Pediatric Care Coordination Curriculum

The authors greatly appreciate the generous support of the Maternal and Child Health Bureau (MCHB), which made development of this curriculum possible. The project was funded through a supplemental grant (U40MC00149) by MCHB, through a cooperative agreement with Family Voices.
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*also a module author

The authors wish to acknowledge the tireless efforts of Hannah Rosenberg, MSc, who coordinated the final compilation of the Curriculum.

Acknowledgement

The creation of this curriculum has been an exciting journey. The authors come from many different backgrounds—families, nursing, social work, medicine, trainees. Our diversity represents how we plan to achieve our strategic goal: in order to develop a high performing health care system, all stakeholders need to actively engage and participate in the transformation.
Module 1
Building Patient/Family-Centered Care Coordination Through Ongoing Delivery System Design

Module 2
Care Coordination as a Continuous Partnership

Module 3
Integrating Care Coordination into Our Everyday Work

Module 4
Health-Related Social Service Needs: Strategies to Assess and Address in the Family-Centered Medical Home

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Module 1

Building Patient/Family-Centered Care Coordination Through Ongoing Delivery System Design

1. Overview
2. Facilitator Guide
3. Presentation Content and Facilitator Notes
4. Presentation Slides
5. In-Session Worksheet – Take Home Action Plan
6. Pre-Session Handout - Tips for Improving Collaboration and Teamwork
7. Pre-Session Worksheet - Collaboration and Teamwork: What is working for you?
8. Pre-Session Reading - Achieving effective care coordination in the medical home
9. Pre-Session Reading - Making care coordination a critical component of the pediatric health system: A multidisciplinary framework
10. Pre-Session Reading - Medical home practice-based care coordination: A workbook


Module Citation: Lindeke L, Presler E, Hackett-Hunter P. Module 1, Building Patient/Family-Centered Care Coordination through Ongoing Delivery System Design. In Antonelli RC et al, Pediatric Care Coordination Curriculum. Boston Children’s Hospital, 2014.

The authors greatly appreciate the generous support of the Maternal and Child Health Bureau (MCHB), which made development of this curriculum possible. The project was funded through a supplemental grant (U40MC00149) by MCHB, through a cooperative agreement with Family Voices.
**Module Title:** Building Patient/Family-Centered Care Coordination through Ongoing Delivery System Design – Module 1

**Module Format:** In-person session (~1.5 Hours)

**Module Overview:** This module provides participants with an overview of the steps involved in developing, evaluating and adapting a care coordination model that will be endorsed and supported by their organizations for use in delivering comprehensive, continuous, longitudinal care.

**Audience:** Care coordinators and/or members of the care coordination team

**Rationale:** This curriculum was created with the goal of offering practical, experience-based principles to facilitate the introduction and continued enrichment of care coordination.

**Module Goals and Learning Objectives:**

1. Identify key components of a high performing pediatric care coordination model
2. Compare and contrast these with how care coordination works at your practice and identify areas for improvement
3. Develop your take-home action plan for next steps in improving collaboration and teamwork in your practice

**Module Activity Summary:**

<table>
<thead>
<tr>
<th>Activity</th>
<th>Time</th>
<th>Materials Required</th>
<th>Faculty</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre-Session Information</td>
<td>N/A</td>
<td>Website with: Pre-session handout, Pre-session worksheet, and 3 articles</td>
<td>N/A</td>
</tr>
<tr>
<td>Introduction to and Discussion of Concepts</td>
<td>45 Minutes</td>
<td>PowerPoint Presentation</td>
<td>Facilitator</td>
</tr>
<tr>
<td>Discussion Activity</td>
<td>15 Minutes</td>
<td></td>
<td>Facilitator &amp; Participants</td>
</tr>
<tr>
<td>Final Discussion, Sharing of Ideas, and Closing Comments</td>
<td>20 Minutes</td>
<td></td>
<td>Facilitator &amp; Participants</td>
</tr>
</tbody>
</table>

**Evaluation:**

**Short term:** Attendees will complete the “Collaboration and teamwork worksheet – What is working for you?” to determine what changes and steps they can reasonably make after gaining the information learned during this module.

**Long term:** Follow up with attendees via conference call or listserv survey to see how their take home action plans are coming along and determine how the information they learned has been put into
**Module 1: Building Patient/Family-Centered Care Coordination through Ongoing Delivery System Design—Facilitator’s Guide**

**Time:** 1.5 hrs

**Authors:** Linda Lindeke, RN, PhD; Elizabeth (Betty) Presler, RN, PhD, and Patti Hackett-Hunter, MEd

<table>
<thead>
<tr>
<th>PARTICIPANTS:</th>
<th>Care Coordinators; additional medical home team members also welcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>FOCUS:</td>
<td>This session assists participants in developing, evaluating and adapting a care coordination model that will be endorsed and supported by their organizations for use in delivering comprehensive, continuous, longitudinal care. It also offers participants the opportunity for reflection and conversation about ongoing practice challenges and realities.</td>
</tr>
</tbody>
</table>
| PRE-SESSION: | **Facilitator Notes**  
* Approximately 1-2 weeks prior to the training, AAP/National Center staff will email participants with general information about the training, including an overall agenda for the day. Participants will be given a link where all pre-session informational handouts, pre-session worksheets, and foundational reading, for all modules, will be available. It will be explained that pre-session worksheets will not be collected on-site, but will be used as a springboard for discussion.  
* Participants will be given a link to SurveyMoney, where they will be asked to fill out information that will provide the trainer and their state leadership team with information about their experience as a care coordinator, specifics about the populations they serve, partners in their state/communities, barriers in their state/communities, etc.  
* Specific to Module 1 – The website will include:  
  - Pre-Session Handout 1: *Tips for improving collaboration and teamwork*  
  - Pre-Session Worksheet 1: *Collaboration and teamwork: What is working for you?*  
# Pediatric Care Coordination Curriculum

## Introduction and Discussion of Concepts - 45 Minutes

<table>
<thead>
<tr>
<th>Slide</th>
<th>Content and Notes</th>
</tr>
</thead>
</table>
| Slide 1 | **Building Patient/Family-Centered Care Coordination through Ongoing Delivery System Design**  
*Title slide*  
**Facilitator Notes:**  
- Make introductions  
- Provide overview of session and timeframe  
  - 45 min - Introduction to and discussion of concepts  
  - 15 min - Discussion – sharing strategies about collaboration and teamwork  
  - 20 min - Sharing what works |
| Slide 2 | **Learning Objectives**  
- Identify key components of a high performing pediatric care coordination model that can be implemented in your medical home practice setting.  
- Design/refine a care coordination model and practice in your medical home practice. |
| Slide 3 | **Learning Objectives**  
- Evaluate strengths and areas for improvement in implementation of care coordination within your medical home practice.  
- Develop your take-home action plan for next steps for improving collaboration and teamwork in your practice.  
**Facilitator Notes**  
- Developing a model of care coordination within the medical home is much like building a home.  
- Care coordinator at times functions like an architect, at other times like an engineer.  
- Care coordinators develop and implement plans; family drives the content/direction of the plans.  
- During the session, think about what strategies you want to take home with you. What will success look like for you, for your practice and for patient/families? |
| Slide 4 | **Graphic: Completed house with all the components labeled**  
**Facilitator Notes**  
- The graphic is a model of high-performing care coordination in a patient/family-centered medical home, with all of its key components, which we will review one by one.  
  The house is:  
  - built on a strong foundation of core values  
  - supported by four pillars  
  - accessed through universal design  
  - nurtured by compassion  
  - protected by a roof comprised of standards for improvement and evaluating outcomes  
  - enhanced by excellent communication  
  - constructed with a barrier-free entrance  
  - built to code, with room to grow  
  - in need of ongoing upkeep and maintenance  
- What elements of the graphic are familiar to you? Which ones are new?  
- Our goal today is to understand and reflect together on these components in our large group session.  
- Then, we will focus in on how to improve collaboration and teamwork in your medical home practice setting. |
### Slide 5: Care Coordination: Heart of the Medical Home

These are the essential outcomes of high performing care coordination in a pediatric medical home. During our conversation and sharing today, we will review the strategies which assure positive outcomes and contribute to quality coordinated care.

- Transforms a house into a home
- Promotes efficiency and continuity of care
- Focuses on helping those in the home get their needs met (immediate and ongoing)
- Makes coming in and going out easier
- Creates a friendly, supportive environment for patients and families and each other
- Prepares patients and families for the future

### Slide 6: Who builds this home?

Care coordination is not a solo effort! It is a team effort involving:

- the patient and family
- the care coordinator
- the entire staff
- the network of healthcare providers and other community caregivers

**Facilitator Notes**

- Throughout this session, our friendly construction worker icon is here to help us see ourselves as builders.
- Sometimes we function like architects; sometimes we function like engineers. *Architects* are skilled at designing things. *Engineers* are skilled at applying those designs to real-world situations.

### Slide 7: Why build this home? THE PATIENTS AND FAMILIES.

Comprehensive care coordination in a medical home leads to:

- greater access to community services
- improved skills for self-advocacy
- opportunity to connect with other families
- knowledge to maintain health & improve quality of life
- greater capacity to navigate the system

**Facilitator Notes**

- Why does care coordination matter to patients and families?
- What do patients/families tell you about care coordination when it is working for them?

### Slide 8: Why build this home? THE PAYERS.

Comprehensive care coordination in a medical home results in:

- lowered cost of care
- timely access to information
- improved patient outcomes/satisfaction

**Facilitator Notes**

- Why is comprehensive care coordination in the interest of payers?
  - When patients and families know when and where to get care, utilization in the emergency department is reduced.
  - Access to services (phone, extended hours, same day appointments and weekends) reduce costs, decrease morbidity/mortality.
| Slide 9 | Why build this home? THE PRACTICE TEAM.  
Could comprehensive care coordination in a medical home results in...  
• improved teamwork  
• effective communication  
• reduction of duplicated effort  
• increased cost-effectiveness  
• Improved staff/provider job satisfaction  
Facilitator Notes  
- Why is comprehensive care coordination in the interest of the practice team?  
  • Enables strategies for efficient/productive encounters (eg, pre-planning, post-encounter follow-up)  
  • Patient/family report greater satisfaction as their needs and voice are heard and respected.  
  • Use of Health/QOL measures mixes evidenced based practices as well as conventional wisdom.  
  • Proactive teams improve practice efficiency (patient encounters, referrals, insurance and benefit documentation.  
  • Proactive teams learn collaboratively, constantly examining/revising what is working & what is not. |
| Slide 10 | Why build this home? THE CARE COORDINATORS.  
Results in:  
• Effective teamwork through coordination & communication  
• Recognition of care coordinator’s unique activities  
  • supporting the practice team  
  • assisting patients/families  
• Respect and support for the care coordinator role  
• Job satisfaction for the care coordinator!  
Facilitator Notes  
- Why is comprehensive care coordination in the interest of the care coordinator?  
  • The services of the care coordinator may not be billable, but their work adds significant value to the efforts of the team.  
  • Care coordinators often have their “ears to the ground” in a way that can uniquely respond to the needs of patients and families. |
| Slide 11 | Consultation for the builder...  
• What are the similarities and differences?  
  • Case management  
  • Disease management  
  • Comprehensive, high performing pediatric care coordination  
Facilitator Notes  
Comparing care coordination, case management and disease management  
- Is it helpful to differentiate these three approaches? |
| Slide 12 | Building your structure as a care coordinator...  
• Requires knowledge of:  
  • the organization’s mission, history, goals & realities  
  • payer requirements  
  • NCQA metrics  
  • professional standards  
• Requires a toolkit of both existing tools and those you create yourself  
Facilitator Notes  
- As architect, you are in the role of designing structures based on your understanding of the practice.  
- As engineer, you are in the role of linking evidenced-based practice, as well as local knowledge that comes from experience, into programs and practices that work.  
- In your practice, what evidence-based tools have you and your team found useful?  
- What tools have you developed, that come from local knowledge (rooted in your practice), that you have found useful? |
<table>
<thead>
<tr>
<th>Slide 13</th>
<th>Building a sturdy home requires:</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Solid foundation of mutually-held values</td>
<td></td>
</tr>
<tr>
<td>• Strong support structures</td>
<td></td>
</tr>
<tr>
<td>• Accessibility: getting in and out easily</td>
<td></td>
</tr>
<tr>
<td>• Convenient and comfortable living space</td>
<td></td>
</tr>
<tr>
<td>• Roof to protect the quality of what goes on inside</td>
<td></td>
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</tbody>
</table>

**Facilitator Notes**
- Consider the importance of the component parts of a sturdy home: ie, foundation, walls, door, roof.
- Each has a purpose and each connects to the others.

<table>
<thead>
<tr>
<th>Slide 14</th>
<th>Solid foundation: Meets Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>• The foundation of comprehensive care coordination in the medical home:</td>
<td></td>
</tr>
<tr>
<td>▪ Proactive</td>
<td></td>
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<tr>
<td>▪ Comprehensive</td>
<td></td>
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<tr>
<td>▪ Developmentally supportive</td>
<td></td>
</tr>
<tr>
<td>▪ Patient/family centered</td>
<td></td>
</tr>
<tr>
<td>▪ Coordinated!</td>
<td></td>
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</table>

<table>
<thead>
<tr>
<th>Slide 15</th>
<th>Foundation: Mutually Held Values</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Proactive (planned and continuous)</td>
<td></td>
</tr>
<tr>
<td>• Comprehensive (linked to the community, attentive to transitions in care)</td>
<td></td>
</tr>
<tr>
<td>• Developmentally supportive</td>
<td></td>
</tr>
<tr>
<td>• Patient/family-centered (includes cultural competence)</td>
<td></td>
</tr>
<tr>
<td>• Coordinated!</td>
<td></td>
</tr>
</tbody>
</table>

**Facilitator Notes**
- What would be a good example of each of these values brought to life?
- Which of these values are strongest in your practice?
- Which values are more difficult to bring to life? Why?
- What do you do when the values of the patient/family and needs of the practice are not in alignment?

<table>
<thead>
<tr>
<th>Slide 16</th>
<th>PILLARS - Weight-bearing support structures</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Practice and team support</td>
<td></td>
</tr>
<tr>
<td>• Interagency partnership</td>
<td></td>
</tr>
<tr>
<td>• Surveillance and tracking systems</td>
<td></td>
</tr>
<tr>
<td>• Evidence-based guidelines</td>
<td></td>
</tr>
</tbody>
</table>

**Facilitator Notes**
- Pillars are support beams.
- Each pillar is essential and requires careful construction and ongoing maintenance.
- Which of these are strongest in your practice?

<table>
<thead>
<tr>
<th>Slide 17</th>
<th>PILLAR 1: Practice and team support</th>
</tr>
</thead>
<tbody>
<tr>
<td>Care coordinators should</td>
<td></td>
</tr>
<tr>
<td>• not be flying solo,</td>
<td></td>
</tr>
<tr>
<td>• be integrated as part of the clinical team.</td>
<td></td>
</tr>
<tr>
<td>• Be part of huddles, team meetings, informal conversations: What has worked for you?</td>
<td></td>
</tr>
</tbody>
</table>

**Facilitator Notes**
- The practice needs to develop a commitment to the team approach and team interactions, interfacing with patients and families.
- Improved practice needs to translate into policies.
<table>
<thead>
<tr>
<th>Slide 18</th>
<th>PILLAR 2: Interagency partnerships</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Connecting patient/family to information and resources on the local, state, or national level</td>
</tr>
<tr>
<td></td>
<td>Developing strategic relationships in order to build integrated network of services</td>
</tr>
<tr>
<td></td>
<td>Cutting through red tape to expedite solutions</td>
</tr>
<tr>
<td></td>
<td>Finding the best “go-to” people and agencies</td>
</tr>
<tr>
<td></td>
<td>What has worked for you?</td>
</tr>
</tbody>
</table>

**Facilitator Notes**
- How do you distinguish trusted information and connections from those that are not? 
- What works best: box of handouts, web-based resources, periodic email communication about informational resources? 
- What are the best ways to facilitate ongoing, efficient sharing – with the team, with patients/families, and with other care coordinators?

<table>
<thead>
<tr>
<th>Slide 19</th>
<th>PILLAR 3: Surveillance and tracking systems</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Utilizing patient registries</td>
</tr>
<tr>
<td></td>
<td>- Special needs (including acuity or complexity)</td>
</tr>
<tr>
<td></td>
<td>Utilizing tracking systems</td>
</tr>
<tr>
<td></td>
<td>- Referrals, tests/procedures, flu shots</td>
</tr>
<tr>
<td></td>
<td>Organizing clinical information</td>
</tr>
<tr>
<td></td>
<td>What has worked for you?</td>
</tr>
</tbody>
</table>

**Facilitator Notes**
- Identifying special needs - is it through a criteria index, agreed-upon definition? 
- The medical file can be a “bear” (chaotic filing/labeling) or a breeze (agreed-upon naming and protocol). 
- Essential elements in EHR/eCW
  - Up to date medication list, care plan; summary reports from referrals or tests. 
  - Archived documents that are legible – are typed or automated forms being used? 
  - Has your practice developed a “naming” protocol to label files that are archived in the EHR/eCW? 

<table>
<thead>
<tr>
<th>Slide 20</th>
<th>Consultation for the builder....</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>How do you balance the time it takes for data surveillance and tracking with the time it takes to connect directly with patients and families?</td>
</tr>
</tbody>
</table>

**Facilitator Notes**
Engage in short discussion. Acknowledge but do not dwell on barriers.

<table>
<thead>
<tr>
<th>Slide 21</th>
<th>PILLAR 4: Evidence-based guidelines</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Identifying PPOC quality measures</td>
</tr>
<tr>
<td></td>
<td>Tracking how well the team incorporates these measures</td>
</tr>
<tr>
<td></td>
<td>Resources for quality measures:</td>
</tr>
<tr>
<td></td>
<td>- AAP Medical Home</td>
</tr>
<tr>
<td></td>
<td>- AAFP Patient-Centered Medical Home</td>
</tr>
<tr>
<td></td>
<td>What has worked for you?</td>
</tr>
</tbody>
</table>

**Facilitator Notes**
- Review reasons for evidence-based practice and typically-used guideline sources from professional organizations and websites such as www.guidelines.gov
- What is your role in the implementation of evidence-based guidelines in your practice? What are the challenges?
<table>
<thead>
<tr>
<th>Slide 22</th>
<th>Graphic: House, foundation, pillars, and walls, with roof added</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td><strong>Facilitator Notes</strong></td>
</tr>
<tr>
<td></td>
<td>• Roof has 2 slopes</td>
</tr>
<tr>
<td></td>
<td>§ First slope is performance improvement</td>
</tr>
<tr>
<td></td>
<td>§ Second slope is outcomes evaluation</td>
</tr>
<tr>
<td></td>
<td>• The roof protects the home and provides insulation from</td>
</tr>
<tr>
<td></td>
<td>external elements.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Slide 23</th>
<th>Outcomes evaluation and performance improvement</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>• How has satisfaction been improved?</td>
</tr>
<tr>
<td></td>
<td>• Which specific patient/family outcome measures are useful?</td>
</tr>
<tr>
<td></td>
<td>• Have the selected measures improved efficiency &amp; productivity</td>
</tr>
<tr>
<td></td>
<td>within the medical home?</td>
</tr>
<tr>
<td></td>
<td>• What has worked for you?</td>
</tr>
<tr>
<td></td>
<td><strong>Facilitator Notes</strong></td>
</tr>
<tr>
<td></td>
<td>• Outcome measures can inform us about decreased ER use,</td>
</tr>
<tr>
<td></td>
<td>reductions in unnecessary hospitalizations, fewer days</td>
</tr>
<tr>
<td></td>
<td>missed from school/work.</td>
</tr>
<tr>
<td></td>
<td>• CQI provides tracking trends and offers feedback about the</td>
</tr>
<tr>
<td></td>
<td>effectiveness of our actions, and the opportunity for</td>
</tr>
<tr>
<td></td>
<td>mid-course redirection.</td>
</tr>
<tr>
<td></td>
<td>• How can we tell when quality and efficiency have improved:</td>
</tr>
<tr>
<td></td>
<td>What does it look like? What does it feel like?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Slide 24</th>
<th>Graphic: House with foundation, pillars, walls, and roof with door added</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td><strong>Facilitator Notes</strong></td>
</tr>
<tr>
<td></td>
<td>• House is almost complete</td>
</tr>
<tr>
<td></td>
<td>• A medical home must be easily accessible: easy to enter, welcoming</td>
</tr>
<tr>
<td></td>
<td>• Next two slides elaborate on what access means</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Slide 25</th>
<th>Care Coordinator: Communication Hub</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>• The “GO TO” person. Accessible &amp; willing to respond.</td>
</tr>
<tr>
<td></td>
<td>• A facilitator, teacher, mentor, connector &amp; clinical expert</td>
</tr>
<tr>
<td></td>
<td>• Champion of patient/family needs</td>
</tr>
<tr>
<td></td>
<td>• Tireless advocate</td>
</tr>
<tr>
<td></td>
<td>• Liaison: Patient, Family, Medical Team, Community &amp; Services</td>
</tr>
<tr>
<td></td>
<td><strong>Facilitator Notes</strong></td>
</tr>
<tr>
<td></td>
<td>Have participants think about their role, which of these essentials are</td>
</tr>
<tr>
<td></td>
<td>they doing? What would they like to be doing?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Slide 26</th>
<th>Care Coordination: Day to Day Living</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>How does it happen?</td>
</tr>
<tr>
<td></td>
<td>• Identification and engagement</td>
</tr>
<tr>
<td></td>
<td>• Comprehensive assessment of patient/family</td>
</tr>
<tr>
<td></td>
<td>• Developing family/child/youth-centered plans of care</td>
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<tr>
<td></td>
<td>• Implementing the plan of care</td>
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<td>• Monitoring and evaluation</td>
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<td>• Ongoing population-based surveillance</td>
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<td></td>
<td><strong>Facilitator Notes</strong></td>
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<tr>
<td></td>
<td>What tools are used? How do you engage other team members? How do you</td>
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<td></td>
<td>become included?</td>
</tr>
</tbody>
</table>
| Slide 27 | Accessible means having access to:  
|         | • Health Care  
|         | • Communication  
|         | • Coordination  
|         | • Information  
|         | • Referrals  
|         | • Education  
|         | • Support  
|         | • Advocacy  

**Facilitator Notes**  
• Care coordination is about providing the supports and navigation strategies to make the system work!  
• What works for you and your team to make this a smoother process for patients and families?

| Slide 28 | Markers of Access  
|         | • Same day appointments / flexible hours  
|         | • Same day call back regarding questions/web portal for appointments or information  
|         | • Communication: phone, email, text and in person  
|         | • Referral to online resources  
|         | • Non visit based support and care  
|         | • Physical access and comfort for CYSHCN/families  

**Facilitator Notes**  
• Which of these markers of access does your practice have in place?

| Slide 29 | Graphic: foundation, pillars, walls, roof and door with *compassion* (heart) and *communication* (satellite dish) added  

**Facilitator Notes**  
Point out as a review, 4 pillars, protective roof, door has compassion and a beating heart, communication

| Slide 29 | Graphic: foundation, pillars, walls, roof and door with *compassion* (heart) and *communication* (satellite dish) added  

**Facilitator Notes**  
• This well-built house requires *compassion* in order for it to function well.  
• Compassion is necessary for the patients, for colleagues, and for ourselves.  
• Communication is essential, via traditional tools, email, the patient portal, etc.  
• How do you think compassion and communication should fit into this picture? How do you think other members of your team might see this?
## Pediatric Care Coordination Curriculum

### Discussion Activity - **15 Minutes**

**Slide 30**

<table>
<thead>
<tr>
<th>Graphic: Stages of team development</th>
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**Facilitator Notes**
- During the discussion activity we will focus on the question, what makes collaboration and teamwork **work**?
- Encourage participants to think about the four stages as one useful framework for thinking about how collaboration and teamwork are working in their practices.

**Slide 31**

<table>
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<tr>
<th>Care Coordination: Heart of the Medical Home</th>
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**Facilitator Notes**
- Reminders before beginning discussion session.
- Essential outcomes of a high performing care coordination.
- Improving performance, increasing quality care and reducing barriers.
  - Transforms a house into a home
  - Promotes efficiency and continuity of care
  - Focuses on helping those in the home get their needs met (immediate and ongoing)
  - Makes coming in and going out easier
  - Creates a friendly, supportive environment for patients and families and each other
  - Prepares patients and families for the future

**DISCUSSION ACTIVITY**

**Facilitator Notes**
- Ask for volunteers for the questions below.
- Invite speaker to briefly introduce themselves: name, practice where they work, how long they have been in the care coordinator role.
- Review participants’ worksheet responses (Pre-Session Worksheet - Collaboration and Teamwork: What is working for you?) to the 4 questions on the worksheet, and ask them to share the examples they listed under each question:
  - Think about times in your practice when collaboration between staff and patients/families is going really well.
  - What are you and your colleagues doing to create and maintain this kind of collaboration?
  - Think about times in your practice when teamwork among staff is going really well.
  - What are you and your colleagues doing to create and maintain this kind of teamwork?
- Invite participants to share strategies for addressing barriers and obstacles that stand in the way of optimal collaboration and teamwork.
## Final Discussion, Sharing of Ideas, and Closing Comments - 20 Minutes

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<th>Slide</th>
<th>Content and Notes</th>
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<tbody>
<tr>
<td><strong>SLIDE 32</strong></td>
<td>Graphic: Completed house with all the components</td>
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</table>
| **Facilitator Notes** | - Group Discussion / Examples when ...
- Times in your practice when collaboration between staff and patients/families is going really well.
- Current activities to create and maintain this kind of collaboration?
- When does teamwork among staff go really well?
- How do you and your colleagues doing to create and maintain this kind of teamwork? |
- Lessons Learned/Strategies to Replicate: Invite participants to share strategies for addressing barriers and obstacles that stand in the way of optimal collaboration and teamwork. |
| **SLIDE 33** | Building collaboration and teamwork... |
| **Facilitator Notes** | - Ask participants to fill out worksheet (workshop handout 3), *Building collaboration and teamwork* prior to in-person session.
- In 7 days, I/my team will...
  [What can you do/your team do immediately? Name it and hold yourself/your team accountable.]
- In 30 days, I/my team will...
  [What needs a little more time to implement? Name it and hold yourself/your team accountable.]
- In 90 days, I/my team will have accomplished...
  [Progress takes time, but there it is hard to achieve progress without a destination in mind. Where do you want collaboration and teamwork to be in 90 days? What do you/your team need to be doing to make that happen?] |
| **SLIDE 34** | Graphic: Completed house with all the components |
| **Facilitator Notes** | - Closing summary and evaluation |
MODULE 1:

Building Patient/Family-centered Care Coordination Through Ongoing Delivery System Design

Module Authors:
Linda Lindeke, RN, PhD
Elizabeth (Betty) Presler, RN, PhD
Patti Hackett-Hunter, ME
Learning Objectives

- Identify key components of a high performing pediatric care coordination model
- Compare and contrast these components with how care coordination works at your practice and identify areas of improvement
- Develop your *take-home action plan* for next steps in improving collaboration and teamwork in your practice
This graphic is a model of high-performing care coordination in a patient/family-centered medical home, with all of its key components, which we will review one by one.
Care Coordination: Heart of the Medical Home

- Transforms a house into a home
- Promotes efficiency and continuity of care
- Focuses on helping those in the home get their needs met (immediate and ongoing)
- Makes coming in and going out easier
- Creates a friendly, supportive environment for patients and families and each other
- Prepares patients and families for the future
Care coordination is not a solo effort! It is a team effort involving:

- the patient and family
- the care coordinator
- the entire staff
- the network of healthcare providers

Care coordinators play a central role as builders—at times functioning like architects—and at others like engineers.
Why Build This Home? The Patients/Families

Comprehensive care coordination in a medical home leads to:

- greater access to community services
- improved skills for self-advocacy
- opportunity to connect with other families
- knowledge to maintain health & living
- greater capacity to navigate the system
Consultation for the Builder…

What are the similarities and differences:

- Case management
- Disease management
- Comprehensive, high performing pediatric care coordination
Why Build This Home? The Payers

Optimal care coordination in a medical home results in...

- lowered cost of care
- timely access to information and care
- improved patient outcomes/satisfaction

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Comprehensive care coordination in a medical home leads to…

- Improved teamwork
  - effective communication
  - reduction of duplicated effort

- Increased cost-effectiveness

- Improved staff/provider job satisfaction
Comprehensive care coordination in a medical home leads to…

• Effective teamwork and improved communication

• Recognition of care coordinator’s unique contribution
  • supporting the practice team
  • assisting patients/families

• Respect and support for the care coordinator role

• Job satisfaction for the care coordinator!
Building Your Structure…

Requires knowledge of:

- the organization’s mission, history, goals and realities
- payer requirements
  - NCQA metric
  - professional standards

Requires a toolkit of both existing tools and those you create yourself
Building a Sturdy Home Requires:

- Solid foundation of mutually-held values
- Strong support structures
- Accessibility: getting in and out easily
- Convenient and comfortable living space
- Roof to protect the quality of what goes on inside...
Solid Foundation: Meets Code
Sustainability, Authentic, Quality, Caring, Partnership
Foundation: Mutually Held Values

- Proactive: Planned & Continuous
- Comprehensive
  - linked to the community
  - attentive to transitions in care
- Developmentally supportive
- Patient/family-centered includes cultural competence
- Coordinated!
Pillars = Weight Bearing Support Structures
Pillar 1: Practice and Team Support

Care coordinators should:

- Not be flying solo
- Be integrated part of the clinical team
- Be part of huddles, team meetings, informal conversations

What has worked for you?
Pillar 2: Interagency Partnerships

- Connecting patient/family to resources on the local, state, or national level
- Developing strategic relationships in order to build integrated network of services
- Cutting through red tape to expedite solutions
- Finding the right “go-to” people and agencies
- Get information from the people you serve
Pillar 3: Surveillance and Tracking Systems

- Utilizing patient registries
  - Special needs (including acuity or complexity)

- Utilizing tracking systems
  - Referrals, tests/procedures, flu shots

- Organizing clinical information

What has worked for you?
Consultation for the Builder…

How do you balance the time it takes for data surveillance and tracking with the time it takes to connect directly with patients and families?
Pillar 4: Evidence-based Guidelines

- Tracking how well the team incorporates these measures
- Resources for quality measures:
  - AAP Medical Home
  - AAFP Patient-Centered Medical Home

What has worked for you?
Performance Improvement & Outcomes Evaluation

- How has satisfaction been improved?
- Which specific patient/family outcomes measures are useful?
- Have the selected measures improved efficiency & productivity within the medical home?
- Have there been decreased costs to the family and to payers?

What has worked for you?
Module 1.4

Pediatric Care Coordination Curriculum

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Care Coordinator: Access - Communication Hub

- The “GO TO” person. Accessible & willing to respond.
- A facilitator, teacher, mentor, connector & clinical expert
- Champion of patient/family needs
- Tireless advocate
- Liaison: Patient, Family, Medical Team, Community & Services
Care Coordination: Day to Day Living

How does it happen?

- Identification and engagement
- Comprehensive assessment of patient/family
- Developing family/child/youth-centered plans of care
- Implementing the plan of care
- Monitoring and evaluation
- Ongoing population-based surveillance
Accessible means having access to...

- Health Care
- Communication
- Coordination
- Information
- Referrals
- Education
- Support
- Advocacy
Markers of Access

- Same day appointments and flexible hours
- Same day call back regarding questions
- Communication - phone, email, text and in person
- Web portal for appointments or information
- Referral to online resources
- Physical access and comfort for CYSHCN and families
- Non visit based support and care
Stages of Team Development

**Forming**
- Defining a task: Scope of a task and how to approach it
- Team Organization: Who does what? When to meet?

**Storming**
- Different ideas compete for consideration
- Team members open up - confront each other’s ideas and perspectives
- Necessary for team growth
- Can cause derailment – challenging stage!

**Norming**
- A single goal is reached and a mutually agreeable plan is outlined
- Team works as a whole
- Sacrifices are made by team members for the betterment of the whole
- Conflicts are addressed and resolved more readily

**Performing**
- Team functions as a unit – highly productive
- Jobs get done smoothly and effectively
- Teams members are interdependent, motivated & knowledgeable
- Opposing opinions are welcomed, quickly addressed, & do not derail team progress
Care Coordination: Heart of the Medical Home

- Transforms a house into a home
- Promotes efficiency and continuity of care
- Focuses on helping those in the home get their needs met (immediate and ongoing)
- Makes coming in and going out easier
- Creates a friendly, supportive environment for patients and families and each other
- Prepares patients and families for the future
Module 1.4

Pediatric Care Coordination Curriculum

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Building Collaboration and Teamwork….

My take-home action plan for building collaboration and teamwork:

• In 7 days, I/my team will…

• In 30 days, I/my team will…

• In 90 days, I/my team will have accomplished…
Curriculum Citation:

Module Citation:
The authors greatly appreciate the generous support of the Maternal and Child Health Bureau (MCHB), which made development of this curriculum possible.

The project was funded through a supplemental grant (U40MC00149) by MCHB, through a cooperative agreement with Family Voices.

MCHB Project Officer: Marie Mann, MD, FAAP
Ripple Effect: Enhancing Teams....
My personal “take home action plan”

Care Coordinator:

In 7 days I will....... 

In 30 days I will ......

In 90 days, team progress & growth will look like?
### Tips for Improving Collaboration and Teamwork

#### Think about the process...
- Collaboration is a tool, not an end in itself.
- Collaboration is hard work!
- Develop patience and endurance regarding collaboration.
- Clarify mutual goals frequently and come to consensus.
- Eliminate duplication of effort to enhance cost-effectiveness.
- Collect, summarize and use data on processes and outcomes.
- Benchmark best practices and re-assess periodically.
- Work towards gradual changes when appropriate.
- Build trust and group momentum before introducing changes.
- Hold meetings only with clear purposes; be respectful of time.
- Analyze events where there was poor collaboration; problem-solve!
- Bring research and best practices to the team meetings and members.
- Summarize meetings; send out meeting summaries to team.
- Respect chain of command; avoid jumping over others for expediency.

#### Communicate with intention and respect...
- Project confidence: slow down; speak calmly, warmly, and clearly.
- Avoid pejorative tag lines such as, “You may disagree but…”
- Beware of forms of humor that may be misunderstood.
- Sandwich negative comments with positive insights and remarks.
- Don’t overcomplicate issues.
- Avoid accusatory statements; use "I" statements.
- Stick to the essentials and avoid unnecessary details.
- Respect deadlines and time constraints, your own and other people’s.

#### Consult appropriately with others...
- Pause before consulting; use your own resources/knowledge first.
- Obtain help input when your own perspectives are limited.
- Consider worst case scenarios; expect the best outcomes.
- Anticipate what information others need to make decisions.
- Analyze areas of responsibility in each situation.
- Examine situations to see how each collaborator can share tasks.

#### Manage conflict creatively...
- Resist defensiveness; label issues/behavior that causes discomfort.
- Speak objectively & calmly; reduce volume, adjectives, intensity.
- Respectfully confront members consistently hinder group processes.
- Handle confrontations individually and privately.
- Refocus team communication towards the goal of patient well-being.
- Examine power imbalances or personality conflicts as they occur.
- Reinforce the message that all team members are all on the same side.
- Bring in skilled mediators/support people for difficult conversations.
- Remain composed; “fake it ‘til you make it.”
- Be a peacemaker, but not at the cost of respectful disagreement.
- Learn from difficult situations; become better, not bitter.

---

http://www.nursingworld.org/mainmenucategories/anamarketplace/anaperiodicals/ojin/tableofcontents/volume102005/no1jan05/tpc26_416011.aspx  
USED WITH PERMISSION
Collaboration and Teamwork
What is working for you?

In preparation for our upcoming workshop, please fill out this worksheet. We will use what you write as the basis for sharing what is working well in your practices.

Think about specific times in your practice when collaboration between staff and patients/families seems to be working really well. List some examples:

1.
2.
3.

At these times, what are you and your colleagues doing to create and maintain this kind of collaboration? List some examples:

1.
2.
3.

Think about specific times in your practice when teamwork among staff seems to be going really well. List some examples:

1.
2.
3.

At these times, what are you and your colleagues doing to create and maintain this kind of teamwork? List some examples:

1.
2.
3.
Pre-session Reading

MAKING CARE COORDINATION A CRITICAL COMPONENT OF THE PEDIATRIC HEALTH SYSTEM: A MULTIDISCIPLINARY FRAMEWORK

Richard C. Antonelli, Jeanne W. McAllister, and Jill Popp

May 2009

ABSTRACT: It is widely acknowledged that the lack of care coordination within the U.S. health care system perpetuates the fragmentation of care, cost inefficiency, and poor health outcomes. This report proposes a framework for care coordination in a high-performing pediatric health care system. To develop this framework, the authors performed a literature review, held key informant interviews, and convened an expert panel. The framework includes a definition of care coordination; outlines its principal characteristics, competencies, and functions; and sets forth a detailed process for its delivery. It also describes a model to implement care coordination across all health care settings and related disciplines.

Support for this research was provided by The Commonwealth Fund. The views presented here are those of the authors and not necessarily those of The Commonwealth Fund or its directors, officers, or staff. This and other Fund publications are available online at www.commonwealthfund.org. To learn more about new publications when they become available, visit the Fund’s Web site and register to receive e-mail alerts. Commonwealth Fund pub. no. 1277.
CONTENTS

About the Authors.............................................................................................................. iv
Acknowledgments................................................................................................................v
Executive Summary........................................................................................................... vi
Introduction..........................................................................................................................1
Review of Care Coordination Literature..............................................................................1
  Defining Care Coordination...........................................................................................2
  Impact of Care Coordination .........................................................................................3
  Case Management Versus Care Coordination ...............................................................5
Findings from Key Informants and Expert Panelists...........................................................6
A Multidisciplinary Framework for Pediatric Care Coordination.......................................7
  A Definition of High-Performing Pediatric Care Coordination ......................................8
  Critical Characteristics of High-Performing Pediatric Care Coordination ....................8
  Essential Competencies for Providing Pediatric Care Coordination .............................9
  The Functions of Care Coordination............................................................................10
  Levels of Care Coordination: Needs and Activities ....................................................12
  Evaluation: Measurement Strategies............................................................................15
Integrating Care Coordination Across the Health Care System ........................................17
Recommendations..............................................................................................................20
Conclusion .........................................................................................................................20
Notes ..................................................................................................................................22
Appendix 1. Key Informants..............................................................................................24
Appendix 2. Expert Panelists.............................................................................................26

LIST OF FIGURES AND TABLES

Figure 1 A Framework for High-Performing Pediatric Care Coordination .................. vii
Table 1 Measuring Care Coordination: Outcomes and Needed Measures ....................16
Table 2 System-Level Framework for Care Coordination in Pediatric Health Care ....18
ABOUT THE AUTHORS

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Jeanne W. McAllister, B.S.N., M.S., M.H.A., is director and cofounder of the Center for Medical Home Improvement (CMHI), Crotched Mountain Foundation, based in Concord, New Hampshire. She is an adjunct assistant professor of Psychiatry and Pediatrics at Dartmouth Medical School in Hanover, New Hampshire. Ms. McAllister’s work focuses on the implementation of the community-based primary care medical home; the quality improvement team processes needed to develop primary care medical homes; the measurement of its quality and value as a fundamental resource for children, youth, adults, and families; and the necessary policy changes to support and sustain its development. Ms. McAllister provides consultation to numerous states and programs, assisting them with their medical home strategic planning and implementation. Ms. McAllister has developed practice-based materials that support primary care teams in implementing care coordination including assessment, care planning, and educational tools. Among other publications, she is the lead author of a Pediatrics article titled “Practice-Based Care Coordination: A Medical Home Essential” and its accompanying implementation workbook.
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**ACKNOWLEDGMENTS**

The authors wish to thank the families who have taught us so much about what the American health care system should be doing to support their needs. We also wish to thank our many expert panelists and key informants who participated in this multilateral process to build a framework for pediatric care coordination, one that holds children, youth, and families at its core. We especially want to thank Ed Schor, M.D., vice president of The Commonwealth Fund’s Child Development and Preventive Care Program, for his encouragement, vision, support, and patience as we worked rigorously to achieve this final product.

May this effort inform the evolution of a high performance health care system that will enhance access, quality, and outcomes for all children, youth, and families.

________________________

*Editorial support was provided by Martha Hostetter*
EXECUTIVE SUMMARY

Care coordination is described in a Commonwealth Fund report as one of seven elements needed to organize care around patients. The Institute of Medicine has explicitly stated that care coordination is needed to improve the quality of health care in the United States. Yet there is a lack of consensus regarding care coordination’s competencies and core functions, who should provide them, the desired outcomes, and how to measure and pay for these services.

This report proposes a framework for pediatric care coordination. It includes a definition of care coordination; outlines its principal characteristics, competencies, and functions; and sets forth a detailed process for its delivery. It also describes a model to implement care coordination across all health care settings and related disciplines.

We employed multiple strategies to develop this framework, including a literature review and consultation with key informants representing families, public and commercial payers, pediatric nurses, pediatric and geriatric social workers, pediatric health care providers, and federal partners including the Maternal and Child Health Bureau and the Agency for Healthcare Research and Quality.

The proposed framework takes a family-centered approach and a health systems view with attention to interdisciplinary and environmental structures, processes, and outcomes (Figure 1). Effective care coordination is best provided in the context of a health care team, real or virtual, that has established working relationships with families, clinicians, community partners, and other professionals.
Care Coordination Definition:

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. Care coordination addresses interrelated medical, social, developmental, behavioral, educational, and financial needs to achieve optimal health and wellness outcomes.

Defining Characteristics of Care Coordination:

1. Patient- and family-centered
2. Proactive, planned, and comprehensive
3. Promotes self-care skills and independence
4. Emphasizes cross-organizational relationships

Care Coordination Competencies:

1. Develops partnerships
2. Communicates proficiently
3. Uses assessments for intervention
4. Is facile in care planning skills
5. Integrates all resource knowledge
6. Possesses goal/outcome orientation
7. Takes an adaptable and flexible approach
8. Desires continuous learning
9. Applies team-building skills
10. Is adept with information technology

Care Coordination Functions:

1. Provides separate visits and care coordination interactions
2. Manages continuous communications
3. Completes/analyzes assessments
4. Develops care plans with families
5. Manages/tracks tests, referrals, and outcomes
6. Coaches patients/families
7. Integrates critical care information
8. Supports/facilitates care transitions
9. Facilitates team meetings
10. Uses health information technology

We conclude that an integrated care coordination infrastructure is essential to create and sustain a high performance pediatric health care system. The success of this process will depend on multiple factors at all levels within the health care system and across multiple sectors of the community. Supporting this transformation will be the development of performance and outcome measures, as well as mechanisms for workforce development, education, policy support, and financing.
It is critical to note that the scope of services for care coordination for children and youth is markedly different from the scope of such services for typical adult populations. With the exception of geriatric services, care coordination for many adults is essentially management of chronic health conditions. While both adult and pediatric health care must focus on chronic conditions, care coordination that supports the comprehensive needs of children, youth, and families must be broader than this strictly medical view.

The effectiveness of a care coordination system can be measured by the experiences of the families that receive these services. Therefore, families must play a proactive role in informing the design of the infrastructure and policies that will support the development of care coordination as an integral part of the health care system.
MAKING CARE COORDINATION A CRITICAL COMPONENT OF THE PEDIATRIC HEALTH SYSTEM: A MULTIDISCIPLINARY FRAMEWORK

INTRODUCTION
Care coordination is a critical factor in a high performance health care system. It is described in a Commonwealth Fund report as one of seven elements needed to organize care and information around the patient.\(^1\) The Institute of Medicine has explicitly stated that care coordination is paramount to improving the quality of health care in the United States.\(^2\) Yet consensus is lacking regarding the competencies and core functions of care coordination, who should provide it, what the desired outcomes are, and how to measure and pay for care coordination services. In addition, the cost-effectiveness of care coordination has not yet been definitively demonstrated. There is also considerable variability in how care coordinators are hired, trained, and supported. In order to achieve a high performance health care system, it is essential and timely to define high-quality care coordination and outline the competencies and accountabilities required for community-based providers of care coordination.

This report defines care coordination; outlines its principal characteristics, competencies, and functions; and sets forth a detailed process for its delivery. It also describes a model to implement care coordination across all health care settings and related disciplines, with the goal of supporting the needs and enhancing the self-management skills of patients and families.

REVIEW OF CARE COORDINATION LITERATURE
Pediatric care coordination links children and their families with appropriate services and resources in a concentrated effort to achieve good health.\(^3\) Patients and families want and deserve quality care in a medical home, defined as care that is family-centered, comprehensive, continuous, community-based, culturally effective, compassionate, and coordinated.\(^4\) According to the professional literature, families and providers say that care coordination is often lacking in primary care. There is broad consensus with respect to the need for care coordination and the challenges health care systems and practices face when attempting to implement it. There is little research, however, on the steps necessary to overcome barriers to sustainable and successful care coordination.

A good deal of the relevant literature focuses on children and youth with special health care needs. According to the Maternal and Child Health Bureau, children and youth with special health care needs are defined as those who have or are at increased
risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally. Though children with special health care needs often require a variety of medical, social, and educational services, they frequently receive fragmented or duplicative services. According to Nolan, Orlando, and Liptak, systems and services such as primary and specialty care and educational programs are often scattered and uncoordinated. Mayer, Skinner, and Slifkin report that children and youth with disabilities or chronic health conditions typically have far more unmet needs related to important medical services than do the majority of children. As a result, they likely receive less than optimal care. Additionally, Denboba et al. and Rosenberg et al. report that poor, uninsured, and minority children may be at a heightened risk for poor coordination of services.

Delivering care coordination services is often described as complex, time-consuming, and frustrating, even though it is key to effectively managing care. Relatively little has been written about the core functions and competencies that should be embedded within care coordination services in primary care practices. Furthermore, how care coordination operations should be structured and organized to foster efficient linkages to extramural health and community-based services is unclear. Additionally, minimal guidance is available for care coordination implementation and strategies for evaluation to ensure accountability of these services.

Care coordination services have the potential to provide multiple benefits to children, their families, and the health care system. Some research has attempted to capture rates of care coordination provided in primary care practices. For example, Gupta, O’Connor, and Quezda-Gomez surveyed members of the American Academy of Pediatrics and found that most pediatricians (71%) report that their practices have a designated care coordinator. However, further inquiry about the types of care coordination services these practices provide indicated that important services for families (e.g., contacting schools or parents about findings or sharing referral information) are not occurring. Stille and Antonelli pointed out that the outcomes and efficacy of care coordination have not been demonstrated.

Defining Care Coordination
A few articles attempt to define care coordination for children and youth with special health care needs. In a technical review funded by the Agency for Healthcare Research and Quality, Wise, Huffman, and Brat conclude that there is no consistent definition of care coordination. Furthermore, many studies replace a formal definition with a list of
objectives or requirements. One reason cited for the lack of a standard definition is that care coordination does not have a strong theoretical foundation. Some of the literature recommends that families serve as the locus of care coordination, with physicians serving principally facilitative roles. There is acknowledgement, however, that the degree of engagement in care coordination by families varies from case to case. The definition of the medical home emphasizes the role of primary care in coordination of services for children. Furthermore, Cooley and McAllister suggest that designating a care coordinator within the physician’s office is essential, as is family involvement in the development and implementation of the medical home. To support the assessment of a primary care practice’s performance, the Medical Home Index has been developed to examine performance on 25 quality indicators within six domains, one of which is care coordination.

The National Quality Forum (NQF) has endorsed a definition of care coordination as a function that helps ensure patients’ needs and preferences for health services and information are met. This definition emphasizes the role that care coordination plays in delivering services to “patients by facilitating beneficial, efficient, safe, and high-quality patient experiences and improving healthcare outcomes.” The NQF framework includes five domains: the health care or medical home; a proactive plan of care that includes follow-up monitoring of progress toward patient-specific goals; communication between and among all members of the health care team and the patient, emphasizing shared decision-making with families; use of standardized, electronic information systems; and an emphasis on the need for coordinated efforts to optimize safety and accuracy during handoffs, or transfers between health care settings. To date, the NQF has endorsed a single measure outlining the content for information transfer from the in-patient setting to home, rehabilitative care, nursing care, and community based primary care settings. Though this measure was not developed to ensure care coordination, it does focus on the preparedness of patients and their caregivers.

**Impact of Care Coordination**

There is a dearth of empirical evidence regarding the impact of care coordination. Most studies have evaluated care coordination interventions for children and youth with special needs and the impact on health care utilization, costs, or health outcomes. Specifically, Criscione et al. found that individuals who were randomized into a coordinated care group had shorter average hospital stays and lower charges compared with a group receiving standard care. In a retrospective design, Liptak et al. found that children receiving care at a hospital-based ambulatory care coordination program had shorter stays and lower costs than comparison groups.
Palfrey et al. conducted a comprehensive evaluative study on care coordination for children and youth with special health care needs. The authors used a pre/post design to assess an intervention using nurse practitioners as coordinators, based within a group of primary care centers. Findings indicated that parental satisfaction increased after care coordination was implemented in primary care practices. Parents report that, compared to before the intervention, they were able to speak with nurses more easily, were more efficiently connected to community resources and supports for prescriptions, and had an enhanced understanding of the goals for care. Most important, parents reported having a stronger relationship with their primary care providers. Parents also reported greater satisfaction with services (e.g., mental health and care coordination services) after implementation of the intervention. Additional findings indicated a reduction in family needs, caregiver strain, and children’s school absences.

R. Antonelli and D. Antonelli reported the costs associated with care coordination for special needs children and youth in a primary care practice. Clinic staff recorded all non-reimbursable care coordination activities occurring over a 95-day period. Notably, half of the encounters involved care for nonmedical issues (e.g., follow-through with referrals in managed care networks, conferencing with school officials, and overseeing psychosocial problems). Extrapolating from the cost of practice-based personnel from national benchmark data, the authors concluded that the total cost of non-reimbursable care coordination activities ranged between $22,809 and $33,048 per year for a practice of four full-time-equivalent (FTE) physicians and one FTE nurse practitioner. In a follow-up study, Antonelli, Stille, and Antonelli looked at time spent performing non-reimbursable care coordination activities and resulting outcomes in six practice models across the United States. Practices representing a diversity of geographic, patient socioeconomic, and payer mix characteristics were selected. The practices used varying models of care coordination, from those with no designated care coordination staff to those with funded staff whose only tasks were related to care coordination. Significantly, care coordination activities delivered by nurses using non-billable telephone-based interventions often led to avoidance of billable office and emergency department visits.

Wise et al. concluded that there are relatively few well-executed studies looking at the impact of managed care on at-risk children. Many of these studies have differing methodologies, contradictory findings, and no direct assessment of care coordination. Future work needs to address both programmatic and structural pathways of care coordination effectiveness.
In a recent review, Bodenheimer concludes that failures in the coordination of care are common and serious. He highlights research suggesting that referrals to specialists often include inadequate information, and reports back to primary care physicians are likely to have insufficient information to sustain continuity of care. Additionally, he reviews several barriers to care coordination that have been documented in the literature. These include an overstressed primary care system, a low number of computerized records, dysfunctional payment systems, and a lack of integrated systems of care (e.g., between private physicians and emergency departments). Bodenheimer’s review highlights several innovative models that may be excellent examples of systematic changes within the pediatric health care system. One that holds promise is the “teamlet” model, in which a primary care provider works proactively and collaboratively with a practice-based coach. The coach may be a nurse, medical assistant, or specially trained care coordinator. He or she works with families to implement a jointly created care plan, which ensures that information flows between primary care and other health system stakeholders. A critical outcome of this model is the development and support of activated patients and families.

**Case Management Versus Care Coordination**

There is confusion between the overlapping services of case management and care coordination. Case management is commonly defined as 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. The process can include assessment, planning, implementation of services, monitoring, and subsequent reassessment. In many cases, targeted case management is one aspect of general disease management. Traditionally, case management services provide services in a benefits package, often supported by a health plan or managed care organization. Individuals who receive case management typically require services likely to result in high costs and have complex medical needs. There are mixed results in the literature regarding the cost-effectiveness of case management and disease management. Specifically, Mattke suggests that more research is needed to determine whether there are improvements in quality of care and lower costs associated with disease management.

In contrast, care coordination can be provided to any patient and includes a range of medical and social support services beyond medical case management. The goal of care coordination is to help link patients and families to services that optimize outcomes articulated in a patient-centered care plan. Care coordination may address the social, developmental, educational, and financial needs of patients and family. Care coordination often includes activities that may or may not be covered by defined benefit packages offered by managed care organizations.
FINDINGS FROM KEY INFORMANTS AND EXPERT PANELISTS
To inform the creation of a care coordination framework, we held teleconference interviews with 27 key informants; subsequently we convened an expert roundtable discussion with 19 panelists. Both groups were chosen for their experience in clinical practice, education, and research promoting the development and evaluation of care coordination for children and adults. Expert panelists specifically included those engaged in policy work related to health system design and delivery, payment for care coordination functions and services, and educational credentialing; others were consumer advocates, clinical experts with experience in practice-based care coordination, and leaders in academic medicine, nursing, and social work.

Twenty-five percent of those interviewed referred to the promise of the medical home model for health care reform. During interviews, the topic of care coordination was frequently associated with the successful implementation of the medical home model.

Of those interviewed, 46 percent stated that care coordination must focus on more than just medical services. Care coordination is facilitated by and in turn supports team-based care. The experts emphasized the enormous amount of coordination needed across systems, agencies, organizations, schools, and Early Intervention programs. Partnering across communities and sharing responsibility for the future of children, with shared program objectives, funding, and accountability, is a priority. Fifty percent of the experts called for research and development to build evidence demonstrating the value of care coordination.

While 35 percent of the experts stress the need for a clear definition of care coordination, including specification of a standardized set of services, there is pervasive concern about the lack of capacity in primary and specialty care to provide such services. For example, communication is particularly weak during patient transitions across care settings and among varied “managers” of health care. Many experts expressed concern about primary care shouldering the burden of filling such gaps. Generally, how much the primary care system can take on to meet current and future needs for comprehensive care coordination is a looming question. Future investment will be necessary for coordination of care to be successfully placed within the hub of primary care. Health information technology has great potential to improve care coordination. A functional information technology infrastructure can enable health care teams to reach their potential in supporting care coordination processes.
Nearly all of the expert informants describe the primary care “hub,” health care home, or medical home as the logical and effective center for care coordination. The critical role of families in care coordination was a common theme, including the notion that family leaders could effectively serve as care coordinators within a system of care. Health coaching to enable transference of knowledge and skills to parents and children needs to be a cornerstone of any care coordination framework. The role of coaches, as described by Bodenheimer and Laing, is a fundamental element of the enhanced primary care model known as a “teamlet.”

Multiple perspectives and sources of information need to be coordinated to deliver proactive care coordination in partnership with parents, youth, health care teams, and community partners. Therefore, a well-functioning “hub” is needed and will require an investment in infrastructure development and adequate reimbursement for services.

The extent and quality of care coordination will depend on the skills, knowledge, and experience of the care coordinator. There is not yet consensus among the experts regarding the necessary or optimal educational level of professionals contributing to or performing care coordination. Recommended levels of preparation range from a coordinator with a doctorate to an array of other health professionals (e.g., medical assistants, social workers, or nurses) providing care coordination under a physician’s leadership. Among the interviewees, most favored having registered nurses serve as care coordinators. Yet nurses are acknowledged as scarce and expensive, and current nursing curricula typically prepare graduates for hospital positions, which are better compensated than those in physician practices. One idealized model includes using a registered nurse who functions as a resource for a team of coordination “extendees,” including social workers, medical assistants, licensed nursing assistants, and licensed practical nurses.

A MULTIDISCIPLINARY FRAMEWORK FOR PEDIATRIC CARE COORDINATION

Based on a review of the literature and input from key informants and expert panelists and relying on a family-centered approach and a health systems view, we developed a multidisciplinary framework for pediatric care coordination. The framework emphasizes cross-disciplinary and environmental structures, processes, and outcomes. It defines care coordination and outlines its core activities—detailing the essential competencies for those involved in the provision of care coordination and establishing the predicted outcomes.

Effective care coordination is best provided in the context of a health care team, real or virtual, that has established working relationships with one another and among families and children, other clinicians, community partners, and other professionals. Team relationships are characterized by mutual respect, trust, and transparency and are grounded in the needs, concerns, and priorities of families.
The framework builds upon the six elements of the chronic care model developed by Wagner and colleagues. These include the core components of self-management support (rearticulated in our work as care partnership support to reflect a more family-centered approach), delivery system design, decision support, clinical information systems, community, and health systems. The underlying assumption is that optimal patient- and family-centered outcomes are the result of relationships in which children, youth, and their families participate in a fully informed partnership with their primary care provider and a supportive, proactive health care team. Care coordination is the ingredient necessary to operationalize care processes leading to the achievement of these outcomes.

A Definition of High-Performing Pediatric Care Coordination

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. Care coordination addresses interrelated medical, social, developmental, behavioral, educational, and financial needs in order to achieve optimal health and wellness outcomes.

To fulfill the standards set by this definition, care coordination must be connected to, or provided within, a clinician-led, proactive health care team. The team fosters partnerships with families and creates opportunities for them to express their needs. Care coordination is integrated within or strongly linked to a community-based primary care medical home setting, which has the resources and trained staff required to serve as a central hub for communication and information exchange among specialists and community partners across the continuum of care.

In its most robust state, care coordination provides linkages to systems of services available within health care, education, early child care, and family support sectors. An important component of care coordination is the creation of individualized care plans, informed by a comprehensive needs assessment and including a clear delineation of goals, roles, and responsibilities and expected outcomes.

Critical Characteristics of High-Performing Pediatric Care Coordination

Organizations and individuals delivering care coordination services should explicitly endorse the principles of high performance pediatric care coordination and implement strategies to support the provision of these services. The foundational characteristics and attributes of excellent pediatric care coordination include the following:
1. Patient- and Family-Centered
   - Links patients and families to an accessible, community-based primary care medical home

2. Proactive, Planned, and Comprehensive
   - Supports anticipatory, proactive, continuous, and longitudinal care
   - Builds on family strengths and is guided by a comprehensive, standardized assessment of needs
   - Supports and relies on team care
   - Facilitates the care-planning process including consultation, referral, testing, goals (jointly developed and shared), monitoring, and follow-up
   - Plans for the transition of youth from pediatric to adult systems of care

3. Promotes Self-Care Skills and Independence
   - Ensures the provision of patient/family education to build self-management skills
   - Equips families with the skills needed to navigate a complex health care system

4. Emphasizes Cross-Organizational Relationships
   - Builds strategic relationships across a community that support integration of care and patient/youth/family self-management skills
   - Ensures effective communication and collaboration along the continuum of care

Essential Competencies for Providing Pediatric Care Coordination

A core care coordination skill is the ability to develop and sustain caring relationships among children, youth, and families, as well as members of the community-wide support system. These competencies need to be held individually or collectively by all clinicians, nurses, social workers, and allied health care professionals who are engaged as a team supporting families. Additional competencies include:

1. Building partnerships that foster family-centered, culturally effective care;
2. Proficiency in interpersonal communication and cross-sector and interdisciplinary communication;
3. Use of team-based, patient- and family-centered assessments that identify strengths and needs of the families;

4. Care-planning skills promoting shared decision-making and patient/family self-management, with thorough follow-up;

5. Integration and shared use of accumulated medical, educational, and community resource information;

6. Efforts and attitudes that are goal- and outcome-oriented;

7. Flexibility and adaptability to the fluctuating needs of children, youth, and families in the context of a changing health care environment;

8. Continuous learning skills and team leadership sharing new knowledge;

9. Capacity to participate in organizational quality improvement activities; and

10. Resourcefulness in the use of information technologies (e.g., tracking and monitoring functions, electronic care plan development and oversight) for optimal care coordination.

Since many patients and their families execute care coordination activities to support their own needs, they should be assisted in developing these competencies. In addition, these competencies should extend to non-health professionals who may provide care coordination services.

The Functions of Care Coordination

Many practices and community-based organizations are looking for clear steps for integrating care coordination services into their fast-paced work environments. The following steps help clarify the roles of coordinators, clinicians, other team members, and families and offer ideas relevant to the testing and implementation of care coordination services.

1. Establish relationships with children, youth, and families through introductory visits dedicated to setting expectations for care coordination.

2. Promote communication with families and among professional partners, and define minimal intervals between communications.

3. Complete a child/youth and family assessment.

4. Working with the family, develop a written care plan, including a medical summary, action plan, and, if needed, an emergency plan, that reflects mutual goals.
5. Arrange for, set up, and coordinate referrals, and track referrals and test results.

6. Provide condition-specific and related medical, financial, educational, and social supportive resource information, while coaching for the transfer of skills supportive of partnerships with families to care for their children and youth.

7. Ensure the health care team integrates multiple sources of health care information; communicate this summary, thereby building caregiver skills and fostering relationships between the health care team and families.

8. Support and facilitate all care transitions from practice to practice and from the pediatric to adult systems of care.

9. Coordinate family-centered team meetings (across organizations as needed).

10. Use health information technology to effectively deliver and continually monitor care coordination and the effectiveness of service delivery.

High-quality care coordination will enable children, youth, and families to access services that support their health, developmental, behavioral, and wellness needs—to get the right care, at the right time, in the right place. Delivery of care coordination must therefore be flexible and responsive to these needs.

Assessment

Care coordination begins with a comprehensive, systematic, and structured assessment of needs, strengths, and assets. Assessment may occur in the primary care medical home or in a community-based, regional health, family support, or educational center linked to the health care system. Under certain circumstances, subspecialty providers may serve as a medical home. Using a co-management model, specialists and primary care providers communicate about care protocols and are explicit about roles and responsibilities for parents. Care coordinators can help with these communications to support integration of care across the health care system.33 The pediatric care coordination assessment includes the following elements:

- Family Status and Home Environment
  - Medical/behavioral/dental health status
  - Social supports of family and friends
  - Financial needs
  - Family demands, relationships, and functioning
  - Cultural beliefs and values of family
Strengths/assets of child, youth, family/caregivers

Current goals of child, youth, and family

Growth and Development

Child/youth developmental progress/status

Child/youth strengths/assets

School performance/needs

Emotional/behavioral strengths and needs

**Flexibility in Care Coordination Approach**

The delivery of care coordination services needs to be flexible, varying by location, encounter type, timing, intensity, and duration. Care providers must take into account the cultural preferences of each family and strive for effectiveness in different circumstances and environments. Innovative approaches to care are essential, from face-to-face visits to nontraditional encounters that optimize use of resources and maximize value for families and providers. These may include the use of:

- Telephone and/or video conferencing;
- E-mail, texting, or instant messaging;
- Group visits for children/youth/families with common conditions or concerns;
- Interactive Web sites;
- School-based visits; and
- Meetings held offsite such as team meetings that “wrap around” the child/youth and family, include a cross organizational representation of professionals involved, and may be held in a variety of community or home settings. These are established collaboratively with youth and families.

**Levels of Care Coordination: Needs and Activities**

Care coordinators use a comprehensive, systematic assessment to identify and stratify families’ needs, taking into account the requirements for carrying out care plans and the resources available to the family. Care coordinators must also have a thorough knowledge of the various health, education, and family support services in the community.

The designation of care coordination levels is critical to the evolution of an integrated system of care coordination. The complexity and intensity of care coordination is a continuum, and the level of care coordination services a family receives will reflect their needs and choices, as well as available resources.
For this framework, we stratified care coordination into three levels, depending on the intensity of services: basic, moderate, or extensive. Children, youth, and families may require different levels of services at different times.

**Level 1: Basic.** At this level, families are informed of care coordination opportunities and services and are assisted in how and when they choose to take advantage of them. Level 1 can be viewed as an “information and referral” transaction, but the services rendered should still be integrated into a comprehensive care plan.

**Example:** The parents of a 2-year-old child wonder what resources are available for child care in their community. The family is given contact information for a community agency, which provides a listing of potential child care providers.

**Level 2: Moderate.** At this level, a care coordination plan is developed with families. It details needs, short- and long-term goals, and related strategies and clarifies how care coordination services will be delivered. Skills, knowledge, and increasing responsibility for care coordination are transferred to children and families, as appropriate. Transactions at this level involve communication among various stakeholders; integration of information into a care plan is essential.

**Example:** A 30-month-old child presents with possible expressive language delay. The medical home team, in conjunction with the family, creates a care plan that includes referrals to audiology, Early Intervention, and a community-based family-to-family support center. These referrals include sufficient information to optimize the contribution of the consultative services to the child’s health and developmental outcomes.

The family is referred to an Early Intervention program. It is learned that they have no access to transportation other than the city buses. The care plan includes a referral for transportation services. A follow-up phone call in one week is arranged between the family and the care coordinator to review scheduling of appointments. An appointment in four to six weeks with the medical home team (including the primary care physician and care coordinator) is scheduled to review diagnostic assessments and propose future interventions. At that visit, assessment will be made to
determine whether active care coordination needs to continue for this family or the family members are able to maintain principal responsibility for follow-up, with supportive care coordination available on an as-needed basis.

**Level 3: Extensive.** At this level, care coordination needs to be longitudinal and far-reaching. The members of the care team and family determine methods of communication and intervals for the coordination of care, as well as assessments of progress and outcomes.

- Eligible families require the commitment of significant time and the services of appropriately trained personnel.
- Patients and families are often identified by health insurers as being eligible for case management services. Indeed, the balance of resources between case management and care coordination providers may work together to serve families—if activities are well coordinated.
- Care coordination at this level may also involve co-management among primary and subspecialty providers and community partners. To be effective, this process requires active definition and communication of the roles and responsibilities of all parties with precise documentation in a shared care plan.

Example: A 17-year-old female has cerebral palsy, a seizure disorder, and nutritional issues including dependence on a G-tube for nighttime feedings, as well as developmental and educational needs. Her care plan is multifaceted to meet her various needs for medical care (neurologic, nutritional, surgical, and gastrointestinal) as well as developmental and educational support. She will require referrals to specialists at community-based agencies and tertiary care settings. In addition, there will be issues related to her transition from pediatric to adult systems of care. Longitudinal, proactive, anticipatory, participatory, and multidisciplinary engagement of the youth with her family and care coordinator will be essential.
Evaluation: Measurement Strategies

For use in the development of a measurement strategy, Batalden and Nelson offer a four-point compass as guide, called the Clinical Values Compass. North, south, east, and west on the compass represent functional, cost, satisfaction, and clinical outcomes respectively. Table 1 uses this compass as an organizing structure to articulate the desired and anticipated outcomes resulting from excellent care coordination. For example, we hypothesize that there will be enhanced child/youth clinical outcomes and child, youth, and family functional outcomes; greater patient, family, and professional satisfaction; and a reduction in costs with an increase in efficiency and effectiveness. There are few measures available to gauge predicted and desired care coordination outcomes; it is anticipated that Figure 1 will provide a map from which to prioritize and develop this future work.
## Table 1. Measuring Care Coordination: Outcomes and Needed Measures

Clinical, cost, functional, and satisfaction outcomes to be measured at the child and family/caregiver levels, the primary care level, at all specialty care points, and from the perspective of critical community partners.

<table>
<thead>
<tr>
<th>Dimension of Value</th>
<th>Source for Measure</th>
<th>Process</th>
<th>Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Satisfaction:</strong></td>
<td></td>
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<tr>
<td>2. Reduce unmet needs</td>
<td>2. Patient, family, caregiver</td>
<td>2. Parent report</td>
<td>2. Reduced percentage of unmet needs</td>
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<tr>
<td>3. Increase provider &amp; staff satisfaction</td>
<td>3. Provider (staff)</td>
<td>3. Provider/staff report</td>
<td>3. Increased satisfaction</td>
</tr>
<tr>
<td><strong>Function:</strong></td>
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<tr>
<td>1. Ease of access to resource information</td>
<td>1. Patient, family, and primary care physician (PCP), specialist</td>
<td>1. Patient, family, PCP, and specialist report</td>
<td>1. Increased family and professional access to information about available resources</td>
</tr>
<tr>
<td>3. Enhance communication among providers/family/community partners</td>
<td>3. Patient, family, community partner, PCP, specialist</td>
<td>3. Care plans</td>
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<tr>
<td>5. Support achievement of optimal developmental trajectory</td>
<td>5. Developmental surveillance/screening tools</td>
<td>5. Standardized screening</td>
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<tr>
<td><strong>Clinical:</strong></td>
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<tr>
<td>1. Enhance communication among providers/family/community partners</td>
<td>1. Patient, family/caregiver, PCP, specialist, team</td>
<td>1. Shared care plans; co-management agreements</td>
<td>1. Reduced percentage of children seen by specialists without info from PCP; reduced percentage of children seen by PCP without information from consultants/specialists</td>
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<tr>
<td>2. Increase measures of health</td>
<td>2. Child/family</td>
<td>2. Family survey, clinical measures/outcomes</td>
<td>2. Clinical goals reached; family perception of child/youth's health increased</td>
</tr>
<tr>
<td>3. Increase activity: developmental screening and health promotion (Early and Periodic Screening, Diagnosis, and Treatment)</td>
<td>3. PCP/medical home</td>
<td>3. Measure screenings, milestone checks, community-focused measures</td>
<td>3. Increased percentage of all children screened for developmental delays and sensory deficits by select periodic well-child visits and/or school entry</td>
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<tr>
<td><strong>Costs of care:</strong></td>
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<tr>
<td>1. Reduce emergency department visits</td>
<td>1. Health plan/family</td>
<td>1. Plan and family report</td>
<td>1. Reduced utilization</td>
</tr>
<tr>
<td>2. Reduce hospitalizations/hospital days</td>
<td>2. Health plan/family</td>
<td>2. Plan and family report</td>
<td>2. Reduced utilization</td>
</tr>
<tr>
<td>4. Reduce repeat data gathering by service providers</td>
<td>4. PCP, specialist</td>
<td>4. Practice report of efficiency</td>
<td>4. Increased care team efficiency</td>
</tr>
<tr>
<td>5. Reduce caregiver work days lost</td>
<td>5. Family/caregiver</td>
<td>5. Family/caregiver report</td>
<td>5. Reduced lost work days</td>
</tr>
</tbody>
</table>
INTEGRATING CARE COORDINATION ACROSS THE HEALTH SYSTEM
Many recent policy discussions focus on care coordination almost exclusively at the level of the primary care pediatric practice. Yet, a multidisciplinary, multi-stakeholder approach is the only effective way to integrate care coordination into the broader system of care. A high-performing health care system will require clearly defined roles and responsibilities for providing and supporting care coordination at multiple levels: national organizations, federal and state governments, regional and community organizations, practices, and family (Table 2). The stakeholders at each level must play a role in ensuring the development, implementation, and monitoring of well-defined functions of care coordination.

Creating a sustainable approach to care coordination will require policy, financing, operational, regulatory, clinical, and infrastructural elements. Since the ultimate measure of effectiveness of a system of health care is how patients and families themselves experience it, process and outcome measures must be tracked at all levels, including key metrics from the perspectives of families and youth.
### Module 1.9
Pediatric Care Coordination Curriculum

#### Table 2. System-Level Framework for Care Coordination in Pediatric Health Care

<table>
<thead>
<tr>
<th>Level</th>
<th>Functions of Care Coordination</th>
<th>Enabling Factors for Care Coordination</th>
<th>Family Experience of Care</th>
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</thead>
<tbody>
<tr>
<td>National Organizations</td>
<td>Well-defined standards for care coordination are declared/disseminated</td>
<td>• Quality-focused organizations define and endorse care coordination functions at national, federal, state, regional, practice, and family levels</td>
<td>Opportunities are created for family and consumer groups to articulate their needs and expectations for care coordination</td>
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<td></td>
<td>Standards for care coordination financing are adopted</td>
<td>• Professional organizations (family advocacy, providers, allied health, payers) adopt and endorse standards for care coordination across continuum of care</td>
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<td></td>
<td></td>
<td>• Public–private partnerships seek to jointly fund aligned care coordination demonstration projects</td>
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<td></td>
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<td>• Commercial and public payers support principles to enable equitable access to care coordination services</td>
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<tr>
<td>Federal Government</td>
<td>Monitoring system-level care coordination performance</td>
<td>• Medicaid policies support care coordination framework</td>
<td>Opportunities are created for families to provide input into federal policies on care coordination and include measures of quality, safety, equity, finance, and transparency</td>
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<tr>
<td></td>
<td></td>
<td>• Link care coordination to EPSDT efforts</td>
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<td>• Public and commercial payers support unified care coordination principles</td>
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<td></td>
<td>• Fiscal support promotes system-level care coordination with quality improvement efforts</td>
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<td></td>
<td></td>
<td>• Interagency collaborations to align care coordination efforts are identified and supported including Title V, Early Intervention, Education, CMS, AHRQ, HRSA, Bureau of Primary Care, MCHB, and others</td>
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</tr>
<tr>
<td></td>
<td></td>
<td>Opportunities are created for families to provide input into federal policies on care coordination and include measures of quality, safety, equity, finance, and transparency</td>
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<tr>
<td>State Government</td>
<td>Tracking system performance:</td>
<td>• Policies promote care coordination competencies and include best-practice guidelines/standards.</td>
<td>Families are involved in developing education and training for care coordination target audiences (other families, agency staff, CBOs, medical personnel)</td>
</tr>
<tr>
<td></td>
<td>- quality and cost outcomes</td>
<td>• Interagency collaborations to align care coordination efforts are identified and supported including Title V, Early Intervention, Education, CMS, AHRQ, HRSA Bureau of Primary Care, MCHB, and others</td>
<td>System performance is transparent to families (e.g., care coordination outcomes are measured and publicly available)</td>
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<tr>
<td></td>
<td>- service provision to families</td>
<td>• Regulatory standards for safety and quality include care coordination competencies and responsibilities</td>
<td>Family leaders are supported as advisors in developing regulatory standards for care coordination provision</td>
</tr>
<tr>
<td></td>
<td>- education and training for practices</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Evaluation includes satisfaction, clinical, functional, and cost outcomes</td>
<td></td>
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</tbody>
</table>
## Module 1.9 Pediatric Care Coordination Curriculum

<table>
<thead>
<tr>
<th>Level</th>
<th>Functions of Care Coordination</th>
<th>Enabling Factors for Care Coordination</th>
<th>Family Experience of Care</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Regional/Community</strong></td>
<td>Tracking system performance:</td>
<td>• Real-time analysis of community resources for provision of care coordination</td>
<td>Families receive equitable, timely care coordination services and information that supports their ability to better care for their children and to navigate the system of care</td>
</tr>
<tr>
<td></td>
<td>- outcomes, costs</td>
<td>• Ongoing assessment of care coordination in meeting needs of patients, families, and practices</td>
<td>Family-to-family support (if desired) is integrated into care plans and easily accessible</td>
</tr>
<tr>
<td></td>
<td>- service provision to families</td>
<td>• Support regional system of protected, secure communication</td>
<td>Accurate information is transferable and shared across all components of the care system (both medical and nonmedical)</td>
</tr>
<tr>
<td></td>
<td>- technical assistance to support care coordination in and across practices</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>- family-to-family support system is at community level</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Evaluation includes satisfaction, clinical, functional, and cost outcomes</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Practice</strong></td>
<td>Colocate care coordinators if hired by outside entity or practice hires/leases trained care coordinators</td>
<td>Educational resources available to practices for care coordination</td>
<td>Well-defined team is apparent to family at point of care</td>
</tr>
<tr>
<td></td>
<td>Practice-based quality improvement to include:</td>
<td>Educational resources to support quality improvement</td>
<td>Access to team clearly defined</td>
</tr>
<tr>
<td></td>
<td>- care plan developed, used, and monitored</td>
<td>Educational resources to support family–professional partnerships</td>
<td>Patient/family responsibility as partners in care established</td>
</tr>
<tr>
<td></td>
<td>- family and/or youth advisory</td>
<td>Health information technology supports care coordination and electronic medical records/electronic</td>
<td>Receipt of care plan is standard of care for health care interaction</td>
</tr>
<tr>
<td></td>
<td>- integrate care coordination information across systems of care</td>
<td>health records and is interoperable with external systems</td>
<td>Care plan is developed and informed by all members of care team (including families)</td>
</tr>
<tr>
<td></td>
<td>Evaluation includes satisfaction, clinical, functional, and cost outcomes</td>
<td>Absent fully developed interoperable health information technology system, secure, asynchronous</td>
<td>Care plan is routinely assessed for accuracy and timeliness, and updating it is a standard part of each care</td>
</tr>
<tr>
<td></td>
<td></td>
<td>communication mechanism must exist</td>
<td>interaction</td>
</tr>
<tr>
<td><strong>Family</strong></td>
<td>Receives ongoing, on time assistance as needed; enables family and care coordination skill development</td>
<td>Availability of training curriculum for family-centered care coordination</td>
<td>Families and youth have access to health information technology for their care (e.g., via a patient portal)</td>
</tr>
<tr>
<td></td>
<td>Skill development is appropriately focused on youth in transition stages</td>
<td>Resources for youth preparing for transition are readily available</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Care coordination is culturally and linguistically competent</td>
<td>Systems of care and standard-setting organizations endorse the expectation by families that they are</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>are entitled to equitable, effective care coordination</td>
<td></td>
</tr>
</tbody>
</table>

Notes: CBO = community-based organization; EI = Early Intervention; AHRQ = Agency for Healthcare Research and Quality; CMS = Centers for Medicare and Medicaid Services; MCHB = Maternal and Child Health Bureau; HRSA = Health Resources and Services Administration; EPSDT = Early and Periodic Screening Diagnosis and Treatment.
RECOMMENDATIONS

Much work remains to be done for care coordination to become a regular feature of health care. The contributions of many sectors, both public and private, will be necessary to achieve this goal. These include:

- identifying promising models, tools, and best practices for care coordination based in medical homes;
- identifying promising community-based models to support care coordination;
- developing consensus standards for care coordination services;
- developing measures of care coordination quality;
- evaluating the effectiveness of various care coordination models and systems;
- assessing the value of care coordination for different patient populations;
- integrating care coordination capacity into electronic medical records and health information systems;
- creating a rigorous, cross-disciplinary, and family-centered curriculum for the education and preparation of care coordinators;
- creating training materials for referral from medical homes to community partners and care coordination collaborators;
- identifying policy frameworks to support the provision of care coordination services by all public and private payers; and
- transferring care coordination practices and policies for pediatric care to the care of other patient populations.

CONCLUSION

To achieve a high performance pediatric health care system, it is essential to create and sustain an integrated care coordination infrastructure. The success of this process will depend upon the design and implementation of multiple elements and promoting factors at all levels within the health care system and across multiple sectors of the community. Supporting this transformation will be the development of performance and outcome measures, as well as strategies for workforce development, education, policy support, and financing.

It is critical to point out that the scope of services that comprises comprehensive care coordination for children and youth is markedly different from the scope of care coordination services that comprises care coordination for many adult populations. With
the notable exception of geriatric services, care coordination for many adult patients is essentially management of chronic illnesses. While both adult and pediatric health care must focus on chronic conditions, care coordination that supports the comprehensive needs of children, youth, and families must be broader than this strictly medical view.

The key components of a high-performing care coordination system are most effectively assessed by how the families that receive those services experience the provision of care. To that end, family input is essential to the design of the infrastructure and policies that will support the development of care coordination as an integral part of the health care system.
NOTES


15 P. H. Wise et al., *A Critical Analysis of Care Coordination Strategies for Children with Special Health Care Needs*.


22

19 C. Parry, E. Mahoney, E. S. Chalmers et al., “Assessing the Quality of Transitional Care: Further Applications of the Care Transitions Measure,” Medical Care, 2008 46(3): 317–22.


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Medical Home Practice-Based Care Coordination:

A Workbook By:

Jeanne W. McAllister
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W. Carl Cooley

Center for Medical Home Improvement (CMHI)
Crotched Mountain Foundation & Rehabilitation Center; Greenfield, New Hampshire

Beyond the Medical Home: Cultivating Communities of Support for Children/Youth with Special Health Care Needs
Funded by: H02MC02613-01-00
United States Maternal and Child Health Bureau, Integrated Services for CSHCN, HRSA

June 2007
Workbook Contents

This workbook includes the tools and supports needed for a primary care practice to develop their capacity to offer a pediatric care coordination service; particularly for children with special health care needs. The health care team, determined to develop such an explicit service, makes an assessment of current care coordination practice and frames their improvement efforts to achieve proactive comprehensive practice-based care coordination. Tools included in this resource are: a definition of care coordination in the medical home, a care coordination position description, a framework for care coordination services including structures and processes, strategies for the protection of devoted staff time, and a logical sequence of care coordination improvement ideas offered in the context of the Model for Improvement (Langley, 1996). Each tool can be used as is or it can be customized in a manner which best fits your practice environment and the strategic plans your organization holds for medical home improvement activities.

Table of Contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical Home Practice Based Care Coordination</td>
<td>3</td>
</tr>
<tr>
<td>Medical Home Care Coordination</td>
<td></td>
</tr>
<tr>
<td>A Definition &amp; A Vision</td>
<td>5</td>
</tr>
<tr>
<td>Is It Medical Home Care Coordination? A Checklist</td>
<td>6</td>
</tr>
<tr>
<td>Medical Home (Practice Based) Care Coordination</td>
<td></td>
</tr>
<tr>
<td>- Position Description</td>
<td>7</td>
</tr>
<tr>
<td>- A Worksheet</td>
<td>8</td>
</tr>
<tr>
<td>A Medical Home (MH) Care Coordination Framework</td>
<td></td>
</tr>
<tr>
<td>- Framework</td>
<td>9</td>
</tr>
<tr>
<td>- Worksheet</td>
<td>10</td>
</tr>
<tr>
<td>Time Protection Tips &amp; Strategies</td>
<td>11</td>
</tr>
<tr>
<td>Care Coordination Development:</td>
<td></td>
</tr>
<tr>
<td>The Model for Improvement</td>
<td>12</td>
</tr>
<tr>
<td>Care Coordination Aim Statement</td>
<td>13</td>
</tr>
<tr>
<td>Care Coordination Outcomes</td>
<td>14</td>
</tr>
<tr>
<td>Plan Do Study Act (PDSA) Worksheet &amp; Examples</td>
<td>15</td>
</tr>
<tr>
<td>1) Care Coordination Role/System</td>
<td>16</td>
</tr>
<tr>
<td>2) Care Coordination – Needs Assessment</td>
<td>18</td>
</tr>
<tr>
<td>3) Comprehensive Care Planning</td>
<td>20</td>
</tr>
<tr>
<td>Medical Summary, Action &amp; Emergency Plans</td>
<td>22</td>
</tr>
<tr>
<td>4) Transition to Adult Care &amp; Services</td>
<td>24</td>
</tr>
<tr>
<td>5) Community Outreach &amp; Resources</td>
<td></td>
</tr>
<tr>
<td>Appendices</td>
<td></td>
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<td>A. Websites and References</td>
<td>26</td>
</tr>
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</table>
Medical Home - Practice-Based Care Coordination

This workbook is designed to support practice-based quality improvement teams in their efforts to build comprehensive primary care “medical homes”. The focus is specifically upon the professional role development for the provision of practice-based care coordination. The ideal care scenario is one where the staff within the medical home is proactively prepared to support the central care giving role of families. The role of care coordination discussed within this workbook is one designed in the service of children/youth with special health care needs (CYSHCN). It is acknowledged that care coordinators in different environments will apply their skills and efforts toward the care of all children as well as adults with special needs or chronic health conditions; you should find the structures and processes offered within suitably applicable.

Workbook Goals and Objectives:

Goal: To put forth a practice-based medical home care coordination framework from which practices can select and suitably customize. Contents include a medical home care coordination checklist, definition, position description, model framework with structures and processes, and strategies for effective and successful care coordination development and implementation.

Objectives:

1) Define practice-based care coordination for children with special health care needs in a medical home
2) Select and appropriately modify a position description that fits each unique medical home improvement team environment
3) Use a care coordination model framework to fit the role well within each practice environment
4) Draw from a list of time protection and resource allocation strategies those with the best fit for the practice environment and related improvements
5) Develop tests of change (PDSA - plan, do, study, act) for the incremental development of a comprehensive care coordination service model to include: care services, assessment of needs, care planning, transition support, and community outreach with resource linkages.

It is established in the literature that the medical home is meant to be a centralizing resource for children and families, particularly for CYSHCN (AAP Medical Home Advisory Committee, 2002). Evidence is building that care coordination is essential to a medical home (Antonelli, 2004). It has been suggested that you cannot be a strong medical home without the capacity to link families with a designated care coordinator; this is the ideal. The policy statement issued by the American Academy of Pediatrics on Care Coordination (CC) describes CC as complex, time consuming, even frustrating but as key to effective management of complex issues in a medical home; and states that a designated care coordinator is necessary to facilitate optimal outcomes and prevent confusion. Care coordination takes resources and time. Practices need to be reimbursed for this labor intensive role (AAP Committee on Children with Disabilities, 1999). Horst, Werner, and Werner (2000) state that in all types of systems, care coordination is an essential element to ensure quality and continuity of care for CSHCN and their families. In a 10 point strategy to
achieve transformational change within health care for all, issued by the Commonwealth Fund, care coordination is cited as one of ten key components to organize care and information around the patient (Davis, K. 2005).

Ideal care coordination provides timely access to services, continuity of care, family support, strengths-based rather than deficit-based thinking and advocacy. This is very time consuming, whether accomplished by parents or by parent professional partnerships (Presler, 1998). At the front lines of care, in the medical home Antonelli (2004) states that without the ability to support care coordination at the level of the medical home, barriers to achieve the Healthy People 2010 objectives remain. In the Future of Children (2005) the author claims that care coordination requires (at the very least) adequate personnel and time and is often limited in primary care by lack of the very time and resources necessary. This is substantiated by the AAP Periodic Survey of Fellows #44, (2000), by a national Family Voices Survey (2000) with parents reporting their physicians have the skill for coordination but are difficult to access and have minimal time available for care coordination activity/implementation. Similarly a survey of state Title V Directors and their perception of barriers to care coordination in the medical home includes: time, reimbursement, lack of physicians, lack of skill/training, and limited cultural effectiveness.

Successful medical homes result when partnerships with families offer fully implemented practice-based care coordination. Proactive care coordination and care planning are fundamentally essential for improved care quality, access to services and resources, health and function of children and youth, and quality of life as well as improved systems of care. No medical home will achieve optimal comprehensive, coordinated and compassionate care without dedicated time and resources to develop, implement, and evaluate a complement of care coordination activities. Such an investment is favorable in terms of cost and benefit for children/youth and families, primary care practices and their broader health care systems.

In summary, care coordination:

- Is accomplished everyday by families with and for their children and youth, but
- Support is desirable, feasible and beneficial coming from the medical home
- Requires critical funding and protected time
- Requires tested tools and strategies (some are included in this workbook, others have been developed and continue to evolve)
- Is a defining characteristic (element) of a fully implemented and comprehensive medical home
Medical Home Care Coordination – A Definition

The literature offers several definitions of care coordination but most have been written for application across varied health care environments such as hospitals, specialty based centers, community & home health agencies. Few definitions focus exclusively on the distinctions found within the primary care medical home for the role of practice-based care coordinator. The focus of the Center for Medical Home Improvement is on the primary care practice with the provision of team-based care coordination, delivered from the centralizing resource of a primary care medical home with physician leadership and by experienced nurses, social workers, and/or comparable professionals.

Care Coordination

Practice-based care coordination within the medical home is a direct, family/youth-centered, team oriented, outcomes focused process designed to:
- Facilitate the provision of comprehensive health promotion and chronic condition care;
- Ensure a locus of ongoing, proactive, planned care activities;
- Build and use effective communication strategies among family, the medical home, schools, specialists, and community professionals and community connections; and
- Help improve, measure, monitor and sustain quality outcomes (clinical, functional, satisfaction and cost)

(McAllister, et al, 2007)

A Vision for Practice Based Care Coordination

Children, youth, and families have seamless access to their team, enhanced by they availability of a designated care coordinator who facilitates a team approach to family-centered care coordination services.

(McAllister, et al, 2007)
## CC CHECKLIST

### Is It Medical Home Care Coordination?

Checklist – how are you doing?
What elements are in place, which require some additional attention?

<table>
<thead>
<tr>
<th>1) Families know who their care coordinator is and how to access him or her (or their backup)?</th>
<th>NO / PARTIALLY / YES</th>
</tr>
</thead>
<tbody>
<tr>
<td>2) Values of family-centeredness are known to the medical home team and drive the development and provision of care coordination?</td>
<td>1 2 3</td>
</tr>
<tr>
<td>3) A medical home care coordination position description is established; roles/activities are clearly articulated and care coordination training and education is available?</td>
<td>1 2 3</td>
</tr>
<tr>
<td>4) Administrative leadership helps to develop/support a care coordination service system; protected time allows for CC role development?</td>
<td>1 2 3</td>
</tr>
<tr>
<td>5) CYSHCN identification and assessment of child/family needs/unmet needs are completed; care planning is a core CC/medical home response?</td>
<td>1 2 3</td>
</tr>
<tr>
<td>6) Education and counseling are offered as an essential part of medical home care coordination?</td>
<td>1 2 3</td>
</tr>
<tr>
<td>7) Care coordination includes comprehensive resource information, referrals, and cross agency/organization communication?</td>
<td>1 2 3</td>
</tr>
<tr>
<td>8) Child/family advocacy is a part of care coordination</td>
<td>1 2 3</td>
</tr>
<tr>
<td>9) Families are asked for feedback about their experiences with health services/care coordination?</td>
<td>1 2 3</td>
</tr>
<tr>
<td>10) Medical home system improvements are implemented simultaneously with the development of care coordination (care coordinator contributes to this quality improvement process)?</td>
<td>1 2 3</td>
</tr>
</tbody>
</table>

Total score: _________ / out of 30.

Notes:
Medical Home (Practice Based) Care Coordination - Position Description

The care coordinator works within the context of a primary care medical home, from a team approach, and in continuous partnership with families and physicians to promote: timely access to needed care, comprehension and continuity of care, and the enhancement of child and family well being.

Care Coordination Qualifications: The care coordinator shall have:

- Bachelor’s preparation as a nurse, social worker, or the equivalent with appropriate past experience in health care
- Three years relevant experience, or the equivalent, in community based pediatrics or primary care, particularly in the care and service of vulnerable populations such as children/youth with special health care needs (CYSHCN)
- Essential leadership, advocacy, communication, education and counseling, and resource research skills
- Core philosophy or values consistent with a family-centered approach to care
- Culturally effective capabilities demonstrating a sensitivity and responsiveness to varying cultural characteristics and beliefs

Medical Home Care Coordination Responsibilities The care coordinator will:

1) Demonstrate and apply knowledge of the philosophy/principles of comprehensive, community based, family-centered, developmentally appropriate, culturally sensitive care coordination services
2) Facilitate family access to medical home providers, staff and resources
3) Assist with or promote the identification of patients in the practice with special health care needs (such as CYSHCN); add to registry and use to plan and monitor care
4) Assess child/patient and family needs and unmet needs, strengths and assets
5) Initiate family contacts; create ongoing processes for families to determine and request the level of care coordination support they desire for their child/youth or family member at any given point in time
6) Build care relationships among family and team; support the primary care-giving role of the family
7) Develop care plan with family/youth/team (emergency plan, medical summary and action plan as appropriate)
8) Carry out care plans, evaluate effectiveness, monitor in a timely way and effect changes as needed; use age appropriate transition timetables for interventions within care plans
9) Serve as the contact point, advocate and informational resource for family and community partners/payers
10) Research, find, and link resources, services and supports with/for the family
11) Educate, counsel, and support; provide developmentally appropriate anticipatory guidance; in a crisis, intervene or facilitate referrals appropriately
12) Cultivate and support primary care & subspecialty co-management with timely communication, inquiry, follow up and integration of information into the care plan
13) Coordinate inter-organizationally among family, medical home, and involved agencies; facilitate “wrap around” meetings or team conferences and attend community/school meetings with family as needed and prudent; offer outreach to the community related to the population of CYSHCN
14) Serve as a medical home quality improvement team member; help to measure quality and to identify, test, refine and implement practice improvements
15) Coordinate efforts to gain family/youth feedback regarding their experiences of health care (focus groups, surveys, other means); participate in interventions which address family/youth articulated needs
### Medical Home (Practice Based) Care Coordination Position Description Responsibilities Worksheet – Customize for Your Practice

<table>
<thead>
<tr>
<th>Care Coordination in a Medical Home – The Care Coordinator will:</th>
<th>Accept</th>
<th>Reject</th>
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<tbody>
<tr>
<td>1) Demonstrate and apply knowledge of the philosophy/principles of comprehensive, community based, family-centered, developmentally appropriate, culturally sensitive care coordination services</td>
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<tr>
<td>2) Facilitate family access to medical home providers, staff and resources</td>
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<td>3) Assist with or promote the identification of those with special health care needs (such as CYSHCN); add them to the registry and use it to plan and monitor care</td>
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<td>4) Assess child/patient and family needs/unmet needs, strengths and assets</td>
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<td>5) Initiate family contacts; create ongoing processes for families to determine and request the level of care coordination support they desire for their child, youth or family member at any given point in time</td>
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<tr>
<td>6) Build care relationships among family and team; support the primary care giving role of the family</td>
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<td>7) Develop care plan with family/youth/team (emergency plan, medical summary and action plan as appropriate)</td>
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<td>8) Carry out care plans, evaluate effectiveness, monitor in a timely way and make changes as needed; use age appropriate transition timetables for interventions within care plans</td>
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<td>10) Research find, and link resources, services and supports with/for the family</td>
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<td></td>
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<tr>
<td>11) Educate, counsel, and support; provide developmentally appropriate anticipatory guidance; in a crisis, intervene or facilitate referrals appropriately</td>
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<tr>
<td>12) Cultivate and support primary care &amp; subspecialty co-management with timely communication, inquiry, follow-up and integration of information into the care plan</td>
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<tr>
<td>13) Coordinate interorganizationally among family, the medical home, and involved agencies; facilitate “wrap around” meetings or team conferences and attend community/school meetings with family as needed and prudent; offer outreach to the community related to the population of CYSHCN</td>
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<tr>
<td>14) Serve as a medical home quality improvement team member; help to measure quality and to identify, test, refine and implement practice improvements</td>
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<tr>
<td>15) Coordinate efforts to gain family feedback regarding their experience with health care (focus groups, surveys, other means); participate in interventions that address family/youth articulated needs</td>
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</table>

***Add additional key responsibilities here (use additional paper):***
## A Medical Home (MH), Team Based, Care Coordination (CC) Framework

<table>
<thead>
<tr>
<th>Fundamental Structures</th>
<th>Medical Home Interventions</th>
<th>Tools</th>
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<tbody>
<tr>
<td><strong>Access to Medical Home, Health Care and Other Resources</strong></td>
<td>- Identify and register the CYSHCN population&lt;br&gt;- Establish with families effective means for medical home/office access&lt;br&gt;- Provide accessible office contract for family and community agencies&lt;br&gt;- Catalog resources to link families to appropriate educational, information and referral sources&lt;br&gt;- Promote and “market” practice-based care coordination to families and others (e.g. brochures, posters, outreach efforts)</td>
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<td><strong>Community Connections</strong></td>
<td>- Establish alliances with community partners&lt;br&gt;- Facilitate practice &amp; family linkages with agencies (e.g. family support, schools, early intervention, home care, day care agencies offering respite, housing, &amp; transportation)&lt;br&gt;- Align transition support activities with schools &amp; other groups&lt;br&gt;- Collaborate to improve systems of care for CYSHCN (families, payers, providers, and agencies)</td>
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<tr>
<td><strong>Fundamental Processes</strong></td>
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<tr>
<td><strong>Proactive Care Planning</strong></td>
<td>- Help to maintain health and wellness &amp; prevent secondary disease complications&lt;br&gt;- Maximize outcomes (e.g. alleviation of the burden of illness, effective communication across organizations, enrollment in needed services, and school attendance/success)&lt;br&gt;- Listen, counsel, educate, &amp; foster family skill building&lt;br&gt;- Screen for unmet family needs&lt;br&gt;- Develop written care plans; implement, monitor and update regularly&lt;br&gt;- Plan for future transition needs; incorporate into plan of care&lt;br&gt;- Facilitate subspecialty referrals, communication &amp; help family integrate recommendations of specialists&lt;br&gt;- Link family, staff to educational/financial resources</td>
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<tr>
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## A Medical Home (MH) Care Coordination Framework - WORKSHEET

### Fundamental Structures

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### Fundamental Processes

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Time Protection Tips & Strategies

The statement (on page 4) that no medical home will achieve optimal comprehensive, coordinated and compassionate care without dedicated time and resources to develop, implement, and evaluate a complement of care coordination activities warrants a few tips about how to achieve such dedicated time. Ideas for the successful implementation of practice based care coordination include administratively supported techniques and the resulting implemented care coordination (systematic) processes. Consider the following suggestions for time protection and use them to craft your own strategic approaches.

Administrative Strategies for Achieving Some “Think” and Implementation Time

- Personnel - proactively allocate a block of dedicated time. This includes the number of hours, days and time blocks or hours and how those hours will be prepared for, spent and accounted for. (This can be done as a trial or test of change)
  - You may need a private place, an office, or even a “my care coordination development hat is on today” sign!
- Clear activities – Use the position description and the CC framework on page 9 to select the focus and logical progression of this role development and how time will be spent
- Determine how you will document and/or account for this time
- Team based care coordination – determine how you will allow for the development of care coordinator - family partnership.
- Could there be a designated clinic time for specific group of CYSHCN, or a special condition focused approach with a care coordination protocol?
  - Some practices have held what is referred to as a DIGMA (drop in group medical appointments) for a group of families with children with similar conditions. A DIGMA can take on many forms such as family education, community resource connections, or even time for care coordination introduction and development with the opportunity to meet, greet and complete care plans.

Approaches Helpful to Building Time into Your System

- Use your population identification system to determine who needs care coordination
- Use the development of your CC role to establish systematized screening assessments and resulting care planning and monitoring
- Hold medical home related staff meetings; offer education regarding CYSHCN and gain buy-in and staff understanding for the value of providing care coordination
- Engage families who can educate staff about the complexity of their child’s needs
- Create a reporting line to senior leaders from the Care Coordinator so that CC development is built into their role expectation
- Develop the capacity for care coordination “rounds” by discussing direct CC efforts around individual children and youth with staff; gaining the input of colleagues will help you with staff education and their buy in to the medical home and practice-based care coordination approach; all will then learn about complex health and community based needs and resources
- Maximizing Reimbursement for Care Coordination:
  - Ensuring affordability and sustainability by:
    - Developing smart legitimate up-coding;
    - Tracking CC data (service/outcome) to negotiate new payment opportunities
  - Prepare for the use of new codes (care plan oversight)
  - Become aware of and access Title V supports

11
Care Coordination Development:

1) The Model for Improvement

2) Care Coordination Aim Statement

3) Plan Do Study Act (PDSA) cycles or “tests of change”

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Model for Improvement Questions

<table>
<thead>
<tr>
<th>Model for Improvement Questions</th>
<th>Medical Home Improvement Responses</th>
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<tbody>
<tr>
<td>1) What are we trying to accomplish?</td>
<td>Medical Home - Care Coordination</td>
</tr>
<tr>
<td>2) How will we know that a change is an improvement?</td>
<td>Measures – Medical Home Index, Medical Home <em>Family</em> Index &amp; Survey, Other</td>
</tr>
<tr>
<td>3) What changes can we make that will result in an improvement?</td>
<td>Good ideas - ready for use (e.g. CC definition, job description, framework &amp; activities, PDSA examples</td>
</tr>
</tbody>
</table>
2) Care Coordination Aim Statement

A good aim statement includes the following elements:

- Population - CYSHCN
- Timeframe – by when
- Intent – what/why
- Stretch goals – e.g. identify 100% CSHCN

Example:

Overarching Aim - Care Coordination

Between Learning Session 2 and spring of 2006 we will customize and use a model of medical home care coordination for children/youth with special health care needs so that a position description and framework of activities are explicit, with time protected and accounted for and \( \sim 75\% \) (goal) of children, youth and families report that they:

- Know who their care coordinator is
- Know they are receiving care coordination
- Participate in decisions about the level of care coordination needed
- Are satisfied with their access to care, care coordination, and resources (most of the time)

\( \forall \) For Veterans - Advanced Care Coordination Aim Goals

Youth and families report that:

- A transition timetable is shared among family, practice and community professionals
- They have coordinated support getting their child’s needs met within the community and from sub-specialists
Thinking Through Some Measurement Ideas – For Practice-Based Care Coordination – PDSA Cycles

Care Coordination Outcomes

Family satisfaction
- decrease in worry and frustration (CMHI survey tools)
- increased sense of partnership with professionals (CMHI survey tools)
- improved satisfaction with team communication (CMHI survey tools)

Staff satisfaction
- improved communication and coordination of care
- improved efficiency of care
- elevated challenge and professional role

Improved child/youth outcomes
- Decrease in ER visits, hospitalizations, & school absences (family, plan report)
- Increase in access to needed resources (CMHI survey tools)
- Enhanced self-management skills (CMHI survey tools)

Improved systems outcomes
- decreased duplication
- decreased fragmentation
- improved communication and coordination (CMHI Medical Home Index)
PDSA Worksheet

CMHI Plan-Do-Study-Act Worksheet

Team:

Aim:

**PLAN:**

Objective: (Including details (who, what, where, when)

What additional information will you need to take action?

What do you predict will happen?

How will you know your change is an improvement?

**DO:**

Was the plan carried out?

What was observed that was not part of the plan?

**STUDY:**

What happened?

Is this what you predicted? What new knowledge was gained?

**ACT:**

As a result, list next actions:

Are there organizational forces that will help or hinder efforts?

Objectives for next test of change:
CMHI Plan-Do-Study-Act (PDSA) Worksheet

PDSA Example  #1 Care Coordination Role/System

Team:

Aim: Use from page 13 or create own

[**PLAN:**]

**Objective:** (Including details (who, what, where, when)
We will develop and test a clearly defined system of care coordination (CC) services using strategies that fit our practice environment. This will include the use of a: 1) clear CC definition, 2) CC position description and 3) CC framework with an outline of activities. CC role, contact and access information will be explicit for families.
(Our test of change will include dedicated time for the CC to share plans with staff and implement CC PDSA cycles (see examples in following pages). We will feed back lessons learned to our Medical Home Improvement team for guidance and direction.

**What additional information will you need to take action?**
Knowledge of and securing the availability of senior leader support with designation of one (or more) staff members to provide CC leadership

**What do you predict will happen?**
There will be false starts with “tyranny of the urgent” keeping us from our task; our will, ideas and execution will overcome this in the end.

**How will you know your change is an improvement?** Staff/families begin to ask for care coordination / CC activities (e.g. care plan); selected outcome measures improve (see page 14)

[**DO:**]

Was the plan carried out?

What was observed that was not part of the plan?

[**STUDY:**]

What happened?

Is this what you predicted? What new knowledge was gained?

[**ACT:**]

As a result, list next actions:

Are there organizational forces that will help or hinder efforts?

Objectives for next test of change:
PDSA Worksheet

**Team:**

**Aim:**

<table>
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<tr>
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<td>What additional information will you need to take action?</td>
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<td>What do you predict will happen?</td>
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<tr>
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<th><strong>ACT:</strong></th>
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<tr>
<td>Objectives for next test of change:</td>
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CMHI Plan-Do-Study-Act Worksheet

PDSA Example #2 Care Coordination Needs Assessment

Team:

Aim: Use from page 13 or create own

PLAN:

Objective: (Including details (who, what, where, when))
With MH lead physician review pending CYSHCN visits; select 3 CYSHCN who will benefit from an assessment for care coordination. By “a week from next Tuesday” complete an assessment (e.g. parent/youth screening tool in appendices behind page 26) either before the office visit or by pre-visit phone call. Begin care planning process with child/youth and family

What additional information will you need to take action?
Listing of pending CYSHCN visits from the CYSHCN list or “registry”

What do you predict will happen?
Some false starts finding the right CYSHCN and with timing; we will succeed if persistent over slightly longer time span

How will you know your change is an improvement?
Follow up with 3 families in 2 weeks to determine if pre-visit assessment and follow-up planning are helpful and what needs to be added/improved; review value with lead physician as well.

DO:

Was the plan carried out?

What was observed that was not part of the plan?

STUDY:

What happened?

Is this what you predicted? What new knowledge was gained?

ACT:

As a result, list next actions:

Are there organizational forces that will help or hinder efforts?

Objectives for next test of change:
PDSA Worksheet

PDSA CMHI Plan-Do-Study-Act Worksheet

Team:
Aim:

**PLAN:**

Objective: (Including details (who, what, where, when)

What additional information will you need to take action?

What do you predict will happen?

How will you know your change is an improvement?

**DO:**

Was the plan carried out?

What was observed that was not part of the plan?

**STUDY:**

What happened?

Is this what you predicted? What new knowledge was gained?

**ACT:**

As a result, list next actions:

Are there organizational forces that will help or hinder efforts?

Objectives for next test of change:
CMHI Plan-Do-Study-Act Worksheet

PDSA Example #3 Comprehensive Care Planning

Team:

Aim: Use from page 13 or create own

<table>
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<th>PLAN:</th>
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| Objective: (Including details (who, what, where, when))  
1) Develop/choose care plan *medical summary* and use with 5 identified CYSHCN/week.  2) Add an *emergency plan* if warranted.  3) Study provider and family feedback and integrate to improve the plan and the process for plan use.  
Create immediate *action plan* for how to meet resource, educational and other needs of CYSHCN/patient and family  4) Use lessons learned to share, engage, educate and spread medical home to staff.  
What additional information will you need to take action?  
Sample care plans to choose from using team priorities; identified CYSHCN with pending visit to initiate plan with.  Also identify educational needs of staff /families.  
What do you predict will happen? Will start slow, 1-2 per week and pick up speed to reach 5.  
*Value* will result in better preservation of care coordinator time to complete plans, thus increased use of CC and team process. Ultimately, we may schedule comprehensive care planning “rounds” with team/staff; review 3-5 CYSHCN/patients who are receiving this care coordination. Use rounds to review successes, challenges, needs of child/family with staff and address questions.  
How will you know your change is an improvement?  
Review with families for benefit, follow up in 4-6 weeks; review also with staff |  

| DO: | Was the plan carried out?  
What was observed that was not part of the plan? |

| STUDY: | What happened?  
Is this what you predicted? What new knowledge was gained? |

| ACT: | As a result, list next actions:  
Are there organizational forces that will help or hinder efforts?  
Objectives for next test of change: |
PDSA Worksheet

Team:

Aim:

**PLAN:**

Objective: (Including details (who, what, where, when)

What additional information will you need to take action?

What do you predict will happen?

How will you know your change is an improvement?

**DO:**

Was the plan carried out?

What was observed that was not part of the plan?

**STUDY:**

What happened?

Is this what you predicted? What new knowledge was gained?

**ACT:**

As a result, list next actions:

Are there organizational forces that will help or hinder efforts?

Objectives for next test of change:
CMHI Plan-Do-Study-Act Worksheet

PDSA Example #4 Transition to Adult Care & Services; Up-coding to maximize reimbursement

Team:

Aim: Use from page 13 or create own

PLAN:

Objective: Have MD & Care Coordinator jointly see (2) YSHCN & family for transition visit; use a transition assessment (timetable) checklist to guide the visit and align activities with community partners. Bill for visit – document nature of complexity

Details (who, what, where, when) CC Schedules 2 YSHCN for transition care plan visit next week, with family permission informs/communicates with key community partners about assets & needs. Codes for “99214” for 60 minute visit with established patient and document extent and complexity of the visit

What additional information will we need to take action? - Extract from list of CYSHCN youth over 14 due for visit; communicate with family and learn community partners - Clarify with senior leaders ability to track reimbursement results for these visits

What do we predict will happen? (E.g. May take time to match YSHCN with open slots; will need to follow up with payers for denials and use documentation to justify activities).

How will you know your change is an improvement? Review with family staff; community partners. Select other ongoing measures (p14)

DO:

Was the plan carried out?

What was observed that was not part of the plan?

STUDY:

What happened?

Is this what you predicted? What new knowledge was gained?

ACT:

As a result, list next actions:

Are there organizational forces that will help or hinder efforts?

Objectives for next test of change:
PDSA worksheet

PDSA  CMHI Plan-Do-Study-Act Worksheet

Team:
Aim:

**PLAN:**
Objective: (Including details (who, what, where, when)

What additional information will you need to take action?

What do you predict will happen?

How will you know your change is an improvement?

**DO:**
Was the plan carried out?

What was observed that was not part of the plan?

**STUDY:**
What happened?

Is this what you predicted? What new knowledge was gained?

**ACT:**
As a result, list next actions:

Are there organizational forces that will help or hinder efforts?

Objectives for next test of change:
CMHI Plan-Do-Study-Act Worksheet

PDSA Example #5 Community Outreach / Resources

Team:

Aim: Use from page 13 or create own

**PLAN:**

**Objective:** (Including details (who, what, where, when))
Plan for care continuity across the: medical home, school, and community agencies with 4 families and children/youth over the next four weeks. Use a selected communication strategy (fax back, e-mail, NCR paper, electronic forum, other) to centralize key information with strengths, goals, care plans, access information, and releases fostering cross organizational communication; the CC performs as a “hub of the wheel function” in these activities.

**What additional information will you need to take action?**
Identification of children/youth and families in need of transition and/or community-based coordination; identification of key community partners; consensus on communication strategy

**What do you predict will happen?**
Territorial barriers will crop up and family will need to be front and central to the process.

**How will you know your change is an improvement?**
Review with family and agencies whether there has been improved care communication, also consider other systematized outcome measures (see page 14).

**DO:**

Was the plan carried out?

What was observed that was not part of the plan?

**STUDY:**

What happened?

Is this what you predicted? What new knowledge was gained?

**ACT:**

As a result, list next actions:

Are there organizational forces that will help or hinder efforts?

Objectives for next test of change:
PDSA Worksheet

Team:
Aim:

**PLAN:**

Objective: (Including details (who, what, where, when)

What additional information will you need to take action?

What do you predict will happen?

How will you know your change is an improvement?

**DO:**
Was the plan carried out?
What was observed that was not part of the plan?

**STUDY:**
What happened?
Is this what you predicted? What new knowledge was gained?

**ACT:**
As a result, list next actions:
Are there organizational forces that will help or hinder efforts?
Objectives for next test of change:
Appendices A.
Key Websites for Care Coordination Tools
1) Center for Medical Home Improvement (CMHI): www.medicalhomeimprovement.org
2) National Center for Medical Home Initiatives (AAP) www.medicalhomeinfo.org
3) Utah Medical Home Portal www.medhomeportal.org

References
5) Antonelli, R., Antonelli, D., Providing a Medical Home: The Cost of Care Coordination: Services in a Community-Based, General Pediatric Practice. Pediatrics (Supplement) 2004; Vol. 113: 1522-1528
Pediatric Care Coordination Curriculum

Module 1.10

Center for Medical Home Improvement (CMHI)
Crotched Mountain Foundation
Greenfield, New Hampshire
2007
Module 2

Care Coordination as a Continuous Partnership

1. Overview
2. Facilitator Guide
3. In-Session Handout – Questions & Tips for Building Partnerships with Families
4. In-Session Handout – Pediatric Care Coordination Assessment
5. Pre-Session Handout – Care Coordination: a Parent’s Perspective
6. Pre-Session Handout – Parents as Practitioners in Pediatrics
7. Videos to Use During This Module
Pediatric Care Coordination Curriculum

Module Title: Care Coordination as a Continuous Partnership – Module 2

Module Format: In-Person Workshop (~2 Hours)

Module Overview: This module enables care coordinators to develop the values, knowledge, and skills necessary for forming effective, continuous partnership relationships that can support and empower children, youth, and families within the context of their patient/family-centered medical home.

Audience: Care coordinators and/or members of the care coordination team

Rationale: This curriculum was created with the goal of offering practical, experience-based principles to facilitate the introduction and continued enrichment of care coordination.

Module Goals and Learning Objectives:

1. Explore the nature and dynamics of different kinds of “care coordination partnership relationships” with children, youth, and families.
2. Define and understand five core components of building partnerships with children, youth and families:
   • Building partnerships means appreciating that the most important tool you will ever use with children, youth and families is yourself
   • Building Partnerships means working with children, youth and families, not doing things to them without their approval, or for them without their involvement.
   • Building partnerships means meeting children, youth and families where they are and learning from them what they want.
   • Building partnerships means helping children, youth and families to realize that they know more than they think they know (and often more than what we think we know).
   • Building partnerships means appreciating that children, youth and families (as well as care coordinators) can learn what they don’t know and need to know through practice.
3. Discuss how these new understandings of building partnerships with children, youth and families can inform their practices going forward.

Module Activity Summary:

<table>
<thead>
<tr>
<th>Activity</th>
<th>Time</th>
<th>Materials Required</th>
<th>Faculty</th>
</tr>
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<tbody>
<tr>
<td>Pre-workshop Email containing Handouts</td>
<td>N/A</td>
<td>“Care Coordination: A Parent’s Perspective”</td>
<td>N/A</td>
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<tr>
<td></td>
<td></td>
<td>“Parents as Practitioners in Pediatrics”</td>
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</tr>
<tr>
<td>Introduction and Overview (including Parent Leader’s experience)</td>
<td>5 Minutes</td>
<td>Note pads &amp; pens for participants</td>
<td>Session Leaders (Family Leader and Experienced Care Coordinator)</td>
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<tr>
<td></td>
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<td></td>
<td>Small Group Facilitators (1/group of 5)</td>
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<tr>
<td>White Board Exercise (Large Group)</td>
<td>20 Minutes</td>
<td>White Board or Large Post-it Easel Markers</td>
<td>Session Leaders</td>
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<td>Small Group Facilitators (1/group of 5)</td>
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</table>
# Pediatric Care Coordination Curriculum

<table>
<thead>
<tr>
<th>Video and Discussion (Large Group)</th>
<th>40 Minutes</th>
<th>“Parents as Practitioners in Pediatrics” Handout Film “Knowing Who We Are” (10 Min)</th>
<th>Session Leaders Small Group Facilitators (1/group of 5)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sharing Narratives &amp; Reflection (Small Groups)</td>
<td>40 Minutes</td>
<td>“Questions and Tips for Building Partnerships” Pediatrics Care Assessment Tool (McAllister/CMHI) Handouts</td>
<td>Small Group Facilitators (1/group of 5)</td>
</tr>
<tr>
<td>Translating Insights into Action (Large Group)</td>
<td>15 Minutes</td>
<td></td>
<td>Session Leaders Small Group Facilitators (1/group of 5)</td>
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</tbody>
</table>

### Evaluation:

**Short term:** Attendees will be asked near the end of the session to come up with 2-3 tips, approaches, and/or strategies that they learned that they will commit to putting into practice over the next few weeks. Once in the large group at the end of the session attendees will be asked to share the strategies they are going to take away and discuss next steps for action with the group.

**Long term:** Follow up with the attendees 4-6 weeks after the session via conference call or listserv survey to see how the strategies they planned to act upon have impacted the relationships that they’ve built.

To purchase the *Knowing Who We Are* video, please contact the Education Development Center, Inc.

Shannon Cassidy  
Health and Human Development Division (HHD)  
43 Foundry Avenue  
Waltham, MA 02453  
Email: scassidy@edc.org

Education Development Center, Inc.  
General Contact Information:  
Email: contact@edc.org  
Phone: 617-969-7100  
Fax: 617-969-5979
Pediatric Care Coordination Curriculum

Module 2: Care Coordination as a Continuous Partnership – Facilitator Guide

Time: 2 hrs

Module Workgroup: Jennie Austin, David Browning, Marion Donohoe, Eileen Forlenza, Jeanne McAllister

Teaching Note: This module should be conducted collaboratively by a family leader and an individual actively involved in care coordination and/or experienced in forming partnership relationships with families.

<table>
<thead>
<tr>
<th>Activity</th>
<th>Instructions and Content</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre-Workshop Activity</td>
<td>One week prior to scheduled session, send advance email to workshop participants. Include as attachment Handout 1 written by a family member (Eileen Forlenza), as well as Handout 2, “Parents as Practitioners in Pediatrics.” Ask participants to begin reflecting on the ingredients of effective partnership relationships between care coordinators and families. Explain that workshop participants will be asked during the workshop to share their own experiences of working to create strong and effective partnership relationships with families.</td>
</tr>
<tr>
<td>Introduction/Overview</td>
<td>1. Describe the overarching goal for this session: The goal of this session is to enable care coordinators (and others performing care coordination functions) to develop the values, knowledge, and skills necessary for forming effective, continuous partnership relationships that can support and empower children, youth and families within the context of their patient/family-centered medical home.</td>
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<td></td>
<td>2. Introduce large-group and small-group facilitators. Give family leader the opportunity to describe briefly his/her experience as the parent of a child with special healthcare needs.</td>
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<td>3. Review format and timeline for this 2-hour session.</td>
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<td></td>
<td>4. Review ground rules for collaborative learning:</td>
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<td></td>
<td>• There are no “stupid” questions or comments.</td>
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<td></td>
<td>• All participants should feel comfortable sharing their perspectives (both quiet and loud voices).</td>
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<tr>
<td></td>
<td>• The process of learning in the workshop should parallel how family members and members of the healthcare team learn together in practice (ie, collaboration and partnership).</td>
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<tr>
<td></td>
<td>In preparation for this session, you were all provided with the narrative of a parent, Eileen Forlenza, who shared her experience about building a partnership with her child’s care coordinator. We also asked you to think about your own experiences forming partnerships with patients and families.</td>
</tr>
</tbody>
</table>
Later, in the small groups, we will delve more deeply into what we can learn from the wealth of experience in this room. But now, based on what you have learned from reflecting on Eileen Forlenza’s account and reflecting on your experience, let’s identify together the ingredients of an effective partnership relationship. Spend a minute thinking about a family you have worked with (in the past or currently) in which you have found either the family or the situation quite challenging but feel that you have been able nevertheless to build a strong and effective partnership. State out loud what you think are the ingredients in that partnership that have made it successful.

List the ingredients on a whiteboard or easel pad.

Transition now to describing the five core components of building partnerships with children, youth, and families that we will be focusing on in this session. If the group has already identified some of these components, make a point of highlighting this fact. Also make a point of highlighting things they have identified that expand on the ideas in the list below.

1. Building partnerships means appreciating that the most important tool you will ever use with children, youth and families is **yourself**.

2. Building partnerships means working **with** children, youth and families, not doing things **to** them without their approval, or **for** them without their involvement.

   Very often, patients and families are accustomed to having healthcare services delivered **TO** them or **FOR** them. A useful way to think about partnership is that care is designed and delivered by members of the healthcare team WITH the active partnership of the patient/family.

3. Building partnerships means meeting children, youth and families where they are and learning from them what they want.

4. Building partnerships means helping children, youth and families (as well as care coordinators) to realize that they know more than they think they know.

5. Building partnerships means appreciating that children, youth and families (as well as care coordinators) can learn what they don’t know and need to know through practice. (Families may need help to know where they should be focusing their attention and what they need to be learning, i.e. anticipatory guidance).

At the core of any effective partnership is the ability of all parties to communicate needs, abilities, and expectations (in order to achieve optimal outcomes.) Communication between the family and a team-based care coordinator builds a foundation of knowledge and sets up realistic expectations as a basis for continuous planning.

Essential to building this kind of partnership is the art of listening. Listening in a partnership means being able to understand the language of one’s partner. This is a competency needed by both the family and the coordinator at multiple levels.

We will explore these components of building partnerships throughout the remainder of the session. Keeping in mind component #2, rather than teaching to you or explaining things **for** you, we will focus instead on learning **with** you, because it is knowledge that comes from practice that helps people develop proficiency in how to go about building partnerships.

So, our content for the remainder of the session will be family members and care coordinators speaking about these issues from their experience. In our large group, we will watch and discuss a video narrative, 14 minutes long. Then, in small groups, we will have the opportunity to explore partnership relationships in greater depth, using your own experience and stories to organize the conversation. We will end the workshop back in the large group, asking workshop participants to each identify 1-2 things about building partnerships with families that they learned in the workshop and intend to put into practice in the coming weeks.
Now, let's hear about the needs of a family of a child with a serious, life-limiting illness. As you watch their story, think about what they are telling us about their own practice as parents, their needs for care coordination, other needs they have, and what they need from the healthcare system in general and from healthcare professionals in particular.

*Show short film, “Knowing Who We Are” [15 min]*

**Begin discussion by asking family leader to respond to the Lilly Family’s story in contrast with her own. What aspects of their experience were similar and what aspects were different, in general and also specifically in relation to care coordination? [10 min]**

**Continue discussion with focus on issues raised by Lilly family and by parent leader [15 min]**

Consider any of the following questions as additional prompts for discussion:

- **What did the Lilly family want health care professionals to know about who they are as a family, about how they were living with Rebecca’s illness, and about their needs?**

- **Mrs. Lilly says that “health care professionals have to be pretty good readers of people.” As a care coordinator, what have you found to be the most helpful or effective ways of “reading people,” that is, ways to gain knowledge about children and families, assess their needs, and respond to their concerns? How do we know when we are reading children and families correctly? How do we know when we are missing the mark?**

- **What are realistic expectations to set for yourself as a care coordinator in getting to know families in some of the ways described by the Lilly family? What are the barriers or obstacles—personal, professional, and organizational—in getting to know families in these ways?**

- **What lesson do you take from the following comments from Anne-Marie Lilly (the adult daughter): “From a healthcare perspective, you need to go in there waiting to see what they bring to you. Seeing what the family make-up is and...supporting them in any way you can versus bringing your structure...because that doesn’t tend to work very well.” How can tools, procedures, and protocols either help or hinder the process of getting to know families on their own terms? How can you tell if they are helping or hindering? How do you know when the needs of the family are being served, versus meeting your own professional needs (to document information, for example) or the needs of the medical practice in which you work?**

- **Mr. Lilly, reflecting on the period in which his daughter’s health was worsening and the burdens on the family were becoming increasingly great, says, “No one ever came up to me and said, ‘This really sucks.’” What do you think he is telling us? Do we sometimes become so focused on helping families to manage whatever they are dealing with that we forget to acknowledge the extent of the emotional burden they may be experiencing? As a care coordinator, what is it like for you when the primary thing you have to offer is compassion and empathy but there is nothing that can be “fixed”? When you do extend yourselves to families at times like these, how do you do it? How do you manage your own feelings at these times?**

*As a transition to meeting in small groups, explain that the group will now re-convene in small groups, in order to learn from each other in greater detail about the different ways care coordinators go about forming effective partnership relationships with families.*
**Pediatric Care Coordination Curriculum**

### Module 2.2

<table>
<thead>
<tr>
<th>Sharing Narratives &amp; Reflection</th>
<th>We want to learn more about building partnerships with families by delving more deeply into your own experience building partnerships with families, and the knowledge that comes from that experience.</th>
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<tbody>
<tr>
<td>Small Groups (40 min)</td>
<td><em>Ask several participants to share their experience. Build upon the themes that were established in the large group conversation following the video.</em></td>
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<td><em>With 10 minutes remaining in the small groups, provide participants Handout 3, “Questions and Tips for Building Partnerships” and Handout 4, the pediatric care assessment tool (McAllister/CMHI). Point out ways in which participants were using some of these approaches and strategies in their narratives. Ask for questions and responses to the ideas represented in the handouts.</em></td>
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<td></td>
<td><em>End the small group session by giving participants a few minutes to identify for themselves 2-3 questions, tips, approaches, or strategies that came from their learning today that they will commit themselves to putting into practice in the coming weeks. Explain that the last minutes of the large group session will be spent asking participants to share these take-home strategies with each other.</em></td>
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<tr>
<th>Translating Insights into Action</th>
<th>Utilizing the energy and momentum of the learning that has happened in the large group and small group settings, the remaining minutes of the workshop will be spent in the large group, summarizing what was learned by discussing action steps participants will take.</th>
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<tbody>
<tr>
<td>Large Group (15 min)</td>
<td>We’ve spent the last two hours exploring how care coordinators build relationships with children, youth and families, and how these relationships change over time. We hope the learning going on in the past few hours has been engaging and valuable. We know, however, that however valuable it is to learn things together, what really matters is what comes of it, that is, how the learning gets carried forward from this workshop, how it get translated into practice.</td>
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<td>We want to finish out our time together by asking each of you to say out loud 1-2 things that stood out in your learning today that you want to commit yourself to applying to your practices in the coming weeks and months. Don’t worry about whether you are repeating things that are said by others. We are doing this in order for all of us to hear what was most important about today’s learning, and for you each to say out loud a few things you learned that you intend to apply in your work going forward.</td>
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<td><em>Ask participants to state out loud their take-home action items. Manage time as needed. Conclude the session.</em></td>
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Questions & Tips for Building Partnerships with Families

To better understand their child and who they are as a family...

- Families and family members have different preferences about names. Would you prefer that we speak to you as Mr./Mrs. ____, or by your first name, or by a nickname? How should we speak to your child?

- Tell me about your child. Tell me about your family. Are there siblings? Are there members of your extended family who play an important role? Are there close friends who you consider part of the family?

- What is your understanding of your child’s condition? What is your child’s understanding of the condition/illness? How do siblings understand the condition/illness?

- Knowing your child as you do, are there things about him/her we as a healthcare teams might be unlikely to know, yet important for us to learn? What are your child’s greatest strengths?

- Knowing your family as you do, are there things about the family we as a healthcare team might be unlikely to know, yet important for us to learn? What are your family’s greatest strengths?

- You can help us to understand your child and your family. Is there anything we (or other healthcare professionals you have come in contact with) do not seem to understand that you want us to understand?

To better understand how they manage/cope with their child’s health condition and find/accept the support of others...

- How have you managed your child’s illness/condition up until now? How are you doing currently?

- How has your child managed up until now? How is he/she doing now? How have siblings been getting along?

- What are the most difficult things you have faced as a family? How have you managed your way through these tough times?

- What are some of the decisions you have needed to make in dealing with your child’s illness/condition? How have you gone about making these decisions? Is there a typical way you go about making decisions as a family?

- How have things changed in the family since your child was diagnosed with this illness/condition? For you as parents? For your child? For siblings? For extended family members?

- Are you the kind of person that is pretty good at recognizing the strengths and good points about yourself/your child/your family? Or, are you the kind of person that has trouble seeing strengths and good points even when they are there?

- Are there particular things you are trying to understand about your child’s illness/condition or about how to get your child’s needs met?

- Where does your support—social, emotional, spiritual—come from? Are there members of the extended family or close friends, health care providers, etc. who are important parts of your support system?

- Do you have a faith tradition or cultural practices that are important in your family? If so, are there ways we can support you in the expression of these?
To better understand the family’s current needs, and how can we help...

- What is most important to you in the care of your child currently? What do you think is most important to your child? Is there anything you are especially worried about? Is there anything your child is especially worried about? What do you want? What do you need? How can we help you?

- What practical concerns do you have related to your child’s illness/condition (e.g., finances, transportation, work schedule, childcare, etc.)?

- We know that good communication is at the core of good health care. How has communication gone with the healthcare team and other healthcare professionals? Are you getting the information and input that you need? Are we explaining things to you in a way that you can understand? When you talk to us, do you feel that we understand what is most important to you?

- We want to help you understand how the healthcare system works. Dealing with this medical world can be a difficult process for families. Is there anything you don’t understand or don’t like about the way we operate, how we communicate, why we do things the way we do?

- Parents sometimes feel that their parental roles become less clear when their child enters the healthcare system and is entrusted to the care of others. Are there ways we can support you and work together with you as partners?

- In your contact with the healthcare team so far, what has been helpful to you? What has not been helpful? What has been helpful to your child? What has not been helpful?
Pediatric Care Coordination “Assessment”

Child’s Name_____________________________ Family Name _____________________________ Date________________

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

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

________________________________________________________________________________________

3) Do you have any concerns or worries for your child? (Some examples below)
   ☐ Their growth/development
   ☐ Learning
   ☐ Sleeping
   ☐ Self-care
   ☐ Making and keeping friends
   ☐ Other (fill in): ____________________________
   ☐ Doing things for themselves
   ☐ Falling behind in school
   ☐ Behavior
   ☐ The future
   ☐ Playing with friends

4) Have there been any changes in your family since we saw you last, such as a:
   ☐ Brother or sister leaving home?
   ☐ Move to a new town?
   ☐ Sickness or death of a loved one?

   ☐ New job or job change?
   ☐ Separation or divorce?
   ☐ Other (fill in below)?

________________________________________________________________________________________

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

   ☐ **Medical Needs** (For example, help finding or understanding medical information; help
     finding health care for yourself or your family)?

   ☐ **Social Needs** (For example, having someone to talk to when you need to; getting support at
     home; finding supports for the rest of your family)?

   ☐ **Educational Needs** (For example, explaining your child’s needs to teachers; help reading or
     understanding medical information)?

   ☐ **Financial Needs** (For example, understanding insurance or finding help paying for needs
     that insurance does not cover - such as medications, formulas, or equipment)?

   ☐ **Legal Needs** (For example, discussing laws and legal rights about your child’s health care or
     their school needs)?

6) What do you want or need? (We will work with you to find answers if we can).

________________________________________________________________________________________

________________________________________________________________________________________

________________________________________________________________________________________

© Jeanne W. McAllister, BSN, MS, MHA.
When my daughter went to her 9-month well-child appointment, I thought it was going to be a pretty typical appointment. The doctor was asking me a lot of interesting questions about how my daughter was scooting around the house. He finally told me that he was a bit concerned that she wasn’t crawling yet and that most babies crawl before they are 7-months old. I never knew that! He told me not to be alarmed, but encouraged me to meet with someone who could help me help my daughter. Since I had been coming to this doctor’s office since my 5-year-old son was born, I trusted him and agreed to meet with this other staff person. Without having to drive to another building, I met with the other staff member who said she was going to help me coordinate the care my child needed. She explained to me that she was called a care coordinator and that she was going to help me, for free, to make sure my daughter got what she needed.

As a parent of a child with special needs, the most important part of care coordination is establishing trust between my family and our care coordinator. I just want to know that the Coordinator believes in the strengths of my family as we face all the barriers in the health care system. Even though I am aware of some resources in my community, I hope my care coordinator will tell me about more and help me walk through the right door to get to those resources. In other words, I don’t know what I don’t’ know. The relationship with my care coordinator is unique – it’s the wisdom of the health care system braided with the fine art of communication and encouragement. What is most important to me is the invitation to fully partner with my care coordinator to get the services and supports I need so that my child can be her very best.

To fully partner with my care coordinator I need to feel safe as I tell her about the needs of my whole family. This includes acknowledging what I do know about the complex health care system and helping me learn even more. I also need to know just exactly what is expected of me and I promise to let my care coordinator know if that expectation is realistic. True of any partnership, I am responsible to let my care coordinator know just exactly what I am expecting from her and we can openly discuss if I am expecting too much. This is an ongoing, continuous conversation, because expectations change based on what is going on at home. Basically, this boils down listening to each other. Sometimes I don’t fully understand what she is proposing because she uses words I am not accustomed to. But, since she knows me so well, she always pauses to ask if I need further clarification. Likewise, I can tell when I am talking too fast or am not articulating my fears very well. I have learned to ask my care coordinator if she really understands what I am saying, not just the words, but also the feelings in my heart. It feels good to have someone so knowledgeable and caring all wrapped up in one person!

When I look back at how I have grown as a parent, I feel like I’ve gone through distinct phases of confidence. The first phase is when I became aware of when something wasn’t right, and, that I had to figure out how to make it better. Just recognizing that there was a problem was a big step for me. I didn’t really know how to get to the solution, but at least I wasn’t in denial anymore. The second phase was in understanding what resources I needed and trying to figure out exactly how to get them. During this phase I experienced the most frustration because I felt like I found the right door, but it was locked. Finally, the third phase of my journey was when I completely understood how the system works and I could respectfully obtain the resources my child needs with very little support from my care coordinator. I go in and out of these phases based on her health care needs, but my goal is to be in Phase 3 as much as possible. I sort of picture it like a seesaw at the park. When I’m feeling high and fully confident, my care coordinator can lay low and watch me soar. Likewise, there are times when I’m not on my game, and I can trust that my care coordinator will rise to the occasion. The great thing is, through the ups and downs, we are always connected. The key to all of this is communication.

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Parents as Practitioners in Pediatrics

It is uncommon, in healthcare settings, for parenting to be acknowledged as a practice, in the same respect that nursing and doctoring are accepted as practices. It is unusual for the knowledge and expertise of parents to be granted the same moral weight as others who conduct practices professions and livelihoods.

Yet, parenting is indeed a practice, drawing from a rich storehouse of learning that includes observation, experiential learning, and the generational transfer of knowledge. Parents invest in their practices by adopting a range of learning strategies – seeking out mentors, learning collaboratively with peers, and reflecting upon their accumulated tacit knowledge. This investment is heightened in families of children with chronic illnesses and disabilities, given the higher stakes involved. These parents routinely become skillful at advocating for their child, navigating complex medical systems, and making complex, ethically challenging healthcare decisions.

The strength and depth of this kind of parental practice is captured in the following account by a parent of a child with special healthcare needs, whose daughter recently graduated from high school.

When my daughter was one year old, I was told she would never have children of her own, go to college or live independently. All my dreams were destroyed in a twenty-minute office visit. That conversation was also the beginning of my becoming an expert, both in terms of understanding my daughter’s physical and developmental disabilities, and in terms of knowing her as a unique human being—a funny and courageous kid, talented artist, lover of animals, and the foundation of our family. Our clinicians understand some pieces of the puzzle; I understand many others. More and more, our relationships with the medical team are fueled by mutual respect. When that happens, I can relax a bit, knowing that my daughter will get what she needs from all of us.

When we think about how best to engage with parents and families, we should consider the nature, extent and depth of parenting practices. When we extend ourselves to acknowledge parents’ skills, knowledge, and values, we put ourselves in the position to learn more deeply from each other and to partner more effectively and robustly on behalf of children with complex healthcare needs.

Institute for Professionalism and Ethical Practice, Children’s Hospital Boston

Revised and adapted from:

http://informahealthcare.com/toc/mte/32/7
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Links to Videos – Module 2

**What is care coordination?** – Richard C. Antonelli, MD, MS, FAAP
http://www.youtube.com/watch?v=zpcrnYYrvg

**What does care coordination look like for a patient, their family, and for health professionals?** – Linda Lindeke, PhD, RN, CNP, FAAN
http://www.youtube.com/watch?v=dZlZ_eXdKz4

**How has having a care coordinator enhanced medical home in your practice?** – Tim Geleske, MD, FAAP
http://www.youtube.com/watch?v=iIR71IMUHeQ

**Care Coordination Success Story** – Tim Geleske, MD, FAAP
http://www.youtube.com/watch?v=uayUJ8r4dY4
Module 3

Integrating Care Coordination into Our Everyday Work

1. Overview

2. Facilitator Guide

3. In-Session Handout – NICHQ Vanderbilt Assessment Scale: Teacher Informant
   In-Session Handout – NICHQ Vanderbilt Assessment Scale: Parent Informant
   In-Session Handout – NICHQ Vanderbilt ADHD Primary Care Initial Evaluation Form
   In-Session Handout – Scoring Instructions for NICHQ Vanderbilt Assessment Scales
   In-Session Handout – What Every Pediatrician Needs to Know About ADHD and School

4. In-Session Handout –
   Case Discussion: How a Child with ADHD Can Open the Door to Practice Improvement

5. In-Session Handout – Oregon IEP Information

6. In-Session Handout –
   Making the Most of Your Child's IEP: Seven Tips for Parents of Children With Special Needs
Module 3.1

Pediatric Care Coordination Curriculum

Module Title: Integrating Care Coordination into our Everyday Work – Module 3

Module Format: In-person workshop (~2 Hours)

Module Overview: This module uses a case-based approach to promote interactive discussion about care coordination amongst participants as well as introducing an integrative portrait of care coordination within the patient-centered medical home (PCMH).

Audience: Care coordinators and/or members of the care coordination team

Rationale: This curriculum was created with the goal of offering practical, experience-based principles to facilitate the introduction and continued enrichment of care coordination.

Module Goals:

1. Develop self-awareness and embrace the role of care coordinator as an agent of change.
2. Discuss ways to focus on proactive, longitudinal care within the patient and family-centered medical home.
3. Recognize patients and families as indispensable, participatory members of the medical home.
4. Integrate patient and family input, appreciating that family satisfaction is central to successful care coordination.
5. Strategize to improve communication and accountability among providers, both within the medical practice and in the extended medical home, including the school and community.

Learning Objectives:

1. Participant sees ways to focus on proactive, longitudinal care within the patient/family-centered medical home.
2. Participant is able to identify and use tools to integrate patient and family input throughout the course of care.
3. Participant sees ways to improve communication and accountability among providers both within the medical practice and in the extended medical home, including the school.
4. Participant recognizes the role of care coordinators in working collaboratively to implement practice improvement.

Module Activity Summary:

<table>
<thead>
<tr>
<th>Activity</th>
<th>Time</th>
<th>Materials Required</th>
<th>Faculty</th>
</tr>
</thead>
<tbody>
<tr>
<td>Introduction of session</td>
<td>20 Minutes</td>
<td>None</td>
<td>Session Leaders</td>
</tr>
</tbody>
</table>
| Case Discussion in Small Groups | 60 Minutes | Suggested in-session handouts: 1) NICHQ Vanderbilt Assessment Scale: Teacher Informant  
                             |       | 2) NICHQ Vanderbilt Assessment Scale: Parent Informant  
                             |       | 3) NICHQ Vanderbilt ADHD Primary Care Initial Evaluation Form  
                             |       | 4) Scoring instructions for NICHQ Vanderbilt Assessment Scales  
                             |       | 5) Case Discussion Handout  
                             |       | 6) What Every Pediatricians Needs to Know About ADHD and School  
                             |       | 7) Getting Ready for Your Child’s IEP Meeting  
                             |       | Session Leaders  
                             |       | Small Group Facilitators (1/group of 5)  
                             |       | Provide Facilitators w/ Module 3 Facilitator Guide with questions for discussion  
| Large Group Whiteboard Exercise | 25 Minutes | Large post-it easels & Markers  
                             |       | Session Leaders              |
| Closing Comments              | 15 Minutes | Meg’s story from parent point of view  
                             |       | Session Leaders              |

Evaluation:

Short Term: During closing comments individuals will share what they will take away. This requires attendees to think about the material they were just presented with and how it relates to their individual positions and clinics.

Long Term: Follow up with attendees via conference call.
Module 3: Integrating Care Coordination in Our Everyday Work - Facilitator Guide

Time: 2 hrs

Authors: Anne Carpinelli, MD, MPH, Kathleen Conroy, MD, David Browning, MSW, BCD, and Wanessa Risko, MD, DSc

Note to Facilitators: This curriculum was created with the goal of offering practical, experience-based principles to facilitate the introduction and continued enrichment of care coordination. This is the 3rd of 4 modules that comprise the curriculum, which is intended to be generalizable, adaptable, and effective for any practice invested in care coordination within the context of the patient-centered medical home (PCMH). Curriculum participants should include care coordinators and any interested members of the care coordination team.

This particular module uses a case-based approach to promote interactive discussion about care coordination amongst active participants. It is recommended that facilitators read through this guide prior to introducing this module, as the guide includes supplementary information that is meant to aid in effectively guiding a fruitful discussion. It is important that the participants have an opportunity to express their views and experiences as well as hear from others about the issues raised in this session.

We recommend the following format for this session:
1. Start with the entire group of participants – introduce the goal and plans for the session.
2. Divide into smaller groups (5-10) participants – conduct the case discussion.
3. Reconvene with the entire group – share the highlights of the small group discussions, reflect as a group, and summarize main learning lessons. Conduct a “white board exercise” to elicit the participants’ views of care coordination.

Points salient to the case are emphasized in this guide. However, facilitators should underscore the information they feel is most beneficial to participating care coordinators, depending on their particular practice needs and time constraints. For those who are interested in further reading about care coordination, there are several footnotes throughout the case with references to current literature relevant to care coordination.
Pediatric Care Coordination Curriculum

Module 3.2

Pediatric Care Coordination Curriculum

Introducing the Module
(20 minutes – entire group)

- **Emphasize the participatory and evolutionary nature of the overall curriculum:**
  - Participants can expect to learn from one another through open, facilitated discussion
  - Care coordinators at various stages in the care coordination integration process will likely benefit from the curriculum in different ways
  - Mastery of ideal care coordination is an evolving and experiential process

- **Share these principles to support the process of participatory learning:**
  - Excellent care coordination requires a practice shift in everyday interactions and everyday ethics. This shift in relationships requires that patients, families, and healthcare providers—from different disciplines and at different levels of the hierarchy—think differently about primary care, learn differently from each other, and have new kinds of conversations with each other.
  - A real and unyielding commitment to understanding the experience of patients and families is at the core of this shift.
  - Any one individual cannot create this shift alone; however, two or more individuals working together can begin to create this shift.

- **Highlight the contents of this specific module:**
  - 3rd module of a 4-part participatory curriculum series developed to introduce and/or enrich care coordination in various practice settings.
  - Case-based discussion as a means of introducing an integrative portrait of care coordination within the PCMH.
  - A reflective “whiteboard activity” to elicit each participant’s individual vision for care coordination, and to identify pragmatic steps toward realizing that vision.

- **Outline the following LEARNING OBJECTIVES for this module:**
  1. Participant sees ways to focus on proactive, longitudinal care within the patient/family-centered medical home
  2. Participant is able to identify and use tools to integrate patient and family input throughout the course of care.
  3. Participant sees ways to improve communication and accountability among providers both within the medical practice and in the extended medical home, including the school.
  4. Participant recognizes the role of care coordinators in working collaboratively to implement practice improvement.
Case Discussion: How a child with ADHD can open the door to practice improvement
(60 minutes – divide into small groups, each group should be led by a facilitator)

Resources: (Distribute these in-session handouts)
• Vanderbilt Assessment Scales, Evaluation Forms, and Scoring Instructions
• What Every Pediatrician Needs to Know about ADHD and School
• Getting Ready for Your Child’s IEP Meeting Brochure
• The American Academy of Pediatrics ADHD toolkit is available for purchase: www.aap.org/bookstore.

Notes:
▪ Begin the small group session with individual introductions (name, practice type, experience with care coordination). Share the care coordinator feedback from the “Note to Facilitators” section above, as well.
▪ The case consists of 3 parts; each part should be discussed individually before proceeding to the next part. Participants will receive a copy of each part. Consider asking for volunteers to read each part. Questions will not be included in participants’ handouts and should be read by facilitator.

PART 1: INITIAL OFFICE VISIT

Isaac Smith is a generally healthy 8-year old boy who comes to your office with his parents for his yearly routine visit. The medical assistant rooming the family has difficulty taking his vitals due to his restlessness and difficulty following directions. His parents inform the pediatrician that they have received calls from Isaac’s teacher, who says he is constantly getting out of his seat, disrupting class, and having trouble focusing on assigned tasks. He is doing “okay” in some subjects but is far behind his peers in reading. His parents have noticed similar behavior at home and say Isaac takes a very long time to finish his homework in comparison to his older brother. His father voices concern that Isaac’s classmates may be making fun of him. The pediatrician, who has known the family for several years, asks Isaac for his input, but he becomes teary-eyed and looks away. The pediatrician is concerned about ADHD as well as a potential learning disability.

After the visit you (the practice care coordinator) overhear the pediatrician talking with a nurse. She conveys her frustration about the limited time she has to deal with this important issue. She believes Isaac should be tested for a possible learning disorder but knows that there is a long waiting list for formal testing by a subspecialist. She is concerned that a delay in diagnosis could put Isaac further behind in his academic progress.

Key questions for discussion: Please orient the discussion to areas of particular interest for your group.
1. Initiating Care Coordination:
   Ideally, how would you as the care coordinator hear about such a case? How might you introduce the idea of care coordination to this family?
     ▪ Discuss how care coordination is part of the medical home and how practices introduce these concepts to patients and their families (business cards, brochures, face-to-face communication, provider referral, etc).
     ▪ Share ideas as to what the next step should be once patients are connected to care coordinators.

2. Identifying Resources:
   Have you faced challenging situations such as Isaac’s case in your practice?
     ▪ Ask what information would be needed from the parents, patient, teacher(s), or school at this point to move forward most effectively.
3. Care Coordination as Practice Improvement:
   How can care coordinators maximize both provider and family satisfaction?
   - Discuss how care coordinators may feel empowered by being in a position to improve the quality of the patient-provider relationship.
   - Examples may include providing pre-visit contact forms to enhance efficiency and quality of “face time” with providers; sending forms/questions to parents via email to be completed at their convenience; including the patient in the initial needs assessment and ongoing conversations.
   - Consider the potential MA/RN role: ensuring that parents complete developmental screening/assessment forms, mentioning observations to provider (such as in Isaac’s case), having pre-visit form available for provider to review prior to entering patient’s room to improve efficiency and satisfaction.

PART 2: PHONE CONVERSATION (1 week later)
As the care coordinator, you contact the family one week after the visit to see how things are progressing.
Some new information is uncovered. Mr. Smith has recently been laid off his job and therefore has been the one in contact with the school while his wife continues working. Mrs. Smith tells you that she and her husband disagree about the severity of Isaac’s problems. Mr. Smith is afraid that Isaac is being made fun of in school and feels that they need to do anything and everything to help Isaac. Mrs. Smith is worried about Isaac, but she is also skeptical about starting medication for possible ADHD. She is concerned about side effects and making Isaac feel different from his peers. Mr. Smith dropped off the forms to be filled out by Isaac’s teacher the day after the last appointment, and the teacher was happy to fill them out. You suggest that they submit a request to the school for a formal educational evaluation, particularly in light of the long wait list to see a developmental specialist.

Key questions for discussion:
1. Care Coordination in Action:
   When families disclose sensitive information to you, how do you decide what/when/how to share with the healthcare provider?
   - Review what information about the Smiths from Part 2 may be beneficial for the pediatrician to know. Strategize about how information should be relayed (email, electronic medical record, scheduled care coordination meetings, etc).

   In what ways can you as care coordinator effectively connect with Isaac’s parents, understanding that they have differing perspectives?
   - Brainstorm about conversations care coordinators could initiate with Isaac’s parents to help allay their concerns. One suggestion might be to give each parent a separate Vanderbilt questionnaire to complete. Another could be to uncover Mr. and Mrs. Smith’s common ground: both want Isaac to get better and neither wishes for Isaac to feel out of place at school.

2. Care Coordination and Education:
   How might you assist Isaac’s parents in asking the school for assistance?
Pediatric Care Coordination Curriculum

- Discuss the school’s responsibilities to a student such as Isaac and how parents are informed of this information. Some clinics may already offer parents a packet that includes a sample letter to the school, as well as literature on requesting formal evaluations, securing an individualized education plan (IEP), etc.
- Encourage care coordinators to talk with each other about how they can learn more about the school’s responsibility if this is not something with which some participants are currently familiar.
- Brainstorm about outside help, such as Medical Legal Partnership for Children, Project Health, community resources.

Module 3 Facilitator Guide

PART 3: NEXT OFFICE VISIT (2 weeks later)

The assessment forms are received from Isaac’s teacher and his parents. Based on these and the pediatrician’s assessment, a diagnosis of ADHD is made, and both parents are now open to a trial of medication. The pediatrician expresses mixed feelings about starting Isaac on medicine, given the possibility of a learning disability that could be clouding the diagnostic picture. She did refer Isaac to a developmental pediatrician to do formal testing, but the waiting list is backed up six months.

Mr. Smith asked Isaac’s teacher for an educational evaluation. The teacher responded by saying that the school has limited resources due to budget cutbacks, and it may take months to get the evaluation. Mr. and Mrs. Smith are encouraged to formally request an educational evaluation from the school. They are willing to do this, but they say they do not feel confident in their ability to get the school to take action.

Key questions for discussion:

1. Longitudinal Coordination:
   - If Isaac were started on medicine at this time, what would be your role as care coordinator in monitoring return visits, medication effectiveness, side effects, need for refills, coordinating referrals, etc?
   - Give examples of how the electronic medical record might facilitate communication of such information. One example might be using EMR to alert/flag the provider/social worker/care coordinator, etc when input is needed.
   - Emphasize the idea of proactive/longitudinal care, as opposed to reactive/episodic encounters.
   - Discuss how efficiency of referrals within the extended medical home is perceived and how it can be improved.

2. Accountability and Collaboration:
   - Think of the concepts of accountability and teamwork: Who is responsible for care coordination beyond the care coordinator?
   - As a specific example, if the school called the clinic to discuss Isaac’s case, to whom would the call be transferred?
   - Introduce the concept of the pre-clinic “huddle” to ensure all members of the medical home are on the same page regarding patients with complex needs
   - How does the emphasis on collaboration in the care coordination model set it apart from traditional case management?

3. Identifying Key Stakeholders:
   - Consider who the decision makers are in your practice. Whose “buy-in” must you secure in order to make care coordination a successful reality? Brainstorm ways in which you can build alliances with these people so that they are meaningfully involved.
Pediatric Care Coordination Curriculum

- Conversely, imagine what might happen if you focus only on these “key” players and exclude the input of others.
- Emphasize that the entire office staff must be informed of and involved in any transformational change in order for it to be successful. Initiate discussion about how this might happen—surveys, staff meetings, etc.

WHITEBOARD EXERCISE
(25 minutes)
Stop and think about your vision of high-quality, effective care coordination in the medical home in its most complete form—your image of exactly what you would like to see. Let’s imagine that you go to work tomorrow morning, and that vision is now a reality.

- How would things look different than they do now?
- What would be the specific indicators you would notice that would indicate that your vision has come true?
- What shifts would you be seeing in how people are interacting with each other?
- Think about this in the context of Isaac’s case—how would his scenario play out in this ideal version of care coordination?
- When was the last time you saw a sign—even if only for a short time—that could lead to your vision? Who was involved in creating that sign? If you were involved, what was your contribution? What skills, knowledge, and/or values did you bring to the situation?

CLOSING COMMENTS
(15 minutes)

- If time permits, ask that one speaker from each small group share memorable take-home points with the large group.
- If your group did not divide into smaller groups for the case, encourage each person to say one thing they will take away from this module.

In closing, consider that patient and family narratives may help our work stay grounded and family-centered. As an example, listen to the words of one mother:

*When my daughter was one year old, I was told she would never have children of her own, go to college or live independently. All my dreams were destroyed in a twenty-minute office visit. That conversation was also the beginning of my becoming an expert, both in terms of understanding my daughter’s physical and developmental disabilities, and in terms of knowing her as a unique human being—a funny and courageous kid, talented artist, lover of animals, and the foundation of our family. Our clinicians understand some pieces of the puzzle; I understand many others. More and more, our relationships with the medical team are fueled by mutual respect. When that happens, I can relax a bit, knowing that my daughter will get what she needs from all of us.*

- Meg Comeau, Institute for Professionalism & Ethical Practice family faculty member (and mother of a child with special healthcare needs)
Case Discussion: How a child with ADHD can open the door to practice improvement

Resources:

- Vanderbilt Assessment Scales, Evaluation Forms, and Scoring Instructions
- What Every Pediatrician Needs to Know about ADHD and School
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OREGON STANDARD INDIVIDUALIZED EDUCATION PROGRAM (IEP)

Part A: GUIDELINES FOR COMPLETION

FOR STUDENTS AGE 15 OR YOUNGER WHEN IEP IS IN EFFECT

☐ Complete all demographic information:
  • Enter student’s name, gender, date of birth, grade, and student ID number.
  • Enter name of school district, name of home school, name of attending school and school district, and name of the special education case manager.
  • Enter student's Disability Code: ______

<table>
<thead>
<tr>
<th>Disability Code</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>10</td>
<td>Intellectual Disability</td>
</tr>
<tr>
<td>20</td>
<td>Hearing Impairment</td>
</tr>
<tr>
<td>40</td>
<td>Visual Impairment</td>
</tr>
<tr>
<td>43</td>
<td>Deafblindness</td>
</tr>
<tr>
<td>50</td>
<td>Communication Disorder</td>
</tr>
<tr>
<td>60</td>
<td>Emotional Disturbance</td>
</tr>
<tr>
<td>70</td>
<td>Orthopedic Impairment</td>
</tr>
<tr>
<td>74</td>
<td>Traumatic Brain Injury</td>
</tr>
<tr>
<td>80</td>
<td>Other Health Impairment</td>
</tr>
<tr>
<td>82</td>
<td>Autism Spectrum Disorder</td>
</tr>
<tr>
<td>90</td>
<td>Specific Learning Disability</td>
</tr>
</tbody>
</table>

• Enter the date of the "annual" IEP meeting. The IDEA requires that, at least annually, the IEP team review the student’s IEP to determine whether the student’s annual goals are being achieved, and to revise the IEP as appropriate to address:
  o Any lack of expected progress toward the annual goals and in the general curriculum, where appropriate;
  o The results of any special education evaluation;
  o Information about the student provided to, or by, the parents about the student’s academic, developmental, and functional needs;
  o The student’s anticipated needs, or
  o Other matters. IDEA 2004, Sec. 614(d) (4) (A).

• Enter any revision date(s) to the annual IEP (if needed). IDEA 2004 permits changes to an IEP between annual IEP meetings without an IEP meeting if the parent and an authorized school district representative agree. Instead, the parent and authorized district representative may develop a written document to amend or modify the IEP. IDEA 2004, Sec. 614(d) (3) (D). See ODE Sample Form: Written Agreements between the Parent and the District or refer to district forms and procedures.

• Enter reevaluation due date. A reevaluation must be conducted at least every three years unless the parent and district agree that a reevaluation is unnecessary. IDEA 2004, Sec. 614(a) (3) (B) (ii). See ODE Sample Form: Written Agreements between the Parent and the District or refer to district forms and procedures.
Identify meeting participants:

- List all members participating in the development of the IEP. This can be accomplished by gathering signatures of participants, or by simply listing the names of individuals that participated. Signatures are not required on an IEP.

IEP Team membership must include:

- The parent(s) of the student;
- At least one regular education teacher of the student (if the student is, or may be, participating in the regular education environment);
- At least one special education teacher of the child, or if appropriate, one special education provider of the child;
- A representative of the school district who:
  - Is qualified to provide, or supervise special education;
  - Is knowledgeable about the general education curriculum;
  - Is knowledgeable about the availability of resources, and has the authority to commit agency resources.
  - The school district may designate another IEP Team member as the district representative, as long as this individual meets the criteria for this role;
- An individual who can interpret instructional implications of evaluation results (may also serve in another role on the IEP Team);
- The student, if appropriate. The student is a required IEP Team member beginning at age 16. The student must be invited when the purpose of the meeting is consideration of the postsecondary goals and transition services needed to assist the student in reaching those goals and have the opportunity to indicate his/her preferences and interests during the IEP meeting. If the student doesn’t attend the IEP meetings when transition services are being discussed, the district must take steps to ensure the student’s interests and preferences are considered;
- For students of transition age: With the consent of the parents or adult student, the district must invite a representative of other agency (ies) that is likely to be responsible for providing or paying for transition services. If an agency does not send a representative to the meeting, the district must take other steps to obtain the participation of the agency in the planning of any transition services;
- At the discretion of the parent, or district, other individuals who have knowledge or special expertise regarding the student.
- For students with limited English proficiency: Members of the IEP team should include speech language pathologists and other professionals with an understanding of how to differentiate between limited English proficiency and a disability.

IEP Meeting Participants may participate by alternative means. When conducting IEP team meetings, the parent of a child with a disability and the school district may agree to use alternative means of meeting participation, such as video conferencing and conference calls. IDEA 2004, Sec. 614(f).

IEP team attendance not necessary. A member of the IEP team is not be required to attend the IEP meeting, in whole or in part, if the parent of a child with a disability and the school district agree that the attendance of such a member is not necessary because the member’s area of the curriculum or related services is not being modified or discussed at the meeting. The district must separately document this agreement in writing, retain the written submission in the student’s education records, and the student’s IEP should
reflect no changes to that area of curriculum or related service. IDEA 2004, Sec. 614(d) (1) (C) (i). See ODE Sample Form: Written Agreements between the Parent and the District or refer to district forms and procedures.

**IEP team attendance written input.** A member of the IEP team may be excused from attending the IEP meeting, in whole or in part, when the meeting involves a modification to or discussion of the member’s area of the curriculum or related services if the parent and the school district consent to the excusal, and the member submits in writing to the parent and to the IEP team input into the development of the IEP before the meeting. The district must separately document this agreement, and retain the written submission in the student’s education records. IDEA 2004, Sec. 614(d) (1) (C) (ii). See ODE Sample Form: Written Agreements between the Parent and the District or refer to district forms and procedures.

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**Guidelines for next page of IEP form**

☐ In developing each child’s IEP, the following are required to be considered and documented on the student’s IEP, as appropriate. These considerations will provide the IEP Team with the information that will guide and inform the development of special education services and strategies that address the individualized special education needs of the student, including needed adaptations or modifications to the curriculum that may be necessary. In considering these factors, the IEP Team determines whether the student needs a particular device or service, including an intervention, accommodation, or other program modification, in order for the student to receive an appropriate education.

**The IEP team must consider these factors as part of IEP development:**

- The assistive technology devices or services needs of the student:
  - AT devices are items, equipment, or product system(s) used to increase, maintain, or improve the functional capabilities of a child. These devices may be either “low-tech” (e.g., picture boards, calculators, specialized pencil grips), or “high-tech” (e.g., computers, software applications, portable note taking equipment). AT services mean any service that assists the student in the selection, acquisition, or use of such devices.
  - Web resources: Assistive Technology Model Operating Guidelines for School Districts and IEP Teams
    An Overview of Education Tech Points for Assistive Technology Planning

- The communication needs of the student:
  - If the student has communication needs, indicate how these needs are addressed in the IEP. This may be through specific goals and objectives, through related services, or through the provision of appropriate supplementary supports, modifications, or program accommodations.

- The behavioral needs of the student if the student exhibits behavior that impedes his/her learning or the learning of others:
  - When a student’s behavior impedes his or her learning, or the learning of others, the IEP must reflect approaches, including considering the use of positive behavioral interventions, strategies, and supports, to address those behaviors. A functional behavioral assessment should be conducted for such a student to provide information on why a student
engages in a behavior, when the student is most likely to demonstrate the behavior, and to identify the situations in which the behavior is least likely to occur. This information will assist Teams in designing appropriate intervention(s) for the student.

- The English language needs of the student if the student is limited English proficient:
  - The IEP must reflect how the student’s language needs relate to the IEP. The IEP Team may consider:
    - Whether the child has been assessed in his/her native language;
    - Whether the disability impacts the student’s involvement in the general education curriculum, including any bilingual or ESL program;
    - What language will be used for instruction;
    - What language or mode of communication will be used to address and report information to parents or family members; and,
    - Accommodations that may be necessary for instruction and testing.
  - For students who are blind or visually impaired: The IEP must reflect instruction in Braille, unless the Team determines, after an evaluation of the student’s reading and writing skills, that Braille is not appropriate for this student. Consideration of future needs for instruction in Braille or the use of Braille must be considered annually.
  - For students who are deaf or hard of hearing The IEP must explain his/her communication and language needs, and the opportunities for direct interaction with peers and educational personnel in the student’s own language and communication mode. The IEP Team must also consider the student’s academic levels and full range of needs, as well as opportunities for direct instruction in the student’s own language and communication mode.

- The Present Levels of Academic Achievement and Functional Performance:
  - The Present Levels of Academic Achievement and Functional Performance (Present Levels) information serves as a foundation for the development of the IEP. The Present Levels statement(s) provide a clear picture of the student’s strengths and needs, as determined through evaluation. These statements guide the Team in identifying all services necessary to address the student’s educational needs related to their disability (ies). These statements should be written in language that is easily understood by all IEP Team members. The Present Levels statement(s) must identify how the student’s disability affects the student’s involvement and progress in the general education curriculum, defined as the curriculum that is the same as for nondisabled students. Present level statements should be based on student data which reflect current academic achievement and functional performance. A clear linkage should be evident between the needs identified by the data in the Present Levels statements, the annual goal statement(s), and all other services identified in the IEP.
  - In developing the Present Levels of Academic Achievement and Functional Performance Statement, the IEP Team must include specific information addressing:
    - The present level of academic performance, including the student’s most recent performance on State or district-wide assessments;
    - The present level of developmental and functional performance; and,
How the student’s disability affects involvement and progress in the general education curriculum.

**Guidelines for next page of IEP form**

- **Participation in Statewide Assessment:**
  All students in Oregon must have full access to the Oregon Statewide Assessment System (OSAS). The IEP Team must document decisions about the student’s participation for each assessment area that is conducted for the student’s grade level while the IEP is in effect.

  Under OAR 581-022-0612, a public agency shall not exempt a student with a disability from participation in the Oregon State Assessment System to accommodate the student’s disability unless the parent has requested an exemption. The student is not exempt for the purposes of AYP. State regulations do not specify the procedures or method of documentation of this request. Teams should complete the assessment decisions for all students on the IEP form, and use district procedures for documenting any parent requested exemptions from the testing. Staff should fully explain to the parent the content of the selected assessment.

  The IEP Team must determine the student’s appropriate levels of participation in the OSAS for each subject area of assessment. For many students with disabilities, the decisions will not be difficult. For some, however, the Team will need to make an extra effort to determine the appropriate test. Input from every member of the IEP Team, including the parent, is helpful in determining the assessment that best allows the student to demonstrate his/her knowledge/skills in each subject area assessed. The chart below shows the assessment options aligned to grade-level achievement standards, and the alternate assessments aligned to alternate achievement standards.

<table>
<thead>
<tr>
<th>Assessment Based on Grade Level Achievement Standards</th>
<th>Alternate Assessments Based on Alternate Achievement Standards</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Assessment (with or without accommodations)</td>
<td>• Extended Assessment (Scaffold or Standard administration)</td>
</tr>
</tbody>
</table>

**Assessment Options**

It is important that the Team consider each assessment individually for the student. While many students may have the same levels of participation in all of the statewide assessments, it is critical that the Team attend carefully to each one. In some situations, a particular assessment makes different demands on the student; it is possible that the student participates under standard conditions for one assessment and receives adaptations for another. The IEP Team must be knowledgeable about the content and demands of each assessment. The assessment options should be fair, sufficiently challenging for the student, and reflective of the student’s performance levels.

- **Oregon Assessment of Knowledge & Skills (OAKS):** [www.ode.state.or.us/search/results/?id=169](http://www.ode.state.or.us/search/results/?id=169)
- **Special Education Assessment:** [www.ode.state.or.us/search/page/?id=554](http://www.ode.state.or.us/search/page/?id=554)
- **Extended Assessment Resources:** [www.ode.state.or.us/search/?id=178](http://www.ode.state.or.us/search/?id=178)
- **General Assessment Administration Manuals:** [www.ode.state.or.us/search/page/?=486](http://www.ode.state.or.us/search/page/?=486)
Teams should also be aware of the implications of assessment decisions for students.

### Assessment Implications

<table>
<thead>
<tr>
<th>Type of Assessment</th>
<th>Assessment Judged Against Grade Level Achievement Standards</th>
<th>Alternate Assessment Judged Against Alternate Achievement Standards</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Assessment (with or without accommodations*);</td>
<td>Extended Assessment (Scaffold or Standard administration)</td>
</tr>
<tr>
<td>Implications for student</td>
<td>These scores will contribute to a student’s graduation requirements if student meets or exceeds standards.</td>
<td>These scores demonstrate student’s learning and performance on academic and prerequisite assessment skills over time.</td>
</tr>
<tr>
<td>Implications for Accountability (AYP)</td>
<td>Student’s proficiency and participation will be counted</td>
<td>Student proficiency** will be counted and participation will be counted (**up to 1% of all students may meet or exceed on the alternate assessment)</td>
</tr>
<tr>
<td>IEP</td>
<td>IEP short-term objectives not required.</td>
<td>IEP short-term objectives required.</td>
</tr>
</tbody>
</table>

*An accommodation is an alteration to the test setting, presentation, response or schedule that does not substantially change the level content or performance criteria of the assessment.

- Determine whether the student will be participating in any statewide assessment during the IEP period. If not, check the “no” box. If yes, check the “yes” box, and indicate the student’s grade level at time of testing. (Each subject area of assessment listed on the IEP form indicates the grade levels that assessment is given.)
- For each type of assessment, determine the appropriate assessment for the student, and check the appropriate box.
- If the IEP team determines that the child will take an alternate assessment, the IEP must include a statement of why the child cannot participate in the regular assessment, and the particular alternate assessment and administration option that is appropriate for the child. Assessments designated by an asterisk on the IEP form need to have an explanation statement. Examples of explanation statements for students taking an alternate assessment are provided in the table below.

### Alternate Assessment Administration

<table>
<thead>
<tr>
<th>Alternate Assessment Administration</th>
<th>Examples of Explanation Statements</th>
</tr>
</thead>
<tbody>
<tr>
<td>Extended Assessment Standard Administration</td>
<td>Student performs at emerging academic skill level, and requires significant reduction of the breadth, depth, and complexity of materials that are based on grade-level content standards in order to meaningfully access instructional information.</td>
</tr>
<tr>
<td>Extended Assessment Scaffold Administration</td>
<td>Student performs at emerging academic skill level, and requires significant supports and adaptations to materials that are based on grade-level content standards even after they have been reduced in depth, breadth, and complexity in order to meaningfully access instructional information.</td>
</tr>
</tbody>
</table>
• The child’s IEP must include a statement of any individual appropriate accommodations necessary to measure the child’s performance on the assessment. The IEP Team should consider the student’s instructional day, including the supplementary aids/services and accommodations the student needs and uses each day. Availability of these needed supplementary aids/services, and accommodations that provide access to Statewide assessment must be ensured (e.g. if the student uses Braille as a primary reading medium, Braille would also be necessary for those portions of Statewide assessment that require the student to read. If a student requires written materials to be read to them, then this provision may also be required during assessment as appropriate to the validity of the assessment). The IEP Team should consider the student’s ability to participate in the assessment(s), and ensure that the student is receiving the instruction and practice needed before such participation, including instruction in the use of accommodations and/or modifications.

Web Resource: Accommodations & Modifications Tables
http://www.ode.state.or.us/search/page/?=487

☐ Participation in Districtwide Assessment(s):
In addition to decisions regarding participation in statewide assessments, all students must have full access to Districtwide assessments. The IEP Team must document their decisions regarding student participation in Districtwide assessment to ensure the student has appropriate access to these assessments. The Team must document these decisions for each assessment area that is being considered for that student during the IEP period. For Districtwide assessments, the Team should consider the student’s ability to participate in the assessment(s), and ensure that the student is receiving the instruction and practice needed before such participation, including instruction in their use of accommodations.

• Determine whether the student will be participating in any districtwide assessment during the IEP period. If not, check the “no” box (Note: this only applies in the circumstances provided in OAR 581-022-0612). If yes, check the “yes” box, and indicate the student’s grade level at time of testing.
• For each type of assessment, determine the appropriate assessment for the student, and check the appropriate box. Districts may list the Social Sciences assessment on the Districtwide assessment page as it is a district option at this time. Also, the National Assessment of Educational Progress (NAEP) may be listed as a Districtwide assessment because only some districts in Oregon conduct this assessment.
• If the IEP team determines that the child will take an alternate assessment, the IEP must include a statement of why the child cannot participate in the regular assessment; and the particular alternate assessment selected that is appropriate for the child. List all necessary accommodations for the student. Only accommodations already familiar to the student should be considered for assessment. It is not appropriate to provide a student with a new or unfamiliar accommodation at the time of assessment.

Two goal page options are available for IEP team use. The first page option allows the team to document the development of measurable annual goals for the student. The second page option allows the team to document the development of both measurable
annual goals and measurable short term objectives for the student. The IEP team must develop both measurable annual goals and measured short-term objectives for students taking alternate assessments based on alternate achievement standards. The team will determine which page(s) to use based on whether the student will be taking alternate assessment aligned to alternate achievement standards in the area of specially designed instruction being considered. It may be necessary for the IEP team to use both pages, if the student will be taking alternate assessment aligned to alternate achievement standards in certain academic areas, but not in all.

☐ **Measurable Annual Goals, including academic and functional goals:**
   Annual goals are statements, written in measurable terms that describe what the student can reasonably accomplish in a 12-month period. There should be a direct relationship between the goal statements and the student’s present levels of educational performance.
   - Each goal must include:
     - **Criteria:** How will the skill be demonstrated by the student to be considered successful; and,
     - **Evaluation Procedures:** How the student’s performance will be evaluated.
   - Identify the Measurable Annual Goals, including academic and functional goals. These goals and objectives must relate to:
     - Meeting the student’s needs that result from the disability;
     - Meeting the student’s needs to enable involvement in and progress in the general education curriculum; and,
     - Meeting other educational needs that result from the disability.
   - Identify the criteria and evaluation procedures for each annual goal.

☐ **How will progress be reported to parents:**
The IEP must include a description of how the child’s progress toward meeting the annual goals will be measured and when periodic reports on the progress the child is making toward meeting the annual goals (such as through the use of quarterly or other periodic reports, concurrent with the issuance of report cards) will be provided. Progress toward each annual goal will be measured through the identified criteria and evaluation measures established for each goal.
   - Identify how progress will be reported to parents (e.g. “written report” or “with regular report card”).
   - Identify the dates or time period (e.g. “quarterly”) that the reports will be provided.

Space is provided for noting the student’s “Progress toward Goal.” This can be used to indicate how the student is progressing on the goal at the review date.

☐ **Short-term objectives:**
The IEP must include measurable short-term objectives for students taking alternate assessments based on alternate achievement standards. IEPs *may* include measurable short-term objectives for all other students.
Write short-term objectives for the student. Short-term objectives are intermediate performance steps that will enable parents, students and teachers to gage, at intermediate times during the year, how well the student is progressing toward the annual goals by either:
- Breaking down the skills described in the goal into discrete components; or
- Describing the amount of progress the student is expected to make within specified segments of the year.

Guidelines for next page of IEP form

☐ Service Summary:
The Service Summary documents the IEP Team’s decisions regarding necessary services for the student. These services must be based on peer-reviewed research, to the extent practicable. Sec. 614(d) (1) (a) (i) (IV).

- Indicate the services that will be provided to the student or on behalf of the child to allow the child to:
  - Advance appropriately toward attaining the annual goals;
  - Be involved in and make progress in the general education curriculum;
  - To participate in extracurricular and other nonacademic activities; and
  - Be educated and participate with other children with disabilities and nondisabled children to the maximum extent appropriate.

- Identify the student’s specially-designed instruction, related services, accommodations, and supplementary aids and services. (If necessary, use a second page to document additional services.)

- Indicate the anticipated amount/frequency, location (e.g., general education class, resource room, self-contained class, work-site, etc.), starting and ending dates for services (month, day, AND year), and provider for:
  - Each area of specially designed instruction (e.g., reading, math, physical education, vocational, travel training);
  - Any related services to be provided (related services are those services necessary to allow a student to benefit from specially designed instruction);
  - Accommodations, and/or Supplementary Aids & Services to be provided to the student;
  - Supports for school personnel (e.g., specified training to be provided to a teacher) provided on behalf of the student.

The amount/frequency of any service should NOT be identified as a “range” (e.g. “30-60 minutes/week”) or as an unspecified period of time (e.g. “as needed”, “if appropriate”). The amount/frequency of each service cannot be established based on convenience of school personnel, or because of shortages of personnel or uncertainty regarding staff availability.

☐ Nonparticipation Justification:
The IEP must explain the extent, if any, to which the student will not participate with non disabled peers in the regular classroom and in extracurricular and other nonacademic activities.
- Describe the extent (amount) of any removal from the regular class environment, and provide justification for the removal.
☐ **Consideration of Extended School Year (ESY) Services:**

ESY services must be provided if the IEP team determines that these services are necessary for the student to receive a free appropriate public education. The purpose of extended school year services is the maintenance of the student’s skills or behaviors, not the teaching of new skills or behaviors. Refer to school district's policies and procedures for criteria for extended school year services.

- If the team determines that the student needs ESY services, check “yes” and identify the specific ESY services to be provided on the “Services Summary.” ESY services must be directly tied to IEP goals and objectives, with services individualized for the student, as appropriate. The IEP must indicate the specific special education and related services to be provided, and the anticipated amount, frequency, location, and starting and ending dates for these services.
- If the Team determines that ESY services are to be considered at a later date, indicate the date by which the Team will meet again to discuss the need for ESY services.
Part B: Oregon Standard INDIVIDUALIZED EDUCATION PROGRAM
For students age 15 and younger when IEP is in effect

To be used in conjunction with Individualized Education Program, Part A: IEP Guidelines for Completion

Student’s Name: ________________  District: ______________________  Annual IEP Meeting Date: __________

__M   __F  Home School: ______________________  Revision date(s) to annual IEP (if needed):

Date of Birth (mm/dd/yy): ________  Attending School/District: __________  Reevaluation Due: ______________

Grade: ______________________  Case Manager: ______________________

Secure Student Identifier (SSID): ______________________  Disability Code: ______________________

* IEP Meeting Participants:

Parent(s): ______________________  Student: ______________________  Other: ______________________

Special Education Teacher / Provider: ______________________

Regular Education Teacher: ______________________  Other: ______________________

District Representative: ______________________  Individual Interpreting Evaluations: ______________________  Other: ______________________

* If a required participant participates through written input or is excused from all or part of the IEP meeting, attach documentation of parents’ and district agreement to participation by written input or excuse.
Student's Name: ___________________ Date: ___________ School District: ________________________________

The IEP team must consider these factors as part of IEP development:

A. Does the student need assistive technology devices or services?
   __ Yes, services/devices addressed in IEP   __ No

B. Does the student have communication needs?
   __ Yes, addressed in IEP   __ No

C. Does the student exhibit behavior that impedes his/her learning or the learning of others?
   __ Yes   __ No
   (if yes, the IEP Team must consider the use of strategies, positive behavioral interventions, and supports to address the behavior(s)

D. Does the student have limited English proficiency?
   __ Yes   __ No
   (If yes, the IEP Team must consider the language needs of the student as those needs relate to the IEP)

E. Is the student blind or visually impaired?
   __ Yes  __ No
   (if yes, Braille needs are addressed in the IEP, or evaluation of reading/writing needs is completed and a determination is made that Braille is
   not appropriate)

F. Is the student deaf or hard of hearing?
   __ Yes  __ No
   (if yes, the IEP addresses the student’s language and communication needs, opportunities for direct communication with peers and
   professional personnel in the child’s language and communication mode, academic level, and full range of needs, including opportunities for
   direct instruction in the student’s language and communication mode).

Present Levels of Academic Achievement and Functional Performance
The Present Levels of Academic Achievement and Functional Performance must include specific information addressing:

• The strengths of the student;
• The concerns of the parents for enhancing the education of their child;
• The present level of academic performance, including the student’s most recent performance on State or district-wide assessments;
• The present level of developmental and functional performance (including the results of the initial or most recent evaluation); and,
• How the student’s disability affects involvement and progress in the general education curriculum.
Statewide Assessment
Will the student participate in any Statewide Assessment during this IEP period?
- No, Statewide Assessment not conducted at student’s grade level (at time of testing)
- Yes (student’s grade level at time of testing ________). If yes, describe participation decisions below:

<table>
<thead>
<tr>
<th>Regular Assessment</th>
<th>Alternate Assessment</th>
<th>* Explanation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reading/Literature: 3, 4, 5, 6, 7, 8, and HS/11</td>
<td>* Extended Assessment</td>
<td>State why student cannot participate in regular assessment and why particular alternate assessment selected is appropriate for student.</td>
</tr>
<tr>
<td></td>
<td>□ Standard (may include accommodations)</td>
<td>□ * Standard Administration</td>
</tr>
<tr>
<td></td>
<td></td>
<td>□ * Scaffold Administration</td>
</tr>
<tr>
<td>Mathematics: 3, 4, 5, 6, 7, 8, and HS/11</td>
<td>* Extended Assessment</td>
<td></td>
</tr>
<tr>
<td></td>
<td>□ Standard (may include accommodations)</td>
<td>□ * Standard Administration</td>
</tr>
<tr>
<td></td>
<td></td>
<td>□ * Scaffold Administration</td>
</tr>
<tr>
<td>Writing: 4, 7 and HS/11</td>
<td>* Extended Assessment</td>
<td></td>
</tr>
<tr>
<td></td>
<td>□ Standard (may include accommodations)</td>
<td>□ * Standard Administration</td>
</tr>
<tr>
<td></td>
<td></td>
<td>□ * Scaffold Administration</td>
</tr>
<tr>
<td>Science: 5, 8 and HS/11</td>
<td>* Extended Assessment</td>
<td></td>
</tr>
<tr>
<td></td>
<td>□ Standard (may include accommodations)</td>
<td>□ * Standard Administration</td>
</tr>
<tr>
<td></td>
<td></td>
<td>□ * Scaffold Administration</td>
</tr>
</tbody>
</table>

Accommodations:
- Standard (may include accommodations)
- Extended Assessment
- Standard Administration
- Scaffold Administration
### Districtwide Assessment

**Will the student participate in any Districtwide assessment during this IEP period?**

- [ ] No. Districtwide Assessment not conducted at student’s grade level (at time of testing)
- [x] Yes, student’s grade level at time of testing _______. If yes, describe participation decisions below:

<table>
<thead>
<tr>
<th>Assessment</th>
<th>Alternate Assessment</th>
<th>Accommodations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Regular Assessment</td>
<td>Alternate Assessment</td>
<td>Accommodations</td>
</tr>
<tr>
<td>Assessment: ________________</td>
<td>District Alternate Assessment</td>
<td>Standard administration</td>
</tr>
<tr>
<td>Grades administered: _____</td>
<td>Other: ________________</td>
<td></td>
</tr>
<tr>
<td>Assessment: ________________</td>
<td>District Alternate Assessment</td>
<td>Standard administration</td>
</tr>
<tr>
<td>Grades administered: _____</td>
<td>Other: ________________</td>
<td></td>
</tr>
<tr>
<td>Assessment: ________________</td>
<td>District Alternate Assessment</td>
<td>Standard administration</td>
</tr>
<tr>
<td>Grades administered: _____</td>
<td>Other: ________________</td>
<td></td>
</tr>
<tr>
<td>Assessment: ________________</td>
<td>District Alternate Assessment</td>
<td>Standard administration</td>
</tr>
<tr>
<td>Grades administered: _____</td>
<td>Other: ________________</td>
<td></td>
</tr>
</tbody>
</table>

*Explanation:*

State why student cannot participate in regular assessment and why particular alternate assessment selected is appropriate for student.

---

Form 581-5138a-P

1/2011: Oregon Standard IEP for students age 15 and younger when IEP is in effect
### Measurable annual goals page:

<table>
<thead>
<tr>
<th>Measurable Annual Goals:</th>
<th>How progress will be measured:</th>
<th>How progress will be reported to parents:</th>
<th>When progress will be reported to parents:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Criteria</td>
<td>Evaluation Procedures</td>
<td>Student's Progress Toward Goal</td>
</tr>
<tr>
<td></td>
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</tr>
</tbody>
</table>
**Student's Name:** ______________  **Date:** ______________  **School District:** ______________________________

**Measurable Annual Goals/Objectives:** (Objectives required for students taking alternate assessments aligned to alternate achievement standards).

<table>
<thead>
<tr>
<th>Measurable Annual Goal:</th>
<th>Progress will be measured as indicated below:</th>
<th>How progress will be reported to parents:</th>
<th>When progress will be reported to parents:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Criteria</td>
<td>Evaluation Procedures</td>
<td>Student's Progress Toward Goal</td>
</tr>
</tbody>
</table>

**Measurable Short-Term Objectives**

__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
### Service Summary (this section may be continued on additional page(s), if necessary)

<table>
<thead>
<tr>
<th>Specially Designed Instruction</th>
<th>Anticipated Amount/Frequency</th>
<th>Anticipated Location</th>
<th>Starting Date</th>
<th>Ending Date</th>
<th>Provider e.g. LEA, ESD, Regional</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Related Services</th>
<th>Anticipated Amount/Frequency</th>
<th>Anticipated Location</th>
<th>Starting Date</th>
<th>Ending Date</th>
<th>Provider</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Supplementary Aids/Services; Modifications; Accommodations</th>
<th>Anticipated Amount/Frequency</th>
<th>Anticipated Location</th>
<th>Starting Date</th>
<th>Ending Date</th>
<th>Provider</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Supports for School Personnel</th>
<th>Anticipated Amount/Frequency</th>
<th>Anticipated Location</th>
<th>Starting Date</th>
<th>Ending Date</th>
<th>Provider</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Nonparticipation Justification

Does the student need to be removed from participating with nondisabled students in the regular classroom, extracurricular, or nonacademic activities for the provision of special education services, related services, or supplementary aids and services?

Yes_________     No___________  

If yes, document the amount/extent of the removal:__________________________________________

If yes, provide explanation justifying the removal:

### Extended School Year (ESY) Services

ESY services will be provided for this student:

__ Yes: ESY services to be provided are described on Services Summary Page  
__ No  
__ To be considered: Will meet to consider ESY by __ (date)
Making the Most of Your Child’s IEP
Seven Tips for Parents of Children With Special Needs

- Kevin C. Brague, Attorney at Law.

Download at: http://braguelaw.com/6.html
Module 4

Health-Related Social Service Needs: Strategies to Assess and Address in the Family-Centered Medical Home

1. Overview
2. Facilitator Guide
3. Presentation Content and Facilitator Notes
4. Presentation Slides
5. Pre-Session Worksheet – Social Service Needs
6. Pre-Session Worksheet – Challenging Case
7. Pre-Session Reading – Poverty grown up: How childhood socioeconomic status impacts adult health
8. Pre-Session Reading – Social determinants: Taking the social context of asthma seriously
9. Pre-Session Reading – Revisiting the social history for child health


Module Citation: Bottino C and Fleegler E. Module 4, Health-Related Social Service Needs: Strategies To Assess and Address in the Family-Centered Medical Home. In Antonelli RC et al, Pediatric Care Coordination Curriculum. Boston Children’s Hospital, 2014

The authors greatly appreciate the generous support of the Maternal and Child Health Bureau (MCHB), which made development of this curriculum possible. The project was funded through a supplemental grant (U40MC00149) by MCHB, through a cooperative agreement with Family Voices.
Pediatric Care Coordination Curriculum

Module 4.1

Pediatric Care Coordination Curriculum

Module Title: Health-Related Social Service Needs: Strategies to Assess and Address in the Family-Centered Medical Home – Module 4

Module Format: In-person session (~1.5 Hours)

Module Overview: This module focuses on understanding care coordination in social/cultural context, and understanding the social determinants of health as they impact on families in the medical home context.

Audience: Care coordinators and/or members of the care coordination team

Rationale: This curriculum was created with the goal of offering practical, experience-based principles to facilitate the introduction and continued enrichment of care coordination.

Module Goals and Learning Objectives:

1. Understand the social determinants of health.
2. Identify commonly encouraged health-related social service needs in pediatric primary care.
3. Recognize barriers to assessing unmet health-related social service needs in clinical practice
4. Develop strategies to address unmet health-related social service needs in the patient- and family-centered medical home.

Module Activity Summary:

<table>
<thead>
<tr>
<th>Activity</th>
<th>Time</th>
<th>Materials Required</th>
<th>Faculty</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre-session Information</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Poverty grown up: how childhood socioeconomic status impacts adult health Conray et al. J Dev Behav Pediatr. 2010</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Social determinants: taking the social context of asthma seriously Williams et al. Pediatrics 2009</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Revisiting the social history for child health Kenyon et al. Pediatrics 2007</td>
<td></td>
</tr>
<tr>
<td>Introduction and PowerPoint Presentation</td>
<td>45 Minutes</td>
<td>PowerPoint Presentation</td>
<td>Facilitator</td>
</tr>
<tr>
<td>Helpsteps Demonstration &amp; Discussion</td>
<td>20 Minutes</td>
<td>Helpsteps Website &amp; PowerPoint Presentation</td>
<td>Facilitator</td>
</tr>
<tr>
<td>Closing</td>
<td>15 Minutes</td>
<td>PowerPoint Presentation</td>
<td>Facilitator</td>
</tr>
</tbody>
</table>

Evaluation:

Short term: Attendees will be asked near the end of the session to come up with 2-3 tips, approaches and/or strategies that they learned that they will commit to putting into practice over the next few weeks. Once in the large group at the end attendees will be asked to share these strategies they are going to take away and discuss next steps for action with the group.

Long term: Follow up with the attendees 4-6 weeks after the session via conference call or listserv survey to see how the strategies they planned to act upon have impacted the relationships that they’ve built with children, youth and their families.
Module 4: Health-Related Social Service Needs: Strategies to Assess and Address in the Family-Centered Medical Home – Facilitator Guide

Time: 1.5 Hours

Authors: Clement Bottino, MD and Eric Fleegler, MD MPH

PREPARATORY NOTES FOR FACILITATOR:
To make this learning activity successful, the facilitator should be sensitive to several key issues:

1. The notion of considering health-related social service needs in pediatric primary care is unfamiliar and daunting to many health care providers. These issues, such as homelessness and food insecurity, are sensitive topics to both patients and providers. The facilitator should work to cultivate a supportive environment where participants feel comfortable discussing their experiences and difficulties with health-related social service needs.

2. Participants may present to the seminar with different levels of familiarity and experience dealing with families’ health-related social service needs. There may also be differences among health care providers in the level of affluence or education of their respective patient populations. The facilitator should meet and engage participants at the level of their contextual background, emphasizing that health-related social service needs are not the exclusive domain of poor populations. Service needs, including those stemming from issues like domestic violence and health-risk behaviors (safety equipment use, substance abuse), may occur across the financial spectrum.

3. Providers may also present with different levels of experience engaging community support and resources. The facilitator should have some basic understanding of community dynamics and level of local resource support in order to effectively engage participants from this pragmatic standpoint.

4. Facilitators should be familiar with HelpSteps prior to teaching the session. Though HelpSteps database of social service agencies may not be specific for health care centers located outside the greater Boston area, the questionnaire and evaluation system can serve as a universal guide to understanding the scope of health-related social service needs experienced by patients regardless of geographic locale.

A NOTE ABOUT THE HELPSTEPS:
While HelpSteps has been applied in both clinical and research settings, it should be thought of as primarily a teaching tool for the purposes of this module. HelpSteps will facilitate participants’ thinking about the types of social service needs that families face, and the different agencies and resources available in their own locales. The database of health and human service agencies contained in HelpSteps is extensive (over 750 agencies), and highly localized to the greater Boston area. Some participants may note frustration that such a database is not available in their own catchment area. The facilitator can use this as an opportunity to underscore the potential for growth and development of these kinds of resources, and their importance, broadly across the health care sector.
Pediatric Care Coordination Curriculum

Module 4.2

Module 4 Facilitator Guide

**MODULE MATERIALS:**
1. Facilitator guide, slides, and slide handouts
2. Case vignette: *Santiago* (hard copy)
3. Key articles - If participants have time to read one article in advance, the Kenyon et al article is recommended.
   a. Conroy et al. JDev BehPed. 2010. *Poverty grown up: how childhood socioeconomic status impacts adult health*
      
      **Summary:** Socioeconomic status and health status are directly related across the world. Children with low socioeconomic status not only experience greater health problems in childhood but also aspects of their socioeconomic status become biologically incorporated through both critical periods of development and cumulative effects, leading to poor health outcomes as adults. The authors explore 3 main influences related to child’s socioeconomic status that impact long-term health: the material environment, the social environment, and the structural or community environment. These influences illustrate the importance of clinical innovations, health services research, and public policies that address the socioeconomic determinants of these distal health outcomes.
   
      
      **Summary:** Although asthma has emerged as a major contributor to disease and disability among US children, the burden of this disease is unevenly distributed within the population. This article provides an overview of social-status variables that predict variations in asthma risks and social exposures, such as stress and violence, that are emerging as important risk factors. The focus is on the distal social variables that have given rise to unhealthy residential environments in which the risk factors for asthma and other diseases are clustered. Effective initiatives for the prevention and treatment of childhood asthma need to address these nonmedical determinants of asthma prevalence.
   
      
      **Summary:** The authors suggest a practical method for eliciting a social history that focuses on 4 specific social domains for the social context: (1) social stressors and support networks; (2) change in environment; (3) life control; and (4) literacy. Pediatricians generally address some of these issues already, such as knowing who a child lives with and where they are from. However, basic needs such as income, food sufficiency, and health environments at home and in school, which are crucial to children’s health and well-being, are not routinely addressed. Building on this model, the authors propose a more explicit set of domains and questions (see *IHELLP* slide) that allow for more-specific inquiry into areas that are amenable to direct intervention that focuses on basic needs and factors that influence health. Using the mnemonic “IHELLP,” their model addresses income, housing/utilities, education, legal status/immigration, literacy, and personal safety, each of which has been shown to directly impact child health.

**MODULE OVERVIEW:**

**PART I: 45 minutes**
- **PowerPoint presentation**
  - Introduction & Learning Objectives
  - Case: *Santiago*
  - Asthma: a multifactorial disease
  - Social Determinants of Health
  - Health-Related Social Service Needs
  - *HelpSteps* – brief description and overview

**PART II: 20 minutes**
- **HelpSteps Demonstration and Discussion**
  - Presenters will demo *HelpSteps* using the case vignette *Santiago* as a conceptual template
  - Presenters will proceed through the screening questionnaire “as Carmen” (Santiago’s mother) and will choose resources that might be helpful for Carmen and Santiago.
  - Individuals will be encouraged to record their thoughts, feelings and reactions during the process

**PART III: 15 minutes**
- **Feedback and closing**
  - Presentation of health-related social service needs identified among adolescents using *HelpSteps* at the Children’s Hospital Adolescent Medicine Center
  - Closing comments
### Pediatric Care Coordination Curriculum

#### Module 4 Presentation Content and Facilitator Notes

<table>
<thead>
<tr>
<th>Slide</th>
<th>Content and Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Slide 1</strong></td>
<td>Pediatric Care Coordination Curriculum (include location, date, facilitator/s)</td>
</tr>
</tbody>
</table>
| **Slide 2** | Health-Related Social Service Needs  
*Strategies to Assess and Address in the Family-Centered Medical Home* |
| **Slide 3** | **Learning Objectives**  
Upon completion of this activity, participants will be able to:  
1. Understand the social determinants of health  
2. Identify health-related social service needs  
3. Recognize barriers to assessing unmet needs  
4. Develop strategies to address unmet needs  
The graphics on this slide highlight two commonly encountered health-related social service needs in pediatric primary care: food insecurity (impaired access to quality nutrition) and housing instability (sub-standard housing conditions or difficulties maintaining residence). |
| **Slide 4** | **Case Vignette: Santiago**  
Santiago has poorly controlled asthma and he and his mother, Carmen, face multiple adverse social hardships. This case is designed to highlight:  
1. Asthma as a multifactorial disease with a spectrum of contributory and associated factors  
2. Components of social determinants of health  
3. Specific health-related social service needs (legal assistance, housing problems) experienced by Carmen and Santiago.  
Each of these features of the case receives attention in the subsequent slides. |
| **Slide 5** | **Asthma: Quick Facts**  
This slide contains basic information about pediatric asthma designed to orient participants to the nature and scope of the clinical problem.  
Asthma is characterized clinically by:  
- Reversible airway obstruction  
- Symptoms of recurrent dyspnea (shortness of breath), cough and wheezing  
Over 6.7 million children (9.1%) in United States suffer from asthma. Asthma has only recently been eclipsed by obesity as the most common chronic condition of childhood.  
Asthma is associated with significant health care utilization. Approximately 2.5% of all outpatient pediatric visits annually are for asthma care.  
Pediatric asthma accounts for 12.8 million days of missed school per year and accounts for over $12 billion in annual direct (medical) & indirect (missed work and foregone productivity) costs.  
The graphic comes from National Heart, Lung, and Blood Institute; National Institutes of Health; U.S. Department of Health and Human Services. Literature references are in the lower right corner of the slide. |
The slide contains a graphic from the previous slide; the goal is to present asthma as a medical entity (disease) with a spectrum of contributory and associated factors (multi-factorial). Each box represents a specific domain of factors:

| 1. Genetic |
| 2. Behavioral |
| 3. Environmental |
| 4. Health Care |
| 5. Social |

**Genetic factors:** A positive family history is a known risk factor for asthma; Burke et al. found that family history for asthma carries a positive predictive value (PPV) of 11-37%\(^5\) (meaning the probability that a child who has asthma also has a positive family history is 11-37%). Researchers have also discovered specific genes that may predispose individuals to asthma and bronchial hyper-responsiveness. One of these is Adam33, which codes for an enzyme (specifically a disintegrin and metalloprotease) thought to be involved in airway wall modeling\(^6\).

**Behavioral factors:** This box highlights individual health-risk behaviors associated with asthma. Ehrlich et al. found that the odds (adjusted odds ratio, AOR) of offspring developing asthma were 1.87 fold greater among women who smoked during pregnancy compared to women who didn’t smoke\(^9\). Nguyen et al. found that the odds of having poorly controlled asthma were 2.5 fold greater among adults who were current smokers compared to non-smokers\(^10\). Kull et al. found that breast feeding was protective for asthma, with an odds ratio (OR) of 0.72 for developing asthma at age 4 (in this study these were children who had been breast fed exclusively for at least 4 months)\(^11\).

**Environmental factors:** emerging evidence points toward environmental pollutants as significant contributors to childhood asthma. Clark et al. measured traffic-related air pollution in a cohort of children living in British Columbia, and found increasing odds of developing asthma with increasing exposure to roadway traffic (1.12 per 10 μg·m\(^{-3}\) increase in ambient nitrogen dioxide ([NO\(_2\)])\(^12\). Friedman et al. found that during the 17 days of the 1996 Olympic Games in Atlanta, during which time road traffic in and around the city was highly restricted, there was an almost 42% reduction in the number of asthma-related visits for children (visits for other problems remained the same)\(^13\).

A 28% decrease in peak daily ozone concentration (a marker of air pollution) was thought to be the primary reason for the decrease in asthma visits.

**Health care factors:** poor access to health care is known to have wide ranging adverse associations with health outcomes through the life course. In their analysis of adults in New England (using 2006-2007 Behavior Risk Factor Surveillance System Adult Asthma Call-Back Survey), Nguyen et al. found that being unable to see a doctor or specialist for asthma care or being unable to buy medication for asthma because of cost was associated with a 7.6 fold increased odds of reporting very poorly controlled asthma\(^10\).

**Social factors:** evidence indicates a strong association between social factors (race, education, income, employment and others) and health outcomes, and serves as the conceptual basis for **social determinants of health** presented subsequently. In their analysis of adults living in New England, Nguyen et al. found that being unemployed or unable to work carried a 17.9 fold increased odds of reporting very poorly controlled asthma. Having a high school education or less carried a 2.8 fold increased odds and Hispanic ethnicity a 4 fold increased odds, each, of reporting very poorly controlled asthma\(^10\).
Factors Affecting Santiago’s Health

The idea here is that on the surface, it seems that the main issue for Santiago’s repeated visits to the ED and doctor’s offices for asthma is that his mother, Carmen, is simply not administering the medicines as prescribed.

The imposing under the surface graphic, alongside text reading Social Determinants of Health and a list of determinants highlighted in the case vignette:

- Housing
- Unemployment
- Can’t afford prescriptions
- Legal issues
- Health literacy

Each bullet represents a different social determinant; the social factors like those presented in the previous slide, which may be contributing to Santiago’s persistent difficulties with asthma. As the below the surface iceberg suggests, these social determinants can feel massive and daunting for the health care provider trying to address a patient’s individual needs.

Social Service Needs and a bulleted list of service needs revealed in the case vignette:

- Housing assistance
- Income assistance
- Health insurance
- Legal aid
- English as second language (ESL)

Each of these health-related social service needs represents a potential venue for assistance that Santiago’s medical home could connect him to. Whereas the broad notion of fixing Santiago’s social determinants of health might seem overwhelming and impossible, narrowing the focus to address the family’s specific social service needs can make the process feel more intuitive. Stated another way, the medical home can’t fix Santiago’s substandard housing, but his health care providers can identify that there is a need for housing assistance and then and connect the family with an appropriate housing agency or community resource.

Social Determinants of Health

The Centers for Disease Control (CDC) has on their website a useful definition of social determinants of health:

“The complex, integrated, and overlapping social structures and economic systems that are responsible for most health inequities.

“These social structures and economic systems include the social environment, physical environment, health services, and structural and societal factors.

“Social determinants of health are shaped by the distribution of money, power, and resources throughout local communities, nations, and the world.”

As with the previous slide, this definition is meant to underscore the scale and complexity of social determinants of health. Notable aspects of this definition include:

- Complex, integrated and overlapping – social determinants of health are highly complex. This session is meant to provide attendees with a taste of what is the subject of entire graduate level coursework and national level research endowment.
- Responsible for health inequities – social determinants, not simply genetics or individual behaviors, are responsible for the differences in health outcomes found across the United States and globally.
- Shaped by distribution...of resources...throughout the world – per the previous slide, the medical home may not be able to address the huge, global issues encompassed by social determinants of health. But honing in on specific health-related social service needs can empower providers in the patient and family centered medical home to take the first steps at improving these aspects of health on behalf of their patients.
### Slide 9

**Determinants of Health**

The CDC identifies 5 fundamental determinants of health, which are factors that contribute to a person’s current state of health. These are:

- **Genetics and Biology**:
  - Age
  - Sex
  - Family history

- **Behavioral**:
  - Smoking
  - Alcohol
  - Diet
  - Exercise
  - Drug use
  - Sex (behavior)

- **Environmental**:
  - Pollution
  - The built environment
  - Green space

- **Health Care**:
  - Access to quality health care
  - Health insurance

- **Social**:
  - Race/ethnicity (through discrimination)
  - Education
  - Income
  - Employment
  - Food security
  - Housing
  - Social support

This slide illustrates how health is traditionally conceptualized in modern medicine. Much like the one-pathogen, one-disease model of infection, each determinant is compartmentalized into a discrete, non-overlapping space. This model, as we shall see, fails to capture the inextricable interrelatedness of these determinants of health.

### Slide 10

**Social Determinants of Health**

This slide is meant as a visual aid to help conceptualize social determinants of health and their relationship to medical care and personal behavior.

The take home message here is that to the medical provider, patients’ issues on the surface are usually related to medical care (do they come to their doctor’s visit, do they take their medicines as prescribed?) and personal behavior (are they dieting, exercising, not smoking?), but the bigger issues, those which may be lurking beneath the surface and are actually driving the health outcomes, are those related to the social determinants of health.

### Slide 11

**Significance of Social Determinants = “Social Gradient” in Health Outcomes**

Now that we have built a conceptual framework for understanding what social determinants of health are, we will transition to discussing why they are significant.
Many Health-Related Behaviors Exhibit a “Social Gradient”


Though the prevalence of smoking has decreased in recent years, rates continue to demonstrate a social gradient pattern, with percent of current smokers decreasing as family income increases. For men and women, cigarette smoking as about twice as common among poor persons as among high-income persons.

Data are obtained using household interviews (National Health Interview Survey) and current cigarette smoking is defined as ever smoking 100 cigarettes in one’s lifetime and smoking now every day or some days.

Family income categories presented are defined as follows:
- **Poor** persons have family incomes below 100% of the Federal poverty level (FPL). For a family of 4, the FPL was $22,050 in 2009
- **Near poor** persons have family incomes between 100 and 199 percent of the FPL
- **Middle income** persons have family incomes between 200-399% FPL
- **High income** persons have family incomes 400% or more of the FPL

| Slide 12 | “Social Gradient”- sedentary Lifestyle |
| Slide 13 | Poverty and Children - Image |
| Slide 14 | Poverty Among Children Under 18 Years |
| Slide 15 | Children in Poverty 1959-2011 |
| Slide 16 | Percentage of Children in Poverty by State (2010) |
| Slide 17 | Income Level of Child’s Household NSCH 2007-all children (ages 0-17) Nationwide vs Alaska |
| Slide 18 | Income Level of Child’s Household NSCH 2007-children with special needs (ages 0-17) Nationwide vs Alaska |
### Pediatric Care Coordination Curriculum

#### Module 4 Presentation Content and Facilitator Notes

**Social Determinant / Health-Related Social Service Need**

This chart is meant to highlight the specific social determinant and the correlated health-related social service need:

<table>
<thead>
<tr>
<th>Social Determinant</th>
<th>Health-Related Social Service Need</th>
</tr>
</thead>
<tbody>
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<td>Poverty</td>
<td>Income Assistance</td>
</tr>
<tr>
<td>• %FPL ($22,350 Family of 4)</td>
<td>• TAFDC, SSI, SSDI</td>
</tr>
<tr>
<td>Housing Instability</td>
<td>Housing Assistance</td>
</tr>
<tr>
<td>• Homeless</td>
<td>• Homeless shelter, section 8</td>
</tr>
<tr>
<td>• Impending eviction</td>
<td>• Housing inspections</td>
</tr>
<tr>
<td>• Structural problems</td>
<td>• NSTAR utilities assistance</td>
</tr>
<tr>
<td>• Utilities, heat</td>
<td></td>
</tr>
<tr>
<td>Food Insecurity</td>
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<td>Unemployment</td>
<td>Job training</td>
</tr>
<tr>
<td>Violence, Abuse</td>
<td>Domestic violence shelter, counseling services</td>
</tr>
</tbody>
</table>

**Definitions**

- **FPL**: Federal Poverty Level ($22,350 for a family of 4 in 2010)
- **TAFDC**: Transitional Aid to Families with Dependent Children; a cash assistance program for low-income families with children
- **SSI**: Supplemental Security Income; a Federal income supplement program that provides cash to meet basic needs for food, clothing and shelter
- **SSDI**: Social Security Disability Insurance; Federal income supplement to people who are physically restricted in their ability to be employed because of a notable disability
- **Housing Instability**: Denotes difficulty with structural housing problems or difficulty maintaining residence. This may be due to:
  - Homelessness or impending homelessness
  - Eviction, impending eviction or foreclosure, failure to pay rent or mortgage
  - Structural problems: peeling paint, broken windows, plumbing or electrical issues
  - Difficulty with utilities or heating bills; threatened or shut off heat or utilities

- **Section 8**: Section 8 of the United States Housing Act of 1937; authorizes the payment of rental housing assistance to private landlords through Federal subsidy
- **NSTAR utilities assistance**: NSTAR is a utility company that provides retail electricity and natural gas to 1.4 million customers in eastern and central Massachusetts, including the Boston urban area. The assistance program provides discounted rates and fuel assistance for families with a gross below 60% of the state median.
- **Food Insecurity**: Denotes problems with availability or access to quality nutrition. This may include hunger or being worried about not being able to feed one’s family, or an inability to afford quality, healthy food.
- **Physical Inactivity**: Included with food insecurity here because in pediatric clinical practice, physical activity and nutrition are often intertwined. The YMCA/community center is an example of a health-related social service need for physical inactivity. Stated another way, children struggling with physical inactivity and limited access to physical activity need a service such as the YMCA to assist them in meeting daily physical activity requirements.
- **SNAP**: Supplemental Nutrition Assistance Program (food stamps)
- **WIC**: Women, Infants and Children; Federal grants to States for supplemental foods, health care referrals and nutrition education for low-income pregnant and postpartum women, and to infants and children up to age five.
- **ESL**: English as a Second Language
- **GED**: General Educational Development; a group of five subject tests which, when passed, certify that the taker has high school-level academic skills.
### Examples - Community Resources Designed to Meet Social Service Needs

This slide contains two graphics: a *Waltham Fields Outreach Market* (note the acceptance of SNAP) and *YMCA Nutri-Fit Kids* (a free physical activity and nutrition resource for children 8-12 years in Roxbury).

These graphics are intended to highlight the presence of community resources designed to meet patients’ health-related social service needs as described above. Given the availability of resources, the challenges faced by health care providers in the patient- and family-centered medical home then become:

1. How to screen for and identify health-related social service needs
2. How to better connect families to helpful local resources

### Suboptimal Screening

The patient and family centered medical home can be a safe environment to identify health-related social needs and connect families to needed services.

However, despite the clear for effective screening for unmet needs, medical providers often fail to probe social circumstances and identify psychosocial problems\(^{24,25}\). Suboptimal screening results in missed referral opportunities to resources that can help families.

The AAP evaluated the barriers to psychosocial screening and found that while 76% of pediatricians felt they should inquire about these issues, only 40% felt comfortable advising parents, only 33% felt they had sufficient training\(^{26}\).

### Barriers to Screening

Prior literature suggests that barriers to screening for social circumstances include\(^{27}\):

1. Insufficient knowledge of how to screen
2. Lack of confidence (self-efficacy) to advise parents
3. Deficiency in knowledge of resources
4. Difficulty accessing the referral process
5. Belief that these issues are outside the pediatric domain
6. Lack of time
7. Lack of reimbursement

### Health-Related Social Problems: Prevalence, Screening and Acceptability

When families receiving pediatric primary care at the Martha Eliot Health Center in Jamaica Plain, MA, were screened on their health-related social service needs (for this study, these were called health-related social problems), there was a notable prevalence of problems:

- 45% reported problems with *access to health care*
- 56% reported problems with *housing*
- 39% reported problems with *food security*
- 17% reported problems with *income security*
- 14% reported problems with *domestic violence*

When asked whether they had been screened for these problems by a health care provider within the last year:

- 23% reported they had been screened for *access to health care*
- 31% reported they had been screened for *housing*
- 17% reported they had been screened for *food security*
- 21% reported they had been screened for *income security*
- 36% reported they had been screened for *domestic violence*
### Health-Related Social Problems: Prevalence, Screening and Acceptability

When asked about the **acceptability of screening**: “If you could be connected to an agency that could help you, how would you feel if [child’s name]’s doctor or health care provider asked you about...”

- 94% reported acceptability for **access to health care**
- 93% reported acceptability for **housing**
- 88% reported acceptability for **food security**
- 90% reported acceptability for **income security**
- 81% reported acceptability for **domestic violence**

These findings suggest that patients want to be asked about these issues, even if they are difficult to broach.

### Innovation: HelpSteps

**HelpSteps** is an innovation designed to address barriers to effective identification of health-related social service needs, and was developed by Dr. Fleegler and his development team at Children’s Hospital, Boston.

*The HelpSteps* includes a Web-Based assessment and referral tool for health-related social service needs.

### Helpsteps.com

This is *HelpSteps* web address; participants may be directed here for further questions about the system.

### IHELLP

In discussing tools to facilitate screening for health-related social service needs in the clinical setting, the IHELLP mnemonic may be helpful. The facilitator may choose to go through each domain or give a more general overview.

- I – Income
- H – Housing
- E – Education
- L – Legal status
- L – Literacy
- P – Personal safety

### MCHB Acknowledgment
Pediatric Care Coordination Curriculum

References

Pediatric Care Coordination Curriculum

Module 4
MODULE 4:

Health-Related Social Service Needs
Strategies to Assess and Address in the Family-Centered Medical Home

Module Authors:
Clement Bottino, MD
Eric Fleegler, MD MPH
Learning Objectives

1. Understand the social determinants of health
2. Identify health-related social service needs
3. Recognize barriers to assessing unmet needs
4. Develop strategies to address unmet needs
Case Vignette: Santiago

Santiago is an 8 year old boy with asthma. He often ends up in emergency rooms when his asthma flares up.

His mother, Carmen, speaks limited English.

Santiago has received many different prescriptions for his asthma. Inhalers are very expensive.

Carmen doesn’t fully understand which medications Santiago should receive daily or only during flare-ups.

Santiago's father moved back to the Dominican Republic because he couldn’t find work in the US.

Carmen can’t work full-time because Santiago is sick so frequently and as a result, they are currently living with relatives in a roach-infected apartment.

Even though she and Santiago are now US citizens, friends have told Carmen that if she accepts any public assistance, she could jeopardize their citizenship.
Asthma: Quick Facts

- **Reversible airway obstruction**
  - Dyspnea, cough, wheezing
- 6.7 million children (9.1%) in US
- ~2.5% of all outpatient pediatric visits
- 12.8 million days of missed school per year
- >$12 billion in annual direct (medical) & indirect (missed work) costs

Akinbami L. *Adv Data*. 2006

Asthma: A Multi-Factorial Disease

**Behavioral Factors**
- Smoking during pregnancy or current smoker
- Breast feeding = protective

**Genetic Factors**
- Family history
- Adam33 = possible “asthma gene”

**Social Factors**
- Unemployed or unable to work
- High school educated or less
- Hispanic ethnicity

**Environmental Factors**
- Proximity to highways

**Health Care Factors**
- Unable to see MD for asthma or can’t afford Rx

---

Holgate ST. Drug News Perspect. 2010
Ehrlich et al. Am J Respir Crit Care Med. 1996
Kull et al. Allergy Clin Immunol. 2004
Nguyen et al. J Asthma. 2011
Factors Affecting Santiago’s Health

Santiago’s Asthma

- Mother not giving Rx

Social Determinants of Health

- Housing
- Unemployment
- Can’t afford Rx
- Legal issues
- Health literacy

Social Service Needs

- Housing assistance
- Income assistance
- Health insurance
- Legal aid
- English as second language
Social Determinants of Health

• “The complex, integrated, and overlapping social structures and economic systems that are responsible for most health inequities.”

• “These social structures and economic systems include the social environment, physical environment, health services, and structural and societal factors.”

• “Social determinants of health are shaped by the distribution of money, power, and resources throughout local communities, nations, and the world.”

**Determinants of Health**

“Factors that contribute to a person's current state of health”

- **Behavioral**
  - Smoking
  - Alcohol
  - Diet
  - Exercise
  - Drugs
  - Sex

- **Social**
  - Race/ethnicity (discrimination)
  - Education
  - Income
  - Employment
  - Food security
  - Housing
  - Social Support

- **Genetics & Biology**
  - Age
  - Sex
  - Family history

- **Environmental**
  - Pollution
  - Built environment
  - Green Space

Health Care
- Access to quality care
- Health insurance

---

Social Determinants of Health
Many Health-Related Behaviors Exhibit a “Social Gradient”

Let’s look at 2 examples...
"Social Gradient" - Smoking

Cigarette Smoking Prevalence, By Family Income

% Adults

Men

Women

Health, United States, SES and Health Chartbook 1998
“Social Gradient” – Sedentary Lifestyle

Sedentary Lifestyle Prevalence Among Adolescents, By Family Income

Health, United States, SES and Health Chartbook 1998
Pediatric Care Coordination Curriculum

Module 4.4

Poverty & Children

Let’s look at this problem and the multiple effects on the pediatric population.

Know your patients. More often than not, there isn’t a “sign”...

Out of Work
Homeless
Anything Helps
Thank you
Poverty among children under 18 years

**Graph:**
- **Y-axis:** Percent below poverty
- **X-axis:** Year (1990, 2000, 2010)
  - **Lines:**
    - Hispanic
    - Black
    - All children
    - White, not Hispanic

**Pie charts** for 2010:
- **Hispanic:** 11%, 24%, 30%, 35%
- **Black:** 11%, 24%, 39%
- **White, not Hispanic:** 12%, 37%, 17%, 34%
- **Asian:** 14%, 40%, 19%, 27%

**Poverty level**:
- Below 100%
- 100%–199%
- 200%–399%
- 400%+

**Source:** CDC/NCHS, *Health, United States, 2011*, Figure 22. Data from the U.S. Census Bureau.
Children in Poverty 1959-2011

21.9% in 2011
Up 20% since 2000

22% (~16 million) children in the US live in families with incomes below the federal poverty level ($23,021/yr for a family of 4).

Source: National Center for Children in Poverty (www.NCCP.org)
Income level of child's household based on SCHIP

Children age 0-17 years
Nationwide vs. Alaska
Household income 0-199% FPL x Age - 3 groups (0-17 yrs)

Note: all children

Income level of child's household based on SCHIP
Children age 0-17 years
Nationwide vs. Alaska
Household income 0-199% FPL x Special health care needs type

Note: children with special needs

National Survey of Children's Health, NSCH 2007. Data query from the Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health:
www.childhealthdata.org
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Examples - Community Resources Designed To Meet Social Service Needs

Waltham Fields Outreach Market
A Special Market for Those Who Need It The Most!
Come Get Fresh Vegetables from Waltham Fields Community Farm!

TUESDAYS
July 19th - Oct. 11th
4:30 — 6:30 PM
517 Moody Street, WATCH Parking Lot
Near intersection with Maple and High St.

$5 per bag
No Proof of Income Necessary!
SNAP/EBT ACCEPTED!

Project Sponsors: Waltham Fields Community Farm, WATCH CDC, Jewish Family & Children’s Service, Healthy Waltham, CHNA 18, Fallon-Smith Foundation, Frederick E. Weber Charities Corporation, First Parish Waltham-Jones Partnership Fund and the Middlesex Savings Charitable Foundation

For more information, contact us at 781-899-2403
www.communityfarms.org

Nutri-Fit Kids (Age 8-12)
Saturdays 12:00pm-1:30pm
Program start date: January 14, 2012

LEARN, GROW, AND THRIVE

Nutri-Fit Kids promotes healthy living through nutrition and physical activity. Youth will learn about the importance of eating right and staying active through 30 minutes of interactive nutrition-based activities and 1 hour of physical activity per session.

Members/Non-member: No Fee
Contact Mariah Tucker at 617-427-5300 ext. 285.

ROXBURY YMCA
285 Martin Luther King Blvd.
Roxbury, MA 02119
P: 617-318-1420
W: www.ymcaboston.org/roxbury
Suboptimal Screening

- Medical providers often fail to probe and identify social problems
  - AAP survey:
    - 76% of pediatricians felt they should inquire about these issues
    - only 40% felt comfortable advising parents
    - only 33% felt they had sufficient training
Barriers To Screening

- Insufficient knowledge of how to screen
- Lack of confidence (self-efficacy) to advise parents
- Lack of knowledge of resources
- Difficulty accessing the referral process
- Belief that these issues are outside the pediatric domain
- Lack of time
- Lack of reimbursement

Health-Related Social Problems: Prevalence, Screening and Acceptability

**Acceptability of screening:** “If you could be connected to an agency that could help you, how would you feel if [child’s name]’s doctor or health care provider asked you about your…”

![Chart showing prevalence, screening, and acceptability for various social problems](chart.png)

- **Access to health care:**
  - Prevalence: 45%
  - Screened by health care provider: 23%
  - Acceptability: 94%

- **Housing:**
  - Prevalence: 56%
  - Screened by health care provider: 31%
  - Acceptability: 93%

- **Food security:**
  - Prevalence: 39%
  - Screened by health care provider: 17%
  - Acceptability: 88%

- **Income security:**
  - Prevalence: 17%
  - Screened by health care provider: 21%
  - Acceptability: 90%

- **Domestic violence:**
  - Prevalence: 14%
  - Screened by health care provider: 36%
  - Acceptability: 81%

Example from Massachusetts:

Developed at Boston Children’s Hospital
Web-based assessment and referral toolset for health-related social service needs
Designed to alleviate disparities in health and social well-being in the community by connecting individuals to local resources

helpsteps.com
Another Tool is “IHELLP” Mnemonic

Income
Housing
Education
Legal Status
Literacy
Personal Safety

To read more tool please refer to Kenyon et al Pediatrics 2007 article
The authors greatly appreciate the generous support of the Maternal and Child Health Bureau (MCHB), which made development of this curriculum possible.

The project was funded through a supplemental grant (U40MC00149) by MCHB, through a cooperative agreement with Family Voices.

MCHB Project Officer: Marie Mann, MD, FAAP
Social Service Needs

In advance of the training, think about the answers to the following questions:

1. How do you screen or identify social service needs your families are facing?

2. How do you identify a resource to refer the family to when you do identify specific needs?

3. How do you know if specific resources are “good” do you have any selection criteria?

4. Do you get feedback from families you’ve sent there?

5. Do you check these places out yourself?

6. After you make a referral how do you close the loop – how do you know if they received the service, and how do you know if the program was able to meet their needs?
Challenging Case

In advance of the training, think about:

A challenging patient/family you care for (or a sample case) reflecting on these 4 main areas specific to their challenges:

1. Health care

2. Behavioral

3. Social

4. Environmental
Pre-session Reading

Pre-session Reading


http://pediatrics.aappublications.org/content/123/Supplement_3/S174.full?sid=dfcca5da-8019-42db-9fa4-cbdf261d51c
Pre-session Reading


http://pediatrics.aappublications.org/content/120/3/e734.full?sid=a3a426e2-4efe-4e08-9434-f8a35d8b32ad
For a copy of the latest AAP Policy Statement on Care Coordination, released in April, 2014, go to: pediatrics.aappublications.org
Pediatric Care Coordination Curriculum