the implications for the data as Gordon Pediatrics prepares for value-based care delivery?
- How can the data help to make the case for additional or different allocation of resources?

Encourage learners to think through what is helpful about the data. For instance, if data collected from the registered nurse and licensed clinical social worker indicate that 30% of the tasks they are performing do not require their licensure, what conclusions might be drawn – perhaps someone else with a different skill set could take responsibility for those items while the nurse and social worker perform tasks that require clinical competence? The term for this is sometimes called "working at the top of your license."

SLIDE 15 » Case Study #1 Gordon Pediatrics, Part 2

Case Study #1

Gordon Pediatrics

Part 2

Case Study #1, Part 2 delves into measurement to inform gaps and assess change.

Allow the learners to read through this next part of the case study in small groups.

Facilitator Guide–Slide Deck
continued

SLIDE 16 » Gordon Pediatrics: Family Experience Data

Gordon Pediatrics: Family Experience Data
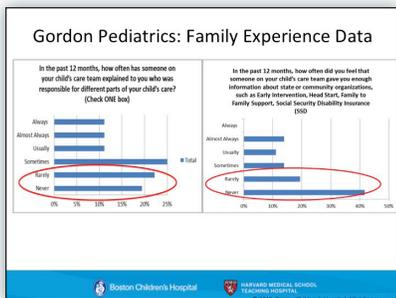
Similar to data from the Care Coordination Measurement Tool, ask learners to consider how they interpret the data. For example, if respondents say that important aspects of integrated care never occur, then this could have implications for the overall health and well-being of patients.

Ask learners to reflect on their experiences as a care team member and/or family member.

These questions are from the Pediatric Integrated Care Survey (PICS). Feel free to use other measures from the PICS if they are more relevant to a case study that has been adapted.

SLIDE 17 » Pause for Reflection

Pause for Reflection

- What do the family experience data tell Gordon Pediatrics?

- How can the data be used to drive changes?

Ask the learners to think through how the data can be used to drive change. What decisions or changes could Gordon Pediatrics make based on the data?

SLIDE 18 » Action Grid

Action Grid

The action grid is a care planning tool intended to document action items resulting from an in-person visit or encounter.

Post-Encounter Action Grid

Answers
- WHO
- WHAT
- WHEN
- WHERE
- HOW

In this case study, Gordon Pediatrics implements the action grid, which is introduced in module 1 and included in module 2. For additional introductory content to the action grid, please refer to the tool guide in module 1.

The action grid can be found at: http://www.childrenshospital.org/integrated-care-program/ multidisciplinary-care-planning

Facilitator Guide–Slide Deck
continued

SLIDE 19 » Pause for Reflection

Pause for Reflection

What are types of process, outcome, and balancing measures that the team could collect?

Based on the interventions that Gordon Pediatrics is implementing, what measures could be put in place to evaluate success? Ask the learners to discuss this in small groups or call out suggestions from the larger group.

SLIDE 20 » Outcome/Process/Balance Measures

Outcome/Process/Balance Measures

Measure Type	Measure
Process	What: Action grids shared with families How: The number of families that received the action grid/the total number of families seen in the clinic
Outcome	What: Emergency department utilization How: Emergency department visits were counted for all patients included in the cohort
Balancing	What: Physician and nonphysician clinician experience with the action grid How: Physicians and nonphysician clinicians were asked rating questions to assess their experience with implementation of the action grid

These are examples of process, outcome, and balancing measures. Different examples may be given, based on how the case study may have been adapted for the learners.

Before offering examples to the learners, give them an opportunity to brainstorm about examples of process, outcome, and balancing measures. Ask them to consider how the measures might be collected in the context of the case.

SLIDE 21 » Case Study #2 Connect Title, V Program

Case Study #2

Connect

Title V Program

This is the second case study. It is not as comprehensive as case study #1, but it shows how a similar measure paradigm can be applied to different contexts.

One of the case studies can be selected to present or this one can be presented in addition to case study #1 to demonstrate how measurement can be applied in different settings.

SLIDE 22 » Pause for Reflection

Pause for Reflection

How could Connect coordinators create a value stream for their work? Are there processes, tools, or measures that could be used?

Ask learners to brainstorm about how the coordinators could collect quantitative data to demonstrate how they are creating value, and to use the following framework: Because of the coordinators, "x, y, and z" are occurring or not occurring (THINK EXPERIENCE, OUTCOMES, and COST).

Facilitator Guide–Slide Deck

continued

SLIDE 23 » Connect Activities and Outcomes

Connect Activities and Outcomes

Activities	Outcomes Occurred	Outcomes Prevented
20% of the time: introduced supplementary insurance options to families	15% of the time: a family was financially able to access a service that supported care for its child at home	15% of the time: prevented a gap in service due to a family's inability to afford the cost
25% of the time: communicated with a community agency, educational facility, or school via telephone or email	20% of the time: a family found an educational program that was suitable for its child's needs	20% of the time: prevented a gap in time so that a child was able to attend school or an educational program
40% of the time: connected families and family support groups	35% of the time: a family connected to a peer support network	
60% of the time: connected families and community services		

Connect Care Coordinators data

Similar to the first case study, encourage the learners to discuss the information obtained from the data.

Display this slide during the upcoming pause for reflection so that the learners can review it during their discussion time.

SLIDE 24 » Pause for Reflection

Pause for Reflection

How could Connect message these outcomes to demonstrate the instrumental role they play?

Ask the learners to brainstorm about how the data could be presented to demonstrate optimal value.

This time could also be an opportunity for the learners to apply concepts to their individual settings: After the data are collected, how are the results messaged? Who are the key players that need to be involved in messaging? With whom are the data shared? WHO to involve and WHEN and HOW they are involved are crucial components.

SLIDE 25 » Closing

Closing

- Ask learners to reflect on what they learned today that they will take back to their individual settings.

- Ask for final questions and thoughts.

Use this final time to reflect on the session and allow the learners time to think through their next steps. A worksheet could be provided so that the learners can record their thoughts and next steps and have something to take with them.

Case-Based Learning

Following are 2 distinct case studies. The first takes place in a general pediatric care practice, and the second is set in a practice funded by the Title V Maternal and Child Health Services Block Grant Program. The authors intentionally chose 2 diverse settings to show that care coordination and care integration measurement can be applied across settings in the pediatric space. These case studies use tools that the Integrated Care Program at Boston Children's Hospital includes in its quality improvement tool kit; however, there are other measurement tools in this space. Some additional tools are listed throughout this module.

CASE STUDY #1 | Gordon Pediatrics

A SMALL, COMMUNITY-BASED, GENERAL PEDIATRIC CARE PRACTICE

PART 1: Why measure? To show value

Gordon Pediatrics is a small, community-based, general pediatric care practice that is part of the network for a larger hospital system. The hospital system is preparing to enter into a risk-based contract with an Accountable Care Entity and will be responsible for improving outcomes for its patient population. The hospital system has tasked the primary care practices in its network with improving care coordination service delivery as a strategy to lead to better outcomes for patients and their families.

In addition to pediatricians and administrative staff members, Gordon Pediatrics has a nurse and licensed clinical social worker who both spend time helping to coordinate care for families. The nurse and social worker both describe their work as piecemeal and say that they are able to do things when they can, but that they are often unable to carve out time in their schedules to help families with care coordination. While brainstorming, the practice gets the idea to hire a part-time, nonclinical care coordinator to offload some of the coordination done by the nurse and social worker. In addition, having a dedicated care coordinator would help Gordon Pediatrics meet outcomes expected by the Accountable Care Entity. In order to move forward with hiring a case coordinator, Gordon Pediatrics has to make a case for why adding a care coordinator to the team would be valuable to the hospital system.

Pause for Reflection

How could Gordon Pediatrics show that there is a need for and value in care coordination?

Case–Based Learning
continued

The team decides to have the nurse and social worker collect data on their daily care coordination activities and outcomes for a 2-week time period.

Example methodology: The nurse and social worker adapt the Care Coordination Measurement Tool to collect care coordination activity and outcomes data. For 2 weeks, they each collect data on their first 10 care coordination encounters every day. They decide that an important goal is to collect data in domains related to activities, outcomes prevented, outcomes occurred, and clinical competence. Included below is a sample of their data.

Table 2
Nurse and Social Worker Care Coordination Activities and Outcomes

Activities	Outcomes Occurred	Outcomes Prevented	Clinical Competence
40% of the time: reconciled medication discrepancies	**30% of the time:** connected families to community agencies	**20% of the time:** prevented gaps in medication	**30% of the time:** recorded tasks did not require clinical competence (neither social worker nor nurse)
35% of the time: advised families on the information needed for a school individualized education plan and processed additional school forms	**45% of the time:** advised patients on home management	**45% of the time:** prevented unnecessary office visits	
30% of the time: discussed insurance options with families	**30% of the time:** helped patients obtain additional services in school	**30% of the time:** prevented additional missed school days	
20% of the time: secured prior authorizations			

Pause for Reflection

- What are conclusions that Gordon Pediatrics can draw based on the data collected with the Care Coordination Measurement Tool?

- What are the implications for the data as Gordon Pediatrics prepares for value-based care delivery?

- How can the data help to make the case for additional or different allocation of resources?

Case-Based Learning

continued

The Gordon Pediatrics team discusses the data and determines that there is a significant volume of care coordination needs from the patients and families it serves. In addition, many of the requests do not require nursing or social work clinical competence to be able to fulfill the need. Rather, they necessitate knowledge about available community, local, and state resources and information about how to access these resources, connect to medical care and education, and link to resources that help pay for medical and health-related expenses. The nurse and social worker also believe that if they were able to give away some of their nonclinical responsibilities, some of their time would be free to focus on proactive intervention, such as reaching out to families that potentially need more frequent support. They conclude that with value-based care, in which they are taking full financial risk for their patient population, they need to operate as an integrated system and address needs outside of the strictly medical domain. Thirty percent of the 200 care coordination encounters were tasks that did not require clinical competence, and they conclude that if these tasks are reallocated to a nonclinical person, the nurse and social worker could focus on expanding their clinical scopes of work.

Gordon Pediatrics uses the data, in conjunction with a description of the volume of requests and different types of roles that the care team members play, to make a request for additional resources to support a nonclinical care coordinator.

PART 2: Why measure? To inform gaps and measure change

Gordon Pediatrics is now fully on board with the Accountable Care Organization (ACO) contract. Clinic leadership has been able to prove that there is value in having care coordination support on the team, and the resources needed for this role have been budgeted into the ACO contract.

The team is granted permission to hire a nonclinical care coordinator to work 20 hours per week. Gordon Pediatrics decides to offer the position to one of its part-time administrative assistants, Anne, who works at the front desk. From working in the clinic, Anne has some knowledge about the health care system and the needs of the patients and families as well as a general understanding of community and state resources. She will begin to work an additional 20 hours as a care coordinator for the office.

With Anne on board as the care coordinator, Gordon Pediatrics wants to ensure that it is optimizing its team's resources. Since Gordon Pediatrics is now accountable for the overall care and well-being of the children it serves, it wants to begin identifying areas for improvement. From talking with families that frequently visit the practice, Gordon Pediatrics knows they often have difficulty accessing community resources and even knowing what resources are available. Families also indicate difficulty with understanding how to pay for their children's services. Even though Gordon Pediatrics knows this qualitatively, it is still struggling with determining where to start and what to prioritize.

Additionally, Gordon Pediatrics wants to ensure that it is focusing on the families that would benefit the most from additional support. In order to select the patients for care coordination support, Gordon Pediatrics decides to choose a cohort of patients who have visited the emergency room 3 or more times in the past year.

Case–Based Learning

continued

The team decides to collect family experience data using the Pediatric Integrated Care Survey (PICS), along with emergency and inpatient service utilization data.

The survey is sent to all families whose children have had 3 or more emergency room visits in the past year. The practice is hoping to identify gaps in the system that can be closed to reduce overall use of emergency services.

Below are data received from the families.

In the past 12 months, how often has someone on your child's care team explained to you who was responsible for different parts of your child's care? (Check ONE box)
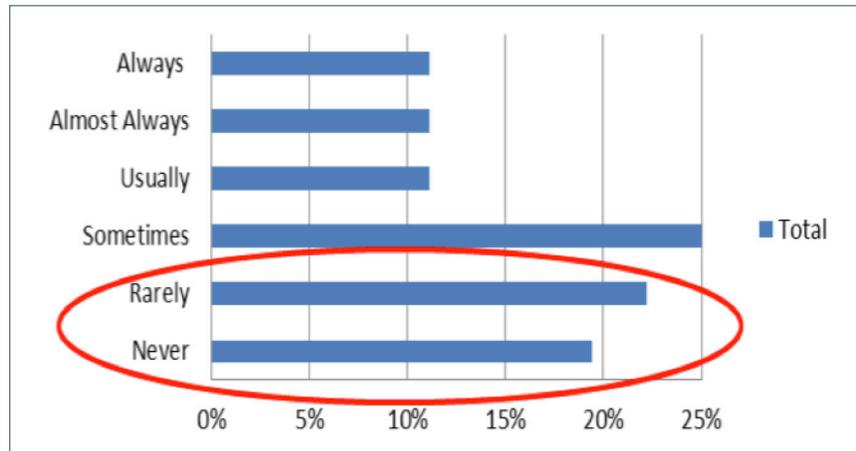
In the past 12 months, how often did you feel that someone on child's care team gave you enough information about state or community organizations, such as Early Intervention, Head Start, Family to Family Support, Social Security Disability Insurance (SSD)
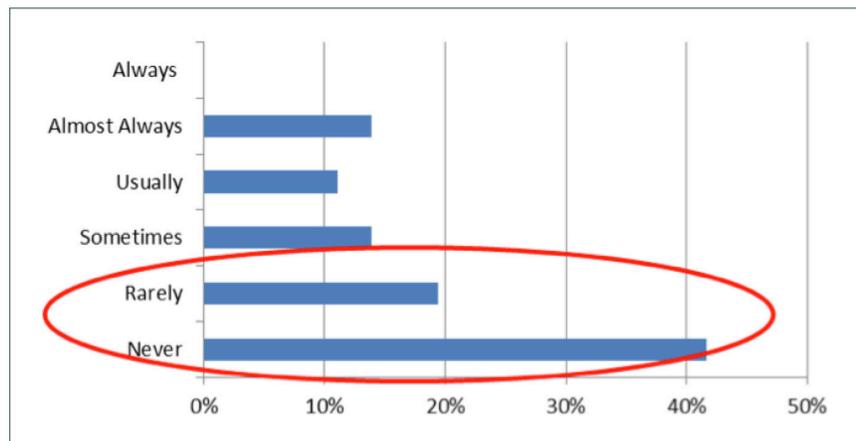
Pause for Reflection

- **What do the family experience data tell Gordon Pediatrics?**
- **How can the data be used to drive changes?**

Case-Based Learning

Inpatient/Emergency Service Utilization Data

Through this initiative, Gordon Pediatrics discovers that patients with complex care needs are more likely to utilize emergency and inpatient services. The survey results also show that families often feel confused about who among the care team is responsible for different elements of their children's care. Additionally, the data identify a gap in the ability of families to connect to community, local, and state resources and that families do not believe they were asked about how making care decisions impacts them.

These 2 measures linked together help Gordon Pediatrics to understand that there is room for improvement in shifting patients from using emergency or inpatient services to care and coordination in the ambulatory setting.

The team works with Anne to craft her role, ensuring that she is focused on the needs of families. In an email and letter sent to all Gordon Pediatrics families, Anne's new role is introduced as a resource to families, along with Anne's contact information. Additionally, whenever a pediatrician or nurse believes that a family would benefit from some help in a nonmedical area, the family is referred to Anne who helps them navigate the system and ensures referral loop closure.

The team implements a short huddle at the beginning of each day to review patient visits from the previous day. The team also launches a registry to identify all children with complex social or medical care needs. Anne participates in the daily huddles and takes responsibility for completing grids for families that list action items resulting from appointments. Action grids include a list of tasks and individual accountability for completing tasks. She sends a completed action grid to each family after its appointment and also follows up with each family to ensure it understands next steps.

Measure

To measure the impact of her efforts, Anne collects data 3 days every month on care coordination activities and outcomes.

Pause for Reflection

What are types of process, outcome, and balancing measures that the team could collect?

Case-Based Learning

continued

The team collects the following measures of process, outcome, and balancing:

Measure Type	Measure
Process	**What:** How often the action grid was shared with families **How:** The number of families that received the action grid/the total number of families seen in the clinic
Outcome	**What:** Emergency department utilization **How:** Emergency department visits were counted for all patients included in the cohort
Balancing	**What:** Provider experience with the action grid **How:** Providers were asked rating questions to assess their experience with implementation of the action grid

Table 3
Process, Outcome, and Balancing Measures

Since Anne was able to take over many nonclinical tasks, the nurse was able to spend more time proactively reaching out to families about medications and clinical care needs in between visits. If a patient had an emergency department visit, the nurse would call the family to assess the reason for the visit, review the care plan, and link the family to the medical home team for follow-up care. The family was able to more readily access the nurse and, therefore, began calling the nurse first with clinical questions rather than going straight to the emergency room.

PART 3: Why measure? To create value stream for social determinants of health support

How might Gordon Pediatrics use this value-capture methodology to address the additional care coordination needs of children, youth, and families with significant social determinant of health (SDoH) risks, such as food insecurity, housing insecurity, poverty, social isolation, and parental co-existing risk factors? This effort allowed the practice to proactively identify those SDoH risk factors that put patients at risk for unnecessary emergency department visits. Potential interventions include office-based encounters or referrals for home visit or payer-based care management intervention. In providing care for vulnerable, high-risk SDoH populations, it is essential to include the value of nonmedical care coordination.

In administering the PICS, Gordon Pediatrics also discovers that families feel disconnected to social services and that, often, this disconnect leads to bad outcomes and higher medical and utilization costs. In order to address this, Gordon Pediatrics determines that it needs to focus resources on addressing social determinants of health.

Gordon Pediatrics decides that it will begin deploying a social determinants of health screener, and if families express a need for support, they will be referred to the social worker. The team hopes that by using a systematic screener, it will be able to capture more families who need these services. The social worker has the ability to spend more time on clinical social work issues and shares some of the administrative tasks with the new care coordinator. Both the care coordinator and social worker continue to use the Care Coordination Measurement Tool.

Note for the facilitator: In module 3 of the Pediatric Care Coordination Curriculum, there are examples of screeners on social determinants of health.

Case-Based Learning
continued

CASE STUDY #2 Title V Program

Connect is a Title V-funded program that sits in the U.S. Department of Health and Human Services.

It helps parents of children with chronic or complex conditions locate appropriate services in local, regional, and state communities, but it does not target diagnoses-specific children. Connect acts as a referral program, which is advertised to pediatric and subspecialty programs. Using a coordinator model, Connect coordinators are each assigned a caseload of families, with whom they initiate partnerships. The coordinators also work together as a team, reviewing their cases in weekly and monthly huddles to draw on the expertise of the group.

Tom, the director of Connect, has found it difficult to quantify Connect's value when asked about its outcomes. The Connect coordinators act as liaisons between families and community service groups, insurance agencies, educational programs, and other state-run initiatives. However, when pressed for quantitative data, Tom has a difficult time showing that this model has improved outcomes and experience or lowered cost. He only has rich qualitative data obtained from family testimonials about how instrumental Connect was when their children were diagnosed.

Pause for Reflection

How could Connect coordinators create a value stream for their work?
Are there processes, tools, or measures that could be used?

Connect coordinators decide to modify the Care Coordination Measurement Tool and collect data for 1 month. Below are sample data.

Table 4
Data Collected with Care Coordination Measurement Tool

Activities	Outcomes Occurred	Outcomes Prevented
20% of the time: introduced supplementary insurance options to families	**15% of the time:** a family was financially able to access a service that supported care for its child at home	**15% of the time:** prevented a gap in service due to a family's inability to afford the cost
25% of the time: communicated with a community agency, educational facility, or school via telephone or email	**20% of the time:** a family found an educational program that was suitable for its child's needs	**20% of the time:** prevented a gap in time so that a child was able to attend school or an educational program
40% of the time: connected families and family support groups	**35% of the time:** a family was connected to a peer support network	
60% of the time: connected families and community services		

Case–Based Learning

continued

Collecting this information enables Tom and his team to link their activities to 3 essential domains of high-value outcomes: quality, cost, and experience. For example, Connect educates families about benefits coverage, therefore, decreasing the likelihood that there will be gaps in their children's medications. These data impact patient safety and health outcomes.

Similarly, by providing guidance and warm handoffs from families to educational programs, Connect is able to improve outcomes and experience for patients and families.

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Pediatric Care Coordination Curriculum: Module 3

SOCIAL DETERMINANTS OF HEALTH

1

Educational Purposes Only –
No Medical Advice

The Pediatric Care Coordination Curriculum is offered for educational purposes only and is not meant as a substitute for independent medical judgment or the advice of a qualified physician or health care professional. Users who choose to use information or recommendations made available by the Pediatric Care Coordination Curriculum do so at their own risk and should not rely on that information as professional medical advice or use it to replace any relationship with their physicians or other qualified health care professionals.

2

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3

Learning Goals

1. Understand **what** social determinants of health and health disparities are.
2. Understand **how** social conditions influence health.
3. Recognize **5 core health-related social needs** for screening and referral.
4. Understand the importance of **bias** and **health equity**.
5. Recognize some **innovations** aimed at addressing social determinants of health.

4

Contents:
5 Micro-Chapters

1. ***What*** Are Social Determinants of Health and Health Disparities?
2. Let's Talk About ***Bias*** and ***Health Equity***
3. ***How*** Do Social Conditions Influence Health?
4. ***Health-Related Social Needs***: Screening and Referral
5. ***Innovations*** for Social Determinants of Health

5

Micro-Chapter 1

WHAT ARE SOCIAL DETERMINANTS OF HEALTH AND HEALTH DISPARITIES?

6

What Are *Social Determinants of Health*?

Social determinants of health are the ***conditions*** in which people are *born, live, learn, work, play, and age.*

7

- Think of these ***conditions*** as being layered like an onion.
- This framework is called the ***social-ecological model***.

8

Individual conditions include:

- Income
- Education
- Employment
- Housing
- Food
- Transportation
- Health care

9

Interpersonal conditions include

- Isolation due to unsupportive relationships
- Exposure to negative situations
  - Domestic violence
  - Abuse
  - Parental mental illness
  - Incarceration
  - Substance abuse/addiction
  - Neglect
    - In early life, these are called **adverse childhood experiences (ACEs)**.
- Discrimination/oppression
  - Racism
  - Sexism
  - Classism
  - LGBTQ+
  - (Dis)ability
  - Religion

10

Community conditions include

- Neighborhood safety/violence
- Education opportunities (eg, early childhood programs, higher education)
- Employment opportunities and conditions
- Access to amenities (eg, food deserts, green spaces)
- Social capital (eg, trust, sense of identity and belonging, networking opportunities)

11

Structural conditions include

- Government (eg, legislation, public policies)
- Economy (eg, income inequality)
- Environment (eg, pollution)
- Discrimination (eg, gender pay gap, mass incarceration, gay marriage)
- Culture (eg, media, advertising)
- History (eg, historical oppression, structural racism)

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Social conditions
- ***Cross different layers*** (eg, discrimination as structural and interpersonal).
- ***Cluster together*** (eg, unemployment, eviction, crime, domestic violence).
- ***Flow in different directions*** (eg, eviction leading to unemployment or unemployment leading to eviction; unemployment leading to poor health or poor health leading to unemployment).
- ***Interact*** with genetics and behavior to determine health.

13

- Differences in social conditions can ***explain big differences in health***.
  - o Between *individuals*
  - o Between *groups of individuals (populations)*
- These differences are reflected in ***health disparities***.

14

What Are *Health Disparities*?

Health disparities refer to ***differences in health between population groups***.

- Disparities occur across many dimensions
  - o Race/ethnicity
  - o Socioeconomic status
  - o Location
  - o Gender expression
  - o Disability status
  - o Sexual orientation
- *Health care disparities* refer to differences in *health care* between different groups.

15

Why Do Health Disparities *Matter*?

- Disparities create ***unfair advantages and disadvantages***
  - o By systematically structuring opportunity and assigning value on the social interpretation of how one looks (eg, race or gender).
- Disparities ***sap the strength of the whole society through the waste of human resources***.
- Disparities result in ***unnecessary costs***.
  - o *Addressing health disparities is increasingly important as the population becomes more diverse.*

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Slide 17

Census tract 8.01: *average life expectancy of 94 years*

26 min 4.8 miles

Census tract 88.04: *average life expectancy of 67 years*

- *For example*, a 2018 study found that life expectancy varies by 27 years across census tracts in Washington, D.C.
- Try to explain these differences using a *social-ecological framework* and in terms of *health disparities.*

17

Slide 18

What Is *Health Equity*?

Health equity **is**

- The *opportunity* for every person to attain their *full health potential without disadvantage* because of social position or circumstance.
- A *framework* for addressing *health disparities*.

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Slide 19

In Summary

What Are Social Determinants of Health and Health Disparities?

- *Social determinants of health* are the *conditions* in which people are born, live, learn, work, play, and age.
  - Can be understood using a *social-ecological framework*
  - Can *explain big differences in health* between individuals and between population groups
- *Health disparities* refer to *differences* in health between population groups.
  - Occur across *many dimensions* (eg, race, gender, income)
  - *Health equity* means *fair opportunities to be healthier* and is a *framework for addressing health disparities.*

19

Slide 20

Micro-Chapter 2

LET'S TALK ABOUT BIAS AND HEALTH EQUITY

20

Why talk about *bias*? To answer this question, let's reconsider the **brain**...

21

Recall that the **brain** is constantly making **predictions**.

For example, when the brain predicts that the body needs energy, it is called *stress.*

22

- The brain also tries to predict who "**us**" is versus who "**not us**" is.
- These predictions happen at every moment, mostly outside of awareness.

23

- People react *differently* to others based on the brain's **us/them** predictions.
- This tendency to react differently is called **BIAS**.
  - o Being consciously aware is called *explicit bias.*
  - o **IMPLICIT bias** is **unconscious**, *automatic,* and *reflexive.*

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Slide 25

"Wealth"

"Whiteness"

"Gender conformity"

Privilege

Historical oppression

"Gender Nonconformity"

"Poverty"

"Blackness"

- It is important to remember that bias is *universal.*
  - *For example,* in every known society, people give preferential treatment to family members.
- However, bias often exhibits a ***directionality*** and an ***intersectionality*** based on ***privilege*** and ***historical oppression***, which is reflected in ***health disparities.***

25

Slide 26

- *For example*, research indicates that *white patients* receive more and better pain treatment than *black patients.*
- Is there racial bias in pain perception?
  - In one 2016 study, 40% of first-year medical students endorsed the false belief that *black skin is thicker than white skin.*
  - Students who held false beliefs often rated pain as being lower in black patients than white patients and made less appropriate recommendations about how they should be treated.

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Slide 27

If *everyone* has **bias** that is *automatic* and *reflexive*, what should be done?

27

Slide 28

- The first steps to ***addressing bias*** are to ***recognize it*** and ***increase personal awareness*** through *humility* and *open-mindedness.*
- A helpful pneumonic is CARE.
  - Conscious empathy
  - Active listening
  - Responsible reaction
  - Environmental awareness

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Slide 29

- Another step is to practice seeing *common humanity* (ie, extend the circle of "us").
- Another step is to take a *strengths-based approach* (ie, identify assets).
- Other steps include
  - Expanding social networks.
  - Practicing continuous learning and reappraisal of biases.
  - Engaging in difficult discussions.

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Slide 30

Our common and ultimate goal is to promote *HEALTH EQUITY*.

Health equity is the opportunity for every person to attain their full health potential without disadvantage because of social position or circumstance.

30

Slide 31

Health Outcomes

Quality of Care

Cost

- *Health equity* is a *guiding framework* for *achieving the Triple Aim* of
  - *Population health.*
  - *Experience of care.*
  - *Per capita cost.*
- In other words... "No Equity, No Triple Aim."

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Slide 32

In Summary

Let's Talk About Bias and Health Equity

- The brain is constantly making predictions about who "*us*" is versus "*not us*."
- Like breathing, this *implicit bias* is automatic, reflexive, universal, and largely outside of awareness.
- Bias often exhibits *directionality* and *intersectionality* of privilege, which is reflected in *health disparities*.
- The first step to addressing *bias* is to *increase personal awareness* though *humility, respect,* and *open-mindedness.*
- The common goal is *health equity*, which is the attainment of every person's full health potential, regardless of social position or circumstance.
  - *"No Equity, No Triple Aim"*

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Micro-Chapter 3

HOW DO SOCIAL CONDITIONS INFLUENCE HEALTH?

33

To understand how social conditions influence health, start by considering the *brain*...

34

The *brain* constantly *predicts* the body's *energy needs* from one moment to the next.

35

- When the brain perceives a threat, it predicts a need for energy (to *fight or flee)*.
- This prediction is called *stress*.

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Slide 37

When the brain predicts a need for energy, it sends signals to the body (**stress hormones**) *that increase*

- Blood sugar
- Blood pressure
- Heart rate
- Muscle tension

...and *decrease*

- Immune function.
- Feelings of calm and contentment.
- Impulse control/planning.
- Neurogenesis (ie, brain growth and development).

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Slide 38

- ***Brief, mild stress is good for health.***
  - o Exercise, for example
- ***But chronic stress is bad for health.***
  - o Diabetes
    - – *Chronically elevated blood sugar*
  - o Hypertension
    - – *Chronically elevated blood pressure*
  - o Headache/back pain
    - – *Chronically elevated muscle tension*
  - o Cancer
    - – *Chronically depressed immune function*
  - o Anxiety and depression
    - – *Chronically not feeling calm and contented*
  - o Addiction
    - – *Chronically depressed impulse control*
  - o Learning/school difficulties
    - – *Chronically disrupted brain development*

Health | Stress

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Slide 39

Many social conditions are characterized by chronic **threat**, **uncertainty**, and **lack of control.**

- *"Will I lose my home?"*
- *"Do I have enough food?"*
- *"Am I safe?"*
- *"Will I be hurt?"*
- *"Am I being treated fairly?"*
- *"Will anyone help?"*
- *"Am I all alone?"*

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Slide 40

- ***Supportive relationships*** can buffer chronic stress, rendering it tolerable.
- But an ***absence of protective relationships*** characterizes **toxic stress**.
  - o For example, ***adverse childhood experiences (ACEs)****, such as*
    - – *Abuse*
    - – *Neglect*
    - – *Domestic violence*
    - – *Incarcerated family member*
   - – *Substance abuse at home*
    - – *Parental mental illness*

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- *For example*, research shows that *adverse childhood experiences (ACEs)* increase the risk of numerous health problems, including heart disease and cancer.
- Try to explain this relationship using this ACE Pyramid framework from the Centers for Disease Control and Prevention.

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In Summary

How Do Social Conditions Influence Health?

- *Stress* can be understood as the brain's predictions about the body's energy needs.
- Although some stress is good, *chronic activation of the stress response* is bad for health.
  o For children, in particular, stress *disrupts brain development*.
- Supportive relationships can buffer chronic stress, but a*dverse childhood experiences*, such as abuse and neglect, characterize *toxic stress* that increases the risk of numerous health problems.

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Micro-Chapter 4

HEALTH-RELATED SOCIAL NEEDS: SCREENING AND REFERRAL

43

Housing instability

Food insecurity

Interpersonal safety needs

Utility help needs

Transportation problems

The Centers for Medicare and Medicaid Services has identified *5 core health-related social needs* for screening and referral.

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Slide 45

Why these 5?

- High-quality evidence links these needs to poor health, increased health care utilization, and cost.
- These needs can be met by community service providers.
- These needs are not universally addressed by physicians and nonphysician clinicians (yet).

Food insecurity

Housing instability

Interpersonal Safety needs

Utility help needs

Transportation problems

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Slide 46

Core Health-Related Social Need:
Housing Instability

Examples
- Homelessness
- Inability to pay mortgage/rent
- Frequent unintended moves
- Eviction

Sample screening question
What is your living situation today?
- ☐ I have a steady place to live.
- ☑ I have a place to live today, but I am worried about losing it in the future.
- ☑ I do not have a steady place to live. (I am temporarily staying with others, in a hotel, in a shelter, living outside on the street, on a beach, in a car, abandoned building, bus or train station, or in a park.)

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Slide 47

Core Health-Related Social Need:
Food Insecurity

Example
Limited or uncertain access to adequate food

Sample screening question
Within the past 12 months, you worried that your food would run out before you got money to buy more.
- ☑ Often true
- ☑ Sometimes true
- ☐ Never true

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Slide 48

Core Health-Related Social Need:
Utility Help Needs

Examples
- Difficulty paying utility bills
- Shut-off notices
- Disconnected phone

Sample screening question
In the past 12 months, has the electric, gas, oil, or water company threatened to shut off services in your home?
- ☑ Yes
- ☐ No
- ☑ Already shut off

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Slide 49

Core Health-Related Social Need:
Transportation Problems

Example
Difficulty accessing or affording medical or public transportation

Sample screening question
In the past 12 months, has lack of reliable transportation kept you from medical appointments, meetings, work or from getting things needed for daily living?
☑ Yes
☐ No

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Slide 50

Core Health-Related Social Need:
Interpersonal Safety Needs

Examples
- Intimate partner violence
- Abuse
- Adverse childhood experiences

Sample screening question
Because violence and abuse happens to a lot of people and affects their health we are asking the following question. How often does anyone, including family and friends, threaten you with harm?
☐ Never
☐ Rarely
☑ Sometimes
☑ Fairly often
☑ Frequently

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Slide 51

To facilitate *SCREENING* for health-related social needs, the *American Academy of Pediatrics* created the **STAR Center** (*Screening, Technical Assistance, and Resource Center*), which contains an array of online resources.

American Academy of Pediatrics
STAR CENTER — Screening Technical Assistance & Resource Center

★ CHILD DEVELOPMENT ★ MATERNAL DEPRESSION ★ SOCIAL DETERMINANTS OF HEALTH ★
Screening Recomendations | Screening Tools | Related AAP Initiatives

Questions? We Can Help. | FAQs | For Practices

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Slide 52

Community Resource Referral Platforms: A Guide for Health Care Organizations

Yuri Cartier, MPH
Caroline Fichtenberg, PhD
Laura Gottlieb, MD, MPH
April 16, 2019

2-1-1
HOW WE HELP | ABOUT
HELP STARTS HERE
2-1-1 is a nation-wide service connecting over 14 million people to services every year. To get help, you can search for local resources through your local 2-1-1 provider, or simply call 2-1-1
FIND YOUR LOCAL 2-1-1 | ZIP CODE | ELK GROVE VILLAGE | SEARCH
Not sure where to turn? We are here for you.

- There is also a growing number of *online REFERRAL tools* for health-related social needs (see resource guide).
- *211 provides free help finding social service resources in all 50 states.*

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In Summary

Health-Related Social Needs
- There are *5 core health-related social needs* that Medicare and Medicaid have identified as targets for screening and referral by physicians and nonphysician clinicians.
  - o *Housing instability*
  - o *Food insecurity*
  - o *Utility help needs*
  - o *Transportation problems*
  - o *Interpersonal safety needs*
- To facilitate *screening and referral*, there is a growing number of *online resources* available.

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Micro-Chapter 5

INNOVATIONS FOR SOCIAL DETERMINANTS OF HEALTH

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Let's finally *zoom out* and consider some big-picture initiatives and strategies.

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Innovation #1: The Affordable Care Act (ACA) - 2010

- Expanded health insurance coverage to 20 million additional people.
- Helped narrow longstanding *health care disparities* in insurance coverage.
- Included provisions focused on addressing disparities.
  - o For example, the Department of Health and Human Services (HHS) Disparities Action Plan
  - o Goal: "A nation free of disparities in health and health care."

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Innovation #2: The Screening in Practices Initiative (*American Academy of Pediatrics*)

STAR CENTER | Screening Technical Assistance & Resource Center

★ CHILD DEVELOPMENT ★ MATERNAL DEPRESSION ★ SOCIAL DETERMINANTS OF HEALTH ★

- *Goal*: "*Improve the health, wellness, and development of children through practice and system-based interventions to increase rates of early childhood screening, referral, and follow-up for developmental milestones, maternal depression, and social determinants of health.*"
- Innovative features
  - o **STAR Center** – screening, technical assistance, and resources
  - o **Screening Time** – scenario-based online training modules for care teams
  - o **The Screen Scene** – a podcast with tips for implementing screening

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A Screenshot of Screening Time

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Innovation #3: SIREN – Social Interventions Research & Evaluation Network (*University of California, San Francisco*)

Contains an extensive evidence library, screening tools, implementation resources, and archived webinars.

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Innovation #4: The Accountable Health Communities Model (*Centers for Medicare & Medicaid Services*)

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Innovation #5: The Maternal, Infant, and Early Childhood Home Visiting Program (*Health Resources & Services Administration*)

Maternal, Infant, and Early Childhood Home Visiting Program

The Maternal, Infant, and Early Childhood Home Visiting Program (MIECHV) gives at-risk pregnant women and families necessary resources and skills to raise children who are physically, socially, and emotionally healthy and ready to learn.

In FY 2017
The MIECHV Program served over **156,000** parents and children and provided more than **942,000** home visits.

The MIECHV Program funds states, territories, and tribal entities to develop and implement evidence-based, voluntary programs that best meet the needs of their communities.

BENCHMARKS

Improved maternal and newborn health

Reduced child injuries, abuse, and neglect

Improved school readiness and achievement

Reduced crime or domestic violence

Improved family economic self-sufficiency

Improved coordination and referrals for community resources

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Innovation #6: Community Health Workers (CHWs) and Patient Navigators (PNs)

CHWs and PNs are frontline public health and health care workers who

- *Support care coordination.*
- *Facilitate communication* between patients and care team members.
- Help patients *address health-related social needs.*
- Enhance *social support.*
- *Advocate* for patient and family needs.

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Innovation #7: Medical-Legal Partnerships

National Center for Medical ◐ Legal Partnership

We're helping to build an integrated health care system that better addresses health-harming social needs by leveraging legal services and expertise to advance individual and population health.

"Medical-legal partnerships integrate the unique expertise of lawyers into health care settings to help clinicians, case managers, and social workers address structural problems at the root of so many health inequities."

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In Summary

Innovations for Social Determinants of Health

- **The Affordable Care Act (ACA)**
  - Expanded coverage helped narrow longstanding health care *disparities.*
- **Screening In Practices Initiative**
  - **STAR Center** – screening, technical assistance, and resources
  - **Screening Time** – video-based training modules
- **SIREN** – **Social Interventions & Research Evaluation Network**
  - Evidence library and informational resources.
- **Accountable Health Communities Model**
  - Systematic screening and referral for health-related social needs.
- **Maternal, Infant, and Early Childhood Home Visiting Program**
  - Aimed at reducing adverse childhood experiences.
- **Community health workers and patient navigators**
  - *Frontline public health and health care workers* who support care coordination, facilitate communication, help address health-related social needs, enhance social support, and advocate for patients and families.
- **Medical-legal partnerships**
  - Integrate the unique expertise of lawyers into health care settings to help address structural problems at the root of health inequities.

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THE END
Thanks for attending.

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MODULE 5

Pediatric Care Coordination Curriculum

Using Technology to Improve Care Planning and Coordination

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**Dr. Fleegler is a consultant to Veta Health.
Otherwise, the authors have no conflicts
of interest to disclose.*

Using Technology to Improve Care Planning and Coordination

> **Module 5—Objectives**
>
> After this session, learners will be able to:
>
> · Assess current practice of care coordination with and without technology.
> · Describe ways to use technology to connect key players in care coordination.
> · Provide an overview of system requirements.
> · Create an action plan for integration of technology platforms.

Note to the facilitator:

This module includes a didactic portion, a set of tools and resources, case studies, worksheets, and suggested literature.

Please be aware that it is important to include local-, state-, and region-specific content, as relevant, if this module is being implemented.

A **L** found in the module indicates places where the authors specifically call out the need for local content, but facilitators should feel free to include local content wherever they see fit. Local content includes, but is not limited to, the following:

· Cultural aspects of the community (including assets, vulnerabilities, and language)
· Sociodemographic factors
· Geography
· Local, state, and/or regional resources

Optimal Facilitation Guidance

To achieve the most efficient and effective outcomes from the learning sessions, it will be essential to assure vital and equitable input from all stakeholders, especially from patients and families. Please see the section in the Introduction Module (page 4) entitled Tips for Facilitator: Ways to Keep the Workshop on Track.

There are 2 tables included below. The first is a high-level agenda of the module. The second is the facilitator guide that includes a breakdown of slide content and talking points. The facilitator should use the guide as a resource to tailor training content.

The curriculum is intended to be tailored to fit the training needs, and the content can be modified for different audiences. Therefore, facilitators may decide to pick and/or choose content from this module and incorporate it into the training. However, a suggested agenda for implementing this module as a stand-alone is included.

Module Overview

Table 1

Agenda Item	Time	Materials Required	Instruction/Notes
Pre-session readings	N/A	"How Care Coordination Tech Helped One Health Network Address Social Determinants" "Use of Technology for Care Coordination Initiatives for Patients With Mental Health Issues: A Systematic Literature Review" "Ten Key Considerations for the Successful Implementation and Adoption of Large-Scale Health Information Technology"	Whether to use these readings as an introduction to this module's topic is optional, but if they are going to be used, they should be sent to the participants prior to the session.
Introduction	10 min	Slides 1-5	Lead an introduction activity, review the module objectives, and present the case study.
Didactic	20 min	Slides 6-18	Present the slide deck using the content in the didactic portion of this guide. Facilitators should look at the prompts in the notes to pause and allow for participant discussions.
Creation of action plan	40 min	Slides 19-30 Whiteboard or flip chart for report back	Give participants an opportunity to have small group discussions. Learners can begin outlining initial steps (steps 1-3) and/or answering questions raised in slide 27. Small groups should scribe answers on a flip chart. After the breakout session, small groups can report back to the larger group to initiate further discussion, obtain feedback, etc. Flipcharts can be displayed for a "gallery walk" at the end of the module.
Didactic	10 min	Slides 31-37	Participants will return to the previously presented case study. The facilitator will review how concepts learned from today's module were applied to adopting new technology to improve coordinated care.
Conclusion	10 min	Slide 38	The final discussion and wrap-up, followed by the gallery walk of small group discussion flip-chart sheets.

Introduction

Note from the authors

The content included in this module provides an overview of both the benefits and challenges associated with the use of technology to improve health care coordination. Use of technology has significantly impacted the health care landscape in recent years. Incorporating various technologies into health care, particularly primary care, increases the potential for overcoming barriers currently experienced by an overburdened health care system. The goal is for learners to critically assess their own care coordination practices, identify weaknesses that may be addressed with increased access to technology, and create action plans that focus on incorporating technological innovation into routine care. Learners may be clinicians, administrators, managers, and other direct service providers of all disciplines from diverse settings. These stakeholders may include clinic staff, Title V personnel, representatives of community-based organizations who play a role in care integration (eg, education, social service supports), and state agency staff responsible for implementing and/or regulating technology to support care coordination.

We present both care team member and patient perspectives and highlight features of available systems, while having learners brainstorm specific challenges to optimizing technology use. Learners will work in both small and large groups to share ideas and strategies. A key aspect of this module is to have each learner create an action plan with concrete steps to begin creating change(s). What are the gaps between current and ideal approaches to coordinating care for patients? How can technology potentially bridge this gap? How can care team members learn more about available systems and test whether they are feasible in their contexts? The facilitator's role is not to be a content expert in the multitude of specific products that are currently available in the marketplace but rather to guide learners in considering how technology can be used to create efficient work processes and planning a thoughtful approach to adopting technology that can be successfully integrated into their sites' long-term mission.

Facilitator Guide–Slide Deck

SLIDE 1 » Title Slide

Using Technology to Improve
Care Planning & Coordination

Areej Hassan, MD, MPH
Eric Fleegler, MD, MPH

SLIDE 2 » Educational Purpose Only–No Medical Advice

Educational Purposes Only –
No Medical Advice

The Pediatric Care Coordination Curriculum is offered for educational purposes only and is not meant as a substitute for independent medical judgment or the advice of a qualified physician or health care professional. Users who choose to use information or recommendations made available by the Pediatric Care Coordination Curriculum do so at their own risk and should not rely on that information as professional medical advice or use it to replace any relationship with their physicians or other qualified health care professionals.

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SLIDE 3 » Faculty Disclosures

Faculty Disclosure Information
- *Dr. Hassan has no disclosures to report.*
- *Dr. Fleegler is a consultant to Veta Health.*

Facilitator Guide–Slide Deck

continued

SLIDE 4 » Learning Goals

Learning Goals

- Assess current practice of care coordination with and without technology.
- Discuss ways to use technology to connect key players in care coordination.
  - Barriers
- Recognize system requirements for care coordination activities.
  - Understand types of coordination.
- Describe an action plan for integration of technology platforms.

Introduce the learning goals to the audience.

SLIDE 5 » Current State: Case Study

Current State: Case Study

- A 14-year-old male, who is struggling in school with failing grades, was transferred to an adolescent clinic in the past year without access to prior medical records.
- His parent requests a refill of ADHD medications, which he has not taken in 6 months.
- The results of the paper "Conners" ADHD questionnaire indicate high levels of inattention and hyperactivity.

Start the session with the case study (after the didactic, go back to the case study to apply what was learned).

Think about particular medical problems that are relevant to the audience.

The case does not have to be extremely complicated; technology can be useful across the continuum.

SLIDE 6 » Current Coordination

Current Coordination

- Write 1-month prescriptions for medications.
- Provide paper questionnaires for parents and teachers to complete.

Case details

Facilitator Guide–Slide Deck

continued

SLIDE 7 » Current Coordination

> ### Current Coordination
>
> - Write 1-month prescriptions for medications.
>   - Problem: Written prescriptions are limited to 1 month, cannot be sent electronically to a pharmacy, and are burdensome on the family, patient, and prescriber.
>   - Problem: Physicians do not receive alerts about unfilled prescriptions.
> - Provide paper questionnaires for parents and teachers to complete.
>   - Problem: These result in poor response rates, especially from teachers.
>   - Problem: It is difficult to track response to therapy.
>

This slide illustrates issues with the current practice for prescription ordering.

A note for the audience: The universal problem is that many patients do not have their prescriptions filled and, even if they do, a high percentage do not take medications correctly.

It is difficult to gather this information using paper questionnaires because, oftentimes, surveys are not returned. When they are returned, however, it can be difficult to track responses because readily seeing or visualizing how data change over time is challenging.

Ask the learners to weigh in on their experiences with this.

SLIDE 8 » Current Coordination: Tech-Enhanced

> ### Current Coordination: Tech-Enhanced
>
> - Electronic medical records (EMRs) enable primary care physicians to enter notes (eg, urgent visit) to be seen by others in the clinic.
> - Patient portals allow patients and parents to send messages to and receive messages from their physicians.
>

This slide introduces 2 technologies used to coordinate care: electronic medical records used by care team members and patient portals used by families.

SLIDE 9 » Current Coordination: Tech-Enhanced

> ### Current Coordination: Tech-Enhanced
>
> - Electronic medical records (EMRs) enable primary care physicians to enter notes (eg, urgent visit) to be seen by others in the clinic.
>   - Problem: This is only helpful if a patient receives other care (eg, emergency, mental health) within the same system; EMRs do not connect with other health care system EMRs.
> - Patient portals allow patients and parents to send messages to and receive messages from their physicians.
>   - Problem: Minimal penetration and usage of this technology because many physicians, patients, and families find it burdensome, physicians have additional responsibilities, and not all patients and families have access.
>   - Problem: Physicians find it challenging when parents have access to sensitive information about their adolescents.
>

This slide is intended to demonstrate that technology alone is insufficient for coordinating care. Even if more advanced technology becomes available, it is valuable to note that there will likely be issues that come with it.

The facilitator should feel free to add examples.

Facilitator Guide–Slide Deck

continued

SLIDE 10 » Other Complex Case Coordination Challenges

Other Complex Care Coordination Challenges

- Subspecialist communication
  - Who is managing a patient's specific needs, especially if care is provided across institutions?
- Adjunct therapy
  - How is information being shared with nonphysician clinicians, such as physical therapists, occupational therapists, nutritionists, or acupuncturists?
- Insurance-assigned care coordination
  - This is good, but insurance providers are not part of the hospital ecosystem, which can make assigning care coordination challenging.
- Non-health care partners
  - Community service partners, such as Big Brothers Big Sisters, DCF, and schools, cannot share information.

This slide is an attempt to outline major problems that can be addressed by enhanced technology

As the facilitator, it may be useful to give specific examples or to ask the audience to share examples.

SLIDE 11 » Learning Goals

Learning Goals

- Assess current practice of care coordination with and without technology.
- Discuss ways to use technology to connect key players in care coordination.
  - Barriers
- Recognize system requirements for care coordination activities.
  - Understand types of coordination.
- Describe an action plan for integration of technology platforms.

Now that the stage has been set for the issues that exist, it is time to examine how technology can be used to close gaps.

SLIDE 12 » Technology to Connect Key Players

Technology to Connect Key Players in Care Coordination

Minimum technology requirements
- Confidential
- HIPAA compliant (including the ability to communicate with physicians, nonphysician clinicians, agencies, and respondents)
- Secure
- Interoperability with current IT systems

This slide illustrates basic needs that accompany the use of technology with patients. The facilitator could ask learners to brainstorm what these might be before showing the slide.

Facilitator Guide–Slide Deck
continued

Technology to Connect Key Players in Care Coordination

Goals
- Facilitate communication between providers within an institution (notifications within EMR) and across institutions (link across EMRs).
- Develop efficient messaging and response methods for the patient portal.
  - Needs to facilitate communication between patient/ family and care team members.
    - Standardized, set intervals
    - Open-ended communication
    - Symptom monitoring/response to therapy in chronic disease

SLIDE 13 » Technology to Connect Key Players

Now it is time to address how technology can help users accomplish goals and reduce issues that were outlined earlier in the session.

This slide shares a few goals around effective and efficient communication.

Technology to Connect Key Players in Care Coordination

Goals
- Provides communication to outside respondents, such as teachers, case managers.
  - Active collection of data from respondents
  - Easily viewable by care team members
  - School ability to view plans and coordinate with care team members
  - Data available as requested by other respondents (parents, teachers, etc.)
- Provides communication between pharmacy and provider.
  - Electronic Rx (when appropriate)
  - Information about Rx being filled and picked up

SLIDE 14 » Technology to Connect Key Players

This slide continues with the goals of technology use and additional ways it can support communication.

Technology to Connect Key Players in Care Coordination

- Adjunct therapy (physical therapy, occupational therapy, nutrition, acupuncture)
  - Share information to develop treatment plans.
- Care coordinators
  - Facilitate bidirectional communication about needs and provided services.
- Non-health care partners (community services, Big Brothers Big Sisters, DCF, schools)
  - Compare unidirectional vs. bidirectional.

SLIDE 15 » Technology to Connect Key Players

Slide 15 continues with the goals of technology use. The facilitator might want to ask learners to discuss these goals and talk about the pros and cons of different types of communication, eg, bidirectional communication.

Facilitator Guide–Slide Deck
continued

Barriers to Technology Use

- Work flow efficiency (ease of implementation by the clinicians and administrative support staff)
- Compatibility between systems (important for the clinic, outside sites, and families)
- When possible, limit the number of technology-based systems.
- Need greater value add -- not just messaging systems but requires analytics that process and display data usefully (summary)
- Parents' and others' potential lack of access to new systems, ability to download apps, and to respond to reminders
- Responsibility/liability for information that arrives off-hours
- Caregivers' health literacy and language barriers

SLIDE 16 » Barriers to Technology Use

The facilitator might want to ask the learners to call out barriers before sharing this slide.

Emphasize the importance of acknowledging barriers when new technology is being introduced.

Barriers should not be shared with the sense that they are insurmountable; all barriers can be addressed.

Learning Goals

- Assess current practice of care coordination with and without technology.
- Discuss ways to use technology to connect key players in care coordination.
  ○ Barriers
- Recognize system requirements for care. coordination activities.
  ○ Understand types of coordination.
- Describe an action plan for integration of technology platforms.

SLIDE 17 » Learning Goals

Now it is time to move on to an overview of system requirements.

What should learners be looking for or considering when adopting new technology?


Learning Goals

- Assess current practice of care coordination with and without technology.
- Discuss ways to use technology to connect key players in care coordination.
  ○ Barriers
- Recognize system requirements for care. coordination activities.
  ○ Understand types of coordination.
- Describe an action plan for integration of technology platforms.

SLIDE 18 » System Requirements Checklist

This slide shares suggestions and questions for learners to consider when reviewing new technology.

Specific platforms have purposely been left off this slide, but facilitators should feel free to give examples about their own experiences with various platforms.

This list is in no particular order. Facilitators can encourage learners to identify which points they find to be most relevant.

Facilitator Guide–Slide Deck
continued

SLIDE 19 » Learning Goals

Learning Goals
- Assess current practice of care coordination with and without technology.
- Discuss ways to use technology to connect key players in care coordination.
  - Barriers
- Recognize system requirements for care coordination activities.
  - Understand types of coordination.
- **Describe an action plan for integration of technology platforms.**

Now the session will move into a discussion about how to create an action plan for integrating technology platforms.

SLIDE 20 » Action Plan

ACTION PLAN
1. Conduct an assessment of technology needs.
2. Establish the need for change.
3. Determine the goals and objectives with new technology.
4. Select and plan for a new system.
5. Implement new technology.
6. Evaluate the new system and obtain feedback.

Ten key considerations for the successful implementation and adoption of large-scale health information technology

Cresswell KM, et al. *J Am Med Inform Assoc.* 2013;**20**:e9-e13. doi:10.1136/amiajnl-2013-001684

This is a suggested list for creating an action plan when implementing new technology. The list has been adapted from the paper "Ten Key Considerations for the Successful Implementation and Adoption of Large-Scale Health Information Technology."

It is important for the facilitator to note that this will take time to complete.

The slides will walk learners through each of these steps as a large group before breaking into small group discussions.

SLIDE 21 » Step 1: Assessment

Step 1: Assessment

General assessment: "map" the current processes
- What is the current technology used in coordinated care?
- What gaps exist?
- What is the ideal approach?
- What works best in your institution/office/setting?

General assessment:
Ideal approach – current approach = defined need

This slide outlines 4 questions that should be determined in the assessment phase.

Note to the facilitator: Consider the role of Title V programs and gaps in current technologies.

L

Facilitator Guide–Slide Deck

continued

Step 2: Establish the Need for Change

Identify and characterize the problem that will be addressed by adopting technology to improve coordinated care.
- What is the problem?
- Whom and what does it affect?
- What is the importance of the effects?
- Can technology address this problem?

SLIDE 22 » Step 2: Establish the Need for Change

Continue along the list of questions for the next step.

Note to the facilitator: If all team members are not at the training, consider how to best create structured discussions. If all of the team members are present, they can brainstorm together as a team.

Step 2: Establish the Need for Change

- Who are the (other) stakeholders?
- How can you build consensus that a technology change is necessary?
- What information do you need (to build a supporting argument or obtain buy-in)?
  - Existing proficiencies and perceived deficiencies
  - Current performance
  - Stakeholder preferences
  - Financial resources
  - Barriers
  - Institutional politics

SLIDE 23 » Step 2: Establish the Need for Change

This slide is intended to help facilitators guide discussion around steps for implementing new technology.

Consider other stakeholders, including Title V personnel. **L**

Use these slides to guide small group discussions or even to create a workshop for learners to brainstorm their own processes.

Step 2: Establish the Need for Change

How will you obtain the information?
- Inventory of existing records
- Informal discussion
- Interviews
- Focus groups
- Surveys
- Observation
- Strategic planning sessions

SLIDE 24 » Step 2: Establish the Need for Change

This slide is to help the facilitator guide discussion around steps for implementing new technology.

Use these slides to guide small group discussions or even to create a workshop for learners to brainstorm their own processes.

Facilitator Guide—Slide Deck

continued

SLIDE 25 » Step 3: Goals and Objectives

Step 3: Goals and Objectives

- Goal = broad target
  - *"Our office will improve XXX."*
- Objective: specific measurable outcome
  - *"By adopting new technology, medical providers will be able to*
    - *Communicate directly with patients via ….*
    - *Receive updates on emergency room visits or inpatient hospitalizations.*
    - *Discuss plan with pediatric medical subspecialists or pediatric surgical specialists.*

This slide will help the facilitator guide discussion around steps for implementing new technology.

Use these slides to guide small group discussions or even to create a workshop for learners to brainstorm their own process.

Note to the facilitator: Ask the learners to develop a goal(s) and objective(s).

SLIDE 26 » Step 4: Selecting and Planning for New System

Step 4: Selecting and Planning for New System

- Commit adequate time and resources to consider options.
- Explore setups in other offices that have been successful.
- Network with potential suppliers.
- Determine whether the system meets the checklist of requirements (these may vary from setting to setting).
- Conduct trials of the new system comparing small group use vs all in and limited initial functionality vs multiple changes.
- Consider the costs – financial, research, and the effort to implement the system.

This slide is designed to help the facilitator guide discussion around steps for implementing new technology.

Use these slides to guide small group discussions or even to create a workshop for learners to brainstorm their own processes.

SLIDE 27 » Step 5: Implementation

Step 5: Implementation

- Identify resources.
- Develop a training plan.
- Anticipate barriers.
- Delineate responsibilities (training, operations, etc.).
- Conduct pilot testing.
  - Obtain feedback from all stakeholders.
- Respond quickly to initial problems.

This slide will help the facilitator guide discussion around steps for implementing new technology.

Use these slides to guide small group discussions or even to create a workshop for learners to brainstorm their own processes.

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Facilitator Guide–Slide Deck
continued

SLIDE 28 » Step 6: Evaluation and Feedback

Step 6: Evaluation and Feedback

- To determine if goals and objectives have been met
- To provide information for continuous improvement
- To assess outcomes
  - ○ Clinical (patient outcomes)
  - ○ Health care dollar outcomes
  - ○ Care team member satisfaction, acceptability, etc.
  - ○ Patient satisfaction, acceptability, etc.
- To maintain and increase support

This slide is intended to help the facilitator guide discussion around steps for implementing new technology.

Use these slides to guide small group discussions or even to create a workshop for learners to brainstorm their own processes.

SLIDE 29 » Breakout—Small Groups

Breakout – Small Groups

- Share information about the system currently used by your institution or office to coordinate care.
- Identify problems to be addressed.
- Determine what resources are available.
- Consider what additional resources are needed.

If it has not already been done, this would be a good place to have small breakout groups take concepts and apply them to their own settings.

Consider having the small breakout groups discuss ideas and then report back to the larger group.

SLIDE 30 » Report Back from Small Groups

Report Back From Small Groups

- Share information about the system currently used by your institution or office to coordinate care.
- Identify problem to be addressed.
- Determine what resources are available.
- Consider what additional resources are needed.

Report back

Facilitator Guide–Slide Deck
continued

SLIDE 31 » Current State: Case Study

Current State: Case Study

- A 14-year-old male, who is struggling in school with failing grades, was transferred to an adolescent clinic in the past year without access to prior medical records.
- His parent requests a refill of his ADHD medications, which he has not taken in 6 months.
- The results of a paper "Conners" ADHD questionnaire indicate high levels of inattention and hyperactivity.

Now, go back to the case study to apply the concepts to the case.

SLIDE 32 » Challenge: Monitoring Children with ADHD

Challenge: Monitoring Children With ADHD

- Parent- and teacher-completed ADHD rating scales are needed to assess the patient response to treatment.

Parents: Early morning	Teachers: School day	Parents: Evening
Stimulant not in effect	Stimulant in effect	Stimulant worn off

- A minimal number of rating scales are typically returned to the medical home.
  - Parent rating scales: ~20%-30%
  - Teacher rating scales: <5%
- Providers are "flying blind" with respect to medication decision-making.

This slide indicates a challenge that cannot be helped by technology. The case does not have to be centered around ADHD. The facilitator should feel free to create a new case, based on the target audience.

SLIDE 33 » Intervention

Intervention

1. Email notifications are sent to parents, patients, and teachers to complete online surveys.
2. Scoring algorithms are automated.
- Vanderbilt (ADHD rating)
- PedsQL (Quality of Life)
- Medication confirmation
- Side effects inventory
3. Email notifications are sent to clinicians with alerts.
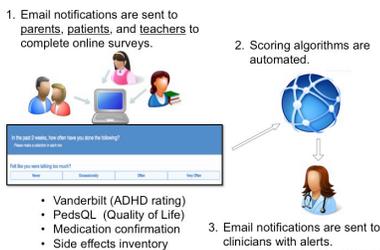
This slide illustrates a framework for a technological platform that helps get the right information to the right people (something that is often described as an issue with ADHD patients).

The facilitator can choose to share different technological platforms.

SLIDE 34 » Responder Interface

Responder Interface

The next few slides demonstrate the different modalities that people use to communicate. This slide includes an example from a computer.

Facilitator Guide–Slide Deck

continued
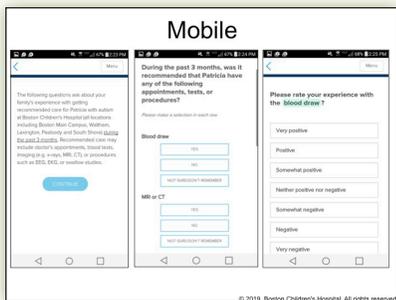
SLIDE 35 » Mobile

This slide is about gathering information through the use of mobile devices. The facilitator might want to note that, generally, trends can be found in the type of information that is provided, depending on the modality that is used.

The facilitator should consider making different modalities accessible. It is also important to think through making platforms accessible in different languages.
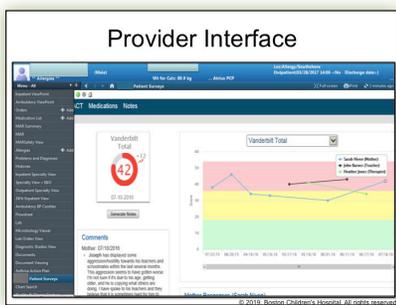
SLIDE 36 » Provider Interface

This slide demonstrates different forms of data results. This is an example of a system collecting ADHD data that has been integrated into the patient's electronic medical record, but other platforms can be used as well.

Visual cues and being able to see progress over time are both important and worth considering when considering new technologies.
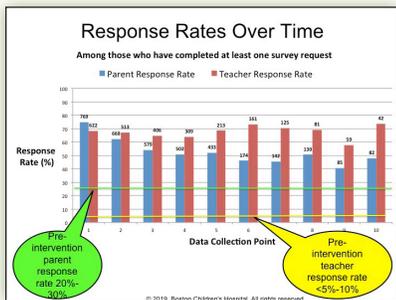
SLIDE 37 » Response Rates Over Time

This slide demonstrates response rates over time and the ability to visualize data using technology.

The facilitator might want to ask learners to weigh in on what they find useful about technology-collected data.
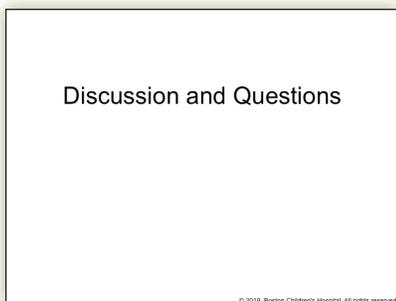
SLIDE 38 » Discussion and Questions

Facilitators may choose to share their experiences—either personal or in preparing to teach this module—with different technological platforms. Instead or in addition, ask learners about their experiences (both positive and negative) with various platforms.

Close with a final discussion and questions. Reiterate the message that this work takes time. The facilitator could ask learners to share what they have decided to bring back to their home institutions based on what they learned during the workshop.

Works Cited

1. Cresswell KM, Bates DW, Sheikh A. Ten key considerations for the successful implementation and adoption of large-scale health information technology. *J Am Med Inform Assoc.* 2013;20(e1):e9-e13

2. Falconer E, Kho D, Docherty JP. Use of technology for care coordination initiatives for patients with mental health issues: a systematic literature review. *Neuropsychiatr Dis Treat.* 2018;14 2337-2349

3. Siwicki B. How care coordination tech helped one health network address social determinants. *Healthcare IT News.* October 3, 2018. https://www.healthcareitnews.com/news/how-care-coordination-tech-helped-one-health-network-address-social-determinants
    Accessed December 20, 2018

Slide 1

Using Technology to Improve Care Planning & Coordination

Areej Hassan, MD, MPH
Eric Fleegler, MD, MPH

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Slide 2

Educational Purposes Only – No Medical Advice

The Pediatric Care Coordination Curriculum is offered for educational purposes only and is not meant as a substitute for independent medical judgment or the advice of a qualified physician or health care professional. Users who choose to use information or recommendations made available by the Pediatric Care Coordination Curriculum do so at their own risk and should not rely on that information as professional medical advice or use it to replace any relationship with their physicians or other qualified health care professionals.

2

Slide 3

Faculty Disclosure Information

- *Dr. Hassan has no disclosures to report.*
- *Dr. Fleegler is a consultant to Veta Health.*

3

Slide 4

Learning Goals

- Assess current practice of care coordination with and without technology.
- Discuss ways to use technology to connect key players in care coordination.
  - o Barriers
- Recognize system requirements for care coordination activities.
  - o Understand types of coordination.
- Describe an action plan for integration of technology platforms.

4

Current State: Case Study

- A 14-year-old male, who is struggling in school with failing grades, was transferred to an adolescent clinic in the past year without access to prior medical records.
- His parent requests a refill of ADHD medications, which he has not taken in 6 months.
- The results of the paper "Conners" ADHD questionnaire indicate high levels of inattention and hyperactivity.

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Current Coordination

- Write 1-month prescriptions for medications.
- Provide paper questionnaires for parents and teachers to complete.

6

Current Coordination

- Write 1-month prescriptions for medications.
  - Problem: Written prescriptions are limited to 1 month, cannot be sent electronically to a pharmacy, and are burdensome on the family, patient, and prescriber.
  - Problem: Physicians do not receive alerts about unfilled prescriptions.
- Provide paper questionnaires for parents and teachers to complete.
  - Problem: These result in poor response rates, especially from teachers.
  - Problem: It is difficult to track response to therapy.

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Current Coordination: Tech-Enhanced

- Electronic medical records (EMRs) enable primary care physicians to enter notes (eg, urgent visit) to be seen by others in the clinic.
- Patient portals allow patients and parents to send messages to and receive messages from their physicians.

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Current Coordination: Tech-Enhanced

- Electronic medical records (EMRs) enable primary care physicians to enter notes (eg, urgent visit) to be seen by others in the clinic.
  - Problem: This is only helpful if a patient receives other care (eg, emergency, mental health) within the same system; EMRs do not connect with other health care system EMRs.
- Patient portals allow patients and parents to send messages to and receive messages from their physicians.
  - Problem: Minimal penetration and usage of this technology because many physicians, patients, and families find it burdensome, physicians have additional responsibilities, and not all patients and families have access.
  - Problem: Physicians find it challenging when parents have access to sensitive information about their adolescents.

9

Other Complex Care Coordination Challenges

- Subspecialist communication
  - Who is managing a patient's specific needs, especially if care is provided across institutions?
- Adjunct therapy
  - How is information being shared with nonphysician clinicians, such as physical therapists, occupational therapists, nutritionists, or acupuncturists?
- Insurance-assigned care coordination
  - This is good, but insurance providers are not part of the hospital ecosystem, which can make assigning care coordination challenging.
- Non-health care partners
  - Community service partners, such as Big Brothers Big Sisters, DCF, and schools, cannot share information.

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Learning Goals

- Assess current practice of care coordination with and without technology.
- Discuss ways to use technology to connect key players in care coordination.
  - Barriers
- Recognize system requirements for care coordination activities.
  - Understand types of coordination.
- Describe an action plan for integration of technology platforms.

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Technology to Connect Key Players in Care Coordination

Minimum technology requirements
- Confidential
- HIPAA compliant (including the ability to communicate with physicians, nonphysician clinicians, agencies, and respondents)
- Secure
- Interoperability with current IT systems

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3

Technology to Connect Key Players in Care Coordination

Goals

- Facilitate communication between providers within an institution (notifications within EMR) and across institutions (link across EMRs).
- Develop efficient messaging and response methods for the patient portal.
  - Needs to facilitate communication between patient/family and care team members.
    - Standardized, set intervals
    - Open-ended communication
    - Symptom monitoring/response to therapy in chronic disease

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Technology to Connect Key Players in Care Coordination

Goals

- Provides communication to outside respondents, such as teachers, case managers.
  - Active collection of data from respondents
  - Easily viewable by care team members
  - School ability to view plans and coordinate with care team members
  - Data available as requested by other respondents (parents, teachers, etc.)
- Provides communication between pharmacy and provider.
  - Electronic Rx (when appropriate)
  - Information about Rx being filled and picked up

14

Technology to Connect Key Players in Care Coordination

- Adjunct therapy (physical therapy, occupational therapy, nutrition, acupuncture)
  - Share information to develop treatment plans.
- Care coordinators
  - Facilitate bidirectional communication about needs and provided services.
- Non-health care partners (community services, Big Brothers Big Sisters, DCF, schools)
  - Compare unidirectional vs. bidirectional.

15

Barriers to Technology Use

- Work flow efficiency (ease of implementation by the clinicians and administrative support staff)
- Compatibility between systems (important for the clinic, outside sites, and families)
- When possible, limit the number of technology-based systems.
- Need greater value add -- not just messaging systems but requires analytics that process and display data usefully (summary)
- Parents' and others' potential lack of access to new systems, ability to download apps, and to respond to reminders
- Responsibility/liability for information that arrives off-hours
- Caregivers' health literacy and language barriers

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4

Learning Goals

- Assess current practice of care coordination with and without technology.
- Discuss ways to use technology to connect key players in care coordination.
  - Barriers
- **Recognize system requirements for care. coordination activities.**
  - Understand types of coordination.
- Describe an action plan for integration of technology platforms.

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System Requirements Checklist

- Usable for both patients and care team members
- Degree of customization
- Desired functionality
- Real-time notifications
- Secure communication
- Cost effective
- Integration capability
- External health system or care team member communication
- Efficient
- Updateable
- Multiple language capability

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18

Learning Goals

- Assess current practice of care coordination with and without technology.
- Discuss ways to use technology to connect key players in care coordination.
  - Barriers
- Recognize system requirements for care coordination activities.
  - Understand types of coordination.
- **Describe an action plan for integration of technology platforms.**

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ACTION PLAN

1. **Conduct an assessment of technology needs.**

2. **Establish the need for change.**

3. **Determine the goals and objectives with new technology.**

4. **Select and plan for a new system.**

5. **Implement new technology.**

6. **Evaluate the new system and obtain feedback.**

Ten key considerations for the successful implementation and adoption of large-scale health information technology
Kathrin M Cresswell, David W Bates, Aziz Sheikh

Cresswell KM, et al. J Am Med Inform Assoc 2013;**20**:e9–e13. doi:10.1136/amiajnl-2013-001684

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Step 1: Assessment

General assessment: "map" the current processes
- What is the current technology used in coordinated care?
- What gaps exist?
- What is the ideal approach?
- What works best in your institution/office/setting?

General assessment:
Ideal approach – current approach = defined need

21

Step 2: Establish the Need for Change

Identify and characterize the problem that will be addressed by adopting technology to improve coordinated care.
- What is the problem?
- Whom and what does it affect?
- What is the importance of the effects?
- Can technology address this problem?

22

Step 2: Establish the Need for Change

- Who are the (other) stakeholders?
- How can you build consensus that a technology change is necessary?
- What information do you need (to build a supporting argument or obtain buy-in)?
  - Existing proficiencies and perceived deficiencies
  - Current performance
  - Stakeholder preferences
  - Financial resources
  - Barriers
  - Institutional politics

23

Step 2: Establish the Need for Change

How will you obtain the information?
- Inventory of existing records
- Informal discussion
- Interviews
- Focus groups
- Surveys
- Observation
- Strategic planning sessions

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Step 3: Goals and Objectives

- Goal = broad target
  - *"Our office will improve XXX."*
- Objective: specific measurable outcome
  - *"By adopting new technology, medical providers will be able to*
    - *– Communicate directly with patients via ….*
    - *– Receive updates on emergency room visits or inpatient hospitalizations.*
    - *– Discuss plan with pediatric medical subspecialists or pediatric surgical specialists.*

25

Step 4: Selecting and Planning for New System

- Commit adequate time and resources to consider options.
- Explore setups in other offices that have been successful.
- Network with potential suppliers.
- Determine whether the system meets the checklist of requirements (these may vary from setting to setting).
- Conduct trials of the new system comparing small group use vs all in and limited initial functionality vs multiple changes.
- Consider the costs – financial, research, and the effort to implement the system.

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Step 5: Implementation

- Identify resources.
- Develop a training plan
- Anticipate barriers.
- Delineate responsibilities (training, operations, etc.).
- Conduct pilot testing.
  - Obtain feedback from all stakeholders.
- Respond quickly to initial problems.

27

Step 6: Evaluation and Feedback

- To determine if goals and objectives have been met
- To provide information for continuous improvement
- To assess outcomes
  - Clinical (patient outcomes)
  - Health care dollar outcomes
  - Care team member satisfaction, acceptability, etc.
  - Patient satisfaction, acceptability, etc.
- To maintain and increase support

28

Breakout – Small Groups

- Share information about the system currently used by your institution or office to coordinate care.
- Identify problems to be addressed.
- Determine what resources are available.
- Consider what additional resources are needed.

29

Report Back From Small Groups

- Share information about the system currently used by your institution or office to coordinate care.
- Identify problem to be addressed.
- Determine what resources are available.
- Consider what additional resources are needed.

30

Current State: Case Study

- A 14-year-old male, who is struggling in school with failing grades, was transferred to an adolescent clinic in the past year without access to prior medical records.
- His parent requests a refill of his ADHD medications, which he has not taken in 6 months.
- The results of a paper "Conners" ADHD questionnaire indicate high levels of inattention and hyperactivity.

31

Challenge: Monitoring Children With ADHD

- Parent- and teacher-completed ADHD rating scales are needed to assess the patient response to treatment.

Parents: Early morning	Teachers: School day	Parents: Evening
Stimulant not in effect	Stimulant in effect	Stimulant worn off

- A minimal number of rating scales are typically returned to the medical home.
  - Parent rating scales: ~20%-30%
  - Teacher rating scales: <5%
- Providers are "flying blind" with respect to medication decision-making.

32

33

34

35

36

37

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Pediatric Care Coordination Curriculum

Evaluation Module

Evaluation Module

Evaluation Module—Objectives

At the end of this session, participants should be able to:

- Describe 4 levels of outcomes in an evaluation framework
- Develop a plan for evaluation of the care coordination curriculum
- Identify practical tips for using data generated from an evaluation

Introduction

Measuring the effectiveness of the care coordination training is a key part of its success. Perhaps it is necessary to show that the curriculum is effective in order to receive or maintain funding support. At a minimum, it is important to learn about what does and does not work well so that improvements can be made for future trainings. Regardless of how the results are used, it is important to build an evaluation plan into the curriculum from the start.

Following are some basic principles for evaluating a curriculum:

- Keep it short and simple to reduce the burden on participants and to ensure that most learners complete the evaluation—this means only asking what is necessary.
- Allow participants to say what is important to them—this means including some open-ended questions or response options.
- Identify the stakeholders—learners and their supervisors or organizations, the facilitator's supervisor or organization, or those who are providing financial or other resources to conduct this training—and what is important to them. They may all have different opinions about the goals for the training, what they want to get out of it, and how they define success. Make sure to get their perspectives and find some way to capture the information that will help them to determine whether or not the training was successful.

This module discusses a framework for evaluating training and practical how-to tips for creating, implementing, and utilizing data from a personalized evaluation plan for the care coordination curriculum. Please be aware that if this module is being implemented, it is crucial to include local-, state-, and region-specific content. The curriculum authors recommend identifying local needs and priorities wherever an is indicated in the curriculum. The role of the facilitator is to solicit input from all of the key stakeholders of the curriculum to identify these priorities in support of evaluating the impact of the curriculum and its implementation.

Identifying Outcomes for the Evaluation

A comprehensive evaluation plan can help identify whether changes have occurred for the learners after participating in a training program[1]. The Kirkpatrick model provides a practical approach for evaluating learner-related outcomes[2] and encourages facilitators to consider outcomes beyond learner satisfaction. Consider the following types of outcomes when developing an evaluation plan:

Satisfaction	· What is the learner's reaction to the training? · Did he or she think it was a valuable learning experience?
Learning	· Have the learning objectives been met? · Has there been a change in learner knowledge, skills, or attitudes?
Behavior	· Has the learner applied the acquired knowledge or skills beyond the training session? · Has there been a change in learner behavior on the job?
Results	· What is the impact of the training program? · Has there been a change in clinical outcomes, patient and family experience, health care utilization and cost, team performance, etc.?

Identifying Outcomes for the Evaluation
continued

The Kirkpatrick model[3]:

Evaluation of
RESULTS
(transfer or impact
on society)

Evaluation of
BEHAVIOR
(transfer of learning to workplace)

Evaluation of
LEARNING
(knowledge or skills acquired)

Evaluation of
REACTION
(satisfaction or happiness)
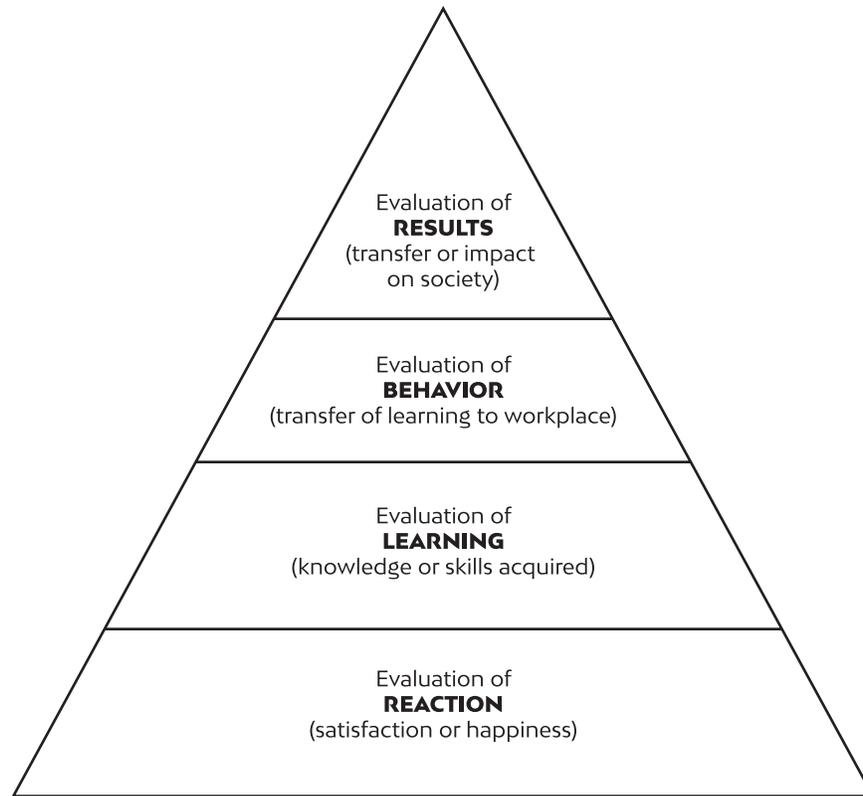
Evaluating higher levels of outcomes is more challenging but is often critical for making meaningful, sustainable improvements to care delivery. Levels 3 and 4 require follow-up after the training session—perhaps weeks, months, or a year or more later—in order to identify changes in behavior and outcomes of the initiative to implement care coordination tools, measures, and processes. Some of these outcomes may include patient and family experience as well as utilization measures, such as unplanned hospitalizations, emergency department visits, and the number of care coordination encounters, to name a few. Choosing what to measure has profound implications for sustainability. Be mindful that experiential data may be solicited from stakeholders who did not attend the training. For example, if the tools of care coordination are implemented following the training, it is reasonable to ask families 6 months after the training whether care processes are more coordinated and integrated than before. In sum, when developing an evaluation framework for the Pediatric Care Coordination Curriculum, consider each of these 4 levels of outcomes in the context of local resources, improvement priorities, and stakeholder interests.

Creating and Implementing an Evaluation Plan

First, identify <u>WHAT</u> information is needed.

Types of information include:

- Characteristics of the participants
- What the participants did or did not like about the training
- What the participants learned or anticipated the impact to be
- What the participants did with the information or how their behavior changed
- What the impact of the training program has been
- What the change has been in clinical outcomes, patient and family experience, health care utilization and cost, and/or team performance

Second, identify <u>WHEN</u> to collect evaluation data.

The best times to collect data are:

- Before the training if there is a plan to measure a change in knowledge or behavior from before to after the training or to become familiar with who the learners are
- Right after the training to measure change in knowledge and/or to measure reaction to the training*
- At a later date to measure knowledge retention, behavior change, and/or patient-related outcomes (Set a follow-up point that is far enough in the future to give people enough time to make behavior changes but close enough to the end of the training to be able to reasonably claim that the change may be due to the training. Common follow-up points tend to be about 3–6 months later.)*

Third, identify from <u>WHOM</u> information needs to be collected.

This may include:

- Learners who attended the curriculum training
- Patients and families (Please see Module 4 for performance indicators and measurements that capture patient- and family-reported experiences and outcomes.)
- Other care coordination stakeholders who may not have attended the curriculum training

Creating and Implementing an Evaluation Plan
continued

*TIP: If responses from 2 or more points in time need to be linked to individual participants but respondent anonymity is necessary, then a unique ID can be generated for each participant by asking all of the participants the same questions at every evaluation point. The questions should generate answers that will not change between evaluation points. For example:

- What are the first 3 letters of the city in which you were born?   _ _ _
- What is the 2-digit number for the day of the date you were born?   _ _

Someone born in Boston on March 7 would answer BOS and 07 to these questions and have the unique ID BOS07. This will link their responses on multiple surveys where they were asked the unique ID questions.

Create the questions that will be used to collect the necessary information.
Sample questions about the characteristics of the participants:

What is your role in your practice?
- ☐ Administrative assistant
- ☐ Care coordinator
- ☐ Clinical manager
- ☐ Nurse
- ☐ Nurse practitioner
- ☐ Office manager
- ☐ Physician
- ☐ Other: _____

How many years have you been in this role? (counting previous practices where you were also in this role)
- ☐ 0-5 years
- ☐ 6-10 years
- ☐ 11-15 years
- ☐ More than 15 years

Are you involved in any of the following care coordination activities in your practice? (check all that apply)
- ☐ Conducting patient and family needs assessments and/or goal setting
- ☐ Creating care plans
- ☐ Coordinating appointments with other providers or for diagnostic testing
- ☐ Communicating with other providers about shared patients
- ☐ Facilitating care transitions (eg, to new providers or to adult services)
- ☐ Connecting patients and families with community resources and/or schools
- ☐ Helping families to access benefits or authorize services
- ☐ Other: _____
- ☐ None

Creating and Implementing an Evaluation Plan
continued

Sample questions about what the participants did or did not like about the training:

How was the amount of information presented in this session/module?
- ☐ Too much
- ☐ Just the right amount
- ☐ Too little

How was the pace of this session/module?
- ☐ Too fast
- ☐ Just right
- ☐ Too slow

To what extent did this session/module meet your expectations?
- ☐ A great extent
- ☐ Some extent
- ☐ A little extent
- ☐ Not at all

How would you rate the quality of the following components of this session/module?

The didactic presentation?
- ☐ Excellent
- ☐ Very good
- ☐ Good
- ☐ Fair
- ☐ Poor

The cases?
- ☐ Excellent
- ☐ Very good
- ☐ Good
- ☐ Fair
- ☐ Poor

Working with the small group?
- ☐ Excellent
- ☐ Very good
- ☐ Good
- ☐ Fair
- ☐ Poor

The large group discussion?
- ☐ Excellent
- ☐ Very good
- ☐ Good
- ☐ Fair
- ☐ Poor

Creating and Implementing an Evaluation Plan
continued

What was the most valuable thing you learned from this session/module?
(open response)

What is something about this session/module that could be improved?
(open response)

Determine how to capture what the participants learned or what they anticipate the impact of their new knowledge will be.

To capture changes in knowledge, formulate some sample knowledge questions that could be asked right before and right after each session/module.* Preferably, the questions will align with the learning objectives for each module and be of strategic priority for the learners (eg, improving measurable quality outcomes, improving patient and family engagement, or optimizing outcomes in value-based contracting). To measure retention of knowledge, these questions can be asked again at a later follow-up point. **L**

*TIP: One of the biggest challenges to writing good knowledge questions is minimizing the chances that people can guess the right answers, which can cause problems for evaluation results. The first problem with good guessing is that it generates inaccurate data—participants may have learned less than what the data suggest. Without accurate data, it will be difficult to determine what about the program works well and what needs to be fixed—important reasons for conducting an evaluation. The second problem is that good guessing makes it difficult to show improvement in participant knowledge between assessments conducted before and after the training. For example, if a participant answers 93% of the questions correctly on a presession assessment, then there is very little room for improvement with a post-session assessment, making it difficult to demonstrate that the training has added value. In addition, participants could answer most of the questions correctly on the pretest because they are typically based on common knowledge rather than the new knowledge imparted through the training.

Short cases or scenarios provide useful information for creating application questions. For example, in a few sentences, describe a situation that would feel realistic to the learners then ask a follow-up action question, such as: "What should (person in the case) do next?" An example of an information question is: "What strategy would be most effective for helping this family resolve its situation?" When developing the response choices, the correct answers should reflect key learning points that will be made in the training. At least one of the incorrect answers should reflect common mistakes or misperceptions that people have.

Creating and Implementing an Evaluation Plan
continued

Following are examples of case-based questions for each module within the Pediatric Care Coordination Curriculum:

Module 1

You are working in a primary care clinic that regularly performs developmental screenings. You refer patients to the local early intervention (EI) agency whenever they screen positive. You do not know how many of those children end up accessing services. What is a potential next step?

a) I do not need to make any changes since I will check on the status of the child's development at the next health maintenance visit in a year.

b) I always rely on the parents to let me know if they have concerns about the referral to EI.

c) I can use a tool that outlines my concerns about the child's developmental screen to the EI agency and track receipt of the EI report back to my office.

d) Since I do not get paid to track EI referrals, there is nothing I can do about this.

Module 2

Your daughter has many long-standing medical conditions, and as a result, you spend many hours ensuring she gets the best possible care. Her pediatrician and several (but not all) of her pediatric medical subspecialists have often called her a "child with special needs." On more than one occasion, tasks that you were told were supposed to occur did not occur. These gaps in care required you to reschedule appointments, pull your daughter out of school extra days, and miss work. You appreciate how hard each of the team members caring for your daughter works, but you are often unsure about whether they work together on your daughter's needs. You feel nervous about telling each of the team members that you want them to collaborate more effectively. You know they are really busy, and you do not want them to get the impression that you are ungrateful. What is a potential next step?

a) Identify at least one member of your daughter's care team with whom you have a trusting relationship and share your experiences of care with specific examples. Ask this individual to support you in sharing this message with all members of the care team.

b) Send a letter to the chief of the hospital.

c) Send anonymous information after your next visit, using the satisfaction survey you get after each visit.

d) Remove the whole team and find new physicians.

Creating and Implementing an Evaluation Plan

continued

Module 3

Over the past month, several of your patients presented to the emergency department with asthma exacerbations. You work in a community health center, which predominantly serves a low-income community. Many of your patients live in housing projects located 45 minutes away by bus. All patients and caregivers receive routine education about the prescribed asthma medications and have established asthma action plans. What is a potential next step to reduce the number of emergency department visits due to asthma exacerbations?

a) Continue to deliver the patient education as recommended by national guidelines.

b) Ask the caregivers about their housing, transportation, utility, food, and safety needs.

c) Hire an asthma educator for the practice.

d) Refer the caregivers to a social worker.

Module 4

You are developing a referral system to connect pediatricians and other physicians, pediatric medical subspecialists, pediatric surgical specialists, and regional services for children with complex medical needs. You are implementing a pilot in a subset of local clinics and hope to eventually scale up to serve all children in the region. What is a potential next step as you prepare for pilot implementation and eventual scale-up of the referral system?

a) Identify what you need to measure to demonstrate the need for and value of your new referral system, and select measurement tools accordingly.

b) Hire a new nonclinical staff member to manage all referrals to free up time of physicians and nonphysician clinicians.

c) Implement, without modification, a referral system that has been shown to be effective in other regions.

d) Ask insurers to pay for care coordinators at the outset.

Module 5

You are seeing a 6-year-old patient for the first time in your clinic. He is brought in by his parent who asks you to consult on what the child's school is calling a lack of attention span. After your thorough history and physical, you recommend using a validated, standardized screening tool in the home and school to inform your final diagnosis and subsequent treatment plan. What are potential next steps to provide coordinated care for this patient?

a) Have the parent complete the screening tool at home and mail other forms to the school to complete.

b) Utilize a web-based, secure platform by which assessment data can be shared among members of the family-designated care team.

Creating and Implementing an Evaluation Plan
continued

An added benefit to having case-based questions on a pretest is that they cue the learners to some of the important points of the training, increasing the chances that they will absorb that knowledge during the training. Case-based questions also prime the learners to think about ways in which the information presented in the training will be relevant to their work.

To measure anticipated impact, consider asking a single, open-response question, such as: "How might your team or individual work change as a result of this session/module?" Another option is to ask a set of specific questions similar to the following:

How likely are you or your team or institution to implement the (care coordination processes, tools) discussed in this module/session?

☐ Very likely
☐ Somewhat likely
☐ Somewhat unlikely
☐ Very unlikely

Note: When asking this question, replace the italicized section with a specific process or tool taught in the module/session being evaluated. Ask this question multiple times to cover the multiple processes or tools discussed in the module that could be implemented by the participants. Consider focusing on processes or tools that align with the priorities of the learners. **L**

Determine what the participants did with the information or how their behavior changed.

To measure behavior 3 months (for example) after the training, ask participants about what new processes or tools were implemented in the 3 months since the training. Ask specifically about processes or tools that were addressed in the training itself. Following is an example:

Did you begin implementing any of the following care coordination processes or tools in the last 3 months? (check all that apply)?

☐ Process/tool #1
☐ Process/tool #2
☐ Process/tool #3 (etc.)
☐ Other new care coordination process or tool _____
☐ No new care coordination process or tool was implemented in the last 3 months

Facilitators may focus on processes or tools that align with the priorities of the learners. **L**

Creating and Implementing an Evaluation Plan

continued

To measure change in the behavior or roles of individual participants, re-ask participants about their care coordination activities and compare their answers to the ones they gave at baseline (with the goal being that they are now involved in more activities).

In the past 3 months, have you been involved in any of the following care coordination activities in your practice? (check all that apply)

☐ Conducting patient and family needs assessment and/or goal setting

☐ Creating care plans

☐ Coordinating appointments with other providers or for diagnostic testing

☐ Communicating with other providers about a patient you share

☐ Facilitating care transitions (eg, to new providers or adult services)

☐ Connecting patients and families with community resources and/or schools

☐ Helping families to access benefits or authorize services

☐ Other: _____

☐ None

What Next? Utilizing Evaluation Data

Evaluation data can provide important information about the program and help to make it the best possible program for the learners.

1) Evaluate the evaluation data as it arrives

For example, do not wait until after all of the follow-up data has been collected to compare it to baseline data. Check it along the way. What percentage of participants completed the evaluation? If it is low, consider rethinking the plan, such as the amount of time given to people to complete the evaluation or the length of the survey. If there are specific questions that are frequently skipped, they may not be relevant or clear.

2) Summarize the data by calculating the counts or percentages for each closed-ended question response

Look through the open-ended questions and try to identify themes. This second process is best done by having at least 2 people look through the open responses separately then convene when they are done to compare opinions about the themes they discovered from the responses.

3) Interpret the findings

What important lessons for the program are in the summarized data? This process is also best done by having at least 2 people look at the results and make independent conclusions. If possible, the conclusions could be shared with the learners to see if the important takeaway points match what they experienced. That time could also be used to ask the learners for additional feedback or suggestions for program improvement.

4) Apply the learned lessons

What changes can be made to the program to address suggestions by the learners for program improvements or any identified concerns, such as ongoing knowledge gaps, ways in which the facilitator and the learners did not develop a shared understanding of the content, or less-than-expected practice or behavior changes? If there is only one cohort of learners with whom the training will not be repeated, the evaluation data might inform the content of a booster session or follow-up materials for those learners. The evaluation data will also indicate what went well to keep for the next time there is a training session. This positive data could be shared with stakeholders who might be responsible for sending new learners or providing financial or other resources for the next training session.

Conclusion

The purpose of an evaluation is to determine whether the training met its goals. Whatever the goals are for the facilitator, learners, or other stakeholders, without a formal evaluation it is difficult to fully understand how effective the training was. With some careful planning ahead of time, a few well-chosen evaluation questions can generate a wealth of information, setting the training up for success.

Works Cited

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