CARE_PATH for Kids:
A Family-Centered Approach to Shared Plans of Care
for Children with Special Health Care Needs

April 15, 2021
Moderator

Christina D. Bethell, PhD, MBA, MPH
Professor, Johns Hopkins University in the Bloomberg School of Public Health
Today’s Speakers

Jonathan Cottor, MBA
Father and Advocate

Melissa Clark Vickers, M.Ed.
Project Director, Family Voices (Retired)

David A. Bergman MD
Professor Emeritus of Pediatrics,
Stanford University School of Medicine
Ask Questions!

We look forward to a lively discussion with our audience. Submit your questions through the Q&A.
Audience Poll

My primary interest in learning about the CPK model and tools is as a:

• CYSHCN Family Member
• Care Coordinator Role
• CYSHCN Care Team – (Nurse, Social Worker, or other)
• CYSHCN Medical Provider
• CYSHCN Daily Living Care Team (e.g. Home Health)
• CYSHCN Education Connection (e.g. School)
• Researcher or Advocate
• Other
What is the CARE_PATH for Kids?

Ensuring Family Foundations of Shared Care Planning

A *novel three-step approach* to *engage families* of children and youth with special health care needs *to improve* child and family *wellbeing* by *anchoring* shared plans of care to a child’s whole-life context, priority needs and aspirations for the child and family.

1. **Engage**
   - Planner
     - Family Foundations of Care (FCC)

2. **Plan**
   - Plan
     - Family Foundations of Care (FCC)

3. **Improve**
   - Partnership
     - Care planning and outcomes with child’s care teams
Start with Family Foundations!

Families reflect on their strengths, priorities, goals, social and environmental context to shape a Family Foundations of Care.
Framework of the CARE_PATH for Kids Model

The Big Picture

Community Connections

Larger Shared Plan of Care

CARE_PATH for Kids Model & Tools

Improved family, child and care team outcomes

Families reflect on their strengths, priorities, goals, social & environmental context to shape a Family Foundations of Care

Based on CPK and including other key elements like medical history, treatment plan, ER plan, etc.
Improved family, child and care team outcomes

The Big Picture

Community Connections

Larger Shared Plan of Care

CARE_PATH for Kids Model & Tools

Integrate other services and supports like school and community-based services into larger shared plan of care

Based on CPK and including other key elements like medical history, treatment plan, ER plan, etc.

Families reflect on their strengths, priorities, goals, social and environmental context to shape a Family Foundations of Care
Families reflect on their strengths, priorities, goals, social and environmental context to shape a Family Foundations of Care. Based on CPK and including other key elements like medical history, treatment plan, ER plan, etc. Integrate other services and supports like school and community-based services into larger shared plan of care. Use learning and data from the CPK process to change systems of care that promote whole child and family.

Improved family, child and care team outcomes

Framework of the CARE_PATH for Kids Model
### Key Steps to Implement the CARE_PATH for Kids

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<tr>
<th>Family Outreach &amp; Engagement</th>
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<tr>
<td>• Check criteria for outreach</td>
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<td>• Conduct outreach to establish interest and value</td>
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<tr>
<th>Team Pre-Work &amp; Readiness</th>
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<tr>
<td>• Assess organization readiness</td>
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<tr>
<td>• Perform pre-visit work with resources provided</td>
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<tr>
<td>• Ensure family engagement prior to appointment</td>
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<th>Relational Meetings with Family</th>
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<tr>
<td>• Family completes the FCC Planner</td>
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<tr>
<td>• Care team member transfers planner response into the FFC Plan</td>
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<tr>
<td>• Family and care team member co-develop the FFC Plan</td>
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<th>Provider &amp; Family Visit</th>
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<td>• Provider uses the FFC Plan during encounters and develops a more comprehensive shared plan of care with family</td>
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<th>Ongoing care-coordination</th>
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<td>• Care teams monitor and update FFC Plan periodically/as needed.</td>
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<tr>
<td>• Care teams use the FFC Plan for care-coordination, communication and relationship building</td>
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Visit carepathforkids.org

• CARE_PATH for Kids Tools
• Education Materials
• Implementation Resources
The Family Context and Need

Jonathan Cottor, MBA
Father and Advocate
Lived Experience

January 23, 2002
Ryan at 9 months and Big Brother Ethan

Ryan at 17 years

Cottor family photos used with permission by Jonathan Cottor
Mountains of Paperwork
Navigating the family journey is...

Exhausting TENSE
deatc STRESSFUL
overwhelming GRIELING
Consuming daunting

....and joyful
Family “Wholistic” Scenarios

- Every child and family are unique
- Medical care for diagnosed child is the beginning
- Often other family stresses

“ Invisible”

Child: Girl - 4 years old  
Diagnosis: Diabetes – 1 year ago  
Child health: Checking blood sugar levels during preschool  
Family:  
- Older sister (5 years) – behavioral problems at Kindergarten, many parent/teacher conferences  
- Grandparents live nearby to help  
- Parents starting a divorce

“ Isolated”

Child: Boy - 13 years old  
Diagnosis: Cerebral palsy  
Child health: Uses braces for walking, chewing & swallowing difficulty  
School: 7th grade transition - hard to make new friends  
Care: Struggling to find consistent attendant care  
Family:  
- Parents both work – thinking one may need to go part-time or quit to provide care  
- Grandparents live out of state

“ Impossible”

Children: Twin Boys – 8 years old  
Diagnosis: Both – Duchenne muscular dystrophy  
Child health: Power Wheelchairs – one spinal rod surgery, the other likely soon – Various timing/needs  
School: Public 3rd Grade – academic challenges  
Family: One parent works, one is full-time caregiver  
Location:  
- Rural – 150 miles from Children’s Hospital and related specialists  
- Lack of community support organizations
The Family Role during Development

Melissa Clark Vickers, M.Ed.
Project Director, Family Voices (Retired)
“As we work with our providers, we also have to understand that they don’t know what they don’t know about us. If we want to be able to develop too and have them support us as family members, we have to give them the whole picture. That’s what the goal of this tool is.”

- Family Leader
Family Leaders Gave Their Input

Methods
- Group focus, group calls
- In-depth, one-on-one cognitive interviews

Types of Suggestions
- What kinds of services to include in the “map of care” –The Whole Picture!
- Best ways to organize the big pieces
- “Family-Friendly-izing” the questions
- Make it “on the go”
Strike a Balance

- TIME to fill out
- VALUE of using tool
The New Tool Had to be Easy!

Easy to:
• Fill out
• Make changes
• Share
• Identify pressing needs
• Identify with
“[This tool is] going to help you help your team understand your situation and your needs. I think we see ourselves as constantly going while trying to get other people on board, on my bus. The way I see it is, this is a tool to get people on this bus and understand where I’m going, and how they are going to support me to keep this bus going. It’s about them understanding our situation so that they can help us.”

- Family Participant
The Basis for Improving Care, Engagement and Shared Plans of Care

David A. Bergman MD
Professor Emeritus of Pediatrics, Stanford University School of Medicine
Will it Rock Your World?

- Works for child/families and providers
- Shown to improve the quality of care for the family and the provider
- You can implement without disrupting your practice
- The antidote to burnout and it’s good for your soul
It Works for:

Parents

• Create a holistic view of your child

• Develop child and family centered goals for care

• Builds a shared plan of care that can be used across the many agencies that care for your child

Providers

• You will know what you don’t know about the child and family

• You can be more efficient and effective by understanding the Family/child needs before the visit

• You have to create a shared plan of care so why not do it right
It Improves the Quality of the Visit for Parents:

- Overall, do you think that FFC Planner will increase the value of your child’s care?
  - Disagree: 18%
  - Agree: 82%

- How likely are you to recommend the FFC Planner to other parents?
  - Unlikely: 5%
  - Likely: 95%

- Did the CARE_PATH for Kids help you learn about the kinds of topics that you can discuss with your child’s doctor(s)?
  - Disagree: 9%
  - Agree: 91%

“If I had something like this when my child was growing up, I would feel really cared about by my providers.”
- Family member testing the CARE_PATH for Kids
It Improves the Quality of the Visit for Providers:

Are you interested in having access to tools to create plans of care with children and their families better?

What effect do you believe engaging children and their families to create a plan of care, as part of patient and family care, would have on your own professional work satisfaction?

“Walking away from a visit where I feel that the family is satisfied, hopeful and understanding about their child’s health would make me sleep better at night.”

- Provider reviewing the CARE_PATH for Kids
You Can Implement without Disrupting Your Practice:

• Provides value without blowing up your workflow
• Flexible, on any given visit you do not have to use all the components
• Much of the work is done before the visit so as to not add time to a busy schedule
• Parents can use the tool without the need to involve a member of your staff
...It’s Good for your Soul

- Practice burn-out and moral injury are widespread
- Too much time filling out forms and documenting care
- What is left out are caring connections - This is the reason you became a health care professional
- The CARE_PATH for Kids creates caring connections and increases your healing power (a personal testimonial)
Audience Poll

Based on what you have learned today, does the CARE_PATH for Kids appear to be valuable to your efforts to support CYSHCN?

• Absolutely
• Very likely / I want to learn more
• Possibly / I’d like to know more
• Not sure / I’ll think about it
• Not really / We already do something similar
• No
Ask Questions!

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Contact: info@cahmi.org
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