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

February 15, 2022
Ryan Coller, MD, MPH
Research Director, Pediatric Complex Care Program
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
Click the link in the chat to view captions
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

RAND/UCLA Appropriateness Method (RAM) priority-setting

Additional stakeholder input with families, clinicians

6 broad areas, and refined research questions

Research Areas
- Transitions of Care
- Caregiving at Home
- Principles of Care
- Child Health Care
- Family Health
- Financing
Conceptualizing Caregiving

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

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

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.
Who takes care of Elanor?

- Self*: 1.5 hrs/day
- Father*: daily
- Mother*: most days
- Boyfriend*: most days
- Therapist: weekly
- Teachers: weekly
- Care coordinator: monthly
- All other health care providers: every three months or less

* health care related only, excludes general care
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
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....
### Figure 2 Family-centeredness and system-centeredness in research

<table>
<thead>
<tr>
<th>Family-centered</th>
<th>System-centered</th>
<th>Absent</th>
<th>Present</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Absent</td>
<td>Self-serving</td>
<td>Relationship-oriented</td>
</tr>
<tr>
<td></td>
<td>Present</td>
<td>Accountability-oriented</td>
<td>Family-driven</td>
</tr>
</tbody>
</table>
Research in Family Centered and Health Care Systems

• Conceptual Model- Reframe the lens- Holistic
  o Understanding, acknowledging, and honoring caregiver work

• Goal setting and care mapping

• Assessment and measurement
  o Technology/Telehealth
  o Transitions
  o Health-related Quality of Life
  o Trust
  o 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
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

Read the Latest Research
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