



SIM Pediatric Office Hours Engaging Families

COMMON CHALLENGES ACROSS CHRONIC CONDITIONS

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Many years experience working with children with chronic health conditions and their families.



PCMH Initiative Introduction

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SIM Pediatric Office Hours

The SIM Pediatric Office Hour facilitates networking and promising practice sharing across the state. This group is open to all Initiative practice teams and pediatric care managers statewide, offering an opportunity for peer to peer learning. Collaboratively, care managers and practice team members will identify areas of interest, topic focus, and prioritize challenges. Outcomes include:

“What works”

“What has been tried and does not work”

Shared learning

Identification of best practices

Identify educational needs



Participant Commitment:

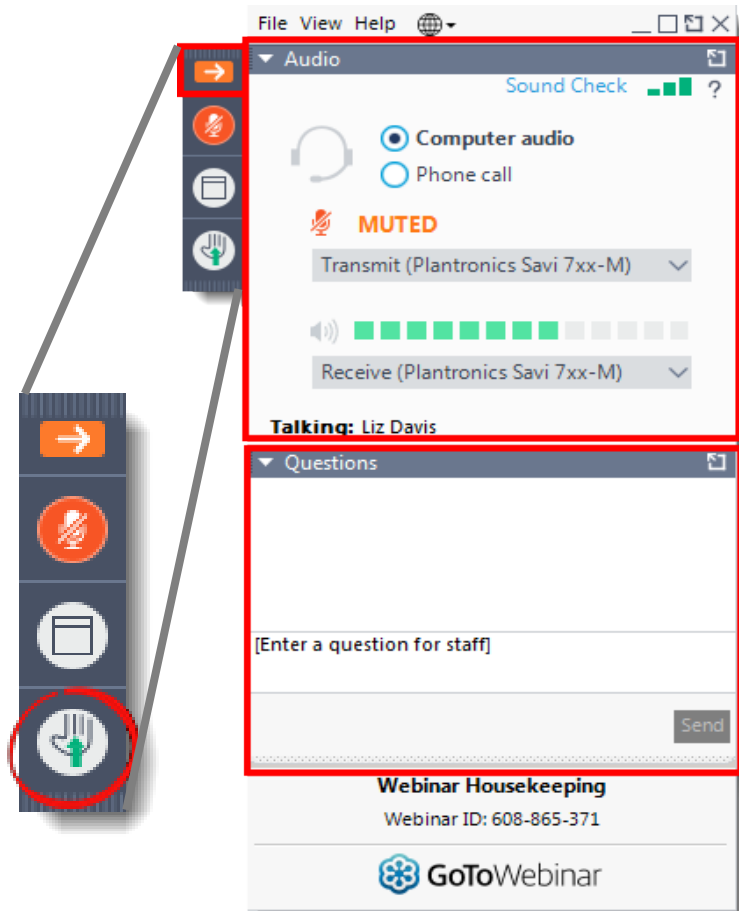
Attendees participate in a variety of ways during this interactive virtual meeting

Posting questions, verbally sharing experiences and lessons learned, responding to polls

Completion of a brief survey



Housekeeping: *Webinar Toolbar Features*



Your Participation

Open and close your control panel

Join audio:

- Choose **Mic & Speakers** to use VoIP
- Choose **Telephone** and dial using the information provided

Submit questions and comments via the Questions panel

Note: If time allows, we will unmute participants to ask questions verbally.

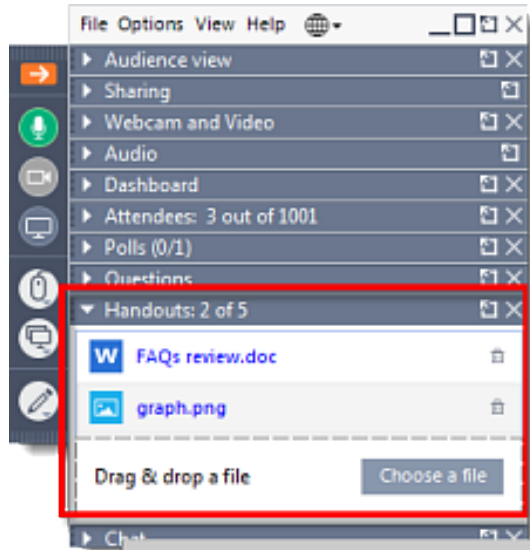
- Please raise your hand to be unmuted for verbal questions.

NOTE:

In the event that there is not time to answer questions live, all questions submitted via the Question Function of the GoToWebinar toolbar will be recorded, an FAQ generated and posted to our webpage

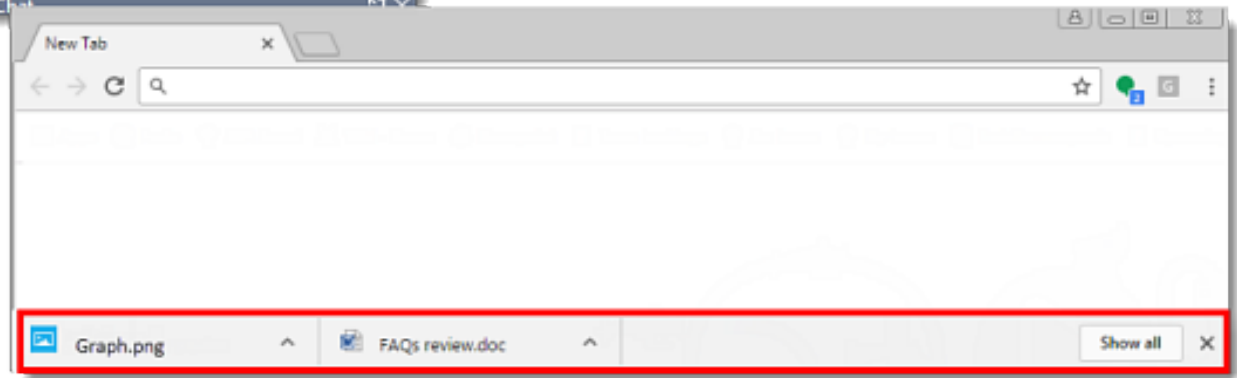


Housekeeping: *Webinar Resources/Handouts*



Handouts

- Webinar slides & other resources are uploaded to the “Handouts” section of your GoToWebinar Toolbar.
- Note: You may need to check the download bar of your browser to view the resources.



Learning Objectives

After participating in this session, listeners will be able to:

1. Recognize the differences between pediatric and adult chronic health conditions.
2. Name the five “Ds” of pediatric care and describe the relevance of at least two of the “Ds” to their work as care managers.
3. List three ways to identify children/youth who will benefit the most from care management.
4. Describe challenges to implementing self-management in pediatrics.
5. Describe two strategies for engaging families in care.

Pediatric vs Adult Care Coordination

Same principles of care coordination and medical home apply

Children are not small adults

Pediatric care managers require additional skills and content

Framework of the 5 D's

- Development
- Dependence
- Differential epidemiology
- Demographic differences
- Dollars



Development

Infants, children and adolescents are developing new skills and capabilities continuously

Development is not always linear and skills are not constant

- Consider the 14 year old who acts like an adult one day and behaves like a 4 year old the next
- Consider the toddler who is thoughtful and shares one minute and has a tantrum an hour later

Care managers must attend to developmentally driven transitions such as that of the high-risk neonate from NICU to home or the adolescent from pediatric to adult providers.

Skills to manage a health condition develop over time and require a foundation of skills to manage one's self.

Self-management support requires constant attention to the child/youth's changing capabilities

Self-management support in pediatrics requires working with a team – not an individual.



Development: Craig

11 year old boy with diabetes type 1.

He knows how to check his blood sugar and he knows how to adjust his insulin.

He knows what he is supposed to eat and what he shouldn't eat.

He is developmentally incapable of seeing the long term consequences of the actions he takes today.

He knows he is not supposed to eat cookies at his friend's house – but he really doesn't get it.

He is at an age where it is developmentally appropriate to spend time with his friend without constant adult supervision.



Dependence

Children depend on their caregivers for EVERYTHING.

Care management always involves a team.

It is common for a child to have multiple caregivers with various levels of responsibility and control over the child's life.

- Custodial parent
- Non-custodial parent
- Guardian
- Foster parent
- Grand parents and others with or without legal status.

The well-being of the caregivers is paramount for the health of the child.



Dependence: Kramer

8 year old boy with ADHD and asthma

Mother is custodial parent.

Father has visitation rights two weekends a month.

Child spends many afternoons/evenings with great grandparents because mother works.

Great grandparents bring him to most clinic visits – mother cannot afford to miss work.

He has been to the ED three times in last three months for asthma flare – one overnight stay.

Father smokes “outside” – great grandmother complains that child’s clothing smells of tobacco smoke when he comes home from father’s house.



Differential epidemiology

A handful of conditions make up much of the chronic illness of adults

congestive heart failure, COPD, hypertension, coronary artery disease, type 2 diabetes, asthma

Asthma, allergies and ADHD are the most common chronic health conditions of children

Many children have uncommon or rare conditions

To learn about specific chronic conditions in children:

- <https://www.medicalhomeportal.org/>
- <https://rarediseases.org/>

Self-management support is challenging because there are no established self-management protocols for most conditions.



Samantha

Samantha is 18 months old.

She has a major malformation of the brain called holoprosencephaly.

She was followed by pediatric surgery (for G-tube), peds ENT (narrow nasal passageways), peds endocrine (diabetes insipidus), peds pulmonology (chronic lung disease due to aspiration).

All her care is now provided by her medical home team.



Demographic differences

Many children are poor

In the 2014 census, 21% of children were poor and approximately 42% were “poor or near poor”.

Poverty has profound influence on health.

Enough said.....



Dollars

We spend much less on health care for children than for adults.

Data collected by MiPCT investigators showed mean expenditure per member per year:

- Pediatric practices: \$2000
- Family Medicine practices: \$4600
- Internal Medicine practices: \$6000

Approximately 1% of children account for 1/3 of child health care costs— those are generally children with medical complexity.



Children with Rising Risk

Overweight

Rapid change in weight

Lack of healthy lifestyle - exercise, nutrition

Behavioral health – examples include early signs of bullying, depression, anxiety

- Isolation from family/friends
- Changes in sleep pattern
- Dramatic change in peer group
- Rapid decline in school performance
- Crying episodes
- Risky behavior
- Increased irritability, change in affect



Children with Medical Complexity

Multiple significant chronic health problems that affect multiple organ systems

Child/youth experiences functional limitations

Medical technology is often needed

Approximately 1% of children account for up to one-third of health care costs



Identify children/youth for care management

Multiple subspecialists.

Hospitalizations.

High utilization and high cost.

Complicating psychosocial factors (child or family)

Someone on the team knows the child's phone number, birth date or medical record number by heart!



Strategies to engage families

Know the players and roles.

Be familiar with the health conditions and treatments.

Communicate effectively – establish rapport and understanding.

Recognize the family as the center.



Know the players

Who is involved in the child's care?

What is their role?

Do they live with the child?

Do they have the right to make medical decisions?

Sometimes “tell me.....” statements work better than questions.



Encounter

Introductions – who is who and what is each person's role

Establish agenda – clarify goals – what do we hope to accomplish today?

Facilitate discussion – make space for everyone to speak

Be sure everyone is heard

Summarize

Clarify next steps



Body language

Sit down.

Communicate at eye level.

Open posture.

Lean forward but not too far.

Put the screen/keyboard aside.

On the phone – body language still matters.



ASK - TELL – ASK

LISTEN more than talk

Useful phrases:

- Tell me about....
- Tell me more....
- I don't quite understand

Learn to interrupt effectively – redirect the conversation

- I'd like to get back to....
- Let's circle back to

Use silence – be patient



ADDRESS EMOTIONS

Name

Understand

Respect

Support

Explore



Hope statements

“I hope we can.....”

“We all hope.....”

A simple “hope” statement provides a positive frame and shows alignment with a goal.



Respond to “conversation grenades”

“You have given up on my child.”

“I am praying for a miracle”

“It’s all my fault”

“No one understands what we live with”



“conversation grenades”

Go for it – don’t ignore the statement

“Tell me what you mean.....”

“I wonder what that means to you...”

Conversation grenades are often misunderstood – don’t assume the meaning.



“I’m praying for a miracle”

What does that mean to you? What would a miracle look like?

- “My child will be like other children.”
- “He will grow up and get a job and get married and have children.”
- “We will sleep through the night.”



If only I could sleep through the night....

Name: you sound frustrated.

Understand: you must be exhausted getting up several times every night to give him treatments.

Respect: we all need sleep – uninterrupted sleep -- to recharge our batteries.

Support: I'll ask his doctor if we can change his treatment schedule so you don't have to get up so many times in the night.

Explore: Let's look for resources for respite – maybe we can arrange for you to have a real break to get some rest.



Hope statement

We all hope he'll be better soon and these treatments will be a distant memory.



Craig

More to the story....

Craig has cerebral palsy as well as diabetes and he needs a surgery.

Surgeon won't do surgery until blood sugar is under better control because he is concerned about the effect of high blood sugar on healing.

Grandmother comes to clinic, plops down and says "now what?"



Kramer

Mother comes to clinic visit with her grandmother and Kramer to follow up on ADHD.

She is upset because the school calls her often because of his behavior– he gets in fights with other students and he talks back to the teacher.

He fights with his younger brother all the time – “he is just plain mean”.

He was in the ED again last weekend because he was coughing and wheezing.



Samantha

Samantha comes for her 18 month “well child visit”

Her mother is angry because she arrived at 4:45 for her 5 pm appointment and she wasn’t put in a room until 5:30 and it is now 5:40 when the nurse care manager enters the room.

“They treat me like this because I’m poor and I’m black and I can’t read”



Summary

The 5 “D’s” that distinguish pediatrics from adult medicine.

- Development
- Dependence
- Differential epidemiology
- Demographic differences
- Dollars

Strategies to engage families: communication skills

- Ask – tell – Ask – emphasis on Listen
- Address emotions: name, understand, respect, support and explore
- Use hope statements
- Don’t dance around the grenades – land on them.



Discussion



Pediatrics Topic Page on micmrc.org

The screenshot displays the Michigan Care Management Resource Center (micmrc.org) website. At the top, the header includes the micmrc logo, a search bar, and the title "Michigan Care Management Resource Center". A red arrow points to the "Topics" menu item in the navigation bar. Below the navigation bar, the "TOPICS" section is visible, with a sidebar menu listing various topics. The "Pediatrics" topic is selected and highlighted. The main content area features a breadcrumb trail "Home > Topics > Pediatrics", the title "Pediatrics", and a photograph of two young children sitting at a table, focused on a craft activity with sticks and jars. To the right of the main content, there is a "DASHBOARD" section with a login button and a "Related Resources" section listing several categories: ADVOCACY, HEALTH LITERACY, PEDIATRIC BEHAVIORAL HEALTH, PEDIATRIC CHRONIC CONDITIONS, PEDIATRIC TRANSITIONS OF CARE, and PEDIATRICS.

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Pediatrics

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- PEDIATRICS



Thank you!

