

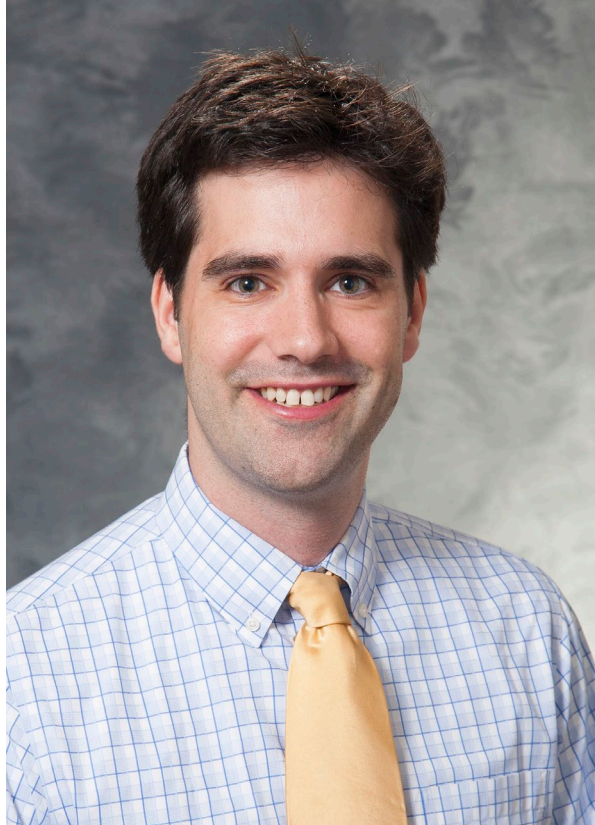


A Family-Centered Research Agenda for Supporting Caregivers of Children with Special Health Care Needs

February 15, 2022



Moderator



Ryan Coller, MD, MPH

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Chief of the Division of Pediatric Hospital Medicine, University of Wisconsin School of Medicine and Public Health

Today's Speakers



Clarissa Hoover, MPH
Project Director, Family Voices



Renee Turchi, MD, MPH, FAAP
Chair of Pediatrics and Pediatrician in Chief, General Pediatrics
St. Christopher's Hospital for Children



Debbi Harris, MS, MA, GCAS-Creative Writing/Narrative Medicine
Systems Specialist, Family Voices of Minnesota

Live Captioning

Select CC CLOSED CAPTIONING in Zoom **or**
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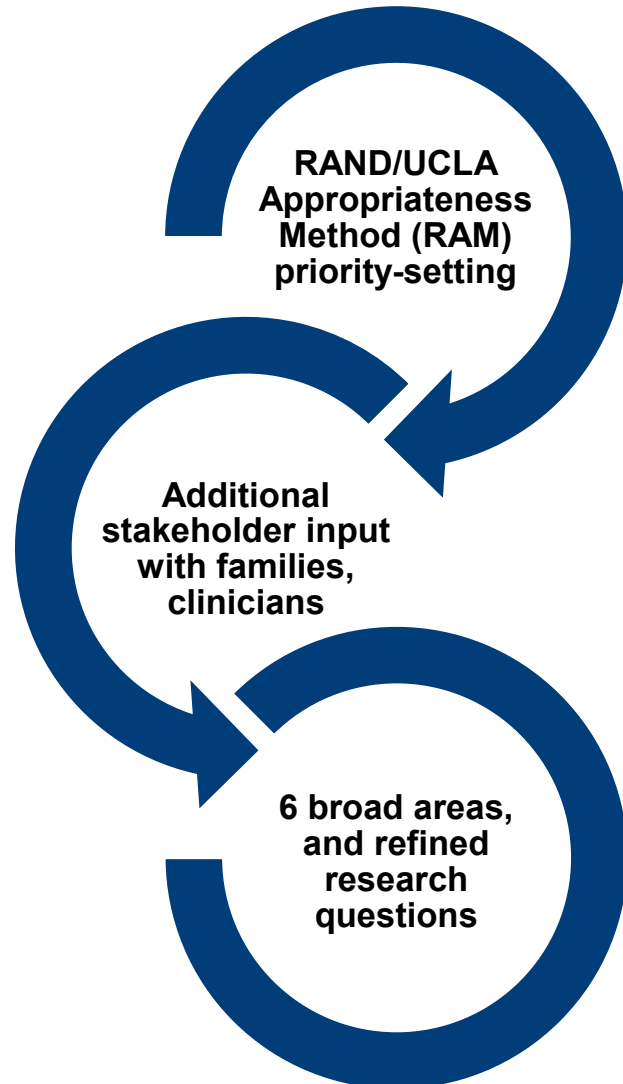
Ask Questions!

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

National Health Systems Research Agenda for CYSHCN

- Children and Youth with Special Health Care Needs National Research Network (CYSHCNet) 5-year Cooperative Agreement with the Maternal and Child Health Bureau (MCHB), Health Resources and Services Administration
- **Rationale** for a Research Agenda:
 - CYSHCN are a prevalent and growing population
 - Outcomes are static, despite:
 - Well-articulated Core Outcomes (MCHB) and System Standards
 - Substantial research with CYSHCN
- **Aspiration** of the Research Agenda:
 - Better integrate and prioritize family priorities
 - Focus efforts of investigators and stakeholders to drive outcome improvements

Development of a National Research Agenda



Health System Research Priorities for Children and Youth With Special Health Care Needs

Ryan J. Collier, MD, MPH,^a Jay G. Berry, MD, MPH,^b Dennis Z. Kuo, MD, MHS,^c Karen Kuhlthau, PhD,^d Paul J. Chung, MD, MS,^{e,f,g} James M. Perrin, MD,^h Clarissa G. Hoover, MPH,ⁱ Gemma Warner, MSW,^j Charlene Shelton, PhD,^k Lindsey R. Thompson, MPH, MS,^l Brigid Garrity, MPH,^m Christopher J. Stille, MD, MPHⁿ

OBJECTIVES: In this study, we sought to establish priorities for a national research agenda for children and youth with special health care needs (CYSHCN) through a structured, multistakeholder, mixed-methods approach.

METHODS: Using surveys, we solicited responses from >800 members of expert-nominated stakeholder organizations, including CYSHCN families, health care providers, researchers, and policymakers, to identify what research with or about CYSHCN they would like to see in a national research agenda. From 2835 individual free-text responses, 96 research topics were synthesized and combined. Using an adapted RAND/UCLA Appropriateness Method (a modified Delphi approach), an expert panel rated research topics across 3 domains: need and urgency, research impact, and family centeredness. Domains were rated on 9-point Likert scales. Panelist ratings were used to sort research topics into 4 relative-priority ranks. Rank 1 (highest priority) research topics had a median of ≥ 7 in all domains.

RESULTS: The RAND/UCLA Appropriateness Method was used to prioritize CYSHCN research topics and depict their varying levels of stakeholder-perceived need and urgency, research impact, and family centeredness. In the 15 topics that achieved rank 1, social determinants of health (disparities and rurality), caregiving (family resilience and care at home), clinical-model refinement (effective model elements, labor divisions, telemedicine, and system integration), value (stakeholder-centered value outcomes, return on investment, and alternative payment models), and youth-adult transitions (planning, insurance, and community supports) were emphasized.

CONCLUSIONS: High-priority research topics identified by CYSHCN experts and family leaders underscore CYSHCN research trends and guide important directions. This study is the first step toward an efficient and cohesive research blueprint to achieve highly-effective CYSHCN health systems.

WHAT'S KNOWN ON THIS SUBJECT: Achieving comprehensive, effective, and coordinated systems for children and youth with special health care needs (CYSHCN) has been elusive. Realizing ideal health systems for CYSHCN requires research to concentrate on the most pressing issues identified by diverse stakeholders.

WHAT THIS STUDY ADDS: As a step toward a national CYSHCN research agenda, diverse experts developed a research topic taxonomy, depicting varying levels of need and urgency, research impact, and family centeredness. Highest-ranked research topics were centered on social determinants of health, family resilience, value, and youth-adult transitions.

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PEDIATRICS Volume 145, number 3, March 2020:e20190673

ARTICLE



Conceptualizing Caregiving

- Focus on CYSHCN
- Caregivers : Caregiving = Doctors : Medicine
- Types of caregiving
 - Family caregiving
 - Paid or unpaid
 - Professional caregiving (home)
 - Institutional caregiving



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YOU ARE HERE
aka "home health"



Caregivers and Family Health

- Caregiver ~~burden~~ labor of love!
- Resiliency orientation
- Caregiver support
- Impact of caregiver health on CYSHCN outcomes

Research Agenda Questions

- “How can the optimal level of home supports (including home health care) that a family needs to improve child/family outcomes be determined and achieved?”
- “How does rurality uniquely affect CYSHCN, and what are effective interventions to support CYSHCN and families living in rural settings?”

General Recommendation

All of these projects, and the projects suggested in other articles in this supplement, should be carried out working with youth and family partners, and with the intent of being family driven.

#2: Social Network Analysis

What do violin lessons have to do with health?

- Being normal
- Working through medical trauma
- Mandatory socializing
- Weekly consultation
- A task that is challenging but not life-threatening
 - Learning to enjoy striving for something



#3: Randomized Controlled Trials

What does the evidence say?

- What does it mean to ME?
 - For where I live, for my race, for my rare condition, for my work schedule?
- Does it answer the questions that I have?
 - Does it really matter whether it's tid or q8h?* (Because tid isn't too bad, but q8h means I can't get a full night's sleep and the school nurse has to give a dose at school...)
- Are we choosing questions that are easier to answer over questions that need answers? Can we push the envelope?

* <https://www.verywellhealth.com/understanding-prescription-abbreviations-189318>

My favorite days of the week....







aregiver

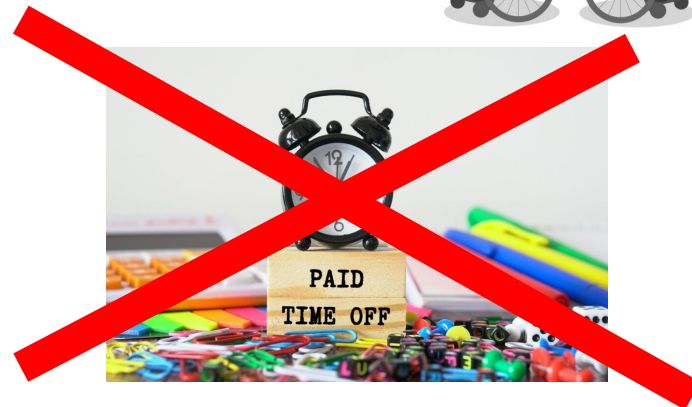
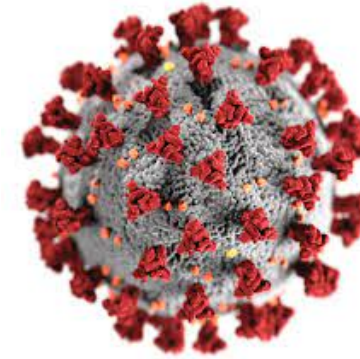
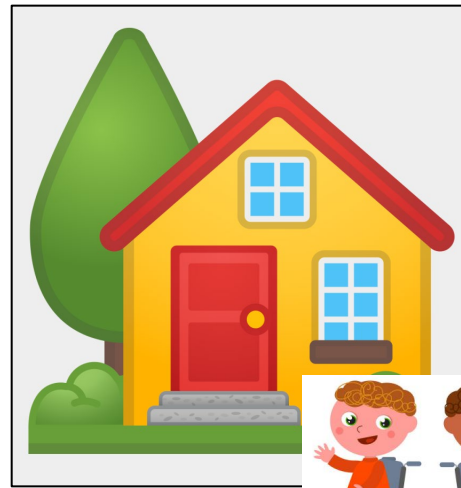


Figure 2 Family-centeredness and system-centeredness in research

		Family-centered	
		Absent	Present
System-centered	Absent	Self-serving	Relationship-oriented
	Present	Accountability-oriented	Family-driven

Understanding Caregiving and Caregivers: Supporting CYSHCN at Home, Hoover et al. 2021

Research in Family Centered and Health Care Systems

- Conceptual Model- Reframe the lens- Holistic
 - Understanding, acknowledging, and honoring caregiver work
- Goal setting and care mapping
- Assessment and measurement
 - Technology/Telehealth
 - Transitions
 - Health-related Quality of Life
 - Trust
 - Social networks
- Honor cultural and ethnic diversity, health equity at every step



The Complexity of Caregiving

In photos



Meet Josh Then

Meet Josh Now



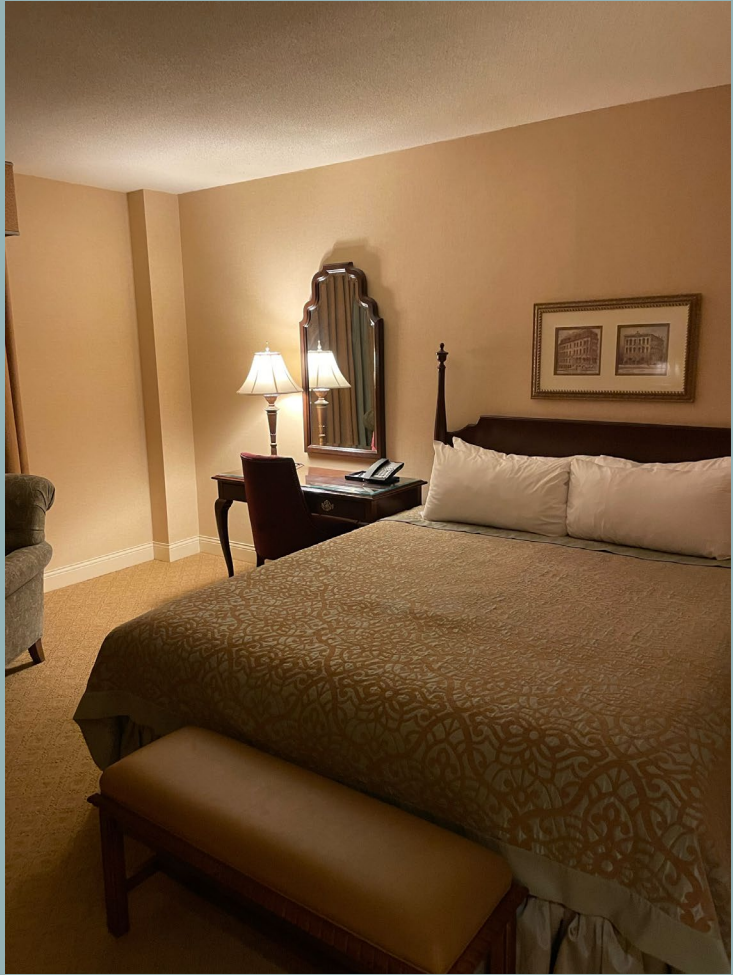






Difficult Times





Self Care (sort of)

Expense Reports

10:47

Search Amazon


View order details

Order date	Dec 3, 2021
Order #	113-0686071-7584251
Order total	\$42.16 (1 item)

Shipment details

Standard Shipping

Delivered
Delivery Estimate
Thursday, December 16, 2021 by 8pm

	Medline Heavy Absorbency 36" x 36" Quilted Fluff And Polymer...	\$41.43
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Qty: 1
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Please allow 24 hours to track your order.
Note that your order might have shipped in additional packages.

Summary:

Order #:	764803
Order Date:	Sat, 04 Dec 2021
Order Total:	\$81.39

Shipping Information:

Debbi Harris

12:35

Instagram

Instagram post content:

\$10,000 for night shift
\$7,500 for day shift

Hiawatha Homecare logo

... NURSES NEEDED
Competitive pay... more

Add a comment... 12 minutes ago

12:28


Search Amazon

Order date	Nov 24, 2021
Order #	112-9029078-3028236
Order total	\$71.96 (4 items)

Shipment details

Rush Shipping

Delivered
Delivery Estimate
Nov 24, 2021 by 7:00 PM

	MedPride Powder-Free Nitrile Exam Gloves, Large, Box/100	\$17.99
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Qty: 4
Sold By: HLmedical

Track shipment >

Buy it again >

Payment information



Safe Spaces



Grateful Days (Everyday)



Josh's People at Home
(Mom and Dad, Nurses, Brothers, Therapists, Cousins)

Ask Questions!

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

We pursue a system that works for children with special health care needs.

Join us: lpfch.org/CSHCN

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Access our library of publications, issue briefs, and fact sheets

Sign-up for our Newsletter

Stay informed about new resources, grants, and events

Apply for a Grant

Submit your idea for system improvement



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