In July 2021, the NRC-PFCMH implemented a virtual roundtable discussion. The discussion included members from the Health Equity Subcommittee (pediatricians, Title V representatives, family partners) in addition to 8 African American and Black family partners with a child or youth with a special health care need (CYSHCN).

The focus of the discussion was on improving relationships between pediatricians and the African American and Black families of CYSHCN whom they serve. Families shared powerful stories from lived experience, in addition to providing expertise on what pediatricians can do to provide more equitable care to African American and Black families and be better allies.

The below graphic illustrations represent the major themes and topics from the virtual roundtable discussion.

Special thanks to our family partners:

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ADDRESSING EQUITY for AFRICAN AMERICAN & BLACK FAMILIES of CYSHCN THROUGH MEDICAL HOME

INTRODUCTION

I CAN'T WAIT to LISTEN & LEARN!

TODAY is DIVIDED into 2 SESSIONS

I AM SO THRILLED FOR this TIME to COLLABORATE!

YOU ARE the EXPERTS of your CHILDREN

This IS a LEARNING SPACE!

WE NEED this SAFE SPACE to SHARE w/CARE PROVIDERS!

TAKE THIS SPACE & OPPORTUNITY!

Don't BE AFRAID TO ASK QUESTIONS!

Don't BE a SHRINKING VIOLET!

Today is divided into 2 sessions. Today is divided into 2 sessions.

This is a learning space. This is a learning space.

We need this safe space to share with care providers. We need this safe space to share with care providers.

Take this space & opportunity. Take this space & opportunity.

Don't be afraid to ask questions. Don't be afraid to ask questions.

Don't be a shrinking violet. Don't be a shrinking violet.

I can't wait to listen & learn. I can't wait to listen & learn.

I am so thrilled for this time to collaborate. I am so thrilled for this time to collaborate.

You are the experts of your children. You are the experts of your children.

This info will inform the strategies of the NRC! This info will inform the strategies of the NRC!

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DEDICATED TO THE HEALTH OF ALL CHILDREN®

For patient/family-centered medical home.
Building Strong Relationships Between Families & Pediatricians

Let's change the landscape!

What more can providers do?

Let's look at intersectionality!

Online therapy not really an option, but wouldn't allow in-home therapy.

Let's center family voices!

Must enroll in school

Experiences

They provided insight & listened

Relief

Information manipulation of info delivery

Omission

It was a relief.

They think they know more about me & my family than I do.

Lots of judgement

Experiences should be customizable

As a physician, I was unaware that patients & families feel like this

We are evolving in this space

Providers don't look like us.

I've experienced the best & worst of healthcare

When one person speaks up, we all benefit!

They treat the symptoms, not the patient

I don't want my 6 yr old on ADHD meds!

Dealing w/ school system

Good w/ rehab & neurology department

Traumatic brain injury

Physical challenges

Hearing impairments

Mental health

Autism

Dyslexia

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National Resource Center

For Patient/Family-Centered Medical Home

American Academy of Pediatrics

Dedicated to the health of all children®
BUILDING STRONG RELATIONSHIPS BETWEEN FAMILIES & PEDIATRICIANS

- PROVIDE MORE HELP
- CARE NAVIGATION
- LISTEN & HEAR
  - Don’t brush us off
  - Don’t miss opportunities for the early diagnoses
  - More training
- FINDING SOLUTIONS
- Don’t discount our concerns
- EQUIP PARENTS WITH TOOLS
- TRAINING
- Shadow parents
- Walk in our shoes
- CHECK YOUR IMPLICIT BIAS
- SPEND TIME ASK QUESTIONS
- PROBLEM SOLVE
- DON’T RE-TRAUMATIZE PARENTS
- DON’T LET SKIN COLOR AFFECT DIAGNOSIS (e.g., Autism vs. ADHD)
- RUN TESTS
- MORE TRAINING
- CULTURAL COMPETENCY & HUMILITY
- TREAT PARENTS LIKE PROS
  - M.D.
  - MOM.
  - DAD.
- DONT ASSUME
  - USE LESS LINGO
- WARM HANDOFFS
- TEAM-BASED CARE
- MAKE PARENTS COMFORTABLE
- Partnership like family
- coordinate service
ALLYSHIP & CULTURAL COMPETENCY WITHIN FAMILY-CENTERED CARE

WHAT DOES IT LOOK & FEEL LIKE?

- More time for dialogue with providers
- Understanding: don't talk at me, talk with me
- Communication: needs to be coordinated
- Advocate
- Advocacy
- Having a team in place (e.g., pediatrician, teacher, audiologist, therapist)
- Team should be the lead
- It's mentally exhausting

WE DON'T KNOW IF HE'S THE BIOLOGICAL FATHER

CULTURAL BACKGROUND

- A tall black man is not a threat!
- Don't stereotype!
- Overarching fear based purely on race
- Only one at a time. (For black family) But white family had multiple ppl allowed.
- I don't trust nurses/practitioners who don't trust us as family members
- My financial situation shouldn't affect care
- Our skin color is part of our culture - it shows up before we do

CALL BACK + FOLLOW UP

Don't shut down parents/advocate
- Should docs acknowledge whiteness?

I WANT TO BE TREATED THE SAME AS EVERYONE ELSE!
ALLYSHIP & CULTURAL COMPETENCY WITHIN FAMILY-CENTERED CARE

1. Takes a Village
   - Doctor Navigator
   - Think about the different lives of your patients
   - Understand cultural differences & pressures
   - Parent's don't have to be loyal...
   - We will find the best care team.

2. Listening
   - Good vibes
   - Spend the time.
   - Don't omit things.
   - Don't over promise...
   - What else?
   - Be on time.

3. Care
   - Center parents
   - Parent's don't have to be loyal...
   - Silver dollar
   - Our remedies are a product of our culture
   - Respect
   - No judgement.
   - Build trust
   - Show vulnerability
   - Don't know...
   - But will find out
   - Meet the person
   - Don't judge
   - Meet the person
   - Ask about preferences (ACE... Adverse Childhood Experience)
   - Understand trauma
   - Ask US!
   - Acknowledge our concerns & experiences
   - Get med's right.
   - Believe our pain levels
   - Home remedies

4. Education for Real
   - Know it.
   - Learn our motivations.
   - Fear of children being taken away.

5. National Resource Center
ADDRESSING EQUITY for AFRICAN AMERICAN & BLACK FAMILIES of CYSHCN THROUGH MEDICAL HOME

DEBRIEF

ACKNOWLEDGE YOUR WHITENESS!

I'M SO GRATEFUL to the PROVIDERS for LISTENING.

I FEEL HEARD.

WE NEED MORE PROVIDERS WHO LOOK LIKE US.

"SHOULD" DON'T USE THIS WORD.

DON'T MAKE ASSUMPTIONS!

JUDGEMENT MAKES US CLAM UP!

"I DON'T KNOW, I WILL FIND OUT" I RESPECT THAT!

MEET PARENTS WHERE THEY ARE.

ADVOCATE!

DON'T MAKE PARENTS DO THIS ALONE!

THANK YOU SO MUCH!

Communicate!!

WE NEED CONTINUITY of CARE!

HOLD PROVIDERS ACCOUNTABLE- REPORT POOR CARE!

PROVIDERS: IDEAS for YOU to IMPLEMENT?

A PARENT-CENTERED REVOLUTION in CARE!!

WE NEED MORE of THIS TYPE of SESSION!

WE HAVE to GRAPPLE w/ INSTITUTIONAL RACISM.

CLOSING REMARKS from the AAP TEAM...

YOUR VOICES ARE POWERFUL

WE ARE ALL PEOPLE.

TEAM WORK MAKES the DREAM WORK

SURVEYS WE CAN TAKE?

AAP: MAKE a PARENT ADVOCATE PROGRAM!

AAP: SHARE our FEEDBACK with DOCTORS!

A PARENT-CENTERED REVOLUTION in CARE!!

MY CHILD IS MY PRIDE & JOY...

they SHOULD be YOURS too WHEN YOU CARE for THEM!

NEEDS TRANSCEND SKIN COLOR!

SPECIALISTS ARE an ISSUE- PCP'S ARE GOOD...

DON'T MAKE ASSUMPTIONS!

HAVE a VILLAGE MENTALITY!

OFFER MENTAL HEALTH RESOURCES to FAMILIES!