Beyond Checklists: Care Planning for Children with Special Health Care Needs

Wednesday, November 9, 2016
10-11 a.m. PT, 1-2 p.m. ET

Sponsored by
Lucile Packard Foundation for Children's Health
Catalyst Center
Family Voices
INTRODUCTION

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• Please enter questions into the GoToWebinar chat box.

• All attendees will be muted for the duration of the webinar.

• Webinar recording and slides will be posted on the Foundation website and shared with all registrants.
PANELISTS

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Care Planning for Children with Special Health Care Needs

Annique K. Hogan, MD
Medical Director, CHOP Compass Care
Medical Director, Integrated Care Service
Children’s Hospital of Philadelphia
• CHOP Compass Care:
  – Tertiary Care/Consultant Model
  – Medically Complex and Fragile Patients:
    • 3 or more complex chronic conditions
    • Multiple subspecialists
    • Multiple admissions and/or ED visits
  – Ambulatory and Inpatient
  – Multi-disciplinary:
    • Physicians, Nurse Practitioners, Nurse Coordinators, Social Work, Administrative
Goals of the Care Plan

• Articulate and Communicate Patient/Family Concerns and Goals
• Provide a Concise Medical Summary
• Communicate Problem-Based Plans
• Provide Contingency Plans
• Clarify Care Team and Roles
KEEP CALM AND GET ORGANIZED
Target Audience for Care Plan

- Patient/Family
- Care Team
- Other Healthcare Providers (determined by patient/family)
  - Emergency Department/Urgent Care
  - Inpatient
  - Home/School Providers
Pre-Work

- Chart Review
  - Abstract
  - Problem List
  - Specialty/Primary Care Visits
  - Hospitalizations/ED Visits
  - Upcoming Events

- Care Team

- Completed by Care Coordinators
Care Plan Development

- Patient and Family Concerns
- Patient and Family Goals
• Determine members of the **Care Team**

• Roles of each member
  – Core team or Advisory team
  – Which problems and which medications

• Missing pieces
Concise Summary

• Consistent Documentation and Collaborative Approach
  – “Smart phrases”
  – Multi-disciplinary team contributions

• Problem-Based Approach
  – Designated care team member(s)
  – Relevant history
  – Current status
  – Associated medications
Key Information

• **Current Feeds**
  – Who is managing
  – Regimen
  – Feeding Tube

• **Current Medications**
  – Dose
  – Route

• **Home Care, Nursing, Therapies, School**
Developing the PLAN within the Care Plan

- Collaborative
- Problem-Based
- Upcoming Planned Events
- Contingency Planning
- Communication Planning
- Scheduling
- Shared and Refined
Documenting the Care Plan

- Visit Encounter → Letter
- Beyond the visit note
  - Longitudinal Plan of Care (LPOC)
Sharing the Care Plan – Accessibility

• **EHR Tools**
  – Example: Epic
  – Longitudinal Plan of Care (LPOC)
  – Patient portal

• **Letter**
  – Available to family and care team members
Implementing the Care Plan

• Post-Visit Communication
  – Within the Care Team
  – With the Patient/Family

• Scheduled Telephone Calls

• Inpatient to Outpatient
  – Facilitate Communication
  – Update Care Plan

• Routine Scheduled Follow-Up Visits
It takes time!
Team approach

- **All** members of the team contribute to creating, maintaining, and implementing the Care Plan.
Questions?
Jill S. Rinehart, MD, FAAP

Partner, Hagan, Rinehart & Connolly Pediatricians, PLLC, and Clinical Associate Professor of Pediatrics at the University of Vermont College of Medicine
Pediatric Care Coordination Learning Collaborative

Achieving a Shared Plan of Care

1. Identify the Needs and Strengths of the Patient and Family:
   - Hold family-centered discussions
   - Complete multi-faceted assessments

2. Build Essential Partnerships:
   - Set personal and clinical goals
   - Share decision making
   - Link to specialists and community service providers

3. Create the Plan of Care:
   - Develop the medical summary
   - Establish “negotiated actions”
   - Add emergency & legal attachments

4. Implement the Plan of Care:
   - Perform actions
   - Oversee, track & monitor
   - Evaluate, update & renew

Following the guidelines of the Lucile Packard Foundation’s “Achieving a Shared Plan of Care Implementation Guide”

Purpose
Plan, implement and evaluate the impact of effective care coordination by working with

- Vermont’s primary and specialty health care professionals
- Patients and their families
- Community-based, child-serving agencies and organizations
Pediatric Care Coordination Participating Practices

**Northwestern Vermont**
- Hagan, Rinehart & Connolly Pediatricians, Burlington
- Timber Lane Pediatrics, Burlington
- Timber Lane Pediatrics, South Burlington
- UVMMC Pediatrics, Burlington

**Northeastern Vermont**
- St. Johnsbury Pediatrics, St. Johnsbury

**Central Vermont**
- Little Rivers Health Care, Bradford & Wells River
- South Royalton Health Center, South Royalton

**Southern Vermont**
- Green Mountain Pediatrics, Bennington
- Brattleboro Primary Care, Brattleboro
- Maplewood Family Practice, Brattleboro
- Community Health Centers of Rutland Regional, Rutland
- Just So Pediatrics, Brattleboro
- Family Medicine Associates, Springfield
- Associates in Pediatrics* - Berlin, Berlin
- Associates in Pediatrics* - Barre, Barre
- Middlebury Pediatric & Adolescent Medicine
- Mt. Ascutney Hospital & Health Center, Windsor
- Rainbow Pediatrics, Middlebury
Independent Practice

- Three pediatricians: Dr. Hagan, Dr. Rinehart, Dr. Connolly
- Three pediatric nurse practitioners
- One main RN Care Coordinator ~4000 active patients
- Insurance mix: 35% Medicaid, 60% private, <5% uninsured
HRC Care Coordination Workflow Draft
Where to Start?

Shared Care Planning Can Begin with: Family, Patient, Community Partner, or Health Care Professional

During a Visit

Wow! This problem list is a mess!

Doc, you may not want to come in on Tuesday…

My son is being discharged tomorrow from Children’s after neurosurgery…

My child’s teacher says his behavior is out of control…

I’m taking control of Asthma!

I’m taking control of Behavioral Health!

Previewing the Schedule

Phone Calls to Medical Home

Condition Specific

This family hasn’t responded to calls from visiting nurses for the past month
Comprehensive Understanding

**Strengths**
- Concrete Support in Time of need
- Knowledge of Parenting and Child Development
- Parental Resilience
- Social and Emotional Competence
- Social Connections

**Family**
- What would you like us to know about your child? (What does s/he do well? Like? Dislike?)
- What would you like us to know about you/your family?

**Needs**
- Developmental Concerns
- Social changes? (Job, Divorce, Death, Move)
- Housing
- Food Security
- Medical
- Educational
- Financial
- Legal
- Transportation

Family Centered Care Coordination

No one has ever asked me these questions before!
~Parent

1) What would you like us to know about your child/youth?
   a. 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/youth? Some examples below.
   - Their growth/development
   - Learning
   - Sleeping
   - Self-care
   - Making and keeping friends
   - Doing things for themselves
   - Falling behind in school
   - Behavior
   - The future
   - Playing with friends
   - Other (fill in)

4) Have there been any changes since we saw you last, such as:
   - Brothers or sisters leaving home?
   - Separation or divorce?
   - Moved to a new town?
   - Other (fill in)
   - Sickness or death of a loved one?
   - New job or job change?

5) Can we help you with any of the following needs?
   - Medical: For example, help finding or understanding medical information, help finding health care for you or your family.
   - Social: For example, having someone to talk to when you need to, getting support at home, finding support for the rest of your family.
   - Educational: For example, explaining your child's needs to teachers, help reading or understanding medical information.
   - Financial: For example, understanding insurance or finding help paying for needs that insurance does not cover – such as medications, formulas, or equipment.
   - Legal: For example, discussing laws and legal rights about your child's health care or their school needs.
   - General: Please let us know what else you need help with (if we don't know, we will work with you to find the answer).

Notes:
Pre-Visit Planning

Before you enter the room…

• Share recent, relevant information
• Screening tests (ACT, PHQ9)
• An agenda from the family for today’s visit
• Labs, radiology, specialist visit reports
• Follow up from community members
### Benefits to Clinicians

- Don’t have to have all of the solutions
- Part of a collaborative team
- More time for medical thinking and deeper understanding of situation
- Improved clinical outcomes
- Feel better prepared
- Less time spinning wheels
- More time discussing the important issues and not “catching up”
- Less phone time
Key to Family Engagement

- Build trusting relationships
- Allows for timely, accurate information sharing
- And…
Problem Solving Discussions

- Each of us has a piece of the puzzle
- Keeping an open mind
- Getting from A to B may require going to C and D first
- Patience
- Kindness
- Humility
- Parking Lot and follow up
Care Conferences

- Introductions/Contacts
- Set Agenda
- Set Roles: Facilitator
- Start with Strengths
- Care Map
- Discussion
- Minutes Recorded
- Update Plan with Next Steps & Accountability
- Next Care Conference Date (if needed)
- Care plan is shared at end of meeting
Self-Awareness

Allows Progression From

Unconscious Incompetence

Conscious Incompetence

Conscious Competence

Unconscious Competence
Conflict is…

Situation in which the concerns of two or more people/parties *appear* to be incompatible.
Thomas-Kilmann Conflict Modes

**Competing**
- Zero-sum orientation
- Win/lose power struggle

**Collaborating**
- Expand range of possible options
- Achieve win/win outcomes

**Compromising**
- Minimally acceptable to all
- Relationships undamaged

**Avoiding**
- Withdraw from the situation
- Maintain neutrality

**Accommodating**
- Accede to the other party
- Maintain harmony

**COOPERATIVENESS**
Focus on others’ needs and mutual relationships

**ASSERTIVENESS**
Focus on my needs, desired outcomes and agenda

Cultural humility acknowledges that it is impossible to be adequately knowledgeable about cultures other than one's own…

Cultural humility requires us to take responsibility for our interactions with others beyond acknowledging or being sensitive to our differences.”
LEARN

- **Listen**: to the person’s perception
- **Explain**: your perception
- **Acknowledge**: similarities & differences
- **Recommend**: both have ideas on what to do
- **Negotiate**: make a plan WITH (not for) the family

(adapted from Berlin & Fowkes, 1982)
Kleinman’s Questions (1980)

• What do you call your problem?
• What do you think caused it? Why?
• What do you think your sickness does to you?
• How severe is it? Short or long course?
• What do you fear the most?
• What are the hardest problems this causes you?
• What kind of treatment do you feel you need?
• What results do you hope for?
Comprehensive Care Plan

Disclaimer: This is a capsular summary and does not replace the patient's full record. For emergency updates please contact PCP

- PCP Name: Dr Nightengale
- PCP Telephone: 508-555-5555

Description of child

Parents describe her as a friendly and strong-willed child. They also say that she is responsive to them, including lighting up when they enter a room or smiling when prompted.

Ava is afraid of needles.

Important Family Information

Both parents have struggled with alcohol and opioid abuse. During a binge in 11/15 both parents intoxicated, Ava had a seizure and was injured, DCF notified. Both parents have completed substance abuse counselling and state a commitment to abstinence. After a brief foster period, Ava returned to stay with parents in 12/15.

Family stressors include financial (both parents unemployed due to substance abuse and prior jail time), and Ava’s complex condition.

Family goals & Actions

1. 12/15/2015 At risk housing. Both parents currently unemployed, struggling to continue rent payments with assistance.
## PARENTS’ VOICES

### NO CARE COORDINATION

- “There was no continuity. We would call the primary care office with a concern and they would say “Oh, you need to talk to your specialist about that.” We would call the specialist and they would say “Oh, you need to talk to your primary care doctor about that.” It was just back and forth all the time and the concerns never got addressed.”

### WITH CARE COORDINATION

- “Now there is a sense that I’m being listened to – that his medical needs are being addressed. We have a plan with where we are headed, especially with the school, we know where we are going.”

Maier, Parent interview, March 6, 2014
Questions?
Final Questions?

Today’s webinar slides and recording will be posted online.
MORE ON CARE PLANNING AND CARE COORDINATION

www.lpfch.org/publications

• A compendium of publications on care coordination, including *Achieving a Shared Plan of Care with Children and Youth with Special Health Care Needs*

www.lpfch.org/about-us/webinars-conferences-convenings

• Coordinating Care for Children with Social Complexity – webinar materials
• Take Action on Care Coordination – webinar materials

www.lpfch.org/symposium/webcast

• Webcast and presentation slides from the 2015 Symposium: Designing Systems That Work for Children with Complex Health Care Needs
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