



Moving from Spending to Investment: A Research Agenda for Improving Health Care Financing for Children and Youth with Special Health Care Needs

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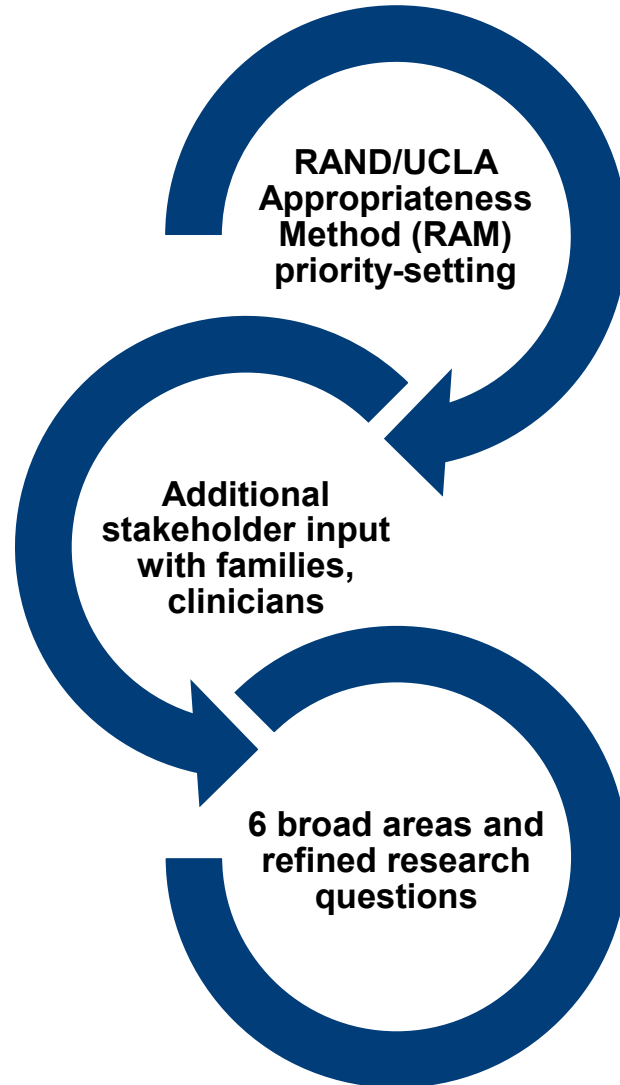
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Submit your questions through the Q&A.



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



OVERVIEW

National Research Agenda on Health Systems for Children and Youth With Special Health Care Needs

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ABSTRACT

Children and youth with special health care needs (CYSHCN) "have or are at increased risk for chronic physical, developmental, behavioral or emotional conditions and also require health and related services of a type or amount beyond that required by children generally." CYSHCN rely on health systems, which extend beyond traditional health care entities, to optimize their health and well-being. The current US health system is not fully equipped and functioning to meet the needs of CYSHCN. Recognizing this, the Maternal and Child Health Bureau and the US Health Resources and Services Administration established the Research Network on Health Systems for CYSHCN (CYSHCNNet, <http://www.cyshcn.net>). With input from >800 US stakeholders, CYSHCNNet developed a national research agenda on health systems for CYSHCN designed to: 1) highlight important health system challenges faced by key stakeholders (ie, patients and families, health care providers,

insurers, administrators, etc.); 2) organize research topics and goals to identify opportunities for improvement, to address challenges and to promote progress toward the ideal health system; and 3) provide a blueprint for health systems research ideas and studies that will guide CYSHCN investigators and other stakeholders going forward. We introduce the 6 research topics currently included in the research agenda—transition to adulthood, caregiving, family health, child health care, principles of care, and financing—to inform and guide investigators as they embark on a trajectory of health systems research on CYSHCN.

KEYWORDS: children and youth with special healthcare needs; health services research; research agenda

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WHAT'S NEW

This paper introduces the papers in the Supplement that describe a new national health systems research agenda for children and youth with special healthcare needs (CYSHCN). It summarizes each paper, and provides readers with examples of how they might be used by different types of stakeholders undertaking or using health systems research for CYSHCN.

CHILDREN AND YOUTH with special health care needs (CYSHCN) are those who "have or are at increased risk for chronic physical, developmental, behavioral or emotional conditions and also require health and related services of a type or amount beyond that required by children generally."¹ An estimated 14.1 million US children and youth (~20%) have a

special health care need.¹ Examples of special health care needs include use of chronic medications, durable medical equipment and supplies, therapies, as well as health services across the care continuum (eg, home, outpatient, inpatient, emergency, perioperative). CYSHCN as a population face a heterogeneous array of health challenges and chronic conditions, including mental and physical.

According to the World Health Organization, a health system comprises all organizations, institutions, and resources that produce actions whose primary purpose is to improve health and well-being.² CYSHCN rely on systems which extend beyond traditional health care entities (eg, hospitals, clinics) to include the network of supports and programs related to education, housing, food, environment, etc., that—when functioning well—enable CYSHCN and their families to reach their optimal level

Research Areas

Transitions of Care

Caregiving at Home

Principles of Care

Child Health Care

Family Health

Financing

CYSHCN and health care financing

- Higher utilization = higher costs
- Often require services from a complex health care system
 - Robust care coordination is required
- Challenges in adequacy, affordability, and continuity of coverage create family financial hardship
- Providers expend significant time and effort on essential but un- or under-reimbursed care

Spending on health care for CYSHCN

- The 20% of children who have special health care needs comprise approximately 50% of pediatric health care spending
- Less than 1% of children, those with complexity, comprise up to 33% of those expenses

Access to public insurance offers better quality coverage

Table 1: Parent report of insurance coverage of CYSHCN and non-CYSHCN that is both adequate and continuous, by % of the Federal Poverty Level (FPL)

| Adequate and Continuous Insurance Percentage (SE) | |
|---|------------|
| Poverty level | CYSHCN |
| <100% FPL | 71.3 (1.5) |
| 100%–199% FPL | 66.9 (1.6) |
| 200%–399% FPL | 56.1 (1.2) |
| ≥400% FPL | 59.3 (1.0) |

SE, standard error.

Source: Schiff, J., Manning, L., VanLandeghem, K., Langer, C., Schutze, M. & Comeau, M. (2022). Financing Care for CYSHCN in the Next Decade: Reducing Burden, Advancing Equity, and Transforming Systems. Pediatrics 149 (Supplement 7).

Public insurance reduces family financial hardship

Table 2: Trends in Coverage for CYSHCN, 2016 – 20

| | CYSHCN, % (SE) | | | |
|---|----------------|------------|------------|------------|
| | 2016* | 2017** | 2018** | 2019** |
| Type of insurance | | | | |
| Public only | 41.3 (1.1) | 38.6 (1.7) | 39.0 (1.3) | 36.6 (1.2) |
| Private only | 47.3 (1.0) | 48.6 (1.6) | 50.1 (1.3) | 51.6 (1.3) |
| Had problems paying medical bills | 15.8 (0.7) | 18.9 (1.3) | 16.4 (0.9) | 18.2 (1.0) |
| Avoided changing job to keep health insurance | 11.7 (0.7) | 11.9 (0.9) | 14.2 (0.9) | 14.3 (0.9) |

All *P* values for the CYSHCN and non-CYSHCN yearly estimates are significant at 0.0001 or <0.0001. (*, .0001; **, <.0001.) SE, standard error.

Increasing value in health care spending

- Alternative payment models (APMs) = increased value?
- Continuum of payment mechanisms aimed at increasing value
 - **Fee-for-Service (FFS)**
 - Providers get paid for what they do, regardless of outcome

APM

- **Pay-for-performance (P4P)**
 - Providers get paid a little more for designated outcome improvements
- **Bundled Payments**
 - A lump sum to cover an “episode of care”
- **Capitation**
 - One amount for each patient’s total care – provider risk

Value and the care of CYSHCN

- **Studies using APMs for pediatric patients to date can show**
 - Decreased costs and/or;
 - Increased quality and/or;
 - Increased family satisfaction
- **Questions about generalizability of findings**
 - Specific settings
 - Small numbers
- **Wide variation across payers and states**
- **Underdeveloped consensus measures of quality**

Research questions

- **2017-18 RAND/UCLA Appropriate Method (RAM) prioritized topics of focus**
 - Payment model -> quality of care
 - Return on investment for care coordination
 - Value outcomes that are meaningful to stakeholders
- **Literature review and gaps in knowledge**
 - Wide variation in current scope and models of practice
 - Underdeveloped quality and outcome measures
 - No consensus on appropriate constructs and paradigm of care
- **Describe existing practices**
 - Range of outcomes
 - Feasibility
 - Next steps

Payment models, quality of care, and CYSHCN well-being

- **Descriptive study of alternative payment mechanisms**
 - 5-8 case studies
 - Accompanying payment models
- **Provide recommendations for pilot projects**
 - Risk stratification
 - Selection of variables
- **Crosswalk of defined needs and payment models**

Return on investment for care coordination for CYSHCN

- **Quantitative study using population data set**
- **Expansive definition of care coordination**
 - Consider use of care mapping
- **Independent variable = care coordination using expansive definition**
 - Outcome variables = costs, utilization, service
 - Especially valuable in an integrated system and across systems, e.g. educational

Determining which value outcomes are most meaningful

- **Qualitative study defining VALUE**
 - Ranked choice method
- Varied groups – parents, providers, payers, educators, disability groups
- Human-centered design facilitated approach
- Define what is “right” that is not currently captured in health system data

Proposed alternative value-based payment methods need:

- Define the population
- Describe what model of care coordination we are paying for
- Determine how to measure quality
- Describe a payment that incrementally builds the model

All this to translate to an implementable incremental system

Quantify!

From a payer perspective

- Avoid misplaced precision
 - Need numbers that are good, not perfect
- A sound construct for the model
- Measures for both outcomes and process of care
- Involvement and ownership across a broad swath of health and other sectors
 - Starting with families, youth and children
- Need the next incremental step

Using our research dollars wisely

- Do we co-create research with families?
 - With Medicaid?
- Can we scale up what we test?
- Can we start to see research as a continuous quality improvement process?
- Who should fund research from dissemination to implementation?



Ask Questions!

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