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# MODULE 2

## Pediatric Care Coordination Curriculum

# Developing and Sustaining Strong Family/Professional Partnerships

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# Developing and Sustaining Strong Family/ Professional Partnerships

## Module 2—Objectives

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

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

### **Note to the facilitator:**

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

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



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

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

### **Optimal Facilitation Guidance**

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

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

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

# Module Overview

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

Table 1

Agenda Item	Time	Materials Required	Instruction/Notes
<b>Pre-session readings</b>	N/A	<ul style="list-style-type: none"> <li>• Welcome to Holland</li> <li>• I Am “That” Parent</li> <li>• From Strangers in a Foreign Land to Active, Engaged Citizens</li> <li>• Patient- and Family-Centered Care and the Pediatrician’s Role</li> </ul>	Distribute readings prior to the day of the session.
<b>Introduction</b>	20 min	N/A	Introduction activity (paper and pencils may be required, depending on the activity)
<b>Didactic</b>	40 min	<ul style="list-style-type: none"> <li>• Slides</li> <li>• Handouts, as needed</li> </ul>	<p>Create a slide deck using content from the didactic portion. Make sure there are opportunities for participants to speak.</p> <p>Add local content to the slides wherever  is indicated.</p> <p>Suggested handouts/worksheets and resources are included in the module.</p>
<b>Case studies</b>	1 hour	<ul style="list-style-type: none"> <li>• Copies of case studies and discussion questions</li> <li>• Whiteboard or flip chart for report back</li> </ul>	<p>Give participants an opportunity to practice the concepts and tools they learned. Case studies can be tailored to fit the relevant audience/population.</p> <p>The case studies are intended for any population, but included below are a few notes about which case study might be most useful, based on the pain points of the group.</p> <p>Case study #1 is best for care teams focused on collaborative decision-making and communication.</p> <p>Case study #2 is best for care teams focused on providing families with tools and resources to guide decisions and care, and for families who want additional resources and/or tactics to guide decision-making and care planning.</p>

# Module Overview

Table 1 » continued

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

# Facilitator Guide–Pre-Session Readings

Pre-session readings and, potentially, a set of discussion questions should be sent to the participants prior to the day of the session to give them time to review and consider the content of the materials before they arrive for the session.

The pre-session readings that are included with this module are listed below, along with a brief annotation to help with the selection of readings. However, the suggested readings can be modified based on the audience. A list of additional recommended readings is included at the end of this module.

## PRE-SESSION READINGS

### **From Strangers in a Foreign Land to Active, Engaged Citizens**

Scharpen AL and Stille CJ. *Pediatrics*. 2018;141(2):e20171845.

Available at: <http://pediatrics.aappublications.org/content/early/2018/01/18/peds.2017-1845>

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

### **I Am That Parent**

Rule ARL. *JAMA*. 2018;319(5):445.

Available at: <https://jamanetwork.com/journals/jama/fullarticle/2671471>

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

### **Patient- and Family-Centered Care and the Pediatrician's Role**

American Academy of Pediatrics Committee on Hospital Care and Institute for Patient- and Family-Centered Care. *Pediatrics*. 2012; 129(2):394-404.

Available at: <https://pediatrics.aappublications.org/content/129/2/394.full>

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

### **Welcome to Holland**

Kingsley EP. 1987.

Available at: <http://www.our-kids.org/Archives/Holland.html>

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

### **Family/Professional Partnerships**

Family Voices, Inc. January 2019.

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

### **Not Just Along For The Ride: Families Are The Engine That Drives Pediatric Home Health Care**

Coleman C. April 2019.

Available at: <https://www.healthaffairs.org/doi/10.1377/hblog20190415.172668/full/>

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

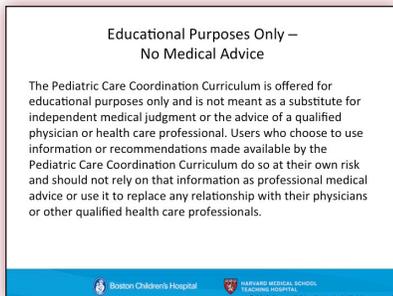
# Facilitator Guide–Slide Deck

## SLIDE 1 » Title Slide



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

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



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# Facilitator Guide–Slide Deck

continued

## SLIDE 3 » Objectives

**Objectives**

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

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

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

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

### *Think through the following:*

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

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

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

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

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

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

**What is Patient- and Family-Centered Care?**

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

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

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

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

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

Source: <http://www.iffcc.org/what-is-pfcc/>

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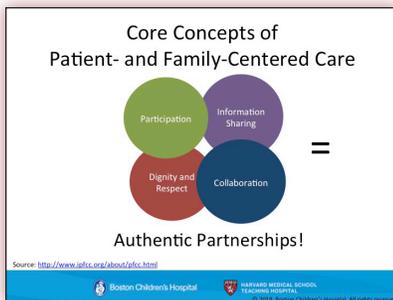
Ask learners to share examples of instances in which they experienced patient- and family-centered care and when they did not (families and care team members both can share their examples). What specifically about the experience made it feel either positive or negative?

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

# Facilitator Guide–Slide Deck

continued

## SLIDE 5 » Core Concepts



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

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

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

## SLIDE 6 » Principles of Family/Professional Partnerships



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

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

### **Suggested questions and discussion:**

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

# Facilitator Guide–Slide Deck

continued

## SLIDE 7 » In Practice

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**In Practice** 

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

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

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

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

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

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

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

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

# Facilitator Guide–Slide Deck

continued

## SLIDE 8 » Tools

**Tools to Support Family/Professional Partnerships**

Tools that will be addressed today

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



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

### **Discussion:**

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

The 3 tools featured in this module address:

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

Examples of ways tools can support operationalization of family/professional partnerships

- Gathers experiences and input from the family in a systematic way
- Develops a structured process for family-driven discussion around goal setting

# Facilitator Guide–Slide Deck

continued

## SLIDE 9 » Family Experience

### Family Experience

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



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

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



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

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

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

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

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

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

# Facilitator Guide–Slide Deck

continued

## SLIDE 10 » Pediatric Integrated Care Survey

**Pediatric Integrated Care Survey**

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

The domains of the instrument are

- Access to care
- Communication
- Family impact
- Care goal creation and planning

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### Tool #1: Pediatric Integrated Care Survey (PICS)

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

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

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

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

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

Another example of a family experience measure is the Family-Centered Care Assessment for Families from Family Voices.

The assessment is available at: <https://medicalhomes.aap.org/Documents/FCCAquestionnaire.pdf>

## SLIDE 11 » PICS

**PICS**

Data are used to

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

How could you use the tool?

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

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

Parents/guardians could say, for example,

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

# Facilitator Guide–Slide Deck

continued

## SLIDE 12 » PICS

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### PICS

- Look through the tool yourself or with someone on your child's care team. Pick out specific items that you believe would improve your child's care and your experience.
- Share the tool with your child's care team members!
- How might you use it or encourage families to use it?

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Encourage the learners to think about how they could use this family experience tool (or others) in their own settings to collect information. Remind them:

- It is important to start small!
- It is important to consider culture and language when deciding how to use the tool.
  - Is it possible to translate the tool or have interpreters translate questions?
  - Can support be available to help families read the survey in case they have questions? (The facilitator can reference the resource Engaging Broad Audiences in this Module 2 facilitator guide for additional context related to reading levels.)

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

## SLIDE 13 » Action Grid

### Action Grid

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

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### Tool #2: Action Grid

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

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

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

#### Note for the facilitator :

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

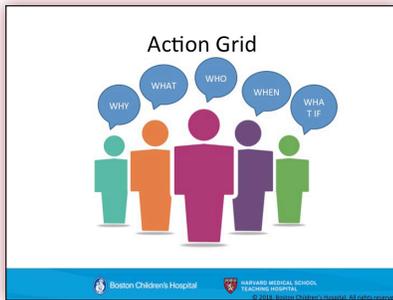
#### An example of a completed action grid:

Goal	Action	Who	When	Contingency
Address headaches	Schedule followup with Neurology	Parent	2 weeks (December 15)	Call back to Smith's office if unable to make appointment
Be able to participate in school sports	Discuss PE at school, adjust SP	Social work to connect with school on IEP	January 1	If parent doesn't hear from school by January 15, call back with at 408-800-XXXX

# Facilitator Guide–Slide Deck

continued

## SLIDE 14 » Action Grid



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

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

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

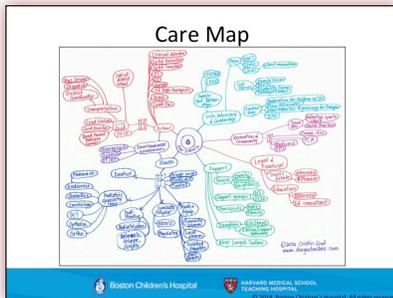
How could having answers to these questions lead to a more productive, healthy partnership?

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

# Facilitator Guide–Slide Deck

continued

## SLIDE 15 » Care Map



### Tool #3: Care Map

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

According to the Boston Children's Hospital website:

<http://bostonchildrenshospital.org/integrated-care-program/care-mapping>.

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

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

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

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

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

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

# Facilitator Guide–Slide Deck

continued

## SLIDE 16 » Author Care Map



*This care map was developed by module author Cara Coleman.*

*Following is a note from the author:*

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

## SLIDE 17 » Let's Practice

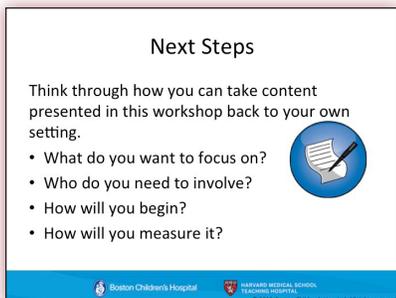


During the next part of the session, case studies should be presented then discussed in smaller groups or with the entire learner group.

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

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

## SLIDE 18 » Next Steps



There should be time for the learners to reflect on what was discussed during the session and to consider how to bring it back to their settings.

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

This could be developed into an action-oriented worksheet.

# Worksheets and Handouts

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

# External Resources

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

# In-Session Content

## Introduction and Warm Up/ Icebreaker

### Telephone and the Empathy Game

Name	Goal	Instructions	Discussion
<b>Telephone</b>	Personify and recognize how easily lines can get crossed in life and in health care	<ol style="list-style-type: none"> <li>1) Pick a sentence to pass through the telephone. To simulate how information is relayed, heard, and repeated on a health care team, the sentence should be a diagnosis, directions for treatment, and/or a physician's order.</li> <li>2) Have the group members sit or stand in a circle or lines so that they cannot overhear others.</li> <li>3) The leader should whisper the message into the first person's ear (or into a disposable cup made into a telephone).</li> <li>4) The message is passed person to person only once and cannot be repeated.</li> <li>5) The last person shares the message out loud.</li> </ol>	<ul style="list-style-type: none"> <li>• Has anyone experienced something like the game of telephone play out on a health care team?</li> <li>• What was the impact of miscommunication?</li> <li>• How did lines get crossed? Where did the crossing occur? Was anyone able to discern who misunderstood, misheard, or misspoke? Did it matter who did it?</li> <li>• How was miscommunication handled?</li> <li>• How can simple miscommunication create barriers that prevent patients, families, physicians, nurses, etc., from speaking the same language? What role, if any, does a person's background, culture, beliefs, etc., play in mishearing or miscommunicating the message? How could or would this affect family/professional partnerships? Care coordination?</li> </ul>

# In-Session Content

continued

Name	Goal	Instructions	Discussion
<p><b>Empathy Game</b></p>	<p>Encourage participants to not just <b>think</b> about illness, family/professional partnerships, teams, and care coordination but to actually <b>feel</b> the depths and ways in which chronic illness can feel and impact a patient, family, and care team.</p>	<ol style="list-style-type: none"> <li>1) Distribute 4 different colors of sticky notes to each participant.</li> <li>2) Ask each participant to write examples of the following on the corresponding colored sticky note:               <ul style="list-style-type: none"> <li>• Blue: a favorite activity</li> <li>• Red: a favorite person</li> <li>• Yellow: a favorite thing or object</li> <li>• Green: a favorite family activity</li> </ul> </li> <li>3) For the first round, the facilitator takes 1 blue and 2 yellow sticky notes from each participant.</li> <li>4) During the second round, ask each participant to hand over 1 red sticky note and 1 green sticky note.</li> <li>5) During the third round, the facilitator (and a helper if it is a large group) moves throughout the participants, taking some or all of the sticky notes at random. (This last round does not require certain colors or a specific amount to be chosen; the facilitator is modeling the way in which illness and disease may affect a person's life). Be prepared for the room to grow quieter with each round of this activity as it begins to more deeply and harshly imitate the ways illness can affect us; for some it may take everything.</li> </ol>	<ul style="list-style-type: none"> <li>• How did this activity make everyone feel?</li> <li>• Has anyone ever started the patient report or care before asking for the patient's name? Before asking how a patient is feeling? Before asking how a patient's chronic illness is impacting his or her life, relationships, or family function? Before asking about cultural or other beliefs or about roles that may affect a person's ability to accept chronic illness, discuss it with others, or just cope with day-to-day life, etc.?</li> <li>• How can this activity make someone a better patient? Family member? Care team member? How can this activity enable more effective partnerships with patients, families, or professionals?</li> </ul>

# In-Session Content

continued

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

# Definitions

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

# Definitions

continued

Term	Definition	Examples
<p><b>Patient- and family-centered care</b></p>	<p>Patient- and family-centered care is an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among care team members, patients, and families.</p> <p>Specific elements of family-centered care:</p> <ul style="list-style-type: none"> <li>• Participation: Patients and families are encouraged and supported in participating in care and decision-making at the level they choose.</li> <li>• Collaboration: Patients, families, health care practitioners, and health care leaders collaborate in policy and program development, implementation, and evaluation and research, facility design, professional education, and delivery of care.</li> <li>• Dignity and respect: Care team members listen to and honor patient and family perspectives and choices. Patient and family knowledge, values, beliefs, and cultural backgrounds are incorporated into the planning and delivery of care.</li> <li>• Information sharing: Care team members communicate and share complete and unbiased information with patients and families in ways that are affirming and useful. Patients and families receive timely, complete, and accurate information in order to effectively participate in care and decision-making.</li> </ul> <p>Available at: <a href="http://www.ipfcc.org/about/pfcc.html">http://www.ipfcc.org/about/pfcc.html</a></p>	<p>Creating a plan of care that is guided by the patient's and family's hopes, dreams, wishes, priorities, and goals for care</p>
<p><b>Family/ professional partnerships</b></p>	<p>A partnership is a relationship between individuals or groups that is characterized by mutual cooperation and responsibility for the achievement of a specified goal. In health care, evidence has shown that strong doctor-patient relationships improve patient and family health outcomes.</p> <p>Source: American Academy of Pediatrics Committee on Hospital Care. Family-centered care and the pediatrician's role. <i>Pediatrics</i>. 2003; 112(3):691-696 <a href="https://pediatrics.aappublications.org/content/112/3/691">https://pediatrics.aappublications.org/content/112/3/691</a></p>	<p>Ensuring that there is shared understanding, accountability, and decision-making across members of the care team</p>
<p><b>Family</b></p>	<p>Families define themselves. Families are big, small, extended, nuclear, multi-generational, with one parent, two parents, and grandparents. We live under one roof or many. A family can be as temporary as a few weeks, as permanent as forever. We become part of a family by birth, adoption, marriage, or from a desire for mutual support. As family members, we nurture, protect, and influence each other. Families are dynamic and are cultures unto themselves, with different values and unique ways of realizing dreams. Together, our families become the source of our rich cultural heritage and spiritual diversity. Each family has strengths and qualities that flow from individual members and from the family as a unit. Our families create neighborhoods, communities, states, and nations.</p> <p>Developed and adopted by the New Mexico Legislative Young Children's Continuum and New Mexico Coalition for Children, June 1990.</p>	

# Definitions

continued

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

# Principles of Family/Professional Partnerships— Turning Concept into Action

## Principles

## What ACTIONS can you take to put these principles into practice?

<b>Best interest of the child and the family</b>	
<b>Child grows into a partnership role</b>	
<b>Covet skills and expertise of all</b>	
<b>Trust</b>	
<b>Communication that is open, objective, and culturally and/or linguistically competent</b>	
<b>Decisions made together</b>	
<b>Willingness to negotiate</b>	

# Engaging Broad Audiences

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

- **Pay attention to reading levels.** The average American reads at the seventh- or eighth-grade level. This means that some technical or medical terms may need to be explained and that written materials should include short sentences and simple vocabulary.
- **Reach out to families before appointments** to determine if a translator will be needed because translators may be difficult to locate at the last minute.
- **Consider distance learning opportunities** for families, such as brief educational pieces that families can watch online and ask their care team members about at a later time.
- **Do not use jargon.** It is shorthand for care team members, but it is indecipherable to families.
- **People learn differently.** If someone does not understand an in-person explanation, try calling that person or writing an email that, if possible, includes a link for further education.
- **Residents in rural areas may not have access to technology**, such as a 4G network, to communicate electronically and view online charts. It might work best to ensure that these families are given hard copies of forms at each office visit.
- **Recognize that parents who have children with complex care needs are tired and stressed.** They may not hear the first or second explanation, and it might be necessary to follow up with a call or email offering to go over the details again. These families are also busy trying to navigate normal daily activities, so communication may need to happen outside of normal business hours.
- **Families living in poverty most likely will not have access to technology in their homes.** They may have a smart phone, but it is important to them to limit use. Try to communicate as much as possible in the fewest messages.
- **Try establishing groups of families to brainstorm** about care coordination problems and solutions. These groups can meet in-person or virtually, depending on the needs.
- **Actions speak louder than words!** The chasm between care team members and families may be enormous, but families will know instantly if care team members care, which may be the most important communication they receive.

# Family Voices Family/Professional Partnerships Handout



## FAMILY/PROFESSIONAL PARTNERSHIPS

### WHAT ARE PARTNERSHIPS?

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

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

### WHY ARE FAMILY/PROFESSIONAL PARTNERSHIPS IMPORTANT IN HEALTH CARE?

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

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

### HOW DO FAMILIES PARTNER WITH PROFESSIONALS TO IMPROVE CARE FOR CYSHCN?

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

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# Family Voices Family/Professional Partnerships Handout

continued

**Partnering with health plans:** The financing of health care for many children with special health care needs is provided by managed care plans, which by definition, control access to services and programs. Many children with special healthcare needs are served by both private health insurance and public programs such as



Medicaid. Just as you do with your child's provider, you can help health insurance plans to understand what works well and what doesn't with their programs and policies. Many health insurance providers work with family advisors to learn more about the populations they serve.

**Partnering with Title V:** There is a federally-funded Title V Program in each state that provides services to enhance the health of women and children, including children/youth with special healthcare needs. State Title V programs are required to partner with families to ensure that family perspectives and lived



experience/expertise help to guide these programs. Families in these partnership roles are critical to helping our government understand family needs in caring for our children with special health care needs.

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



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

## SOURCES

1. [American Academy of Pediatrics, Committee on Hospital Care: Policy statement: Family-Centered Care and the Pediatrician's Role Pediatrics, Vol. 112, No. 3, September 2003](#)
2. [Maternal and Child Health Bureau: Family-Centered Care](#)



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# Pediatric Integrated Survey Guide for Family Leaders

## Pediatric Integrated Care Survey (PICS)

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

### *How it can be used:*

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

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

---

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

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

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

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

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

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

---

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

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

# Action Grid Guide for Family Leaders



**Boston Children's Hospital**  
Until every child is well

Boston Children's Hospital  
Integrated Care Program

## Post-Encounter Action Grid

Date:  
Patient Name:  
Clinic:  
Provider Name:

Goal <small>What is action contributing to?</small>	Action <small>What needs to be completed?</small>	Who <small>Who is responsible for completing action?</small>	When <small>What is the timeline that the action needs to be completed?</small>	Contingency <small>If there is an issue or barrier, what are next steps?</small>

Action Grid © 2017 Boston Children's Hospital, Integrated Care Program  
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## Action Grid

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

*How can this grid be used:*

---

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

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

---

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

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

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

# Perspectives on the Action Grid

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

*Brigit Frank*

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

- It helps the family understand why a care team member is recommending an appointment, treatment, or other action. (goals)
- It is a way to track next steps to be completed by the care team for the child's care. (actions)
- It increases family understanding of each care team member's purpose. (who)
- It prioritizes and organizes appointments to fit with the family's daily schedule. (when)
- It increases family confidence to know there is a backup plan if the care team runs into a problem. (contingency)
- It reduces the chances of duplicate tests and appointments.
- It enables a family to monitor progress on the child's long-term goals from the care team's perspective.
- It can be kept in a file as a tool to help track a child's progress toward long-term goals.
- It can serve as a visual aid to show status to other care team members (eg, school nurses).
- It keeps care team members informed, including those in different hospital systems.

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

*Cara Coleman*

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

### **Communication**

- **TALKING TOOL:**  
The grid can be used as a neutral way to broach a sensitive topic, bring clarity, or make tasks related to care manageable.
- **GETTING ON THE SAME PAGE:**  
The grid can be used to foster open and honest dialogue so that each member of the team fully understands and is on the same page.

# Perspectives on the Action Grid

continued

## Education

- **CLINICAL ACCESSIBILITY:**  
If a patient or family is struggling to understand an issue and/or build a skill for care, use the action grid to provide education about a specific aspect of care.
- **INTRODUCE AND INFORM:**  
Use parts of the action grid, or the grid in its entirety, to inform patients and families or to introduce them to new members of the team or new aspects of care.
- **TRIGGER TO LEARN:**  
Using the grid as a way to make health care knowledge and practice accessible triggers patient ability to learn (what is in front of them and so much more), thus fostering engagement in their own care, empowerment to communicate and participate, and ultimately, the ability to feel comfort and strength in the partnership and shared decision-making.

## Organization

- **OF CARE:**  
Use the grid during each visit with each patient so that there is continuity of care with each family, as well as in the clinic overall.
- **OF COMMUNICATION:**  
Use the grid to ensure that a visit flows in a smooth and methodical way so that all issues are addressed.
- **OF PATIENTS AND FAMILIES:**  
In addition to filling out the grid at each visit, blank copies of the grid can be given to patients' families to help organize their thoughts, questions, needs, desires, priorities, wishes, and goals. In turn, when patients and/or families are more organized in these thoughts, they are more likely to communicate them with their care team and engage in all aspects of care.
- **OF OTHER CARE TEAM MEMBERS:**  
The grid can be used within the practice, but it is especially helpful to share it with care team members outside of the clinic so that they are also informed, engaged, reinforcing, contributing, fostering, and partnering.

## Expectations

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

## Accountability

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

# Perspectives on the Action Grid

*continued*

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

- Use the information recorded in each action grid cumulatively over a specific time span to help identify gaps, needs, strengths, and progress to inform updating or creation of a care plan.
- Use the action grid with new parents receiving a new diagnosis(es) who may feel overwhelmed. The grid can break down various aspects of care to make them more digestible. It may inform them at the level they are ready to receive and, eventually, at the level at which they are ready to engage. Furthermore, for new parents who are unwilling or not yet able to accept and engage, the action grid requires them to engage as a member of the team. The grid can also begin to teach the language of the new world they have entered, while also equipping them with the necessary skills to communicate clinical and other relevant information, provide care, become organized, be flexible, and move forward, among others.
- Use the action grid when there is a break down in care with communication, goals, or shared decision-making. The grid neutralizes some of the raw emotions, shines a light on the gaps in care, and provides a platform to co-develop the goals, action, and accountability so that care can be shared and progress.

# Case-Based Learning

## CASE STUDY #1

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

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

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

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

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## Discussion Questions

- Is there something that could have been done before Trinity's care coordination meeting to make sure that the care team members knew the goals for the meeting?
- Do you think that the neurologist thought of David, Alexis, and Trinity as members of the care team? Do you think the social worker's explanation of the meeting's purpose helped him understand the team concept?
- Alexis and David felt overwhelmed by the number of specialists and therapists who were caring for their daughter. Can you think of a way to show families in a similar situation that these specialists and therapists are working together and communicating as a team?
- In this case, the nurse and social worker stepped into the role of integrator. What could David and Alexis have said or done if the nurse and social worker had not played that role?

## CASE STUDY #2

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

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

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

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

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

## Discussion Questions

- **How can this team work together better to develop a feeding schedule that works for Javier?**
- **Are there any strategies Maria can use to feel more confident in her ability to share her concerns as a parent and caregiver? Are there any strategies the health care team can use to make the plan of care and decision-making genuinely shared?**
- **What are some of the ways that Maria’s embarrassment over her fear that she may not be understanding English be handled in a way that offers her dignity and respect?**
- **Why did the nutritionist, nurse, and physician respond the way they did when Maria asked about the feeding schedule? How could they create a structure and process so they are able to incorporate family input and feedback into care instructions and process family concerns?**

## Additional Readings

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