

**WELCOME! Please use the chat box to announce yourself
by typing in first your state and then your – this will help
speed things up in assigning breakout rooms!
Thank you!**



**COLIN to Advance Care for
Children with Medical Complexity
State Team Webinar #3
July 12, 2018
Family Engagement**



Housekeeping

- This webinar is being recorded
- CMC CoIIN public-facing website LAUNCHED!
 - <http://cahpp.org/project/CoIIN-CMC>
 - Thanks for reviewing state team info
- Shared workspace set up within the next month
- BU IRB application is in process
- Any other questions? – type into chat box anytime

This project is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under grant number #UJ6MC31113: *Health Care Delivery System Innovations for Children with Medical Complexity* (\$2,700,000 annually). This information or content and conclusions are those of the authors and should not be construed as the official position or policy of, nor should any endorsement be inferred, by HRSA, HHS or the U.S. government. Anna Maria Padlan, HRSA/MCHB Project Officer

State Team Updates

What's been your biggest success since the May webinar?



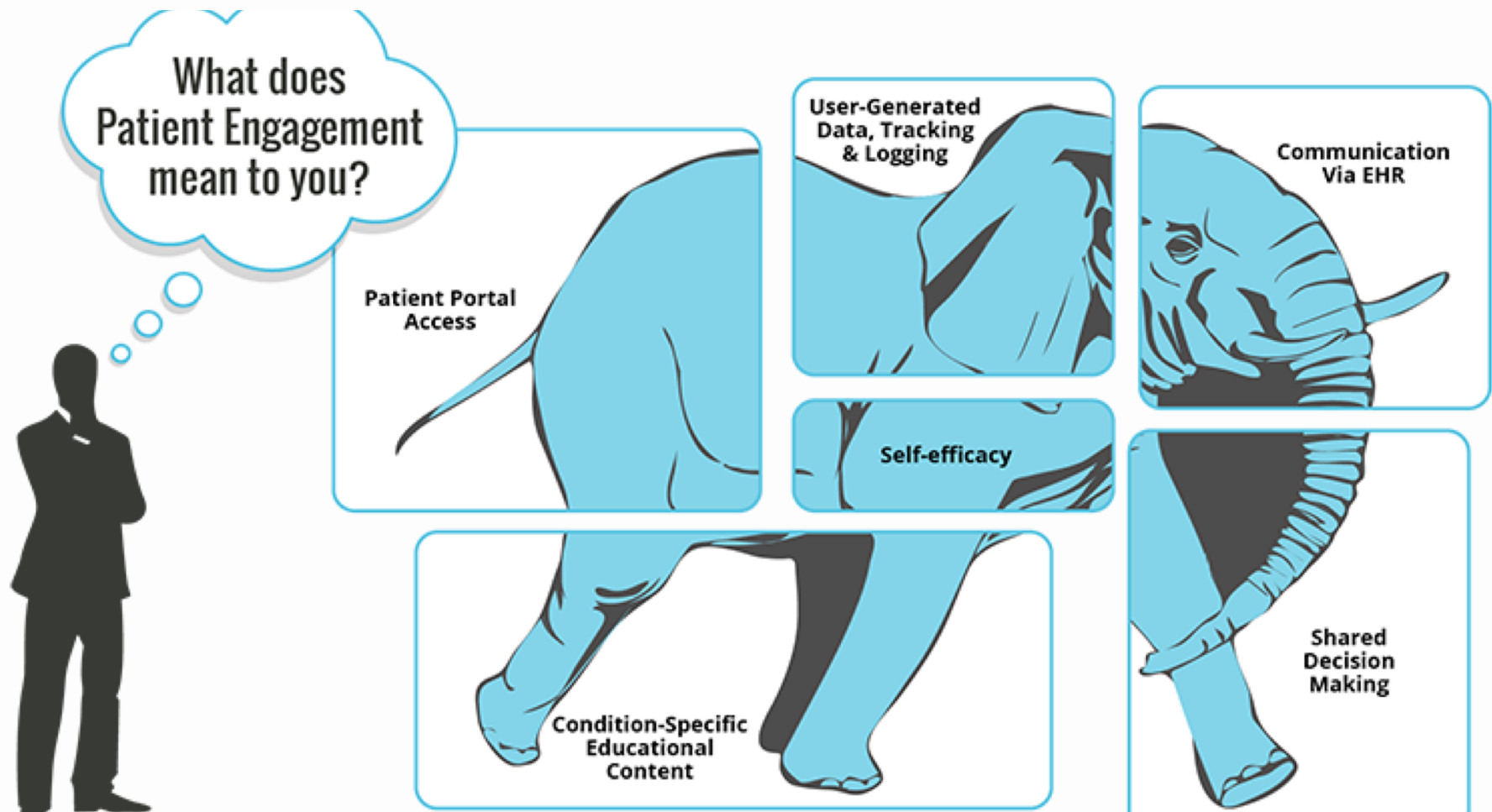
Cowboys, CMC CollN & Herding Cats??

- <https://www.youtube.com/watch?v=Pk7yqlTMvp8>

Webinar Objectives/Outline:

- Share/ highlight ongoing Family Engagement (FE)
- Step back: shared understanding of FE
- Aha Moments of FE
- Questions- Operationalizing FE

Let's get on the same page- what is family engagement?



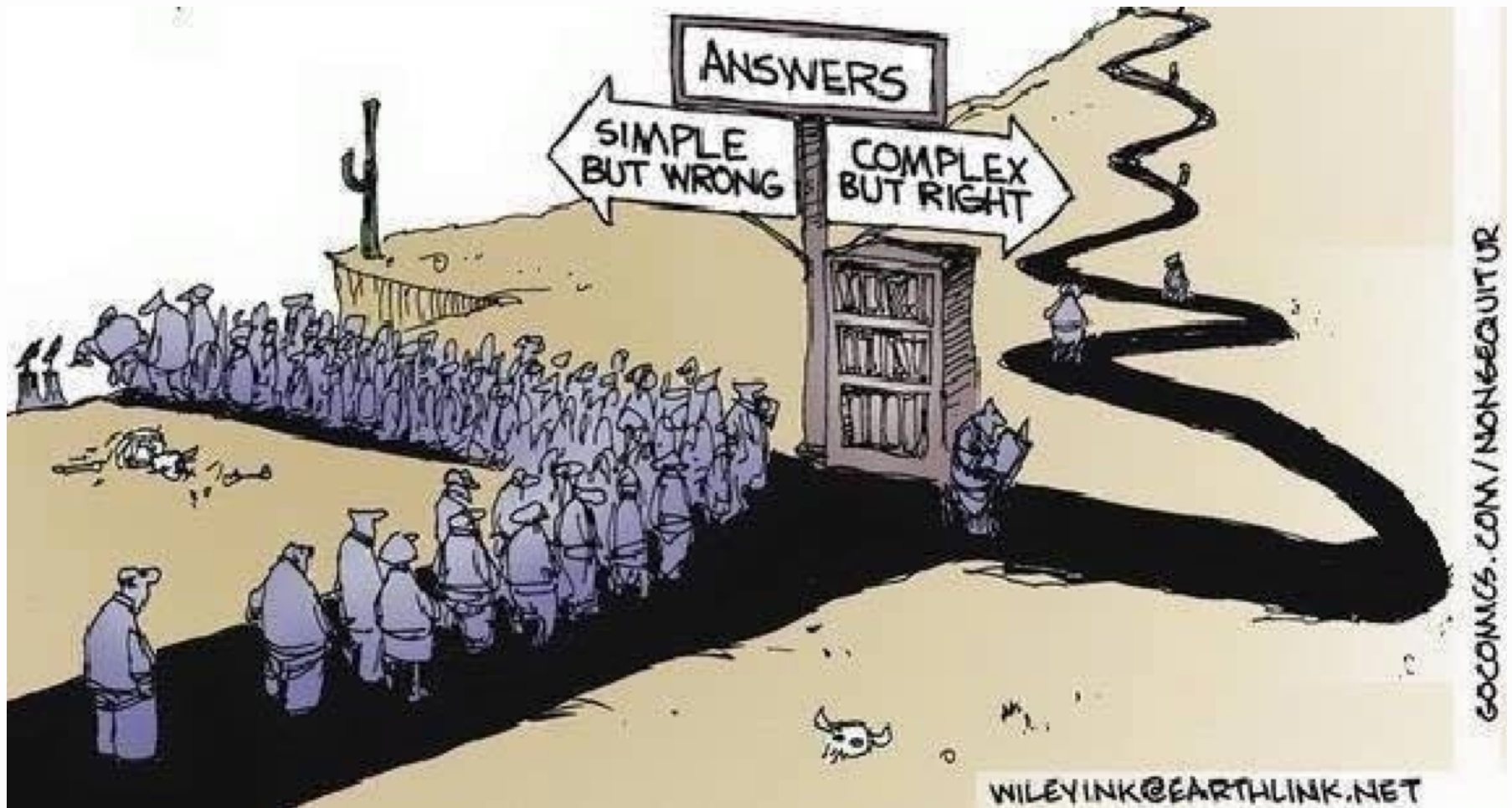
We're Engaged!!



Family Engagement (formally) defined

“An authentic partnership between professionals and family leaders who reflect the diversity of the communities they represent, working together at the systems level to develop better policies and practices.”

Story of healthcare system for CMC..



Domains to guide FE in systems

- Representation
 - Diversity of community
 - Family led orgs and CBOs
- Transparency
 - Access
 - Partnership in all stages
- Impact
 - Change? In general and with families
- Commitment
 - Core values

AHA Moments

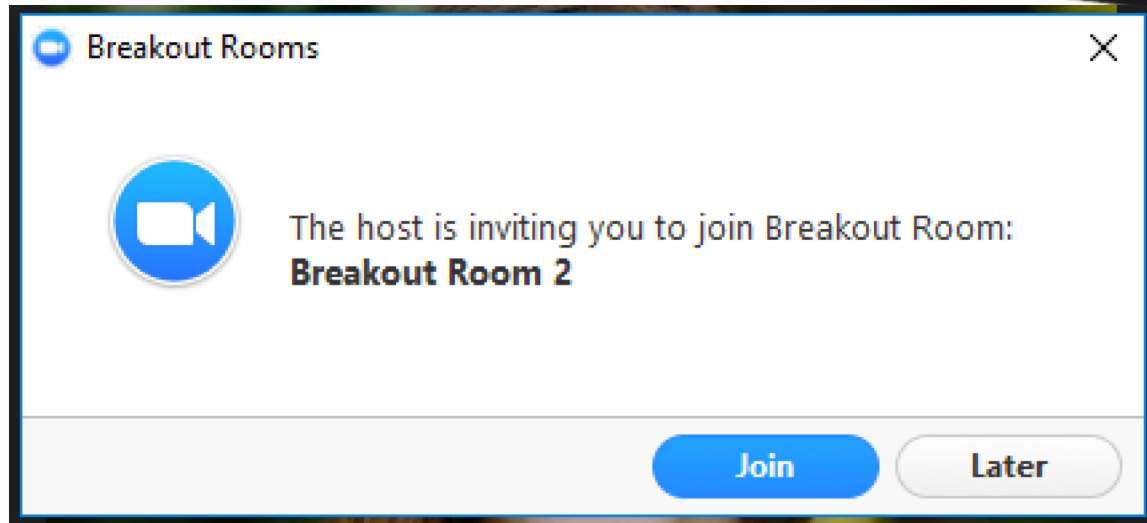


- <https://www.youtube.com/watch?v=rw9c8CSnDaU>

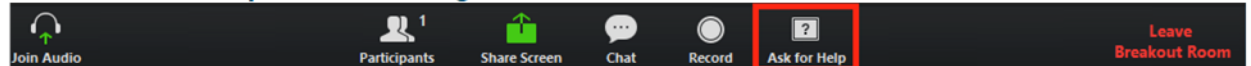
State Team Breakouts

- Share your *aha moments* with each other
- Nominate one person to share their aha moment with the larger group (as time allows)

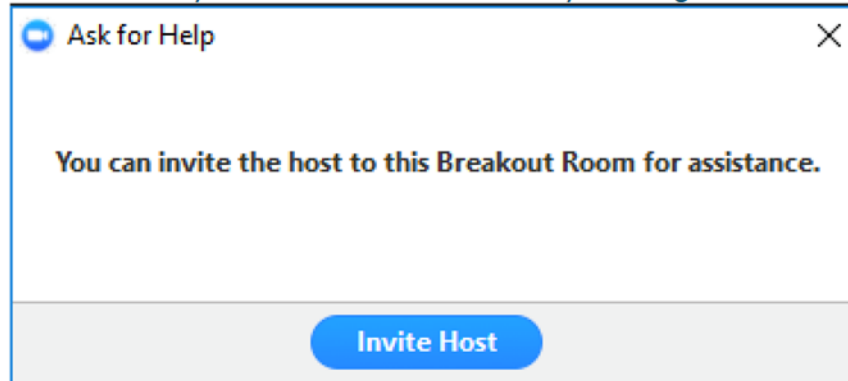
Breakout – How-to Instructions



Click **Ask for Help** in the meeting controls.



Confirm that you would like assistance by clicking **Invite Host**.



ALLOWED IN



BUY-IN



Tell me and I forget. Teach me
and I remember. Involve me
and I learn.

- Benjamin Franklin



How do we “operationalize” family engagement?



Resources on Family Engagement

https://drive.google.com/open?id=1YyCYyPBp_ZujmVTL1ygrzr-z7f2Inkg4



Powerful Partnerships

A Handbook for Providers and Parents
Working Together to Improve Care

Authors:
Elizabeth Aspin
Tara E. Brown, MD
Tiffany Green, BS, PhD
Janet Chaffenger
Joe Boushey, MD, PhD

NICHQ
National Children's Hospital
Children's Healthcare Quality

Families of Children With Medical Complexity: A View From the Front Lines

Robert M. Kaplan, MD, PhD, and David A. Asch, MD, PhD

This article, written for a group of experienced parents of children with medical complexity (CMC), provides an overview of the demands of managing care from their unique perspective. The authors discuss the challenges of managing the care of their child, the importance of family engagement, and the importance of family engagement in the delivery of medical care, and the importance of family engagement in the delivery of medical care. The authors discuss the importance of family engagement in the delivery of medical care, and the importance of family engagement in the delivery of medical care. The authors discuss the importance of family engagement in the delivery of medical care, and the importance of family engagement in the delivery of medical care.

doi:10.1016/j.peds.2015.05.010

This article was published in the journal *Pediatrics*, Volume 135, Number 5, May 2015, Pages 900-905. The authors are grateful to the many families who provided feedback on this article.

© 2015 American Academy of Pediatrics. All rights reserved. No part of this publication may be reproduced without permission in writing from the American Academy of Pediatrics.

For more information, please contact the American Academy of Pediatrics, 540 North Dearborn Street, Chicago, IL 60610, or visit our website at www.aap.org.

For more information, please contact the American Academy of Pediatrics, 540 North Dearborn Street, Chicago, IL 60610, or visit our website at www.aap.org.

For more information, please contact the American Academy of Pediatrics, 540 North Dearborn Street, Chicago, IL 60610, or visit our website at www.aap.org.

For more information, please contact the American Academy of Pediatrics, 540 North Dearborn Street, Chicago, IL 60610, or visit our website at www.aap.org.

For more information, please contact the American Academy of Pediatrics, 540 North Dearborn Street, Chicago, IL 60610, or visit our website at www.aap.org.

For more information, please contact the American Academy of Pediatrics, 540 North Dearborn Street, Chicago, IL 60610, or visit our website at www.aap.org.

For more information, please contact the American Academy of Pediatrics, 540 North Dearborn Street, Chicago, IL 60610, or visit our website at www.aap.org.

For more information, please contact the American Academy of Pediatrics, 540 North Dearborn Street, Chicago, IL 60610, or visit our website at www.aap.org.

For more information, please contact the American Academy of Pediatrics, 540 North Dearborn Street, Chicago, IL 60610, or visit our website at www.aap.org.

For more information, please contact the American Academy of Pediatrics, 540 North Dearborn Street, Chicago, IL 60610, or visit our website at www.aap.org.

For more information, please contact the American Academy of Pediatrics, 540 North Dearborn Street, Chicago, IL 60610, or visit our website at www.aap.org.

For more information, please contact the American Academy of Pediatrics, 540 North Dearborn Street, Chicago, IL 60610, or visit our website at www.aap.org.

For more information, please contact the American Academy of Pediatrics, 540 North Dearborn Street, Chicago, IL 60610, or visit our website at www.aap.org.

For more information, please contact the American Academy of Pediatrics, 540 North Dearborn Street, Chicago, IL 60610, or visit our website at www.aap.org.

For more information, please contact the American Academy of Pediatrics, 540 North Dearborn Street, Chicago, IL 60610, or visit our website at www.aap.org.

For more information, please contact the American Academy of Pediatrics, 540 North Dearborn Street, Chicago, IL 60610, or visit our website at www.aap.org.

For more information, please contact the American Academy of Pediatrics, 540 North Dearborn Street, Chicago, IL 60610, or visit our website at www.aap.org.

For more information, please contact the American Academy of Pediatrics, 540 North Dearborn Street, Chicago, IL 60610, or visit our website at www.aap.org.

For more information, please contact the American Academy of Pediatrics, 540 North Dearborn Street, Chicago, IL 60610, or visit our website at www.aap.org.

For more information, please contact the American Academy of Pediatrics, 540 North Dearborn Street, Chicago, IL 60610, or visit our website at www.aap.org.

For more information, please contact the American Academy of Pediatrics, 540 North Dearborn Street, Chicago, IL 60610, or visit our website at www.aap.org.

For more information, please contact the American Academy of Pediatrics, 540 North Dearborn Street, Chicago, IL 60610, or visit our website at www.aap.org.

For more information, please contact the American Academy of Pediatrics, 540 North Dearborn Street, Chicago, IL 60610, or visit our website at www.aap.org.

For more information, please contact the American Academy of Pediatrics, 540 North Dearborn Street, Chicago, IL 60610, or visit our website at www.aap.org.

For more information, please contact the American Academy of Pediatrics, 540 North Dearborn Street, Chicago, IL 60610, or visit our website at www.aap.org.

For more information, please contact the American Academy of Pediatrics, 540 North Dearborn Street, Chicago, IL 60610, or visit our website at www.aap.org.

For more information, please contact the American Academy of Pediatrics, 540 North Dearborn Street, Chicago, IL 60610, or visit our website at www.aap.org.

For more information, please contact the American Academy of Pediatrics, 540 North Dearborn Street, Chicago, IL 60610, or visit our website at www.aap.org.

For more information, please contact the American Academy of Pediatrics, 540 North Dearborn Street, Chicago, IL 60610, or visit our website at www.aap.org.

For more information, please contact the American Academy of Pediatrics, 540 North Dearborn Street, Chicago, IL 60610, or visit our website at www.aap.org.

For more information, please contact the American Academy of Pediatrics, 540 North Dearborn Street, Chicago, IL 60610, or visit our website at www.aap.org.

For more information, please contact the American Academy of Pediatrics, 540 North Dearborn Street, Chicago, IL 60610, or visit our website at www.aap.org.

For more information, please contact the American Academy of Pediatrics, 540 North Dearborn Street, Chicago, IL 60610, or visit our website at www.aap.org.

For more information, please contact the American Academy of Pediatrics, 540 North Dearborn Street, Chicago, IL 60610, or visit our website at www.aap.org.

For more information, please contact the American Academy of Pediatrics, 540 North Dearborn Street, Chicago, IL 60610, or visit our website at www.aap.org.

For more information, please contact the American Academy of Pediatrics, 540 North Dearborn Street, Chicago, IL 60610, or visit our website at www.aap.org.

For more information, please contact the American Academy of Pediatrics, 540 North Dearborn Street, Chicago, IL 60610, or visit our website at www.aap.org.

For more information, please contact the American Academy of Pediatrics, 540 North Dearborn Street, Chicago, IL 60610, or visit our website at www.aap.org.

For more information, please contact the American Academy of Pediatrics, 540 North Dearborn Street, Chicago, IL 60610, or visit our website at www.aap.org.

For more information, please contact the American Academy of Pediatrics, 540 North Dearborn Street, Chicago, IL 60610, or visit our website at www.aap.org.

For more information, please contact the American Academy of Pediatrics, 540 North Dearborn Street, Chicago, IL 60610, or visit our website at www.aap.org.

For more information, please contact the American Academy of Pediatrics, 540 North Dearborn Street, Chicago, IL 60610, or visit our website at www.aap.org.

For more information, please contact the American Academy of Pediatrics, 540 North Dearborn Street, Chicago, IL 60610, or visit our website at www.aap.org.

For more information, please contact the American Academy of Pediatrics, 540 North Dearborn Street, Chicago, IL 60610, or visit our website at www.aap.org.

For more information, please contact the American Academy of Pediatrics, 540 North Dearborn Street, Chicago, IL 60610, or visit our website at www.aap.org.

For more information, please contact the American Academy of Pediatrics, 540 North Dearborn Street, Chicago, IL 60610, or visit our website at www.aap.org.

For more information, please contact the American Academy of Pediatrics, 540 North Dearborn Street, Chicago, IL 60610, or visit our website at www.aap.org.

For more information, please contact the American Academy of Pediatrics, 540 North Dearborn Street, Chicago, IL 60610, or visit our website at www.aap.org.

For more information, please contact the American Academy of Pediatrics, 540 North Dearborn Street, Chicago, IL 60610, or visit our website at www.aap.org.

For more information, please contact the American Academy of Pediatrics, 540 North Dearborn Street, Chicago, IL 60610, or visit our website at www.aap.org.

For more information, please contact the American Academy of Pediatrics, 540 North Dearborn Street, Chicago, IL 60610, or visit our website at www.aap.org.

For more information, please contact the American Academy of Pediatrics, 540 North Dearborn Street, Chicago, IL 60610, or visit our website at www.aap.org.

For more information, please contact the American Academy of Pediatrics, 540 North Dearborn Street, Chicago, IL 60610, or visit our website at www.aap.org.

For more information, please contact the American Academy of Pediatrics, 540 North Dearborn Street, Chicago, IL 60610, or visit our website at www.aap.org.

For more information, please contact the American Academy of Pediatrics, 540 North Dearborn Street, Chicago, IL 60610, or visit our website at www.aap.org.

For more information, please contact the American Academy of Pediatrics, 540 North Dearborn Street, Chicago, IL 60610, or visit our website at www.aap.org.

For more information, please contact the American Academy of Pediatrics, 540 North Dearborn Street, Chicago, IL 60610, or visit our website at www.aap.org.

For more information, please contact the American Academy of Pediatrics, 540 North Dearborn Street, Chicago, IL 60610, or visit our website at www.aap.org.

For more information, please contact the American Academy of Pediatrics, 540 North Dearborn Street, Chicago, IL 60610, or visit our website at www.aap.org.

For more information, please contact the American Academy of Pediatrics, 540 North Dearborn Street, Chicago, IL 60610, or visit our website at www.aap.org.

For more information, please contact the American Academy of Pediatrics, 540 North Dearborn Street, Chicago, IL 60610, or visit our website at www.aap.org.

For more information, please contact the American Academy of Pediatrics, 540 North Dearborn Street, Chicago, IL 60610, or visit our website at www.aap.org.

For more information, please contact the American Academy of Pediatrics, 540 North Dearborn Street, Chicago, IL 60610, or visit our website at www.aap.org.

For more information, please contact the American Academy of Pediatrics, 540 North Dearborn Street, Chicago, IL 60610, or visit our website at www.aap.org.

For more information, please contact the American Academy of Pediatrics, 540 North Dearborn Street, Chicago, IL 60610, or visit our website at www.aap.org.

For more information, please contact the American Academy of Pediatrics, 540 North Dearborn Street, Chicago, IL 60610, or visit our website at www.aap.org.

For more information, please contact the American Academy of Pediatrics, 540 North Dearborn Street, Chicago, IL 60610, or visit our website at www.aap.org.

For more information, please contact the American Academy of Pediatrics, 540 North Dearborn Street, Chicago, IL 60610, or visit our website at www.aap.org.

For more information, please contact the American Academy of Pediatrics, 540 North Dearborn Street, Chicago, IL 60610, or visit our website at www.aap.org.

For more information, please contact the American Academy of Pediatrics, 540 North Dearborn Street, Chicago, IL 60610, or visit our website at www.aap.org.



PREPARING FOR PATIENT AND FAMILY ADVISOR PARTICIPATION ON QUALITY IMPROVEMENT AND SAFETY INITIATIVES

There are many benefits to involving patient and family advisors on quality improvement and safety teams, initiatives, and ongoing committees. In order to realize these benefits, a core team of activities have been identified to maximize advisor participation, effectiveness, and value. Put a check mark next to each item that has been completed and how to address those items that are not completed in the notes column. This will ensure that your clinicians and staff as well as patient and family advisors are prepared for a successful partnership to improve quality and safety in your organization.

✓	Notes
Making Key Decisions about Advisor Participation	
The executive sponsor and/or the Safety/QI champion of the project/committee have identified the importance and value of advisor participation.	
The key leaders are prepared to communicate their support in words and actions with other members, staff, and clinicians for the involvement of advisors on the project team/committee.	
The role of patient and family advisors has been defined for this particular project/team/committee. Consider the following options: Full team member*, Ad hoc team member, Consultant/Reviewer, or Guest/Spokesperson*.	
The number of advisors needed for the project team/committee has been determined. Recruiting two or more advisors is advised.	
The special skills and experience needed for advisors to effectively participate has been identified (e.g., patients with challenges for a team to improve diabetes education materials or programs).	
The time commitment and length of participation anticipated for advisors to serve on the project team/committee have been determined.	
The meetings have been scheduled at times that make advisor participation possible.	
If the time of existing project team/committee meetings cannot be changed, flexible ways for advisors to meaningfully participate have been identified and adopted (e.g., participatory conference call, Skype, video).	



TIPS FOR GROUP LEADERS AND FACILITATORS ON INVOLVING PATIENTS AND FAMILIES ON COMMITTEES AND TASK FORCES

Selecting Patients and Families to Serve as Advisors

- Look for people who are:
 - interested in the topic being addressed by the committee or task force;
 - comfortable in speaking in a group with clinicians;
 - able to use their personal experience constructively and
 - able to listen and learn differing opinions.
- Having just one patient or family member on a committee is not usually successful. Invite for patients and family members to be one-third to one-half of the committee's membership.
- Remember that serving as a patient or family advisor is a new role for many people. Some patients and family members will need more support than others. Recognize the individuals who grow and develop in this role.

Preparation for Meetings

- Consider the convenience and schedules of patients and families as well as planning the time and location for meetings.
- Send agenda and minutes ahead of time to all committee members, emphasizing to allow time for material to reach patients and families (they may not have fax machines, email, etc.).
- Provide a list of committee members with a brief description of their person.
- Offer a minute, an experienced patient or family advisor or another committee member, to support a new advisor.
- Offer to have someone come to the first meeting with a new member and debrief afterwards.
- Remember that this type of collaboration is new for many people so preparation and orientation is important for staff, as well as patients and family members.

TIPS FOR GROUP LEADERS AND FACILITATORS ON INVOLVING PATIENTS AND FAMILIES ON COMMITTEES AND TASK FORCES

Enhancing Family Engagement through Quality Improvement

Lessons Learned from the Family Engagement Quality Improvement Project

Family engagement is an innovative approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families.1

Family engagement or family involvement can improve patient and family outcomes, increase family and clinician satisfaction, decrease health care costs, and improve efficiency of care.2

The National Family Engagement Quality Improvement Project identified strategies to do the following:

1. Engage patients and families in the planning, delivery, and evaluation of health care.

2. Increase family engagement in patient and family care.

3. Increase family engagement in patient and family care.

4. Increase family engagement in patient and family care.

5. Increase family engagement in patient and family care.

6. Increase family engagement in patient and family care.

7. Increase family engagement in patient and family care.

8. Increase family engagement in patient and family care.

9. Increase family engagement in patient and family care.

10. Increase family engagement in patient and family care.

11. Increase family engagement in patient and family care.

12. Increase family engagement in patient and family care.

13. Increase family engagement in patient and family care.

14. Increase family engagement in patient and family care.

15. Increase family engagement in patient and family care.

16. Increase family engagement in patient and family care.

17. Increase family engagement in patient and family care.

18. Increase family engagement in patient and family care.

19. Increase family engagement in patient and family care.

20. Increase family engagement in patient and family care.

21. Increase family engagement in patient and family care.

22. Increase family engagement in patient and family care.

23. Increase family engagement in patient and family care.

24. Increase family engagement in patient and family care.

25. Increase family engagement in patient and family care.

26. Increase family engagement in patient and family care.

27. Increase family engagement in patient and family care.

28. Increase family engagement in patient and family care.

29. Increase family engagement in patient and family care.

30. Increase family engagement in patient and family care.

31. Increase family engagement in patient and family care.

32. Increase family engagement in patient and family care.

33. Increase family engagement in patient and family care.

34. Increase family engagement in patient and family care.

35. Increase family engagement in patient and family care.

36. Increase family engagement in patient and family care.

37. Increase family engagement in patient and family care.

38. Increase family engagement in patient and family care.

39. Increase family engagement in patient and family care.

40. Increase family engagement in patient and family care.

41. Increase family engagement in patient and family care.

42. Increase family engagement in patient and family care.

43. Increase family engagement in patient and family care.

44. Increase family engagement in patient and family care.



FAMILY VOICES

Communicating the Tools of the Change Package with Families

Developing partnerships with families requires unique communication skills that demonstrates the importance of the team working together and recognizes that everyone on the team brings expertise and experience that is unique, but has equal value.

Quality improvement teams have the opportunity to learn from families about what is and not working and then use the quality improvement framework to make improvements. The quality improvement team may want to think about these questions:

- How are staff/providers partnering with families in developing the change package tools for the individual child?
- How are staff/providers helping families understand QI and WICVA to use these tools?
- What small tools of change on the QI team do to improve how staff/providers are engaged these processes and how they are communicating with families?
- These issues get at the heart of the guiding principles of the change package. When the clinic staff and providers are really partnering with families to develop the tools individually for their child, the family will become invested in the quality and outcomes of the tool, and as part of the process if staff/providers are talking about and give examples of how families use the tools, and using basic teach-back communication skills the family will learn how to use the tools.

For example some ideas for staff working with families:

- As the provider and family are creating the care plan – the discussion about the child's conditions helps the family understand the child's conditions and are able to discuss things such as:
 - What are the conditions are impacting the child?
 - How are the medications working or not working?
 - What are upcoming specialty visits?
 - Any upcoming procedures?
 - How are things going at school?
 - Are there medical supports at school and at home?
- As they are creating the Dynamic Care Plan – they are discussing:
 - What is the value of having an identified DCP, how have other families used this idea?
 - Who are the most important specialists to the family and child?
 - What are some complications that have occurred in the past, what did we learn from those complications, how should they be handled in the future by staff?
 - Are there concerns the family/parent has about their child's health status how should those concerns be handled in the future by staff?
 - Are there equipment issues that could be addressed to have adequate back up as needed

When the team is having these types of discussions with the family they are doing a number of things:

- They are really recognizing the families' experience and concerns and are therefore learning from the family more about the child.
- They are giving the family the opportunity to learn why and how to use these tools.
- Ideally this should be done at a specific visit dedicated to this work.

Next Steps

- Continue this fundamental work as a team
 - Coaching calls for guidance/support/TA
 - Ask BU anytime re: expert TA on family engagement
 - State cross-sharing support through coaches

Next Steps (cont'd)

- Upcoming Dates of Note
 - Fri, July 27: Next team update form due
 - Sept 17, 12p-1:30p EST: Webinar #4 (Topic TBD)
 - M/T Oct 29/30, 8:30a-4:30p: In-person state team meeting @ Chicago
 - State team input request, including top 3 team-specific objectives out of the meeting
 - Poll – Sunday evening start?
 - Nov 29, 1:30p-3p EST: State team webinar #5

Lucille Packard Foundation webinar

JOIN US

A Conversation on Care Coordination for Children with Medical Complexity: Whose Care Is It, Anyway?

Date and time: July 26, 2018 10-11 am PST

Care coordination is an important approach to addressing the fragmented care that children with medical complexity often encounter. What are optimal care coordination services? How does care coordination intersect with care integration and case management? Learn best practices and how to implement a process that will achieve improved outcomes and value for children with special health care needs and their families.

Join us for a lively discussion on the article, [Care Coordination for Children with Medical Complexity: Whose Care Is It, Anyway?](#) The lead author and experts in the field will review the article's key content and discuss why care coordination is vital to improving the system of care. We suggest attendees read the article prior to the event. Audience Q&A is highly encouraged. Attendees can listen via web or phone. [Read more.](#)

REGISTER

<https://register.gotowebinar.com/register/6314492371449423875>

REMINDER: CSHCN Challenge

HRSA MCHB Care Coordination for Children with Special Health Care Needs (CSHCN) Challenge

- The Care Coordination for CSHCN Challenge will award \$375,000 in prizes to support the creation of tech innovations to help families and case managers with the care and coordination of children with special health care needs.
- This Challenge will support the development and testing of low-cost, scalable tech innovations to meet the information needs of families of CSHCN, particularly those with complex medical conditions, and case managers. These innovations should improve the quality of care and enhance patient and family engagement and health care quality while saving costs to families and the health care system.
- Launch date August, 2018. Click here to learn more:
<https://mchbgrandchallenges.hrsa.gov/challenges/care-coordination-children-complex-needs>

And one last thing ...

WEBINAR EVALUATION:

<https://www.surveymonkey.com/r/BCS6F97>



Cara Coleman

ccoleman@familyvoices.org

www.familyvoices.org

www.fv-ncfpp.org

